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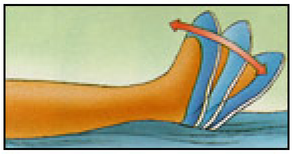
# Total Hip Replacement Exercise Guide

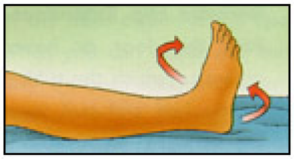
Regular exercises to restore your normal hip motion and strength and a gradual return to everyday activities are important for your full recovery. Your orthopaedic surgeon and physical therapist may recommend that you exercise 20 to 30 minutes 2 or 3 times a day during your early recovery. They may suggest some of the following exercises. This can help you better understand your exercise and activity program.

## Early Postoperative Exercises

These exercises are important for increasing circulation to your legs and feet to prevent blood clots. They also are important to strengthen muscles and to improve your hip movement. You may begin these exercises in the recovery room shortly after surgery. It may feel uncomfortable at first but these exercises will speed your recovery and reduce your postoperative pain. These exercises should be done as you lie on your back with your legs spread slightly apart.

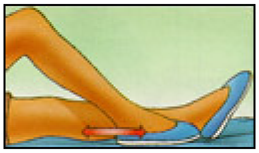


**Ankle Pumps** - Slowly push your foot up and down. Do this exercise several times as often as every 5 or 10 Minutes. This exercise can begin immediately after surgery and continue until you are fully recovered.

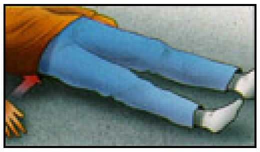


**Ankle Rotations** - Move your ankle inward toward your other foot and then outward away from your other foot. Repeat 5 times in each direction 3 or 4times a day.

**Repeat the following three exercises 10 times 3 or 4 times a day**



**Bed-Supported Knee Bends** - Slide your heel toward your buttocks, bending your knee and keeping your heel on the bed. Do not let your knee roll inward.



**Buttock Contractions** - Tighten buttock muscles and hold to a count of 5.

**Abduction Exercise** - Slide your leg out to the side as far as you can and then back.

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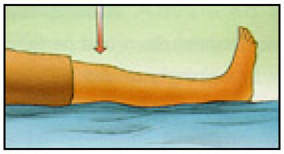
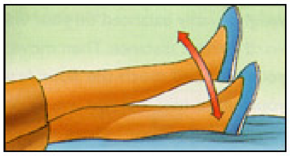


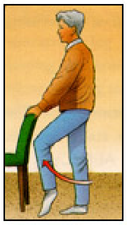
**Quad Set** - Tighten your thigh muscle. Try to straighten your knee. Hold for 5 to 10 seconds. Repeat this exercise 10 times during a 10-minute period. Continue until your thigh feels fatigued.



**Straight Leg Raises** - Tighten your thigh muscle with your knee fully straightened on the bed. As your thigh muscle tightens, lift your leg several inches off the bed. Hold for 5 to 10 seconds. Slowly lower. Repeat until your thigh feels fatigued.

**Standing Exercises** - Soon after your surgery, you will be out of bed and able to stand. You will require help since you may become dizzy the first several times you stand. As you regain your strength, you will be able to stand independently. While doing these standing exercises, make sure you are holding on to a firm surface such as a bar attached to your bed or a wall.

**Repeat the following exercises 10 times 3 or 4 times a day**



**Standing Knee Raises** - Lift your operated leg toward your chest. Do not lift your knee higher than your waist. Hold for 2 or 3 counts and put your leg down.

**Standing Hip Abduction** - Be sure your hip, knee and foot are pointing straight forward. Keep your body straight. With your knee straight, lift your leg out to the side. Slowly lower your leg so your foot is back on the floor.

**Standing Hip Extensions** - Lift your operated leg backward slowly. Try to keep your back straight. Hold for 2 or 3 counts. Return your foot to the floor.

## Walking and Early Activity

Soon after surgery, you will begin to walk short distances in your hospital room and perform light everyday activities. This early activity helps your recovery by helping your hip muscles regain strength and movement.

**Walking with Walker** - Full Weight Bearing - Stand comfortably and erect with your weight evenly balanced on your walker or crutches. Move your walker or crutches forward a short distance. Then move forward, lifting your operated leg so that the heel of your foot will touch the floor first. As you move, your knee and ankle will bend and your entire foot will rest evenly on the floor. As you complete the step allow your toe to lift off the floor. Move the walker again and your knee and hip will again reach forward for your next step. Remember, touch your heel first, then flatten your foot, then lift your toes off the floor. Try to walk as smoothly as you can. Don’t hurry. As your muscle strength and endurance improve, you may spend more time walking. Gradually, you will put more and more weight on your leg.

**Walking with Cane or Crutch** - A walker is often used for the first several weeks to help your balance and to avoid falls. A cane or a crutch is then used for several more weeks until your full strength and balance skills have returned. Use the cane or crutch in the hand opposite the operated hip. You are ready to use a cane or single crutch when you can stand and balance without your walker, when your weight is placed fully on both feet, and when you are no longer leaning on your hands while using your walker.

**Stair Climbing and Descending** - The ability to go up and down stairs requires both flexibility and strength. At first, you will need a handrail for support and you will only be able to go one step at a time. Always lead up the stairs with your good leg and down the stairs with your operated leg. Remember "up with the good" and "down with the bad." You may want to have someone help you until you have regained most of your strength and mobility. Stair climbing is an excellent strengthening and endurance activity. Do not try to climb steps higher than those of the standard height Of seven inches and always use the handrail for balance.

## Advanced Exercises and Activities

A full recovery will take many months. The pain from your problem hip before your surgery and the pain and swelling after surgery have weakened your hip muscles. The following exercises and activities will help your hip muscles recover fully. These exercises should be done in 10 repetitions four times a day with one end of the tubing around the ankle of your operated leg and the opposite end of the tubing attached to a stationary object such as a locked door or heavy furniture. Hold on to a chair or bar for balance.

### Elastic Tube Exercises

**Resistive Hip Flexion** - Stand with your feet slightly apart. Bring your operated leg forward keeping the knee straight. Allow your leg to return to its previous position.

**Resistive Hip Abduction** -Stand sideways from the door and extend your operated leg out to the side. Allow your leg to return to its previous position.

**Resistive Hip Extensions** - Face the door or heavy object to which the tubing is attached and pull your leg straight back. Allow your leg to return to its previous position.

**Exercising** - Exercising is an excellent activity to help you regain muscle strength and hip mobility. Adjust the seat height so that the bottom of your foot just touches the pedal with your knee almost straight. Pedal backwards at first. Pedal forward only after comfortable cycling motion is possible backwards. As you become stronger (at about 4 to 6 weeks) slowly increase the tension on the exercycle. Exercycle forward 10 to 15 minutes twice a day, gradually building up to 20 to 30 minutes 3 to 4 times a week.

**Walking** - Take a cane with you until you have regained your balance skills. In the beginning, walk 5 or 10 minutes 3 or 4 times a day. As your strength and endurance improves, you can walk for 20 or 30 minutes 2 or 3 times a day. Once you have fully recovered, regular walks, 20 or 30 minutes 3 or 4 times a week, will help maintain your strength.

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# Do's and Don'ts of Hip Replacement Post-op

**Some of the most common precautions:**

- Don't cross your legs at the knees for at least 8 weeks.
- Don't bring your knee up higher than your hip.
- Don't lean forward while sitting or as you sit down.
- Don't try to pick up something on the floor while you are sitting.
- Don't turn your feet excessively inward or outward when you bend down.
- Do keep the leg facing forward.
- Do keep the affected leg in front as you sit or stand.
- Don't reach down to pull up blankets when lying in bed.
- Don't bend at the waist beyond 90 degrees.
- Don't stand pigeon-toed.
- Do use a high kitchen or bar stool in the kitchen.
- Don't kneel on the knee on the unoperated leg (the good side).
- Do kneel on the knee on the operated leg (the bad side).
- Don't use pain as a guide for what you may or may not do.
- Do use ice to reduce pain and swelling, but remember that ice will diminish sensation. Don't apply ice directly to the skin; use an ice pack or wrap it in a damp towel.
- Do apply heat before exercising to assist with range of motion. Use a heating pad or hot, damp towel for 15 to 20 minutes.
- Do cut back on your exercises if your muscles begin to ache, but don't stop doing them!

# Kidney Failure

## Definition

Renal failure or kidney failure is the condition in which the kidneys fail to function adequately. This occurs due to a decrease in the glomerular filtration rate which results in an elevated serum creatinine.

## Characteristics

Causes of kidney failure include:

  - Diabetic Nephropathy
  - High Blood Pressure
  - Glomerular Diseases
  - Inherited and Congenital Kidney Diseases
  - Poisons and trauma
  - Over-the-counter medicines
- Primary symptoms due to buildup of wastes in the blood system and absence of hormones normally made in the healthy kidney.
- There is no cure.
- Treatments consist of hemodialysis, peritoneal dialysis or transplant.
- Diet is important in both preventing or furthering disease and during treatment.

## Functional Considerations

- These are primarily related to anemia, fatigue, diet, depression and other systemic issues related to treatment and disease state.
- What is the diet? There may be a basis to exceed HTGs for Meal Prep to prepare the diet.
- Does the consumer need transportation to hemodialysis center? Both ways? This would be medical accompaniment; wait time would not be authorized. Time would not be authorized if the dialysis center provides transportation, or public transportation is available.
- Can the consumer manage all aspects of Peritoneal dialysis if this is the treatment?
- Does the consumer need creams applied to treat itchy skin?
- If the consumer is depressed, refer to the appropriate local resource.

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

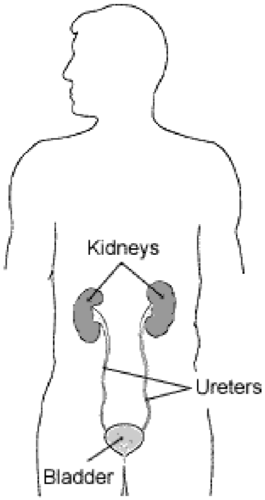
# The Kidneys and How They Work

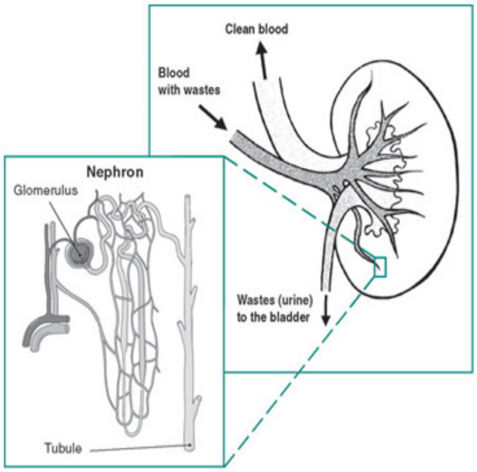
The kidneys are vital organs that perform many functions to keep blood clean and chemically balanced.

## What Do the Kidneys Do?

The kidneys are bean-shaped organs, each about the size of a fist. They are located near the middle of the back, just below the rib cage. The kidneys are sophisticated reprocessing machines. Every day, the kidneys process about 200 quarts of blood to sift out about 2 quarts of waste products and extra water. The waste and extra water become urine, which flows to the bladder through tubes called ureters. The bladder stores urine until emptying.

Wastes in the blood come from the normal breakdown of active tissues and from the food. The body uses the food for energy and self-repair. After the body has taken what it needs from the food, waste is sent to the blood. If the kidneys did not remove these wastes, the wastes would build up in the blood and damage the body.





The actual filtering occurs in tiny units inside the kidneys called nephrons. Every kidney has about a million nephrons. In the nephron, a glomerulus—which is a tiny blood vessel, or capillary—intertwines with a tiny urine-collecting tube called a tubule. A complicated chemical exchange takes place, as waste materials and water leave the blood and enter the urinary system.

At first, the tubules receive a combination of waste materials and chemicals that the body can still use. The kidneys measure out chemicals like sodium, phosphorus, and potassium and release them back to the blood to return to the body. In this way, the kidneys regulate the body's level of these substances. The right balance is necessary for life, but excess levels can be harmful.

In addition to removing wastes, kidneys release three important hormones:

- **erythropoietin** (eh-RITH-ro-POY-eh-tin), or EPO, which stimulates the bone marrow to make red blood cells
- **renin** (REE-nin), which regulates blood pressure
- **calcitriol** (kal-suh-TRY-ul), the active form of vitamin D, which helps maintain calcium for bones and for normal chemical balance in the body

## What is Renal Function?

With two healthy kidneys, there is 100 percent of renal function. This is more renal function than is really needed. Some people are born with only one kidney, and these people are able to lead normal, healthy lives. Many people donate a kidney for transplantation to a family member or friend. Small declines in renal function may not cause a problem.

But many people with reduced renal function have a kidney disease that will get worse. Serious health problems occur if there is less than 25 percent of normal renal function. If renal function drops below 10 to 15 percent, a person cannot live long without some form of renal replacement therapy—either dialysis or transplantation.

## Why Do Kidneys Fail?

Most kidney diseases attack the nephrons, causing them to lose their filtering capacity. Damage to the nephrons may happen quickly, often as the result of injury or poisoning. But most kidney diseases destroy the nephrons slowly and silently. Only after years or even decades will the damage become apparent. Most kidney diseases attack both kidneys simultaneously.

The two most common causes of kidney disease:

- **Diabetic Nephropathy**
- **High Blood Pressure**
- **Glomerular Diseases -** include autoimmune diseases, infection-related diseases, and sclerotic diseases which attack the tiny blood vessels (glomeruli) within the kidney.
- **Inherited and Congenital Kidney Diseases –** include Polycystic kidney disease (PKD)

Other causes of kidney disease:

- Poisons and trauma, for example a direct and forceful blow to the kidneys, can lead to kidney disease.
- Over-the-counter medicines can be poisonous to the kidneys if taken regularly over a long period of time. Products that combine aspirin, acetaminophen, and other medicines such as ibuprofen have been found to be the most dangerous to the kidneys.

## How Do Kidneys Fail?

Many factors that influence the speed of kidney failure are not completely understood. Researchers are still studying how protein in the diet and cholesterol levels in the blood affect kidney function.

### Acute Renal Failure (ARF)

- Sudden drops in kidney function are called acute renal failure.
- Often due to poisons, drugs or trauma.
- May lead to permanent loss of kidney function.

If the kidneys are not seriously damaged, acute renal failure may be reversed.

### Chronic Kidney Disease (CKD)

- Most kidney problems - happens slowly.
- People may have “silent” kidney disease for years. Is a gradual loss of kidney function.
- May go on to permanent kidney failure.
- Have a high risk of dying from a stroke or heart attack.

### End-Stage Renal Disease

Total or nearly total and permanent kidney failure is called end-stage renal disease (ESRD). People with ESRD must undergo dialysis or transplantation to stay alive.

## What are the Signs of Kidney Disease?

People in the early stages of kidney disease usually do not feel sick at all.

Signs of worsening kidney disease:

- need to urinate more often or less often
- feeling tired or itchy
- losing appetite or experiencing nausea and vomiting
- hands or feet may swell or feel numb
- increased drowsy or have trouble concentrating
- skin may darken
- muscle cramps.

## What Medical Tests are Used to Detect Kidney Disease?

Since someone can have kidney disease without any symptoms, the doctor may first detect the condition through routine blood and urine tests. The National Kidney Foundation recommends simple tests to screen for kidney disease:

- A blood pressure measurement,
- A spot check for protein or albumin in the urine (proteinuria),
- A calculation of glomerular filtration rate (GFR) based on a serum creatinine measurement, and
- Measuring urea nitrogen in the blood provides additional information.

### Additional Tests for Kidney Disease

If blood and urine tests indicate reduced kidney function, a doctor may recommend additional tests to help identify the cause of the problem.

**Renal imaging**:

- ultrasound,
- computed tomography (CT scan), and
- magnetic resonance imaging (MRI).

These tools are most helpful in finding unusual growths or blockages to the flow of urine.

**Renal biopsy:**

Done for direct examination or tissue sample.

## What are the Stages of Kidney Disease?

GFR is the best indicator of how well the kidneys are working.

**Five Stages of Kidney Chronic Kidney Failure**

(National Kidney Foundation 2002)

| | | |
|---|---|---|
| **Increased risk of CKD** | A GFR of 90 or above is considered normal. | ▪ Diabetes, high blood pressure, or a family history of kidney disease. ↑ risk<br>▪ ↑ risk with age: over 65 2x as likely to develop CKD as people between the ages of 45 and 65<br>▪ African Americans also have a higher risk of developing CKD |
| **Stage 1** | Kidney damage with normal GFR (90 or above) | ▪ Kidney damage may be detected before the GFR begins to decline<br>▪ Goals of treatment are to slow the progression of CKD and reduce the risk of heart and blood vessel disease. |
| **Stage 2** | Kidney damage with mild decrease in GFR (60 to 89) | ▪ Continue treatment to reduce the risk of other health problems. |
| **Stage 3** | Moderate decrease in GFR (30 to 59) | ▪ Anemia and bone problems become more common. |
| **Stage 4** | Severe reduction in GFR (15 to 29) | ▪ Patient may need hemodialysis, peritoneal dialysis or consider transplantation |
| **Stage 5** | Kidney failure (GFR less than 15) | ▪ Dialysis or a kidney transplant is needed. |

## What Can be Done about Kidney Disease?

Chronic kidney disease often cannot be cured. In the early stages of a kidney disease, a person may be able to make their kidneys last longer by taking certain steps:

| | |
|---|---|
| Blood Glucose | • Keep in close control |
| Blood Pressure | • Keep blood pressure below 130/80<br>• Diuretic plus antihypertensive medication may be needed |
| Diet<br>• Protein<br>• Cholesterol<br>• Sodium<br>• Potassium | • Low protein diet - impaired kidneys may fail to separate the protein from the wastes<br>• Low fat and low cholesterol to prevent heart disease<br>• Low sodium to decrease chance of high blood pressure<br>• Diseased kidneys may fail to remove excess potassium, and with very poor kidney function, high potassium levels can affect the heart rhythm |
| Pain medications | • Consult with MD before taking – may further damage kidney |
| Smoking | • Increases risk of kidney disease |
| Anemia | • Injections of a man-made form of EPO may be required (diseased kidneys may not make enough EPO). |

## What Happens if the Kidneys Fail Completely?

1. Complete and irreversible kidney failure is sometimes called **end-stage renal disease, or ESRD**.
2. If the kidneys stop working completely, the body fills with extra water and waste products. This condition is called **uremia**.
    - Untreated uremia may lead to **seizures or coma** and will ultimately result in death.
    - If the kidneys stop working completely, they will need to undergo **dialysis or kidney transplantation**.

### Symptoms of Kidney Failure

Kidney failure can hit in surprising ways. Symptoms of kidney failure are as a result of the build – up of waste products in the blood (uremic toxins) and lack of hormones normally produced in the kidneys.

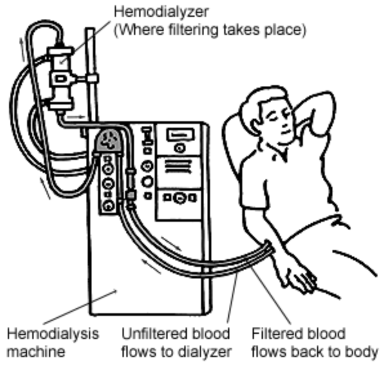
| *Symptom* | *Description* | *Treatments in addition to dialysis* |
|---|---|---|
| **Anemia and Fatigue** | ▪ due to decreased red blood cells resulting in decrease in oxygen to the tissues and low production of EPO due to kidney insufficiencies. | ▪ EPO injections may be given |
| **Loss of Appetite and Nausea** | ▪ uremia can change the way food tastes. | |
| **Itching (Pruritus)** | ▪ often worse during or just after the dialysis treatment<br>▪ caused by uremic toxins that aren't removed from the blood during dialysis<br>▪ or may be caused by high levels of parathyroid hormone (PTH) | ▪ General cure not found. Possible treatments:<br>o removing parathyroid glands<br>o oral phosphate binders<br>o ultraviolet light<br>o EPO shots<br>o Antihistamines (Benadryl, Atarax, Vistaril)<br>o Capsaicin cream<br>o Lanolin or camphor creams |

| | | |
|---|---|---|
| **Sleep Disorders** | ▪ **insomnia** (trouble getting to sleep<br>▪ **sleep apnea** syndrome - breaks in breathing during sleep<br>▪ "day-night reversal" (insomnia at night, sleepiness during the day)<br>▪ **"restless" legs** - aching, uncomfortable, jittery, feelings in legs, often kick or thrash their legs during sleep. | ▪ Apnea treatments:<br>o losing weight,<br>o changing sleeping position, and<br>o wearing a mask that gently pumps air continuously into the nose (nasal continuous positive airway pressure, or CPAP)<br>▪ Restless legs treatments:<br>o Moderate exercise during the day<br>o Avoid exercise before going to bed<br>o Avoid or reduce caffeine, alcohol, and tobacco<br>o massages or warm baths<br>o benzodiazepines may help such as Klonopin, Librium, Valium, and Halcion<br>o levodopa (Sinemet) – also used to treat Parkinson's |
| **Renal Osteodystrophy** | ▪ bone disease of kidney failure<br>▪ affects 90 percent of dialysis patients<br>▪ bones to become thin, weak, or malformed<br>▪ Older patients and women who have gone through menopause are at greater risk | |
| **Amyloidosis(DRA)** | ▪ common in people who have been on dialysis for more than 5 years<br>▪ causes pain, stiffness, and fluid in the joints, as is the case with arthritis | |
| **Depression** | ▪ time spent on dialysis<br>▪ have less energy<br>▪ changes in work or home life<br>▪ giving up some activities and responsibilities<br>▪ Accepting new reality | ▪ Make sure treatments are attending to the life impacts of ESRD<br>▪ A counselor or social worker can help with coping |

## Treatment Choice: Dialysis

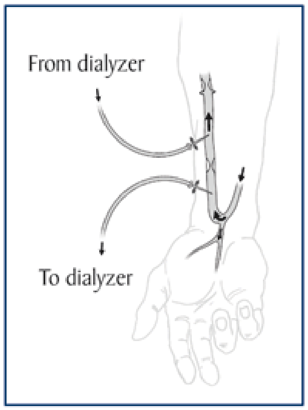
The two major forms of dialysis are hemodialysis and peritoneal dialysis.

In **hemodialysis,** the blood is sent through special filter called a dialyzer that functions as an artificial kidney to clean the blood. The blood travels through tubes into the dialyzer, which filters out wastes and extra water. The clean blood is returned to the body. Hemodialysis is usually performed at a dialysis center three times per week for 3 to 4 hours. During treatment, the patient can read, write, sleep, talk, or watch TV.



**Vascular Access for Hemodialysis**

This access provides an efficient way for blood to be carried from the body to the dialyzer and back without causing discomfort. The two main types of access are a fistula and a graft.

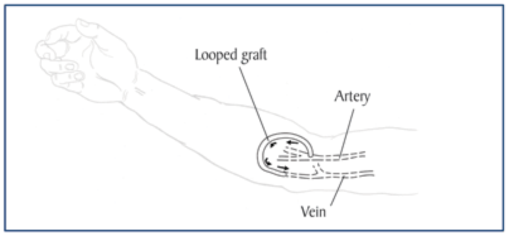


**Fistula**

- using the patient's own blood vessels;
- an artery is connected directly to a vein,
- usually in the forearm.
- the increased blood flow makes the vein grow larger and stronger so that it can be used for repeated needle insertions.
- is the preferred type of access
- It may take several weeks to be ready for use

**Graft**

- connects an artery to a vein by using a synthetic tube.
- doesn't need to develop as a fistula does, so it can be used sooner after placement.
- is more likely to have problems with infection and clotting.



**Catheter**

- for quickly progressing kidney failure.
- not time to place a permanent vascular access –usually temporary access
- the catheter is a tube inserted into a vein in the neck, chest, or leg near the groin
- some people use a catheter for long-term access as well
- Catheters that will be needed for more than about 3 weeks are placed under the skin to increase comfort and reduce complications

**Possible Complications of Hemodialysis**

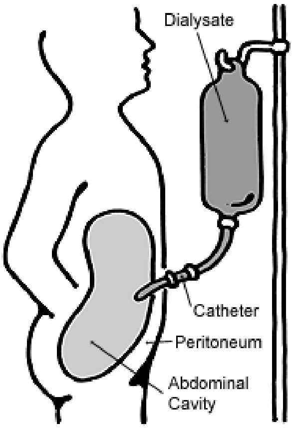
- **Vascular access problems** are the most common reason for hospitalization among people on hemodialysis.
    - infection,
    - blockage from clotting, and
    - poor blood flow. These problems can keep treatments from working.

A patient may need to undergo repeated surgeries in order to get a properly functioning access.

- **Other problems** can be caused by rapid changes in the body's water and chemical balance during treatment.
    - Muscle cramps and
    - hypotension—a sudden drop in blood pressure— can make patients feel weak, dizzy, or nauseated.

People usually need a few months to adjust to hemodialysis. Side effects can often be treated quickly and easily, so they should always be reported to the doctor and dialysis staff. Many side effects can be avoided by following a proper diet, limiting liquid intake, and taking medicines as directed.

**Peritoneal dialysis** uses the lining of the abdomen, or belly, to filter the blood. This lining is called the peritoneal membrane and acts as the artificial kidney.



A mixture of minerals and sugar dissolved in water, called dialysis solution, travels through a soft tube into the belly. The sugar—called dextrose—draws wastes, chemicals, and extra water from the tiny blood vessels in the peritoneal membrane into the dialysis solution. After several hours, the used solution is drained from the abdomen through the tube, taking the wastes from the blood with it. Then the abdomen is filled with fresh dialysis solution, and the cycle is repeated. The process of draining and refilling is called an exchange.

**Vascular Access for Peritoneal Dialysis**

- soft tube catheter surgically placed into the abdomen
- usually from 10 days to 2 or 3 weeks—for the insertion site to heal
- best to use after adequate healing
- is permanent

## Types of Peritoneal Dialysis

Three types of peritoneal dialysis are available. All are performed by the patient, usually without need of another to help.

| | |
|---|---|
| **Continuous Ambulatory Peritoneal Dialysis (CAPD)** | ▪ CAPD requires no machine and can be done in any clean, well-lit place<br>▪ blood is always being cleaned<br>▪ dialysis solution stays in the abdomen for a dwell time of 4 to 6 hours, or more<br>▪ process of draining the used dialysis solution and replacing it with fresh solution takes about 30 to 40 minutes<br>▪ change the dialysis solution at least four times a day<br>▪ most people and sleep with solution in their abdomens at night<br>▪ not necessary to wake up and perform dialysis tasks during the night |
| **Continuous Cycler-Assisted Peritoneal Dialysis (CCPD)** | ▪ uses a machine called a cycler to fill and empty the abdomen three to five times during the night during sleep<br>▪ in the morning, begin one exchange occurs with a dwell time that lasts the entire day<br>▪ additional exchange may be done in the middle of the afternoon without the cycler to increase the amount of waste removed and to reduce the amount of fluid left behind in the body |
| **Combination of CAPD and CCPD** | ▪ if the patient weighs more than 175 pounds<br>▪ if the peritoneum filters wastes slowly |

**Possible Complications of Peritoneal Dialysis**

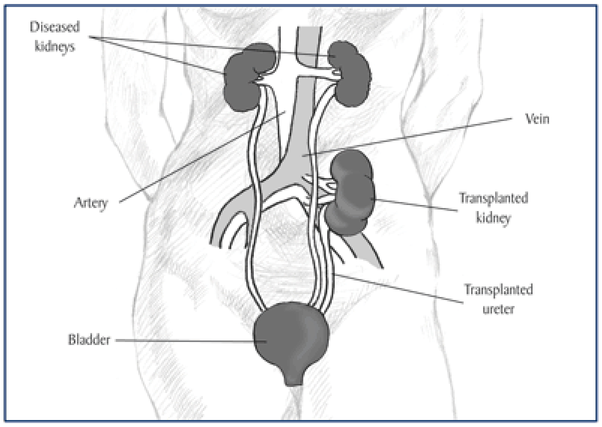
- **peritonitis**, a serious abdominal infection.
  - can occur if the opening where the catheter enters the body becomes infected or if contamination occurs as the catheter is connected or disconnected from the bags.
  - Peritonitis requires antibiotic treatment by the doctor
  - To avoid peritonitis,
    - procedures must be followed exactly with clean technique
  - early signs of peritonitis –report to MD immediately
    - fever,
    - unusual color or cloudiness of used fluid
    - redness or pain around the catheter.

**Dialysis is Not a Cure**

Hemodialysis and peritoneal dialysis are **treatments** that help replace the work the kidneys did. These treatments help the patient feel better and live longer, but they don't cure kidney failure.

## Treatment Choice: Kidney Transplantation

Kidney transplantation surgically places a healthy kidney from another person into the body. The donated kidney does the work that the two failed kidneys used to do. The new kidney may start working right away or may take up to a few weeks to make urine. Unless the patient's own kidneys are causing infection or high blood pressure, they are left in place.



A donated kidney may come from an anonymous donor who has recently died or from a living person, usually a relative. The wait for a deceased donor kidney can be several years.

The kidney that is received must be a good match. The transplant team considers three factors in matching kidneys with potential recipients. These factors help predict whether the body's immune system will accept the new kidney or reject it.

- **Blood type.** Blood type (A, B, AB, or O) must be compatible with the donor's. Blood type is the most important matching factor.
- **Human leukocyte antigens (HLAs).** The cells carry six important HLAs, three inherited from each parent. Family members are most likely to have a complete match. The patient may still receive a kidney if the HLAs aren't a complete match as long as their blood type matches the organ donor's and other tests are negative.
- **Cross-matching antigens**. The last test before implanting an organ is the cross-match. A small sample of the patient's blood will be mixed with a sample of the organ donor's blood in a tube to see if there's a reaction. If no reaction occurs, the result is called a negative cross-match, and the transplant operation can proceed.

The more the new kidney is like the recipient, the less likely their immune system is to reject it. Between 85 and 90 percent of transplants from deceased donors are working 1 year after surgery. Transplants from living relatives often work better than transplants from deceased donors because they're usually a closer match.

The surgery takes 3 to 4 hours. The usual hospital stay is about a week. After the patient leaves the hospital, they will have regular follow-up visits.

The donor will probably stay in the hospital about the same amount of time – about a week. However, a new technique for removing a kidney for donation uses a smaller incision and may make it possible for the donor to leave the hospital in 2 to 3 days.

**Possible Complications of Transplantation**

- **Rejection** – Transplantation is the closest thing to a cure. But no matter how good the match, the body may reject the new kidney.
    - A common cause of rejection is not taking medication as prescribed.
    - immunosuppressants to help prevent the body's immune system from attacking (rejecting) the kidney
    - need to take immunosuppressants every day for as long as the transplanted kidney is functioning
    - sometimes, even if take correctly, the drugs can't stop the body from rejecting the new kidney
    - If rejection occurs – will restart dialysis and possibly wait for another transplant.

- **Immunosuppressant side effects** – In some patients:
    - facial fullness
    - weight gain
    - development of acne or facial hair
    - ↑ risk of developing cancer –due to diminished immune system
    - cataracts
    - diabetes
    - extra stomach acid
    - high blood pressure
    - bone disease

## Treatment Choice: Refusing or Withdrawing from Treatment

For many people, dialysis and transplantation not only extend life but also improve quality of life. For others who have serious ailments in addition to kidney failure, dialysis may seem a burden that only prolongs suffering. Patients have the right to refuse or withdraw from dialysis if they feel they have no hope of leading a life with dignity and meaning. This decision should be made in conjunction with the spouse, family, religious counselor, or social worker.

With withdraw from dialysis treatments or refusal to begin them, the patient may live for a few days or for several weeks, depending on the health and the remaining kidney function. The doctor can provide medicines to make the patient more comfortable during this time. Patients my change their mind about refusing dialysis, and may start or resume the treatments at any time.

Even if the patient is satisfied with the quality of life on dialysis, they should think about circumstances that might make them want to stop dialysis treatments. At some point in a medical crisis, they might lose the ability to express the wishes to the doctor. An advance directive is a statement or document in which gives instructions either to withhold treatment or to provide it, depending on the wishes and the specific circumstances.

### Paying for Treatment

Treatment for kidney failure is expensive, but Federal health insurance plans pay much of the cost, usually up to 80 percent. Often, private insurance or state programs pay the rest.

Adapted from the following NIH Publications: No. 06–4241 (November 2005); No. 06–6059 (July 2006); No. 07–2412 (March 2007) National Kidney and Urologic Diseases Information Clearinghouse, 3 Information Way Bethesda, MD 20892–3580 www. niddk.nih.gov

## Diet and Dialysis

Once the kidneys have stopped working, hemodialysis removes wastes from the blood. Between dialysis sessions, wastes can build up in the blood and cause problems. The amount of wastes can be reduced by monitoring what the patient eats and drinks. A good meal plan can improve dialysis and health.

### What about Fluids?

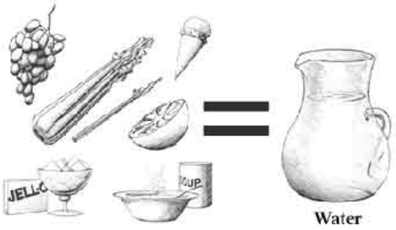
The hemodialysis patient must watch how much fluids they drink daily. Any food that is liquid at room temperature also contains water. These foods include soup, Jell-O, and ice cream. Many fruits and vegetables contain lots of water, too. They include melons, grapes, apples, oranges, tomatoes, lettuce, and celery. All these foods add to fluid intake.

Fluid can build up between dialysis sessions, causing swelling and weight gain. The extra fluid affects blood pressure and can make the heart work harder. Serious heart trouble can result from overloading the system with fluid.

**Control Thirst**
The best way to reduce fluid intake is to reduce thirst caused by the salt intake. Avoid salty foods like chips and pretzels. Choose low-sodium products.

Keep fluids down by drinking from smaller cups or glasses. Freeze juice in an ice cube tray and eat it like a popsicle.

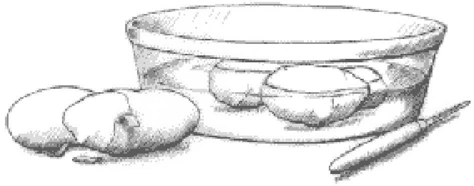
"Dry weight" is the weight after a dialysis session when all of the extra fluid in has been removed. If too much fluid builds up between sessions, it is harder to get down to a proper dry weight. The patient's dry weight may change over a period of 3 to 6 weeks. The each patient has a different goal dry weight determined by the doctor.



Even on hemodialysis, the kidneys may still be able to remove some fluid. It is also likely the kidneys may not remove any fluid at all. This is why every patient has a different daily allowance for fluid. Each patient should be aware of that allowance.

**What about Potassium?**
Potassium is a mineral found in many foods, especially milk, fruits, and vegetables. It affects how steadily the heart beats. Healthy kidneys keep the right amount of potassium in the blood to keep the heart beating at a steady pace. Potassium levels can rise between dialysis sessions and affect the heartbeat. Eating too much potassium can be very dangerous. It may even cause death.

To control potassium levels in the blood, avoid foods like avocados, bananas, kiwis, and dried fruit, which are very high in potassium. Also, eat smaller portions of other high-potassium foods. For example, eat half a pear instead of a whole pear. Eat only very small portions of oranges and melons.



**Dialyzing Potatoes and Other Vegetables**
Some of the potassium from potatoes and other vegetables can be removed by peeling them, then soaking them in a large amount of water for several hours. Drain and rinse the vegetables before cooking them.

**High-Potassium Foods:**

apricots
avocados
bananas
beets
Brussels sprouts
cantaloupe
clams
dates
figs
kiwi fruit
lima beans
melons
milk
nectarines
orange juice
oranges
peanuts
pears (fresh)
potatoes
prune juice
prunes
raisins
sardines
spinach
tomatoes
winter squash
yogurt

**What about Phosphorus?**
Phosphorus is a mineral found in many foods. If there is too much phosphorus in the blood, it pulls calcium from the bones. Losing calcium will make the bones weak and likely to break. Also, too much phosphorus may cause skin itching. Foods like milk and cheese, dried beans, peas, colas, nuts, and peanut butter are high in phosphorus. Usually, people on dialysis are limited to 1/2 cup of milk per day.

Most patients will probably need to take a phosphate binder like Renagel, PhosLo, Tums, or calcium carbonate to control the phosphorus in the blood between dialysis sessions. These medications act like sponges to soak up, or bind, phosphorus while it is in the stomach.

Because it is bound, the phosphorus does not get into the blood. Instead, it is passed out of the body in the stool. Taking a phosphate binder helps control phosphorus in the blood.

**What about Protein?**
Before the patient is on dialysis, their doctor may have told them to follow a low-protein diet. Being on dialysis changes this. Most people on dialysis are encouraged to eat as much high-quality protein as they can. Protein helps keep muscle and repair tissue. The better nourished the patient is, the healthier they will be. They will also have greater resistance to infection and recover from surgery more quickly.

Protein is broken down in the body into a waste product called urea. If urea builds up in the blood, it's a sign of declining condition. Eating mostly high-quality proteins is important because they produce less waste than others. High-quality proteins come from meat, fish, poultry, and eggs (especially egg whites).

Poultry and fish, like broiled flounder, are good sources of high-quality protein.

**What about Sodium?**
Sodium is found in salt and other foods. Most canned foods and frozen dinners contain large amounts of sodium. Too much sodium creates thirst. But if more fluid is consumed, the heart has to work harder to pump the fluid through the body. Over time, this can cause high blood pressure and congestive heart failure.

The patient should try to eat fresh foods that are naturally low in sodium. Look for products labeled *low sodium*.

Find new ways to spice up food. Do not use salt substitutes because they contain potassium. A dietitian can help the patient find spices and spice blends to use to flavor foods that are sodium and potassium free.

**What about Calories?**
Calories provide energy for the body. Some people on dialysis may need to cut calories. A dietitian will need to help plan the appropriate diet for the patient.

Some people need to gain weight and will need to find ways to add calories to their diet. Vegetable oils—like olive oil, canola oil, and safflower oil—are good sources of calories. Use them generously on breads, rice, and noodles.

Butter and margarines are rich in calories. But these fatty foods can also clog arteries. Use them less often. Soft margarine that comes in a tub is better than stick margarine. Vegetable oils are the healthiest way to add fat to the diet if the patient needs to gain weight.

Hard candy, sugar, honey, jam, and jelly provide calories and energy without clogging arteries or adding other things that the body does not need. **If the patient has diabetes, be very careful about eating sweets. A dietitian's guidance is very important for people with diabetes.**

**What about Vitamin and Mineral Supplements?**
Vitamins and minerals may be missing from the patient's diet because so many foods must be avoided. The doctor may prescribe a vitamin and mineral supplement like Nephrocaps.

**Warning:** Do not take vitamin supplements off the store shelf. They may contain vitamins or minerals that are harmful to the hemodialysis patient. Only vitamins prescribed by a doctor should be taken.

**Diet for Peritoneal Dialysis**

A peritoneal dialysis diet is slightly different from a hemodialysis diet.

- Still need to limit salt and liquids, but may be able to have more of each, compared with hemodialysis.
- The patient must eat more protein.
- The patient may have different restrictions on potassium.
- The patient may need to cut back on the number of calories they eat because there are calories in the dialysis fluid that may cause them to gain weight.

Adapted (8-07) from NIH Publication No. 07–4274 Publication date, December 2006.

# Systemic Lupus Erythematosus (Lupus)

## Definition

Lupus is a chronic autoimmune disease that is potentially debilitating and sometimes fatal as the immune system attacks the body's cells and tissue, resulting in inflammation and tissue damage. There is no cure for Lupus.

## Characteristics

- Lupus is characterized by periods of illness, called flares, and periods of wellness, or remission.
- Understanding how to prevent flares and how to treat them when they do occur helps people with lupus maintain better health.
- Intense research is underway, and scientists funded by the NIH are continuing to make great strides in understanding the disease, which may ultimately lead to a cure.
- This can damage many parts of the body such as the:
    - Joints
    - Skin
    - Kidneys
    - Heart
    - Lungs
    - Blood vessels
    - Brain

## Functional Considerations

- Needs are variable depending upon severity of illness and type of Lupus.
- Needs will intensify during periods of flares.
- Determine the frequency and duration of flare and functional capacity during flare and the functional capacity during remission.
- Medication therapy may negatively affect functionality, especially if on high dose long-term Corticosteroids.
- Medical information may be necessary from several medical specialists to get a complete picture of the consumer's impairments.
- Anticipate there may be frequent medical appointments to several doctors.
- Determine how lupus affects the consumer (fatigue, painful or swollen joints, unexplained fever, skin rashes, and kidney problems, all of the above, other).

NIAMS
National Institute of Arthritis and
Musculoskeletal and Skin Diseases

National Institutes of Health
Department of Health & Human Services

# Systemic Lupus Erythematosus (Lupus)

## What is Lupus?

Lupus is one of many disorders of the immune system known as **autoimmune diseases**. In autoimmune diseases, the immune system turns against parts of the body it is designed to protect. This leads to inflammation and damage to various body tissues.

At present, there is **no cure for lupus**. However, lupus can be effectively treated with drugs, and most people with the disease can lead active, healthy lives. Lupus is characterized by periods of illness, called flares, and periods of wellness, or remission. Understanding how to prevent flares and how to treat them when they do occur helps people with lupus maintain better health. Intense research is underway, and scientists funded by the NIH are continuing to make great strides in understanding the disease, which may ultimately lead to a cure.

This can damage many parts of the body such as the:

- Joints
- Skin
- Kidneys
- Heart
- Lungs
- Blood vessels
- Brain

Although people with the disease may have many different symptoms, some of the most common ones include extreme fatigue, painful or swollen joints (arthritis), unexplained fever, skin rashes, and kidney problems.

There are many kinds of lupus:

- **Systemic lupus erythematosus,** the most common type affects many parts of the body. The word "systemic" means the disease can affect many parts of the body. The symptoms of SLE may be mild or serious. Although SLE usually first affects people between the ages of 15 and 45 years, it can occur in childhood or later in life as well.
- **Discoid lupus erythematosus** – a chronic skin disorder in which a red, raised rash appears on the face, scalp, or elsewhere. The raised areas may become thick and scaly and may cause scarring. The rash may last for days or years and may recur. A small percentage of people with discoid lupus have or develop SLE later.
- **Subacute cutaneous lupus erythematosus** – causes skin lesions that appear on parts of the body exposed to sun. The lesions do not cause scarring.
- **Drug-induced lupus** – can be caused by medications.
- **Neonatal lupus** – a rare type of lupus that affects newborns.

## Who Gets Lupus?

Anyone can get lupus, but it most often affects women. Lupus is also more common in women of African American, Hispanic, Asian, and Native American descent than in Caucasian women.

## What Causes Lupus?

Lupus is a complex disease, and its cause is unknown. It is likely that a combination of genetic, environmental, and possibly hormonal factors work together to cause the disease. The fact that lupus can run in families indicates that its development has a genetic basis.

## What are the Symptoms of Lupus?

Symptoms of lupus vary, but some of the most common symptoms of lupus are:

- Pain or swelling in joints
- Muscle pain
- Fever with no known cause
- Red rashes, most often on the face
- Chest pain when taking a deep breath
- Hair loss
- Pale or purple fingers or toes
- Sensitivity to the sun
- Swelling in legs or around eyes
- Mouth ulcers
- Swollen glands
- Feeling very tired

Less common symptoms include:

- Anemia (a decrease in red blood cells)
- Headaches
- Dizzy spells
- Feeling sad
- Confusion
- Seizures

Symptoms may come and go. The times when a person is having symptoms are called **flares**, which can range from mild to severe. New symptoms may appear at any time.

In some people with lupus, only one system of the body, such as the skin or joints, is affected. Other people experience symptoms in many parts of their body. Just how seriously a body system is affected varies from person to person. The following systems in the body also can be affected by lupus.

- **Kidneys**: Inflammation of the kidneys (nephritis) can impair their ability to get rid of waste products and other toxins from the body effectively. There is usually no pain associated with kidney involvement, although some patients may notice swelling in their ankles. Most often, the only indication of kidney disease is an abnormal urine or blood test. Because the kidneys are so important to overall health, lupus affecting the kidneys generally requires intensive drug treatment to prevent permanent damage.
- **Lungs**: Some people with lupus develop pleuritis, an inflammation of the lining of the chest cavity that causes chest pain, particularly with breathing. Patients with lupus also may get pneumonia.
- **Central nervous system**: In some patients, lupus affects the brain or central nervous system. This can cause headaches, dizziness, memory disturbances, vision problems, seizures, stroke, or changes in behavior.
- **Blood vessels**: Blood vessels may become inflamed (vasculitis), affecting the way blood circulates through the body. The inflammation may be mild and may not require treatment or may be severe and require immediate attention.
- **Blood:** People with lupus may develop anemia, leukopenia (a decreased number of white blood cells), or thrombocytopenia (a decrease in the number of platelets in the blood, which assist in clotting). Some people with lupus may have an increased risk for blood clots.
- **Heart:** In some people with lupus, inflammation can occur in the heart itself (myocarditis and endocarditis) or the membrane that surrounds it (pericarditis), causing chest pains or other symptoms. Lupus can also increase the risk of atherosclerosis (hardening of the arteries).

## How is Lupus Diagnosed?

Diagnosing lupus can be difficult. It may take months or even years for doctors to piece together the symptoms to diagnose this complex disease accurately. No single test can determine whether a person has lupus. The doctor may use many tools to make a diagnosis:

- Medical history
- Complete exam
- Blood tests - The most useful tests identify certain autoantibodies often present in the blood of people with lupus
- Skin biopsy (looking at skin samples under a microscope)
- Kidney biopsy (looking at tissue from the kidney under a microscope)

## How is Lupus Treated?

There are many specialists who will be involved in treatment of the symptoms of lupus.

The **health care team** may include:

- A family doctor
- Rheumatologists – doctors who treat arthritis and other diseases that cause swelling in the joints
- Clinical immunologists – doctors who treat immune system disorders
- Nephrologists – doctors who treat kidney disease
- Hematologists – doctors who treat blood disorders
- Dermatologists – doctors who treat skin diseases
- Neurologists – doctors who treat problems with the nervous system
- Nurses
- Psychologists
- Social workers

The range and effectiveness of treatments for lupus have increased dramatically, giving doctors more choices in how to manage the disease. It is important for the patient to work closely with the doctor and take an active role in managing the disease. Once lupus has been diagnosed, the doctor will develop a treatment plan based on the patient’s age, sex, health, symptoms, and lifestyle. Treatment plans are tailored to the individual’s needs and may change over time. The patient should report new symptoms to the doctor right away so that treatment can be changed if needed.

The **goals of the treatment** plan are to:

- Prevent flares
- Treat flares when they occur
- Reduce organ damage and other problems

Treatments may include **medications** to:

- Reduce swelling and pain
- Prevent or reduce flares
- Calm the immune system
- Reduce or prevent damage to joints

**Nonsteroidal anti-inflammatory drugs (NSAIDs):**

- Drugs that decrease inflammation.
- For people with joint or chest pain or fever.
- May be used alone or in combination with other types of drugs to control pain, swelling, and fever.
- Common side effects of NSAIDs can include stomach upset, heartburn, diarrhea, and fluid retention. Some people with lupus also develop liver, kidney, or even neurological complications, making it especially important to stay in close contact with the doctor while taking these medications.

**Antimalarials:**

- It may be used alone or in combination with other drugs and generally is used to treat fatigue, joint pain, skin rashes, and inflammation of the lungs.
- Clinical studies have found that continuous treatment with antimalarials may prevent flares from recurring.
- A common antimalarial used to treat lupus is hydroxychloroquine (Plaquenil)*.
- Side effects of antimalarials can include stomach upset and, extremely rarely, damage to the retina of the eye.
- Antimalarials are another type of drug commonly used to treat lupus.

**Corticosteroids:**

- The mainstay of lupus.
- Are related to cortisol which is a natural anti-inflammatory hormone. They work by rapidly suppressing inflammation.
- Commonly used drugs: prednisone (Deltasone), hydrocortisone, methylprednisolone (Medrol), and dexamethasone (Decadron, Hexadrol).
- Can be given by mouth, in creams applied to the skin, or by injection.
- Because they are potent drugs, the doctor will seek the lowest dose with the greatest benefit.
- Short-term side effects include swelling, increased appetite, and weight gain. These side effects generally stop when the drug is stopped.
- **It is dangerous to stop taking corticosteroids suddenly**, so it is very important that the doctor and patient work together in changing the corticosteroid dose.
- Long-term side effects of corticosteroids can include stretch marks on the skin, weakened or damaged bones (osteoporosis and osteonecrosis), high blood pressure, damage to the arteries, high blood sugar (diabetes), infections, and cataracts. Typically, the higher the dose and the longer they are taken, the greater the risk and severity of side effects.

**Immunosuppressives:**

- Restrain the overactive immune system by blocking the production of immune cells.
- Used with patients whose kidneys or central nervous systems are affected by lupus.
- Commonly used drugs: cyclophosphamide (Cytoxan) and mycophenolate mofetil (CellCept).
- May be given by mouth or by IV infusion.
- Side effects may include nausea, vomiting, hair loss, bladder problems, decreased fertility, and increased risk of cancer and infection. The risk for side effects increases with the length of treatment.
- As with other treatments for lupus, there is a risk of relapse after the immunosuppressives have been stopped.

**Methotrexate:**

- Not as commonly used.
- Disease-modifying antirheumatic drug.
- Commonly used drugs: Folex, Mexate, Rheumatrex.
- Treatments may cause harmful side effects, it is important to report any new symptoms to the doctor promptly.

**Alternative treatments** are those that are not part of standard treatment. No research shows that this kind of treatment works for people with lupus. The patient should talk to their doctor about alternative treatments.

## What Can I Do?

It is vital that the patient take an active role in their treatment. One key to living with lupus is to know about the disease and its impact. Being able to spot the warning signs of a flare can help prevent the flare or make the symptoms less severe.

Many people with lupus have certain symptoms just before a flare, such as:

- Feeling more tired
- Pain
- Rash
- Fever
- Stomach ache
- Headache
- Dizziness

The patient should **see the doctor often**, even when symptoms are not severe. These visits will help:

- Look for changes in symptoms
- Predict and prevent flares
- Change the treatment plan as needed
- Detect side effects of treatment

## Patient Tips for Working with their Doctor(s)

Seek a health care provider who is familiar with SLE and who will listen to and address concerns.

- Provide complete, accurate medical information.
- Make a list of questions and concerns in advance.
- Be honest and share their point of view with the health care provider.
- Ask for clarification or further explanation if needed.
- Talk to other members of the health care team, such as nurses, therapists, or pharmacists.
- Do not hesitate to discuss sensitive subjects (for example, birth control, intimacy).
- Discuss any treatment changes with before making them.

It is also important to find **ways to cope with the stress** of having lupus.

- **Exercising**
- Finding ways to **relax** may make it easier to cope.
- **Good support system** can also help. A support system may include family, friends, community groups, or doctors.
- **Support groups** to be very useful. Besides providing support, taking part in a support group can make the patient feel better about himself and help keep a good outlook.

Learning more about lupus is very important. Studies have shown that **patients who are informed and involved in their own care**:

- Have less pain.
- Make fewer visits to the doctor.
- Feel better about themselves.
- Remain more active.

## What Do Pregnant Women with Lupus Need to Know?

Although a lupus pregnancy is considered high risk, most women with lupus carry their babies safely to the end of their pregnancy. Women with lupus have a higher rate of miscarriage and premature births compared with the general population. In addition, women who have antiphospholipid antibodies are at a greater risk of miscarriage in the second trimester because of their increased risk of blood clotting in the placenta.

## What are Researchers Trying to Learn about Lupus?

Lupus is the focus of intense research. Studies are looking at:

- The genes that play a role in lupus and in the immune system
- Ways to change the immune system in people with lupus
- Lupus in ethnic groups
- Things in the environment that may cause lupus
- The role of hormones in lupus
- Birth control pills and hormone therapy in women with lupus
- Heart disease in people with lupus
- Drugs that lower cholesterol in children with lupus
- The causes of nervous system damage in people with lupus
- Treatments for lupus

Adapted (8-07) from NIH Publication No. 03-4178(August 2003) from U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Institute of Arthritis and Musculoskeletal and Skin Diseases http://www.niams.nih.gov.

# Multiple Sclerosis (MS)

## Definition

MS is a chronic, inflammatory, demyelinating disease that affects the central nervous system.

## Characteristics

MS can cause a variety of symptoms, including changes in sensation, visual problems, muscle weakness, depression, difficulties with coordination and speech, severe fatigue, cognitive impairment, problems with balance, overheating, and pain.

MS will cause impaired mobility and disability in more severe cases.

Clinically categorized as:

- Relapsing-remitting (RR)
- Chronic progressive MS
    - Primary-progressive (PP)
    - Secondary-progressive (SP)
    - Progressive-relapsing (PR)
- Benign
- Malignant

## Functional Considerations

- Functional implications are dependent upon the type of MS and progression.
- The consumer may have severe functional limitations or minor impacts.
- Once the progression has stopped, function can improve.
- Many people with MS have cycles of impairment and relief which should be considered in the assessment process.
- If MS is progressive, functioning may deteriorate over time.
- Symptoms of MS are wide ranging including bowel, bladder, muscle, vision, cognitive and emotional function.
- Tolerance to heat and fatigue is nearly always a problem.

National Institute of
Neurological
Disorders and Stroke

# Multiple Sclerosis

## What is Multiple Sclerosis?

During an MS attack, inflammation occurs in areas of the white matter of the central nervous system in random patches called **plaques**. This process is followed by **destruction of myelin**, the fatty covering that insulates nerve cell fibers in the brain and spinal cord. Myelin facilitates the smooth, high-speed transmission of electrochemical messages between the brain, the spinal cord, and the rest of the body; when it is damaged, neurological transmission of messages may be slowed or blocked completely, leading to diminished or lost function. The name "multiple sclerosis" signifies both the number (multiple) and condition (sclerosis, from the Greek term for scarring or hardening) of the demyelinated areas in the central nervous system.

## How Many People Have MS?

No one knows exactly how many people have MS. It is believed that, currently, there are approximately 250,000 to 350,000 people in the United States with MS diagnosed by a physician. This estimate suggests that approximately 200 new cases are diagnosed each week.

## Who Gets MS?

Most people experience their first symptoms of MS between the ages of 20 and 40, but a diagnosis is often delayed.

**Whites** are more than twice as likely as other races to develop MS. In general, **women** are affected at almost twice the rate of men; however, among patients who develop the symptoms of MS at a later age, the gender ratio is more balanced.

MS is five times more prevalent in **temperate climates**-such as those found in the northern United States, Canada, and Europe-than in tropical regions. Furthermore, the age of 15 seems to be significant in terms of risk for developing the disease: some studies indicate that a person moving from a high-risk (temperate) to a low-risk (tropical) area before the age of 15 tends to adopt the risk (in this case, low) of the new area and vice versa. Other studies suggest that people moving after age 15 maintain the risk of the area where they grew up.

These findings indicate a **strong role for an environmental factor** in the cause of MS. It is possible that, at the time of or immediately following puberty, patients acquire an infection with a long latency period. Or, conversely, people in some areas may come in contact with an unknown protective agent during the time before puberty. Other studies suggest that the unknown geographic or climatic element may actually be simply a matter of genetic predilection and reflect racial and ethnic susceptibility factors.

Periodically, scientists receive reports of MS "clusters." The most famous of these MS "epidemics" took place in the Faeroe Islands north of Scotland in the years following the arrival of British troops during World War II. Despite intense study of this and other clusters, no direct environmental factor has been identified. Nor has any definitive evidence been found to link daily stress to MS attacks, although there is evidence that the risk of worsening is greater after acute viral illnesses.

## What Causes MS?

Scientists have learned a great deal about MS in recent years; still, its cause remains elusive. Many investigators believe MS to be an autoimmune disease-one in which the body, through its immune system, launches a defensive attack against its own tissues. In the case of MS, it is the nerve-insulating myelin that comes under assault. Such assaults may be linked to an unknown environmental trigger, perhaps a virus.

Scientists have studied a number of infectious agents (such as viruses) that have been suspected of causing MS, but have been unable to implicate any one particular agent. Viral infections are usually accompanied by inflammation and the production of gamma interferon, a naturally occurring body chemical that has been shown to worsen the clinical course of MS. It is possible that the immune response to viral infections may themselves precipitate an MS attack. There seems to be little doubt that something in the environment is involved in triggering MS.

## Genetics

In addition, increasing scientific evidence suggests that **genetics may play a role in determining a person's susceptibility to MS**.

In the population at large, the chance of developing MS is less than a tenth of one percent. However, if one person in a family has MS, that person's first-degree relatives-parents, children, and siblings-have a one to three percent chance of getting the disease. For identical twins, the likelihood that the second twin may develop MS if the first twin does is about 30 percent; for fraternal twins (who do not inherit identical gene pools), the likelihood is closer to that for non-twin siblings, or about 4 percent. Studies have confirmed a possible genetic link.

## What is the Course of MS?

Each case of MS displays one of several patterns of presentation and subsequent course.

| | |
|---|---|
| Relapsing-remitting (RR) | A series of attacks followed by complete or partial remissions as symptoms mysteriously lessen, only to return later after a period of stability |
| Chronic progressive MS | |
| • Primary-progressive (PP) | Characterized by a gradual clinical decline with no distinct remissions, although there may be temporary plateaus or minor relief from symptoms |
| • Secondary-progressive (SP) | Begins with a relapsing-remitting course followed by a later primary-progressive course |
| • progressive-relapsing (PR) | Rare - a course in which the disease takes a progressive path punctuated by acute attacks |
| Benign form | Twenty percent of the MS population-symptoms show little or no progression after the initial attack; these patients remain fully functional |
| Malignant MS | A swift and relentless decline resulting in significant disability or even death shortly after disease onset |

MS is very rarely fatal and most people with MS have a fairly normal life expectancy.

## What are the Symptoms of MS?

| | |
|---|---|
| Vision disturbances | • Often initial symptom<br>• May be blurred or double vision, red-green color distortion, or even blindness in one eye |
| Muscle weakness | • These symptoms may be severe enough to impair walking or even standing. In the worst cases, MS can produce partial or complete paralysis. |
| Spasticity | • Spasticity-leads to stiffness and spasms |
| Fatigue | • May be triggered by physical exertion and improve with rest, or it may take the form of a constant and persistent tiredness |

| | |
|---|---|
| Paresthesias | • Transitory abnormal sensory feelings such as numbness, prickling, or "pins and needles" sensations |
| Heat sensitivity | • Heat-whether generated by temperatures outside the body or by exercise-may cause temporary worsening of many MS symptoms |
| Pain | • Moderate to severe - more uncommon, but may occur |
| Speech disturbances | • Speech disorders are called dysarthrias.<br>• Long Pauses - one pattern that is commonly associated with MS is so-called "scanning'" speech which produces speech in which the speech pattern is disrupted, with abnormally long pauses between words or individual syllables of words.<br>• Slurred or Nasal Sounding speech |
| Cognitive abnormalities | • Difficulties with concentration, attention, memory, and poor judgment, but such symptoms are usually mild and are frequently overlooked<br>• Impairments are usually mild, rarely disabling, and intellectual and language abilities are generally spared<br>• Scientists do not yet know whether altered cognition in MS reflects problems with information acquisition, retrieval, or a combination of both. |
| Ataxia | • All effect steadiness on feet and ambulation |
| Tremor | |
| Vertigo | |
| Bladder dysfunction | • Most common bladder problems encountered by MS patients are urinary frequency, urgency, or incontinence. A small number of patients, however, retain large amounts of urine |
| Bowel dysfunction | • Constipation being the most frequent problem |
| Depression | • Depression can intensify symptoms of fatigue, pain, and sexual dysfunction.<br>• Five percent may experience episodes of inappropriate euphoria and despair-unrelated to the patient's actual emotional state-known as "laughing/weeping syndrome." This syndrome is thought to be due to demyelination in the brainstem, the area of the brain that controls facial expression and emotions, and is usually seen only in severe cases. |
| Euphoria | |
| Sexual dysfunction | • Men may experience occasional failure to attain an erection.<br>• Women may experience insufficient lubrication or have difficulty reaching orgasm. |

The erratic symptoms of MS can affect the entire family as patients may become unable to work at the same time they are facing high medical bills and additional expenses for housekeeping assistance and modifications to homes and vehicles. The emotional drain on both patient and family is immeasurable. Support groups (listed on a card in the pocket at the back of this pamphlet) and counseling may help MS patients, their families, and friends find ways to cope with the many problems the disease can cause.

## Drugs Used to Treat Symptoms of Multiple Sclerosis

| Symptom | Drug |
|---|---|
| Spasticity | Baclofen (Lioresal)<br>Tizanidine (Zanaflex)<br>Diazepam (Valium)<br>Clonazepam (Klonopin)<br>Dantrolene (Dantrium) |
| Optic neuritis | Methylprednisolone (Solu-Medrol)<br>Oral steroids |
| Fatigue | Antidepressants<br>Amantadine (Symmetrel)<br>Pemoline (Cylert) |
| Pain | Aspirin or acetaminophen<br>Antidepressants<br>Codeine |
| Trigeminal neuralgia | Carbamazapine, other anticonvulsant |
| Sexual dysfunction | Papaverine injections(in men) |

## How is MS Diagnosed?

There is no single test that unequivocally detects MS. When faced with a patient whose symptoms, neurological exam results, and medical history suggest MS, physicians use a variety of tools to rule out other possible disorders and perform a series of laboratory tests which, if positive, confirm the diagnosis.

| | |
|---|---|
| **MRI** | • Can help locate central nervous system lesions resulting from myelin loss<br>• If used in conjunction with a contrast agent can help distinguish new plaques from old<br>• However, since these lesions can also occur in several other neurological disorders, they are not absolute evidence of MS. |
| **Magnetic resonance spectroscopy (MRS)** | • Yields information about the brain's biochemistry<br>• Decreased levels of brain chemical N-acetyl aspartate can indicate nerve damage |
| **Magnetization transfer imaging (MTI)** | • Able to detect white matter abnormalities before lesions can be seen on standard MRI scans by calculating the amount of "free" water in tissues<br>• Demyelinated tissues and damaged nerves show increased levels of free" (versus "bound") water particles |

| | |
|---|---|
| **Diffusion-tensor magnetic resonance imaging (DT-MRI or DTI)** | • Measures the random motion of water molecules creating three-dimensional images indicating the size and location of demyelinated areas of the brain<br>• Can measure disease progression |
| **Functional MRI (fMRI)** | • Uses radio waves and a strong magnetic field to measures the correlation between physical changes in the brain (such as blood flow) and mental functioning during the performance of cognitive tasks |
| **Visual evoked potential (VEP)** | • Measure the speed of the brain's response to visual stimuli<br>• Can sometimes detect lesions that the scanners miss and is particularly useful when abnormalities seen on MRI do not meet the specific criteria for MS |
| **Studies of cerebrospinal fluid** | • Can show cellular and chemical abnormalities often associated with MS<br>• Includes increased numbers of white blood cells and higher-than-average amounts of protein, especially myelin basic protein and an antibody called immunoglobulin G |

## Can MS be Treated?

There is as yet no cure for MS. Many patients do well with no therapy at all, especially since many medications have serious side effects and some carry significant risks.

| | |
|---|---|
| **Steroids**<br>adrenocorticotropic hormone (ACTH), prednisone, prednisolone, methylprednisolone, betamethasone, and dexamethasone | • Used for anti-inflammatory purposes |
| **Interferon**<br>Avonex, Betaseron, and Rebif) | • naturally occurring antiviral proteins Beta interferon has been shown to reduce the number of exacerbations and may slow the progression of physical disability<br>• MRI scans suggest that beta interferon can decrease myelin destruction. |
| **Immunotherapy**<br>Novantrone (mitoxantrone) | • Results of recent clinical trials have shown that immunosuppressive agents and techniques can positively (if temporarily) affect the course of MS; however, toxic side effects often preclude their widespread use.<br>• Generalized immunosuppression leaves the patient open to a variety of viral, bacterial, and fungal infections. Most of these therapies are, at this time, still considered experimental. |
| **Monoclonal antibodies**<br>natalizumab (Tysabri), | • are identical, laboratory-produced antibodies that are highly specific for a single antigen. They are injected into the patient in the hope that they will alter the patient's immune response. |

| | |
|---|---|
| **Plasmapheresis** (plasma exchange) | • blood is removed from the patient and the blood plasma is separated from other blood substances that may contain antibodies and other immunologically active products<br>• These other blood substances are discarded and the plasma is then transfused back into the patient<br>• Effectiveness not proven |
| **Bone marrow transplantation** | • No data of effectiveness – being studied |
| **Honey bee venom** | • No data of effectiveness – being studied |

## Diet

Over the years, many people have tried to implicate diet as a cause of or treatment for MS. Some physicians have advocated a diet low in saturated fats; others have suggested increasing the patient's intake of linoleic acid, a polyunsaturated fat, via supplements of sunflower seed, safflower, or evening primrose oils. Other proposed dietary "remedies" include megavitamin therapy, including increased intake of vitamins B12 or C; various liquid diets; and sucrose-, tobacco-, or gluten-free diets. To date, clinical studies have not been able to confirm benefits from dietary changes; in the absence of any evidence that diet therapy is effective; patients are best advised to eat a balanced, wholesome diet.

## Unproven Therapies

At one time or another, many ineffective and even potentially dangerous therapies have been promoted as treatments for MS. A partial list of these "therapies" includes: injections of snake venom, electrical stimulation of the spinal cord's dorsal column, removal of the thymus gland, breathing pressurized (hyperbaric) oxygen in a special chamber, injections of beef heart and hog pancreas extracts, intravenous or oral calcium orotate (calcium EAP), hysterectomy, removal of dental fillings containing silver or mercury amalgams, and surgical implantation of pig brain into the patient's abdomen. None of these treatments is an effective therapy for MS or any of its symptoms.

## Glossary of Terms

**antibodies** - proteins made by the immune system that bind to structures (antigens) they recognize as foreign to the body.

**antigen** - a structure foreign to the body, such as a virus. The body usually responds to antigens by producing antibodies.

**ataxia** - a condition in which the muscles fail to function in a coordinated manner.

**autoimmune disease** - a disease in which the body's defense system malfunctions and attacks a part of the body itself rather than foreign matter.

**blood/brain barrier** - a membrane that controls the passage of substances from the blood into the central nervous system.

**cerebrospinal fluid** - the colorless liquid, consisting partially of substances filtered from blood and partially by secretions released by brain cells, that circulates around and through the cavities of the brain and spinal cord. Physicians use a variety of tests-electrophoresis, isoelectric focusing, capillary isotachophoresis, and radioimmunoassay-to study cerebrospinal fluid for abnormalities often associated with MS.

**cytokines** - powerful chemical substances secreted by T cells. Cytokines are an important factor in the production of inflammation and show promise as treatments for MS.

**demyelination** - damage caused to myelin by recurrent attacks of inflammation. Demyelination ultimately results in nervous system scars, called plaques, which interrupt communications between the nerves and the rest of the body.

**experimental allergic encephalomyelitis** (EAE) - a chronic brain and spinal cord disease similar to MS which is induced by injecting myelin basic protein into laboratory animals.

**fatigue** - tiredness that may accompany activity or may persist even without exertion.

**gadolinium** - a chemical compound given during MRI scans that helps distinguish new lesions from old.

**human leukocyte antigens** (HLAs) - antigens, tolerated by the body, that correspond to genes that govern immune responses. Also known as major histocompatibility complex.

**immunoglobulin G** (IgG) - an antibody-containing substance produced by human plasma cells in diseased central nervous system plaques. Levels of IgG are increased in the cerebrospinal fluid of most MS patients.

**immunosuppression** - suppression of immune system functions. Many medications under investigation for the treatment of MS are immunosuppressants.

**interferons** - cytokines belonging to a family of antiviral proteins that occur naturally in the body. Gamma interferon is produced by immune system cells, enhances T-cell recognition of antigens, and causes worsening of MS symptoms. Alpha and beta interferon probably exert a suppressive effect on the immune system and may be beneficial in the treatment of MS.

**lesion** - an abnormal change in the structure of an organ due to disease or injury.

**magnetic resonance imaging** (MRI) - a non-invasive scanning technique that enables investigators to see and track MS lesions as they evolve.

**myelin** - a fatty covering insulating nerve cell fibers in the brain and spinal cord, myelin facilitates the smooth, high-speed transmission of electrochemical messages between these components of the central nervous system and the rest of the body. In MS, myelin is damaged through a process known as demyelination, which results in distorted or blocked signals.

**myelin basic protein** (MBP) - a major component of myelin. When myelin breakdown occurs (as in MS), MBP can often be found in abnormally high levels in the patient's cerebrospinal fluid. When injected into laboratory animals, MBP induces experimental allergic encephalomyelitis, a chronic brain and spinal cord disease similar to MS.

**oligodendrocytes** - cells that make and maintain myelin.

**optic neuritis** - an inflammatory disorder of the optic nerve that usually occurs in only one eye and causes visual loss and sometimes blindness. It is generally temporary.

**paresthesias** - abnormal sensations such as numbness, prickling, or "pins and needles."

**plaques** - patchy areas of inflammation and demyelination typical of MS, plaques disrupt or block nerve signals that would normally pass through the regions affected by the plaques.

**receptor** - a protein on a cell's surface that allows the cell to identify antigens.

**retrobulbar neuritis** - an inflammatory disorder of the optic nerve that is usually temporary. It causes rapid loss of vision and may cause pain upon moving the eye.

**spasticity** - involuntary muscle contractions leading to spasms and stiffness or rigidity. In MS, this condition primarily affects the lower limbs.

**T cells** - immune system cells that develop in the thymus gland. Findings suggest that T cells are implicated in myelin destruction.

**transverse myelitis** - an acute spinal cord disorder causing sudden low back pain and muscle weakness and abnormal sensory sensations in the lower extremities. Transverse myelitis often remits spontaneously; however, severe or long-lasting cases may lead to permanent disability.

**white matter** - nerve fibers that are the site of MS lesions and underlie the gray matter of the brain and spinal cord.

Adapted (8-07) from: "Multiple Sclerosis: Hope through Research," NINDS. Publication date September 1996. NIH Publication No. 96-75, Last updated April 16, 2007

# Osteoarthritis

## Definition

Osteoarthritis is the most common type of arthritis, and is seen especially among older people. Sometimes it is called degenerative joint disease or osteoarthrosis. People with osteoarthritis often have joint pain and reduced motion.

## Characteristics

Osteoarthritis is a joint disease that mostly affects cartilage. The top layer of cartilage breaks down and wears away. This allows bones under the cartilage to rub together. The rubbing causes pain, swelling, and loss of motion of the joint. Over time, the joint may lose its normal shape. Also, bone spurs may grow on the edges of the joint. Bits of bone or cartilage can break off and float inside the joint space, which causes more pain and damage.

## Functional Considerations

- Limitations will be based on location and severity of disease.
- If in the hands, fine motor control and function will be greatly diminished.
- If in the joints of the back and legs, the consumer will have difficulties with bending, stooping and ambulation.
- Exercise (without overexerting) is one of the best treatments for osteoarthritis.
- Weight control is important.
- Consumers, whose pain is not controlled by medications, may have an increased need for IHSS.

NIAMS
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
National Institutes of Health
Department of Health & Human Services

# Osteoarthritis

## What is Osteoarthritis?

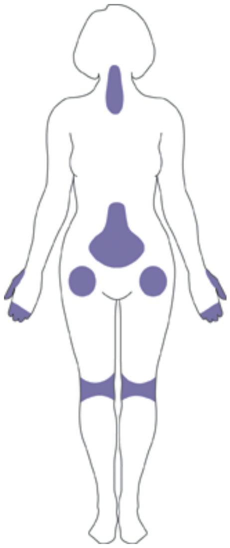
Osteoarthritis (AH-stee-oh-ar-THREYE-tis) is the most common type of arthritis, and is seen especially among older people. Sometimes it is called degenerative joint disease or osteoarthrosis.

Osteoarthritis is a joint disease that mostly affects cartilage. Cartilage is the slippery tissue that covers the ends of bones in a joint. Healthy cartilage allows bones to glide over each other. It also helps absorb shock of movement. In osteoarthritis, the top layer of cartilage breaks down and wears away. This allows bones under the cartilage to rub together. The rubbing causes pain, swelling, and loss of motion of the joint. Over time, the joint may lose its normal shape. Also, bone spurs may grow on the edges of the joint. Bits of bone or cartilage can break off and float inside the joint space, which causes more pain and damage.
People with osteoarthritis often have joint pain and reduced motion. Unlike some other forms of arthritis, osteoarthritis affects only joints and not internal organs. Osteoarthritis is the most common type of arthritis.

## Who Gets Osteoarthritis?

Osteoarthritis occurs most often in older people. An estimated 12.1 percent of the U.S. population (nearly 21 million Americans) age 25 and older have osteoarthritis. Before age 45, more men than women have osteoarthritis; after age 45, it is more common in women.

Younger people sometimes get osteoarthritis-usually as the result of a joint injury, a joint malformation, or a genetic defect in joint cartilage primarily from joint injuries.



## What Causes Osteoarthritis?

The cause of osteoarthritis is unknown. Factors that might cause it include:

- Being overweight
- Getting older
- Joint injury
- Joints that are not properly formed
- A genetic defect in joint cartilage
- Stresses on the joints from certain jobs and playing sports.

## What Areas Does Osteoarthritis Affect?

People with osteoarthritis usually experience joint pain and stiffness. The most commonly affected joints are those at the ends of the fingers (closest to the nail), thumbs, neck, lower back, knees, and hips.

Osteoarthritis affects different people differently. Although in some people it progresses quickly, in most individuals joint damage develops gradually over years. In some people, osteoarthritis is relatively mild and interferes little with day-to-day-life; in others, it causes significant pain and disability.

While osteoarthritis is a disease of the joints, its effects are not just physical. In many people with osteoarthritis, lifestyle and finances also decline.

Lifestyle effects include

- depression
- anxiety
- feelings of helplessness
- limitations on daily activities
- job limitations
- difficulty participating in everyday personal and family joys and responsibilities.

Financial effects include

- the cost of treatment
- wages lost because of disability.

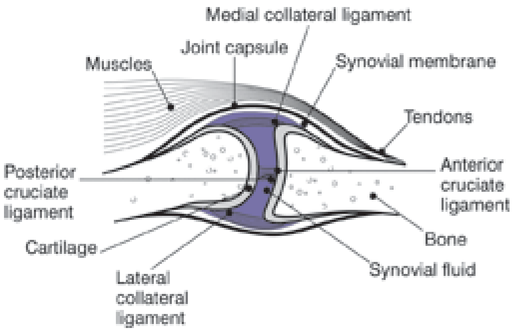
Fortunately, most people with osteoarthritis live active, productive lives despite these limitations. They do so by using treatment strategies such rest and exercise, pain relief medications, education and support programs, learning self-care, and having a "good attitude."

## Osteoarthritis Basics: The Joint

A joint is the point where two or more bones are connected. With a few exceptions (in the skull and pelvis, for example), joints are designed to allow movement between the bones and to absorb shock from movements like walking or repetitive motions.

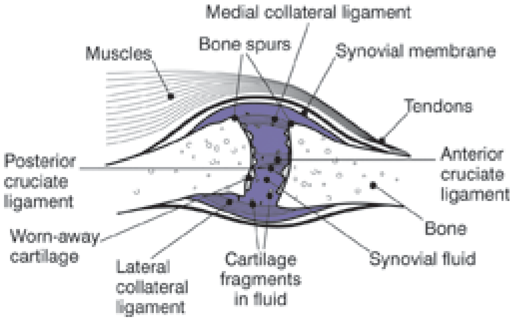
**A Healthy Joint**

In a healthy joint, the ends of bones are encased in smooth cartilage. Together, they are protected by a joint capsule lined with a synovial membrane that produces synovial fluid. The capsule and fluid protect the cartilage, muscles, and connective tissues.



**A Joint With Severe Osteoarthritis**

With osteoarthritis, the cartilage becomes worn away. Spurs grow out from the edge of the bone, and synovial fluid increases. Altogether, the joint feels stiff and sore.



## Signs of Osteoarthritis

Usually, osteoarthritis comes on slowly. Early in the disease, the joints may ache after physical work or exercise. Later on, joint pain may become more persistent. There also may be joint stiffness, particularly first thing in the morning or after having been in one position for a long time.

For information on the joints most often affected by osteoarthritis, please see the following descriptions below:

| | |
|---|---|
| **Hands** | • Osteoarthritis of the hands seems to have some hereditary characteristics; that is, it runs in families<br>• Women are more likely than men to have hand involvement and, for most, it develops after menopause.<br>• Small, bony knobs may appear on the end joints (those closest to the nails) of the fingers cause deformity and further disability.<br>• The base of the thumb joint also is commonly affected by osteoarthritis. |
| **Knees** | • The knees are among the joints most commonly affected by osteoarthritis.<br>• Symptoms include stiffness, swelling, and pain, which make it hard to walk, climb, and get in and out of chairs and bathtubs.<br>• Can lead to disability. |
| **Hips** | • The hips are also common sites of osteoarthritis<br>• Symptoms of hip osteoarthritis include pain and stiffness of the joint itself.<br>• May limit moving and bending, making daily activities such as dressing and putting on shoes a challenge. |
| **Spine** | • May show up as stiffness and pain in the neck or lower back.<br>• In some cases, changes in the spine can cause pressure on the nerves where they exit the spinal column, resulting in weakness or numbness of the arms and legs. |

## How is Osteoarthritis Diagnosed?

Osteoarthritis can occur in any joint. It occurs most often in the hands, knees, hips, and spine.

## The Warning Signs of Osteoarthritis

- stiffness in a joint after getting out of bed or sitting for a long time
- swelling in one or more joints
- a crunching feeling or the sound of bone rubbing on bone

About a third of people whose x-rays show evidence of osteoarthritis report **pain** or other symptoms. For those who experience steady or intermittent pain, it is typically aggravated by activity and relieved by rest.

If the patient feels **hot** or their skin turns **red**, they probably do not have osteoarthritis. Check with the doctor about other causes, such as rheumatoid arthritis.

No single test can diagnose osteoarthritis. Most doctors use a combination of the following methods to diagnose the disease and rule out other conditions:

| | |
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| **Clinical history** | • Description of symptoms, when and how they condition started, as well as how they have changed over time<br>• Other medical problems the patient and close family members have<br>• Any medications the patient is taking |

| | |
|---|---|
| **Physical examination** | • The doctor will check the patient's reflexes and general health, including muscle strength.<br>• Will also examine bothersome joints and observe the patient's ability to walk, bend, and carry out activities of daily living. |
| **X-rays** | • To see how much joint damage has been done.<br>• X-rays of the affected joint can show such things as cartilage loss, bone damage, and bone spurs.<br>• Often is a big difference between the severity of osteoarthritis as shown by the x-ray and the degree of pain and disability felt by the patient.<br>• May not show early osteoarthritis damage before much cartilage loss has taken place. |
| **Magnetic resonance imaging (MRI)** | • Provides high-resolution computerized images of internal body tissues.<br>• Used if there is pain; if x-ray findings are minimal; and if the findings suggest damage to other joint tissues such as a ligament, or the pad of connective tissue in the knee known as the meniscus. |
| **Other tests** | • Blood tests to rule out other causes of symptoms<br>• Joint aspiration, which involves drawing fluid from the joint through a needle and examining the fluid under a microscope. |

## How is Osteoarthritis Treated?

Doctors often combine treatments to fit a patient's needs, lifestyle, and health. Osteoarthritis treatment has **four main goals**:

1. Improve joint function
2. Keep a healthy body weight
3. Control pain
4. Achieve a healthy lifestyle.

Most successful treatment programs involve a combination of treatments tailored to the patient's needs, lifestyle, and health. Most programs include ways to manage pain and improve function.

Doctors prescribe medicines to eliminate or reduce pain and to improve functioning. Doctors consider a number of factors when choosing medicines for their patients with osteoarthritis. These include the intensity of pain, potential side effects of the medication, medical history, and other medications taken.

| | |
|---|---|
| **Exercise** | • Exercise is one of the best treatments for osteoarthritis.<br>• Can improve mood and outlook, decrease pain, increase flexibility, strengthen the heart and improve blood flow, maintain weight, and promote general physical fitness.<br>• Amount and form of exercise prescribed will depend on which joints are involved<br>• Walking, swimming, and water aerobics are a few popular types of exercise<br>• May take NSAIDs to make exercising easier and/or use ice afterward. |
| **Weight control** | • Patients who are overweight or obese should try to lose Weight. Weight loss can reduce stress on weight-bearing joints, limit further injury, and increase mobility. |

| | |
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| **Rest and relief from stress on joints** | • Patients must learn to recognize the body's signals, and know when to stop or slow down to prevent the pain caused by overexertion.<br>• Getting proper sleep is important for managing arthritis pain - relaxation techniques, stress reduction, and biofeedback<br>• Time medications to provide maximum pain relief through the night.<br>• Walking aides can take pressure off painful joints.<br>• Splints or braces to provide extra support for joints and/or keep them in proper position during sleep or activity. |
| **Nondrug pain relief** | • **Heat and cold**<br>o Heat can be applied in a number of different ways – with warm towels, hot packs, or a warm bath or shower – to increase blood flow and ease pain and stiffness.<br>o Cold packs (bags of ice or frozen vegetables wrapped in a towel), which reduce inflammation, can relieve pain or numb the sore area. |
| | • **Transcutaneous electrical nerve stimulation (TENS)**<br>o A technique that uses a small electronic device to direct mild electric pulses to nerve endings that lie beneath the skin in the painful area.<br>o It seems to work by blocking pain messages to the brain and by modifying pain perception. |
| | • **Massage**<br>o May increase blood flow and bring warmth to a stressed area.<br>o Must be careful over painful joint |
| **Medications to control pain** | • **Acetaminophen** – non prescription; used to relieve pain<br>• **NSAIDs (nonsteroidal anti-inflammatory drugs) -** A large class of medications useful against both pain and inflammation, they are staples in arthritis treatment; some over the counter and some prescription<br>• **Topical pain-relieving creams, rubs, and sprays -** contain ingredients that work in one of three different ways: by stimulating the nerve endings to distract the brain's attention from the joint pain; by depleting the amount of a neurotransmitter called substance P that sends pain messages to the brain; or by blocking chemicals called prostaglandins that cause pain and inflammation. |
| | • **Tramadol (Ultram) –** prescription pain reliever has the potential for addiction. |
| | • **Mild narcotic painkillers –**usually used short term because of dependency potential. |
| | • **Corticosteroids -** powerful anti-inflammatory hormones; may be injected into the affected joints to temporarily relieve pain; is a short-term measure. Oral corticosteroids are not routinely used to treat osteoarthritis. They are occasionally used for inflammatory flares. |
| | • **Hyaluronic acid substitutes -** designed to replace a normal component of the joint involved in joint lubrication and nutrition; given in a series of three to five injections; approved only for knee. |
| **Surgery** | • helps relieve the pain and disability of osteoarthritis<br>• may be performed to achieve one or more of the following:<br>o removal of loose pieces of bone and cartilage from the joint if they are causing symptoms of buckling or locking<br>o repositioning of bones<br>o resurfacing (smoothing out) of bones.<br>**Artificial joint replacement**<br>o can last 10 to 15 years or longer. |

| | |
|---|---|
| | o The decision to use surgery depends on several factors, including the patient's age, occupation, level of disability, pain intensity, and the degree to which arthritis interferes with his or her lifestyle.<br>o After surgery and rehabilitation, the patient usually feels less pain and swelling, and can move more easily. |
| **Complementary and alternative therapies** | • **Acupuncture –** used for pain relief; shown to help some patients<br>• **Folk remedies -** include wearing copper bracelets, drinking herbal teas, taking mud baths, and rubbing WD-40 on joints to "lubricate" them; there is no scientific research to date shows that they are helpful in treating osteoarthritis.<br>• **Nutritional supplements -** glucosamine and chondroitin sulfate have been reported to improve the symptoms of people with osteoarthritis, as have certain vitamins. |

## Questions to Ask the Doctor or Pharmacist about Medicines

- How often should I take this medicine?
- Should I take this medicine with food or between meals?
- What side effects might occur?
- Should I take this medicine with the other prescription medicines I take?
- Is this medication safe considering other medical conditions I have?

## How Can Self-Care and a "Good-Health Attitude" Help?

Three kinds of programs help people learn about osteoarthritis and self-care and improve their good-health attitude:

- Patient education programs
- Arthritis self-management programs
- Arthritis support groups.

These programs teach people about osteoarthritis and its treatments. They also have clear and long-lasting benefits. People in these programs learn to:

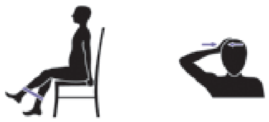
- Exercise and relax
- Talk with their doctor or other health care providers
- Solve problems.

People with osteoarthritis find that self-management programs help them:

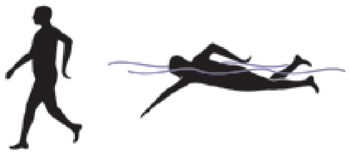
- Understand the disease
- Reduce pain while staying active
- Cope with their body, mind, and emotions
- Have more control over the disease
- Live an active, independent life.

People with a good-health attitude:

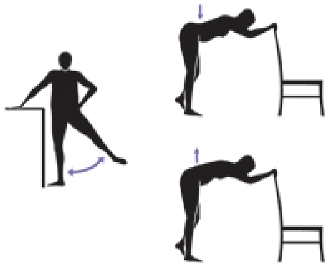
- Focus on what they can do, not what they can't do
- Focus on their strengths, not their weaknesses
- Break down activities into small tasks that are easy to manage
- Build fitness and healthy eating into their daily routines
- Develop ways to lower and manage stress
- Balance rest with activity
- Develop a support system of family, friends, and health care providers.



Strengthening



Aerobic conditioning



Range of motion

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## What Research is Being Done on Osteoarthritis?

Osteoarthritis is not simply a disease of “wear and tear” that happens in joints as people get older. There is more to the disease than aging alone. Researchers are studying:

- Tools to detect osteoarthritis earlier
- Genes
- Tissue engineering
- A wide range of treatment strategies
- Osteoarthritis in animals
- Medicines to prevent joint damage
- Complementary and alternative therapies
- Vitamins and other supplements
- Injection of hyaluronic acid (a natural part of cartilage and joint fluid)
- Estrogen
- Biological and structural markers (biomarkers) for osteoarthritis.

## Key Words

**Acupuncture** – the use of fine needles inserted at specific points on the skin. Primarily used for pain relief, acupuncture may be a helpful component of an osteoarthritis treatment plan for some people.

**Analgesics** – medications designed to relieve pain. Pure analgesics do not have an effect on inflammation.

**Biomarkers** – physical signs or biological substances that indicate changes in bone or cartilage. Doctors believe they may one day be able to use biomarkers for diagnosing osteoarthritis before it causes noticeable joint damage and for monitoring the progression of the disease and its responsiveness to treatment.

**Bone spurs** – small growths of bone that can occur on the edges of a joint affected by osteoarthritis. These growths are also known as osteophytes.

Bouchard's nodes – small, bony knobs associated with osteoarthritis of the hand that can occur on the middle joints of the fingers.

**Cartilage** – a hard but slippery coating on the end of each bone. The breakdown of joint cartilage is the primary feature of osteoarthritis.

**Chondrocytes** – components of cartilage. Chondrocytes are cells that produce cartilage, are found throughout cartilage, and help it stay healthy as it grows. Sometimes, however, they release certain enzymes that destroy collagen and other proteins.

**Chondroitin sulfate** – a naturally existing substance in joint cartilage that is believed to draw fluid into the cartilage. Chondroitin is often taken in supplement form along with glucosamine as a treatment for osteoarthritis. See the "glucosamine and chondroitin sulfate" section under Complementary and Alternative Therapies for more information.

**Collagen** – a family of fibrous proteins that are components of cartilage. Collagens are the building blocks of skin, tendon, bone, and other connective tissues.

**Corticosteroids** – powerful anti-inflammatory hormones made naturally in the body or man made for use as medicine. Corticosteroids may be injected into the affected joints to temporarily reduce inflammation and relieve pain.

**COX-2 inhibitors** – a relatively new class of nonsteroidal anti-inflammatory drugs (NSAIDs) that are formulated to relieve pain and inflammation. For information about the risk posed by NSAIDs, see "NSAIDs" in the "How Is Osteoarthritis Treated?" section.

**Estrogen** – the major sex hormone in women. Estrogen is known to play a role in regulation of bone growth. Research suggests that estrogen may also have a protective effect on cartilage.

**Glucosamine** – a substance that occurs naturally in the body, providing the building blocks to make and repair cartilage. See the "glucosamine and chondroitin sulfate" section under Complementary and Alternative Therapies for more information.

**Heberden's nodes** – small, bony knobs associated with osteoarthritis of the hand that can occur on the joints of the fingers closest to the nail.

**Hyaluronic acid** – a substance that gives healthy joint fluid its viscous (slippery) property and that may be reduced in people with osteoarthritis. For some people with osteoarthritis of the knee, replacing hyaluronic acid with injections of agents referred to as visco-supplements is useful for increasing lubrication, reducing pain, and improving function.

**Joint capsule** – a tough membrane sac that holds the bones and other joint parts together.

**Ligaments** – tough bands of connective tissue that attach bones to each other, providing stability.

**Magnetic resonance imaging (MRI)** – provides high resolution computerized images of internal body tissues. This procedure uses a strong magnet that passes a force through the body to create these images.

**Muscles** – bundles of specialized cells that contract and relax to produce movement when stimulated by nerves.

**Nonsteroidal anti-inflammatory drugs (NSAIDs**) – a class of medications available over the counter or with a prescription that ease pain and inflammation. Commonly used NSAIDs include ibuprofen (Advil, Motrin), naproxen sodium (Aleve), and ketoprofen (Orudis, Oruvail). For information about the risk posed by NSAIDs, see "NSAIDs" in the "How Is Osteoarthritis Treated?" section.

**Osteoarthritis** – the most common form of arthritis. It is characterized by the breakdown of joint cartilage, leading to pain, stiffness, and disability.

**Osteophytes** – small growths of bone that can appear on the edges of a joint affected by osteoarthritis. These growths are also known as bone spurs.

**Prolotherapy** – an unregulated, unproven therapy for chronic musculoskeletal pain. Prolotherapy uses an irritant solution, which is injected into painful ligaments and adjacent joint spaces to promote inflammation and subsequent healing.

**Proteoglycans** – components of cartilage. Made up of proteins and sugars, strands of proteoglycans interweave with collagens and form a mesh-like tissue. This allows cartilage to flex and absorb physical shock.

**Rheumatoid arthritis** – a form of arthritis in which the immune system attacks the tissues of the joints, leading to pain, inflammation, and eventually joint damage and malformation. It typically begins at a younger age than osteoarthritis does, causes swelling and redness in joints, and may make people feel sick, tired, and uncommonly feverish. Rheumatoid arthritis may also affect skin tissue, the lungs, the eyes, or the blood vessels.

**Stem cells** – primitive cells, usually taken from the bone marrow, that can transform into other kinds of cells, such as muscle or bone cells. In the future, researchers hope to be able to insert stem cells into cartilage and stimulate them to replace cartilage damaged by arthritis or injury.

**Synovium** – a thin membrane inside the joint capsule that secretes synovial fluid.

**Synovial fluid** – a fluid secreted by the synovium that lubricates the joint and keeps the cartilage smooth and healthy.

**Tendons** – tough, fibrous cords that connect muscles to bones.

**Transcutaneous electrical nerve stimulation (TENS)** – a technique that uses a small electronic device to direct mild electric pulses to nerve endings that lie beneath the skin in a painful area. TENS may relieve some arthritis pain. It seems to work by blocking pain messages to the brain and by modifying pain perception.

**X ray** – a procedure in which low-level radiation is passed through the body to produce a picture called a radiograph. X rays of joints affected by osteoarthritis can show such things as cartilage loss, bone damage, and bone spurs.

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NIAMS
National Institute of Arthritis and
Musculoskeletal and Skin Diseases

National Institutes of Health
Department of Health & Human Services

Medical Content Reviewed by the Faculty of the Harvard Medical School

# Complementary and Alternative Therapies for Osteoarthritis

People with the most common form of arthritis, osteoarthritis, frequently turn to complementary or alternative therapies. In 1997, a national survey reported that 26 percent of people with self-reported arthritis had used a complementary or alternative therapy within the previous 12 months. The same year, another survey reported that nearly two-thirds of rheumatology patients used complementary or alternative therapies, with osteoarthritis patients constituting the most frequent users. The most common complementary and alternative remedies are discussed below.

**Facts About Osteoarthritis**

There are more than 100 types of arthritis, the most common of which is osteoarthritis.

This "wear and tear" arthritis is seen most frequently in older people. Recent research suggests that genetic effects, weight, diet and injuries are also risk factors for this disease.

At present, there is no cure, but this does not mean there is no relief for the usual symptoms of pain and joint stiffness. Physical therapy, weight loss and exercise are helpful for many patients.

Conventional drug treatment with analgesics (such as acetaminophen) and nonsteroidal anti-inflammatory drugs (such as ibuprofen) is often effective in controlling pain and inflammation, but these agents do not always work well. In addition, side effects may limit their usefulness.

In severe cases, joint injections or joint surgery is appropriate.

### Glucosamine

- Used for many years in Germany and other parts of Europe
- Recent research supports its effectiveness, at least as a pain reliever.
- Although glucosamine's effect on joint damage is still debated, many medical experts believe this supplement reduces pain and is safe.
- The usual dose is 500 milligrams three times a day. Twice this amount may be recommended for the first few weeks. It may take four to eight weeks to get significant benefit, and like most remedies, glucosamine does not work for everyone.
- Consider stopping after eight to 10 weeks if there is no improvement.

### Chondroitin And Sam-e

- not as well studied or accepted in the United States as glucosamine.
- Most studies of these agents are of insufficient quality to draw firm conclusions.
- One study of SAM-e found the agent to have similar benefits as naproxen (Naprosyn, Aleve), used to relieve pain and inflammation.

### Herbal Remedies

- Some herbs, including evening primrose, ginger, stinging nettle and curcumin, are sold as remedies for arthritis pain, but there is not enough evidence to support their use.
- Always discuss the use of herbs or other supplements with a doctor to check for interactions and side effects.
- Before seeking an herbal therapy practitioner, first consult with a doctor
- Another source of information is the National Center for Complementary and Alternative Medicine (www.nccam.nih.gov)

### Homeopathy

- Homeopathy is based on administering tiny (often undetectable) amounts of a substance that in higher doses might cause symptoms or disease in healthy persons.
- Scientific evidence of benefit is lacking.

### Vitamins and Fish Oil

- Evidence that antioxidant vitamins can prevent arthritis is lacking.
- Fish oil capsules (containing omega-3 fatty acids) may decrease pain and swelling in some people with rheumatoid arthritis.
- Fish oil for osteoarthritis cannot be recommended.

### Acupuncture and Acupressure

- Acupuncture is an ancient Chinese practice. By inserting hair-fine needles into the skin along defined tracts called meridians, practitioners believe they can stimulate the flow of "qi," or vital life energy.
- Acupressure and shiatsu, a Japanese form of acupressure, use no needles. Instead intense local pressure is applied to certain points on the body.
- Although medical experts do not understand how acupuncture and acupressure work, some people experience less joint pain with these techniques.
- Recent, well-controlled trials of acupuncture for osteoarthritis of the knee suggest a benefit not only for pain relief but also with respect to function.

### Magnet Therapy

- Though popular, scientific evidence of its benefit is lacking.
- No proof that one strength is better than another or that any magnet really helps.

### Diet Therapy

- Efforts to find food allergies that cause arthritis have not yielded definitive results.
- The most common approach is to eliminate vegetables from the nightshade family: white potatoes, tomatoes, peppers and eggplant.
- Some people with arthritis also feel that dairy products aggravate their symptoms.
- If a patient suspects food allergies may be affecting his arthritis (for example, if symptoms become worse after eating certain foods), keep a record of what is eaten for several weeks, along with notes about arthritis symptoms.
- Eliminate from diet foods that seem to cause trouble; after a period of time, gradually reintroduce these foods one at a time, noting any change in symptoms.
- Research-based evidence on the value of this approach is lacking, but diet therapy still may be worth a try.

### Exercise and Weight Control

- Exercise and weight control are among the most effective self-help measures for alleviating the symptoms of osteoarthritis (and perhaps other types of arthritis).
- The objective is to avoid obesity and improve or maintain cardiovascular fitness, range of motion and muscle tone while avoiding excessive stress or injury to joints.
- Walking, biking, cross-country skiing and swimming are the best choices. Water offers support and gentle resistance; if possible, water temperature should be 83 to 88 F or warmer.
- In one study, 33 adults with arthritis reported being better able to manage their disease symptoms and enjoyed better health after a three-month tai chi program; another study found improved balance and abdominal muscle strength.
- Other studies of moderate, low-impact exercise have suggested a benefit in arthritis symptoms.
- Guidelines for appropriate exercise may be obtained from the Arthritis Foundation (800-283-7800; www.arthritis.org).
- Consider setting up an exercise program with the advice of a physician or physical therapist. He or she can also suggest effective weight control measures if needed.

### Self-Help Measures

- Many arthritis sufferers find that warm showers and baths -- particularly whirlpool baths -- are often helpful in reducing pain and stiffness, especially first thing in the morning.
- For arthritis in the hands, the simple act of squeezing a sponge in a basin or sink full of warm water provides gentle exercise and relief of stiffness.
- Warm, wet compresses, especially castor oil compresses (available where specialty health products are sold), may provide comfort for sore joints.
- Occupational therapists are trained professionals who can teach these and many more helpful techniques.

### Massage

- Massage by an expert in therapeutic massage can contribute to an overall feeling of relaxation and well-being.

## A Positive Outlook

- Like any person with a chronic disease, a person with osteoarthritis may be more prone to depression. They may worry about becoming increasingly unable to perform activities of daily living or doing enjoyable things.
- The capacity to adapt, cope and continue full function varies greatly among patients. Some patients feel disabled by their symptoms, but only a very small percentage will ever become severely disabled.
- A positive outlook, focusing on what the person is able to do rather than what they are unable to do, can be immensely helpful.
- Some people find that meditation and other stress-reduction techniques help them to relax and better adjust the pace of their lives to the limitations imposed by their arthritis.

## The Bottom Line

- Recognize that for many unproven approaches, uncertainty about benefit and risk must be accepted before pursuing treatment.
- A particular source of concern is that the treatment may interact with another medication, something the small studies cannot predict.
- Keep in mind that herbs and supplements such as glucosamine are not regulated by the Food and Drug Administration; active ingredients, purity and quality may vary greatly.

Last updated October 14, 2005
http://www.intelihealth.com/IH/ihtIH?d=dmtContent&c=317554&p=~br,IHW|~st,9339|~r,WSIHW000|~b,*|

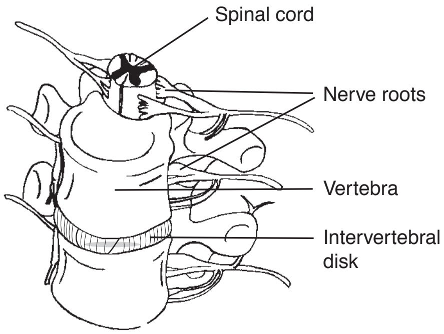
# What Is Spinal Stenosis?

*Fast Facts: An Easy-to-Read Series of Publications for the Public*

The spine, a row of 26 bones in your back, allows you to stand up straight and bend over. The spine also protects your spinal cord from being hurt. In people with spinal stenosis, the spine is narrowed in one or more of three parts:

- The space at the center of the spine
- The canals where nerves branch out from the spine
- The space between vertebrae (the bones of the spine).

This narrowing puts pressure on the spinal cord and nerves and can cause pain.



**Section of the Spine**

## Who Gets Spinal Stenosis?

Spinal stenosis is most common in men and women over 50 years old. Younger people who were born with a narrow spinal canal or who hurt their spines may also get spinal stenosis.

## What Causes Spinal Stenosis?

Aging

Changes that occur in the spine as people get older are the most common cause of spinal stenosis. As people get older:

- The bands of tissue that support the spine may get thick and hard.
- Bones and joints may get bigger.
- Surfaces of the bones may bulge out (these are called bone spurs).

Arthritis

In some cases arthritis, a degenerative (gets worse over time) condition can cause spinal stenosis. Two forms of arthritis may affect the spine: osteoarthritis and rheumatoid arthritis.

Osteoarthritis:

- The most common form of arthritis
- Most often occurs in middle-aged and older people
- Doesn't go away
- May involve many joints in the body
- Wears away the tough tissue (cartilage) that keeps the joints in place
- Causes bone spurs and problems with joints.

U.S. Department of Health
and Human Services
Public Health Service

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TTY: 301–565–2966
Fax: 301–718–6366
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www.niams.nih.gov

September 2005

Rheumatoid arthritis:

- Affects most people at a younger age than osteoarthritis
- Causes the soft tissues of the joints to swell and can affect the internal organs and systems
- Is not a common cause of spinal stenosis
- Can cause severe damage, especially to joints.

Inherited Conditions

Some people are born with conditions that cause spinal stenosis. For instance, some people are born with a small spinal canal. Others are born with a curved spine (scoliosis).

Other Causes

Other causes of spinal stenosis are:

- Tumors of the spine
- Injuries
- Paget's disease (a disease that affects the bones)
- Too much fluoride in the body
- Calcium deposits on the ligaments that run along the spine.

## What Are the Symptoms of Spinal Stenosis?

There may be no symptoms of spinal stenosis, or symptoms may appear slowly and get worse over time. Signs of spinal stenosis include:

- Pain in the neck or back
- Numbness, weakness, cramping, or pain in the arms or legs
- Pain going down the leg
- Foot problems.

One type of spinal stenosis, cauda equine syndrome, is very serious. This type occurs when there is pressure on nerves in the lower back. Symptoms may include:

- Loss of control of the bowel or bladder
- Problems having sex
- Pain, weakness, or loss of feeling in one or both legs.

If you have any of these symptoms, you should call your doctor right away.

## How Is Spinal Stenosis Diagnosed?

To diagnose spinal stenosis, your doctor will ask about your medical history and conduct a physical exam. Your doctor may also order one or more tests, such as:

- X rays

- Magnetic resonance imaging (MRI) – a test that uses radio waves to look at your spine
- Computerized axial tomography (CAT) – a series of x rays that give your doctor a detailed image of your spine
- Myelogram – a test in which the doctor injects liquid dye into your spinal column
- Bone scan – a test in which you are given a shot of radioactive substance that shows where bone is breaking down or being formed.

## Who Treats Spinal Stenosis?

Because spinal stenosis has many causes and symptoms, you may require treatment from doctors who specialize in certain aspects of the condition. Based on your symptoms, your doctor may refer you to:

- Rheumatologists (doctors who treat arthritis and related disorders)
- Neurologists and neurosurgeons (doctors who treat diseases of the nervous system)
- Orthopedic surgeons (doctors who treat problems with the bones, joints, and ligaments)
- Physical therapists.

## What Are Some Nonsurgical Treatments for Spinal Stenosis?

There are many nonsurgical treatments for spinal stenosis. Your doctor may prescribe:

- Medicines to reduce swelling
- Medicines to relieve pain
- Limits on your activity
- Exercises and/or physical therapy
- A brace for your lower back.

## When Should Surgery Be Considered?

Your doctor will likely suggest nonsurgical treatment first unless you have:

- Symptoms that get in the way of walking
- Problems with bowel or bladder function
- Problems with your nervous system.

Your doctor will take many factors into account in deciding if surgery is right for you. These include:

- The success of nonsurgical treatments
- The extent of the pain
- Your preferences.

## What Are Some Alternative Treatments for Spinal Stenosis?

Alternative treatments are those that are not part of standard treatment. For spinal stenosis, such treatments include chiropractic treatment and acupuncture. More research is needed on the value of these treatments. Your doctor may suggest alternative treatments in addition to standard treatments.

## What Research Is Being Done on Spinal Stenosis?

Questions about spinal stenosis that scientists are trying to answer include:

- Which is more effective in treating spinal stenosis, surgery or other treatments?
- Can MRIs identify who should have surgery?

## For More Information About Spinal Stenosis and Other Related Conditions:

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
National Institutes of Health
1 AMS Circle
Bethesda, MD 20892–3675
Phone: 301–495–4484 or
877–22–NIAMS (226–4267) (free of charge)
TTY: 301–565–2966
Fax: 301–718–6366
E-mail: NIAMSInfo@mail.nih.gov
www.niams.nih.gov

The information in this publication was summarized in easy-to-read format from information in a more detailed NIAMS publication. To order the Spinal Stenosis Q&A full-text version, please contact NIAMS using the contact information above. To view the complete text or to order online, visit http://www.niams.nih.gov.

# Osteoporosis

## Definition

Osteoporosis is a disease marked by reduced bone strength leading to an increased risk of fractures or broken bones.

## Characteristics

- Is often called a **"silent disease"** because it usually progresses without any symptoms until a fracture occurs.
- Can happen to any bones, but is most common in the hip, wrist, and in the spine. Also called the vertebrae.
- Osteoporosis in the vertebrae will result in:
    - Sloping shoulders
    - Curve in the back
    - Height loss
    - Back pain
    - Hunched posture
    - Protruding abdomen
- More often seen in women with a greater incident after menopause, though 1 in 4 men over the age of 50 will suffer a fracture because of osteoporosis.

## Functional Considerations

- After fracture, functional limitations will be based on location of the fracture.
- A person with known disease should take precautions to avoid falls.
- If osteoporosis impacts posture, the person's balance is likely to be impaired, making him/her at greater risk for falls.
- A person with osteoporosis may experience chronic pain, particularly back pain and muscle spasms; regular exercise can help.
- People with osteoporosis should not bend forward, twist or lift heavy objects.

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

NIAMS
National Institute of Arthritis and Musculoskeletal and Skin Diseases
National Institutes of Health
Department of Health & Human Services

# Osteoporosis

## What is Osteoporosis?

Osteoporosis (oss-tee-oh-puh-ro-sis) is a disease marked by reduced bone strength leading to an increased risk of fractures, or broken bones. Bone strength has two main features:

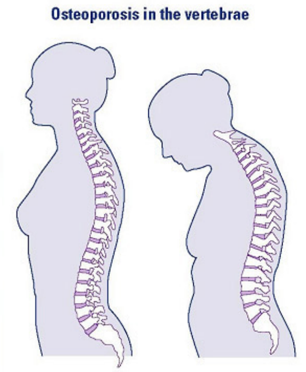
- bone mass (amount of bone) and
- bone quality.

Osteoporosis is the major underlying cause of fractures in postmenopausal women and the elderly. Fractures occur most often in bones of the hip, spine, and wrist, but any bone can be affected. Some fractures can be permanently disabling, especially when they occur in the hip.

Osteoporosis is often called a **“silent disease”** because it usually progresses without any symptoms until a fracture occurs or one or more vertebrae (bones in the spine) collapse. Collapsed vertebrae may first be felt or seen when a person develops severe back pain, loss of height, or spine malformations such as a stooped or hunched posture. Bones affected by osteoporosis may become so fragile that fractures occur spontaneously or as the result of minor bumps, falls, or normal stresses and strains such as bending, lifting, or even coughing.

## What Bones Does Osteoporosis Affect?

Osteoporosis can happen to any bones, but is most common in the hip, wrist, and in the spine, also called the vertebrae (ver-tuh-bray). Vertebrae are important because these bones support the body to stand and sit upright. See the picture below.



Osteoporosis in the vertebrae can cause serious problems for women. A fracture in this area occurs from day-to-day activities like climbing stairs, lifting objects, or bending forward

- Sloping shoulders
- Curve in the back
- Height loss
- Back pain
- Hunched posture
- Protruding abdomen

## Risk Factors for Getting Osteoporosis

Things that can increase someone’s chances of developing osteoporosis include:

- being female
- small, thin body (under 127 pounds)
- family history of osteoporosis
- being postmenopausal or of an advanced age
- Caucasian or Asian race, but African American and Hispanic women are also at significant risk for developing the disease
- abnormal absence of menstrual periods or having an eating disorder, such as anorexia nervosa or bulimia that can cause menstrual periods to stop before menopause, and loss of bone tissue from too much exercise
- low testosterone levels in men
- a diet low in dairy products or other sources of calcium and vitamin D

- inactive lifestyle
- long-term use of glucocorticoids (medicines prescribed for many diseases, including arthritis, asthma, and lupus) anti-seizure medications; gonadotropin releasing hormone for treatment of endometriosis; aluminum-containing antacids; certain cancer treatments; and excessive thyroid hormone
- cigarette smoking and drinking too much alcohol

## How is Osteoporosis Diagnosed?

A bone mineral density test (called a DXA) is the best way to check bone health. This test can:

- Diagnose osteoporosis
- Check bone strength
- See if treatments are making the bones stronger.

People age 65 and older, should get a bone density test.

Women between ages 60 and 64, who weighs less than 154 pounds, and doesn't take estrogen, should get a bone density test. Don't wait until age 65.

## Prevention

The best way to prevent weak bones is easy – start by building strong ones. No matter how old, it is never too late to start! Building strong bones during childhood and adolescence is the best defense against getting osteoporosis later. Building strong bones at a young age will lessen the effects of the natural bone loss that starts around age 30. As a person gets older, their bones don't make new bone quickly enough to keep up with the bone loss. And after menopause, bone loss increases more quickly. But there are steps that can be taken to stop bones from becoming weak and brittle.

**1. Get enough calcium each day.**

Bones are made of calcium. The best way to prevent osteoporosis is to get enough calcium in the diet. A person needs enough calcium each day for strong bones throughout life. Calcium comes from foods and/or calcium pills, which can be bought at the drug store.

Daily Calcium Needs

| **Ages** | **Milligrams per day** |
|---|---|
| 9-18 | 1300 |
| 19-50 | 1000 |
| 51 and older | 1200 |

Some foods to help get the needed calcium are listed below. Check the food labels for more information.

| **Food** | **Portion** | **Milligrams** | **Percent*** |
|---|---|---|---|
| Plain, fat free (or low fat) yogurt | 1 cup | 450 | 45 |
| American cheese | 2 ounces | 348 | 35 |
| Milk (fat free or low fat) | 1 cup | 300 | 30 |
| Orange juice with added calcium | 1 cup | 300 | 30 |
| Broccoli, cooked or fresh | 1 cup | 90 | 10 |

*% Daily Value tells how much of the recommended daily amount of that nutrient is in that portion of food – these % reflect need for those of age 19-50.

**2. Get enough vitamin D each day.**
It is also important to get enough vitamin D, which helps the body take in calcium. Vitamin D comes through sunlight and foods like milk. 10-15 minutes of sunlight to the hands, arms, and face, two to three times a week is needed to get enough vitamin D. The amount of time depends on how sensitive the skin is to light, use of sunscreen, skin color, and pollution. Vitamin D can also be obtained by eating foods or in vitamin pills. It's measured in international units (IU).

Here's how much vitamin D needed each day.

| Ages | IU per day |
|---|---|
| 19-50 | 200 |
| 51-70 | 400 |
| 71 and older | 600 |

Here are some foods to help get needed vitamin D. Check the food labels for more information.

| Food | Portion | IU | Percent |
|---|---|---|---|
| Salmon, cooked | 3 1/2 oz | 360 | 90 |
| Milk, nonfat, reduced fat, & whole, vitamin D fortified | 1 cup | 98 | 25 |
| Egg (vitamin D is in the yolk) | 1 whole | 25 | 6 |
| Pudding (made from mix & vitamin D fortified milk) | 1/2 cup | 50 | 10 |

White milk is a good source of vitamin D, most yogurts are not.

**3. Eat a healthy diet.**
Other nutrients, like vitamin A, vitamin C, magnesium, and zinc, as well as protein, help build strong bones too. Milk provides many of these nutrients. But these nutrients can be obtained by eating a healthy diet, including foods that have these nutrients. Some examples are lean meat, fish, green leafy vegetables, and oranges.

**4. Get moving.**
Being active really helps the bones by:

- slowing bone loss
- improving muscle strength
- helping balance

Do weight-bearing physical activity, which is any activity in which the body works against gravity. There are many activities that will help: walk, dance, run, climb stairs, garden, do yoga or tai chi, jog, hike, play tennis, or lift weights – it all helps!

**5. Don't smoke.**
Smoking raises a risk of getting osteoporosis. It damages the bones and lowers the amount of estrogen in a woman's body. Estrogen can help slow bone loss.

**6. Drink alcohol moderately.**
Do not drink more than one alcoholic drink per day. Alcohol can make it harder for the body to use ingested calcuim.

**7. Make the home safe.**
Reduce the chances of falling by making the home safer. For example, use a rubber bath mat in the shower or tub. Keep floors free from clutter. Remove throw rugs that cause tripping. Make sure there are grab bars in the bath or shower. **Fall prevention is a primary consideration**.

**8. Consider taking medicines to prevent or treat bone loss.**
Talk with the doctor or nurse about the risks and benefits of medicines for bone loss.

These drugs are approved for the treatment or prevention of osteoporosis:

| | |
|---|---|
| **Alendronate (Fosamax®)** | • belongs to a class of drugs called biophosphonates and is approved for both prevention and treatment of osteoporosis.<br>• used to treat bone loss from the long-term use of osteoporosis-causing medications and is used for osteoporosis in men |
| **Risedronate (Actonel®)** | • also is a bisphosphonate |
| **Calcitonin (Miacalcin®)** | • naturally occurring hormone involved in calcium regulation and bone metabolism<br>• can be injected or taken as a nasal spray<br>• slows bone loss and increases spinal bone density |
| **Raloxifene (Evista®)** | • a selective estrogen receptor modulator (SERM) that has many estrogen-like properties<br>• approved for prevention and treatment of osteoporosis and can prevent bone loss at the spine, hip, and other areas of the body |
| **Estrogen therapy (ET), or Hormone Therapy (HT)** | • which have been used to treat the symptoms of menopause, also are used to prevent bone loss<br>• might not be a good option for many women |
| **Parathyroid Hormone or Teriparatide (Fortéo®)** | • approved for the treatment of osteoporosis in postmenopausal women and men who are at high risk for a fracture<br>• It helps new bone to form and increases bone density<br>• Can be given as a daily injection for up to 24 months |

## How Can the Lactose Intolerant Patient Get Enough Calcium?

For the lactose intolerant, it can be hard to get enough calcium. Lactose intolerance means the body is not able to easily digest foods that contain lactose, or the sugar that is found in dairy products like milk. Gas, bloating, stomach cramps, diarrhea, and nausea are common symptoms. It can start at any age but often begins as people age.

**Things to do:**

- Eat Lactose-reduced and lactose-free products sold in food stores including milk, cheese, and ice cream
- Take special pills or liquids before eating to help digest dairy foods
- Eat foods that have calcium added (fortified), like some cereals and orange juice
- Think about taking calcium pills

## Osteoporosis and Quality of Life

Aside from its effects on the bones, osteoporosis can change life in many other ways. Osteoporosis affects each person differently and to different degrees. For example, people with a single fracture and people who have had multiple fractures do not face the same challenges. The particular site of a fracture (hip, spine, etc.) may also influence a person's life in different ways. The effects of osteoporosis on quality of life can include:

- Anxiety and depression
- Reduced self-image
- Limitations in the ability to work and enjoy leisure activities
- Acute or chronic pain

- Difficulties in performing the activities of daily life
- Loss of independence
- Changes in relationships with family and friends.

## Men and Osteoporosis

Before the 1990s, we used to think only women got osteoporosis. Now we know that men also have to worry about weak bones. In fact, one in four men over age 50 will suffer a fracture caused by osteoporosis. But four fifths of Americans over the age of 50 who have osteoporosis are women. They are more likely than men to develop osteoporosis because of the loss of estrogen at menopause. Estrogen blocks or slows down bone loss.

**Recommended Calcium and Vitamin D Intakes3**

| **Age** | **Calcium (milligrams)** | **Vitamin D (International Units)** |
|---|---|---|
| **Infants:** | | |
| Birth–6 months | 210 | 200 |
| 6 months–1 year | 270 | 200 |
| **Children/Young Adults:** | | |
| 1–3 years | 500 | 200 |
| 4–8 years | 800 | 200 |
| 9–18 years | 1,300 | 200 |
| **Adult Women and Men:** | | |
| 9–18 years | 1,000 | 200 |
| 51–70 years | 1,200 | 400 |
| Over 70 years | 1,200 | 600 |

**Pregnant or Nursing Women:** Note that the recommended levels for women 19-50 years are the same as those for women of the same age who are not pregnant or nursing: there are no different recommendations for pregnancy or breastfeeding. Women under 18 should follow the age guidelines.

| | | |
|---|---|---|
| 18 years or younger | 1,300 | 200 |
| 19–50 years | 1,000 | 200 |

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[3] Food and Nutrition Board, Institute of Medicine, National Academy of Sciences, 1997

Adapted (8-07) from what is osteoporosis, http://www.4woman.gov/faq/osteopor.htmUpdated: August 2004 and NIH Pub. No. 07-5158, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the Department of Health and Human Services' National Institutes of Health (NIH) www.niams.nih.gov/bone

# Parkinson's Disease (PD)

## Definition

PD is a degenerative disorder of the central nervous system that often impairs the sufferer's motor skills and speech.

## Characteristics

- The **four primary symptoms** of PD are:
  - tremor, or trembling in hands, arms, legs, jaw, and face
  - rigidity, or stiffness of the limbs and trunk
  - bradykinesia, or slowness of movement
  - postural instability, or impaired balance and coordination
- **Other symptoms** may include:
  - depression and other emotional changes
  - difficulty in swallowing, chewing, and speaking
  - urinary problems or constipation
  - skin problems
  - sleep disruptions
- PD usually affects people over the age of 50.
- Early symptoms of PD are subtle and occur gradually.
- In some people the disease progresses more quickly than in others.
- PD is both chronic, meaning it persists over a long period of time, and progressive, meaning its symptoms grow worse over time.
- It is not contagious.
- Many researchers now believe that PD results from a combination of genetic susceptibility and exposure to one or more environmental factors that trigger the disease

## Functional Considerations

- In the early stages watch for subtle cognitive losses that could effect decision making capabilities.
- Due to slow progression people may overestimate abilities.
- Mobility and cognition can be severe at the end stages of the disease.
- Functional impairments are likely to worsen as the disease progresses.
- Consider exception to Domestic standard because of spilling and missing the toilet when a man urinates.
- If feeding is authorized, the risk of choking and difficulty in swallowing should be considered.
- Additional time for feeding, dressing, and grooming may be required due to tremors and stiffness, possibly warranting an exception.
- The consumer may look flat without facial expressions. This does not mean they do not understand the conversation.

# Parkinson's Disease

## What is Parkinson's Disease?

Parkinson's disease (PD) belongs to a group of conditions called motor system disorders, which are the result of the loss of dopamine-producing brain cells.

- PD usually affects people over the age of 50.
- Early symptoms of PD are subtle and occur gradually.
- In some people the disease progresses more quickly than in others.
- PD is both chronic, meaning it persists over a long period of time, and progressive, meaning its symptoms grow worse over time.
- It is not contagious.
- Although some PD cases appear to be hereditary, and a few can be traced to specific genetic mutations, most cases are sporadic — that is, the disease does not seem to run in families.
- Many researchers now believe that PD results from a combination of genetic susceptibility and exposure to one or more environmental factors that trigger the disease.

## What Causes the Disease?

**Dopamine**- Parkinson's disease occurs when nerve cells, or neurons, in an area of the brain known as the substantia nigra die or become impaired. Normally, these neurons produce an important brain chemical known as dopamine. Dopamine is a chemical messenger responsible for transmitting signals between the substantia nigra and the next "relay station" of the brain, the corpus striatum, to produce smooth, purposeful movement. Loss of dopamine results in abnormal nerve firing patterns within the brain that cause impaired movement. Studies have shown that most Parkinson's patients have lost 60 to 80 percent or more of the dopamine-producing cells in the substantia nigra by the time symptoms appear.

**Norepinephrine** - Recent studies have shown that people with PD also have loss of the nerve endings that produce the neurotransmitter norepinephrine. Norepinephrine, which is closely related to dopamine, is the main chemical messenger of the sympathetic nervous system, the part of the nervous system that controls many automatic functions of the body, such as pulse and blood pressure. The loss of norepinephrine might help explain several of the non-motor features seen in PD, including fatigue and abnormalities of blood pressure regulation.

**Lewy bodies** - Many brain cells of people with PD contain Lewy bodies – unusual deposits or clumps of the proteins. Researchers do not yet know why Lewy bodies form or what role they play in development of the disease. The clumps may prevent the cell from functioning normally, or they may actually be helpful, perhaps by keeping harmful proteins "locked up" so that the cells can function.

## Who Gets Parkinson's Disease?

PD strikes about 50 percent more men than women, but the reasons for this discrepancy are unclear. While it occurs in people throughout the world, a number of studies have found a higher incidence in developed countries, possibly because of increased exposure to pesticides or other toxins in those countries. Other studies have found an increased risk in people who live in rural areas and in those who work in certain professions, although the studies to date are not conclusive and the reasons for the apparent risks are not clear.

One clear risk factor for PD is age. The average age of onset is 60 years, and the incidence rises significantly with increasing age. However, about 5 to 10 percent of people with PD have "early-onset" disease that begins before the age of 50. Early-onset forms of the disease are often inherited, though not always, and some have been linked to specific gene mutations. People with one or more close relatives who have PD have an increased risk of developing the disease themselves, but the total risk is still just 2 to 5 percent unless the family has a known gene mutation for the disease. An estimated 15 to 25 percent of people with PD have a known relative with the disease.

## What are the Symptoms of the Disease?

Early symptoms of PD:

- are subtle and occur gradually
- people may feel mild tremors or have difficulty getting out of a chair
- may notice that they speak too softly
- that their handwriting is slow and looks cramped or small
- may lose track of a word or thought
- may feel tired, irritable, or depressed for no apparent reason
- person's face lacks expression and animation (known as "masked face")
- person seems stiff, unsteady, or unusually slow

This very early period may last a long time before the more classic and obvious symptoms appear. Friends or family members may be the first to notice changes in someone with early PD.

As the disease progresses,

- shaking or tremor may begin to interfere with daily activities.
- may not be able to hold utensils steady
- may find that the shaking makes reading a newspaper difficult.
- tremor is usually the symptom that causes people to seek medical help
- “parkinsonian gait” that includes a tendency to lean forward, small quick steps as if hurrying forward (called festination), and reduced swinging of the arms
- may have trouble initiating movement (start hesitation)
- may stop suddenly as they walk (freezing).

PD does not affect everyone the same way, and the rate of progression differs among patients. Tremor is the major symptom for some patients, while for others; tremor is nonexistent or very minor.

PD symptoms often begin on one side of the body. However, as it progresses, the disease eventually affects both sides. Even after the disease involves both sides of the body, the symptoms are often less severe on one side than on the other.

The **four primary symptoms** of PD are:

| | |
|---|---|
| **Tremor** | • has a characteristic appearance<br>• typically, takes the form of a rhythmic back-and-forth motion at a rate of 4-6 beats per second<br>• may involve the thumb and forefinger and appear as a "pill rolling" tremor often begins in a hand, although sometimes a foot or the jaw is affected first<br>• is most obvious when the hand is at rest or when a person is under stress the shaking may become more pronounced a few seconds after the hands are rested on a table<br>• usually disappears during sleep or improves with intentional movement |
| **Rigidity**<br>(a resistance to movement) | • affects most people<br>• The muscles remain constantly tensed and contracted so that the person aches or feels stiff or weak<br>• rigidity becomes obvious when another person tries to move the patient's arm, which will move only in ratchet-like or short, jerky movements known as "cogwheel" rigidity |
| **Bradykinesia**<br>(slowing down and loss of spontaneous and automatic movement) | • particularly frustrating because it may make simple tasks somewhat difficult<br>• person cannot rapidly perform routine movements<br>• activities once performed quickly and easily — such as washing or dressing — may take several hours |
| **Postural instability**<br>(impaired balance) | • causes patients to fall easily<br>• may develop a stooped posture in which the head is bowed and the shoulders are drooped |

A number of **other symptoms may accompany PD**. Some are minor; others are not. Many can be treated with medication or physical therapy. No one can predict which symptoms will affect an individual patient, and the intensity of the symptoms varies from person to person.

| | | |
|---|---|---|
| **Depression** | • common problem and may appear early in the course of the disease, even before other symptoms are noticed | • may be successfully treated with antidepressant medications |
| **Emotional changes** | • some people become fearful and insecure<br>• may not want to travel, go to parties, or socialize with friends.<br>• may lose their motivation and become dependent on family members<br>• may become irritable or uncharacteristically pessimistic | |

| | | |
|---|---|---|
| **Difficulty with swallowing and chewing** | • muscles used in swallowing may work less efficiently in later stages of the disease<br>• in these cases, food and saliva may collect in the mouth and back of the throat, which can result in choking or drooling<br>• these problems also may make it difficult to get adequate nutrition | • Speech-language therapists, occupational therapists, and dieticians can often help with these problems |
| **Speech changes** | • about half of all patients have problems with speech.<br>• may speak too softly or in a monotone, hesitate before speaking, slur or repeat their words, or speak too fast. | • A speech therapist may be able to help patients reduce some of these problems |
| **Urinary problems** | • bladder and bowel problems can occur due to the improper functioning of the autonomic nervous system, which is responsible for regulating smooth muscle activity<br>• Some people may become incontinent, while others have trouble urinating | • May improve with medication treatment for MD |
| **Constipation** | • may occur because the intestinal tract operates more slowly<br>• can also be caused by inactivity, eating a poor diet, or drinking too little fluid<br>• medications used to treat PD also can contribute to constipation<br>• can be a persistent problem and, in rare cases, can be serious enough to require hospitalization | |
| **Skin problems** | • common for the skin on the face to become very oily, particularly on the forehead and at the sides of the nose<br>• scalp may become oily too, resulting in dandruff<br>• in other cases, the skin can become very dry<br>• another common symptom is excessive sweating, | • standard treatments for skin problems can help.<br>• excessive sweating is usually controllable with medications used for PD |
| **Sleep problems** | • common and include:<br>o difficulty staying asleep at night<br>o restless sleep<br>o nightmares<br>o emotional dreams<br>o drowsiness or sudden sleep onset during the day.<br>• patients with PD should never take over-the-counter sleep aids without consulting their physicians | |

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

| | | |
|---|---|---|
| **Dementia or other cognitive problems** | • some, but not all, people may develop memory problems and slow thinking<br>• cognitive problems may become more severe, leading to a condition called Parkinson's dementia late in the course of the disease<br>• dementia may affect memory, social judgment, language, reasoning, or other mental skills | • currently there is no way to halt PD dementia, but studies have shown that a drug called rivastigmine may slightly reduce the symptoms.<br>• the drug donepezil also can reduce behavioral symptoms in some people with PD-related dementia |
| **Orthostatic hypotension** (a sudden drop in blood pressure when a person stands up from a lying-down position) | • may cause dizziness, lightheadedness, and, in extreme cases, loss of balance or fainting<br>• this problem results from a loss of nerve endings in the sympathetic nervous system that controls heart rate, blood pressure, and other automatic functions in the body<br>• medications used to treat PD also may contribute to this symptom | • may be helped by increasing salt intake, reducing antihypertension drugs, or prescribing medications such as fludrocortisone |
| **Muscle cramps and dystonia** | • muscle cramps seen especially in the legs and toes<br>• dystonia — sustained muscle contractions that cause forced or twisted positions is often caused by fluctuations in the body's level of dopamine | • Massage, stretching, and applying heat may help with these cramps<br>• Dystonia can usually be relieved or reduced by adjusting the person's medications |
| **Pain** | • aching muscles and joints because of the rigidity and abnormal postures often associated with the disease<br>• may develop pain due to compression of nerve roots or dystonia-related muscle spasms<br>• in rare cases may develop unexplained burning, stabbing sensations- called "central pain," originates in the brain | • Treatment with levodopa and other dopaminergic drugs often alleviates these pains to some extent<br>• Certain exercises also may help<br>• Dopaminergic drugs, opiates, antidepressant, and other types of drugs may all be used to treat “central pain” |
| **Fatigue and loss of energy** | • fatigue, especially late in the day<br>• Fatigue may be associated with depression or sleep disorders, but it also may result from muscle stress or from overdoing activity when the person feels well<br>• may result from akinesia – trouble initiating or carrying out movement | • Exercise, good sleep habits, staying mentally active, and not forcing too many activities in a short time may help to alleviate fatigue |

| | | |
|---|---|---|
| **Sexual dysfunction** | • often causes erectile dysfunction because of its effects on nerve signals from the brain or because of poor blood circulation<br>• depression or use of antidepressant medication also may cause decreased sex drive and other problems | • These problems are often treatable |

## How is Parkinson's Disease Diagnosed?

There are currently no blood or laboratory tests that have been proven to help in diagnosing sporadic PD. Therefore the diagnosis is based on medical history and a neurological examination. The disease can be difficult to diagnose accurately. Doctors may sometimes request brain scans or laboratory tests in order to rule out other diseases.

## What is the Prognosis?

PD is not by itself a fatal disease, but it does get worse with time. The average life expectancy of a PD patient is generally the same as for people who do not have the disease. However, in the late stages of the disease, PD may cause complications such as choking, pneumonia, and falls that can lead to death.

One commonly used system for describing how the symptoms of PD progress is called the Hoehn and Yahr scale.

## Hoehn and Yahr Staging of Parkinson's Disease

| | |
|---|---|
| **Stage one** | Symptoms on one side of the body only. |
| **Stage two** | Symptoms on both sides of the body. No impairment of balance. |
| **Stage three** | Balance impairment. Mild to moderate disease. Physically independent. |
| **Stage four** | Severe disability, but still able to walk or stand unassisted. |
| **Stage five** | Wheelchair-bound or bedridden unless assisted. |

With appropriate treatment, most people with PD can live productive lives for many years after diagnosis.

## How is the Disease Treated?

At present, there is no cure for PD. But medications or surgery can sometimes provide dramatic relief from the symptoms.

## Drug Treatments

Medications for PD fall into three categories:

- The first category includes **drugs that work directly or indirectly to increase the level of dopamine in the brain**. The most common drugs for PD are dopamine precursors – substances such as levodopa that cross the blood-brain barrier and are then changed into dopamine. Other drugs mimic dopamine or prevent or slow its breakdown.

| Characteristics | | Side effects |
|---|---|---|
| **Levodopa** | • Cornerstone of therapy for PD<br>• Nerve cells can use levodopa to make dopamine and replenish the brain's dwindling supply<br>• Levodopa usually helps most with bradykinesia and rigidity.<br>• Problems with balance and other non-motor symptoms may not be alleviated at all.<br>• People often see dramatic improvement in their symptoms after starting levodopa therapy.<br>• However, they may need to increase the dose gradually for maximum benefit<br>• **Never** stop taking levodopa without their physician's knowledge or consent because rapidly withdrawing the drug can have potentially serious side effects, such as immobility or difficulty breathing | • Most common initial side effects include nausea, vomiting, low blood pressure, and restlessness. Can cause drowsiness or sudden sleep onset, which can make driving and other activities dangerous.<br>• Long-term use of levodopa may cause hallucinations and psychosis.<br>• Nausea and vomiting are greatly reduced by combining levodopa and carbidopa, which enhances the effectiveness of a lower dose.<br>• Dyskinesias, or involuntary movements such as twitching, twisting, and writhing, commonly develop in people who take large doses of levodopa over an extended period.<br>• After long-term use ↓effectiveness, and coverage time may lessen causing "breakthrough symptoms" |
| **Dopamine agonists** | • mimic the role of dopamine in the brain<br>• include bromocriptine, apomorphine, pramipexole, and ropinirole<br>• can be given alone or in conjunction with levodopa<br>• generally less effective than levodopa in controlling rigidity and bradykinesia<br>• May be used to lessen long-term effects of levodopa | • Many of the potential side effects are similar to those associated with the use of levodopa, including drowsiness, sudden sleep onset, hallucinations, confusion, dyskinesias, edema, nightmares, and vomiting.<br>• Can cause compulsive behavior, such as an uncontrollable desire to gamble, hypersexuality, or compulsive shopping.<br>• Bromocriptine can also cause fibrosis, or a buildup of fibrous tissue, in the heart valves or the chest cavity. Fibrosis usually goes away once the drugs are stopped. |
| **MAO-B inhibitors** | • Inhibit the enzyme monoamine oxidase B which breaks down dopamine in the brain<br>• Cause dopamine to accumulate in surviving nerve cells and reduce the symptoms of PD<br>• Selegiline (deprenyl), is an MAO-B inhibitor that is commonly used | • Selegiline is usually well-tolerated, although side effects may include nausea, orthostatic hypotension, or insomnia.<br>• It should not be taken with the antidepressant fluoxetine or the sedative mepiridine, because combining seligiline with these drugs can be harmful. |

| | | |
|---|---|---|
| **COMT inhibitors** | • Stands for catechol-O-methyltransferase, another enzyme that helps to break down dopamine<br>• Two are approved to treat PD in the United States: entacapone and tolcapone<br>• Usually make it possible to reduce the person's dose of levodopa | • The most common side effect is diarrhea.<br>• The drugs may also cause nausea, sleep disturbances, dizziness, urine discoloration, abdominal pain, low blood pressure, or hallucinations.<br>• In a few rare cases, tolcapone has caused severe liver disease. |
| **Amantadine** | • Antiviral drug can help reduce symptoms of PD and levodopa-induced dyskinesia<br>• After several months, amantadine's effectiveness wears off in up to half of the patients taking it | • side effects may include insomnia, mottled skin, edema, agitation, or hallucinations.<br>• Researchers are not certain how amantadine works in PD, but it may increase the effects of dopamine. |

- The second category of PD drugs **affects other neurotransmitters in the body in order to ease some of the symptoms of the disease**. For example, anticholinergic drugs interfere with production or uptake of the neurotransmitter acetylcholine. These drugs help to reduce tremors and muscle stiffness, which can result from having more acetylcholine than dopamine.

| | | |
|---|---|---|
| **Anticholinergics** | • include trihexyphenidyl, benztropine, and ethopropazine<br>• decrease the activity of the neurotransmitter acetylcholine and help to reduce tremors and muscle rigidity<br>• Only about half the patients who receive anticholinergics are helped by it, usually for a brief period and with only a 30 percent improvement | • Side effects may include dry mouth, constipation, urinary retention, hallucinations, memory loss, blurred vision, and confusion |

- The third category of drugs prescribed for PD includes **medications that help control the non-motor symptoms of the disease**, that is, the symptoms that don't affect movement. For example, people with PD-related depression may be prescribed antidepressants.

## Surgery

Treating PD with surgery was once a common practice. But after the discovery of levodopa, surgery was restricted to only a few cases. Studies in the past few decades have led to great improvements in surgical techniques, and surgery is again being used in people with advanced PD for whom drug therapy is no longer sufficient.

**Pallidotomy and Thalamotomy**. The earliest types of surgery for PD involved selectively destroying specific parts of the brain that contribute to the symptoms of the disease. Investigators have now greatly refined the use of these procedures. The most common of these procedures is called pallidotomy. In this procedure, a surgeon selectively destroys a portion of the brain to improve symptoms of tremor, rigidity, and bradykinesia. Some studies have also found that pallidotomy can improve gait and balance and reduce the amount of levodopa patients require, thus reducing drug-induced dyskinesias and dystonia. A related procedure, called thalamotomy, involves surgically destroying part of the brain's thalamus. Thalamotomy is useful primarily to reduce tremor.

Because these procedures cause permanent destruction of brain tissue, they have largely been replaced by deep brain stimulation for treatment of PD.

**Deep Brain Stimulation**. Deep brain stimulation, or DBS, uses an electrode surgically implanted into part of the brain. The electrodes are connected by a wire under the skin to a small electrical device called a pulse generator that is implanted in the chest beneath the collarbone. The pulse generator and electrodes painlessly stimulate the brain in a way that helps to stop many of the symptoms of PD. DBS has now been approved by the U.S. Food and Drug Administration, and it is widely used as a treatment for PD. DBS can be used on one or both sides of the brain.

One advantage of DBS compared to pallidotomy and thalamotomy is that the electrical current can be turned off using a handheld device. The pulse generator also can be externally programmed.

## How Can People Cope with Parkinson's Disease?

While PD usually progresses slowly, eventually the most basic daily routines may be affected — from socializing with friends and enjoying normal relationships with family members to earning a living and taking care of a home. These changes can be difficult to accept. Support groups can help people cope with the disease emotionally. These groups can also provide valuable information, advice, and experience to help people with PD, their families, and their caregivers deal with a wide range of issues, including locating doctors familiar with the disease and coping with physical limitations. A list of national organizations that can help patients locate support groups in their communities appears at the end of this brochure. Individual or family counseling also may help people find ways to cope with PD.

People with PD also can benefit from being proactive and finding out as much as possible about the disease in order to alleviate fear of the unknown and to take a positive role in maintaining their health. Many people with PD continue to work either full- or part-time, although eventually they may need to adjust their schedule and working environment to cope with the disease.

## Glossary of Terms

- **anticholinergic drugs** — drugs that interfere with production or uptake of the neurotransmitter acetylcholine.
- **akinesia** — trouble initiating or carrying out movements.
- **bradykinesia** — gradual loss of spontaneous movement.
- **corpus striatum** — a part of the brain that helps regulate motor activities.
- **deep brain stimulation** — a treatment that uses an electrode implanted into part of the brain to stimulate it in a way that temporarily inactivates some of the signals it produces.
- **dementia** — loss of intellectual abilities.
- **dopamine** — a chemical messenger, deficient in the brains of PD patients, that transmits impulses from one nerve cell to another.
- **dyskinesias** — abnormal involuntary twisting and writhing movements that can result from long-term use of high doses of levodopa.
- **dysphagia** — difficulty swallowing.
- **festination** — a symptom characterized by small, quick, forward steps.
- **myoclonus** — muscular jerks.
- **on-off effect** — a change in the patient's condition, with sometimes rapid fluctuations between uncontrolled movements and normal movement, usually occurring after long-term use of levodopa and probably caused by changes in the ability to respond to this drug.
- **orthostatic hypotension** — a sudden drop in blood pressure when a person stands up from a lying-down position. It may cause dizziness, lightheadedness, and, in extreme cases, loss of balance or fainting.
- **pallidotomy** — a surgical procedure in which a part of the brain called the globus pallidus is lesioned in order to improve symptoms of tremor, rigidity, and bradykinesia.
- **parkinsonian gait** — a characteristic way of walking that includes a tendency to lean forward; small, quick steps as if hurrying forward (called festination); and reduced swinging of the arms.
- **parkinsonism** — a term referring to a group of conditions that are characterized by four typical symptoms—tremor, rigidity, postural instability, and bradykinesia.
- **"Parkinson's-plus"** — a group of diseases that includes corticobasal degeneration, progressive supranuclear palsy, and multiple system atrophy. These diseases cause symptoms like those of PD in addition to other symptoms.
- **postural instability** — impaired balance that causes a tendency to lean forward or backward and to fall easily.
- **rigidity** — a symptom of the disease in which muscles feel stiff and display resistance to movement even when another person tries to move the affected part of the body, such as an arm.
- **secondary parkinsonism** — any condition with symptoms that resemble those of PD but which result from other causes.
- **substantia nigra** — movement-control center in the brain where loss of dopamine-producing nerve cells triggers the symptoms of PD; substantia nigra means "black substance," so called because the cells in this area are dark.
- **thalamotomy** — a procedure in which a portion of the brain's thalamus is surgically destroyed, usually reducing tremors.
- **tremor** — shakiness or trembling, often in a hand, which in PD is usually most apparent when the affected part is at rest.
- **wearing-off effect** — the tendency, following long-term levodopa treatment, for each dose of the drug to be effective for shorter and shorter periods.

Adapted (8-07) from: "Parkinson's Disease: Hope Through Research," NINDS. Publication date June 22, 2007. NIH Publication No. 06-139

# Peripheral Arterial Disease (PAD)

## Definition

Fatty material called plaque builds up on the inside walls of the arteries that carry blood from the heart to the head, internal organs, and limbs. PAD is also known as atherosclerotic peripheral arterial disease.

## Characteristics

- **Atherosclerosis** can affect arteries anywhere in the body, including the arteries that carry blood to the heart and brain.
- **Peripheral Arterial Disease (PAD) –** affects the arteries that supply blood to the limbs, especially the legs. PAD can impair physical health and diminish the ability to walk.
- **Chronic Critical Limb Ischemia (CLI) –** in the advanced stages of PAD, blood flow to one or both legs can be completely or mostly blocked. CLI may lead to painful leg or **foot sores**, and it could eventually lead to **gangrene**. If this condition is left untreated, the foot or leg may need to be **amputated**.

Major risk factors for developing PAD include:

- **Smoking**. Smoking is more closely related to developing PAD than any other risk factor.
- **Diabetes**.
- **Other diseases and conditions** such as:
    - Kidney disease
    - High blood pressure or a family history of it
    - A high cholesterol level or a family history of it
    - Heart disease or a family history of it
- **A family history of stroke**
- **Age** – risk increases with age

## Functional Considerations

- Symptoms such as claudication, pain and sores can make walking a very difficult issue for these patients.
- Amputation can create many functional limitations.
- Leg pain and cramping may impede functional ability.
- The amount of walking or standing the consumer can do before pain occurs will give an idea of stamina.
- Supervised exercise may improve functioning – this should be doctor directed.
- Paramedical services for wound care may be indicated.

National Heart
Lung and Blood Institute

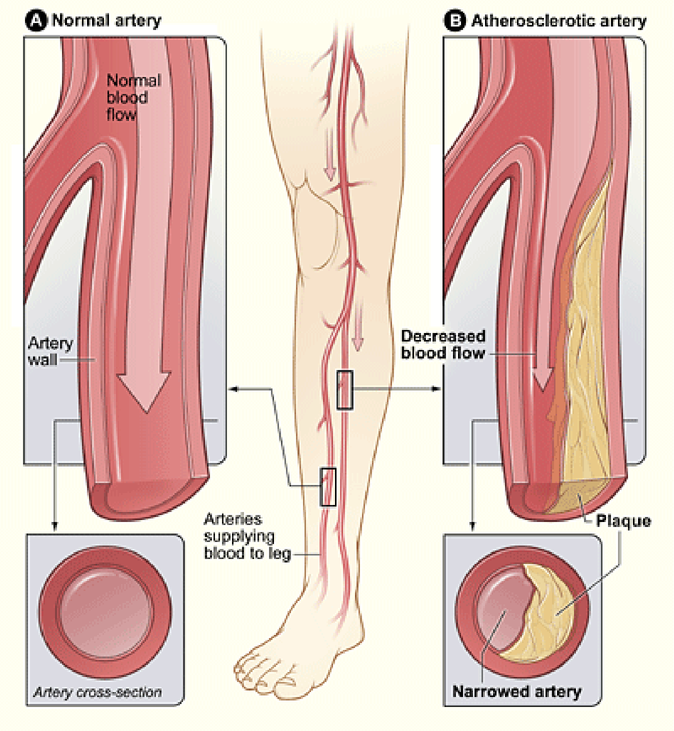
# Peripheral Arterial Disease

Peripheral arterial disease (PAD) occurs when a fatty material called plaque (plak) builds up on the inside walls of the arteries that carry blood from the heart to the head, internal organs, and limbs. PAD is also known as atherosclerotic peripheral arterial disease.

The buildup of plaque on the artery walls is called atherosclerosis, or hardening of the arteries. Atherosclerosis causes the arteries to narrow or become blocked, which can reduce or block blood flow**. PAD most commonly affects blood flow to the legs.**

Blocked blood flow can cause pain and numbness. It also can increase a person's chance of getting an infection, and it can make it difficult for the person's body to fight the infection. If severe enough, blocked blood flow can cause tissue death (gangrene). **PAD is the leading cause of leg amputation**.

The illustration shows the location of leg arteries that can be affected by peripheral arterial disease. Figure A shows a normal artery with normal blood flow (the inset image shows a cross-section of the normal artery). Figure B shows an artery with plaque buildup, which is partially blocking blood flow (the inset image shows the degree to which the artery is blocked).



## Important General Information

**Atherosclerosis** can affect arteries anywhere in the body, including the arteries that carry blood to the heart and brain.

**Coronary artery disease (CAD) -** When atherosclerosis affects the arteries of the heart. CAD can cause a heart attack. If atherosclerosis is in the limbs, it also is likely to be in the coronary arteries.
**Carotid artery disease -** When atherosclerosis affects the major arteries supplying the brain, it is called carotid artery disease. This can cause a stroke.

**Peripheral Arterial Disease (PAD) -** Atherosclerosis in the arteries that supply blood to the limbs, especially the legs. PAD can impair physical health and diminish the ability to walk.

In the advanced stages of PAD, blood flow to one or both legs can be completely or mostly blocked. This is known as **chronic critical limb ischemia (CLI**). A very severe blockage in the legs and feet means that the legs do not receive the oxygen or nutrition needed for cellular or skin growth and repair. CLI may lead to painful leg or **foot sores**, and it could eventually lead to **gangrene**. If this condition is left untreated, the foot or leg may need to be **amputated**.

## Outlook

A person with PAD has a six to seven times greater risk of CAD, heart attack, stroke, or transient ischemic attack ("mini stroke") than the rest of the population. If a person has heart disease, he or she has a 1 in 3 chance of having blocked arteries in the legs. Early diagnosis and treatment of PAD, including screening high-risk individuals, are important to prevent disability and save lives. PAD treatment may stop the disease from progressing and reduce the risk of heart attack, heart disease, and stroke.

**Although PAD is serious, it is treatable**. The buildup of plaque in the arteries can often be stopped or reversed with dietary changes, exercise, and efforts to lower high cholesterol levels and high blood pressure. In some patients, blood flow in the vessels may be improved by medicines or surgery.

## Other Names for Peripheral Arterial Disease

- Atherosclerotic peripheral arterial disease
- Peripheral vascular disease (PVD)
- Vascular disease
- Hardening of the arteries
- Claudication
- Poor circulation
- Leg cramps from poor circulation

## Who is At Risk for Peripheral Arterial Disease?

Peripheral arterial disease (PAD) affects 8 to 12 million people in the United States. An estimated 5 percent of U.S. adults over age 50 have PAD. Among adults age 65 and older, 12 to 20 percent may have PAD.

Major risk factors for developing PAD include:

- **Smoking**. Smoking is more closely related to developing PAD than any other risk factor.
    - Smoking increases the risk of developing PAD three to five times.
    - On average, smokers who develop PAD experience symptoms 10 years earlier than nonsmokers who develop PAD.
    - Stopping smoking will slow the progress of PAD.
    - Smoking even one or two cigarettes daily can interfere with the treatment for PAD.
    - Smokers and diabetics have the greatest risk of complications from PAD, including gangrene in the leg from decreased blood flow.
- **Chronic or serious illnesses, such as diabetes**. One in three people over age 50 with diabetes is likely to have PAD. Anyone over age 50 with diabetes should be screened for PAD.
- **Other diseases and conditions**, such as:
    - Kidney disease
    - High blood pressure or a family history of it
    - A high cholesterol level or a family history of it
    - Heart disease or a family history of it
- **A family history of stroke**
- **Age.** Men who are older than age 50 and women who are older than age 55 are at higher risk for PAD.

## What are the Signs and Symptoms of Peripheral Arterial Disease?

At least half of the people who have peripheral arterial disease (PAD) don't have any signs or symptoms of the disease.

If they are present, the typical signs and symptoms of the disease include:

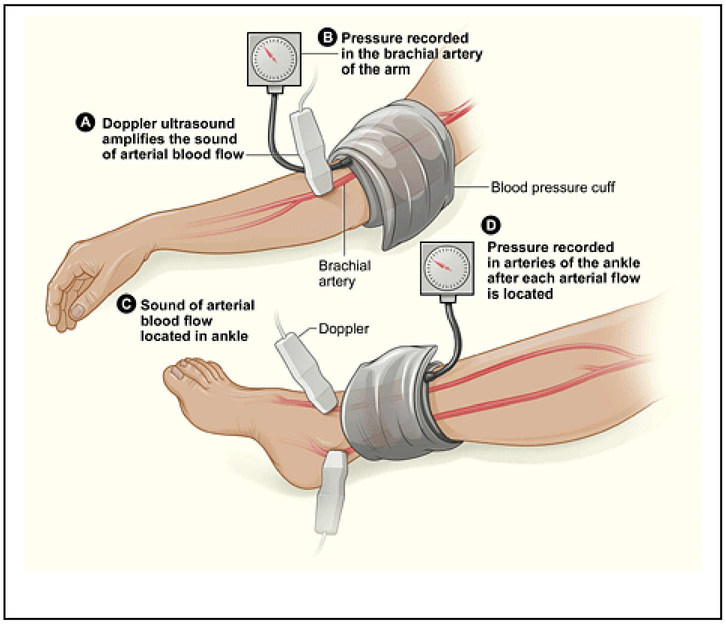
- **Claudication**—fatigue, heaviness, tiredness, cramping in the leg muscles (buttocks, thigh, or calf) that occurs during activity such as walking or climbing stairs. This pain or discomfort goes away once the activity is stopped and during rest. Many people do not report this problem to their health care providers because they think it is a natural part of aging or due to some other cause.
- **Pain in the legs and/or feet** that disturbs sleep.
- **Sores or wounds on toes, feet, or legs** that heal slowly, poorly, or not at all.
- **Color changes in the skin of the feet**, including paleness or blueness.
- **A lower temperature in one** leg compared to the other leg.
- **Poor nail growth and decreased hair growth on toes and legs**.

## How is Peripheral Arterial Disease Diagnosed?

Peripheral arterial disease (PAD) is diagnosed based on general medical and family history, history of leg or heart problems, personal risk factors, a physical exam, and test results. An accurate diagnosis is critical, because people with PAD face a six to seven times higher risk of heart disease or stroke than the rest of the population. PAD is often diagnosed after symptoms are reported. If you have PAD, your doctor also may want to look for signs of coronary artery disease (CAD).

### Diagnostic Tests and Procedures

A simple test called an **ankle-brachial index (ABI)** can be used to diagnose PAD. The ABI compares blood pressure in the ankle with blood pressure in the arm to see how well blood is flowing. A normal ABI is 1.0 or greater (with a range of 0.90 to 1.30). The test takes about 10–15 minutes to measure both arms and both ankles. It can help the doctor find out if PAD is affecting the legs, but it will not identify which blood vessels are blocked. The ABI can be performed yearly if necessary to see if the disease is getting worse.



The illustration shows the ankle-brachial index (ABI) test. The ABI gives the ratio of the systolic blood pressure in the ankle to the systolic blood pressure in the brachial artery of the arm.

A **Doppler ultrasound** is a test that uses sound waves to tell whether a blood vessel is open or blocked. This test uses a blood pressure cuff and special device to measure blood flow in the veins and arteries in the arms and legs. The Doppler ultrasound can help to determine the level and degree of PAD.

A **treadmill test** will provide more information on the severity of the symptoms and the level of exercise that provokes symptoms. For this test, the patient walks on a treadmill, which will help identify any difficulties that they may have during normal walking.

A **magnetic resonance angiogram (MRA)** uses radio wave energy to take pictures of blood vessels inside the body. MRA is a type of magnetic resonance imaging (MRI) scan. An MRA can detect problems that may cause reduced blood flow in the blood vessels. It can determine the location and degree of blockage. A patient with a pacemaker, prosthetic joint, stent, surgical clips, mechanical heart valve, or other metallic devices in his or her body might not be eligible for an MRA depending on the type of metallic device.

An **arteriogram i**s a "road map" of the arteries used to pinpoint the exact location of the blockage in a limb. An x-ray is taken after injecting dye through a needle or catheter into an artery. When the dye is injected, the patient may feel mildly flushed. The pictures from the x-ray can determine the location, type, and extent of the blockage. Some hospitals are using a newer method that uses tiny ultrasound cameras to take pictures inside the blood vessel.

**Blood tests** may be done to check the patient's blood sugar level to screen for diabetes. Blood tests also may be used to check the patient's cholesterol levels.

## How is Peripheral Arterial Disease Treated?

### Goals of Treatment

The **overall goals** for treating peripheral arterial disease (PAD) are to:

1. reduce symptoms,
2. improve quality of life, and
3. prevent complications.

Treatment is based on symptoms, risk factors, physical exam results, and diagnostic tests.

## Specific Types of Treatment

**Lifestyle Changes** – Treatment often includes making long-lasting lifestyle changes, such as:

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| **Quitting smoking** | • Smoking increases the risk of developing PAD three to five times.<br>• The risk for coronary artery disease (CAD) decreases rapidly if the smoker quits.<br>• The risk for CAD decreases 40 percent within 5 years of stopping smoking. |
| **Lowering blood pressure** | • Lowering blood pressure can help to avoid the risk of stroke, heart attack, congestive heart failure, and kidney disease. |
| **Lowering high cholesterol levels** | • Lowering cholesterol levels can delay or even reverse the buildup of plaque in the arteries. |
| **Lowering blood glucose levels if you have diabetes** | • A hemoglobin A1C test—a test that gives an estimate of how well blood sugar has been controlled over the past 3 months—may be performed. |
| **Exercise therapy** | • Should be monitored by a doctor |
| **Healthy diet** | • Low-saturated fat, low-cholesterol diet, and eat foods with less salt, total fat.<br>• Eat more fruits, vegetables, and low-fat dairy products. |
| **Weight loss** | • If you are overweight or obese, work with your doctor to develop a reasonable weight-loss plan. |

## Medicines

Medicines may be prescribed to:

- **Lower high cholesterol levels** - may include statins, such as lovastatin, simvastatin, pravastatin, fluvastatin, and atorvastatin. Other medicines may include ezetimibe, gemfibrozil, and certain binding agents.
- **Lower high blood pressure** - should aim for a blood pressure lower than 130/80 mmHg. Many medicines are available to lower blood pressure, such as angiotensin-converting enzyme (ACE) inhibitors, angiotensin receptor blockers (ARBs), beta-blockers, diuretics ("water pills"), and calcium channel blockers.
- **Thin the blood to prevent clots** from forming due to low blood flow – such as heparin or coumadin
- **Dissolve blood clots** - antiplatelet drugs such as clopidogrel (Plavix®) and aspirin may be prescribed
- **Help improve pain in the legs** that is the result of walking or climbing stairs (claudication) – such as pentoxifylline (Trental®) or cilostazol (Pletal®)

## Surgeries or Special Procedures

Surgery may be necessary if blood flow in a limb is completely or almost completely blocked. In **bypass grafting surgery**, the doctor uses a blood vessel from another part of your body or a tube made of synthetic (man-made) material to make a graft. This graft bypasses the blockage in the artery, allowing blood to flow around it. Surgery does not cure PAD, but it may increase blood flow to the limb.

**Angioplasty** may be performed to restore blood flow through a narrowed or blocked artery. During the procedure, a thin tube (catheter) is inserted into a blocked artery and a small balloon on the tip of the catheter is inflated. When the balloon is inflated, plaque is pushed against the artery walls. This causes the artery to widen, restoring blood flow. A **stent**, a tiny mesh tube that looks like a small spring, is now used in most angioplasties. Some stents are coated with medicine to help prevent the artery from closing again.

## How Can Peripheral Arterial Disease be Prevented?

There are a number of ways to try to prevent peripheral arterial disease (PAD). If you are a smoker, quit smoking. On average, smokers who develop PAD experience symptoms 10 years earlier than nonsmokers who develop PAD. Work to control your blood pressure, cholesterol, and glucose levels. Talk with your doctor about beginning a supervised exercise therapy program. If you are overweight or obese, work with your doctor to develop a reasonable weight-loss plan. Finally, follow a low-fat, low-cholesterol diet and eat more fruits and vegetables.

## Living with Peripheral Arterial Disease

### Ongoing Health Care Needs

Peripheral arterial disease (PAD) can be treated and controlled.

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|---|---|
| Intermittent claudication | Try to take a break and allow the pain to ease before walking again.<br>Over time, this should increase the distance that you can walk without pain. |
| Foot inspection | Check feet and toes regularly for sores or any possible infection.<br>Maintain good foot hygiene and have professional medical treatment for corns, bunions, or calluses.<br>Wear comfortable shoes that fit well. |
| Keep tract of important lab values | Be sure to keep your blood pressure, cholesterol, and blood sugar (if diabetic) within normal ranges. |

Treatment should decrease pain when walking and allow you to walk longer distances without discomfort. There should be less painful cramping of leg muscles. There may be improvement in the skin's appearance and improvement in ulcers on your legs and feet.

## Support Groups

The Peripheral Arterial Disease Coalition is an alliance of leading health organizations, vascular health professional organizations, and Government agencies that have united to raise public and health professional awareness about lower extremity PAD. The coalition's Patient Education Workgroup is developing patient education tools.

The Amputee Coalition of America and National Limb Loss Information Center provide support for people with limb loss.

## Long-Term Care

For severe cases of chronic clinical limb ischemia (CLI), a patient may be bed-bound and need total supportive care. CLI is a severe blockage of the arteries that seriously decreases blood flow to the hands, legs, and feet. People with severe CLI may experience burning pain in the affected limb, and they can suffer from wounds that do not heal or from tissue death (gangrene).

Revised (8-07) from: http://www.nhlbi.nih.gov/health/dci/Diseases/pad/pad_all.html, NHLBI, Publication Date: June 2006.

# Rheumatoid Arthritis (RA)

## Definition

RA is a chronic, inflammatory autoimmune disorder that causes the immune system to attack the joints. It is a disabling and painful inflammatory condition, which can lead to substantial loss of mobility due to pain and joint destruction. RA is a systemic disease, often affecting extra-articular tissues throughout the body including the skin, blood vessels, heart, lungs, and muscles.

## Characteristics

- It has several **special features** that make it **different from other kinds of arthritis**. Characterized by:
    - Tender, warm, swollen joints
    - Symmetrical pattern of affected joints
    - Joint inflammation often affecting the wrist and finger joints closest to the hand
    - Joint inflammation sometimes affecting other joints, including the neck, shoulders, elbows, hips, knees, ankles, and feet
    - Fatigue, occasional fevers, a general sense of not feeling well
    - Pain and stiffness lasting for more than 30 minutes in the morning or after a long rest
    - Symptoms that last for many years
    - Variability of symptoms among people with the disease
- Characterized by periods of flares and remissions.
- About 60% of RA patients are unable to work 10 years after the onset of their disease

## Functional Considerations

- Movement and function is greatly affected by diseased and deformed joints.
- Not all consumers with RA will require IHSS.
- Joints are very painful and the consumer may be unable to move or grasp normally.
- Systemic effects, when present, can be debilitating and result in a loss of endurance and function.
- It is good to find out: How long do flares last? How well does the consumer function when there is a flare? When they are In remission?
- It may be appropriate to authorize assistance in exercise (assistive walking if needed and ROM exercises).
- May need to have splints put on and removed; may benefit from assistive devices and grab bars.
- Consumers who have had joint replacement surgery may require a temporary increase in IHSS. A time-limited authorization with a reassessment should be considered.

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

NIAMS
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
National Institutes of Health
Department of Health & Human Services

# Rheumatoid Arthritis

## Features of Rheumatoid Arthritis

Rheumatoid arthritis is an inflammatory disease that causes pain, swelling, stiffness, and loss of function in the joints.

It has several **special features** that make it **different from other kinds of arthritis**. For example,

- Rheumatoid arthritis generally occurs in a symmetrical pattern, meaning that if one knee or hand is involved, the other one also is.
- The disease often affects the wrist joints and the finger joints (knuckles) closest to the hand – starts at the biggest knuckles.
- It can also affect other parts of the body besides the joints.
- People with rheumatoid arthritis may have fatigue, occasional fevers, and a general sense of not feeling well.

Rheumatoid arthritis **affects people differently**.

- For some people, it lasts only a few months or a year or two and goes away without causing any noticeable damage.
- Other people have mild or moderate forms of the disease, with periods of worsening symptoms, called flares, and periods in which they feel better, called remissions.
- Still others have a severe form of the disease that is active most of the time, lasts for many years or a lifetime, and leads to serious joint damage and disability.

Although rheumatoid arthritis can have serious effects on a person's life and well-being, current treatment strategies – including pain-relieving drugs and medications that slow joint damage, a balance between rest and exercise, and patient education and support programs – allow most people with the disease to lead active and productive lives. In recent years, research has led to a new understanding of rheumatoid arthritis and has increased the likelihood that, in time, researchers will find even better ways to treat the disease.

## Occurrence and Impact of Rheumatoid Arthritis

Scientists estimate that about 2.1 million people, or between 0.5 and 1 percent of the U.S. adult population, have rheumatoid arthritis.

Some recent studies have suggested that the overall number of new cases of rheumatoid arthritis actually may be going down. Scientists are investigating why this may be happening.

- Occurs in all races and ethnic groups
- Often begins in middle age and occurs with increased frequency in older people
- Can also be seen in children and young adults
- Occurs much more frequently in women than in men. About two to three times as many women as men have the disease.

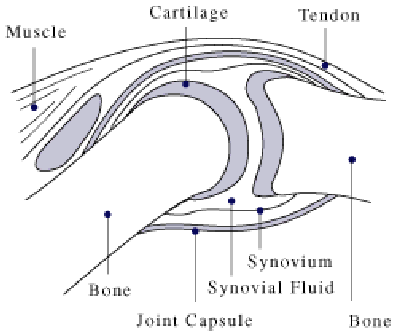
## How Rheumatoid Arthritis Develops and Progresses

### The Joints

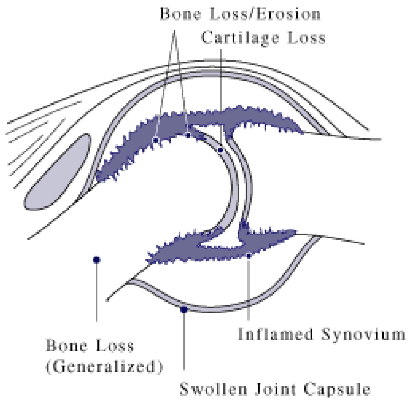
Like many other rheumatic diseases, rheumatoid arthritis is an **autoimmune disease** (auto means self), so-called because a person's immune system, which normally helps protect the body from infection and disease, attacks joint tissues for unknown reasons.

1. White blood cells, the agents of the immune system, travel to the synovium and cause inflammation (synovitis), characterized by warmth, redness, swelling, and pain--typical symptoms of rheumatoid arthritis.
2. During the inflammation process, the normally thin synovium becomes thick and makes the joint swollen and puffy to the touch.
3. As rheumatoid arthritis progresses, the inflamed synovium invades and destroys the cartilage and bone within the joint.
4. The surrounding muscles, ligaments, and tendons that support and stabilize the joint become weak and unable to work normally. These effects lead to the pain and joint damage often seen in rheumatoid arthritis.

**Normal Joint**



**Joint Affected by Rheumatoid Arthritis**



Researchers studying rheumatoid arthritis now believe that it begins to damage bones during the first year or two that a person has the disease, one reason why early diagnosis and treatment are so important.

### Other Parts of the Body

Some people with rheumatoid arthritis also have symptoms in places other than their joints such as:

- anemia – very common
- neck pain and dry eyes and mouth - occur less often
- inflammation of the blood vessels, the lining of the lungs, or the sac enclosing the heart - very rarely

### Personal Impacts

- From an economic standpoint, the medical and surgical treatment for rheumatoid arthritis and the wages lost because of disability caused by the disease add up to billions of dollars annually.
- Daily joint pain is an inevitable consequence of the disease, and most patients also experience some degree of depression, anxiety, and feelings of helplessness.
- For some people, rheumatoid arthritis can interfere with normal daily activities, limit job opportunities, or disrupt the joys and responsibilities of family life.

## Searching for the Causes of Rheumatoid Arthritis

Scientists still do not know exactly what causes the immune system to turn against itself in rheumatoid arthritis, but research over the last few years has begun to piece together the factors involved:

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| **Genetic (inherited) factors** | • A person's genetic makeup plays an important role in determining if he or she will develop rheumatoid arthritis, but it is not the only factor<br>• More than one gene is involved in determining whether a person develops rheumatoid arthritis and how severe the disease will become |

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| **Environmental factors** | • Many scientists think that something must occur to trigger the disease process in people whose genetic makeup makes them susceptible to rheumatoid arthritis.<br>• A viral or bacterial infection appears likely, but the exact agent is not yet known. This does not mean that rheumatoid arthritis is contagious: a person cannot catch it from someone else. |
| **Other factors** | • Hormones, or possibly deficiencies or changes in certain hormones, may promote the development of rheumatoid arthritis in a genetically susceptible person who has been exposed to a triggering agent from the environment.<br>• Women are more likely to develop rheumatoid arthritis than men, pregnancy may improve the disease, and the disease may flare after a pregnancy. Breastfeeding may aggravate the disease and contraceptive use may alter a person's likelihood of developing rheumatoid arthritis. |

## Diagnosing and Treating Rheumatoid Arthritis

Diagnosing and treating rheumatoid arthritis requires a team effort involving the patient and several types of health care professionals. A person can go to his or her family doctor or internist or to a rheumatologist. A rheumatologist is a doctor who specializes in arthritis and other diseases of the joints, bones, and muscles. As treatment progresses, other professionals often help. These may include nurses, physical or occupational therapists, orthopaedic surgeons, psychologists, and social workers.

Studies have shown that patients who are well informed and participate actively in their own care have less pain and make fewer visits to the doctor than do other patients with rheumatoid arthritis.

Patient education and arthritis self-management programs, as well as support groups, help people to become better informed and to participate in their own care. These programs help people:

- understand the disease
- reduce their pain while remaining active
- cope physically, emotionally, and mentally
- feel greater control over the disease and build a sense of confidence in the ability to function and lead full, active, and independent lives.

## Diagnosis

Rheumatoid arthritis can be difficult to diagnose in its early stages for several reasons:

1. there is no single test for the disease.
2. symptoms differ from person to person and can be more severe in some people than in others.
3. symptoms can be similar to those of other types of arthritis and joint conditions, and it may take some time for other conditions to be ruled out.
4. the full range of symptoms develops over time, and only a few symptoms may be present in the early stages.

Doctors will use a variety tools to diagnose the disease and to rule out other conditions:

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| **Medical history** | the patient's description of pain, stiffness, and joint function and how these change over time is critical to the doctor's initial assessment of the disease and how it changes over time |
| **Physical examination** | includes the doctor's examination of the joints, skin, reflexes, and muscle strength |

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| **Laboratory tests** | • rheumatoid factor – blood antibody - Has a high false positive and negative so not conclusive<br>• check white blood cell count – high if there is an infection<br>• check red blood cell count to look for anemia, and a test of the erythrocyte sedimentation rate - measures inflammation in the body.<br>• C-reactive protein - measures disease activity |
| **X rays** | • used to determine the degree of joint destruction<br>• not useful in the early stages<br>• can be used later to monitor the progression of the disease |

## Treatment

Doctors use a variety of approaches to treat rheumatoid arthritis. These are used in different combinations and at different times during the course of the disease and are chosen according to the patient's individual situation.

## Goals of Treatment

- Relieve pain
- Reduce inflammation
- Slow down or stop joint damage
- Improve a person's sense of well-being and ability to function

Good communication between the patient and doctor is necessary for effective treatment. Talking to the doctor can help ensure that exercise and pain management programs are provided as needed, and that drugs are prescribed appropriately. Talking to the doctor can also help people who are making decisions about surgery.

## Current Treatment Approaches

| **Health behavior changes** – improve ability to function independently and maintain a positive outlook | |
|---|---|
| **Rest and exercise** | • need a good balance between rest and exercise – ↑rest when the disease is active and ↑exercise when in remission<br>• **Rest** – helps to reduce active joint inflammation, pain and to fight fatigue<br>o Occasional shorter rest breaks every are more helpful than long times spent in bed<br>• **Exercise** – important for maintaining healthy and strong muscles, preserving joint mobility, and maintaining flexibility<br>o helps improve sleep, reduce pain, maintain a positive attitude, and lose weight |
| **Joint care** | • **splints** to reduces pain and swelling – supports join to let it rest<br>o usually on wrists or hands, also ankles and feet<br>o should be ordered my doctor and fitted by OT or PT<br>• **assistive devices** to increase function and decrease stress on joints<br>o zipper pullers, long-handled shoe horns<br>o devices to help with getting on and off chairs, toilet seats, and beds |

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| **Stress reduction** emotions - fear, anger, and frustration- combined with pain and physical limitations can increase stress level | • regular rest periods<br>• relaxation, distraction, or visualization exercises<br>• exercise programs<br>• participation in support groups<br>• good communication with the health care team |
| **Healthful diet**<br>no scientific evidence that any specific food or nutrient helps or harms people with rheumatoid arthritis | • nutritious diet with enough-but not an excess of-calories, protein, and calcium is important<br>• careful about drinking alcoholic beverages because of possible interaction with medications |
| **Climate** | • Moving to a new place with a different climate usually does not make a long-term difference in a person's rheumatoid arthritis |
| **Medications**<br>general condition, current and predicted severity of the illness, length of time will take the drug, and the drug's effectiveness and potential side effects are important considerations in prescribing drugs | • for pain relief<br>• to reduce inflammation<br>• to slow the course of the disease - disease-modifying antirheumatic drugs (DMARDs)<br>• early treatment with more powerful drugs, and the use of drug combinations instead of one medication alone, may be more effective in reducing or preventing joint damage<br>• decrease medications during remissions |
| **Surgery**<br>Several types of surgery are available to patients with severe joint damage<br>Goal is to improve function and ↓pain | |
| **Joint replacement** | • most frequently performed surgery<br>• primarily to relieve pain and improve or preserve joint function<br>• careful consideration with young people – may need to be replaced after time |
| **Tendon reconstruction** | • used most frequently on the hands<br>• reconstructs the damaged tendon by attaching an intact tendon to it<br>• can help to restore hand function |
| **Synovectomy:** | • inflamed synovial tissue is removed<br>• seldom done on own –cannot remove all tissue<br>• done in connection with reconstructive surgery such as tendon reconstruction |

## Routine Monitoring and Ongoing Care

Regular medical care is important to:

- monitor the course of the disease
- determine the effectiveness and any negative effects of medications
- change therapies as needed
- regular visits to the doctor
- blood, urine, and other laboratory tests and x rays

People with rheumatoid arthritis may want to discuss preventing **osteoporosis** with their doctors as part of their long-term, ongoing care. Having rheumatoid arthritis increases the risk of developing osteoporosis for both men and women, particularly if a person takes corticosteroids. Such patients may want to discuss with their doctors the potential benefits of calcium and vitamin D supplements, hormone therapy, or other treatments for osteoporosis.

## Hope for the Future

Scientists are making rapid progress in understanding the complexities of rheumatoid arthritis: how and why it develops, why some people get it and others do not, why some people get it more severely than others. Results from research are having an impact today, enabling people with rheumatoid arthritis to remain active in life, family, and work far longer than was possible 20 years ago. There is also hope for tomorrow, as researchers begin to apply new technologies such as stem cell transplantation and novel imaging techniques. (Stem cells have the capacity to differentiate into specific cell types, which gives them the potential to change damaged tissue in which they are placed.) These and other advances will lead to an improved quality of life for people with rheumatoid arthritis.

Adapted (8-07) from NIH Publication No. 04-4179, National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), Department of Health and Human Services' National Institutes of Health (NIH), www.niams.nih.gov.

NIAMS
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
National Institutes of Health
Department of Health & Human Services

## Medications Used to Treat Rheumatoid Arthritis

| **Medications** | **Uses/Effects** | **Side Effects** | **Monitoring** |
|---|---|---|---|
| Analgesics and Nonsteroidal Anti-inflammatory Drugs (NSAIDs) | Analgesics relieve pain; NSAIDs are a large class of medications useful against pain and inflammation. A number of NSAIDs are available over the counter such as Aspirin, Advil, Aleve. More than a dozen others—including a subclass called COX-2 inhibitors—are available only with a prescription. | NSAIDs can cause stomach irritation or, less often, can affect kidney function. The longer a person uses NSAIDs, the more likely he or she is to have side effects, ranging from mild to serious. Many other drugs cannot be taken when a patient is being treated with NSAIDs because they alter the way the body uses or eliminates these other drugs. NSAIDs sometimes are associated with serious gastrointestinal problems, including ulcers, bleeding, and perforation of the stomach or intestine. People over age 65 and those with any history of ulcers or gastrointestinal bleeding should use NSAIDs with caution. | Check with your health care provider or pharmacist before you take NSAIDs. Before taking traditional NSAIDs, let your provider know if you drink alcohol or use blood thinners or if you have any of the following: sensitivity or allergy to aspirin or similar drugs, kidney or liver disease, heart disease, high blood pressure, asthma, or peptic ulcers. |
| Acetaminophen | Nonprescription medications used to relieve pain. Examples are aspirin-free Anacin*, Excedrin caplets, Panadol, Tylenol, and Tylenol Arthritis. | Usually no side effects when taken as directed. | Not to be taken with alcohol or with other products containing acetaminophen. Not to be used for more than 10 days unless directed by a physician. |
| Aspirin<br>Buffered<br>Plain | Aspirin is used to reduce pain, swelling, and inflammation, allowing patients to move more easily and carry out normal activities. It is generally part of early and ongoing therapy. | Upset stomach; tendency to bruise easily; ulcers, pain, or discomfort; diarrhea; headache; heartburn or indigestion; nausea or vomiting. | Doctor monitoring is needed. |
| Traditional NSAIDs<br>Ibuprofen<br>Ketoprofen<br>Naproxen | NSAIDs help relieve pain within hours of admin-istration in dosages available over-the-counter (available for all three medications). They relieve pain and inflammation in dosages available in prescription form (ibuprofen and ketoprofen). It may take several days to reduce inflammation. | For all traditional NSAIDs: Abdominal or stomach cramps, pain, or discomfort; diarrhea; dizziness; drowsiness or light-headedness; headache; heartburn or indigestion; peptic ulcers; nausea or vomiting; possible kidney and liver damage (rare). | For all traditional NSAIDs: Before taking these drugs, let your doctor know if you drink alcohol or use blood thinners or if you have or have had any of the following: sensitivity or allergy to aspirin or similar drugs, kidney or liver disease, heart disease, high blood pressure, asthma, or peptic ulcers. |

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| Corticosteroids | These are steroids given by mouth or injection. They are used to relieve inflammation and reduce swelling, redness, itching, and allergic reactions. | Increased appetite, indigestion, nervousness, or restlessness. | For all corticosteroids, let your doctor know if you have one of the following: fungal infection, history of tuberculosis, underactive thyroid, herpes simplex of the eye, high blood pressure, osteoporosis, or stomach ulcer. |
| Methylprednisolone<br>Prednisone | These steroids are available in pill form or as an injection into a joint. Improvements are seen in several hours up to 24 hours after administration. There is potential for serious side effects, especially at high doses. They are used for severe flares and when the disease does not respond to NSAIDs and DMARDs. | Osteoporosis, mood changes, fragile skin, easy bruising, fluid retention, weight gain, muscle weakness, onset or worsening of diabetes, cataracts, increased risk of infection, hyper-tension (high blood pressure). | Doctor monitoring for continued effectiveness of medication and for side effects is needed. |
| Disease-modifying antirheumatic drugs (DMARDs) | These are common arthritis medications. They relieve painful, swollen joints and slow joint damage, and several DMARDs may be used over the disease course. They take a few weeks or months to have an effect, and may produce significant improvements for many patients. Exactly how they work is still unknown. | Side effects vary with each medicine. DMARDs may increase risk of infection, hair loss, and kidney or liver damage. | Doctor monitoring allows the risk of toxicities to be weighed against the potential benefits of individual medications. |
| Azathioprine | This drug was first used in higher doses in cancer chemotherapy and organ transplantation. It is used in patients who have not responded to other drugs, and in combination therapy. | Cough or hoarseness, fever or chills, loss of appetite, lower back or side pain, nausea or vomiting, painful or difficult urination, unusual tiredness or weakness. | Before taking this drug, tell your doctor if you use allopurinol or have kidney or liver disease. This drug can reduce your ability to fight infection, so call your doctor immediately if you develop chills, fever, or a cough. Regular blood and liver function tests are needed. |

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| Cyclosporine | This medication was first used in organ transplantation to prevent rejection. It is used in patients who have not responded to other drugs. | Bleeding, tender, or enlarged gums; high blood pressure; increase in hair growth; kidney problems; trembling and shaking of hands. | Before taking this drug, tell your doctor if you have one of the following: sensitivity to castor oil (if receiving the drug by injection), liver or kidney disease, active infection, or high blood pressure. Using this drug may make you more susceptible to infection and certain cancers. Do not take live vaccines while on this drug. |
| Hydroxychloroquine | It may take several months to notice the benefits of this drug, which include reducing the signs and symptoms of rheumatoid arthritis. | Diarrhea, eye problems (rare), headache, loss of appetite, nausea or vomiting, stomach cramps or pain. | Doctor monitoring is important, particularly if you have an allergy to any antimalarial drug or a retinal abnormality. |
| Gold sodium thiomalate | This was one of the first DMARDs used to treat rheumatoid arthritis. | Redness or soreness of tongue; swelling or bleeding gums; skin rash or itching; ulcers or sores on lips, mouth, or throat; irritation on tongue. Joint pain may occur for one or two days after injection. | Before taking this drug, tell your doctor if you have any of the following: lupus, skin rash, kidney disease, or colitis. Periodic urine and blood tests are needed to check for side effects. |
| Leflunomide | This drug reduces signs and symptoms and slows structural damage to joints caused by arthritis. | Bloody or cloudy urine; congestion in chest; cough; diarrhea; difficult, burning, or painful urination or breathing; fever; hair loss; headache; heartburn; loss of appetite; nausea and/or vomiting; skin rash; stomach pain; sneezing; and sore throat. | Before taking this medication, let your doctor know if you have one of the following: active infection, liver disease, known immune deficiency, renal insufficiency, or underlying malignancy. You will need regular blood tests, including liver function tests. Leflunomide must not be taken during pregnancy because it may cause birth defects in humans. |

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| Methotrexate | This drug can be taken by mouth or by injection and results in rapid improvement (it usually takes 3-6 weeks to begin working). It appears to be very effective, especially in combination with infliximab or etanercept. In general, it produces more favorable long-term responses compared with other DMARDs such as sulfasalazine, gold sodium thiomalate, and hydroxychloroquine. | Abdominal discomfort, chest pain, chills, nausea, mouth sores, painful urination, sore throat, unusual tiredness or weakness. | Doctor monitoring is important, particularly if you have an abnormal blood count, liver or lung disease, alcoholism, immune-system deficiency, or active infection. Methotrexate must not be taken during pregnancy because it may cause birth defects in humans. |
| Sulfasalazine | This drug works to reduce the signs and symptoms of rheumatoid arthritis by suppressing the immune system. | Abdominal pain, aching joints, diarrhea, headache, sensitivity to sunlight, loss of appetite, nausea or vomiting, skin rash. | Doctor monitoring is important, particularly if you are allergic to sulfa drugs or aspirin, or if you have a kidney, liver, or blood disease. |
| Biologic Response Modifiers | These drugs selectively block parts of the immune system called cytokines. Cytokines play a role in inflammation. Long-term efficacy and safety are uncertain. | Increased risk of infection, especially tuberculosis. Increased risk of pneumonia, and listeriosis (a foodborne illness caused by the bacterium Listeria monocytogenes). | It is important to avoid eating undercooked foods (including unpasteurized cheeses, cold cuts, and hot dogs) because undercooked food can cause listeriosis for patients taking biologic response modifiers. |
| Tumor Necrosis Factor Inhibitors<br>Etanercept<br>Infliximab<br>Adalimumab | These medications are highly effective for treating patients with an inadequate response to DMARDs. They may be prescribed in combination with some DMARDs, particularly methotrexate. Etanercept requires subcutaneous (beneath the skin) injections two times per week. Infliximab is taken intravenously (IV) during a 2-hour procedure. It is administered with methotrexate. Adalimumab requires injections every 2 weeks. Long-term efficacy and safety are uncertain. | Etanercept: Pain or burning in throat; redness, itching, pain, and/or swelling at injection site; runny or stuffy nose.<br>Infliximab: Abdominal pain, cough, dizziness, fainting, headache, muscle pain, runny nose, shortness of breath, sore throat, vomiting, wheezing.<br>Adalimumab: Redness, rash, swelling, itching, bruising, sinus infection, headache, nausea. | Long-term efficacy and safety are uncertain. Doctor monitoring is important, particularly if you have an active infection, exposure to tuberculosis, or a central nervous system disorder. Evaluation for tuberculosis is necessary before treatment begins. |
| Interleukin1 Inhibitor<br>Anakinra | This medication requires daily injections. Long-term efficacy and safety are uncertain. | Redness, swelling, bruising, or pain at the site of injection; headache; upset stomach; diarrhea; runny nose; and stomach pain. | Doctor monitoring is required. |

## Staging

The American College of Rheumatology criteria to aid in determining the progression, remission, and functional status of patients with RA.

**Progression of RA (clinical and radiological staging)**

- **Stage I** (early RA)
  - No destructive changes observed upon roentgenographic examination
  - Radiographic evidence of osteoporosis possible
- **Stage II** (moderate progression)
  - Radiographic evidence of periarticular osteoporosis with or without slight subchondral bone destruction
  - Slight cartilage destruction possible
  - Joint mobility possibly limited; no joint deformities observed
  - Adjacent muscle atrophy
  - Extra-articular soft tissue lesions (e.g. nodules, tenosynovitis) possible
- **Stage III** (severe progression)
  - Radiographic evidence of cartilage and bone destruction in addition to periarticular osteoporosis
  - Joint deformity (e.g. subluxation, ulnar deviation, hyperextension) without fibrous or bony ankylosis
  - Extensive muscle atrophy
  - Extra-articular soft tissue lesions (e.g. nodules, tenosynovitis) possible
- **Stage IV** (terminal progression)
  - Fibrous or bony ankylosis
  - Criteria of stage III

**Remission of RA** - Five or more of the following conditions present for at least 2 consecutive months

- Duration of morning stiffness not exceeding 15 minutes
- No fatigue
- No joint pain
- No joint tenderness or pain with motion
- No soft tissue swelling in joints or tendon sheaths
- ESR of less than 30 mm/h for a female or less than 20 mm/h for a male

**Functional Status of Patients with RA**

- **Class I** - Completely able to perform usual activities of daily living
- **Class II** - Able to perform usual self-care and vocational activities but limited in avocational activities
- **Class III** - Able to perform usual self-care activities but limited in vocational and avocational activities
- **Class IV** - Limited in ability to perform usual self-care, vocational, and avocational activities

# Scleroderma

## Definition

Scleroderma is a rare, chronic disease characterized by excessive deposits of collagen in the skin or other organs. The localized type of the disease tends not to be fatal. Diffuse scleroderma or systemic sclerosis, the generalized type of the disease, can be fatal as a result of heart, kidney, lung or intestinal damage.

## Characteristics

Scleroderma is called both a **rheumatic disease** and a **connective tissue disease**.

- The term rheumatic disease refers to a group of conditions characterized by inflammation and/or pain in the muscles, joints, or fibrous tissue.
- A connective tissue disease is one that affects tissues such as skin, tendons, and cartilage.

**Side effects include:**

- Raynaud's Phenomenon (Cold sensitivity of fingers with red, white, and blue discoloration)
- Stiff, painful joints Skin problems
- Dry mouth and dental problems
- Gastrointestinal (GI) problems
- Lung damage Heart problems
- Kidney problems
- Cosmetic problems

## Functional Considerations

Expect possible effect in the following areas:

- Appearance and self-esteem
- Self care
- Family relationships
- Pregnancy and childbearing
- Sexual relations
- Tight, hard connective tissue in the hands can impair functioning
- Energy level is often significantly impaired
- Because this is a system disease the consumer may not look as sick as they are feeling.

NIAMS
National Institute of Arthritis and Musculoskeletal and Skin Diseases
National Institutes of Health
Department of Health & Human Services

# Scleroderma

## What is Scleroderma?

- Derived from the Greek words “sklerosis,” meaning hardness, and “derma,” meaning skin, scleroderma literally means hard skin.
- It is a symptom of a group of diseases that involve the abnormal growth of connective tissue, which supports the skin and internal organs.
- In some forms of scleroderma, hard, tight skin is the extent of this abnormal process.
- In other forms, however, the problem goes much deeper, affecting blood vessels and internal organs, such as the heart, lungs, and kidneys.

Scleroderma is called both a **rheumatic** (roo-MA-tik) **disease** and a **connective tissue disease**.

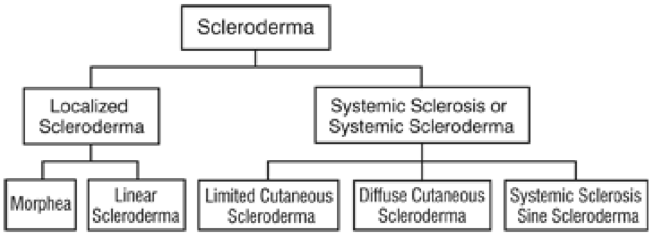
- The term rheumatic disease refers to a group of conditions characterized by inflammation and/or pain in the muscles, joints, or fibrous tissue.
- A connective tissue disease is one that affects tissues such as skin, tendons, and cartilage.

## What are the Different Types of Scleroderma?

The group of diseases we call scleroderma falls into two main classes:

- **localized scleroderma** (affect only certain parts of the body)
- **systemic sclerosis**. (can affect the whole body)

Both groups include subgroups. (See chart.)



## Localized Scleroderma

- Localized types of scleroderma are those limited to the skin and related tissues and, in some cases, the muscle below.
- Internal organs are not affected by localized scleroderma, and localized scleroderma can never progress to the systemic form of the disease.
- Often, localized conditions improve or go away on their own over time, but the skin changes and damage that occurs when the disease is active can be permanent.
- For some people, localized scleroderma is serious and disabling.

**Morphea:** (mor-FEE-ah)

- The first signs of the disease are reddish patches of skin that thicken into firm, oval-shaped areas.
- The center of each patch becomes ivory colored with violet borders.
- These patches sweat very little and have little hair growth.
- Patches appear most often on the chest, stomach, and back. Sometimes they appear on the face, arms, and legs.

**Morphea can be either localized or generalized**:

- Localized morphea limits itself to one or several patches, ranging in size from a half-inch to 12 inches in diameter. The condition sometimes appears on areas treated by radiation therapy.
- Generalized morphea is when people have both morphea and linear scleroderma (described below). The skin patches become very hard and dark and spread over larger areas of the body.

Regardless of the type, morphea generally fades out in 3 to 5 years; however, people are often left with darkened skin patches and, in rare cases, muscle weakness.

**Linear scleroderma**:

- Is characterized by a single line or band of thickened and/or abnormally colored skin.
- Usually, the line runs down an arm or leg, but in some people it runs down the forehead.

## Systemic Scleroderma (also known as Systemic Sclerosis)

This is the form of the disease that not only includes the skin, but also involves the tissues beneath, the blood vessels, and the major organs.

**Limited cutaneous scleroderma**:

- Typically comes on gradually and affects the skin only in certain areas: the fingers, hands, face, lower arms, and legs.
- Most people have Raynaud's phenomenon for years before skin thickening starts. Telangiectasias and calcinosis often follow. (See definitions below.)
- Gastrointestinal involvement occurs commonly and some patients have severe lung problems, even though the skin thickening remains limited.
- Set of complications described as **CREST**, which stands for the following:
    - **Calcinosis** (KAL-sin-OH-sis): the formation of calcium deposits in the connective tissues, which can be detected by x-ray. When the deposits break through the skin, painful ulcers can result.
    - **Raynaud's** (ray-NOHZ) **phenomenon**: a condition in which the small blood vessels of the hands and/or feet contract in response to cold or anxiety. As the vessels contract, the hands or feet turn white and cold, then blue. As blood flow returns, they become red. Fingertip tissues may suffer damage, leading to ulcers, scars, or gangrene.
    - **Esophageal** (eh-SOFF-uh-GEE-ul) **dysfunction**: impaired function of the esophagus that occurs when smooth muscles in the esophagus lose normal movement. In the upper and lower esophagus, the result can be swallowing difficulties. In the lower esophagus, the result can be chronic heartburn or inflammation.
    - **Sclerodactyly** (SKLER-oh-DAK-till-ee): thick and tight skin on the fingers, resulting from deposits of excess collagen within skin layers. The condition makes it harder to bend or straighten the fingers. The skin may also appear shiny and darkened, with hair loss.
    - **Telangiectasias** (tel-AN-jee-ek-TAY-zee-uhs): a condition caused by the swelling of tiny blood vessels, in which small red spots appear on the hands and face. While not painful, these red spots can create cosmetic problems.

**Diffuse cutaneous scleroderma**:

- Typically comes on suddenly.
- Skin thickening begins in the hands and spreads quickly and over much of the body, affecting the hands, face, upper arms, upper legs, chest, and stomach in a symmetrical fashion. Some people may have more area of their skin affected than others.
- Internally, it can damage key organs such as the intestines, lungs, heart, and kidneys.
- People are often tired, lose appetite and weight, and have joint swelling and/or pain.
- Skin changes can cause the skin to swell, appear shiny, and feel tight and itchy.
- Damage typically occurs over a few years.
- After the first 3 to 5 years, the disease often enters a stable phase lasting for varying lengths of time. During this phase, symptoms subside: joint pain eases, fatigue lessens, and appetite returns. Progressive skin thickening and organ damage decrease.
- Gradually, however, the skin may begin to soften, which tends to occur in reverse order of the thickening process: the last areas thickened are the first to begin softening. Some patients' skin returns to a somewhat normal state, while other patients are left with thin, fragile skin without hair or sweat

glands. Serious new damage to the heart, lungs, or kidneys is unlikely to occur, although patients are left with whatever damage they have in specific organs.

People with diffuse scleroderma face the most serious long-term outlook if they develop severe kidney, lung, digestive, or heart problems. Fortunately, less than one third of patients with diffuse disease develop these severe problems. Early diagnosis and continual and careful monitoring are important.

## What Causes Scleroderma?

Although scientists don't know exactly what causes scleroderma, they are certain that people cannot catch it from or transmit it to others. Studies of twins suggest it is also not inherited. Scientists suspect that scleroderma comes from several factors that may include:

- **Abnormal immune or inflammatory activity:** In scleroderma, the immune system is thought to stimulate cells called fibroblasts so they produce too much collagen. The collagen forms thick connective tissue that builds up within the skin and internal organs and can interfere with their functioning. Blood vessels and joints can also be affected.
- **Genetic makeup**: While genes seem to put certain people at risk for scleroderma and play a role in its course, the disease is not passed from parent to child like some genetic diseases.
- **Hormones:** By the middle to late childbearing years (ages 30 to 55) women develop scleroderma 7 to 12 times more often than men. Because of female predominance at this and all ages, scientists suspect that hormonal differences between women and men play a part in the disease. However, the role of estrogen or other female hormones has not been proven.

## Who Gets Scleroderma?

Although scleroderma is more common in women, the disease also occurs in men and children. It affects people of all races and ethnic groups. However, there are some patterns by disease type. For example:

- Localized forms of scleroderma are more common in people of European descent than in African Americans.
- Morphea usually appears between the ages of 20 and 40
- Linear scleroderma usually occurs in children or teenagers
- Systemic scleroderma, whether limited or diffuse, typically occurs in people from 30 to 50 years old. It affects more women of African American than European descent.

## How is Scleroderma Treated?

Currently, there is no treatment that controls or stops the underlying problem – the overproduction of collagen – in all forms of scleroderma. Thus, treatment and management focus on relieving symptoms and limiting damage. Treatment will depend on the particular problems experienced.

- Below is a listing of the potential problems that can occur in systemic scleroderma and the medical and nonmedical treatments for them.
- These problems do not occur as a result or complication of localized scleroderma.
- This listing is not complete because different people experience different problems with scleroderma and not all treatments work equally well for all people.

| Side Effect | Treatments / Preventative Actions |
|---|---|
| **Raynaud's Phenomenon**<br>More than 90 percent of people with scleroderma have this condition | • Don't smoke! Smoking narrows the blood vessels even more and makes Raynaud's phenomenon worse.<br>• Dress warmly, with special attention to hands and feet.<br>• Dress in layers and try to stay indoors during cold weather.<br>• Use biofeedback and relaxation exercises.<br>• For severe cases, calcium channel blockers, such as nifedipine (Procardia*), can open up small blood vessels and improve circulation.<br>• For skin sores or ulcers, an increased dose of calcium channel lockers may help or protect skin ulcers from further injury or infection by applying nitroglycerine paste or antibiotic cream. Severe ulcerations on the fingertips can be treated with bioengineered skin. |
| **Stiff, painful joints**<br>In diffuse systemic sclerosis, hand joints can stiffen due to hardened skin around the joints or inflammation within them. Other joints can also become stiff and swollen. | • Stretching exercises under the direction of a physical and/or occupational therapist are extremely important to prevent loss of joint motion. These should be started as soon as the diagnosis of scleroderma is made.<br>• Exercise regularly. Swimming can help maintain muscle strength, flexibility, and joint mobility.<br>• Medications: NSAIDs over the counter or rx if need stronger.<br>• Learn to perform daily tasks, such as lifting and carrying objects or opening doors, in ways that will put less stress on tender joints. |
| **Skin problems**<br>When too much collagen builds up in the skin, it crowds out sweat and oil glands, causing the skin to become dry and stiff. | • Apply oil-based creams and lotions frequently, and always right after bathing.<br>• Apply sunscreen before going outdoors, to protect against further damage from the sun's rays.<br>• Use humidifiers to moisten the air in the home in colder winter climates. Clean humidifiers often to stop bacteria from growing in the water.<br>• Avoid very hot baths and showers, as hot water dries the skin.<br>• Avoid harsh soaps, household cleaners, and caustic chemicals, if at all possible. Otherwise, be sure to wear rubber gloves when using such products.<br>• Exercise regularly. Exercise, especially swimming, stimulates blood circulation to affected areas. |
| **Dry mouth and dental problems**<br>Dental problems are common; tightening facial skin can make the mouth opening smaller and narrower, which makes it hard to care for teeth; dry mouth due to salivary gland damage speeds up tooth decay; and damage to connective tissues in the mouth can lead to loose teeth. | • Brush and floss teeth regularly. If hand pain and stiffness are present adaptive aids may be of help.<br>• Have regular dental checkups. Contact the dentist immediately if experience mouth sores, mouth pain, or loose teeth.<br>• If decay is a problem, ask the dentist about fluoride rinses or prescription toothpastes that remineralize and harden tooth enamel.<br>• Keep mouth moist by drinking plenty of water, sucking ice chips, using sugarless gum and hard candy, and |

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| | avoiding mouthwashes with alcohol. If dry mouth is a problem, ask the doctor about a saliva substitute, or prescription medications such as Salagen or Evoxac, that can stimulate the flow of saliva. |
| **Gastrointestinal (GI) problems**<br>May experience problems such as heartburn, difficulty swallowing, early satiety (the feeling of being full after barely starting to eat), or intestinal complaints such as diarrhea, constipation, and gas. In cases where the intestines are damaged, the body may have difficulty absorbing nutrients from food. | • Eat small, frequent meals.<br>• To keep stomach contents from backing up into the esophagus, stand or sit for at least an hour (preferably two or three) after eating. When it is time to sleep, keep the head of the bed raised using blocks.<br>• Avoid late-night meals, spicy or fatty foods, alcohol, and caffeine, which can aggravate GI distress.<br>• Eat moist, soft foods, and chew them well.<br>• For swallowing difficulties, or if the body doesn't absorb nutrients properly, a special diet may be prescribed.<br>• Ask about prescription medications for problems such as diarrhea, constipation, and heartburn. Some drugs called proton pump inhibitors are highly effective against heartburn. Oral antibiotics may stop bacterial overgrowth in the bowel that can be a cause of diarrhea in some people with systemic sclerosis. |
| **Lung damage**:<br>Virtually all people with systemic sclerosis have some loss of lung function.<br>Some develop severe lung disease, which comes in two forms: **pulmonary fibrosis** (hardening or scarring of lung tissue because of excess collagen) and **pulmonary hypertension** (high blood pressure in the artery that carries blood from the heart to the lungs). | Treatment for the two conditions is different:<br>• Pulmonary fibrosis may be treated with drugs that suppress the immune system.<br>• Pulmonary hypertension may be treated with drugs that dilate the blood vessels.<br>To minimize lung complications, work closely with the medical team. Do the following:<br>• Watch for signs of lung disease, including fatigue, shortness of breath or difficulty breathing, and swollen feet. Report these symptoms to a doctor.<br>• Have lungs closely checked, using standard lung-function tests, during the early stages of skin thickening. These tests, which can find problems at the earliest and most treatable stages, are needed because lung damage can occur even before symptoms are noticed.<br>• Get regular flu and pneumonia vaccines as contracting either illness could be dangerous for a person with lung disease. |
| **Heart problems**<br>A common problem, include scarring and weakening of the heart (cardiomyopathy), inflamed heart muscle (myocarditis), and abnormal heart beat (arrhythmia). All of these problems can be treated. | • Treatment ranges from drugs to surgery, and varies depending on the nature of the condition. |

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| **Kidney problems**<br>Renal crisis occurs in about 10 percent of all patients with scleroderma, primarily those with early diffuse scleroderma. Renal crisis results in severe uncontrolled high blood pressure, which can quickly lead to kidney failure. It's very important that hypertension is treated as soon as it occurs. | • Check blood pressure regularly. Also check it if there are any new or different symptoms such as a headache or shortness of breath. If blood pressure is higher than usual, call the doctor right away.<br>• Take prescribed medications faithfully. In the past two decades, drugs known as ACE (angiotensin-converting enzyme) inhibitors, including captopril (Capoten), enalapril (Vasotec), or lisinopril, have made scleroderma-related kidney failure a less threatening problem than it used to be. They must be taken as soon as the hypertension is present. |
| **Cosmetic problems**<br>Even if scleroderma doesn't cause any lasting physical disability, its effects on the skin's appearance – particularly on the face – can take their toll on self-esteem. | • The appearance of telangiectasias may be reduced or even eliminated with the use of guided lasers.<br>• Facial changes of localized scleroderma may be corrected through cosmetic surgery. (However, such surgery is not appropriate for areas of the skin where the disease is active.) |

## How Can Scleroderma Affect Daily Life?

Here are some areas in which scleroderma could intrude:

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| **Appearance and self-esteem** | Aside from the initial concerns about health and longevity, people with scleroderma quickly become concerned with how the disease will affect their appearance. Thick, hardened skin can be difficult to accept, particularly on the face that may eventually cause the opening to the mouth to become smaller and the upper lip to virtually disappear. Linear scleroderma may leave its mark on the forehead. | Effects may be minimized with proper treatment and special cosmetics – and in some cases, plastic surgery – can help conceal scleroderma's damage. |
| **Self care** | Tight, hard connective tissue in the hands can make it difficult to do what were once simple tasks, such as brushing teeth and hair, pouring a cup of coffee, using a knife and fork, unlocking a door, or buttoning a jacket. | Devices as simple as Velcro fasteners and built-up brush handles can help improve independence. |
| **Family relationships** | Spouses, children, parents, and siblings may have trouble understanding why the patient doesn't have energy to keep house, drive to soccer practice, prepare meals, and hold a job the way they used to. If the condition isn't that visible, others may suggest the patient is just being lazy. Or they may be overly concerned and eager to help, not allowing the patient to be independent or to sacrifice their own needs. | It's important the patient learns as much about their form of the disease as possible and share it with their family. Involving family in counseling or a support group may allow them to understand how to best be supportive. |

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| **Sexual relations** | For men, the disease's effects on the blood vessels can lead to problems achieving an erection. For women, damage to the moisture-producing glands can cause vaginal dryness. People of either sex may find they have difficulty moving the way they once did. They may be self-conscious about their appearance or afraid that their sexual partner will no longer find them attractive. | With communication between partners, good medical care, and perhaps counseling, many of these changes can be overcome or at least worked around. |
| **Pregnancy and childbearing** | Although blood vessel involvement in the placenta may cause premature birth, many women with the disease can have safe pregnancies and healthy babies if they follow some precautions. It is important to wait a few years after the disease starts before attempting a pregnancy. | It is important to monitor the patient regularly. The patient will need to see all treating doctors during the pregnancy. |

## The Patient's Role in their Health Care

The relationship between the patient and the doctors is a partnership, and the patient is the most important partner. Here's how to make the most of this important role:

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| **Get educated** | Knowledge is the best defense against this disease. |
| **Seek support** | Recruit family members, friends, and coworkers or use a support group to build a support network. |
| **Assemble a health care team** | The team should include both doctors and therapists (OT and PT). |
| **Be patient** | Understand that a final diagnosis can be difficult and may take a long time. |
| **Speak up** | When there are problems or changes in condition, the patient should speak up and share with the health care provider. No problem is too small to inquire about, and early treatment for any problem can make the disease more manageable. |
| **Don't accept depression** | While it's understandable that a person with a chronic illness like scleroderma would become depressed, it is not a normal consequence. If the patient can't shake the depressed feeling he may benefit from speaking with a psychologist or social worker or from using one of the effective medications on the market. |
| **Learn coping skills** | Meditation, calming exercises, and relaxation techniques may help cope with emotional difficulties, and relieve pain and fatigue. |
| **Ask the experts** | If the patient has problems doing daily activities, such as brushing hair and teeth, to driving the car, consult an occupational or physical therapist. They have helpful hints and devices than can help. |

## Key Words

**Antibodies** – special proteins produced by the body’s immune system. They recognize and help fight infectious agents, such as bacteria and other foreign substances that invade the body. The presence of certain antibodies in the blood can help to diagnose some diseases, including some forms of scleroderma.

Atherosclerosis – abnormal fatty deposits in the inner layers of large or medium-sized arteries, which can lead to hardening and narrowing of the arteries and blockages of the blood supply, especially to the heart.

**Autoimmune disease** – a disease in which the body’s immune system turns against and damages its own tissues.

**Calcinosis** – the formation of calcium deposits in the connective tissues, which can be detected by x-ray. They are typically found on the fingers, hands, face, and trunk and on the skin above elbows and knees. When the deposits break through the skin, painful ulcers can result.

**Calcium channel blockers** – medicines that lower blood pressure, relieve chest pain, and stabilize normal heart rhythms by inhibiting calcium movement into the heart muscles and smooth muscle cells. They are used to treat a variety of conditions and to prevent circulatory and kidney problems in scleroderma.

**Collagen** – a fabric-like material of fibrous threads that is a key component of the body’s connective tissues. In scleroderma, either too much collagen is produced or it is produced in the wrong places, causing stiff and inflamed skin, blood vessels, and internal organs.

**Connective tissue** – tissues such as skin, tendons, and cartilage that support and hold body parts together. The chief component of connective tissue is collagen.

**CREST syndrome** – an acronym for a collection of symptoms that occur to some degree in all people with systemic sclerosis. The symptoms are Calcinosis, Raynaud’s phenomenon, Esophageal dysfunction, Sclerodactyly, and Telangiectasia. Because of the predominance of CREST symptoms in people with limited systemic sclerosis, some people use the term CREST syndrome when referring to that form of the disease.

**Eosinophilic fasciitis** – a scleroderma-like disorder (often considered to be a localized form of scleroderma) featuring inflammation of the fascia (the thin, sheet-like connective tissues surrounding the muscles and other body structures) and an abnormally high number of a specific kind of white blood cells (eosinophils). The result of the inflammation may be fibrous buildup in the skin of arms and legs, contractures, and carpal tunnel syndrome.

**Esophageal dysfunction** – impaired function of the esophagus (the tube connecting the throat and the stomach) that occurs when smooth muscles in the esophagus lose normal movement. In the upper and lower esophagus, the result can be swallowing difficulties. In the lower esophagus, the result can be chronic heartburn or inflammation.

**Fibroblast** – a type of cell in connective tissue that secretes proteins, including collagen.

**Fibrosis** – a condition marked by increased fibrous tissue that develops between the cells of various organs or tissues. It is a common feature of scleroderma and some other diseases. Fibrosis causes hardening or stiffening of tissues in the skin, joints, and internal organs.

**Graft-versus-host disease** – a major complication of bone marrow transplantations and sometimes blood transfusions in which white blood cells called lymphocytes, which are found in the marrow or blood, attack tissues in the body into which they were transplanted.

**Pulmonary fibrosis** – hardening or scarring of lung tissue because of excess collagen. Pulmonary fibrosis occurs in a small percentage of people with systemic sclerosis.

**Pulmonary hypertension** – abnormally high blood pressure in the arteries supplying the lungs that may be caused by a number of factors, including damage from fibrosis.

**Raynaud’s phenomenon** – a condition in which the small blood vessels of the hands and/or feet contract in response to cold or anxiety. As the vessels contract, the hands or feet turn white and cold, then blue. As blood flow returns, they become red. Fingertip tissues may suffer damage, leading to ulcers, scars, or gangrene.

**Rheumatic** – an adjective used to describe a group of conditions characterized by inflammation or pain in the muscles, joints, and fibrous tissue. Rheumatic diseases or disorders can be related to autoimmunity or other causes.

**Sclerodactyly** – thick and tight skin on the fingers, resulting from deposits of excess collagen within skin layers. The condition makes it harder to bend or straighten the fingers. The skin may also appear shiny and darkened, with hair loss.

**Systemic condition** – a condition involving the body as a whole, as opposed to limited conditions that affect particular parts of the body.

**Systemic lupus erythematosus** – a systemic rheumatic disease that occurs predominantly in women and is characterized by autoimmune activity, a facial rash across the bridge of the nose and cheeks, Raynaud's phenomenon, joint pain and swelling, fever, chest pain, hair loss, and other symptoms. Many of its symptoms overlap with those of scleroderma.

**Telangiectasia** – a condition caused by the swelling of tiny blood vessels, in which small red spots appear on the hands and face. While not painful, these red spots can create cosmetic problems.

Adapted (8-07) from National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), Health and Human Services' National Institutes of Health (NIH), NIH Publication No. 06–4271, www.niams.nih.gov. Publication Date: May 2001,Revised July 2006

# Stroke

## Definition

A stroke, or "brain attack," occurs when blood circulation to the brain fails. Brain cells can die from decreased blood flow and the resulting lack of oxygen. Also called a cerebrovascular accident or CVA.

## Characteristics

- Caused either by bleeding in the brain (hemorrhage) or the interruption of blood to the brain (ischemic)
- TIA (transient ischemic attack) may be a warning sign to stoke.
- Risk factors include: Diabetes, high blood pressure, cigarette smoking, cardiovascular disease.
- Disabilities related to stroke vary depending upon the severity of the "attack".

## Functional Limitations

Functional needs will be related to disabilities common after stroke such as:

- Paralysis or Problems Controlling Movement (Motor Control).
- Bowel or Bladder Control.
- Sensory Disturbances Including Pain.
- Problems Using or Understanding Language (Aphasia).
- Problems with Thinking and Memory.
- Emotional disturbances.
- If stroke is recent, functioning may improve with therapy.
- Dexterity may be so poor and/or the consumer may have incontinence to the point that extra Domestic and Related may be justifiable.
- ROM exercises and other activities are frequently recommended by a physical therapist and/or occupational therapist; performance of them most likely it will be appropriate as Rubbing Skin and Repositioning (not Paramedical).
- Consumer should be encouraged to be as independent as possible while not over-taxing him/her.
- Consumer may be unable to sense temperature so that would be an important part of the task of Bathing, Oral Hygiene and Grooming.
- Adaptive equipment and DMEs could make the consumer safer and more independent.
- Consumer is probably at increased risk of decubitis ulcers so frequent repositioning may be appropriate if s/he cannot move independently or reminding if the consumer can move independently.
- Consider a service plan that gives provider some respite to prevent/minimize caregiver burnout.
    - Encourage provider to keep to a routine.

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

# Stroke

## What is a Stroke?

Stroke is the third leading cause of death in the United States and causes more serious long-term disabilities than any other disease. Nearly three-quarters of all strokes occur in people over the age of 65 and the risk of having a stroke more than doubles each decade after the age of 55.

A stroke, or **"brain attack,"** occurs when blood circulation to the brain fails. Brain cells can die from decreased blood flow and the resulting lack of oxygen.

There are two types of strokes:

**Ischemic Stroke:**
- A blockage of a blood vessel in the brain or neck
- The most frequent cause of stroke (80 percent).
- These blockages stem from three conditions:
    - **Thrombosis**: the formation of a clot within a blood vessel of the brain or neck
    - **Embolism:** the movement of a clot from another part of the body such as the heart to the neck or brain
    - **Stenosis:** a severe narrowing of an artery in or leading to the brain

**Hemorrhagic Stroke:**
- Bleeding into the brain or the spaces surrounding the brain
- Usually caused my breakage of brain blood vessel

Stroke is an emergent condition and must be treated as soon as the symptoms are recognized. The longer blood flow is cut off to the brain, the greater the damage.

New treatments are available that greatly reduce the damage caused by a stroke.
The patient must arrive at the hospital within 60 minutes after symptoms start to prevent disability.

## Stroke Warning Signs

If you notice one or more of these signs, don't wait. Stroke is a medical emergency. **Call 9-1-1 or your emergency medical services**. Get to a hospital right away!

It is important to know the warning signs of stroke:
- Sudden numbness or weakness of the face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden, severe headache with no known cause

Many risk factors for stroke can be managed, some very successfully. Although risk is never zero at any age, by starting early and controlling risk factors one can lower his or her risk of death or disability from stroke.

## Transient ischemic Attack (TIA): Warning Signs of Stroke

Sometimes the warning signs may last only a few moments and then disappear. These brief episodes, known as transient ischemic attacks or TIAs, are sometimes called "mini-strokes." Although brief, they identify an underlying serious condition that isn't going away without medical help.

- Sudden numbness or weakness of face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause

Other danger signs that may occur include:

- double vision,
- drowsiness, and
- nausea or vomiting.

## Stroke Prevention

Stroke prevention is very important following a transient ischemic attack (TIA) or mini-stroke. Though, TIAs usually don't cause permanent damage or disability, they can be a serious warning sign of an impending stroke.

**Up to one third of people who have a TIA are expected to have a stroke.**

## Recurrent Strokes

Of the 750,000 Americans who have a stroke each year, 5 to 14 percent will have a second stroke within one year. Within five years, stroke will recur in 24 percent of women and 42 percent of men.

Percentage of Recurrence after First Stroke
3% to 10% 30-Day
5% to 14% 1-Year
25% to 40% 5-Year

There are two types of stroke risk factors: **controllable** and **uncontrollable**.

**Uncontrollable stroke risk factors** include:

- Being over age 55
- Being a man
- Family History

**Controllable stroke risk factors**
Having one or more of these factors does not guarantee a stroke. However, Risk of stroke grows as the number and severity of risk factors increases.

Preventing or treating the following will reduce the risk of a first or recurrent stroke:

| Factor | Risk | Treatment / Prevention |
|---|---|---|
| **Diabetes** | • Weakens blood vessels<br>• Increases brain damage in case of stroke | • Physician recommended treatment<br>• Insulin supplements<br>• Diet control (control sugar intake) |
| **High Blood Pressure** (Hypertension) | • Most potent risk factor for stroke | • Maintain proper weight<br>• Cut down on salt and increase potassium intake<br>• Physician prescribed medication |
| **Cigarette Smoking** | • Causes blockage of carotid artery - leading cause of stroke in Americans<br>• Nicotine raises blood pressure<br>• Makes blood thicker and more likely to clot | • Physician recommended programs and medications can aid in quitting smoking |
| **Heart Disease** (coronary artery disease, valve defects, irregular heart beat, enlarged heart chambers, atherosclerosis, high cholesterol, atrial fibrilation) | • Can create blood clots that may break loose and block vessels in the brain | • Physician prescribed treatment including medication and surgery<br>• Diet control (low sodium and fat) |
| **History of Stroke or Exhibiting Warning Signs** (TIA: Mini-stroke) | • Identify an underlying serious condition that may cause stroke<br>• Second stroke likely to cause more damage/disability | • If any symptoms are experienced, dial 911 immediately |

It is important to note that diet control, regular exercise, and limiting alcohol intake are all simple lifestyle changes that can be implements to aid in prevention and treatments of stroke as well as the common risk factors.

## Post-stroke: Rehabilitation and Disabilities

The goals of rehabilitation are to help survivors become as independent as possible and to attain the best possible quality of life. Even though rehabilitation does not "cure" stroke in that it does not reverse brain damage, rehabilitation can substantially help people achieve the best possible long-term outcome.

**Post-stroke Rehabilitation**

1. Rehabilitation helps stroke survivors relearn skills that are lost when part of the brain is damaged. For example, these skills can include coordinating leg movements in order to walk or carrying out the steps involved in any complex activity.
2. Rehabilitation also teaches survivors new ways of performing tasks to circumvent or compensate for any residual disabilities. Patients may need to learn how to bathe and dress using only one hand, or how to communicate effectively when their ability to use language has been compromised (See below for common disabilities resulting from stroke and how to manage them).
3. Rehabilitative therapy begins in the acute-care hospital after the patient's medical condition has been stabilized, often within 24 to 48 hours after the stroke.
    - The first steps involve promoting independent movement because many patients are paralyzed or seriously weakened.
    - Patients are prompted to change positions frequently while lying in bed and to engage in passive or active range-of-motion exercises to strengthen their stroke-impaired limbs.<br>("Passive" range-of-motion exercises are those in which the therapist actively helps the patient move a limb repeatedly, whereas "active" exercises are performed by the patient with no physical assistance from the therapist.)
    - Patients progress from sitting up and transferring between the bed and a chair to standing, bearing their own weight, and walking, with or without assistance.
    - Rehabilitation nurses and therapists help patients perform progressively more complex and demanding tasks, such as bathing, dressing, and using a toilet, and they encourage patients to begin using their stroke-impaired limbs while engaging in those tasks.

Beginning to reacquire the ability to carry out these basic activities of daily living represents the first stage in a stroke survivor's return to functional independence.

For some stroke survivors, rehabilitation will be an ongoing process to maintain and refine skills and could involve working with specialists for months or years after the stroke.

## Disabilities Resulting from Stroke

The types and degrees of disability that follow a stroke depend upon which area of the brain is damaged. The following are some common disabilities resulting from a stroke and how they can be managed.

**Paralysis or Problems Controlling Movement (Motor Control)**

The following are motor control problems that can result from a stroke.

- **Hemiplegia:** One-sided paralysis. Paralysis is one of the most common disabilities resulting from stroke. The paralysis is usually on the side of the body opposite the side of the brain damaged by stroke, and may affect the face, an arm, a leg, or the entire side of the body.
- **Hemiparesis:** One-sided weaknes. Stroke patients with hemiparesis or hemiplegia may have difficulty with everyday activities such as walking or grasping objects.
- **Dysphagia:** Problems with swallowing. Caused by damage to the part of the brain that controls the muscles for swallowing.
- **Ataxia:** Problems with body posture, walking, and balance. Damage to a lower part of the brain, the cerebellum, affects the body's ability to coordinate movement

Adapted from National Institute of Neurological Disorders and Stroke NIH Publication No. 04-5517 (June 2007)

**Bowel or Bladder Control**
Problems with bladder and bowel function are common in stroke survivors. Some may lack enough mobility to reach a toilet in time. Permanent incontinence after a stroke is uncommon. But even a temporary loss of bowel or bladder control can be emotionally difficult for stroke survivors.

These issues occur when stroke has damaged the part of the brain that controls waste removal or the brain signals for it.

“Going to the bathroom” after suffering a stroke may be complicated by:

| Problem | Symptoms | Issues / Treatment Options |
|---|---|---|
| **Urinary Incontinence** | ▪ Inability to control urination | *Treatment:* Catheter; trying to urinate at regular intervals; limiting liquid, caffeine, and alcohol consumption at night; Pelvic floor muscle (Kegel) exercises |
| **Urinary Retention** | ▪ Trouble urinating or inability to completely empty the bladder | If untreated, can lead to bladder stones, reflux (reverse flow of urine back to the kidneys) or a urinary tract infection (UTI) (see below for UTI symptoms and treatment) |
| | | *Treatment:* Physician prescribed medication; pantiliners, waterproof underpants, or disposable adult diapers |
| **Urinary Tract Infection (UTI)** | ▪ Urine with a bad smell, cloudiness, blood or sediment (solid deposits).<br>▪ Burning when urinating<br>▪ Fever and chills<br>▪ Cramps in lower abdomen or side<br>▪ Pain in lower back<br>▪ Frequent urination | Needs immediate treatment. See physician for antibiotics or other treatment medication |
| **Constipation and Bowel Incontinence** | ▪ Inability to have a regular bowel movement<br>▪ Inability to control release of stool | Caused by:<br>▪ Reduced fluid intake<br>▪ Diet<br>▪ Not moving around enough<br>▪ Side effects from prescription drugs<br>▪ Being unaware of need to use the bathroom<br>▪ Weakness in the rectal muscle<br>▪ Being unable or reluctant to ask for help |
| | | *Treatments*: stool softener or bulk agent (suppository) inserted into the anus 30 minutes after a meal to stimulate a bowel movement; shot of liquid put into the rectum through the anus (Enema); Oral Laxatives (can be unpredictable and can cause incontinence in a person with poor bowel control) |

**Sensory Disturbances Including Pain**
Stroke patients may lose the ability to feel touch, pain, temperature, or position. Sensory deficits may also hinder the ability to recognize objects that patients are holding and can even be severe enough to cause loss of recognition of one's own limb.

- **Pain after stroke can be**:
    - mild, moderate or severe
    - constant or on-and-off.
    - on part or all of the side of the body affected by the stroke
    - felt in face, arm, leg or torso
    - aching, burning, sharp, stabbing or itching

- **Paresthesia:** pain, numbness or odd sensations of tingling or prickling in paralyzed or weakened limbs

- **Local pain**: pain that is localized to specific parts of the body due to physical results of a stroke. Can be caused by the following:
    - **Muscle spasticity**: tightness or stiffness common to stroke survivors caused by unusual positioning of the limb. Mostly seen in the shoulder.
    - **"Frozen" joint**: a joint becoming immobilized due to lack of movement. The tendons and ligaments around the joint become fixed in one position, resulting in severe pain. "Passive" movement at the joint in a paralyzed limb is essential to prevent painful "freezing" and to allow easy movement if and when voluntary motor strength returns.

- **Neuropathic or central pain**: stroke-induced damage to the nervous system. It is a consistent, moderate or severe pain, worsened by touch, movement, emotions and changes in temperature. The pain tends to be felt in one part of the body, usually an arm or a leg. It is always on the side of the body affected by the stroke. Central pain is caused by damage to the pathways for sensation in the brain, which cause the transmission of false signals that result in the false sensation of pain. **Thalamic pain syndrome**: Most common of several central pain syndromes in stroke patients

  **Stroke survivors with central pain may**:
    - feel nothing when a sharp pin, warmth or cold is applied to their skin.
    - experience normal touch as unpleasant and painful.
    - feel more pain with emotional stress, cold or movement.

  **Chronic central pain can cause one to:**
    - stop using the parts of the body where one feels pain
    - allow muscles to weaken
    - misuse drugs, suffer from depression, and increase dependency on family members.

## Treating Post-Stroke Pain

The first step toward pain relief is to figure out the source of the pain. Through cataloguing when it occurs, what part of the body is affected, whether it is caused by touch and other factors will allow a physician to help with treatment.

Treatments that can be implemented at home include:
- Avoiding things that can cause pain, such as hot baths, tight or easily bunched clothing, and pressure on the side of the body affected by the stroke.
- Position or splint weakened or paralyzed arms or legs to reduce discomfort.
- Use heat packs or simple exercises prescribed by a physical therapist.

- While sitting or lying down, support the paralyzed arm on an armrest or pillow to relieve shoulder pain from the arm’s weight.
- Support the weakened or paralyzed arm with a sling while walking to reduce shoulder pain.
- Standard treatments to control chronic pain have limited success in stroke survivors. Over-the-counter pain medicines have not been effective in relieving stroke-related pain. Nor have prescription pain relief drugs.

## Problems Using or Understanding Language (Aphasia)

At least one-fourth of all stroke survivors experience language impairments, involving the ability to speak, write, and understand spoken and written language. A stroke-induced injury to any of the brain's language-control centers can severely impair verbal communication.

- **Global aphasia:** the most severe form of aphasia, resulting in loss of nearly all linguistic abilities, with neither the ability to understand language nor the ability to use it to convey thought. Caused by extensive damage to several areas involved in language function.

- **Expressive (nonfluent) aphasia**: difficulty conveying thoughts through words or writing. Loss of the ability to speak the words one is thinking and to put words together in coherent, grammatically correct sentences. Caused by damage to a language center located on the dominant side of the brain, known as Broca's area. People with this type of aphasia often omit certain kinds of words from sentences, speak slowly and with effort, and have a hard time with grammar. They mainly speak short statements of less than four words, like “walk dog.”

- **Receptive (fluent) aphasia:** difficulty understanding spoken or written language and often have incoherent speech. Caused by damage to a language center located in a rear portion of the brain, called Wernicke's area. People with this type of aphasia talk easily, but use the wrong sounds in words, say the wrong words, or even make up words.

- **Anomic/amnesic aphasia:** A less severe form of aphasia, which occurs when there is only a minimal amount of brain damage; its effects are often quite subtle. People with anomic aphasia may simply selectively forget interrelated groups of words, such as the names of people or particular kinds of objects.

### Communication Tips

The goal is to improve ones ability to communicate with other people.

- Use props to make conversation easier (photos, maps).
- Draw or write things down on paper.
- Go slowly and make sure to communicate in a way that is easiest and most comfortable
- Create a communication book that includes words, pictures and symbols that are helpful.

## Problems with Thinking and Memory

Stroke can cause damage to parts of the brain responsible for memory, learning, and awareness. Stroke survivors may have dramatically shortened attention spans or may experience deficits in short-term memory. Individuals also may lose their ability to make plans, comprehend meaning, learn new tasks, or engage in other complex mental activities.

Three fairly common deficits resulting from stroke are:

- **Anosognosia**: an inability to acknowledge the reality of the physical impairments resulting from stroke
- **Neglect:** the loss of the ability to respond to objects or sensory stimuli located on one side of the body, usually the stroke-impaired side.

- **Apraxia:** loss of ability to plan the steps involved in a complex task and to carry the steps out in the proper sequence. May also have problems following a set of instructions. Apraxia appears to be caused by a disruption of the subtle connections that exist between thought and action.

Memory loss after stroke is common, but does not manifest the same for everyone. There are many ways that memory can be affected by stroke:

- **Verbal memory**: memory of names, stories and information having to do with words.
- **Visual memory**: memory of faces, shapes, routes and things one sees.
- **Trouble learning new information or skills**. One may be unable to remember and retrieve information.
- **Vascular dementia (VaD):** a greater decline in thinking abilities.

Therapies or medicines almost never fully restore memory after stroke. However, many people do recover at least some memory spontaneously after stroke; others improve through rehabilitation.

**Ways to Help Combat and Adjust to Memory Loss**

- Try to form a routine – doing certain tasks at regular times during the day.
- Break tasks down into steps, not attempting to do too much at once.
- If something needs to be done, write it down or do it right away.
- Put things away in the same place where they can be easily found.

## Emotional Disturbances

Many people who survive a stroke feel fear, anxiety, frustration, anger, sadness, and a sense of grief for their physical and mental losses. These feelings are a natural response to the psychological trauma of stroke. Some emotional disturbances and personality changes are caused by the physical effects of brain damage.

| Emotional Distance | Symptoms | Treatment |
|---|---|---|
| **Clinical Depression** | ▪ A sense of hopelessness that disrupts an individual's ability to function<br>▪ Feeling sad or “empty” most of the time<br>▪ Loss of interest or pleasure in ordinary activities<br>▪ Fatigue<br>▪ Sudden trouble sleeping or oversleeping<br>▪ Sudden loss of appetite or weight gain<br>▪ Being unable to concentrate, remember or make decisions<br>▪ Feeling worthless or helpless<br>▪ Feelings of guilt<br>▪ Ongoing thoughts of death or suicide, suicide planning or attempts<br>▪ A sudden change in how easily one is annoyed<br>▪ Crying all the time | ▪ Physician prescribed antidepressant medications<br>▪ Psychological counseling |

| | | |
|---|---|---|
| **Extreme Anxiety** | ▪ An overwhelming sense of worry or fear<br>▪ Increased sweating/ heart rate<br>▪ Ongoing worrying, fear, restlessness and irritability that don't seem to let up<br>▪ Low energy<br>▪ Poor concentration<br>▪ Muscle tension<br>▪ Feeling panicky and out of breath<br>▪ Scary rapid heart beat<br>▪ Shaking<br>▪ Headache<br>▪ Feeling sick to your stomach | ▪ Physician prescribed antidepressant medications<br>▪ Psychological counseling |
| **Pseudobulbar Affect (PBA) (Uncontrolled emotions, emotional incontinence or pathologic lability)** | ▪ Not the same as depression<br>▪ Unable to control emotional expression<br>▪ Can lead to fear, shame and isolation | ▪ No treatment approved by the FDA<br>▪ Physician prescribed antidepressants can help |

## Managing Life at Home after a Stroke

Managing life at home is an important part of stroke recovery. The following are common challenges faced by stroke survivors and some tips to restore functionality:

| Issue | Nature of the Problem | Functional Tips |
|---|---|---|
| **Getting Around Safely** | Forty percent (40%) of stroke survivors suffer serious falls within a year after a stroke | ▪ Move extra furniture out of the way, either to corners or another room.<br>▪ Clear paths to the kitchen, bedroom and bathroom<br>▪ Move electrical cords out of pathways<br>▪ Wear non-skid shoes and avoid slick surfaces<br>▪ Remove loose carpets and runners in hallways and stairwells or fasten them with non-skid tape<br>▪ Replace thick carpeting with lower pile carpeting to make wheelchair or walker movement easier<br>▪ Install handrails for support in going up and down stairs. Make sure they're securely fastened to the wall<br>▪ Consider stair glides, stair lifts and platform lifts if stairs are used many times during the day |
| **Cleaning Up** | Disabilities caused by stroke can cause difficulties in cleaning up and keeping house | ▪ Use simple cleaning products such as disposable wipes and mop heads<br>▪ Choose one multipurpose cleaning solution for most cleaning.<br>▪ Use smaller, lightweight containers, wheeled push carts and cleaning tools with long handles or extensions<br>▪ Working on small areas<br>▪ Frequent breaks |

| | | |
|---|---|---|
| **Doing Laundry** | Disabilities caused by stroke can cause difficulties in keeping house, including doing the laundry | ▪ Move laundry machines to an easily accessible place<br>▪ Stackable, front-loading machines may be easier to reach and take up less space<br>▪ Label and make accessible detergents and laundry supplies.<br>▪ Machines with easy-to-read markings for wash settings<br>▪ Nearby table or cart at the right height to sort and fold clothes<br>▪ Ironing board that folds down from the wall |
| **Using the Bathroom** | Bathrooms are customarily small spaces and can pose mobility problems | ▪ Sturdy hand rails<br>▪ Grab bars in the tub or shower<br>▪ Non-slip flooring strips installed inside and outside of the tub<br>▪ Bath tub benches and toilet chairs<br>▪ Easy-to-use water control knobs with easily seen settings or long-handled levers<br>▪ An adjustable or handheld showerhead<br>▪ Bathing supplies that are easy to reach and use<br>▪ A raised toilet seat or toilet seat riser to reduce the distance and difficulty in sitting down and getting up. |
| **Getting Dressed** | | ▪ Avoid tight-fitting sleeves, armholes, pant legs and waistlines<br>▪ Clothes with fasteners in the front<br>▪ Replace buttons, zippers and laces with Velcro fasteners.<br>▪ Dressing aids and adaptable clothing can be found on Internet sites and at health supply stores.<br>▪ Check out the following websites for adaptable clothing:<br>o http://www.makoa.org/clothing.htm<br>o http://www.professionalfit.com/ |
| **In the Kitchen** | Space can be small and items hard to reach. Dangers of handling sharp and hot objects. | ▪ Controls at the front of the stove are easier and safer to use than the traditional back-of-the-stove controls.<br>▪ Push-button controls are easier to use than those that turn.<br>▪ Automatic shut-off controls for safety<br>▪ An over-the-stove mirror will help in viewing stovetop contents if cooking while seated.<br>▪ Keep a clear space near the stove to place a hot pot or pan quickly.<br>▪ Accessible oven mitts<br>▪ Fire extinguisher in kitchen<br>▪ The kitchen table should be at the right height for a wheelchair or for a chair with arms that support posture |

Adapted (8-07) from the National Institute of Neurological Disorders and Stroke, National Institutes of Health NIH Publication No. 04-3440b (December 20, 2006); NIH Publication No. 04-5517 (June 19, 2007);NSA Fact Sheet, Recovering After Stroke: Bladder and Bowel Function (2006);NSA Fact Sheet, Recovering After Stroke: Dealing with Pain (2006); NSA Fact Sheet, Recovering After Stroke: Thinking and Cognition (2006);Fact Sheet, Recovering After Stroke: Coping with Emotions (2006);Adapted from NSA Fact Sheet, Recovering After Stroke: Managing Life At Home (2006).

## Scoring Stroke Risk

**Score stroke risk for the next 10 years-MEN**

Key: **SBP** = systolic blood pressure (score one line only, untreated or treated); ; **Diabetes** = history of diabetes; **Cigarettes** = smokes cigarettes; **CVD** (cardiovascular disease) = history of heart disease; **AF** = history of atrial fibrillation; **LVH** = diagnosis of left ventricular hypertrophy

| **Points** | **0** | **+1** | **+2** | **+3** | **+4** | **+5** | **+6** | **+7** | **+8** | **+9** | **+10** |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Age** | 55-56 | 57-59 | 60-62 | 63-65 | 66-68 | 69-72 | 73-75 | 76-78 | 79-81 | 83-84 | 85 |
| **SBP-untreated** | 97-105 | 106-115 | 116-125 | 126-135 | 136-145 | 146-155 | 156-165 | 166-175 | 176-185 | 186-195 | 196-205 |
| **or SBP-treated** | 97-105 | 106-112 | 113-117 | 118-123 | 124-129 | 130-135 | 136-142 | 143-150 | 151-161 | 162-176 | 177-205 |
| **Diabetes** | No | | Yes | | | | | | | | |
| **Cigarettes** | No | | | Yes | | | | | | | |
| **CVD** | No | | | | Yes | | | | | | |
| **AF** | No | | | | Yes | | | | | | |
| **LVH** | No | | | | | Yes | | | | | |

**Score stroke risk for the next 10 years-MEN**

| Points | 10-Year Probability | Points | 10-Year Probability | Points | 10-Year Probability |
|---|---|---|---|---|---|
| 1 | 3% | 11 | 11% | 21 | 42% |
| 2 | 3% | 12 | 13% | 22 | 47% |
| 3 | 4% | 13 | 15% | 23 | 52% |
| 4 | 4% | 14 | 17% | 24 | 57% |
| 5 | 5% | 15 | 20% | 25 | 63% |
| 6 | 5% | 16 | 22% | 26 | 68% |
| 7 | 6% | 17 | 26% | 27 | 74% |
| 8 | 7% | 18 | 29% | 28 | 79% |
| 9 | 8% | 19 | 33% | 29 | 84% |
| 10 | 10% | 20 | 37% | 30 | 88% |

| Compare with Your Age Group | Average 10-Year Probability of Stroke |
|---|---|
| 55-59 | 5.9% |
| 60-64 | 7.8% |
| 65-69 | 11.0% |
| 70-74 | 13.7% |
| 75-79 | 18.0% |
| 80-84 | 22.3% |

**Score stroke risk for the next 10 years-WOMEN**

Key: **SBP** = systolic blood pressure (score one line only, untreated or treated); ; **Diabetes** = history of diabetes; **Cigarettes** = smokes cigarettes; **CVD** (cardiovascular disease) = history of heart disease; **AF** = history of atrial fibrillation; **LVH** = diagnosis of left ventricular hypertrophy

| **Points** | **0** | **+1** | **+2** | **+3** | **+4** | **+5** | **+6** | **+7** | **+8** | **+9** | **+10** |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Age | 55-56 | 57-59 | 60-62 | 63-64 | 65-67 | 68-70 | 71-73 | 74-76 | 77-78 | 79-81 | 82-84 |
| SBP-untreated | | 95-106 | 107-118 | 119-130 | 131-143 | 144-155 | 156-167 | 168-180 | 181-192 | 193-204 | 205-216 |
| or SBP-treated | | 95-106 | 107-113 | 114-119 | 120-125 | 126-131 | 132-139 | 140-148 | 149-160 | 161-204 | 205-216 |
| Diabetes | No | | | Yes | | | | | | | |
| Cigarettes | No | | | Yes | | | | | | | |
| CVD | No | | Yes | | | | | | | | |
| AF | No | | | | | | Yes | | | | |
| LVH | No | | | | Yes | | | | | | |

**Score stroke risk for the next 10 years-WOMEN**

| Points | 10-Year Probability | Points | 10-Year Probability | Points | 10-Year Probability |
|---|---|---|---|---|---|
| 1 | 1% | 10 | 6% | 19 | 32% |
| 2 | 1% | 11 | 8% | 20 | 37% |
| 3 | 2% | 12 | 9% | 21 | 43% |
| 4 | 2% | 13 | 11% | 22 | 50% |
| 5 | 2% | 14 | 13% | 23 | 57% |
| 6 | 3% | 15 | 16% | 24 | 64% |
| 7 | 4% | 16 | 19% | 25 | 71% |
| 8 | 4% | 17 | 23% | 26 | 78% |
| 9 | 5% | 18 | 27% | 27 | 84% |

| Compare with Your Age Group | Average 10-Year Probability of Stroke |
|---|---|
| 55-59 | 3.0% |
| 60-64 | 4.7% |
| 65-69 | 7.2% |
| 70-74 | 10.9% |
| 75-79 | 15.5% |
| 80-84 | 23.9% |

Source: D'Agostino, R.B.; Wolf, P.A.; Belanger, A.J.; & Kannel, W.B. "Stroke Risk Profile: The Framingham Study." *Stroke,* Vol. 25, No. 1, pp. 40-43, January 199

Stroke facts

*There are more than 5 million stroke survivors in the U.S.*

# Recovery After Stroke: Bladder & Bowel Function

Problems with bladder and bowel function are common but distressing for stroke survivors. “Going to the bathroom” after suffering a stroke may be complicated by:

- Urinary incontinence – being unable to control your urination.
- Urinary retention – trouble urinating or not completely emptying your bladder.
- Constipation – being unable to have a regular bowel movement.
- Bowel incontinence – being unable to control your release of stool.

These issues occur when stroke has damaged the part of the brain that controls waste removal or the brain signals for it. In some cases, an infection or other issue may be the problem.

## Urinary Incontinence

Soon after stroke, many survivors need to use a small flexible tube, called a catheter, to urinate. When they improve, the catheter is removed and they begin a regular urination pattern again.

Most stroke survivors do regain control of their bladders and urinate normally. Others continue to suffer from urinary incontinence and are unable to control their urination.

### Treatments

Treatments vary depending on the cause of your problem. Some feel the urge to urinate but cannot hold it until they reach the bathroom.

Some tips that may help:

- Go to the bathroom at regular times to help train your bladder. Urinating every 2-3 hours – whether you feel the urge or not – can help prevent accidents.
- Get help from others as soon as you feel the urge to urinate. They may be able to get you to the bathroom in time.
- Drink plenty of fluids during the day and limit them in the evening. This will reduce the number of times you have to go to the bathroom at night.
- Limit caffeine and alcohol at night.
- Ask your physical therapist to help you strengthen the muscles around your bladder. Pelvic floor muscle exercises, called Kegel exercises, may help. These exercises were designed to improve urine control in women after childbirth. They may help you as well.
- Make sure that you have privacy and plenty of time to sit on the toilet or commode chair.

## Urinary Retention

Also common among stroke survivors is urinary retention. This is when you do not completely empty your bladder. If untreated, it can lead to bladder stones, reflux (reverse flow of urine back to the kidneys) or a urinary tract infection (UTI).

A UTI needs immediate treatment, so see your doctor as soon as you notice symptoms.

UTI symptoms include:

- Urine with a bad smell, cloudiness, blood or sediment (solid deposits).
- Burning when urinating or around a catheter.
- Fever and chills.
- Cramps in lower abdomen or side.
- Pain in lower back.
- Frequent urination or feeling like you have to go to the bathroom even though your bladder is empty.

### Treatments

Special treatments may be needed for conditions that cause urine retention. In these cases, your doctor may prescribe a drug such as Ditropan®, Levsin® or Cystospaz®. Inform your doctor of other drugs you are taking, because they may be the cause of your urinary-retention.

## Ongoing Problems

You may still have problems, despite all attempts to correct.

- Use a catheter if needed. Ask your doctor which type is best for you.
- Try pantiliners, waterproof underpants or disposable adult diapers. Be sure to carefully clean and lubricate the urinary area to avoid skin irritations. Also, drink plenty of water to dilute your urine.

## Constipation and Bowel Incontinence

Constipation and bowel incontinence (involuntary release of stool) may result from:

- Reduced fluid intake.
- Diet.
- Not moving around enough.
- Side effects from prescription drugs.
- Being unaware that you need to use the bathroom.
- Weakness in the muscle that holds a bowel movement until you reach a bathroom.
- Being unable or reluctant to ask for help.

To prevent problems, plan ahead and take extra efforts to retrain the bowel.

### Useful Tips

- Schedule a predictable pattern. It is important to restore a regular schedule of bowel movements at established times as soon as possible. Opportunities to use the bathroom should be planned according to previous bowel habits.
- Give yourself privacy.
- The sitting position allows you to lean forward, aiding the process.
- Be active during the day to stimulate the process of bowel movement.
- Eat healthy foods to reduce constipation and improve bowel control.

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## Treatments

If problems persist, your doctor may suggest one of these drugs or treatments:

- A **stool softener or bulk agent,** called a suppository. Shaped like a bullet, suppositories are inserted into the anus 30 minutes after a meal to stimulate a bowel movement. At first, you may need a strong suppository. As your pattern changes, you can switch to a more mild form (such as glycerin).

  When using suppositories, you should drink more liquids than usual. Never use them for a long period of time.

- **Enema** or shot of liquid put into the rectum through the anus. Do the enema at a set time every day (usually morning or evening) and adhere to your schedule. If enemas cause bleeding or abdominal pain, consult your doctor right away.

- **Oral Laxatives** maybe helpful in some cases, but be aware that their action times can be unpredictable and they can cause incontinence in a person with poor bowel control.

## What Can Help

- Talk with your doctor about symptoms and treatments.
- Be kind to yourself and remember that you are not alone. Many people have – and are embarrassed by – these issues.
- Get information on stroke recovery from National Stroke Association. Visit www.stroke.org or call 1-800-STROKES (1-800-787-6537).
- Contact your local stroke association.
- Join a stroke support group. Other survivors will understand your issues, and offer support and ideas to manage your bladder and bowel movement problems.
- Speak honestly with your caregivers about these issues. They'll be glad you did, and together you can work out the best solution.

## Professionals Who Can Help

- A general physician or doctor
- Urologist, a doctor who specializes in diseases of the urinary systems.
- Gastroenterologist, or a specialist in medical problems of the stomach, intestines and associated organs.
- Many nurses are trained to deal with continence problems.
- Physiotherapists can provide training and exercises to improve walking and transferring from a bed or chair to a commode or toilet
- Occupational therapists can help if your home needs to be adapted or equipment is needed to make it easier for you to use the toilet.
- Social workers can help with financial issues. They can with grants to adapt the bathroom or to build a new one, and can also arrange for a variety of support services, such as walking aids or wheelchairs.

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Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as speaking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

**Remember to ask your doctor, "Where am I on my stroke recovery journey?"**

Note: This fact sheet is compiled from general, publicly available medical information and should not be considered recommended treatment for any particular individual. Stroke survivors should consult their doctors about any personal medical concerns.

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Stroke facts

***There are more than 5 million stroke survivors in the U.S.***

# Recovery After Stroke: Coping with Emotions

Dealing with a flood of emotions can be hard for stroke survivors. Some emotions are normal responses to the changes in your life after stroke. Others are common but should not be considered a normal part of stroke recovery. If you suffer from depression, anxiety or emotions that are not in line with the occasion, seek help.

## Dealing with Depression

Grieving for what you have lost is good for you. But when sadness turns to depression, it's time to act. Depression can take hold right after a stroke, during rehabilitation (rehab) or after you go home. It can be – but not always – caused by brain damage from the stroke. Mild or major, it is the most common emotional problem faced by survivors.

Depression symptoms include:
- Feeling sad or "empty" most of the time
- Loss of interest or pleasure in ordinary activities
- Fatigue or feeling "slowed down"
- Sudden trouble sleeping or oversleeping
- Sudden loss of appetite or weight gain
- Being unable to concentrate, remember or make decisions like you used to
- Feeling worthless or helpless
- Feelings of guilt
- Ongoing thoughts of death or suicide, suicide planning or attempts
- A sudden change in how easily you are annoyed
- Crying all the time

Some useful tips:
- Make the most of rehab; the more you recover, the better you will feel
- Spend time with family and friends
- Maintain your quality of life by staying active and doing things you enjoy
- Seek help soon after you note symptoms

Your treatment may include counseling, medicine or both.

## Having Extreme Anxiety

Anxiety is an overwhelming sense of worry or fear. It can include increased sweating or heart rate. Among stroke survivors, feelings of anxiety are common. Often, stroke survivors suffer from both depression and anxiety at the same time.

Anxiety can affect rehab progress, daily living, relationships and quality of life. So, be sure to seek help right away.

Anxiety symptoms include:

- Ongoing worrying, fear, restlessness and irritability that don't seem to let up
- Low energy
- Poor concentration
- Muscle tension
- Feeling panicky and out of breath
- Scary rapid heart beat
- Shaking
- Headache
- Feeling sick to your stomach

Again, treatment may include counseling, medicine or both.

## Uncontrolled Emotions

Do you find yourself laughing or crying at all the wrong times? If so, you may suffer from Pseudobulbar Affect (PBA). Also called emotional incontinence or pathologic lability, PBA is a common medical problem among stroke survivors. It can cause you to laugh at a funeral or cry at a comedy club. It can even make you cry uncontrollably for little or no reason. For this, it is often confused with depression. But, *PBA is not depression*.

People with PBA are unable to control their emotional expressions the way they used to. When this happens in social settings, they feel embarrassed, frustrated and angry. They also sense that others are uneasy. They may avoid work, public places and family get-togethers. This can lead to feelings of fear, shame and isolation.

There is no treatment approved by the Federal Drug Administration (FDA) for PBA, though antidepressant drugs can help.

These things may help you cope with PBA:

- Be open about it. Warn people that you cannot always control your emotions. Explain that the emotions you show on the outside don't always reflect how you feel on the inside.
- Distract yourself. If you feel an outburst coming on, focus on something boring or unrelated. Try counting the number of items on a shelf.
- Note the posture you take when crying. When you think you are about to cry, change your posture.
- Breathe in and out slowly until you are in control.
- Relax your forehead, shoulders and other muscles that tense up when crying.

## What Can Help

- Ask your doctor about emotional changes and symptoms early on.
- Ask your family to stimulate your interest in people and social activities.
- Stay as active as possible and stay involved in your hobbies.
- Set goals and measure accomplishment.
- Plan daily activities to provide structure and sense of purpose.
- Stay involved with people, thoughts and activities that you enjoy.

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- Get information on stroke recovery from National Stroke Association. Visit www.stroke.org or call 1-800-STROKES (1-800-787-6537).
- Contact your local stroke association.
- Join a stroke support group. Other survivors will understand your issues, and offer support and ideas to help you manage your emotions.
- Speak openly and honestly to your caregivers about your emotional changes. They'll be glad you did, and together you can work out a solution.

## Professionals Who Can Help

- Psychologists, psychiatrists and other mental health professionals experienced with stroke-related emotional disorders.

Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

**Remember to ask your doctor, "Where am I on my stroke recovery journey?**

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# Recovery After Stroke: Dealing with Pain

Some survivors have to deal with pain caused by their strokes. In most people, pain is a sign that the body is being harmed in some way. With stroke, that is not always the case. Sometimes stroke damage to the brain can make even normal touch feel painful. In other cases, pain is felt as a result of muscle tightness or weakness.

You may experience one type of pain or several kinds. The key is to figure out what is causing the pain so that you can treat it.

## Types of Pain After Stroke

Pain after stroke can be:

- mild, moderate or severe.
- constant or on-and-off.
- on part or all of the side of your body affected by the stroke.
- felt in your face, arm, leg or torso (trunk).
- aching, burning, sharp, stabbing or itching.

**Local pain** after stroke is felt in the joints. Often, it comes from the unusual positioning of a joint due to spasticity, a muscle tightness or stiffness common to stroke survivors. Mostly it is seen in the shoulder.

**Central pain** is constant, moderate or severe, and worsened by touch, movement, emotions and changes in temperature. The pain tends to be felt in one part of the body, usually an arm or a leg. It is always on the side of the body affected by the stroke. You may not feel central pain in your body until weeks or months after a stroke.

Central pain is produced within the brain as a result of the stroke. It does not stem from damaged nerve endings. Rather, the body sends normal messages to the brain in response to touch, warmth, cold and other stimuli. But, the brain does not understand these signals correctly. Instead, it registers even slight sensations in the skin as painful.

Stroke survivors with central pain may:

- feel nothing when a sharp pin, warmth or cold is applied to their skin.
- experience normal touch as unpleasant and painful.
- feel more pain with emotional stress, cold or movement.

Chronic central pain can cause you to:

- stop using the parts of your body where you feel pain.
- allow muscles to weaken.
- misuse drugs, suffer from depression, and increase dependency on family members.

## Treating Your Pain

To find relief, you need to figure out the source of your pain. Pay attention to when it occurs and in what part of your body. Note whether it seems to be caused by something or someone touching you. Report your symptoms to your doctor. Together, you can determine the best treatment.

Some **fairly simple solutions** you can try at home include:

- Avoid things that can cause pain, such as hot baths, tight or easily bunched clothing, and pressure on the side of your body affected by the stroke.
- Position or splint weakened or paralyzed arms or legs to reduce discomfort.
- Use heat packs or simple exercises prescribed by your physical therapist.
- While sitting or lying down, support your paralyzed arm on an armrest or pillow to relieve shoulder pain from the arm's weight.
- Support your weakened or paralyzed arm with a sling while walking to reduce shoulder pain.

Standard treatments to control chronic pain have limited success in stroke survivors. Over-the-counter pain medicines – aspirin, acetaminophen (Tylenol®), ibuprofen (Advil®) – have not been effective in relieving stroke-related pain. Nor have prescription pain relief drugs. Surgery has not provided much relief, although research continues in this area.

However, these treatments may help:

- Antidepressant, anti-seizure and anti-spasticity drugs.
- Treatment with a physical therapist.
- Injections of cortisone (steroid shots).
- Heat and stretching exercises (for shoulder pain).
- Electrical nerve stimulation, or the application of electrical currents to the skin, may stimulate nerves and muscle fibers and improve muscle tone and strength. This may reduce pain.

Luckily, some stroke survivors with chronic pain have spontaneous remission. That is, one day the pain just goes away.

## What Can Help

- Ask you doctor about the best treatments for your symptoms.
- Focus on thoughts or activities that you enjoy. You can still be active, productive and have a good quality of life.
- Get information on stroke recovery from National Stroke Association. Visit www.stroke.org or call 1-800-STROKES (1-800-787-6537).
- Contact your local stroke association.
- Join a stroke support group. Other survivors will understand, validate your issues, and offer encouragement and ideas for pain relief.
- Try relaxation, meditation or hypnosis to manage your pain.
- Don't let pain keep you from being active. Not using your muscles can lead to muscle spasms and/or loss of muscle.
- Depression is common among those who suffer from chronic pain. Seek help if you are depressed. Counseling and/or antidepressant medicine can help.
- Speak honestly with your caregivers about your pain issues. They'll be glad you did, and, together, you can often work out the best solution.

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## Professionals Who Can Help

- A general physician or doctor.
- Neurologist – specializes in prevention, diagnosis and treatment of stroke and other diseases of the brain and spinal cord.
- Physiatrist – specializes in rehabilitation following injuries, accidents or illness.
- Physical therapist – figures out and treats problems with movement, balance and coordination.
- Psychologist – specializes in the study of the mind and behavior.

Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

**Remember to ask your doctor, "Where am I on my stroke recovery journey?"**

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# Traumatic Brain Injury (TBI)

## Definition

Traumatic injuries to the brain, also called intracranial injury, or simply head injury, occurs when a sudden trauma causes brain damage.

## Characteristics

The damage can be:

- **focal** - confined to one area of the brain - or
- **diffuse** - involving more than one area of the brain.

TBI can result from:

- closed head injury - occurs when the head suddenly and violently hits an object but the object does not break through the skull
- penetrating head injury - occurs when an object pierces the skull and enters brain tissue

A TBI can cause problems with arousal, consciousness, awareness, alertness, and responsiveness.

Disabilities resulting from a TBI depend upon the severity of the injury, the location of the injury, and the age and general health of the patient.

Some common disabilities include problems with cognition (thinking, memory, and reasoning), sensory processing (sight, hearing, touch, taste, and smell), communication (expression and understanding), and behavior or mental health (depression, anxiety, personality changes, aggression, acting out, and social inappropriateness).

## Functional Considerations

- Functional limitations will be dependent upon the type and location of the injury.
- Behavioral issues can be the most challenging when working with these patients.
  - Minimize distractions during the assessment interview.
  - If the consumer has outbursts, it is important to remain calm; validate the person’s emotions.
  - Don’t challenge or confront; rather negotiate.
- When developing a plan, include respite for the provider.
- Encourage the provider to maintain a routine as much as feasible.

National Institute of Neurological Disorders and Stroke

# Traumatic Brain Injury

## What is a Traumatic Brain Injury?

TBI, also called acquired brain injury or simply head injury, occurs when a sudden trauma causes damage to the brain. The damage can be:

- **focal** - confined to one area of the brain - or
- **diffuse** - involving more than one area of the brain.

TBI can result from:

| | |
|---|---|
| **closed head injury** | occurs when the head suddenly and violently hits an object but the object does not break through the skull |
| **penetrating head injury** | occurs when an object pierces the skull and enters brain tissue |

## What are the Signs and Symptoms of TBI?

Symptoms of a TBI can be **mild, moderate, or severe**, depending on the extent of the damage to the brain. Some symptoms are evident immediately, while others do not surface until several days or weeks after the injury.

| | |
|---|---|
| **Mild TBI** | • Remain conscious or may experience a loss of consciousness for a few seconds or minutes<br>• May also feel dazed or not like himself for several days or weeks after the initial injury<br>• Other symptoms include headache, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, bad taste in the mouth, fatigue or lethargy, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking |
| **Moderate or Severe TBI** | • Same symptoms of mild but may also have a headache that gets worse or does not go away, repeated vomiting or nausea, convulsions or seizures, inability to awaken from sleep, dilation of one or both pupils of the eyes, slurred speech, weakness or numbness in the extremities, loss of coordination, and/or increased confusion, restlessness, or agitation<br>• In young children, such as persistent crying, inability to be consoled, and/or refusal to nurse or eat |

**Anyone with signs of moderate or severe TBI should receive medical attention as soon as possible.**

## What are the Causes of and Risk Factors for TBI?

Half of all TBIs are due to transportation accidents involving automobiles, motorcycles, bicycles, and pedestrians. These **accidents** are the major cause of TBI in people under age 75.

For those 75 and older, **falls** cause the majority of TBIs.

Approximately 20 percent of TBIs are due to **violence**, such as firearm assaults and child abuse, and about 3 percent are due to sports injuries.

Fully half of TBI incidents involve alcohol use.

## What are the Different Types of TBI?

| | |
|---|---|
| **Concussion** | • Most minor and the most common type short loss of consciousness in response to a head injury |
| **Skull fractures** | • Depressed skull fracture-pieces of the broken skull press into the tissue of the brain<br>• Penetrating skull fracture- occurs when something pierces the skull |
| **Contusion** | • A distinct area of swollen brain tissue mixed with blood released from broken blood vessels |
| **Contrecoup** | • Contusion which occurs in response to shaking of the brain back and forth within the confines of the skull – bleeding is on the opposite side of the injury |
| **Axonal injury** | • Is a shearing injury which involved damage to nerve cells and loss of overall communication within the brain |
| **Hematoma** | • Damage to a major blood vessel in the head, or heavy bleeding into or around the brain |
| **Anoxia** | • A condition in which there is an absence of oxygen supply<br>• This type of injury is often seen in near-drowning victims, in heart attack patients, or in people who suffer significant blood loss from other injuries that decrease blood flow to the brain |

## How Does a TBI Affect Consciousness?

A TBI can cause problems with arousal, consciousness, awareness, alertness, and responsiveness. Generally, there are five abnormal states of consciousness that can result from a TBI:

| | |
|---|---|
| stupor | • Patient is unresponsive but can be aroused briefly by a strong stimulus, such as sharp pain |
| coma | • Patient is totally unconscious, unresponsive, unaware, and unarousable<br>• Do not respond to external stimuli, such as pain or light, and do not have sleep-wake cycles.<br>• Results from widespread and diffuse trauma to the brain<br>• Generally is of short duration, lasting a few days to a few weeks<br>• After this time, some patients gradually come out of the coma, some progress to a vegetative state, and others die<br>• Have lower brain and brain stem damage |
| vegetative state | • Patients are unconscious and unaware of their surroundings, but they continue to have a sleep-wake cycle and can have periods of alertness<br>• Often open their eyes and may move, groan, or show reflex responses<br>• Do not have lower brain and brain stem damage<br>• Many patients emerge from a vegetative state within a few weeks |
| persistent vegetative state | • Patients that do not emerge or vegetative state within 30 days<br>• The longer a patient is in a PVS, the more severe the resulting disabilities will be |
| locked-in syndrome | • Patient is aware and awake, but cannot move or communicate due to complete paralysis of the body<br>• Is caused by damage to specific portions of the lower brain and brainstem with no damage to the upper brain<br>• Patients can communicate through movements and blinking of their eyes, which are not affected by the paralysis |
| brain death | • Is the lack of measurable brain function due to diffuse damage to the cerebral hemispheres and the brainstem, with loss of any integrated activity among distinct areas of the brain |

Advances in imaging and other technologies have led to devices that help differentiate among the variety of unconscious states. The use of CT and MRI is standard in TBI treatment, but other imaging and diagnostic techniques that may be used to confirm a particular diagnosis include cerebral angiography, electroencephalography (EEG), transcranial Doppler ultrasound, and single photon emission computed tomography (SPECT).

## What Disabilities Can Result from a TBI?

Disabilities resulting from a TBI depend upon:

- the severity of the injury,
- the location of the injury,
- the age and general health of the patient.

**Some common disabilities include:**

| | |
|---|---|
| **Problems with cognition**<br>(thinking, memory, and reasoning) | Severe TBI<br>• Most patients with severe TBI, if they recover consciousness, suffer from cognitive disabilities, including the loss of many higher level mental skills<br>• most common cognitive impairment is memory loss, characterized by some loss of specific memories and the partial inability to form or store new ones |
| | Mild to Moderate TBI<br>• become easily confused or distracted and have problems with concentration and attention<br>• have problems with higher level, so-called executive functions, such as planning, organizing, abstract reasoning, problem solving, and making judgments, which may make it difficult to resume pre-injury work-related activities<br>• Recovery from cognitive deficits is greatest within the first 6 months after the injury and more gradual after that |

Patients with moderate to severe TBI have more problems with cognitive deficits than patients with mild TBI, but a history of several mild TBIs may have an additive effect, causing cognitive deficits equal to a moderate or severe injury.

| | |
|---|---|
| **Sensory processing**<br>(sight, hearing, touch, taste, and smell) | • Vision problems common<br>• may not be able to register what they are seeing or may be slow to recognize objects<br>• difficulty with hand-eye coordination - often bumping into or dropping objects, or may seem generally unsteady causing difficulty driving a car, working complex machinery, or playing sports<br>• TBI may develop tinnitus, a ringing or roaring in the ears<br>• person with damage to the part of the brain that processes taste or smell may develop a persistent bitter taste in the mouth or perceive a persistent noxious smell<br>• Damage to the part of the brain that controls the sense of touch may cause a TBI patient to develop persistent skin tingling, itching, or pain. |

| | |
|---|---|
| **Communication**<br>(expression and understanding) | • Common disabilities in TBI patients<br>• **Broca's aphasia** - difficulty with understanding and producing spoken and written language; others may have difficulty with the more subtle aspects of communication, such as body language and emotional, non-verbal signals<br>• **Wernicke's aphasia** - display little meaning in their speech, even though they speak in complete sentences and use correct grammar. Instead, they speak in flowing gibberish, drawing out their sentences with non-essential and invented words.<br>• **Dysarthria** - the patient can think of the appropriate language, but cannot easily speak the words because they are unable to use the muscles needed to form the words and produce the sounds. Speech is often slow, slurred, and garbled<br>• **prosodic dysfunction** - problems with intonation or inflection |

These language deficits can lead to miscommunication, confusion, and frustration for the patient as well as those interacting with him or her.

| | |
|---|---|
| **Behavior or mental health**<br>(depression, anxiety, personality changes, aggression, acting out, and social inappropriateness) | • Personality changes and behavioral problems<br>• Psychiatric problems that may surface include depression, apathy, anxiety, irritability, anger, paranoia, confusion, frustration, agitation, insomnia or other sleep problems, and mood swings<br>• Behaviors may include aggression and violence, impulsivity, disinhibition, acting out, noncompliance, social inappropriateness, emotional outbursts, childish behavior, impaired self-control, impaired self-awareness, inability to take responsibility or accept criticism, egocentrism, inappropriate sexual activity, and alcohol or drug abuse/addiction<br>• Some patients' personality problems may be so severe that they are diagnosed with borderline personality disorder<br>• Some patients suffer from developmental stagnation, meaning that they fail to mature emotionally, socially, or psychologically after the trauma |

Most TBI patients have emotional or behavioral problems that fit under the broad category of psychiatric health

## Are There Other Long-Term Problems Associated with a TBI?

| | |
|---|---|
| **Alzheimer's disease (AD)** | Recent research suggests an association between head injury in early adulthood and the development of AD later in life; the more severe the head injury, the greater the risk of developing AD. |
| **Parkinson's disease** | Movement disorders as a result of TBI are rare but can occur. Parkinson's disease may develop years after TBI as a result of damage to the basal ganglia. |
| **Dementia pugilistica** | Also called chronic traumatic encephalopathy, primarily affects career boxers. The most common symptoms of the condition are dementia and parkinsonism caused by repetitive blows to the head over a long period of time |
| **Post-traumatic dementia** | very similar to those of dementia pugilistica, except that post-traumatic dementia is also characterized by long-term memory problems and is caused by a single, severe TBI that results in a coma |

## Rehabilitation

The overall goal of rehabilitation after a TBI is to improve the patient's ability to function at home and in society. Therapists help the patient adapt to disabilities or change the patient's living space, called environmental modification, to make everyday activities easier.

Some patients may need **medication** for psychiatric and physical problems resulting from the TBI. Great care must be taken in prescribing medications because TBI patients are more susceptible to side effects and may react adversely to some pharmacological agents.

## How Can TBI be Prevented*?

- Wear a seatbelt every time you drive or ride in a car.
- Buckle your child into a child safety seat, booster seat, or seatbelt (depending on the child's age) every time the child rides in a car.
- Wear a helmet and make sure your children wear helmets when
    - riding a bike or motorcycle;
    - playing a contact sport such as football or ice hockey;
    - using in-line skates or riding a skateboard;
    - batting and running bases in baseball or softball;
    - riding a horse;
    - skiing or snowboarding.
- Keep firearms and bullets stored in a locked cabinet when not in use.
- Avoid falls by
    - using a step-stool with a grab bar to reach objects on high shelves;
    - installing handrails on stairways;
    - installing window guards to keep young children from falling out of open windows;
    - using safety gates at the top and bottom of stairs when young children are around.
- Make sure the surface on your child's playground is made of shock-absorbing material (e.g., hardwood mulch, sand).

Adapted from: "Traumatic Brain Injury: Hope Through Research," NINDS. February 14, 2007 NIH Publication No. 02-2478

National Institute of Neurological Disorders and Stroke

# Glasgow Coma Scale

**The eye opening part of the Glasgow Coma Scale has four scores:**

| | |
|---|---|
| **4** | indicates that the patient can open his eyes spontaneously |
| **3** | is given if the patient can open his eyes on verbal command |
| **2** | indicates that the patient opens his eyes only in response to painful stimuli |
| **1** | is given if the patient does not open his eyes in response to any stimulus |

**The best verbal response part of the test has five scores:**

| | |
|---|---|
| **5** | is given if the patient is oriented and can speak coherently |
| **4** | indicates that the patient is disoriented but can speak coherently |
| **3** | means the patient uses inappropriate words or incoherent language |
| **2** | is given if the patient makes incomprehensible sounds |
| **1** | indicates that the patient gives no verbal response at all |

**The best motor response test has six scores:**

| | |
|---|---|
| **6** | means the patient can move his arms and legs in response to verbal commands |
| **5, 4, 3, 2** | given if the patient shows movement in response to a variety of stimuli, including pain |
| **1** | indicates that the patient shows no movement in response to stimuli |

The results of the three tests are added up to determine the patient's overall condition.

| | |
|---|---|
| **3 to 8** | indicates a **severe** head injury |
| **9 to 12** | indicates a **moderate** head injury |
| **13 to 15** | indicates a **mild** head injury |

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

## Glossary

**aneurysm** - a blood-filled sac formed by disease-related stretching of an artery or blood vessel.

**anoxia** - an absence of oxygen supply to an organ's tissues leading to cell death.

**aphasia** - difficulty understanding and/or producing spoken and written language. (See also non-fluent aphasia.)

**apoptosis** - cell death that occurs naturally as part of normal development, maintenance, and renewal of tissues within an organism.

**arachnoid membrane** - one of the three membranes that cover the brain; it is between the pia mater and the dura. Collectively, these three membranes form the meninges.

**brain death** - an irreversible cessation of measurable brain function.

**Broca's aphasia** - see non-fluent aphasia.

**cerebrospinal fluid (CSF)** - the fluid that bathes and protects the brain and spinal cord.

**closed head injury** - an injury that occurs when the head suddenly and violently hits an object but the object does not break through the skull.

**coma** - a state of profound unconsciousness caused by disease, injury, or poison.

**compressive cranial neuropathies** - degeneration of nerves in the brain caused by pressure on those nerves.

**computed tomography (CT)** - a scan that creates a series of cross-sectional X-rays of the head and brain; also called computerized axial tomography or CAT scan.

**concussion** - injury to the brain caused by a hard blow or violent shaking, causing a sudden and temporary impairment of brain function, such as a short loss of consciousness or disturbance of vision and equilibrium.

**contrecoup** - a contusion caused by the shaking of the brain back and forth within the confines of the skull.

**contusion** - distinct area of swollen brain tissue mixed with blood released from broken blood vessels.

**CSF fistula** - a tear between two of the three membranes - the dura and arachnoid membranes - that encase the brain.

**deep vein thrombosis** - formation of a blood clot deep within a vein.

**dementia pugilistica** - brain damage caused by cumulative and repetitive head trauma; common in career boxers.

**depressed skull fracture** - a fracture occurring when pieces of broken skull press into the tissues of the brain.

**diffuse axonal injury** - see shearing.

**dysarthria** - inability or difficulty articulating words due to emotional stress, brain injury, paralysis, or spasticity of the muscles needed for speech.

**dura** - a tough, fibrous membrane lining the brain; the outermost of the three membranes collectively called the meninges.

**early seizures** - seizures that occur within 1 week after a traumatic brain injury.

**epidural hematoma** - bleeding into the area between the skull and the dura.

**erosive gastritis** - inflammation and degeneration of the tissues of the stomach.

**fluent aphasia** - a condition in which patients display little meaning in their speech even though they speak in complete sentences. Also called Wernicke's or motor aphasia.

**Glasgow Coma Scale** - a clinical tool used to assess the degree of consciousness and neurological functioning - and therefore severity of brain injury - by testing motor responsiveness, verbal acuity, and eye opening.

**global aphasia** - a condition in which patients suffer severe communication disabilities as a result of extensive damage to portions of the brain responsible for language.

**hematoma** - heavy bleeding into or around the brain caused by damage to a major blood vessel in the head.

**hemorrhagic stroke** - stroke caused by bleeding out of one of the major arteries leading to the brain.

**hypermetabolism** - a condition in which the body produces too much heat energy.

**hypothyroidism** - decreased production of thyroid hormone leading to low metabolic rate, weight gain, chronic drowsiness, dry skin and hair, and/or fluid accumulation and retention in connective tissues.

**hypoxia** - decreased oxygen levels in an organ, such as the brain; less severe than anoxia.

**immediate seizures** - seizures that occur within 24 hours of a traumatic brain injury.

**intracerebral hematoma** - bleeding within the brain caused by damage to a major blood vessel.

**intracranial pressure** - buildup of pressure in the brain as a result of injury.

**ischemic stroke** - stroke caused by the formation of a clot that blocks blood flow through an artery to the brain.

**locked-in syndrome** - a condition in which a patient is aware and awake, but cannot move or communicate due to complete paralysis of the body.

**magnetic resonance imaging (MRI)** - a noninvasive diagnostic technique that uses magnetic fields to detect subtle changes in brain tissue.

**meningitis** - inflammation of the three membranes that envelop the brain and spinal cord, collectively known as the meninges; the meninges include the dura, pia mater, and arachnoid.

**motor aphasia** - see non-fluent aphasia.

**neural stem cells** - cells found only in adult neural tissue that can develop into several different cell types in the central nervous system.

**neuroexcitation** - the electrical activation of cells in the brain; neuroexcitation is part of the normal functioning of the brain or can also be the result of abnormal activity related to an injury.

**neuron** - a nerve cell that is one of the main functional cells of the brain and nervous system.

**neurotransmitters** - chemicals that transmit nerve signals from one neuron to another.

**non-fluent aphasia** - a condition in which patients have trouble recalling words and speaking in complete sentences. Also called Broca's or motor aphasia.

**oligodendrocytes** - a type of support cell in the brain that produces myelin, the fatty sheath that surrounds and insulates axons.

**penetrating head injury** - a brain injury in which an object pierces the skull and enters the brain tissue.

**penetrating skull fracture** - a brain injury in which an object pierces the skull and injures brain tissue.

**persistent vegetative state** - an ongoing state of severely impaired consciousness, in which the patient is incapable of voluntary motion.

**plasticity** - ability of the brain to adapt to deficits and injury.

**pneumocephalus** - a condition in which air or gas is trapped within the intracranial cavity.

**post-concussion syndrome (PCS)** - a complex, poorly understood problem that may cause headache after head injury; in most cases, patients cannot remember the event that caused the concussion and a variable period of time prior to the injury.

**post-traumatic amnesia (PTA)** - a state of acute confusion due to a traumatic brain injury, marked by difficulty with perception, thinking, remembering, and concentration; during this acute stage, patients often cannot form new memories.

**post-traumatic dementia** - a condition marked by mental deterioration and emotional apathy following trauma.

**post-traumatic epilepsy** - recurrent seizures occurring more than 1 week after a traumatic brain injury.

**prosodic dysfunction** - problems with speech intonation or inflection.

**pruning** - process whereby an injury destroys an important neural network in children, and another less useful neural network that would have eventually died takes over the responsibilities of the damaged network.

**seizures** - abnormal activity of nerve cells in the brain causing strange sensations, emotions, and behavior, or sometimes convulsions, muscle spasms, and loss of consciousness.

**sensory aphasia** - see fluent aphasia.

**shaken baby syndrome** - a severe form of head injury that occurs when an infant or small child is shaken forcibly enough to cause the brain to bounce against the skull; the degree of brain damage depends on the extent and duration of the shaking. Minor symptoms include irritability, lethargy, tremors, or vomiting; major symptoms include seizures, coma, stupor, or death.

**shearing (or diffuse axonal injury)** - damage to individual neurons resulting in disruption of neural networks and the breakdown of overall communication among neurons in the brain.

**stupor** - a state of impaired consciousness in which the patient is unresponsive but can be aroused briefly by a strong stimulus.

**subdural hematoma** - bleeding confined to the area between the dura and the arachnoid membranes.

**subdural hygroma** - a buildup of protein-rich fluid in the area between the dura and the arachnoid membranes, usually caused by a tear in the arachnoid membrane.

**syndrome of inappropriate secretion of antidiuretic hormone (SIADH)** - a condition in which excessive secretion of antidiuretic hormone leads to a sodium deficiency in the blood and abnormally concentrated urine; symptoms include weakness, lethargy, confusion, coma, seizures, or death if left untreated.

**thrombosis or thrombus** - the formation of a blood clot at the site of an injury.
**vasospasm** - exaggerated, persistent contraction of the walls of a blood vessel.
**vegetative state** - a condition in which patients are unconscious and unaware of their surroundings, but continue to have a sleep/wake cycle and can have periods of alertness.
**ventriculostomy** - a surgical procedure that drains cerebrospinal fluid from the brain by creating an opening in one of the small cavities called ventricles.
**Wernicke's aphasia** - see fluent aphasia.

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FAMILY CAREGIVER ALLIANCE®
*National Center on Caregiving*

# Fact Sheet: Traumatic Brain Injury

## Introduction

Each year, an estimated 1.5 million people in the U.S. sustain a traumatic brain injury. The impact on their families and caregivers is immense. This fact sheet discusses traumatic brain injury (TBI) and its consequences, and provides information about the helpful resources available to families caring for a loved one affected by TBI.

## Definition

Traumatic brain injury, also called brain injury or head injury, occurs when a blow or jolt to the head results in damage to the brain. TBIs range in severity from mild to severe.

Mild TBI occurs when a person has a brief change in mental status or loss of consciousness. The most common type of brain injury, a **concussion**, is classified as a *mild traumatic brain injury*. Mild TBI often goes undiagnosed and consequently the person suffering the injury loses out on the benefits of rehabilitation and medical care.

Severe TBIs may involve loss of consciousness for hours or weeks and can result in permanent disability. Any TBI, whether mild or severe, can result in short- or long-term disability.

There are many different types of traumatic brain injury, including:

- Concussions - the most common type of TBI
- Penetration injury - from bullets or other objects entering the skull
- Contusions - bleeding that results from blows to the head
- Diffuse axonal injury - damage from tearing of the brain tissue (includes shaken baby syndrome and some bicycle, car or motorcycle accident injuries)

## Facts

- 5.3 million Americans, approximately 2% of the population, currently live with disabilities related to brain injury.
- Males are more than twice as likely as females to experience a TBI.
- TBI is most common among adolescents (aged 15-24) and older adults (75 and older).
- The most common causes of TBI:
    - Motor vehicle collisions
    - Falls
    - Violence
    - Sports
- Research has shown that approximately 85% of head injuries from bicycle accidents can be prevented with the use of helmets.

## Consequences

A TBI may result in mild, moderate or severe changes in one or more areas, including thinking, speech, physical functions and social behavior. The consequences of TBI can be lifelong for some people, while others may be able to recover and resume activities they enjoyed before the injury occurred.

A partial list of **Cognitive Changes** (or **Changes in Thinking**) which can occur due to a brain injury include:

- Shortened attention span
- Memory problems
- Problem-solving difficulties

- Poor judgment
- Partial or complete loss of reading and writing skills
- Language problems, including communication deficits and loss of vocabulary
- Inability to understand abstract concepts
- Difficulty learning new things

Some of the **Physical Changes** that can occur due to a brain injury include:

- Weakness
- Muscle coordination problems
- Full or partial paralysis
- Changes in sexual functioning
- Changes in the senses (hearing, sight, touch, etc.)
- Seizures (also called traumatic epilepsy)
- Sleep problems
- Speech difficulties

**Personality and Behavioral Changes** may be subtle or severe and include:

- Difficulty with social skills
- Inability to empathize with others
- Tendency to be more self-centered
- Inability to control one's emotions
- Increases in irritability and frustration
- Inappropriate and/or aggressive behavior
- Extreme mood swings
- Depression (individuals with TBI are considered to be at a high risk for depression)

For further information about how to cope with behavior problems that result from a TBI, see the FCA Fact Sheet *"Coping with Behavior Problems after Head Injury."*

## Prognosis (or Chance of Recovery)

It is difficult to predict how well someone who has had a brain injury will recover, partly because there is no test a doctor can use to predict recovery. The Glasgow Coma Scale is used to determine the initial severity of a brain injury. It is often used at the scene of the accident or in the emergency room. This scale uses eye movements and ability to speak and move other parts of the body to determine the seriousness of the injury. Ask your doctor to explain the tests used to determine your loved one's ability to recover.

Your loved one's prognosis will depend on many factors, including the severity of the injury, the type of injury, and what parts of the brain have been affected. Prompt diagnosis and treatment will help the recovery process.

## Recovery Tips for People Who Have Had a TBI

The recovery process is different for everyone. Just as no two people are alike, no two brain injuries are alike. Recovery is typically lengthy—from months to years—because the brain takes a long time to heal. These tips, directed at the person with a brain injury, will help your loved one improve after the injury:

- Get lots of rest.
- Avoid doing anything that could cause another blow or jolt to the head.
- Ask the doctor when it's safe to drive a car, ride a bike, play sports or use heavy equipment, because reaction time may be slower after a brain injury.
- Take prescription medication according to the doctor's instructions.
- Do not drink alcohol or use street drugs.

- Write things down to help with memory problems.
- Ask the doctor to recommend rehabilitation services that might help recovery, and follow those recommendations.

## Rehabilitation

The goal of rehabilitation is to help your loved one live and function as independently as possible. Rehabilitation helps the body heal and assists the brain in relearning processes so that an individual recovers as quickly and efficiently as possible. Rehabilitation will also help the person with TBI learn new ways to do things if any previous abilities have been lost.

After your loved one's initial life-saving treatment at the time of the injury, he or she will most likely start a rehabilitation program and will work with a team of specialists. The person with TBI and his or her family are the most important members of the rehabilitation team. Family members should be included in the rehabilitation and treatment as much as possible. Some of the other professionals who may be part of this team include:

- **Physiatrists** - doctors who are experts in rehabilitation medicine who typically oversee the rehabilitation process.
- **Neurologists** - doctors who are trained in the diagnosis and treatment of nervous system disorders, including diseases of the brain, spinal cord, nerves, and muscles.
- **Occupational, physical, speech and language therapists** - therapists that help the person regain thinking skills, communication skills, physical abilities and behavioral skills.
- **Neuropsychologists** - specialized psychologists who focus on thinking skills and behavior problems.
- **Vocational rehabilitation experts** - employment coaches who help with regaining job skills.

It is important to remember that rehabilitation may last years and that your loved one will benefit from the ability to receive rehabilitation services throughout this time. Appropriate programs and treatments will also change as your family member's needs change.

A variety of treatment and rehabilitation programs may help your loved one. Some of the different types of rehabilitation facilities include:

- **Acute rehabilitation** - an intensive rehabilitation program.
- **Coma treatment centers** - provide coma-specific medical care.
- **Transitional living programs** - nonmedical residential programs that teach skills for community living.
- **Long-term care and supervised living programs** - residential facilities that provide care and rehabilitation to people with TBI who are not able to live independently.
- **Behavior management programs** - typically community-based (i.e., not residential) programs that teach self-control and appropriate social behaviors.
- **Day treatment programs** - provide rehabilitation during the day so the person can return home at night.

The Brain Injury Association of America's *Guide to Selecting and Monitoring Brain Injury Rehabilitation Programs* is a good resource for figuring out what questions to ask a rehabilitation provider and can help in choosing a rehabilitation facility. The Brain Injury Association of America also publishes the *National Directory of Brain Injury Rehabilitation Services*, which lists services in each state.

## Caregiving

When someone suffers a Traumatic Brain Injury (TBI), the entire family is affected. Studies show that caregivers of people who have suffered a brain injury may experience feelings of burden, distress, anxiety, anger and depression. If you are caring for a partner, spouse, child, relative or close friend with TBI, it is important to recognize how stressful this situation can be and to seek support services.

Services that may be most helpful to you include in-home assistance (home health aides or personal care assistants), respite care to provide breaks from caregiving, brain injury support groups, and ongoing or short-term counseling for caregivers to adjust to the changes that have come as a result of the injury. You also may need to ask your support system of family, friends and community members for help with your loved one's care, so that you don't get burned out. (See Family Caregiver Alliance's Fact Sheet: *Taking Care of YOU: Self-Care for Family Caregivers* for additional tips on taking care of yourself.)

In your role as a caregiver, you will probably find that it can be difficult to find appropriate and adequate services for your loved one. It is important to know that you will most likely need to be persistent in your search for assistance. You should use your network of family and friends, as well as professionals, to get tips about available resources.

## Useful Resources & Services for Families Affected by TBI

### Protection and Advocacy (P&A) System and Client Assistance Program (CAP)

This nationwide network of congressionally mandated disability rights agencies provides various services to people with disabilities, including TBI. P&A agencies provide information and referral services and help people with disabilities find solutions to problems involving discrimination and employment, education, health care and transportation, personal decision-making, and Social Security disability benefits. These agencies also provide individual and family advocacy. CAP agencies help clients seeking vocational rehabilitation.
For more information on P&A and CAP programs, contact the National Association of Protection and Advocacy Systems, Inc. at: www.napas.org or (202) 408-9514.

### Traumatic Brain Injury Model Systems

Funded through the National Institute on Disability and Rehabilitation Research, the TBI Model Systems consist of 16 TBI treatment centers throughout the U.S. The TBI Model Systems have extensive experience treating people with TBI and are linked to well established medical centers which provide high quality trauma care from the onset of head injury through the rehabilitation process.
For more information on the TBI Model Systems, go to www.tbindc.org/main_centers.php or call (800) 248-3221 x4812 to find the center nearest you.

### State Brain Injury Programs

Some states have developed programs to assist individuals with TBI. These programs are often called brain injury programs, task forces or advisory councils and are typically part of the state's Department of Rehabilitation or Health Services. To see if your state has any state-funded TBI programs that can be of assistance, check with the Brain Injury Association of America's State Affiliate at www.biausa.org (click on "State Affiliates"), or (800) 444-6443. You can also contact the TBI Technical Assistance Center, which provides information about TBI resources in each state-see www.tbitac.org/site/StateProfile.cfm or call (301) 443-5599.

### Social Security Disability Insurance (SSDI) & Supplemental Security Income (SSI)

It is possible that your loved one may be entitled to SSDI and/or SSI. SSDI and SSI eligibility is dependent on a number of factors including the severity of the disability and what assets and income your loved one has. You should contact the Social Security Administration to find out more about these programs and whether your loved one will qualify for these benefits. For more information on SSDI and SSI, contact the Social Security Administration at www.ssa.gov or (800) 772-1213

### Centers for Independent Living (CIL)

Some families have found that it is important to encourage their loved one with a TBI to continually learn skills that can allow them to live independently in the community.
The CILs exist nationwide to help people with disabilities live independently in the community and may have resources to help your loved one reach a goal of living alone. CIL services include advocacy, peer counseling, case management, personal assistance and counseling, information and referral, and independent living skills

development. For more information on the CIL system, contact the National Council on Independent Living at www.virtualcil.net/cils or (703) 525-3406.

## Recommended Readings

***Living with Brain Injury: A Guide for Families, Second Edition.*** Richard Senelick, MD and Karla Dougherty. 2001: HealthSouth Press. ISBN#: 189152509-3

***Traumatic Head Injury: Cause, Consequence and Challenge.*** Dennis P. Swiercinsky, Terrie L. Price and Lief Erick Leaf, 1993, Head Injury Association of Kansas and Greater Kansas City, 1100 Pennsylvania Ave., Suite 305, Kansas City, MO 64105. 1993. Kansas City: Brain Injury Association of Kansas.

***Head Injury: Information and Answers to Commonly Asked Questions: A Family's Guide to Coping.*** Christopher D. Strum, MD, Thomas R. Forget, Jr., MD, and Janet L. Strum, RN. 1998: Quality Medical Publishing, St. Louis, MO. ISBN# 1-57626-096-8

***Children with Traumatic Brain Injury: A Parent's Guide.*** Edited by Lisa Schoenbrodt, Ed. D. 2001: Woodbine House. ISBN#0-933149-99-9.

***The HDI Coping Series and the HDI Professional Series on Traumatic Brain Injury,*** William Burke, Michael Wesolowski and William Blacker, 1996 (revised), HDI Publishers, 10131 Alfred Lane, Houston, TX 77041, (800) 321-7037.

***Fact Sheet: Taking Care of YOU: Self-Care for Family Caregivers,*** Family Caregiver Alliance. www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=847

***Fact Sheet: Coping with Behavior Problems After Head Injury,*** Family Caregiver Alliance. www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=396

## Credits

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The National Institute of Neurological Disorders and Stroke. *NINDS Traumatic Brain Injury Information Page*. www.ninds.nih.gov/health_and_medical/disorders/tbi_doc.htm

This fact sheet was prepared by the National Center on Caregiving at Family Caregiver Alliance and was reviewed by Catherine Sebold, Communications Specialist of the Brain Injury Association of America. Funded by the Archstone Foundation. September 2003.

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# Fact Sheet: Coping with Behavior Problems after Head Injury

## Identifying Behavior Problems

Head injury survivors may experience a range of neuropsychological problems following a traumatic brain injury. Depending on the part of the brain affected and the severity of the injury, the result on any one individual can vary greatly. Personality changes, memory and judgement deficits, lack of impulse control, and poor concentration are all common. Behavioral changes can be stressful for families and caregivers who must learn to adapt their communication techniques, established relationships, and expectations of what the impaired person can or cannot do.

In some cases extended cognitive and behavioral rehabilitation in a residential or outpatient setting will be necessary to regain certain skills. A neuropsychologist also may be helpful in assessing cognitive deficits. However, over the long term both the survivor and any involved family members will need to explore what combination of strategies work best to improve the functional and behavioral skills of the impaired individual.

## Personality Changes

Even a person who makes a “good” recovery may go through some personality changes. Family members must be careful to avoid always comparing the impaired person with the way he/she “used to be.” Personality changes are often an exaggeration of the person's pre-injury personality in which personality traits become intensified. Some changes can be quite striking. It may be, for example, the head injury survivor used to be easy going, energetic, and thoughtful and now seems easily angered, self-absorbed, and unable to show enthusiasm for anything. Nonetheless, try not to criticize or make fun of the impaired person’s deficits. This is sure to make the person feel frustrated, angry, or embarrassed.

## Memory Problems

Head injury survivors may experience short-term problems and/or amnesia related to certain periods of time. Generally, *new learning* presents the greatest challenge to memory or remembering. In contrast, pre-injury knowledge is more easily retained.

The ability to focus and concentrate are keys to addressing some short-term memory problems.

Keep distractions (e.g., music, noise) to a minimum and focus on one task at a time.

Have the individual repeat the name of a person or object, after you, if memory impairment is severe.

Whenever possible, have the person write down key information (e.g., appointments, phone messages, list of chores).

Keep to routines. Keep household objects in the same place. Use the same route to walk to the mail box or bus stop.

If getting lost is a problem, you can label doors or color code doors inside the house or hang arrows to indicate directions. When going out, the person should be accompanied initially to ensure the route is understood. A simple map can be sketched from the bus stop to the house. And make sure that the person always carries his/her address and emergency phone numbers.

## Establishing Structure

A structured environment can be essential in helping a head injury survivor relearn basic skills. A written routine schedule of activities and repetition make it easier to remember what's expected and what to do next.

## Lack of Emotion

After a head injury a person may lack emotional responses such as smiling, laughing, crying, anger, or enthusiasm or their responses may be inappropriate. This may be especially present during the earlier stages of recovery.

Recognize that this is part of the injury. Try not to take it personally if the person does not show an appropriate response.

Encourage the person to recognize your smile at a humorous situation (or tears if you are sad) and to take note of the proper response.

## Emotional Lability

In some cases, neurological damage after a head injury may cause emotional volatility (intense mood swings or extreme reactions to everyday situations). Such overreactions could be sudden tears, angry outbursts, or laughter. It is important to understand that the person has lost some degree of control over emotional responses. The key to handling lability is recognizing that the behavior is unintentional. Caregivers should model calm behavior and try not to provoke further stress by being overly critical. Help the person recognize when his/her emotional responses are under control and support/reinforce techniques that work.

## Aggressive Behaviors

Provided a situation does not present a physical threat, various approaches may be used to diffuse hostile behavior:

- Remain as calm as you can; ignore the behavior.
- Try to change the person's mood by agreeing with the person (if appropriate) and thus avoiding an argument. Show extra affection and support to address underlying frustrations.
- Validate the emotion by identifying the feelings and letting the person know these feelings are legitimate. Frustration over the loss of functional and/or cognitive abilities can reasonably provoke anger.
- Do not challenge or confront the person. Rather, negotiate (e.g., if you don't like what's planned for dinner tonight, how about choosing Friday's menu?).
- Offer alternative ways to express anger (e.g., a punching bag, a gripe list).
- Try to understand the source of the anger. Is there a way to address the person's need/frustration? (e.g., make a phone call, choose an alternative activity).
- Help the person regain a sense of control by asking if there is anything that would help him/her feel better.
- Isolate the disruptive impaired person. Consider you own safety and his/hers. Treat each incident as an isolated occurrence as the survivor may not remember having acted this way before or may need to be prompted to remember. Try to establish consistent, non-confrontational responses from all family members (children may need to learn some "dos" and "don'ts" in reacting to the survivor).
- Seek support for yourself as a caregiver. Support groups, professional counselors, and, if necessary, protective services or law enforcement may be contacted.

## Self-Centered Attitude

The person who has survived a head injury may lack empathy. That is, some head injury survivors have difficulty seeing things through someone else's eyes. The result can be thoughtless or hurtful remarks or unreasonable, demanding requests. This behavior stems from a lack of abstract thinking.
Help cue the person to recognize thoughtlessness. Remind him/her to practice polite behavior. Realize that awareness of other people's feelings may have to be relearned.

## Poor Concentration

“Cueing” or reminders can be helpful in improving concentration and attention. Repeat the question. Don’t give too much information at once, and check to see that the person is not tired.

Head injury survivors should be encouraged to develop self-checks by asking themselves questions such as “*Did I understand everything?*”, “*Did I write it down?*”, “*Is this what I’m supposed to be doing?”. “I made a mistake*” or “*I’m not sure*” should lead to the conclusion, “*let me slow down and concentrate so I can correct the error*”. Correct actions should be consciously praised, “*I did a good job*”.

## Lack of Awareness of Deficits

It is relatively common for a head injury survivor to be unaware of his/her deficits. Remember that this is a part of the neurological damage and not just obstinance. Be aware, however, that denial can also be a coping mechanism to conceal the fear that he/she cannot do a particular task. The person may insist that the activity cannot be done or is “stupid.”

Build self-esteem by encouraging the person to try a (non-dangerous) activity that he/she feels confident doing.

Give the person visual and verbal reminders or “hints” (e.g., a smile or the words *"good job")* to improve confidence in carrying out basic activities more independently.

If you feel the person can handle confrontation, challenge him/her to try the activity. Demonstrate that **you** can do the task easily.

## Inappropriate Sexual Behavior

After a head injury, a person may experience either increased or decreased interest in sex. The causes could be a result of brain regulation of hormonal activity or an emotional response to the injury.

Sexual disinterest from a head injured spouse should not be taken personally. Avoiding sexual contact could stem from fear or embarrassment about potential performance. Do not pressure the person to resume sexual activity before he/she is ready. Helping the person dress nicely and practice good hygiene may help increase his/her confidence in feeling attractive.

Increased sexual interest can be particularly stressful and embarrassing to families and caregivers. Without good impulse control, the survivor may make crude remarks out in public, make a pass at a married friend, try to touch someone in an inappropriate setting, or demand sexual attention from a spouse or significant other.

It is important to remind the person that the behavior is not acceptable.

A spouse should not feel pressured into submitting to sexual demands which are unwanted.

A sexually aggressive person may need to be isolated from others where inappropriate behavior is not controlled. A call for help may be necessary, if physical threats are made.

Support groups may be useful in helping the person realize the consequences of inappropriate sexual behaviors.

## Learning to Cope/Getting Support

Coping with behavior problems after a head injury requires identification and acknowledgment of the impaired individual's deficits. A comprehensive neuropsychological assessment is recommended. This may help both the survivor and the family to better understand neurological and cognitive deficits.

In some cases, it may be easier for the family caregiver to recognize personality changes than to resolve the problem behavior. Targeted strategies may be used to deal with specific behavioral issues.

Finally, it is critical that family members seek and receive support (family, friends, support group, counselor) in dealing with their own emotional responses to caring for a head injured loved one.

## Recommended Reading

***Therapeutic Fun for Head Injured Persons and Their Families***, Sally Kneipp (ed) 1988, Community Skills Program, c/o Counseling and Rehabilitation, Inc., 1616 Walnut St., #800, Philadelphia, PA 19103.

***Professional Series*** and ***Coping Series***, HDI Publishers, PO Box 131401, Houston, TX 77219. (800) 321–7037.

***Head Injury Peer Support Group Training Manual***, Family Caregiver Alliance (1993): San Francisco, CA.

***Head Injury and the Family: A Life and Living Perspective***, Arthur Dell Orto and Paul Power (1994) GR Press, 6959 University Blvd., Winter Park, FL 32193. (800) 438–5911.

***Awake Again,*** Martin Krieg (1994), WRS Publishing, available from the author: P.O. Box 3346, Santa Cruz, CA 95063. (408) 426–8830.

## Credits

Burke, William, H. et al. (1988). ***HDI Professional Series on Traumatic Brain Injury***, HDI Publishers, Galvaston, TX.

San Jose Chapter Pi Lamda Theta (1983). ***Helping Head Injury and Stroke Patients at Home: A Handbook for Families***, San Jose, CA.

Eames, P. (1988). Behavior disorders after severe brain injury: their nature and causes and strategies for management, ***Journal of Head Trauma Rehabilitation*** 3(3), 1-6.

DeBoskey, D. and Morin, K., (1985). ***A "How to Handle" Manual for Families of the Brain Injured***, Tampa General Hospital, Tampa, FL.

Reviewed by: Claude Munday, Ph.D., Neurospychology Associates of the Bay Area; William Lynch, Ph.D., Director of Brain Injury Rehabilitation Unit, Outpatient Program, Department of Veteran Affairs, Palo Alto, CA; and John Haller, Traumatic Brain and Spinal Cord Injury Project, San Jose, CA.

Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Revised July 1996. Funded by the California Department of Mental Health. ©All rights reserved.

# The Consumer at Risk for Falls

## Characteristics

Falls don't "just happen," and people don't fall because they get older. Often, more than one underlying cause or risk factor is involved in a fall. As the number of risk factors rises, so does the risk of falling.

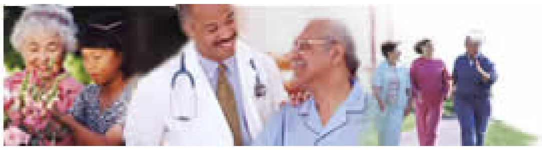
- Many falls are linked to a person's physical condition or a medical problem, such as a chronic disease.
- Other causes could be safety hazards in the person's home or community environment.

## Functional Considerations / Appropriate Referrals

- Physical activity to the level of capacity, such as doing housework and going shopping, reduces the risk of falling by maintaining muscular strength, flexibility, endurance and bone density.
- Clutter, especially on the floors, increases the risk of falling. Consider the appropriateness of Heavy Cleaning if clutter poses a risk.
- Refer for the installation of grab bars in the bathroom (by the toilet and in the shower and by the tub), banisters by stairs (all bars should be secured to wall studs).
- Encourage the use of a cane or walker, if the consumer has one, particularly when going outside.
- If the consumer does not have assistive devices and is experiencing falls suggest that they talk to their physician about getting a prescription for these items.
- Consumers who are experiencing frequent falls may require assistance with ambulation.
- Suggest the removal of throw rugs, or securing all carpets and rugs to the floor or stairs.
- Refer for a personal emergency response system such as Lifeline, if appropriate.

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

NIH SeniorHealth



**National Institute on Aging**

# Falls and Older Adults

**More than one in three people age 65 years or older falls each year**. The risk of falling -- and fall-related problems -- rises with age.

- Each year, more than 1.6 million older U.S. adults go to emergency departments for fall-related injuries.
- Among older adults, falls are the number one cause of fractures, hospital admissions for trauma, loss of independence, and injury deaths.
- Fractures caused by falls can lead to hospital stays and disability.
- Most often, fall-related fractures are in the person's hip, pelvis, spine, arm, hand, or ankle.

**Hip fractures** are one of the most serious types of fall injury.

- They are a leading cause of medical problems and death among older adults.
- Only half of older adults hospitalized for a broken hip can return home or live on their own after the injury.

**Osteoporosis**, a disease that involves loss of bone mass, increases the chance of hip and other fractures if a person falls.

## Fear of Falling

- Many older adults are afraid of falling.
- This fear becomes more common as people age, even among those who haven't fallen.
- It may lead older people to avoid activities such as walking, shopping, or taking part in social activities.
- Muscles and bones can weaken over time without the physical activity that comes with doing daily tasks or exercise. As a result, a person could become more -- not less -- likely to fall.

## Causes and Risk Factors

Falls don't "just happen," and people don't fall because they get older. Often, more than one underlying cause or risk factor is involved in a fall. As the number of risk factors rises, so does the risk of falling.

- Many falls are linked to a person's physical condition or a medical problem, such as a chronic disease.
- Other causes could be safety hazards in the person's home or community environment.

## Personal Risk Factors to Falling

- **Muscle weakness**
  - is one of the most important risk factors
  - Older people with weak muscles are more likely to fall than are those who maintain their muscle strength, as well as their flexibility and endurance.

- **Balance and gait** are other key factors.
    - Older adults who have poor balance or difficulty walking are more likely than others to fall.
    - These problems may be linked to a lack of exercise or to a neurological cause, arthritis, or another condition that might be treated or managed.

- **Postural hypotension**
    - Blood pressure that drops too much when standing from lying down or sitting can increase the chance of falling.
    - Might be a result from a drop in blood volume, dehydration, or certain medications. It might also be linked to diabetes, Parkinson's disease, or an infection.
    - Some people with postural hypotension feel dizzy when their blood pressure drops. Other people don't feel dizzy, even if their blood pressure drops a lot when they get up.

- **Slow reflexes**
    - Reflexes may also be slower than when younger.
    - The increased amount of time it takes to react may make it harder to maintain balance when starting to fall.

- **Foot problems**
    - Painful feet, and wearing unsafe footwear can increase the chance of falling.
    - Backless shoes and slippers, high-heeled shoes, and shoes with smooth leather soles are examples of unsafe footwear that could cause a fall.

- **Sensory problems** can cause falls, too.
    - Having numb feet may mean a person won’t sense where they are stepping.

- **Eye sight**
    - Not seeing well can also result in falls.
    - It may take a while for eyes to adjust to see clearly when moving between darkness and light.
    - Other vision problems include poor depth perception, cataracts, and glaucoma.
    - Wearing multi-focal glasses while walking or having poor lighting around the home can also lead to falls.

- **Confusion**
    - Even if it is only for a short while, can sometimes lead to falls. For example, if waking up in an unfamiliar environment, may make a person feel unsure about where they are. When feeling confused it is best to wait for a few minutes to clear the mind before trying to get up and walk around.

- **Medication**
    - May be increased risk because of the health problems for which the person takes the medications.
    - Medications cause side effects like dizziness or confusion.
    - Drug interactions can also lead to falls.
    - The more medications taken the more likely a person is to fall. People who take four or more prescription drugs have a greater risk of falling than do people who take fewer drugs.
    - Never add or stop taking medications without talking with the doctor first.
    - Ask the doctor if changes in medications could lower the risk of falls.

**All falls should be reported to the doctor:**

- A fall could be a sign of a **medical problem** such as an infection or a cardiovascular disorder. It could also suggest that a chronic ailment, such as Parkinson's disease or dementia, is progressing.

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## Preventing Falls and Fractures - Personal Changes

Here are some changes to make:

- **Be physically active**
  - Regular physical activity is a first line of defense against falls and fractures
  - Physical activity strengthens muscles and increases flexibility and endurance

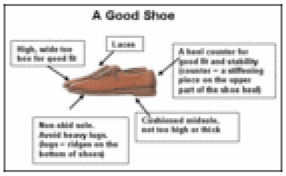
- **Review medications**
  - Find out about the possible side effects of medications
  - Some medications might affect coordination or balance, or cause dizziness, confusion, or sleepiness
  - Some medications don't work well together, adding to the risk of falls

- **Limit the amount of alcohol**
  - Even a small amount can affect balance and reflexes

- **Have blood pressure checked when lying and standing**
  - check blood pressure and pulse after lying down for at least 5 minutes and again after getting up
  - If there is a significant drop:
    - Look at need for medication changes
    - Check for dehydration
    - Consider using pressure stockings

- **Get a vision check-up**
  - Have vision tested regularly or if it has changed. Even small changes in sight can make a person less stable.
  - Wear eyeglasses if they are warranted. Keep them clean and check to see that the frames are straight.
  - Be extra cautious while adjusting to new eye glass prescription
  - Take off reading glasses or multi-focal lenses when walking

- **Choose safe footwear.**
  - The soles of the feet have nerves that help in judging the position of the body.
  - The feet need to be in touch with the ground and shoes need to stay securely with the foot at each step.
  - Wear sensible, low-heeled shoes that fit well and support the feet. Shoes should completely surround the feet.
  - Wearing only socks or wearing floppy, backless slippers or shoes without backs can be unsafe.
  - Choose shoes with non-slip soles. Smooth soles can cause slipping on waxed or polished floors.



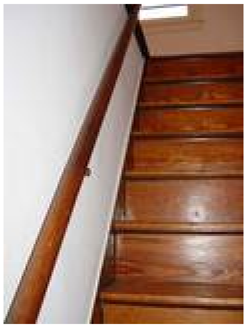
## Preventing Falls and Fractures - Home Safety

Well over half of all falls happen at home. Falls at home often happen while a person is doing normal daily activities.

**Some tips to help prevent falls outdoors are:**

- Use a cane or walker
- Wear rubber-soled shoes to prevent slipping
- Walk on grass when sidewalks are slick
- Put salt or kitty litter on icy sidewalks.

**Some ways to help prevent falls indoors are:**



- Keep rooms free of clutter, especially on floors
- Arrange furniture to give plenty of room to walk freely.
- Use plastic or carpet runners
- Wear low-heeled shoes
- Do not walk in socks, stockings, or slippers
- Be sure rugs have skid-proof backs or are tacked to the floor
- Put non-slip strips on floors and steps
- Be sure stairs are well lit and have rails on both sides
- Put grab bars on bathroom walls near tub, shower, and toilet
- Use a nonskid bath mat in the shower or tub
- Avoid wet floors and clean up spills right away.
- Use a cane or walker
- Keep a flashlight next to the bed
- Use a sturdy stepstool with a handrail and wide steps
- Add more lights in rooms
- Buy a cordless phone - keep it close to answer or to call for help in case of a fall

After a fall the doctor might suggest that an occupational therapist, physical therapist, or nurse visit the home. To assess the home's safety and give advice about making changes to prevent falls.

## Preventing Falls and Fractures - Bone Health

Maintaining the strength of the bones can help prevent fractures.
Having healthy bones won't prevent a fall, but can help prevent hip or other fractures.

**Osteoporosis** makes bones thin and more likely to break. It is a major reason for fractures in women past menopause. It also affects older men. If bones are fragile, even a minor fall can cause fractures.

**Ways to keep bones strong:**
**Calcium**

- Be sure to consume adequate amounts of calcium.
- People over age 50 should consume 1,200 mg of calcium daily by eating calcium-rich foods and taking calcium supplements.
- Good dietary sources of calcium include dairy products such as low-fat milk, yogurt, and cheese orange juice, cereals, and other foods fortified with calcium dark green, leafy vegetables such as broccoli, collard greens, and bok choy sardines, salmon with bones, soybeans, tofu, and nuts such as almonds.

**Vitamin D**

- Be sure to consume adequate amounts of calcium and vitamin D.
- Vitamin D helps the body absorb calcium.
- Exposure to sunlight causes the body to make vitamin D. Many older people don't get enough vitamin D this way.
- As a person grows older, their need for vitamin D increases. People ages 51 to 70 should consume at least 400 international units (IU) of vitamin D daily. People over age 70 should consume at least 600 IU daily.
- Herring, sardines, salmon, tuna, liver, eggs, and fortified milk and foods are good sources of vitamin D.
- Vitamin D supplements may also be needed. Talk with the doctor about how much vitamin D is needed. Taking too much may be harmful.

**Physical activity**

- Should get a total of at least 30 minutes of physical activity a day.
- Find time for activities like walking, dancing, stair climbing, gardening, and weight-lifting.

**Bone density**

- Talk with the doctor about having a bone density test. This safe, painless test assesses bone health and risk of future fractures.
- Medicare and many private insurers cover this test for eligible people. Women over age 65 and all men over 70 should have a bone density test.

**Prescription medications**

- Some people will need to take prescription medications to improve bone health.
- These medications can slow bone loss, improve bone density, and lessen the risk of fractures.

**Smoking and Alcohol**

- Quit smoking and limit alcohol use.
- Smoking and heavy alcohol use can decrease bone mass and increase the chance of fractures.

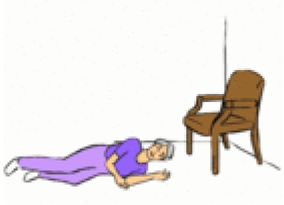
**Weight**

- Maintain a healthy weight.
- Being underweight increases the risk of bone loss and broken bones.

## In Case of a Fall

Whether at home or somewhere else, a sudden fall can be startling and upsetting.

**After a fall tell the patient to:**



- Stay as calm as possible
- Take several deep breaths to try to relax
- Remain still on the floor or ground for a few moments.
  - This will help get over the shock of falling.
  - It will allow time to decide if there is injury before getting up.
  - Getting up too quickly or in the wrong way could make an injury worse.

- To get up safely without help
    - Roll over onto a side
    - Push into a seated position.
    - Rest let blood pressure adjust
    - Slowly get up on hands and knees, and crawl to a sturdy chair
    - Put hands on the chair seat and slide one foot forward so that it is flat on the floor. Keep the other leg bent so the knee is on the floor
    - From this kneeling position, slowly rise and turn to sit in the chair

- If there is an injury or the person can't get up on his own
    - ask someone for help or call 911
    - If alone, try to get into a comfortable position and wait for help to arrive

- If a patient has problems with balance or dizziness and are often alone, consider getting a personal emergency response system
    - This service, through the telephone line and provides a button or bracelet to wear at all times in the home
    - If the patient falls or needs emergency assistance for any reason, a push of the button will alert the service
    - Emergency medical services will be called. There is a fee for medical monitoring services

- Carry a portable phone
    - Keep it nearby as they move about the house to make it easier to call someone if assistance is needed.
    - The may also put a telephone in a place that can be reached from the floor in case of a fall and help is needed.

Any fall should be reported to the doctor. Write down information about when, where, and how the fall occurred so it can be discussed with the doctor.  The doctor can assess whether a medical issue or other cause of the fall needs to be addressed. Knowing the cause can help plan to prevent future falls.

Adapted (8-07) from: MedlinePlus, a service of the National Library of Medicine, provides more resources about falls and fall prevention. Click here for additional resources available through MedlinePlus: http://www.nlm.nih.gov/medlineplus/falls.html Topic last reviewed: 16 October 2006  Topic first published: 16 October 2006

# What Are Ways to Prevent Falls and Related Fractures?

*Fast Facts: An Easy-to-Read Series of Publications for the Public*

Falls are serious at any age, but especially for older people who are more likely to break a bone when they fall.

If you have a disease called osteoporosis, you are more likely to break a bone if you fall. Osteoporosis is called the "silent disease" because bones become weak with no symptoms. You may not know that you have it until a strain, bump, or fall causes a bone to break.

Falls are especially dangerous for people with osteoporosis. If you break a bone, you might need a long time to recover. Learning how to prevent falls can help you avoid broken bones and the problems they can cause.

## Why Do People Fall?

Some of the reasons people fall are:

- Tripping or slipping due to loss of footing or traction
- Slow reflexes, which make it hard to keep your balance or move out of the way of a hazard
- Balance problems
- Reduced muscle strength
- Poor vision
- Illness
- Taking medicines
- Drinking alcohol.

Illness and some medicines can make you feel dizzy, confused, or slow. Medicines that may increase the risk of falls are:

- Blood pressure pills
- Heart medicines
- Diuretics (water pills)
- Muscle relaxants
- Sleeping pills.

Drinking alcohol can lead to a fall because it can:

- Slow your reflexes
- Cause you to feel dizzy or sleepy
- Alter your balance
- Cause you to take risks that can lead to falls.

National Institutes of Health
Osteoporosis and Related Bone
Diseases~National Resource Center
2 AMS Circle
Bethesda, MD 20892–3676

Phone: 202–223–0344;
1–800–624–BONE (free of charge)
TTY: 202–466–4315
Fax: 202–293–2356
E-mail: NIAMSBoneInfo@mail.nih.gov
www.niams.nih.gov/bone

The NIH Osteoporosis and Related Bone Diseases~National Resource Center is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases with contributions from the National Institute of Child Health and Human Development, National Institute of Dental and Craniofacial Research, National Institute of Diabetes and Digestive and Kidney Diseases, NIH Office of Research on Women's Health, DHHS Office on Women's Health, and the National Institute on Aging.

The National Institutes of Health (NIH) is a component of the U.S. Department of Health and Human Services.

July 2006

## How Can I Prevent Falling?

At any age, people can make changes to lower their risk of falling. Some tips to help prevent falls outdoors are:

- Use a cane or walker
- Wear rubber-soled shoes so you don't slip
- Walk on grass when sidewalks are slick
- Put salt or kitty litter on icy sidewalks.

Some ways to help prevent falls indoors are:

- Keep rooms free of clutter, especially on floors
- Use plastic or carpet runners
- Wear low-heeled shoes
- Do not walk in socks, stockings, or slippers
- Be sure rugs have skid-proof backs or are tacked to the floor
- Be sure stairs are well lit and have rails on both sides
- Put grab bars on bathroom walls near tub, shower, and toilet
- Use a nonskid bath mat in the shower or tub
- Keep a flashlight next to your bed
- Use a sturdy stepstool with a handrail and wide steps
- Add more lights in rooms
- Buy a cordless phone so that you don't have to rush to the phone when it rings and so that you can call for help if you fall.

You can also do exercises to improve your balance. While holding the back of a chair, sink, or counter:

- Stand on one leg at a time for a minute and then slowly increase the time. Try to balance with your eyes closed or without holding on.
- Stand on your toes for a count of 10, and then rock back on your heels for a count of 10.
- Make a big circle to the left with your hips, and then to the right. Do not move your shoulders or feet. Repeat five times.

## How Can I Prevent Broken Bones if I Fall?

Sometimes you cannot prevent a fall. If you do fall, you can try to prevent breaking a bone. Try to fall forwards or backwards (on your buttocks), because if you fall to the side you may break your hip. You can also use your hands or grab things around you to break a fall. Some people wear extra clothes to pad their hips or use special hip pads.

## How Can I Keep My Bones Healthy?

Some ways to protect your bones are:

- Get 1,000 to 1,200 mg of calcium each day
- Get 200 to 600 IU of vitamin D each day
- Walk, climb stairs, lift weights, or dance each day
- Talk with your doctor about having a bone mineral density (BMD) test
- Talk with your doctor about taking medicine to make your bones stronger.

**Daily Need for Calcium and Vitamin D**

| Age | Calcium | Vitamin D |
|---|---|---|
| 19 to 30 years | 1,000 mg | 200 IU |
| 31 to 50 years | 1,000 mg | 200 IU |
| 51 to 70 years | 1,200 mg | 400 IU |
| Over 70 years | 1,200 mg | 600 IU |
| Safe Upper Limit | 2,500 mg | 2,000 IU |

*Source: National Academy of Sciences, 1997*

## For More Information on Preventing Falls and Other Related Conditions:

**NIH Osteoporosis and Related Bone Diseases~National Resource Center**
2 AMS Circle
Bethesda, MD 20892–3676
Phone: 202–223–0344 or
800–624–BONE (624–2663) (free of charge)
TTY: 202–466–4315
Fax: 202–293–2356
E-mail: NIAMSBoneInfo@mail.nih.gov
www.niams.nih.gov/bone

**National Institute on Aging (NIA)**
Building 31, Room 5C27
31 Center Drive, MSC 2292
Bethesda, MD 20892
Phone: 301–496–1752 or
800–222–2225 (free of charge)
TTY: 800–222–4225
Fax: 301–496–1072
E-mail: niainfo@nia.nih.gov
www.nia.nih.gov

For the NIA publication on fall prevention, go to: www.niapublications.org/agepages/falls.asp on the Web.

The NIH Osteoporosis and Related Bone Diseases~National Resource Center acknowledges the assistance of the National Osteoporosis Foundation in the preparation of this publication.

## For Your Information

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration at 1–888–INFO–FDA (1–888–463–6332, a toll-free call) or visit their Web site at www.fda.gov.

**Vial of Life**

See Refrigerator
Door for medical
Information

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# Vial of Life Project

A Public Charity

Sponsored by **American Senior Safety Agency 888-473-2800**

VIALOFLIFE.COM 1-888-724-1200

American Senior Safety Agency - Medical Alarms 1-888-473-2800

Date Completed

FIRST NAME

INITIAL

LAST NAME

STREET

CITY

STATE

ZIP

SOCIAL SECURITY NUMBER

TELEPHONE

DATE OF BIRTH

MALE/FEMALE

HEIGHT

WEIGHT

HAIR COLOR

EYE COLOR

BLOOD TYPE

RELIGION

Tell us about your hearing

Tell us about your vision

DENTURES UPPER LOWER

UNABLE TO SPEAK ☐

NATIVE LANGUAGE IF NOT ENGLISH

Identifying Marks

Past Medical Conditions

Current Medical Conditions

Medications: Dosage and Frequency

Allergies to Medications

Doctors Name and Telephone Number

Last Hospitalization

## 1. Fill out the Vial of Life form

- Fill out the vial form located on reverse side. Answer all or any pertinent questions.
- Make blank copies of this form to keep information current or go to www.vialoflife.com to maintain and store updated information.

## 2. Place decal on front of a plastic baggie

- Place filled out vial form in the plastic baggie.

  You may also consider placing the following items in the baggie.

  - Copy of EKG
  - Living Will or equivalent
  - DNR (Do Not Resuscitate)
  - Recent picture of self

## 3. Place the baggie on your refrigerator door

- Securely tape plastic baggie to front of refrigerator door.
- Place plastic baggie at eye level so that anyone responding to a medical emergency can find complete medical information.

## 4. Place the second decal on your front door

- Place second decal on the front door or window for easy visiblity by anyone responding to a medical emergency..

**For convenience maintain this information at www.VialofLife.com**

Date Completed ____________

# VIALOFLIFE.com

**1-888-724-1200**

| | | | | |
|---|---|---|---|---|
| FIRST NAME | INITIAL | LAST NAME | | SOCIAL SECURITY NUMBER |
| STREET | CITY | STATE | ZIP | TELEPHONE |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| DATE OF BIRTH | MALE/FEMALE | HEIGHT | WEIGHT | HAIR COLOR | EYE COLOR | BLOOD TYPE | RELIGION |

| | | |
|---|---|---|
| List hearing difficulties | DENTURES<br>UPPER LOWER | UNABLE TO SPEAK<br>☐ |
| List vision difficulties | NATIVE LANGUAGE IF NOT ENGLISH | |

**Identifying Marks**

**Current Medical Conditions**

**Past Medical Conditions**

**Current Medications: Dosage and Frequency**

**Allergies to Medications**

**Doctors Name and Telephone Number**

**Last Hospitalization**

**Special Instructions such as health directives, etc...**

**Health Insurance Policy**

**Emergency Contact Notification - Name - Address - Phone - Relationship**

**PLACE ON REFRIGERATOR DOOR - PLEASE PRINT CLEARLY**

# Fact Sheet: Taking Care of YOU: Self-Care for Family Caregivers

## First, Care for Yourself

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When *your* needs are taken care of, the person you care for will benefit, too.

## Effects of Caregiving on Health and Well Being

We hear this often: "My husband is the person with Alzheimer's, but now I'm the one in the hospital!" Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and well being. For example, if you are a caregiving spouse between the ages of 66 and 96 and are experiencing mental or emotional strain, you have a risk of dying that is 63 percent higher than that of people your age who are not caregivers.[1] The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death.

Older caregivers are not the only ones who put their health and well being at risk. If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and raising adolescent children, you face an increased risk for depression, chronic illness and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than noncaregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- sleep deprivation
- poor eating habits
- failure to exercise
- failure to stay in bed when ill
- postponement of or failure to make medical appointments.

Family caregivers are also at increased risk for excessive use of alcohol, tobacco and other drugs and for depression. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

## Taking Responsibility for Your Own Care

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well being and to get your own needs met.

## Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, "What good will I be to the person I care for if I become ill? If I die?" Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done—regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. For example,

- Do you feel you have to prove that you are worthy of the care recipient's affection?
- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help? Why?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care. Here are some of the most commonly expressed:

- I am responsible for my parent's health.
- If I don't do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.

"I never do anything right," or "There's no way I could find the time to exercise" are examples of negative "self-talk," another possible barrier that can cause unnecessary anxiety. Instead, try positive statements: "I'm good at giving John a bath." "I can exercise for 15 minutes a day." Remember, your mind believes what you tell it.

Because we base our behavior on our thoughts and beliefs, attitudes and misconceptions like those noted above can cause caregivers to continually attempt to do what cannot be done, to control what cannot be controlled. The result is feelings of continued failure and frustration and, often, an inclination to ignore your own needs. Ask yourself what might be getting in your way and keeping you from taking care of yourself.

## Moving Forward

Once you've started to identify any personal barriers to good self-care, you can begin to change your behavior, moving forward one small step at a time. Following are some effective tools for self-care that can start you on your way.

### Tool #1: Reducing Personal Stress

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress you feel is not only the result of your caregiving situation but also the result of your perception of it—whether you see the glass as half-full or half-empty. It is important to remember that you are not alone in your experiences.
Your level of stress is influenced by many factors, including the following:

- Whether your caregiving is voluntary. If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress, and resentment.
- Your relationship with the care recipient. Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- Your coping abilities. How you coped with stress in the past predicts how you will cope now. Identify your current coping strengths so that you can build on them.
- Your caregiving situation. Some caregiving situations are more stressful than others. For example, caring for a person with dementia is often more stressful than caring for someone with a physical limitation.
- Whether support is available.

### Steps to Managing Stress

1. *Recognize warning signs early*. These might include irritability, sleep problems, and forgetfulness. Know your own warning signs, and act to make changes. Don't wait until you are overwhelmed.
2. *Identify sources of stress*. Ask yourself, "What is causing stress for me?" Sources of stress might be too much to do, family disagreements, feelings of inadequacy, inability to say no.
3. *Identify what you can and cannot change*. Remember, we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration. Ask yourself, "What do I have some control over? What can I change?" Even a small

change can make a big difference. The challenge we face as caregivers is well expressed in words from the Serenity Prayer:

*…Grant me the serenity to*
*Accept the things I cannot change,*
*Courage to change the things I can,*
*And the wisdom to know the difference.*

4. *Take action*. Taking some action to reduce stress gives us back a sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation, having coffee with a friend. Identify some stress reducers that work for you.

**Tool #2: Setting Goals**

Setting goals or deciding what you would like to accomplish in the next three to six months is an important tool for taking care of yourself. Here are some sample goals you might set:

- Take a break from caregiving.
- Get help with caregiving tasks like bathing and preparing meals.
- Feel more healthy.

Goals are generally too big to work on all at once. We are more likely to reach a goal if we break it down into smaller action steps. Once you've set a goal, ask yourself, "What steps do I take to reach my goal?" Make an action plan by deciding which step you will take first, and when. Then get started!

**Example: Goal and Action Steps**

*Goal*: Feel more healthy.
*Possible action steps:*

1. Make an appointment for a physical check-up.
2. Take a half-hour break once during the week.
3. Walk three times a week for 10 minutes.

**Tool #3: Seeking Solutions**

Seeking solutions to difficult situations is, of course, one of the most important tools in caregiving. Once you've identified a problem, taking action to solve it can change the situation and also change your attitude to a more positive one, giving you more confidence in your abilities.

**Steps for Seeking Solutions**

1. *Identify the problem*. Look at the situation with an open mind. The real problem might not be what first comes to mind. For example, you think that the problem is simply that you are tired all the time, when the more basic difficulty is your belief that "no one can care for John like I can." The problem? Thinking that you have to do everything yourself.
2. *List possible solutions*. One idea is to try a different perspective: "Even though someone else provides help to John in a different way than I do, it can be just as good." Ask a friend to help. Call Family Caregiver Alliance or the Eldercare Locator (see Resources List) and ask about agencies in your area that could help provide care.
3. *Select one solution from the list*. Then try it!
4. *Evaluate the results*. Ask yourself how well your choice worked.
5. *Try a second solution*. If your first idea didn't work, select another. But don't give up on the first; sometimes an idea just needs fine tuning.
6. *Use other resources*. Ask friends, family members and professionals for suggestions.
7. *If nothing seems to help, accept that the problem may not be solvable now.* You can revisit it at another time.

***Note***: All too often, we jump from step one to step seven and then feel defeated and stuck. Concentrate on keeping an open mind while listing and experimenting with possible solutions

**Tool #4: Communicating Constructively**
Being able to communicate constructively is one of a caregiver's most important tools. When you communicate in ways that are clear, assertive and constructive, you will be heard and get the help and support you need. The box below shows basic guidelines for good communication.

**Communication Guidelines**
- *Use "I" messages rather than "you" messages*. Saying "I feel angry" rather than "You made me angry" enables you to express your feelings without blaming others or causing them to become defensive.
- *Respect the rights and feelings of others*. Do not say something that will violate another person's rights or intentionally hurt the person's feelings. Recognize that the other person has the right to express feelings.
- *Be clear and specific*. Speak directly to the person. Don't hint or hope the person will guess what you need. Other people are not mind readers. When you speak directly about what you need or feel, you are taking the risk that the other person might disagree or say no to your request, but that action also shows respect for the other person's opinion. When both parties speak directly, the chances of reaching understanding are greater.
- *Be a good listener*. Listening is the most important aspect of communication.

**Tool #5: Asking for and Accepting Help**
When people have asked if they can be of help to you, how often have you replied, "Thank you, but I'm fine." Many caregivers don't know how to marshal the goodwill of others and are reluctant to ask for help. You may not wish to "burden" others or admit that you can't handle everything yourself.

Be prepared with a mental list of ways that others could help you. For example, someone could take the person you care for on a 15-minute walk a couple of times a week. Your neighbor could pick up a few things for you at the grocery store. A relative could fill out some insurance papers. When you break down the jobs into very simple tasks, it is easier for people to help. And they do want to help. It is up to you to tell them how.

Help can come from community resources, family, friends and professionals. Ask them. Don't wait until you are overwhelmed and exhausted or your health fails. Reaching out for help when you need it is a sign of personal strength.

**Tips on How to Ask**
- *Consider the person's special abilities and interests*. If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.
- *Resist asking the same person repeatedly*. Do you keep asking the same person because she has trouble saying no?
- *Pick the best time to make a request*. Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time.
- *Prepare a list of things that need doing*. The list might include errands, yard work, a visit with your loved one. Let the "helper" choose what she would like to do.
- *Be prepared for hesitance or refusal*. It can be upsetting for the caregiver when a person is unable or unwilling to help. But in the long run, it would do more harm to the relationship if the person helps only because he doesn't want to upset you. To the person who seems hesitant, simply say, "Why don't you think about it." Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.
- *Avoid weakening your request*. "It's only a thought, but would you consider staying with Grandma while I went to church?" This request sounds like it's not very important to you. Use "I" statements to make specific requests: "I would like to go to church on Sunday. Would you stay with Grandma from 9 a.m. until noon?"

**Tool #6: Talking to the Physician**

In addition to taking on the household chores, shopping, transportation, and personal care, 37 percent of caregivers also administer medications, injections, and medical treatment to the person for whom they care. Some 77 percent of those caregivers report the need to ask for advice about the medications and medical treatments. The person they usually turn to is their physician.

But while caregivers will discuss their loved one's care with the physician, caregivers seldom talk about their own health, which is equally important. Building a partnership with a physician that addresses the health needs of the care recipient *and* the caregiver is crucial. The responsibility of this partnership ideally is shared between you the caregiver, the physician, and other healthcare staff. However, it will often fall to you to be assertive, using good communication skills, to ensure that everyone's needs are met—including your own.

**Tips on Communicating with Your Physician**

- *Prepare questions ahead of time*. Make a list of your most important concerns and problems. Issues you might want to discuss with the physician are changes in symptoms, medications or general health of the care recipient, your own comfort in your caregiving situation, or specific help you need to provide care.
- *Enlist the help of the nurse*. Many caregiving questions relate more to nursing than to medicine. In particular, the nurse can answer questions about various tests and examinations, preparing for surgical procedures, providing personal care, and managing medications at home.
- *Make sure your appointment meets your needs*. For example, the first appointment in the morning or after lunch and the last appointment in the day are the best times to reduce your waiting time or accommodate numerous questions. When you schedule your appointment, be sure you convey clearly the reasons for your visit so that enough time is allowed.
- *Call ahead*. Before the appointment, check to see if the doctor is on schedule. Remind the receptionist of special needs when you arrive at the office.
- *Take someone with you*. A companion can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said.
- *Use assertive communication and "I" messages*. Enlist the medical care team as partners in care. Present what you need, what your concerns are, and how the doctor and/or nurse can help. Use specific, clear "I" statements like the following: "I need to know more about the diagnosis; I will feel better prepared for the future if I know what's in store for me." Or "I am feeling rundown. I'd like to make an appointment for myself and my husband next week."

**Tool #7: Starting to Exercise**

You may be reluctant to start exercising, even though you've heard it's one of the healthiest things you can do. Perhaps you think that physical exercise might harm you or that it is only for people who are young and able to do things like jogging. Fortunately, research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities like walking and gardening. Even household chores can improve your health. The key is to increase your physical activity by exercising and using your own muscle power.

Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity. Perhaps the care recipient can walk or do stretching exercise with you. If necessary, do frequent short exercises instead of those that require large blocks of time. Find activities you enjoy.

Walking, one of the best and easiest exercises, is a great way to get started. Besides its physical benefits, walking helps to reduce psychological tension. Walking 20 minutes a day, three times a week, is very beneficial. If you can't get away for that long, try to walk for as long as you can on however many days you can. Work walking into your life. Walk around the mall, to the store or a nearby park. Walk around the block with a friend.

**Tool #8: Learning from Our Emotions**
It is a strength to recognize when your emotions are controlling you (instead of you controlling your emotions). Our emotions are messages we need to listen to.

They exist for a reason. However negative or painful, our feelings are useful tools for understanding what is happening to us.

Even feelings such as guilt, anger and resentment contain important messages. Learn from them, then take appropriate action.

For example, when you cannot enjoy activities you previously enjoyed, and your emotional pain over-shadows all pleasure, it is time to seek treatment for depression—especially if you are having thoughts of suicide. Speaking with your physician is the first step. (Please refer to the Fact Sheet on Caregiving and Depression, listed below.)

Caregiving often involves a range of emotions. Some feelings are more comfortable than others. When you find that your emotions are intense, they might mean the following:

- That you need to make a change in your caregiving situation.
- That you are grieving a loss.
- That you are experiencing increased stress.
- That you need to be assertive and ask for what you need.

**Summing Up**
Remember, it is not selfish to focus on your own needs and desires when you are a caregiver—it's an important part of the job. You are responsible for your own self-care. Focus on the following self-care practices:

- Learn and use stress-reduction techniques.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to a trusted counselor or friend.
- Identify and acknowledge your feelings.
- Change the negative ways you view situations.
- Set goals.

It's up to you!

## Credits

1 Shultz, Richard and Beach, Scott (1999). *Caregiving as A Risk for Mortality: The Caregiver Health Effects Study*. JAMA, December 15, 1999 - Vol. 282, No.23

A special thank you to Legacy Caregiver Services, Legacy Health System, Portland, OR., for permission to use information from *The Caregiver Helpbook: Powerful Tools for Caregiving* and the *Powerful Tools for Caregivers Class Leaders Guide.*

*The Caregiver Helpbook*, written by Vicki Schmall, Ph.D., Marilyn Cleland, R.N. and Marilynn Sturdevant, RN, MSW, LCSW, (2000) is highly recommended reading for caregivers. The book can be ordered directly from Legacy Health Systems, (530) 413–6578. caregiver@lhs.org or www.legacyhealth.org

## For More Information

**Family Caregiver Alliance**
**National Center on Caregiving**
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434–3388
(800) 445–8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating disorders that strike adults.

Family Caregiver Alliance Fact Sheet on Caregiving and Depression
**Family Caregiver Alliance Fact Sheet on Dementia, Caregiving and Controlling Frustration**
**Because We Care: A Guide for People Who Care**

**Administration on Aging**
Washington, DC 20201
Phone: (202) 619–0724
www.aoa.gov

**Area Agency on Aging**
For caregiver support groups, respite providers, and other caregiving services. Eldercare Locator:
(800) 677–1116
www.eldercare.gov

**ARCH National Respite Network and Resource Center**
Call to find local respite providers.
(800) 473–1727
www.chtop.com/ARCH

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FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

# Fact Sheet: Caregiver's Guide to Understanding Dementia Behaviors

Caring for a loved one with dementia poses many challenges for families and caregivers. People with dementia from conditions such as Alzheimer’s and related diseases have a progressive *brain* disorder that makes it more and more difficult for them to remember things, think clearly, communicate with others, or take care of themselves. In addition, dementia can cause mood swings and even change a person’s personality and behavior. This Fact Sheet provides some practical strategies for dealing with the troubling behavior problems and communication difficulties often encountered when caring for a person with dementia.

## Ten Tips for Communicating with a Person with Dementia

We aren’t born knowing how to communicate with a person with dementia—but we can learn. Improving your communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness.

1. **Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.

2. **Get the person’s attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have her attention; address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.

3. **State your message clearly.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If she doesn’t understand the first time, use the same wording to repeat your message or question. If she still doesn’t understand, wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns or abbreviations.

4. **Ask simple, answerable questions.** Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, *“Would you like to wear your white shirt or your blue shirt?”* Better still, show her the choices—visual prompts and cues also help clarify your question and can guide her response.

5. **Listen with your ears, eyes and heart.** Be patient in waiting for your loved one’s reply. If she is struggling for an answer, it’s okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately. *Always strive to listen for the meaning and feelings that underlie the words.*

6. **Break down activities into a series of steps.** This makes many tasks much more manageable. You can encourage your loved one to do what he can, gently remind him of steps he tends to forget, and assist with steps he’s no longer able to accomplish on his own. Using visual cues, such as showing him with your hand where to place the dinner plate, can be very helpful.

7. **When the going gets tough, distract and redirect.** When your loved one becomes upset, try changing the subject or the environment. For example, ask him for help or suggest going for a walk. *It is important to connect with the person on a feeling level, before you redirect.* You might say, *“I see you’re feeling sad—I’m sorry you’re upset. Let’s go get something to eat.”*

**8. Respond with affection and reassurance.** People with dementia often feel confused, anxious and unsure of themselves. Further, they often get reality confused and may recall things that never really occurred. *Avoid trying to convince them they are wrong.* Stay focused on the feelings they are demonstrating (which are real) and respond with verbal and physical expressions of comfort, support and reassurance. Sometimes holding hands, touching, hugging and praise will get the person to respond when all else fails.

**9. Remember the good old days.** Remembering the past is often a soothing and affirming activity. Many people with dementia may not remember what happened 45 minutes ago, but they can clearly recall their lives 45 years earlier. Therefore, *avoid asking questions that rely on short-term memory*, such as asking the person what they had for lunch. Instead, try asking general questions about the person's distant past—this information is more likely to be retained.

**10. Maintain your sense of humor.** *Use humor whenever possible, though not at the person's expense.* People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

## Handling Troubling Behavior

Some of the greatest challenges of caring for a loved one with dementia are the personality and behavior changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. It also helps to not take things personally and maintain your sense of humor.

To start, consider these ground rules:
**We cannot change the person.** The person you are caring for has a brain disorder that shapes who he has become. When you try to control or change his behavior, you'll most likely be unsuccessful or be met with resistance. It's important to:

- *Try to accommodate the behavior, not control the behavior.* For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.
- *Remember that we **can** change our behavior or the physical environment.* Changing our own behavior will often result in a change in our loved one's behavior.

**Check with the doctor first.** Behavioral problems may have an underlying medical reason: perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem.

**Behavior has a purpose.** People with dementia typically cannot tell us what they want or need. They might do something, like take all the clothes out of the closet on a daily basis, and we wonder why. It is very likely that the person is fulfilling a need to be busy and productive. *Always consider what need the person might be trying to meet with their behavior—and, when possible, try to accommodate them.*

**Behavior is triggered.** It is important to understand that all behavior is triggered—it doesn't occur out of the blue. It might be something a person did or said that triggered a behavior or it could be a change in the physical environment. *The root to changing behavior is disrupting the patterns that we create.* Try a different approach, or try a different consequence.

**What works today, may not tomorrow.** The multiple factors that influence troubling behaviors and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all. The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

**Get support from others.** You are not alone—there are many others caring for someone with dementia. Call your local Area Agency on Aging, the local chapter of the Alzheimer's Association, a Caregiver Resource Center or one of the groups listed below in *Resources* to find support groups, organizations and services that can help you. Expect that, like the loved one you are caring for, you will have good days and bad days. Develop strategies for coping with the bad days (see the FCA Fact Sheet, *Dementia, Caregiving and Controlling Frustration*).

The following is an overview of the most common dementia-associated behaviors with suggestions that may be useful in handling them. You'll find additional resources listed at the end of this Fact Sheet.

## Wandering

People with dementia walk, seemingly aimlessly, for a variety of reasons, such as boredom, medication side effects or to look for "something" or someone. They also may be trying to fulfill a physical need—thirst, hunger, a need to use the toilet or exercise. Discovering the triggers for wandering are not always easy, but they can provide insights to dealing with the behavior.

- Make time for regular exercise to minimize restlessness.
- Consider installing new locks that require a key. Position locks high or low on the door; many people with dementia will not think to look beyond eye level. Keep in mind fire and safety concerns for all family members; the lock(s) must be accessible to others and not take more than a few seconds to open.
- Try a barrier like a curtain or colored streamer to mask the door. A "*stop*" sign or "*do not enter*" sign also may help.
- Place a black mat or paint a black space on your front porch; this may appear to be an impassable hole to the person with dementia.
- Add "child-safe" plastic covers to doorknobs.
- Consider installing a home security system or monitoring system designed to keep watch over someone with dementia. Also available are new digital devices that can be worn like a watch or clipped on a belt that use global positioning systems (GPS) or other technology to track a person's whereabouts or locate him if he wanders off..
- Put away essential items such as the confused person's coat, purse or glasses. Some individuals will not go out without certain articles.
- Have your relative wear an ID bracelet and sew ID labels in their clothes. Always have a current photo available should you need to report your loved one missing. Consider leaving a copy on file at the police department or registering the person with the Alzheimer's Association Safe Return program (see *Resources*).
- Tell neighbors about your relative's wandering behavior and make sure they have your phone number.

## Incontinence

The loss of bladder or bowel control often occurs as dementia progresses. Sometimes accidents result from environmental factors; for example, someone can't remember where the bathroom is located or can't get to it in time. If an accident occurs, your understanding and reassurance will help the person maintain dignity and minimize embarrassment.

- Establish a routine for using the toilet. Try reminding the person or assisting her to the bathroom every two hours.
- Schedule fluid intake to ensure the confused person does not become dehydrated. However, avoid drinks with a diuretic effect like coffee, tea, cola, or beer. Limit fluid intake in the evening before bedtime.
- Use signs (with illustrations) to indicate which door leads to the bathroom.
- A commode, obtained at any medical supply store, can be left in the bedroom at night for easy access.
- Incontinence pads and products can be purchased at the pharmacy or supermarket. A urologist may be able to prescribe a special product or treatment.
- Use easy-to-remove clothing with elastic waistbands or Velcro$^{\text{Ò}}$ closures, and provide clothes that are easily washable.

## Agitation

Agitation refers to a range of behaviors associated with dementia, including irritability, sleeplessness, and verbal or physical aggression. Often these types of behavior problems progress with the stages of dementia, from mild to more severe. Agitation may be triggered by a variety of things, including environmental factors, fear and fatigue. Most often, agitation is triggered when the person experiences “control” being taken from him.

- Reduce caffeine intake, sugar and junk food.
- Reduce noise, clutter or the number of persons in the room.
- Maintain structure by keeping the same routines. Keep household objects and furniture in the same places. Familiar objects and photographs offer a sense of security and can suggest pleasant memories.
- Try gentle touch, soothing music, reading or walks to quell agitation. Speak in a reassuring voice. Do not try to restrain the person during a period of agitation.
- Keep dangerous objects out of reach.
- Allow the person to do as much for himself as possible—support his independence and ability to care for himself.
- Acknowledge the confused person’s anger over the loss of control in his life. Tell him you understand his frustration.
- Distract the person with a snack or an activity. Allow him to forget the troubling incident. Confronting a confused person may increase anxiety.

## Repetitive Speech or Actions (perseveration)

People with dementia will often repeat a word, statement, question or activity over and over. While this type of behavior is usually harmless for the person with dementia, it can be annoying and stressful to caregivers. Sometimes the behavior is triggered by anxiety, boredom, fear or environmental factors.

- Provide plenty of reassurance and comfort, both in words and in touch.
- Try distracting with a snack or activity.
- Avoid reminding them that they just asked the same question. Try ignoring the behavior or question and distract the person into an activity.
- Don’t discuss plans with a confused person until immediately prior to an event.
- You may want to try placing a sign on the kitchen table, such as, “*Dinner is at 6:30*” or “*Lois comes home at 5:00*” to remove anxiety and uncertainty about anticipated events.
- Learn to recognize certain behaviors. An agitated state or pulling at clothing, for example, could indicate a need to use the bathroom.

## Paranoia

Seeing a loved one suddenly become suspicious, jealous or accusatory is unsettling. Remember, what the person is experiencing is very real to them. It is best not to argue or disagree. This, too, is part of the dementia—try not to take it personally.

- If the confused person suspects money is “missing,” allow her to keep small amounts of money in a pocket or handbag for easy inspection.
- Help them look for the object and then distract them into another activity. Try to learn where the confused person’s favorite hiding places are for storing objects, which are frequently assumed to be “lost.” Avoid arguing.
- Take time to explain to other family members and home-helpers that suspicious accusations are a part of the dementing illness.
- Try nonverbal reassurances like a gentle touch or hug. Respond to the feeling behind the accusation and then reassure the person. You might try saying, “I see this frightens you; stay with me, I won’t let anything happen to you.”

## Sleeplessness/Sundowning

Restlessness, agitation, disorientation and other troubling behavior in people with dementia often get worse at the end of the day and sometimes continue throughout the night. Experts believe this behavior, commonly called *sundowning,* is caused by a combination of factors, such as exhaustion from the day's events and changes in the person's biological clock that confuse day and night.

- Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.
- Watch out for dietary culprits, such as sugar, caffeine and some types of junk food. Eliminate or restrict these types of foods and beverages to early in the day. Plan smaller meals throughout the day, including a light meal, such as half a sandwich, before bedtime.
- Plan for the afternoon and evening hours to be quiet and calm; however, *structured, quiet activity is important*. Perhaps take a stroll outdoors, play a simple card game or listen to soothing music together.
- Turning on lights well before sunset and closing the curtains at dusk will minimize shadows and may help diminish confusion. At minimum, keep a nightlight in the person's room, hallway and bathroom.
- Make sure the house is safe: block off stairs with gates, lock the kitchen door and/or put away dangerous items.
- As a last resort, consider talking to the doctor about medication to help the agitated person relax and sleep. Be aware that sleeping pills and tranquilizers may solve one problem and create another, such as sleeping at night but being more confused the next day.
- It's essential that you, the caregiver, get enough sleep. If your loved one's nighttime activity keeps you awake, consider asking a friend or relative, or hiring someone, to take a turn so that you can get a good night's sleep. Catnaps during the day also might help.

## Eating/Nutrition

Ensuring that your loved one is eating enough nutritious foods and drinking enough fluids is a challenge. People with dementia literally begin to forget that they need to eat and drink. Complicating the issue may be dental problems or medications that decrease appetite or make food taste "funny." The consequences of poor nutrition are many, including weight loss, irritability, sleeplessness, bladder or bowel problems and disorientation.

- Make meal and snack times part of the daily routine and schedule them around the same time every day. Instead of three big meals, try five or six smaller ones.
- Make mealtimes a special time. Try flowers or soft music. Turn off loud radio programs and the TV.
- Eating independently should take precedence over eating neatly or with "proper" table manners. Finger foods support independence. Pre-cut and season the food. Try using a straw or a child's "sippy cup" if holding a glass has become difficult. Provide assistance only when necessary and allow plenty of time for meals.
- Sit down and eat with your loved one. Often they will mimic your actions and it makes the meal more pleasant to share it with someone.
- Prepare foods with your loved one in mind. If they have dentures or trouble chewing or swallowing, use soft foods or cut food into bite-size pieces.
- If chewing and swallowing are an issue, try gently moving the person's chin in a chewing motion or lightly stroking their throat to encourage them to swallow.
- If loss of weight is a problem, offer nutritious high-calorie snacks between meals. Breakfast foods high in carbohydrates are often preferred. On the other hand, if the problem is weight gain, keep high-calorie foods out of sight. Instead, keep handy fresh fruits, veggie trays and other healthy low-calorie snacks.

## Bathing

People with dementia often have difficulty remembering "good" hygiene, such as brushing teeth, toileting, bathing and regularly changing their clothes. From childhood we are taught these are highly private and personal activities; to be undressed and cleaned by another can feel frightening, humiliating and embarrassing. As a result, bathing often causes distress for both caregivers and their loved ones.

- Think historically of your loved one's hygiene routine – did she prefer baths or showers? Mornings or nights? Did she have her hair washed at the salon or do it herself? Was there a favorite scent, lotion or talcum powder she always used? Adopting—as much as possible—her past bathing routine may provide some comfort. Remember that it may not be necessary to bathe every day—sometimes twice a week is sufficient.
- If your loved one has always been modest, enhance that feeling by making sure doors and curtains are closed. Whether in the shower or the bath, keep a towel over her front, lifting to wash as needed. Have towels and a robe or her clothes ready when she gets out.
- Be mindful of the environment, such as the temperature of the room and water (older adults are more sensitive to heat and cold) and the adequacy of lighting. It's a good idea to use safety features such as non-slip floor bath mats, grab-bars, and bath or shower seats. A hand-held shower might also be a good feature to install. Remember—people are often afraid of falling. Help them feel secure in the shower or tub.
- Never leave a person with dementia unattended in the bath or shower. Have all the bath things you need laid out beforehand. If giving a bath, draw the bath water first. Reassure the person that the water is warm—perhaps pour a cup of water over her hands before she steps in.
- If hair washing is a struggle, make it a separate activity. Or, use a dry shampoo.
- If bathing in the tub or shower is consistently traumatic, a towel bath provides a soothing alter-native. A *bed* bath has traditionally been done with only the most frail and bed-ridden patients, soaping up a bit at a time in their beds, rinsing off with a basin of water and drying with towels. A growing number of nurses in and out of facilities, however, are beginning to recognize its value and a variation—the "*towel* bath"—for others as well, including people with dementia who find bathing in the tub or shower uncomfortable or unpleasant. The towel bath uses a large bath towel and washcloths dampened in a plastic bag of warm water and no-rinse soap. Large bath-blankets are used to keep the patient covered, dry and warm while the dampened towel and washcloths are massaged over the body. For more information, see the book *Bathing Without a Battle*, (details in the *Recommended Reading* section below), or visit *www.bathingwithoutabattle.unc.edu/main_page.html*.

## Additional Problem Areas

- Dressing is difficult for most dementia patients. Choose loose-fitting, comfortable clothes with easy zippers or snaps and minimal buttons. Reduce the person's choices by removing seldom-worn clothes from the closet. To facilitate dressing and support independence, lay out one article of clothing at a time, in the order it is to be worn. Remove soiled clothes from the room. Don't argue if the person insists on wearing the same thing again.
- Hallucinations (seeing or hearing things that others don't) and delusions (false beliefs, such as someone is trying to hurt or kill another) may occur as the dementia progresses. State simply and calmly your perception of the situation, but avoid arguing or trying to convince the person their perceptions are wrong. Keep rooms well-lit to decrease shadows, and offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard. Distractions may help. Depending on the severity of symptoms, you might consider medication.
- Sexually inappropriate behavior, such as masturbating or undressing in public, lewd remarks, unreasonable sexual demands, even sexually aggressive or violent behavior, may occur during the course of the illness. Remember, this behavior is caused by the disease. Talk to the doctor about possible treatment plans. Develop an action plan to follow before the behavior occurs, i.e., what you will say and do if the behavior happens at home, around other adults or children. If you can, identify what triggers the behavior.

- Verbal outbursts such as cursing, arguing and threatening often are expressions of anger or stress. React by staying calm and reassuring. Validate your loved one's feelings and then try to distract or redirect his attention to something else.
- "Shadowing" is when a person with dementia imitates and follows the caregiver, or constantly talks, asks questions and interrupts. Like sundowning, this behavior often occurs late in the day and can be irritating for caregivers. Comfort the person with verbal and physical reassurance. Distraction or redirection might also help. Giving your loved one a job such as folding laundry might help to make her feel needed and useful.
- People with dementia may become uncooperative and resistant to daily activities such as bathing, dressing and eating. Often this is a response to feeling out of control, rushed, afraid or confused by what you are asking of them. Break each task into steps and, in a reassuring voice, explain each step before you do it. Allow plenty of time. Find ways to have them assist to their ability in the process, or follow with an activity that they can perform.

## Credits and Recommended Reading

***Bathing Without a Battle***, by Ann Louise Barrick, Joanne Rader, Beverly Hoeffer and Philip Sloane, (2002), Springer Publishing, (877) 687–7476.

***Caring for a Person with Memory Loss and Confusion: An Easy Guide for Caregivers,*** (2002), Journeyworks Publishing, Santa Cruz, CA, (800) 775–1998.

***Communicating Effectively with a Person Who Has Alzheimer's,*** (2002), Mayo Clinic Staff, *www.mayoclinic.com/invoke.cfm?id=AZ00004*

***Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease,***(1996), Alzheimer's Association, Chicago, IL, (800) 272–3900.

***Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease,*** (1996), Alzheimer's Association, Chicago, IL, (800) 272–3900.

***The Validation Breakthrough: Simple Techniques for Communicating with People with "Alzheimer's-Type Dementia,"*** Naomi Feil , 2nd Edition 2002, Health Professions Press, Baltimore, MD, (410) 337–8539.

***Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses,*** A. Robinson, B. Spencer, and L.White, (2001), Eastern Michigan University, Ypsilanti, MI, (734) 487–2335.

## For More Information

**Family Caregiver Alliance**
180 Montgomery St., Suite 1100
San Francisco, CA  94104
(415) 434–3388
(800) 445–8106
*www.caregiver.org*
*info@caregiver.org*

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer’s disease, stroke, traumatic brain injury, Parkinson’s and other debilitating health conditions that strike adults.

**FCA Publications**
***Practical Skills Training for Family Caregivers,*** Mary A. Corcoran, 2003, Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, CA 94104, (800) 445–8106. *www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=954*
**FCA Fact Sheets.** All Family Caregiver Alliance Fact Sheets are available free online. Printed versions are $1.00 for each title—send your requests to FCA Publications, 180 Montgomery St., Suite 1100, San Francisco, CA 94104. For the full list, see: *www.caregiver.org/caregiver/jsp/publications.jsp?nodeid=345*
***FCA Fact Sheet:*** ***Dementia, Caregiving and Controlling Frustration***
***FCA Fact Sheet:*** ***Taking Care of YOU: Self-Care for Family Caregivers***
***FCA Fact Sheet:*** ***Hiring In-Home Help***
***FCA Fact Sheet:*** ***Community Care Options***

**Other Web Sites**
**Alzheimer's Disease Education and Referral (ADEAR) Center**
(800) 438-4380
*www.alzheimers.org*
This service of the National Institute on Aging offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and research related to Alzheimer’s disease.

**Eldercare Locator**
(800) 677–1116
*www.eldercare.gov*
This service of the Administration on Aging offers information about and referrals to respite care and other home and community services offered by state and Area Agencies on Aging.

**Alzheimer’s Association Safe Return Program**
(800) 272–3900
*www.alz.org/SafeReturn*
A nationwide program that identifies people with dementia who wander away and returns them to their homes. For a $40 registration fee, families can register their loved one in a national confidential computer database. They also receive an identification bracelet or necklace and other identification and educational materials.

This fact sheet was prepared by Family Caregiver Alliance in cooperation with California’s statewide system of Caregiver Resource Centers. Reviewed by Beth Logan, M.S.W., Education and Training Consultant and Specialist in Dementia Care. Funded by the California Department of Mental Health. © 2004 Family Caregiver Alliance. All rights reserved. FS-CGTU20050610.

# Fact Sheet: Dementia, Caregiving and Controlling Frustration

## The Stresses of Caregiving

Caring for an individual with Alzheimer's disease or a related dementia can be challenging and, at times, overwhelming. Frustration is a normal and valid emotional response to many of the difficulties of being a caregiver. While some irritation may be part of everyday life as a caregiver, feeling extreme frustration can have serious consequences for you or the person you care for. Frustration and stress may negatively impact your physical health or cause you to be physically or verbally aggressive towards your loved one. If your caregiving situation is causing you extreme frustration or anger, you may want to explore some new techniques for coping.

When you are frustrated, it is important to distinguish between *what is and what is not within your power to change.* Frustration often arises out of trying to change an uncontrollable circumstance. As a caregiver of someone with dementia, you face many uncontrollable situations. Normal daily activities—dressing, bathing and eating—may become sources of deep frustration for you. Behaviors often associated with dementia, like wandering or asking questions repeatedly, can be frustrating for caregivers but are uncontrollable behaviors for people with dementia. Unfortunately, you cannot simply change the behavior of a person suffering from dementia.

When dealing with an uncontrollable circumstance, you do control one thing: *how you respond to that circumstance*.

In order to respond without extreme frustration, you will need to:

- learn to recognize the warnings signs of frustration;
- intervene to calm yourself down physically;
- modify your thoughts in a way that reduces your stress;
- learn to communicate assertively;
- learn to ask for help.

## Warning Signs of Frustration

If you can recognize the warning signs of frustration, you can intervene and adjust your mood before you lose control. Some of the common warning signs of frustration include:

- shortness of breath
- knot in the throat
- stomach cramps
- chest pains
- headache
- compulsive eating
- excessive alcohol consumption
- increased smoking
- lack of patience
- desire to strike out

## Calming Down Physically

When you become aware of the warning signs of frustration, you can intervene with an immediate activity to help you calm down. This gives you time to look at the situation more objectively and to choose how to respond in a more controlled way.

When you feel yourself becoming frustrated, try counting from one to ten slowly and taking a few deep breaths. If you are able, take a brief walk or go to another room and collect your thoughts. It is better to leave the situation, even for a moment, than to lose control or react in a way you will regret. If you think someone may be offended when you leave the room, you can tell that person you need to go to the restroom. You can also try calling a friend, praying, meditating, singing, listening to music or taking a bath. Try experimenting with different responses to find out what works best for you and the person you care for.

The regular practice of relaxation techniques can also help prepare you for frustrating circumstances. If possible, try the following relaxation exercise for at least ten minutes each day:

Sit in a comfortable position in a quiet place. Take slow, deep breaths and relax the tension in your body. While you continue to take slow, deep breaths, you may want to imagine a safe and restful place and repeat a calming word or phrase.

## Modifying Your Thoughts

As you take time out to collect your thoughts, try rethinking your situation in ways that reduce frustration. How you think often affects how you feel. Of course, feelings of frustration arise from difficult circumstances. If, however, you analyze your response to a frustrating situation, you will usually find some form of *maladaptive*—or negative—thinking that has the effect of increasing your frustration, preventing you from looking at your situation objectively, or finding a better way to deal with it.

Below are six major types of unhelpful thought patterns common among caregivers. Following each unhelpful thought pattern is an example of an *adaptive*—or more helpful—thought that can be used as self-defense against frustration. Familiarizing yourself with the unhelpful thought patterns and the adaptive responses can help you control your frustration.

*Over-generalization:* You take one negative situation or characteristic and multiply it. For example, you're getting ready to take the person in your care to a doctor's appointment when you discover the car battery has died. You then conclude, "This always happens; something always goes wrong."

Adaptive response: "This does not happen all the time. Usually my car is working just fine. At times things don't happen the way I would like, but sometimes they do."

*Discounting the positive:* You overlook the good things about your circumstances and yourself. For example, you might not allow yourself to feel good about caregiving by thinking, "I could do more" or "anyone could do what I do."

Adaptive response: "Caregiving is not easy. It takes courage, strength, and compassion to do what I do. I am not always perfect, but I do a lot and I am trying to be helpful."

*Jumping to conclusions:* You reach a conclusion without having all the facts. You might do this in two ways:

- *Mindreading*: We assume that others are thinking negative thoughts about us. For example, a friend doesn't return a phone call, and we assume that he or she is ignoring us or doesn't want to talk to us.

  Adaptive response: "I don't know what my friend is thinking. For all I know, she didn't get the message. Maybe she is busy or just forgot. If I want to know what she is thinking, I will have to ask her."

- *Fortune-telling*: You predict a negative outcome in the future. For example, you will not try adult day care because you assume the person in your care will not enjoy it. You think, "He will never do that. Not a chance!"

  Adaptive response: "I cannot predict the future. I don't think he is going to like it, but I won't know for sure unless I try."

*"Should" statements*: You try to motivate yourself using statements such as "I should call mother more often" or "I shouldn't go to a movie because Mom might need me." What you think you "should" do is in conflict with what you want to do. You end up feeling guilty, depressed or frustrated.

Adaptive response: "I would like to go to a movie. It's okay for me to take a break from caregiving and enjoy myself. I will ask a friend or neighbor to check in on Mom."

*Labeling*: You identify yourself or other people with one characteristic or action. For example, you put off doing the laundry and think, "I am lazy."

Adaptive response: "I am not lazy. Sometimes I don't do as much as I could, but that doesn't mean I am lazy. I often work hard and do the best that I can. Even I need a break sometimes."

*Personalizing*: You take responsibility for a negative occurrence that is beyond your control. For example, you might blame yourself when the person in your care requires hospitalization or placement in a facility.

Adaptive response: "Mom's condition has gotten to the point where I can no longer take care of her myself. It is her condition and not my shortcomings that require her to be in a nursing home."

*Using the "Triple-Column Technique":* Unhelpful thought patterns are usually ingrained reactions or habits. To modify your negative thoughts, you will have to learn to recognize them, know why they are false, and talk back to them.

One helpful way to practice using more adaptive thinking processes is to use the "triple-column technique." Draw two lines down the center of a piece of paper to divide the paper into thirds. When you are feeling frustrated, take a personal "time out" and write your negative thoughts in the first column.

In the second column, try to identify the type of unhelpful pattern from the six examples above. In the third column, talk back to your negative thoughts with a more positive point of view. See below for examples.

| Negative Thoughts | Thought Patterns | Adaptive Thoughts |
|---|---|---|
| (Caregiver burns dinner.) "I can't do anything right!" | Over-generalization | I'm not perfect, but nobody is perfect. Sometimes I make mistakes, and sometimes I do things well. |
| (Caregiver has coffee with a friend and spouse has accident at home.) "I'm selfish and rotten! If I had been home, he wouldn't have fallen." | Labeling; personalizing | I'm not selfish or rotten. I do a lot to take care of my husband, but I need to take care of myself as well. He might have fallen even if I had been home. |
| (Brother does not show up to take your Dad to the doctor.) "I knew I couldn't trust him. I should just do it myself next time." | Jumping to conclusions; should statements | I don't know why he didn't come, but I need his help, so we'll have to find ways for him to share the burden of Dad's care. |

## Communicating Assertively

Good communication can reduce frustration by allowing you to express yourself while helping others to understand your limits and needs. *Assertive* communication is different from passive or aggressive communication. When you communicate passively, you may be keeping your own needs and desires inside to avoid conflict with others. While this may seem easier on the surface, the long-term result may be that others feel they can push you around to get their way.

When you communicate aggressively, you may be forcing your needs and desires onto others. While this allows you to express your feelings, aggressive communication generally makes others more defensive and less cooperative.

When you communicate assertively, you express your own needs and desires while respecting the needs and desires of others. Assertive communication allows both parties to engage in a dignified discussion about the issue at hand.

*Keys to assertive communication are:*

- Respecting your own feelings, needs and desires.
- Standing up for your feelings without shaming, degrading or humiliating the other person.
- Using "I" statements rather than "you" statements. For example, say, "I need a break" or "I would like to talk to you and work this out" instead of "You are irresponsible" or "You never help out!"
- Not using "should" statements. For example, say, "It's important to me that promises be kept," instead of "You should keep your promise."

## The Critical Step: Asking for Help

You cannot take on all the responsibilities of caregiving by yourself. It is essential that you ask for and accept help. Discuss your needs with family members and friends who might be willing to share caregiving responsibilities. People will not realize you need help if you do not explain your situation and ask for assistance. Remember, you have the right to ask for help and express your needs.

*When to say Yes*

Don't be afraid to say "Yes" if someone offers to help. Say "Yes" at the moment a person offers to help rather than saying "maybe" and waiting until you are in a fix. Have a list handy of errands or tasks you need help with. Keep in mind that people feel useful and gratified when they are able to help others.

*When to say "No"*

Often, caregivers are pulled in multiple directions. In addition to the demands of caregiving, you may feel compelled to meet the demands of your immediate and extended family, your friends and your employer. Learn how to say "No" to the demands of others when you are overwhelmed or need a break. It is your right to say "No" to extra demands on your time without feeling guilty.

*Learning Effective Communication Techniques for Dementia Caregiving*

Many families find it frustrating to communicate with a loved one who has dementia. The person with dementia may repeat questions over and over or mistake you for someone else. It is important to remember that the person with dementia cannot control behavior caused by their disease. They do not need to be corrected or grounded in "reality." You can distract them or just agree with them as a way to reduce your frustration.

It can be helpful, however, to learn more about dementia and effective communication techniques which will ease your frustration. For example, use simple, direct statements, and place yourself close when speaking to a person with a cognitive disorder. Try not to argue about unimportant things such as what the date is. Allow extra time to accomplish tasks such as dressing. Remember, people with dementia often react more to our feelings than our words. Finding ways to be calm can help you to gain cooperation.

## Self-Care to Prevent Frustration

Caregiving can be tiring and stressful. When you're caring for others, it's easy to forget to care for yourself. While it may be difficult to find time to focus on yourself and your needs, it is very important that you do so to prevent frustration and burnout.

Here are three steps to taking better care of YOU:

### Make Time for Yourself

You may feel guilty about needing or wanting time out for rest, socialization and fun. However, everyone deserves regular and ongoing breaks from work, including caregivers. "Respite" providers can give you the opportunity to take the breaks you need. Respite breaks may be provided by in-home help, adult day care, "friendly visitor" programs, friends and neighbors, or other means. The important point is to allow yourself to take a break from caregiving. See "Resources" at the end of this fact sheet for organizations that might help you give yourself time off from caregiving.

### Take Care of Yourself

Although caregiving may make it difficult to find time for yourself, it is important to eat well, exercise, get a good night's sleep and attend to your own medical needs.

When you do not take care of yourself, you are prone to increased anxiety, depression, frustration and physical distress that will make it more difficult to continue providing care.

**Seek Outside Support**

Sharing your feelings with a counselor, pastor, a support group, or with another caregiver in a similar situation can be a great way to release stress and get helpful advice. You may want to contact the organizations under "Resources" at the end of this Fact Sheet or look in the community services section at the front of the *Yellow Pages*, under "Counseling" or "Senior Services" to find services to help you get some caregiver support.

## Credits

Burns, David D., M.D., (1980, 1999). *Feeling Good: The New Mood Therapy*, Revised and Updated Edition, Avon Books, New York, NY.

Gallagher-Thompson, D., Rose, J., Florsheim, M., Gantz, F., Jacome, P., Del Maestro, S., Peters, L., Arguello, D., Johnson, C., Moorehead, R.S., Polich, T.M., Chesney, M., Thompson, L.W., (1992). *Controlling Your Frustration: A Class for Caregivers*. Palo Alto, CA: Department of Veterans Affairs Medical Center.

Parrish, Monique, L.C.S.W., Dr. PH., (2000). *"Stress: What is it? What can be done about it?" Stress Reduction Instruction Manual,* written for John Muir Mount Diablo Medical Center, Concord, CA.

## For More Information

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Family Caregiver Alliance Fact Sheet on Behavior Management Strategies (Dementia)

Family Caregiver Alliance Fact Sheet on Hiring-In-Home Help

Family Caregiver Alliance Fact Sheet on Taking Care of YOU: Self-Care for Family Caregivers

**Alzheimer's Association**
225 N. Michigan Ave., Ste. 1700
Chicago, IL 60601–7633
(800) 272–3900
www.alz.org

**Eldercare Locator**
Call to find your local Area Agency on Aging and services for the elderly and caregivers, including respite care providers.
(800) 677–1116
www.eldercare.gov

**Faith in Action**
Call to find volunteer caregiving assistance.
(877) 324–8411
www.fiavolunteers.org

**ARCH National Respite Network and Resource Center**
Call to find local respite providers.
(800) 473–1727
www.archrespite.org/index.htm

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**U.S. Department of Health and Human Services**
**Administration on Aging**

# National Family Caregiver Support Program Resources

## Adult Day Services: How Can They Help You?

## Introduction

Adult Day Service centers provide social activities and health care services for adults with physical disabilities or cognitive impairments. People who attend an Adult Day Service center usually live at home or in the home of a family caregiver. Centers usually open early and stay open late during the week to help working caregivers, and some have weekend hours. Adult Day Services can improve the quality of life of those who attend and help each person function at their best. Adult Day Services cost less than in-home care and the intensity of therapeutic activities and social contact is also greater. Plus, caregivers using adult day services feel less depressed and more confident in their role as caregiver.

## Is Adult Day Services For You?

If you answer “yes” to any of the following questions, adult day services will benefit both you and your loved one.

- Do you worry about your loved one’s safety at home alone?
- Do you worry that your loved one is unhappy or bored sitting at home all day?
- Do you worry about the health of your loved one?
- Do you want help to be able to keep your loved one at home as long as possible?
- Does your loved one seem depressed and have no one to talk to?

## Who Should Use Adult Day Services?

- Adults who <u>require supervision or assistance</u> to live at home and to do day-to-day activities.
- Adults who can’t attend a senior center due to their need for assistance and supervision.
- Adults who are considering moving to a nursing home.

## What Can Adult Day Services Offer?

Adult Day Service centers offer a wide range of services such as nursing care, meals, personal care, recreational activities and rehabilitation services.

### Therapeutic Activities:

- Physical and mental exercises to improve functioning
- Creative expression via music, art and dance
- Community programs for cultural enrichment
- Activities with youth
- Socialization
- Support with activities of daily living
- Physical, occupational and speech therapy

### Nursing Services:

- Monitor vital signs and observe health changes
- Administer and monitor medications
- Injections
- Wound care
- Tube feedings
- Respiratory treatments
- Continence re-training
- Assist with personal care (e.g. dressing)

### Family Support:

- Integrate goals of family, participant, health and social services into a care plan
- Caregiver support groups
- Education on managing behavior and home care
- Counsel and refer to caregiver support services
- Convenience services – bathing, hair and nail

care, hair dresser, extended hours, podiatrist

## Finding An Adult Day Services Center That's Right For You

### Places to call to locate centers:

- Area Agency on Aging (AAA) 1-800-677-1116 for the AAA in your area
- National Adult Day Services Association, Inc.
  Phone: (800) 558-5301 or (703) 435-8630
  E-mail: info@nadsa.org
- Health care providers: physicians, hospital or nursing home social worker, home health nurse
- Telephone book yellow pages or blue pages, see "Adult Day Care" or "Aging Services"

### Steps in Selecting a Center:

- ***Call for information***. Request written material be sent to you so that you can review it when you have quiet time.
- ***Ask questions.*** Adult Day Services staff should welcome inquiries, and want to help people fully understand their services.
- ***Visit the center.*** Make an appointment and visit more than one center to compare and find the best "fit". The checklist to the right will help you decide which Adult Day Services center is right for you.
- ***Try it out.*** Give your family member the opportunity to try Adult Day Services. It can take you and your family member a little time to feel comfortable. Once that happens you can both feel good about your decision.

### Site Visit Checklist:

☐ Did you feel welcomed?

☐ Did someone spend time finding out what you want and need?

☐ Did someone clearly explain what services and activities the Center provides?

☐ Did they present information about staffing, program, procedures, costs and what they expect of family caregivers?

☐ Was the facility clean, pleasant and free of odor?

☐ Were the building and rooms wheelchair accessible?

☐ Was there sturdy, comfortable furniture?

☐ Loungers for relaxation? Chairs with arms?

☐ Was there a quiet place for conferences?

Checklist courtesy of:
National Adult Day Services Association, Inc.,Herndon, VA. Toll Free Phone: (800) 558-5301. www.nadsa.org.

*Information provided in this fact sheet was adapted from materials submitted by Mid-County Senior Services, Newton Square, PA.*

**FOR MORE INFORMATION**

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov

**U.S. Department of Health and Human Services**
**Administration on Aging**

## National Family Caregiver Support Program Resources

# Care Receiving: Creating Partnerships in Self Care

## Introduction

The relationship of the caregiver and care receiver has an important effect on the care process. A strong positive partnership between caregivers and care receivers can lessen caregiver stress and result in better quality-of-care for the care-receiver. Limited attention has been paid to the role of care receivers and the challenges they face in this role. Most of us fear losing our abilities for self-care and having to receive help from others. At various points in our lives we all need help and assistance.

## Facing Feelings And Values

Most of us never thought we would be in a position to need help. It is important to acknowledge that while we now need assistance with our lives, we also have much to give. The following is advice on coping with the emotional components of receiving care:

- Allow yourself to accept the assistance of others.
- Accept assistance graciously. Frequent expressions of guilt make caregiving more difficult.
- Acknowledge feelings of guilt and/or anger at having to receive care. Don't allow these feelings to affect your relationship with your caregiver.
- Focus on the positive aspects of your life; on the things you can do.
- Keep your sense of humor
- Live in the present; focus on life now and what you are able to do. Celebrate accomplishments.
- Be creative in exploring and developing interests and activities that enhance your self esteem.
- Keep in frequent contact with friends.

## Being An Effective Partner

All partnerships require give and take. The partnership you have with your caregiver requires active participation and compromise in order for it to be rewarding and enduring. Below are suggestions for creating a successful partnership:

- Do what you are able to do for yourself. Small efforts are recognized and appreciated.
- Provide moral support; listen to your caregiver.
- Have fun together. Share ideas. Be a good friend.
- Plan as much in advance as possible. Provide your caregiver as much advance notice as possible regarding doctor's appointments, etc.
- Accept help from other sources to give your caregiver needed time off.
- Compromise and problem solve with your caregiver.
- Look for things, small or large, that you can do for your caregiver or family.

## Communicating Well

Open, honest communication is essential to create and maintain a successful partnership. Below are strategies that current care receivers suggest:

- Listen to your caregiver's concerns. What are their joys, successes, and problems? What is going on in their lives?
- Be kind. Show affection. Express love.
- Express gratitude but don't overdo it.
- Speak up for yourself; make your needs known.
- Respect your caregiver's scheduling and time limitations.
- Be fully involved in decision-making about your care.

## Participating In Self-Care

You are the best source of knowledge about your own health. Participating in your self-care can be an important ingredient in maintaining positive feelings of independence.

- Learn new ways to function. Use mechanical devices such as walkers and wheelchairs to increase mobility.
- Learn as much as you can about your own emotional/physical condition.
- Participate in care by taking an active role with health care providers. Exercise and follow diet recommendations.

## Relating To Professional Caregivers

Partnerships with professional caregivers such as doctors, nurses, and social workers involve some of the same issues as partnerships with family or friends. There are also important differences. The following are suggestions for dealing effectively with professional caregivers and agencies:

- Learn all you can about your own physical and/or emotional situation: ask questions, read, attend classes. Do not hesitate to ask professionals to repeat or rephrase what they have said.
- Learn all you can about the beliefs and attitudes of the professional with whom you are dealing.
- Learn about service agencies and how to use them.
- Speak up for yourself. Be sure you understand what is being said.
- Don't hesitate to change doctors if you feel you are not receiving the care you need.
- Become an advocate for yourself and others in the same situation.
- Be persistent about your needs – don't give up.
- Two can be better than one when dealing with professional caregivers. Bring your caregiver or friend to appointments.
- Advocate for yourself with professional caregivers. Be assertive. Take the time you need to explain your problems.

*Information provided in this fact sheet was adapted from materials submitted by the Institute of Gerontology, University of Denver, Denver, CO.*

**FOR MORE INFORMATION**

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov

**U.S. Department of Health and Human Services**
**Administration on Aging**

National Family Caregiver Support Program Resources

# Communicating Better with Health Professionals

## Introduction

Sometimes it can seem like health professionals speak a different language. When we feel worried about a loved one's health condition, it can be hard to keep up with everything being said by a doctor or nurse. It's important to communicate clearly with health professionals. Good communication helps you be a more effective caregiver, leads to better care, helps family members feel like part of the healthcare team, and helps clear up confusion quickly.

## Four Keys To Effective Communication

We can all improve our communication skills. Researchers have found four key ways that we can strengthen communication in healthcare:

### 1. Be fully present

- Before entering the health setting, take a moment to calm your mind. Breathe deeply.
- Make eye contact.
- Focus on the present moment – don't worry about yesterday or tomorrow.
- Set a positive tone.
- Maintain a strong sense of yourself.

### 2. Participate

- Be prepared.
- Clearly state your purpose.
- Offer information about your loved one's condition.
- Ask questions.
- Assert yourself. When you assert yourself you ask questions, clearly state what you want, offer compromises, and set limits about what is acceptable in a care plan.

### 3. Build understanding

- Really listen – with your full attention.
- If you hear something you don't understand, ask the health professional to clarify the point.
- Show that you understand what someone is saying by repeating it back in your own words.
- Avoid assumptions. Don't jump to conclusions. Allow others to finish speaking.
- State difficulties and concerns. Ask for help in understanding the reasons for treatment choices and recommendations.

### 4. Encourage working together

- Focus on goals that you, your loved one, and the health professional can agree upon.
- Be clear about who is responsible for what and get extra help with certain tasks, if needed.
- Speak openly and honestly.
- Help with problem solving. Share information that you have that can help the health team make good decisions about care.
- Express appreciation. Saying "thank you" to health professionals who gave you help means more than you can imagine.

## Family Caregivers As Team Members

The role of the family caregiver is to serve as an effective member of the healthcare team, along with the patient, doctor, nurse, social worker, therapists, and other team members. Your goal is to help your loved one navigate the healthcare system and get the best quality care possible. Here is a list of key activities for you as a team member:

- Set up a file with detailed records of important medical information.
- Go to appointments with your loved one and speak up for him or her, as needed.
- Write down notes during appointments.
- Ask questions about anything that is not clear or sounds complicated.
- If you disagree or have a concern, speak up.
- Ask others to listen to your loved one's concerns in his or her own words.
- Provide progress reports to health professionals.
- If your loved one's needs are not being met by his or her team of health professionals, find a new team.

## How To Support Treatment Plans

- Make sure your loved one follows medical instructions. If you have any questions or doubts about what is to be done, call and ask.
- Come prepared. Bring complete information about your loved one's current symptoms, condition, medication, and therapies.
- Be a good reality check. Help your loved one not to exaggerate, dramatize, or under-report symptoms.
- Reach out for help if something changes. Don't attempt to play doctor yourself.
- Tell the doctor when you seek a second opinion. It's okay. Health professionals are used to this and usually find a second opinion to be helpful.
- Educate yourself about the particular disorder your loved one has. Share what you learn with health professionals. They won't always have all the answers or know the latest research about a particular disorder.

## Respect Health Professionals' Limits

- Be respectful of health professionals' time and emotional limits
- Be patient; most health care offices are busy and see many patients every day
- Learn the office routine – including the best time to call with medical questions, how to make appointments, and the name of the person who handles billing information.

*Information provided in this fact sheet was adapted from materials submitted by the National Family Caregivers Association, Kensington, MD. For more information, visit their website at [www.nfcacares.org](http://www.nfcacares.org).*

**FOR MORE INFORMATION**

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MOUNTAIN CAREGIVER RESOURCE CENTER

# Fact Sheet:
# End-of-Life Decision-Making

Americans are a people who plan. We plan everything: our schedules, our careers and work projects, our weddings and vacations, our retirements. Many of us plan for the disposal of our estates after we die. The one area that most of us avoid planning is the end of our life. Yet, if we don’t plan, if we don’t at least think about it and share our ideas with those we love, others take over at the very time when we are most vulnerable, most in need of understanding and comfort, and most longing for dignity.

Big issues confront us when we think about our own death or that of someone we love. Our attitudes and beliefs about religion, pain, suffering, loss of consciousness, and leaving behind those we love come into play. We can let things unfold as they may, and for some of us that’s exactly right. For others of us, it is good to plan.

This Fact Sheet is not intended to provide a comprehensive planning tool. It outlines areas we need to think about and resources that can help, whether we are caring for someone who is already incapacitated, or making decisions for ourselves.

## How to Begin

Begin simply… with yourself. Try to confront and understand any fears you might have: do they relate to the possibility of pain? Loss of dignity while undergoing treatment? Not being clearly understood by those around you? Being alone? Being overly-sedated or in a lingering state of unconsciousness? Leaving loved ones or unfinished projects behind? Leaving your loved ones without adequate financial resources? Dying in a strange place?

Once you know that you want to explore these topics and make some plans, most experts suggest that you begin by talking. Talk openly to family and friends about your values and beliefs, your hopes and fears about the end stage of your life and theirs. Someone who is uncomfortable with the subject can be led to talk with indirect topics. Use “openings” in conversations, such as recalling a family event and talking about a future event where you might not be present. Talk about whom you wish to leave a possession to, whom you’d like to have near if you were seriously ill.

Ask your doctor for a time when you can go over your ideas and questions about end-of-life treatment and medical decisions. Tell him or her you want guidance in preparing advance directives. If you are already ill, ask your doctor what you might expect to happen when you begin to feel worse. Let him or her know how much information you wish to receive about your illness, prognosis, care options, and hospice programs.

Discuss with your lawyer and/or financial adviser whether your legal and financial affairs are in order. Talk to a religious adviser about spiritual concerns.

### What do you need to talk about?

Specific issues relate to the end of one's life. They include:

- Whom do you want to make decisions for you if you are not able to make your own, both on financial matters and health care decisions? The same person may not be right for both.
- What medical treatments and care are acceptable to you? Are there some that you fear?
- Do you wish to be resuscitated if you stop breathing and/or your heart stops?
- Do you want to be hospitalized or stay at home, or somewhere else, if you are seriously or terminally ill?
- How will your care be paid for? Do you have adequate insurance? What might you have overlooked that will be costly at a time when your loved ones are distracted by grieving over your condition or death?
- What actually happens when a person dies? Do you want to know more about what might happen? Will your loved ones be prepared for the decisions they may have to make?

## Taking Control

### Financial Decisions

Sometimes the easiest place to begin taking control of planning is in your estate and finances because the content is more concrete. Make sure you have a valid, up-to-date will, or trust documents if desired or needed. A durable power of attorney for financial affairs is a legally binding document that you prepare, or have prepared for you to sign, that designates a trusted person to act for you if you become incapacitated. A lawyer should help you complete these documents.

Keep all your insurance information - medical, long-term care, life and special needs policies advance directives. Every state now recognizes advance directives, but the laws governing directives vary from state to state.

Probably the most commonly used form of advance directive is the durable power of attorney for health care. A more limited type of advance directive is the living will. There are important differences between these two documents.

- The durable power of attorney for health care (also called the "medical power of attorney") names someone - a relative or friend - to make medical decisions for you when you are not able. Depending on the state where you live, the person you designate is called an agent, attorney-in-fact, proxy, or surrogate. (California uses the first two terms.) A durable power of attorney deals with all medical decisions unless you decide to limit it. You can also give specific instructions about treatments you want or don't want, or about other issues that concern you. For example, your agent will have access to your medical records unless you limit this right.

  Because a durable power of attorney is a legal document, special forms are available and the power of attorney must be signed to be valid. Some states require witnesses and have specific rules about who can witness. It is important to select a proxy who knows you well and whom you trust. You should also name a backup proxy in case the first person is unavailable. A relative or friend can be your proxy, but an attending physician or hospital staff person usually cannot be.

  The agent will be able to make all decisions regarding your health care, from flu shots to the need for surgery. And your agent or proxy can decide whether to withdraw or withhold life-sustaining procedures. While you can be as specific as you wish in the guidelines you give in the document, remember that your agent must also have the flexibility to make decisions in changing circumstances. You do not need a lawyer to complete a DPA-HC, nor can a nursing home require you to sign one before admission.

- The living will, in some states called "instructions," "directive to physicians," or "declaration," states your desires regarding life-sustaining or life-prolonging medical treatment. These instructions generally apply to specific circumstances that may arise near the end of your life, such as prolonged unconsciousness. They do not appoint a surrogate to make decisions for you. Most states include these types of instructions in their medical durable power of attorney forms. Not all states recognize separate living wills as legally binding; California does not.

California's new Health Care Decisions law, effective July 1, 2000, combines the durable power of attorney for health care and the instructions for health care decisions into one form called the Advance Health Care Directives. New forms are available from several agencies and web sites. (See Resources.) Older forms, executed before July 1, 2000, are still valid, however. Note that the durable power of attorney for health care does not authorize anyone to make legal or financial decisions for you. That is done through a separate financial durable power of attorney, as discussed above under "Taking Control - Financial Decisions."

Other forms or methods of instruction may also be available to you, including:

- A Do Not Resuscitate or DNR order, which instructs medical personnel, including emergency medical personnel, not to use resuscitative measures.
- A preferred intensity of care document, a form for your physician that outlines your preferences for care under special circumstances.

Check with the laws in your state regarding oral directives. Some allow you to designate a surrogate without a written directive, with some restrictions.

## Why would I want to prepare an advance directive?

It is wise to prepare an advance directive so that medical personnel and your loved ones know what care and services you desire and what treatment you would refuse if you were able to communicate your wishes. You also can designate the person or more than one person who you would like to make decisions on your behalf. In a surprising number of families, there is disagreement over what a very ill relative would prefer. The advance directive makes your wishes clear.

## What are the care or treatments covered by advance directives?

Most advance directives cover life-sustaining treatment such as artificial feeding, mechanical ventilators, resuscitation, defibrillation, antibiotics, dialysis and other invasive procedures.

You can give broad or specific instructions for care providers for each type of circumstance or treatment. For example, you can state that you do not want life-prolonging treatments if you will never recover your physical and mental health to live without constant care and supervision. Or you can state that you want your life prolonged as long as possible. You can address what you wish to occur in the event of trauma, a prolonged state of unconsciousness, a diagnosis of dementia, and so on.

You can also state that you wish to receive only palliative or comfort care. Such care is designed to manage terminal symptoms, including pain. It is important to understand these terms before making decisions about your preferences. Your surrogate should also become informed about the difference between comfort care and life-sustaining treatments. Health professionals and family members may disagree on the nature of a particular treatment. For example, a relative may become alarmed to see that fluids are being administered and think that this will extend life against the patient's wishes. However, the physician might believe fluids are making the dying person more comfortable and are appropriate palliative care. Another example could be the temporary need for a ventilator (mechanical breathing apparatus) and antibiotics following routine surgery.

Pain alleviation or management is among the most controversial end-of-life topics. Because of ethical concerns and the confusion over laws regulating drug addiction, Congress is debating the role of habit-forming and potentially lethal drugs in the management of pain and discomfort at the end of life. Studies have found that addiction among seriously ill people is rarer than once thought. Some individuals, however, fear being over-sedated at the very time when they want and need to recognize and interact with others.

Before making decisions about these treatments they should be discussed with a well-informed health professional. You can also ask what to expect during the last days and hours of your life, and what your surrogate and other loved ones should expect.

## What other decisions can my proxy make?

Depending on where you live and your written instructions, your proxy or agent can be authorized to decide where you will die (at home or in a facility), and can arrange for autopsy, organ donation, disposal of remains, and funeral or memorial plans.

## Whom should I select to be my proxy or agent?

Choose a responsible person to be your surrogate who shares your values and beliefs about medical care and dying. You must also make sure that the person is willing to take on this responsibility before you name her or him in the directive. An alternate should also be selected (and informed of your choice). Some states do not allow certain people, such as health care providers or health facility operators, to serve as agents. Remember also that the person you select to be your surrogate does not have to be the same person who oversees your financial affairs.

## Can someone take over making decisions before I'm ready?

Though laws vary by state, most states ensure that you remain in charge of your care as long as you are able. Usually laws are in place that require at least two physicians to declare you to be incapacitated. Agents/proxies are not allowed to commit you to a mental institution or to consent for experimental mental health research, psychosurgery or electroconvulsive treatment. Your proxy may not deny comfort measures for you.

## Can a medical professional refuse to observe my wishes?

A health care provider may refuse to observe your stated wishes or the decisions of your agent because of conscience or the institution's policies or standards. The provider must inform you or your surrogate immediately and transfer to another provider should be arranged.

Advance directives must be reviewed periodically and kept current. Keep the original and give copies of the signed documents to your proxy/agent (including alternates), your physician, and your hospital. Put a card or notation in your wallet or purse stating that you have an advance directive. You may also leave a copy with your lawyer. Some people take their directives with them when they travel. If you spend extended time in another state you should also complete advance directives there, using that state's forms and rules. Advance directives remain in effect until they are revoked. Any written change you make on a directive may invalidate it, so consult with a professional or hospital if you wish to make changes.

## Where to get forms and instructions

A local hospital, Long-Term Care Ombudsman program, senior legal service or senior information and referral program, a local or state medical society, or your physician usually have forms appropriate for your state. Some medical centers offer classes in preparing directives. Attorneys may also draft their own forms. Partnership for Caring, Inc., (formerly Choice in Dying) has forms and instructions for each state that can be downloaded from its web sites (www.partnershipforcaring.org or www.choices.org).

## What if I don't sign an advance directive?

Someone has to make decisions when an ill person cannot. Without directives in the person's medical or hospital files, and without the appointment of a surrogate through the durable power of attorney, your doctors, hospital staff and loved ones will do the best they can. To your spouse or child or life-long friend, this might mean struggling with what they think you would want. To the medical staff, it means letting their training and professional experience guide them. Unfortunately, in a world of good intentions, that training has traditionally led health care professionals to do all they can to keep you alive. Recent laws are making it easier for these able professionals to find the best ways to make you comfortable. But the ways all these wonderful people employ may not be what you want. Eventually, of course, a conservator (or guardian) could be appointed by a court. A public agency can request designation of a conservator and, if your family cannot be located, the conservator may be a public agency.

## What if I can't sign a directive: What to do when someone is already incapacitated

What if you don't have a chance to plan for your own or a loved one's death? What if you are responsible for a person who has suffered a severe stroke, is already in late-stage dementia, or becomes severely disabled from a traumatic brain injury? Laws and programs exist for these situations, too.

If the impairment is gradual, it may be possible to employ many planning measures already discussed. This depends on the degree of impairment the person has experienced and their legal ability to sign documents. If the impairment or incapacity is sudden and permanent, it is imperative that the responsible person-spouse, child, grandchild, a favorite niece or nephew, long-time friend or companion or other individual-seek guidance quickly from an attorney, hospital social work staff, and accountant or financial planner. The person's own physician as well as the hospital medical personnel should also be consulted. Several legal mechanisms are available, the most common being the conservatorship.

Questions to ask if you are responsible for an incapacitated person include:

- What is the prognosis?
- Has the person prepared and signed advance directives?
- Who would the person most want to take responsibility?
- Would he or she want that responsibility shared, perhaps among more than one adult child?

- Does the hospital provide an ethics committee or other staff that can help you sort through options for care decisions?

- What are the person's financial assets?

- Do they have Medicare, medical or long-term care insurance or other specialized insurance plans for hospital or illness coverage?

- Are they eligible for Medicaid?

Some aspects of an incapacitated person's financial affairs could be handled through joint tenancy of property, community property (husband and wife) provisions, and representative payees. Joint tenancy is the registration of various assets, such as real estate or bank accounts, in the names of two or more joint tenants. Potential problems include the ability of one joint tenant to withdraw money from a jointly held account without the other's knowledge and possible adverse tax and estate planning consequences. While a spouse can manage the community property owned with an incapacitated spouse, court approval may be required for transactions including sales of real property, borrowing money, signing leases or giving gifts of property. Also, many states do not have community property laws. A representative payee can be named for a person who receives only governmental benefits, such as Social Security or SSI. The payee, who can be a trustworthy relative, friend or professional, manages the person's funds. The most effective means of handling an incapaci tated person's affairs is the conservatorship or guardianship.

## Conservatorships or Guardianships

A judicial procedure that appoints someone to take charge of an incapacitated person's legal, financial and personal affairs may be called a "conservatorship," "guardianship," or some other term in your state. The term "conservatorship" is used in this Fact Sheet.

A conservatorship may be established after a relative, friend or public official petitions the court for appointment of a "conservator." The petition must contain information on why the individual (the "conservatee") cannot manage his or her financial affairs or make decisions concerning his or her personal care. An investigation is conducted under the court's direction to determine if the individual is truly incapacitated and whether appointment of a conservator is justified. The court holds hearings and determines whether or not the conservatorship is required. The types of special powers to be granted to the conservator are decided.

Advantages of a conservatorship include a higher degree of protection for the conservatee than with other mechanisms. The conservator must file reports and inventories and accountings with the court. A court investigator also visits the conservatee regularly to determine if a conservatorship continues to be necessary. Disadvantages include the costs of the legal proceedings and the cumbersome requirements to return to court for approval of various transactions. Also, the details of a conservatorship become part of a public record, a loss of privacy that many find intolerable.

The two types of conservatorship are "of the estate" and "of the person."

- Conservator of the Estate: In this type of conservatorship, the conservator handles the financial and legal affairs of the conservatee. The conservator collects the person's assets, pays bills, makes investments, etc. However, court supervision must be sought for some transactions, such as the purchase or sale of real property, borrowing money or "gifting" of assets.

- Conservator of the Person: Decisions about medical care, food, clothing and residence are made by this type of conservator. In the case of mental health facility placement, however, special requirements must be followed.

## Mental illness or developmental disability

If the person for whom decisions must be made has a mental illness or developmental disability, various federal and state laws apply. No one can be committed to a mental institution, for example, without specific legal proceedings.

## A special model for dementia

A study published in the Journal of the American Medical Association (July, 2000) reported that doctors often fail to acknowledge the final stages of Alzheimer's disease and other forms of dementia as a terminal illness. This can mean that patients are subjected to invasive procedures rather than comfort care. One problem area discussed in the study is the administration of pain medication to dementia patients. The study found that less pain relief is often prescribed for dementia patients than may be needed because the patient is unable to communicate the presence of pain. Treatment models developed for dementia patients suggest hospice and comfort care, rather than life-prolonging treatments, might be more appropriate in the end-stages of the disease. This would mean that in the event of a hip fracture, pneumonia, localized infection or other treatable condition, treatments might be withheld in favor of medications and methods that bring comfort and ease.

There is much that we can plan and attend to in advance of our own death. We can make our wishes known about where we want to be, who we want to be with and what we want to happen to us and around us. We can set up ways to pay the costs of care and even pay for our own funeral. But financial and legal planning and medical advance directives must be made with the knowledge that some day other people will have to implement our wishes and live with the results. For that reason our plans should, when possible, allow for flexibility and trust in the discretion of our surrogates.

## Credits

"Start the Conversation: The Modern Maturity Guide to End-of-Life care," and "The Last Taboo" by Mark Matousek, Modern Maturity/AARP, September-October, 2000.

"How to Talk about End-of-Life Concerns," by JoAnne Lynn, M. D., author,. WNET/PBS Program Guide, "On Our Own Terms: Moyers on Dying in America."

"Issues: Background on the Right to Die" and "Advance Directives," Partnership for Caring, Inc. (formerly Choice in Dying), www.choices.org or www.partnershipforcaring.org. (See "Advance Directives Forms" below.)

Fact Sheets, Family Caregiver Alliance: Legal Planning for Incapacity, Durable Powers of Attorney, Conservatorships, Grief and Loss.

"Advance Directives," California Department of Health Services, Licensing & Certification Division, Sacramento, CA. Contact State Ombudsman Program (916) 323-6681, or regional offices of the Licensing & Certification Division or the Ombudsman Program.

"California Health Care Decisions Law Fact Sheet," California Coalition for Compassionate Care.

"Ethical Considerations: Issues in Death and Dying," Alzheimer's Association, 1997. (800) 272-3900.

"The Living Will and The Durable Power of Attorney for Health Care," APDA Educational Supplement No. 6, American Parkinson's Disease Association, 1995. 1250 Hylan Blvd., Suite 4B, Staten Island, NY, 10305. (718) 981-8001 or (800) 223-2732.

"Power of Attorney for Health Care," HealthSpan, Buck Center for Research on Aging, 505A San Marin Drive, Suite 300, Novato, CA, 94945. (415) 899-1800.

Information on Pain Management and Palliative Care, Growth House, Inc., San Francisco, CA (415) 255-9045. www.growthhouse.org/pain.html and www.growthhouse.org/palliat.html

"Changing Care for End-Stage Dementia,"
Washington Post,
July 5, 2000.

## Resources

Mountain Caregiver Resource Center
2491 Carmichael Drive, Suite 400
Chico, CA 95928
(530) 898-5925
(800) 995-0878
www.caregiverresources.org

Mountain Caregiver Resource Center offers a full complement of family services designed to assist caregivers of adults with brain disorders. Most services are offered free or on a low-cost sliding scale.

Services include: specialized information, family consultation and care planning, support groups, short-term counseling, respite care, legal and financial assistance, in addition to family and professional training.

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
Website: http://www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, services, research and advocacy.

FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

American Association of Critical-Care Nurses
101 Columbia
Aliso Viejo, CA 92656-1491
(800) 899-2226 or (949) 362-2000
www.aacn.org

American Hospice Foundation
2120 L Street, NW, Suite 200
Washington, D. C. 20037
(202) 223-0204
www.americanhospice.org

American Pain Society
4700 W. Lake Avenue
Glenview, IL 60025
(847) 375-4715
www.ampainsoc.org

Americans for Better Care of the Dying (ABCD)
4125 Albemarle St., NW
Suite 210
Washington, DC 20016
(202) 895-9485
www.abcd-caring.com

City of Hope Pain Resource Center
1500 E. Duarte Road
Duarte, CA 91010
mayday.coh.org

Education for Physicians on End-of-Life Care (EPEC)
American Medical Association (with Robert Wood Johnson Foundation)
515 North State Street
Chicago, IL 60610
(312) 464-5000
www.ama-assn.org/ethic/epec

Growth House, Inc.
San Francisco, CA
(415) 255-9045
www.growthhouse.org

Hospice Foundation of America
2001 S St., NW #300
Washington, D. C. 20009
(800) 854-3402
www.hospicefoundation.org

Last Acts Coalition
www.lastacts.org

Medicare Rights Center
(800) 333-4114 or (212) 869-3850
www.medicarerights.org

National Hospice and Palliative Care Organization
1700 Diagonal Road, Suite 300
Alexandria, VA 22314 (800) 658-8898 or (703) 243-5900
www.nhpco.org

Supportive Care of the Dying: A Coalition for Compassionate Care
c/o Providence Hospital System
4805 NE Glisan St.
Portland, OR 97213 (503) 215-5053
www.careofdying.org

U. S. Living Will Registry
523 Westfield Ave. (P. O. Box 2789)
Westfield, NJ 07091-2789
(800) LIV WILL (800-548-9455)
www.uslivingwillregistry.com

WNET/PBS Channel 13, New York “On Our Own Terms” Program Web Site
www.wnet.org/onourownterms
”Before I Die: Medical Care and Personal Choices”
www.wnet.org/archive/bid/index.html Video available through (800) 424-7963 or shop.pbs.org

## Additional Reading

Hospice Care for Patients with Advanced Progressive Dementia
Edited by Ladislav Volicer and Anne Hurley, Springer Publishing Company, 1998

Finding Your Way: A Guide for End-of-Life Medical Decisions
Sacramento Healthcare Decisions
(916) 484-2485 (www.sachealthdecisions.org)

Dying Well
Ira Byock, M. D., Riverhead Books, 1997

Books by Joanne Lynn, M.D.
Handbook for Mortals (with Joan Harrold, M. D.), Oxford University Press, 1999

By No Extraordinary Means, Indiana University Press, 1990

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Prepared by Family Caregiver Alliance in cooperation with the State of California’s Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Reviewed by John P. Bosshardt, Attorney at Law. Funded by the California Department of Mental Health.

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# Medications that Can Cause Confusion in Elderly Persons

Below is a list of medications that can cause confusion in elderly persons because of the potential affect of the actions of these medications:

Products with anticholinergic activities are listed below by generic name or classification and brand name

- thioridazine – **Mellaril**
- amitriptyline – **Elavil, Endep**
- tricyclic antidepressants – **Elavil, Endep, Etrafon, Triavil, Limbitrol**
- atropine - **Sal-Tropine**
- theophylline - **Slo-Bid, Slo-Phyllin, Accurbron, Aerolate, Brokodyl, Elixophyllin, Quibron, Respbid, Theoclear, and others**
- diphenhydramine – **Benadryl, Sleep-Eze, Unisom, Complete Allergy Medicine and many others**
- OTC antihistamines – **Contac, Actifed, Allerest, Triaminic, Tavist and many others that contain phenylprop HCL and pseudoephedrine HCL**

Histamine2 - blocking agents

- cimetidine – **Tagamet**

Analgesics

- merperidine – **Demerol**
- nonsterodoidal anti-inflammatory drugs (NSAIDs) – **Naprosyn, Naproxen**

Sedative - hypnotics

- halcion – **Halcion, Triazolam**
- benzidiazepines – **Ativan, Dalmane, Diazepam, Librium, Lorazepam, Restoril, Serax, Tranxene, Valium, Xanax and others**

Cardiovascular drugs

- nifedipine – **Adalat, Procardia**
- quinidine – **Qinaglute**
- beta blockers – **Betachron, Inderal, Propranolol, Cardizem, Cardene, Adalat, Vascor, Vasotec, Lopressor, Lanoxin**

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*Helping You Make the Best Use of Your Medicines*

# Medications That Should be Avoided, If Possible, When Certain Diseases are Present

**Seek the advice of your pharmacist and/or physician before making any changes to your medication regimen.**

| DISEASE/ CONDITION | MEDICATIONS | ALERT |
|---|---|---|
| **Heart Failure** | Disopyramide (Norpace®, Norpace CR®) | May weaken the pumping of the heart and may worsen heart failure. |
| | medications with high salt (sodium) content | May lead to water retention, which may worsen heart failure. |
| **Diabetes** | beta blockers (Tenormin®, Inderal®, Lopressor®) | May block symptoms of low blood sugar in diabetics on treatment with insulin or an oral diabetes medication. |
| | Corticosteroids (prednisone) | May worsen diabetic control. |
| **Hypertension/high blood pressure** | diet pills; amphetamines | May increase blood pressure. |
| **Respiratory or lung diseases, such as asthma, emphysema** | beta blockers (Tenormin®, Inderal®, Lopressor®) | May worsen breathing function in persons with respiratory or lung diseases, such as asthma, emphysema, or bronchitis. |
| | sedative/hypnotics (Halcion®, Ambien®, Dalmane®) | May slow breathing in persons with respiratory or lung diseases, such as asthma, emphysema, or bronchitis. |
| **Ulcers** | non-steroidal anti-inflammatory medications (ibuprofen, Motrin®, Aleve®) | May worsen ulcer disease and GERD (reflux disease). |
| | Aspirin in doses above 325 MG | May worsen ulcer disease and GERD (reflux disease). |
| | potassium supplements (all) | May cause stomach irritation with symptoms similar to ulcer disease. |
| **Seizures/Epilepsy** | clozapine (Clozaril®)<br>chlorpromazine (Thorazine®)<br>thioridazine (Mellaril®)<br>chlorprothixene (Taractan®) | Make seizures more likely. |
| **Circulation Problems** | beta blockers (Tenormin®, Inderal®, Lopressor®) | May worsen blood flow through small arteries and cause circulation problems |
| | metoclopramide (Reglan®) | May worsen blood flow through small arteries and cause circulation problems. |

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| **Blood Clotting Disorders**<br>(Only those on blood thinners/anticoagulant therapy) | Aspirin | May cause bleeding in those using blood thinners/anticoagulants. |
| | non-steroidal anti-inflammatory medications (ibuprofen, Motrin®, Aleve®) | May cause bleeding in those using blood thinners/anticoagulants. |
| | dipyridamole (Persantine®)<br>Ticlopidine (Ticlid®) | May cause bleeding in those using blood thinners/anticoagulants. |
| **Prostate Disease/Benign Prostatic Hyperplasia (BPH)** | Antihistamines<br>chlorpheniramine (Chlor-Trimeton®)<br>diphenhydramine (Benadryl®)<br>hydroxyzine (Vistaril®, Atarax®)<br>cyproheptadine (Periactin®) | May impair urination and cause obstruction in persons with BPH. |
| | stomach and intestinal antispasmodics<br>dicyclomine (Bentyl®)<br>hyoscyamine (Levsin®, Levsinex®)<br>propantheline (Pro-Banthine®)<br>belladonna alkaloids (Donnatal®)<br>clidinium/chlordiazepoxide (Librax®) | May impair urination and cause obstruction in persons with BPH. |
| | muscle relaxants<br>cyclobenzaprine (Flexeril®)<br>methocarbamol (Robaxin®)<br>carisoprodol (Soma®)<br>oxybutynin (Ditropan®);<br>chlorzoxazone (Paraflex®);<br>metaxalone (Skelaxin®) | May impair urination and cause obstruction in persons with BPH. |
| | narcotics<br>propoxyphene and combination products (Darvon®, Darvocet N-100®)<br>meperidine (Demerol®) | May impair urination and cause obstruction in persons with BPH. |
| | oxybutynin (Ditropan®) | May impair the ability to urinate in persons with BPH. |
| | urecholine (Bethanechol®) | May impair the ability to urinate in persons with BPH. |
| | certain antidepressants<br>amitriptyline (Elavil®)<br>chlordiazepoxide/amitriptyline (Limbitrol®)<br>perphenazine/amitriptyline (Triavil®)<br>doxepin (Sinequan®) | May impair the ability to urinate in persons with BPH. |

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| **Incontinence** | alpha blockers<br>Doxazosin (Cardura®)<br>Prazosin (Minipress®)<br>Terazosin (Hytrin®) | May cause incontinence by relaxing the bladder. |
| **Constipation** | Narcotic pain relievers | Will cause or worsen constipation. |
| | Certain antidepressants<br>amitriptyline (Elavil®)<br>chlordiazepoxide/amitriptyline (Limbitrol®)<br>perphenazine/amitriptyline (Triavil®)<br>doxepin (Sinequan®) | May worsen constipation. |
| | Iron products | Will cause or worsen constipation. |
| **Dizziness/Lightheadedness or Falls** | beta blockers<br>(Tenormin®, Inderal®, Lopressor®) | May slow the heart and weakens the pumping action of the heart. May cause dizziness/lightheadedness or falls. |
| | Antianxiety medications<br>diazepam (Valium®)<br>flurazepam (Dalmane®) | May contribute to falls due to sleepiness, confusion, and other side effects. |
| **Abnormal heart rhythms/Arrhythmias** | tricyclic antidepressants<br>amitriptyline (Elavil®)<br>chlordiazepoxide/amitriptyline (Limbitrol®)<br>perphenazine/amitriptyline (Triavil®)<br>doxepin (Sinequan®) | May induce abnormal heart rhythm. |
| **Insomnia** | Decongestants (Sudafed®) | May cause or worsen insomnia. |
| | Theophylline (Theodur®) | May cause or worsen insomnia. |
| | Certain antidepressants (Desipramine, SSRIs, MAO Inhibitors) | May cause or worsen insomnia. |
| | beta agonists<br>albuterol (Proventil®, Ventolin®) | May cause or worsen insomnia. |

Adapted from Beers MH, Ouslander JG, Rollinger I, Reuben DB, Brooks J, Beck JC. Explicit criteria for determining inappropriate medication use in nursing home residents. Arch Intern Med 1991; 151:1825-32. and Beers MH. Explicit criteria for determining potentially inappropriate medication use by the elderly: an update. Arch Intern Med 1997; 157:1531-6.

http://www.seniorcarepharmacist.com/diseases/

# Potentially Inappropriate Medications for Older Persons

**Always seek the advice of your pharmacist and/or physician before making any changes to your medication regimen.**

| Medications | Reason that Use is a Problem |
|---|---|
| **Pain Relievers** | |
| propoxyphene and combination products<br>(Darvon®, Darvocet N-100®) | Used to control pain. Propoxyphene offers little pain-relieving advantage over acetaminophen (Tylenol®), yet has the side effects of other narcotics. |
| indomethacin (Indocin®, Indocin SR®) | Used to control pain and swelling. Indomethacin produces many side effects, especially confusion, agitation, and ulcers. |
| pentazocine (Talwin®) | Used to control pain. Pentazocine is a narcotic pain reliever that causes confusion and hallucinations, more commonly than other narcotic medications. |
| cyclobenzaprine (Flexeril®)<br>methocarbamol (Robaxin®)<br>carisoprodol (Soma®)<br>oxybutynin (Ditropan®);<br>chlorzoxazone (Paraflex®);<br>metaxalone (Skelaxin®); | Used to ease muscle spasms. Most drugs used to relax muscles and reduce muscle spasms are poorly tolerated by older persons. These medications can cause sleepiness and weakness. |
| Meperidine (Demerol®) | Used to treat pain. Meperidine is not an effective oral pain reliever and has many disadvantages compared to other narcotics. Avoid using in older persons. |
| **Antidepressants** | |
| amitriptyline (Elavil®)<br>chlordiazepoxide/amitriptyline (Limbitrol®)<br>perphenazine/amitriptyline (Triavil®)<br>doxepin (Sinequan®) | Used to treat depression. These medications can cause sedation, weakness, blood pressure changes, dry mouth, problems with urination, and can lead to falls and fractures. |

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| **Sleeping Pills and Antianxiety Medications** | |
| flurazepam (Dalmane®) | Used to treat insomnia. This medication produces prolonged sedation/sleepiness (often lasting for days and can worsen if taken daily) and can increase the risk of falls and fractures. |
| meprobamate (Miltown®, Equanil®) | Used to treat anxiety. Meprobamate is a highly addictive and sedating. Those who have been using it for long periods may be addicted and may need to be withdrawn slowly. |
| alprazolam (Xanax®) 2 mg<br>lorazepam (Ativan®) 3 mg<br>oxazepam (Serax®) 60 mg<br>temazepam (Restoril®) 15 mg<br>triazolam (Halcion®) 0.25mg<br>zolpidem (Ambien®) 5 mg | Used to treat insomnia and anxiety. Older people should be prescribed small doses of these medications. Total daily doses should rarely exceed the suggested maximum doses noted to the left. |
| chlordiazepoxide (Librium®)<br>chlordiazepoxide/amitriptyline (Limbitrol®)<br>clidinium/chlordiazepoxide (Librax®)<br>diazepam (Valium®) | Used to treat insomnia and anxiety. Chlordiazepoxide and diazepam produce prolonged sedation (often lasting several days and can worsen if taken daily) and can increase the risk of falls and fractures. |
| All barbiturates except phenobarbital | Used to treat insomnia and anxiety. Barbiturates cause more side effects than most other drugs used to induce sleep in the elderly and are highly addictive. They should not be started as new therapy in the elderly except when used to control seizures; patients who have used barbiturates for a long period may be addicted. |
| **Heart Medications** | |
| disopyramide (Norpace®, Norpace CR®) | Used to treat abnormal heart rhythms (arrhythmias). Disopyramide, of all drugs used to treat arrhythmias, is the most likely to decrease the pumping action of the heart, which can lead to heart failure in older persons. When appropriate, other antiarrhythmics should be used. |
| digoxin (Lanoxin®)<br>Doses ABOVE 0.125 MG | Used to treat abnormal heart rhythms and heart failure. Because of decreased processing of digoxin by the kidney, doses in older persons should rarely exceed 0.125 mg daily, except when treating certain types of abnormal heart rhythms. |
| dipyridamole (Persantine®) | Used to help stop blood from clotting in people who have experienced strokes, heart attacks, and other conditions. Dipyridamole frequently causes light-headedness upon standing in older persons. Dipyridamole has been proven beneficial only in patients with artificial heart valves. Whenever possible, its use in older persons should be avoided. |

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| methyldopa (Aldomet®)<br>methyldopa/HCTZ (Aldoril®) | Used to treat high blood pressure. Methyldopa may cause a slowed heart beat and worsen depression. Alternate treatments for hypertension are generally preferred. |
| reserpine (Serpasil®)<br>reserpine/HCTZ (Hydropres®) | Used to treat high blood pressure. Reserpine imposes unnecessary risk in older persons, inducing depression, impotence, sedation, and light-headedness upon standing. Safer alternatives exist. |
| Ticlopidine (Ticlid®) | Used to help prevent blood from clotting in people who have had strokes, heart attacks, and other conditions. Ticlopidine has been shown to be no better than aspirin in preventing clotting (except in a few specific conditions, such as after use of a cardiac artery stent) and is considerably more toxic. Avoid use in older people. |
| **Diabetes Medications** | |
| chlorpropamide (Diabinese®) | Used to control blood sugar in people with diabetes. Chlorpropamide can cause prolonged and serious low blood sugar. |
| **Stomach and Intestinal Medications** | |
| dicyclomine (Bentyl®)<br>hyoscyamine (Levsin®, Levsinex®)<br>propantheline (Pro-Banthine®)<br>belladonna alkaloids (Donnatal®)<br>clidinium/chlordiazepoxide (Librax®) | Used to treat stomach and intestinal cramps. These medications can cause sedation, weakness, blood pressure changes, dry mouth, problems with urination, and can lead to falls and fractures. All of these drugs are best avoided in older persons, especially for long term use. |
| trimethobenzamide (Tigan®) | Used to control nausea. Trimethobenzamide is one of the least effective medications used to control nausea and vomiting, yet it can cause severe side effects, such as stiffness, shuffling gate, difficulty swallowing, and tremor. |
| **Antihistamines** | |
| chlorpheniramine (Chlor-Trimeton®)<br>diphenhydramine (Benadryl®)<br>hydroxyzine (Vistaril®, Atarax®)<br>cyproheptadine (Periactin®)<br>promethazine (Phenergan®)<br>tripelennamine (PBZ®)<br>dexchlorpheniramine (Polaramine®) | Used to treat the runny nose of the common cold and allergy symptoms. Most nonprescription and many prescription antihistamines can cause sedation, weakness, blood pressure changes, dry mouth, problems with urination, and can lead to falls and fractures. Many cough and cold preparations are available without antihistamines, and these are safer substitutes in older persons. |

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| Actifed C®<br>Poly-Histine CS®<br>Bromfed DM®<br>Ambenyl®<br>Novahistine DH®<br>Polyhistine DM®<br>Tussionex® | |
| diphenhydramine (Benadryl®) | Used to treat allergies and insomnia. Diphenhydramine can cause sedation, weakness, blood pressure changes, dry mouth, problems with urination, and can lead to falls and fractures.. When used to treat or prevent allergic reactions, it should be used in the smallest possible dose and with great caution. |
| **Miscellaneous** | |
| iron supplements<br>Doses ABOVE 325 MG | Used to treat low iron, but frequently given to older people with other types of anemia, for which they do not help. Iron supplements rarely need to be given in doses exceeding 325 mg of ferrous sulfate daily. A common side effect of iron supplements is constipation. |

Adapted from Beers MH, Ouslander JG, Rollinger I, Reuben DB, Brooks J, Beck JC. Explicit criteria for determining inappropriate medication use in nursing home residents. Arch Intern Med 1991; 151:1825-32. and Beers MH. Explicit criteria for determining potentially inappropriate medication use by the elderly: an update. Arch Intern Med 1997; 157:1531-6.

http://www.seniorcarepharmacist.com/inappropriate/

FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

# Fact Sheet: Caregiver's Guide to Medications and Aging

## Medications: A Double-Edged Sword

*"Any symptom in an elderly patient should be considered a drug side effect until proved otherwise."* Brown University Long-term Care Quality Letter, 1995.

Modern medicines have contributed to longer life spans, improved health and better quality of life. Medications are the most common treatment for many diseases and conditions seen in older people and persons with disabilities. Medicines now not only treat and cure diseases that were untreatable just a few years ago, they aid in the early diagnosis of disease; prevent life-threatening illnesses; relieve pain and suffering; and allow people with terminal illnesses to live more comfortably during their last days.

However, for older adults and people with disabilities, medications—prescription, over-the-counter, social drugs such as alcohol, and herbal remedies/alternative medicines—can be a double-edged sword. When not used appropriately, effectively and safely, medications can have devastating consequences.

The changes that occur with aging and disability make people more likely to suffer *medication-related problems (MRPs)*. Nevertheless, research has shown that medication-related problems are often preventable. Caregivers can play a key role in helping to identify when an actual or potential MRP is occurring. This assistance can help prevent the costly and unwanted negative consequences of medication use, such as admission to acute care hospitals, assisted living facilities or nursing homes. About one quarter of all nursing home admissions are due at least in part to the inability to take medication correctly.

Research has shown that a high percentage of caregivers help their friends or relatives manage medications. Caregivers for people with Alzheimer's disease and other memory impairments commonly report problems with getting their relative or friend to take medications on time, in the right amount, and as directed. In surveys, caregivers often report that *their* knowledge of their loved one's medications—intended uses, directions for use, side effects, possible interactions—is greater than that of the care recipients themselves.

When patients, caregivers, doctors and pharmacists function as a team, medication-related problems can be avoided, contributing to better outcomes and improved daily functioning. This Fact Sheet serves as a caregiver's guide to medication use and provides tips on what to do about the challenges of that use.

## How a Pharmacist Can Help You

Older adults, people with disabilities and caregivers may encounter challenges when taking medications. Resolving these problems can lead to much better results from medicines. Consumers and caregivers must alert their doctors and pharmacists to any difficulties they have taking medications, including the following:

- **Memory: Difficulty remembering to take medications.** The pharmacist can provide a variety of special pill boxes or other aids that re-mind a caregiver and senior to take medications. The devices range from low-tech, such as simple containers with compartments labeled for meals and bedtime, to high-tech, such as containers that beep when it's time for a dose, or a special bottle cap that counts openings of a prescription bottle to tell if the day's doses have been taken. For those with severe memory impairments, caregivers are key to the proper administration of all medicines. In addition, some aging-related service organizations offer medication reminder telephone calls for older persons with memory problems.

- **Vision: Difficulty reading labels on prescription labels and over-the-counter products**. Pharmacists may be able to provide prescription labels in large print. Health care providers and caregivers can read the information on over-the-counter products for consumers with vision impairment. Magnifying glasses may also be helpful.
- **Hearing: Difficulty hearing instructions from health care professionals**. Ask doctors, nurses, and pharmacists to speak louder and/or write down important information relevant to the safe use of medications. Caregivers can also be "the ears" for seniors with hearing impairments.
- **Dexterity: Difficulty opening bottles, inability to break tablets, problems handling medicines** such as eye drops, inhalers for asthma and other lung disease, and insulin injections. These problems are common for people with arthritis and certain types of disabilities. Large, easy-open bottle tops are available for prescription medicines. If a prescription dose is one-half tablet, the pharmacist can split the tablets for you. Caregivers are key to assisting with the administration of eye drops, inhaled medications, injections, and other dosage forms that require fine motor skills. Again, pharmacies can provide instruction sheets on administration of medicines.
- **Swallowing: Difficulty swallowing tablets or capsules**. Many prescription and over-the-counter products are available in a variety of dosage forms such as a liquid, skin patch, or suppository, greatly reducing difficulties associated with swallowing. Ask your pharmacist about alternative dosage forms.
- **Scheduling logistics: Scheduling many different medications throughout the day**. One of the greatest challenges for older persons and caregivers is working medication schedules into daily routines. Special pill boxes and other aids, described above, can help. It's essential that older people and caregivers devise a plan for medication administration that fits their daily schedule. For example, meal times or bedtimes can be used as cues for scheduling medication if mealtimes and bedtimes are regularly scheduled. Doctors and pharmacists can assist in developing a plan to best suit your daily schedule.

## Too Many Medicines

One very common problem associated with medication use among older adults and many people with disabilities is the use of multiple medications at one time, also referred to as "polypharmacy." Research has shown that the more medications a person takes, the greater the risk of experiencing a medication-related problem. For most older persons, multiple medication use is the norm. Many chronic conditions or diseases—diabetes, heart disease, Parkinson's disease, arthritis, incontinence, high blood pressure, pulmonary disease, osteoporosis, Alzheimer's disease—often require the use of multiple medications. The focus must be the appropriateness, effectiveness, and safety of all prescription and over-the-counter medications. Caregivers must ask questions about each medication, such as:

- Is this medication really needed?
- Is the medication the most appropriate for the medical condition being treated?
- Will the medication be a problem with other medical conditions that are occurring at the same time?
- Is the medication being prescribed at the right dose?
- Does the medication interact with other medications?
- Can the medication be taken correctly based on specific patient circumstances?

Some of the challenges faced by caregivers who must juggle multiple medications for their loved ones include keeping all the prescriptions filled, especially during weekends and holidays, and managing medications prescribed by multiple doctors. Planning ahead to refill prescriptions on time is essential; keeping an up-to-date medication record can inform doctors of all medicines prescribed by others. A *"Caregiver's Notebook"*—a looseleaf binder maintained by a caregiver—is an ideal way to com-pile information on medical diagnoses, doctors' appointments, questions, and medication history.

## Preventing Medication-Related Problems

An important step to preventing problems is for health care professionals, consumers and caregivers to understand what medication-related problems are, to recognize the signs and symptoms of actual and potential MRPs, and to identify appropriate steps that can be taken to reduce the incidence of these common and costly problems.

It's important to keep in mind that medication effects can directly impact the daily functioning of older and disabled persons. These effects or "symptoms" of MRPs may include:

- excessive drowsiness
- confusion
- depression
- delirium
- insomnia
- Parkinson's-like symptoms
- incontinence
- muscle weakness
- loss of appetite
- falls and fractures
- changes in speech and memory.

When these symptoms appear, they should be considered "red flags" to caregivers that an MRP may be happening.

## Need for New Medication

This medication-related problem occurs when a person has a medical condition that requires a new or additional medication, but none has been provided. Examples among the older and disabled population include pain and depression, which often go undiagnosed, undertreated or untreated. These conditions are frequently assumed by some health care professionals to be a "normal part of aging." Inadequate treatment for pain and depression can lead to declines in functioning and participation in social activities.

Seniors often do not discuss all their symptoms with their health care professionals; many health care professionals do not adequately assess for all possible diseases and conditions. Proper assessment by health care professionals is essential so that symptoms can be identified and proper treatment initiated. Seniors and their caregivers must also feel comfortable discussing their symptoms—no matter how sensitive—with health care professionals.

## Unnecessary Medication

This medication-related problem occurs when a patient is taking a medication that is unnecessary given the patient's current medical problems—i.e., there is no longer a valid medical reason to use the medication. In addition, if a patient receives combination therapy when a single drug would be equally effective, then the patient would be receiving unnecessary medication. Patients who are exposed to unnecessary medications may experience toxic effects. The cost of unnecessary medications is also a consideration, especially for many seniors who have limited incomes.

## Wrong Medication

This medication-related problem occurs when a person has a medical condition for which the wrong medication is being taken. When a patient is not experiencing the intended positive outcomes from a certain medication, then the wrong medication may have been prescribed. Examples include inappropriate dosage form; the condition is nonresponsive to the medication; medication is not indicated for the condition being treated; or a more effective medication is available. Patients and their caregivers must have a clear understanding of what to expect—and when to expect it—when taking medications. When the result is different, the doctor should be contacted to make him or her aware of the situation.

## Dose Too Low

This type of MRP occurs when a patient has a medical condition for which too little of the correct medication has been prescribed or too little is taken. Medication dosages are considered too low if a patient has an appropriate indication for a medication, is not experiencing any side effects from the medication, yet is not realizing the desired benefit. When the correct medication is prescribed and the dose is too low, the benefits of the medication can be minimal or none at all, and may result in serious unpleasant effects through poor treatment. Simply adjusting the dosage and/or dosage interval can improve the clinical outcomes. Again, patients and their caregivers must have a clear understanding of what to expect from their medications.

## Dose Too High

Perhaps the most common medication-related problem among older persons is when the correct medication is prescribed, but the dose is too high. This MRP frequently occurs in older people because the physical changes of aging can alter the way our bodies process and react to medications. For example, in the aging body, the liver and kidneys may not as easily remove medications. In addition, changes in the distribution of fat and muscle can make seniors more susceptible to adverse drug events.

These changes increase an older person's sensitivity to a potential adverse effect. A "normal dose" of a medication can be an overdose for many older per-sons. Some medications, however, are used in the same doses for both older and younger adults. Medications that act on the central nervous system (CNS) are particularly problematic because older persons are extra sensitive to the adverse effects of these medications. Examples include antidepressants, sedatives, antipsychotics, and some blood pressure medications. Signs that a dose may be too high include dizziness, confusion, delirium, insomnia, Parkinson's-like symptoms, loss of appetite, falls, and changes in memory.

## Adverse Drug Reactions (ADRs)

ADRs can occur when a patient is receiving a medication considered to be unsafe based on:

- the characteristics of the patient;
- an allergic reaction to the medication;
- an interaction with another medication or food;
- the incorrect administration of the medication; or
- a medication dosage increased or decreased too rapidly.

Drug interactions can produce uncomfortable or dangerous adverse effects. A very common drug interaction involves blood-thinning medications that can thin the blood even more when combined with aspirin and some other pain relievers. Before prescribing any new drug, the doctor should be aware of all the other drugs the patient may be taking.

## Failure to Receive Drugs

For medications to be safe and effective, they must be taken at a particular dosage, at specified times, and for a specific period of time. There are many reasons why patients don't receive medications as prescribed. A patient, for example, may perceive that the medication has caused or will cause some adverse event, is confused about why and how to take the medication, or finds it inconvenient to take the medication.

The high cost of medications and the limited coverage for prescription drugs in public and private health insurance are major causes people don't take their medicines. The use of generic medications, if available, helps reduce out-of-pocket expenses. Many pharmaceutical companies provide free medications or special discounts to persons with low incomes. Call around for the lowest price; many pharmacies will match the prices of their competitors. Ask your doctor for samples.

Several states offer pharmaceutical assistance programs for low-income seniors who are not Medicaid-eligible. Pharmacists can assist seniors in obtaining medications through these programs. (Food stamps and rental assistance can also help by making additional money available for medications.) Medicare outpatient prescription drug benefit changes may also provide assistance with certain medication costs to a select group of older people when they go into effect in 2006.

## "Natural" Does Not Necessarily Mean Safe and Effective

The sale of herbal products in the U.S. is largely unregulated. Companies that sell these products are not required to demonstrate their safety and effectiveness. Some herbal ingredients are not listed on the packaging or the listing may be incomplete or inaccurate, so you may not know what you are taking. Although some herbal and other natural products may be beneficial in some instances, they can have significant and sometimes unpredictable side effects. Many herbals also interact with prescription and over-the-counter medicines. For example, ginkgo biloba, frequently used for memory loss, may interact with blood thinners, high blood pressure medications, and certain pain relievers such as ibuprofen and naproxen. To avoid problems with herbal medicines, talk to your doctor or pharmacist about any herbals you use or are considering using.

## The Basics of Safe Medication Use

- Keep updated lists of all medicines, both for yourself and for the person you are caring for. Keep the lists with you at all times ( click here to download a sample Medication Record Form). Include prescription drugs, over-the-counter medicines, vitamins, other nutritional products, and herbal remedies on the list. Share the lists with your doctors or the doctors of the person you are caring for.
- Some caregivers have to prepare and administer injectable medicines, such as insulin. Injections involve the use of a syringe and needle, which may be inserted under the skin or into a vein or muscle. Be certain that you understand and are comfortable with preparing the proper dosage and administering the injection. Nurses in doctors offices and pharmacists can and should instruct you on the proper techniques for injectable medicines.
- Store all of your medications in a designated location in your home. Keep all medications stored together in one place unless they require refrigeration or are labeled "store in a cool place." This will help if an emergency situation occurs and your doctor needs to review all your medications.

- Be sure that your medications are stored out of reach of any children that may visit, especially if you have non-child proof containers. If you are caring for someone with cognitive or memory problems, be sure all medications are safely stored away.
- Do not mix different medications together in one container; this will make it difficult if not impossible to identify your medications in an emergency.

- Medicines should be stored in a cool, dry area. Do not store your medications in the medicine cabinet in the bathroom or in the kitchen because heat and moisture cause deterioration. Instead, store your medications in a designated area in your bedroom, dining room or living room.
- Medications stored in the refrigerator should be separated from other items in the refrigerator. Consider keeping refrigerated medications in a plastic box or container in one consistent location in the refrigerator.
- Medications taken by mouth should be kept separate from other items that are for external use only, such as creams and ointments.
- Expired medications (there are expiration dates on all of your medications) and any medication that your doctor has discontinued should be discarded.
- Never share or give your medications to another person.

## Questions about Medications for Physicians and Pharmacists

One responsibility of patients and their caregivers is to fully prepare for medical appointments. Before visits, write down everything you want to talk about, including important questions related to medications. Take notes during appointments, and review the notes after the appointment. You may have additional questions to ask of doctors and pharmacists, such as:

- Why is this medicine prescribed?
- How does the medicine work in my body?
- How can I expect to feel once I start taking this medicine?
- How will I know that the medicine is working? Is there a typical time period after which my symptoms should improve?
- How long will I have to take the medicine? Will I need a refill when I finish this prescription?
- Will this medicine interact with other medications—prescription and nonprescription—that I am taking now?
- Should I take this medicine with food? Are there any foods or beverages I should avoid? (Grapefruit, for example, may interfere with the action of certain medications.) Is it safe to drink alcohol while on this medicine?
- Are there any activities I should avoid while taking this medicine?
- Can this medicine be chewed, crushed, dissolved, or mixed with other medicines?
- What possible problems might I experience with the medicine? How can I prevent these problems from occurring? At what point should I report problems with the medicine?
- What should I do if I miss a dose of this medicine, or take too much?
- What is the cost of the medicine prescribed? Is there a less expensive alternative prescription?
- Is a generic version of this medicine available? If so, should I purchase the generic instead of the brand name medicine?
- Do you have written information about the medicine that I can take home with me?
- Does the pharmacy provide special services such as home delivery or comprehensive medication review and counseling?

## Sharing the Responsibility

The scope and severity of problems that can occur with medication therapy are tremendous. To prevent these problems from occurring, consumers and caregivers, as well as their health care professionals, have a responsibility to ensure appropriate, safe and effective medication use. All professionals involved in prescribing and dispensing—as well as the consumer and caregiver—should consider themselves essential members of the health care team. The consumer or caregiver who alerts their doctor or nurse to the need for changes to medication therapy plays a vital role in getting the best treatment.

Consumer and caregiver responsibilities center on effective communication with the health care team. This includes presenting actual or potential medication-related problems in a timely manner to health care professionals, and participating in resolution of the problems. Before this can happen, consumers and caregivers must be able to recognize the possible signs and symptoms of a medication-related problem. *For older adults, any symptom should be considered a medication-related problem until proved otherwise.* When symptoms interfere with daily functioning and when the time sequence of the symptom indicates that it was caused by a medication, then a health care professional should be informed immediately.

Consumers and caregivers share responsibilities by expressing their concerns, expectations, and any lack of understanding about medication therapy and demanding answers to their questions. Consumers need to be able to present health care professionals with accurate and complete information about health conditions. It is important for consumers with new medical problems to fully describe the problem, indicate how long it has been a problem, if the problem has been experienced before, how it started, what was done to relieve it, and what worked or didn't work. For seniors with cognitive impairments, caregivers play a vital role in recognizing changes in health conditions and effectively describing problems to health care professionals.

## For More Information

**Family Caregiver Alliance**
180 Montgomery Street, Suite 1100
San Francisco, CA  94104
(415) 434–3388
(800) 445–8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating brain disorders that strike adults.

**American Society of Consultant Pharmacists (ASCP) and the ASCP Research and Education Foundation**
www.ascp.com and www.ascpfoundation.org
(800) 355–2727

ASCP is the international professional association that works to advance the practice of senior care pharmacy. ASCP's 6,500+ members manage and improve drug therapy and improve the quality of life of geriatric patients and other individuals residing in a variety of environments, including nursing facilities, subacute care and assisted living facilities, psychiatric hospitals, hospice programs, and home and community-based care.

**SeniorCarePharmacist.com**
www.SeniorCarePharmacist.com

This web site provides practical information about safe medication use for older persons and includes a directory of senior care pharmacists across the country who are specialists in geriatric drug therapy and the unique medication-related needs of older persons. Senior Care Pharmacists can identify and prevent medication-related problems through careful evaluation and monitoring of patients' drug regimens.

**American Geriatrics Society**
www.americangeriatrics.org/products/booktoc.shtml
(212) 308–1414

The American Geriatrics Society's Complete Guide to Aging & Health is a comprehensive resource for the lay audience that includes invaluable and expert ad-vice for those of us who want to prepare ourselves for a healthy old age or ensure proper care for our older loved ones.

**Food and Drug Administration**
www.fda.gov/cder/consumerinfo/DPAdefault.htm
(888) 463–6332

FDA provides consumers with information on prescription, generic, and over-the-counter drug products. The Center for Drug Evaluation and Research has developed numerous informational materials to help consumers make informed decisions about using medicines.

**National Council on Patient Information and Education (NCPIE)**
www.talkaboutrx.org
(301) 656–8565

NCPIE is a coalition of over 130 organizations committed to safer, more effective medicine use through better communication. NCPIE's information is de-signed to help consumers make sound decisions about the use of medicines.

**Peter Lamy Center for Drug Therapy and Aging, School of Pharmacy, University of Maryland**
www.pharmacy.umaryland.edu/lamy/
(877) 706–2434

The Center is dedicated to improving drug therapy for aging adults through programs and publications including a series called the ElderCare Brochures, in-tended to address the complexities of medications and multiple disease states.

For information on **Medicare prescription coverage**, visit www.medicare.gov and www.medicarerights.org.

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This fact sheet was prepared for the National Center on Caregiving at Family Caregiver Alliance by Kathleen A. Cameron, R.Ph., M.P.H., Executive Director, American Society of Consultant Pharmacists, and reviewed by Ron Finley, R.Ph., Department of Clinical Pharmacy, University of California, San Francisco, School of Pharmacy. Funded by the Archstone Foundation.

# Pharmaceutical Waste: Disposing of Unwanted Medications

Expired or unwanted prescription or over-the-counter medications from households have traditionally been disposed of by flushing them down the toilet or a drain. Although this method of disposal prevents immediate accidental ingestion, it can cause pollution in wastewater, which has been demonstrated to cause adverse effects to fish and other aquatic wildlife. When the water is eventually reused, it can also cause unintentional human exposure to chemicals in medications.

## Disposing of Medications at Home

Your unwanted medications may be disposed of in your trash. Follow these precautions to prevent accidental or intentional ingestion.

1. **Keep the medication in its original container**. The labels may contain safety information and the caps are typically childproof. Leaving the content information clearly visible, scratch the patient's name out or cover it over with permanent maker.

2. **Modify the contents to discourage consumption**.
   - Solid medications: add a small amount of water to pills or capsules to at least partially dissolve them.
   - Liquid medications: add enough table salt, flour, charcoal, or nontoxic powdered spice, such as turmeric or mustard to make a pungent, unsightly mixture that discourages anyone from eating it.
   - Blister packs: wrap packages containing pills in multiple layers of opaque tape like duct tape.

3. **Seal and conceal.** Tape the medication container lid shut with packing or duct tape and put it inside a non-transparent bag or container such as an empty yogurt or margarine tub to ensure that the contents cannot be seen.

4. **Discard the container in your garbage can**—do not place in the recycling bin. Do not conceal medicines in food products because they could be inadvertently consumed by wildlife scavengers.

## Managing Other Types of Pharmaceutical Waste

**Unused ampules, vials, and IV bags** should not be opened (other than to scratch out the patient's name). Wrap the container with tape to minimize breakage, then place in an opaque plastic container (such as an empty yogurt or margarine tub). Wrap the outside of the container or bag with additional duct or shipping tape to prevent leakage and further obscure the contents. Dispose of the container in the trash.

**Chemotherapy drugs** may require special handling. Work with your healthcare provider on proper disposal options for this type of medication.

# Proper Disposal of Prescription Drugs

Office of National Drug Control Policy    February 2007

## *Federal Guidelines:*

- Take unused, unneeded, or expired prescription drugs out of their original containers and throw them in the trash.
- Mixing prescription drugs with an undesirable substance, such as used coffee grounds or kitty litter, and putting them in impermeable, non-descript containers, such as empty cans or sealable bags, will further ensure the drugs are not diverted.
- Flush prescription drugs down the toilet *only* if the label or accompanying patient information specifically instructs doing so (see box).
- Take advantage of community pharmaceutical take-back programs that allow the public to bring unused drugs to a central location for proper disposal. Some communities have pharmaceutical take-back programs or community solid-waste programs that allow the public to bring unused drugs to a central location for proper disposal. Where these exist, they are a good way to dispose of unused pharmaceuticals.

The FDA advises that the following drugs be flushed down the toilet instead of thrown in the trash:

**Actiq** (fentanyl citrate)
**Daytrana Transdermal Patch** (methylphenidate)
**Duragesic Transdermal System** (fentanyl)
**OxyContin Tablets** (oxycodone)
**Avinza Capsules** (morphine sulfate)
**Baraclude Tablets** (entecavir)
**Reyataz Capsules** (atazanavir sulfate)
**Tequin Tablets** (gatifloxacin)
**Zerit for Oral Solution** (stavudine)
**Meperidine HCl Tablets**
**Percocet** (Oxycodone and Acetaminophen)
**Xyrem** (Sodium Oxybate)
**Fentora** (fentanyl buccal tablet)

Note: Patients should always refer to printed material accompanying their medication for specific instructions.

Office of National Drug Control Policy
ONDCP, Washington, D.C. 20503
p (202) 395-6618    f (202) 395-6730

# Pain

## Introduction: The Universal Disorder

In its most benign form, pain warns us that something isn't quite right, that we should take medicine or see a doctor. At its worst, however, pain robs us of our productivity, our well-being, and, for many of us suffering from extended illness, our very lives. Pain is a complex perception that differs enormously among individual patients, even those who appear to have identical injuries or illnesses.

In 1931, the French medical missionary Dr. Albert Schweitzer wrote, "Pain is a more terrible lord of mankind than even death itself." Today, pain has become the universal disorder, a serious and costly public health issue, and a challenge for family, friends, and health care providers who must give support to the individual suffering from the physical as well as the emotional consequences of pain.

## The Two Faces of Pain: Acute and Chronic

**What is pain?** The International Association for the Study of Pain defines it as: An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.
It is useful to distinguish between two basic types of pain, acute and chronic, and they differ greatly.

- **Acute pain**, for the most part, results from disease, inflammation, or injury to tissues. This type of pain generally comes on suddenly, for example, after trauma or surgery, and may be accompanied by anxiety or emotional distress. The cause of acute pain can usually be diagnosed and treated, and the pain is self-limiting, that is, it is confined to a given period of time and severity. In some rare instances, it can become chronic.

- **Chronic pain** is widely believed to represent disease itself. It can be made much worse by environmental and psychological factors. Chronic pain persists over a longer period of time than acute pain and is resistant to most medical treatments. It can—and often does—cause severe problems for patients.

## The A to Z of Pain

Hundreds of pain syndromes or disorders make up the spectrum of pain. There are the most benign, fleeting sensations of pain, such as a pin prick. There is the pain of childbirth, the pain of a heart attack, and the pain that sometimes follows amputation of a limb. There is also pain accompanying cancer and the pain that follows severe trauma, such as that associated with head and spinal cord injuries. A sampling of common pain syndromes follows, listed alphabetically.

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| **Arachnoiditis** | Is a condition in which one of the three membranes covering the brain and spinal cord, called the arachnoid membrane, becomes inflamed. A number of causes, including infection or trauma, can result in inflammation of this membrane. Arachnoiditis can produce disabling, progressive, and even permanent pain. |
| **Arthritis.** | Millions of Americans suffer from arthritic conditions such as osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, and gout. These disorders are characterized by joint pain in the extremities. Many other inflammatory diseases affect the body's soft tissues, including tendonitis and bursitis. |

The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

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| **Back pain** | Has become the high price paid by our modern lifestyle and is a startlingly common cause of disability for many Americans, including both active and inactive people. Back pain that spreads to the leg is called sciatica and is a very common condition. Another common type of back pain is associated with the discs of the spine. Discs protect the spine by absorbing shock, but they tend to degenerate over time and may sometimes rupture. |
| **Burn pain** | Can be profound and poses an extreme challenge to the medical community. First-degree burns are the least severe; with third-degree burns, the skin is lost. Depending on the injury, pain accompanying burns can be excruciating, and even after the wound has healed patients may have chronic pain at the burn site. |
| **Central pain syndrome** | see "Trauma" below |
| **Cancer pain** | Can accompany the growth of a tumor, the treatment of cancer, or chronic problems related to cancer's permanent effects on the body. Fortunately, most cancer pain can be treated to help minimize discomfort and stress to the patient. |
| **Headaches** | Affect millions of Americans. The three most common types of chronic headache are migraines, cluster headaches, and tension headaches. Each comes with its own telltale brand of pain. |

- **Migraines** are characterized by throbbing pain and sometimes by other symptoms, such as nausea and visual disturbances. Migraines are more frequent in women than men. Stress can trigger a migraine headache, and migraines can also put the sufferer at risk for stroke.
- **Cluster headaches** are characterized by excruciating, piercing pain on one side of the head; they occur more frequently in men than women.
- **Tension** headaches are often described as a tight band around the head.

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| **Head and facial pain** | can be agonizing, whether it results from dental problems or from disorders such as cranial neuralgia, in which one of the nerves in the face, head, or neck is inflamed. Another condition, **trigeminal neuralgia** (also called tic douloureux), affects the largest of the cranial nerves and is characterized by a stabbing, shooting pain. |
| **Muscle pain** | Can range from an aching muscle, spasm, or strain, to the severe spasticity that accompanies paralysis. |

- **Fibromyalgia** is a disabling syndrome characterized by fatigue, stiffness, joint tenderness, and widespread muscle pain.
- **Polymyositis, dermatomyositis**, and **inclusion body myositis** are painful disorders characterized by muscle inflammation. They may be caused by infection or autoimmune dysfunction and are sometimes associated with connective tissue disorders, such as lupus and rheumatoid arthritis.

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| **Myofascial pain syndromes** | Affect sensitive areas known as trigger points, located within the body's muscles. Myofascial pain syndromes are sometimes misdiagnosed and can be debilitating. **Fibromyalgia** is a type of myofascial pain syndrome. |
| **Neuropathic pain** | Is a type of pain that can result from injury to nerves, either in the peripheral or central nervous system. Neuropathic pain can occur in any part of the body and is frequently described as a hot, burning sensation, which can be devastating to the affected individual. It can result from diseases that affect nerves (such as diabetes) or from trauma, or, because chemotherapy drugs can affect nerves, it can be a consequence of cancer treatment. |

- **Diabetic neuropathy,** which results from nerve damage secondary to vascular problems that occur with diabetes
- **reflex sympathetic dystrophy syndrome,** which can follow injury
- **phantom limb** and **post-amputation pain,** which can result from the surgical removal of a limb
- **postherpetic neuralgia**, which can occur after an outbreak of shingles
- **central pain syndrome**, which can result from trauma to the brain or spinal cord

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| **Reflex sympathetic dystrophy syndrome (RSDS)** | Is accompanied by burning pain and hypersensitivity to temperature. Often triggered by trauma or nerve damage, RSDS causes the skin of the affected area to become characteristically shiny. In recent years, RSDS has come to be called **complex regional pain syndrome** (CRPS); in the past it was often called **causalgia**. |

Repetitive stress injuries are muscular conditions that result from repeated motions performed in the course of normal work or other daily activities. They include:

- **writer's cramp**, which affects musicians and writers and others,
- compression or entrapment neuropathies, including **carpal tunnel syndrome**, caused by chronic overextension of the wrist
- **tendonitis** or tenosynovitis ( inflammation of the lining of the sheath that surrounds a tendon (the cord that joins muscle to bone). affecting one or more tendons

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| **Sciatica** | Is a painful condition caused by pressure on the sciatic nerve, the main nerve that branches off the spinal cord and continues down into the thighs, legs, ankles, and feet. Sciatica is characterized by pain in the buttocks and can be caused by a number of factors. Exertion, obesity, and poor posture can all cause pressure on the sciatic nerve. One common cause of sciatica is a herniated disc. |
| **Shingles** and other painful disorders affect the skin | Pain is a common symptom of many skin disorders, even the most common rashes. One of the most vexing neurological disorders is shingles or herpes zoster, an infection that often causes agonizing pain resistant to treatment. Prompt treatment with antiviral agents is important to arrest the infection, which if prolonged can result in an associated condition known as **postherpetic neuralgia**. |

Other painful disorders affecting the skin include:

- **vasculitis**, or inflammation of blood vessels
- other infections, including **herpes simplex**
- **skin tumors** and **cysts**
- tumors associated with **neurofibromatosis**, a neurogenetic disorder.

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| **Sports injuries** | Are common. Sprains, strains, bruises, dislocations, and fractures are all well-known words in the language of sports. Pain is another. In extreme cases, sports injuries can take the form of costly and painful spinal cord and head injuries, which cause severe suffering and disability. |
| **Spinal stenosis** | Refers to a narrowing of the canal surrounding the spinal cord. The condition occurs naturally with aging. Spinal stenosis causes weakness in the legs and leg pain usually felt while the person is standing up and often relieved by sitting down. |
| **Surgical pain** | May require regional or general anesthesia during the procedure and medications to control discomfort following the operation. Control of pain associated with surgery includes presurgical preparation and careful monitoring of the patient during and after the procedure. |

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| **Temporomandibular disorders** | Are conditions in which the temporomandibular joint (the jaw) is damaged and/or the muscles used for chewing and talking become stressed, causing pain. The condition may be the result of a number of factors, such as an injury to the jaw or joint misalignment, and may give rise to a variety of symptoms, most commonly pain in the jaw, face, and/or neck muscles. Physicians reach a diagnosis by listening to the patient's description of the symptoms and by performing a simple examination of the facial muscles and the temporomandibular joint. |
| **Trauma** | Can occur after injuries in the home, at the workplace, during sports activities, or on the road. Any of these injuries can result in severe disability and pain.<br>Some patients who have had an injury to the spinal cord experience intense pain ranging from tingling to burning and, commonly, both. Such patients are sensitive to hot and cold temperatures and touch. For these individuals, a touch can be perceived as intense burning, indicating abnormal signals relayed to and from the brain. This condition is called **central pain syndrome** or, if the damage is in the thalamus (the brain's center for processing bodily sensations), **thalamic pain syndrome**. It affects as many as 100,000 Americans with multiple sclerosis, Parkinson's disease, amputated limbs, spinal cord injuries, and stroke. Their pain is severe and is extremely difficult to treat effectively. A variety of medications, including analgesics, antidepressants, anticonvulsants, and electrical stimulation, are options available to central pain patients. |
| **Vascular disease or injury** | Such as vasculitis or inflammation of blood vessels, coronary artery disease, and circulatory problems-all have the potential to cause pain. Vascular pain affects millions of Americans and occurs when communication between blood vessels and nerves is interrupted. Ruptures, spasms, constriction, or obstruction of blood vessels, as well as a condition called ischemia in which blood supply to organs, tissues, or limbs is cut off, can also result in pain |

## How is Pain Diagnosed?

There is no way to tell how much pain a person has. No test can measure the intensity of pain, no imaging device can show pain, and no instrument can locate pain precisely. Sometimes, as in the case of headaches, physicians find that the best aid to diagnosis is the patient's own description of the type, duration, and location of pain.

**Defining pain** as sharp or dull, constant or intermittent, burning or aching may give the best clues to the cause of pain. These descriptions are part of what is called the pain history, taken by the physician during the preliminary examination of a patient with pain.

Physicians, however, do have a number of technologies they use to find the cause of pain. Primarily these include:

- **Electrodiagnostic** procedures include:
    - **Electromyography (EMG)** - can help physicians tell precisely which muscles or nerves are affected by weakness or pain.
    - **Nerve conduction studies** - from this information the doctor can determine if there is nerve damage.
    - **Evoked potential (EP) studies** - records the speed of nerve signal transmission to the brain.

- **Magnetic resonance imaging or MRI** - provides physicians with pictures of the body's structures and tissues differentiating between healthy and diseased tissue.
- **Neurological examination** - the physician tests movement, reflexes, sensation, balance, and coordination.
- **X-rays** - to examine the body's structures, such as bones and joints.

## How is Pain Treated?

The **goal of pain management** is to improve function, enabling individuals to work, attend school, or participate in other day-to-day activities. Patients and their physicians have a number of options for the treatment of pain; some are more effective than others. Sometimes, relaxation and the use of imagery as a distraction provide relief. These methods can be powerful and effective, according to those who advocate their use. Whatever the treatment regime, it is important to remember that pain is treatable.

The following treatments are among the most common:

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| **Acetaminophen** | Is the basic ingredient found in **Tylenol®** and its many generic equivalents. It is sold over the counter, in a prescription-strength preparation, and in combination with codeine (also by prescription). |
| **Acupuncture** | Dates back 2,500 years and involves the application of needles to precise points on the body. It is part of a general category of healing called traditional Chinese or Oriental medicine. Acupuncture remains controversial but is quite popular and may one day prove to be useful for a variety of conditions as it continues to be explored by practitioners, patients, and investigators. |
| **Analgesic** | Refers to the class of drugs that includes most painkillers, such as aspirin, acetaminophen, and ibuprofen. Nonprescription or over-the-counter pain relievers are generally used for mild to moderate pain. Prescription pain relievers, sold through a pharmacy under the direction of a physician, are used for more moderate to severe pain. |

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| **Anticonvulsants** | Are used for the treatment of seizure disorders but are also sometimes prescribed for the treatment of pain. **Carbamazepine** in particular is used to treat a number of painful conditions, including trigeminal neuralgia. Another antiepileptic drug, **gabapentin**, is being studied for its pain-relieving properties, especially as a treatment for neuropathic pain. |
| **Antidepressants** | Are sometimes used for the treatment of pain and belong to a category of drugs called psychotropic drugs. In addition, anti-anxiety drugs called benzodiazepines also act as muscle relaxants and are sometimes used as pain relievers. Physicians usually try to treat the condition with analgesics before prescribing these drugs. |

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| **Antimigraine** | Drugs include the triptans- **sumatriptan (Imitrex®), naratriptan (Amerge®),** and **zolmitriptan (Zomig®)-**and are used specifically for migraine headaches. They can have serious side effects in some people and therefore, as with all prescription medicines, should be used only under a doctor's care. |
| **Aspirin** | May be the most widely used pain-relief agent and has been sold over the counter since 1905 as a treatment for fever, headache, and muscle soreness. |

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| **Biofeedback** | Is used for the treatment of many common pain problems, most notably headache and back pain. Using a special electronic machine, the patient is trained to become aware of, to follow, and to gain control over certain bodily functions, including muscle tension, heart rate, and skin temperature. The individual can then learn to effect a change in his or her responses to pain, for example, by using relaxation techniques. Biofeedback is often used in combination with other treatment methods, generally without side effects. Similarly, the use of relaxation techniques in the treatment of pain can increase the patient's feeling of well-being. |
| **Capsaicin** | Is a chemical found in chili peppers that is also a primary ingredient in pain-relieving creams. Capsaicin is currently available as a prescription or over-the-counter cream for the treatment of a number of pain conditions, such as shingles. It works by reducing pain receptors found in nerve endings and interferes with the transmission of pain signals to the brain. |
| **Chemonucleolysis** | Is a treatment in which an enzyme, chymopapain, is injected directly into a herniated lumbar disc in an effort to dissolve material around the disc, thus reducing pressure and pain. The procedure's use is extremely limited, in part because some patients may have a life-threatening allergic reaction to chymopapain. |

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| **Chiropractic** | Refers to hand manipulation of the spine, usually for relief of back pain, and is a treatment option that continues to grow in popularity among many people who simply seek relief from back disorders. It has never been without controversy, however. Chiropractic's usefulness as a treatment for back pain is, for the most part, restricted to a select group of individuals with uncomplicated acute low back pain who may derive relief from the massage component of the therapy. |

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| **Cognitive-behavioral therapy** | Involves a wide variety of coping skills and relaxation methods to help prepare for and cope with pain. It is used for postoperative pain, cancer pain, and the pain of childbirth. |

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| **Counseling** | Can give a patient suffering from pain much needed support, whether it is derived from family, group, or individual counseling. Support groups can provide an important adjunct to drug or surgical treatment. Psychological treatment can also help patients learn about the physiological changes produced by pain. |
| **COX-2 inhibitors** | May be effective for individuals with arthritis. The newer COX-2 inhibitors are less likely to have the gastrointestinal side effects sometimes produced by NSAIDs.<br>In 1999, the Food and Drug Administration approved a COX-2 inhibitor-celecoxib-for use in cases of chronic pain. The long-term effects of all COX-2 inhibitors are still being evaluated, especially in light of new information suggesting that these drugs may increase the risk of heart attack and stroke. Patients taking any of the COX-2 inhibitors should review their drug treatment with their doctors. |
| **Electrical stimulation** | Including transcutaneous electrical stimulation (TENS), implanted electric nerve stimulation, and deep brain or spinal cord stimulation, is the modern-day extension of age-old practices in which the nerves of muscles are subjected to a variety of stimuli, including heat or massage. Electrical stimulation, no matter what form, involves a major surgical procedure and is not for everyone, nor is it 100 percent effective. The following techniques each require specialized equipment and personnel trained in the specific procedure being used. |
| **Exercise** | Has come to be a prescribed part of some doctors' treatment regimes for patients with pain. Because there is a known link between many types of chronic pain and tense, weak muscles, exercise-even light to moderate exercise such as walking or swimming, can contribute to an overall sense of well-being by improving blood and oxygen flow to muscles. Just as we know that stress contributes to pain, we also know that exercise, sleep, and relaxation can all help reduce stress, thereby helping to alleviate pain. Exercise has been proven to help many people with low back pain. It is important, however, that patients carefully follow the routine laid out by their physicians or physical therapists. |
| **Hypnosis** | First approved for medical use by the American Medical Association in 1958, continues to grow in popularity, especially as an adjunct to pain medication. In general, hypnosis is used to control physical function or response, that is, the amount of pain an individual can withstand. Hypnosis may result in relief of pain by acting on chemicals in the nervous system, slowing impulses. Whether and how hypnosis works involves greater insight-and research-into the mechanisms underlying human consciousness. |
| **Low-power lasers** | Have been used occasionally by some physical therapists as a treatment for pain, but like many other treatments, this method is not without controversy. |

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| **Nerve blocks** | Employ the use of drugs, chemical agents, or surgical techniques to interrupt the relay of pain messages between specific areas of the body and the brain. There are many different names for the procedure, depending on the technique or agent used. Types of surgical nerve blocks include **neurectomy**; spinal dorsal, cranial, and trigeminal **rhizotomy**; and **sympathectomy**, also called sympathetic blockade. |

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| **Nonsteroidal anti-inflammatory drugs (NSAIDs)** | Including aspirin and ibuprofen, are widely prescribed and sometimes called non-narcotic or non-opioid analgesics. They work by reducing inflammatory responses in tissues. Many of these drugs irritate the stomach and for that reason are usually taken with food. Although acetaminophen may have some anti-inflammatory effects, it is generally distinguished from the traditional NSAIDs. |
| **Opioids** | Are derived from the poppy plant and are among the oldest drugs known to humankind. They include **codeine** and perhaps the most well-known narcotic of all, **morphine**. Opioids have a narcotic effect, that is, they induce sedation as well as pain relief, and some patients may become physically dependent upon them. For these reasons, patients given opioids should be monitored carefully; in some cases stimulants may be prescribed to counteract the sedative side effects. In addition to drowsiness, other common side effects include constipation, nausea, and vomiting. |
| **Physical therapy and rehabilitation** | Date back to the ancient practice of using physical techniques and methods, such as heat, cold, exercise, massage, and manipulation, in the treatment of certain conditions. These may be applied to increase function, control pain, and speed the patient toward full recovery. |
| **R.I.C.E.**<br>(**R**est, **I**ce, **C**ompression, and **E**levation) | Are four components prescribed by many orthopedists, coaches, trainers, nurses, and other professionals for temporary muscle or joint conditions, such as sprains or strains. While many common orthopedic problems can be controlled with these four simple steps, especially when combined with over-the-counter pain relievers, more serious conditions may require surgery or physical therapy, including exercise, joint movement or manipulation, and stimulation of muscles. |
| **Surgery** | Although not always an option, may be required to relieve pain, especially pain caused by back problems or serious musculoskeletal injuries. Surgery may take the form of a nerve block or it may involve an operation to relieve pain from a ruptured disc. |

## Pain Patient's Bill of Rights

You have the right to:

— Have your pain prevented or controlled adequately.

— Have your pain and pain-medication history taken.

— Have your pain questions answered freely.

— Develop a pain plan with your doctor.

— Know what medication, treatment or anesthesia will be given.

— Know the risks, benefits and side effects of treatment.

— Know what alternative pain treatments may be available.

— Sign a statement of informed consent before any treatment.

— Be believed when you say you have pain.

— Have your pain assessed on an individual basis.

— Have your pain assessed using the 0 = no pain, 10 = worst pain scale.

— Ask for changes in treatments if your pain persists.

— Receive compassionate and sympathetic care.

— Receive pain medication on a timely basis.

— Refuse treatment without prejudice from your doctor.

— Seek a second opinion or request a pain-care specialist.

— Be given your records on request.

— Include your family in decision-making.

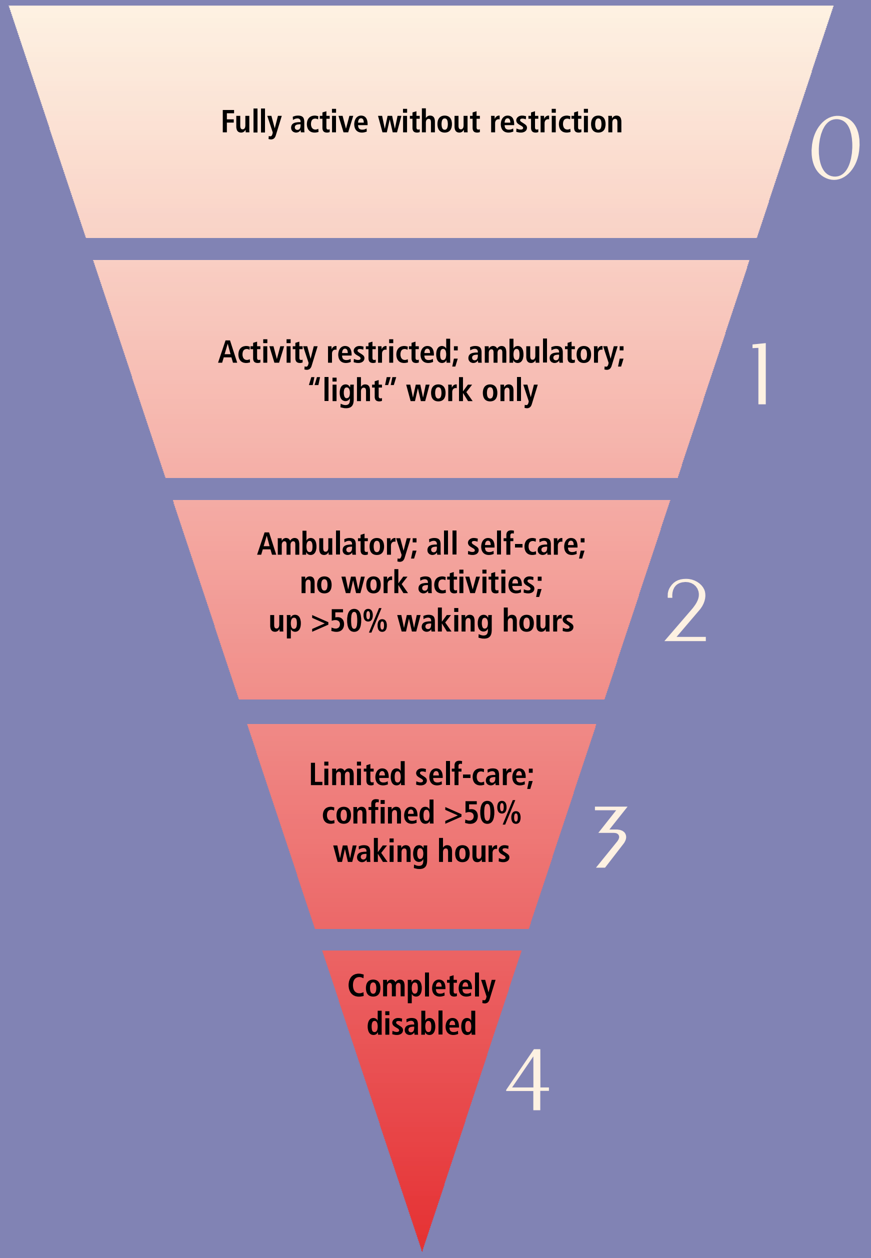
— Remind those who care for you that your pain management is part of your diagnostic, medical or surgical care.

Adapted from the book "Pain Relief!" by *Jane Cowles, Ph.D. (1994)*

## ASK IF PAIN AFFECTS YOUR PATIENTS' ACTIVITY LEVELS

Chronic pain can have a significant impact on your patients' quality of life, interfering with day-to-day functioning. Evaluating limitations on activities is important in managing your patients' pain.

*The chart below has been adapted from ECOG Performance Status: Oken MM et al. Am J of Clin Onc 5(6):649-655, 1982. In addition, you may want to assess psycho-social functioning when indicated.*



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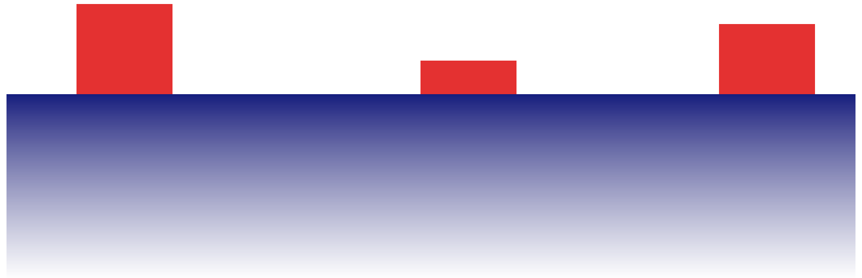
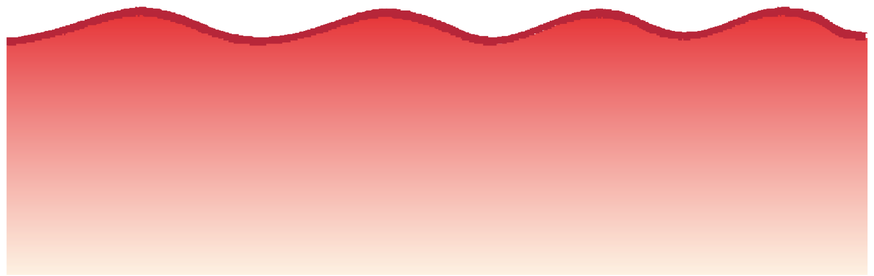
# CHRONIC PAIN:

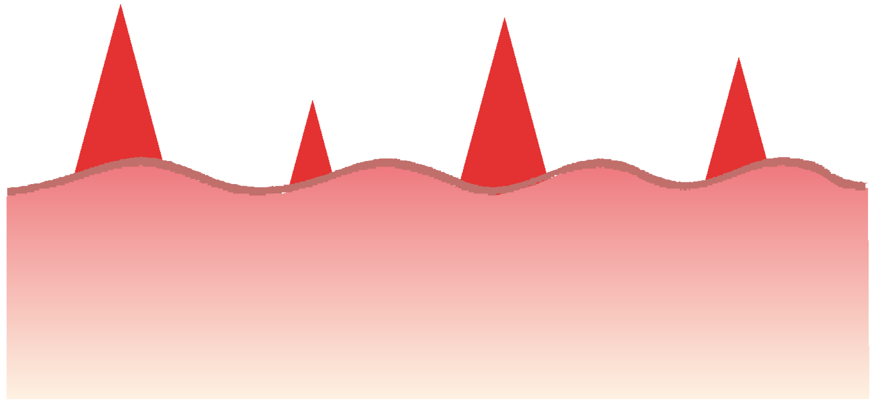
## INTERMITTENT, PERSISTENT, BREAKTHROUGH



**Intermittent Pain**
Pain that is episodic. It may occur in waves or patterns. Intermittent pain is often treated with NSAIDs, adjuvant medicines, and non-drug therapies. Moderate to severe intermittent pain may be treated with short-acting opioids.



**Persistent Pain (static, constant, or continuous)**
Pain that lasts 12 or more hours every day. This pain is usually treated with medicines taken around-the-clock as well as non-drug therapies. Moderate to severe pain may be treated with opioids.



**Breakthrough Pain (dynamic, sudden, or incidental)**
Pain that flares up or breaks through the relief provided by around-the-clock pain medicines. This pain may be treated with short-acting pain medicine that is taken as needed to quickly relieve the pain. Long-acting and short-acting medicines can be used together to provide continuous relief—the goal of pain management.

---

# TARGET CHRONIC PAIN

**T** Talk to your patients about their pain.

**A** Ask about current treatments.

**R** Rate pain intensity and get details.

**G** Get details about breakthrough pain.

**E** Evaluate limitations on activities.

**T** Treat side effects.

AMERICAN PAIN FOUNDATION

| PAIN ASSESSMENT QUESTIONS TO ASK | SUGGESTIONS FOR MANAGING YOUR PATIENTS' PAIN |
|---|---|
| **Talk to your patients about their pain.**<br>Where is the pain located?<br>What does it feel like (e.g., sharp, dull, burning)?<br>When did it begin? How long does it last?<br>What makes it better? What makes it worse? | Accept your patients' reports of pain.<br>Assess chronic pain as part of each visit.<br>Look for causes of pain.<br>Ask about any history of substance abuse or addiction.<br>Treat pain until optimal relief and functional outcomes are reached. |
| **Ask about current treatments.**<br>What medicines are you taking to relieve pain (prescription, over-the-counter)? What is the dose?<br>What other pain relief methods do you use (e.g., acupuncture, heat/cold, massage, home remedies)?<br>When do you use these medications and methods and how well do they work? | Develop a treatment plan that relates directly to the pain assessment findings. For prescribing medicines, consider using guidelines (see resources).<br>Review treatment plan with patients. Discuss expectations. Make sure patients understand the plan and are willing to follow it. If patients are not following the plan, find out why and work to correct the problem. |
| **Rate pain intensity and get details.**<br>What is your level of pain most of the time (0-10 scale)?<br>When is your pain the worst/best?<br>What is your pain level when you rest? During movement? | Evaluate need for multimodal pain treatment. That may include NSAIDs, opioids, adjuvants such as anticonvulsants or antidepressants, and/or non-drug therapies.<br>Among non-drug strategies consider rehabilitative and behavioral therapies.<br>Treat persistent moderate to severe pain for continuous relief. If a trial of opioid therapy is indicated, consider around-the-clock (ATC) dosing of long-acting opioids (LAO). For challenging cases, (e.g., refractory pain, psychiatric disease, disability, drug abuse risk), consider referrals to pain specialist, mental healthcare provider, addiction specialist, or others. |
| **Get details about breakthrough pain (BTP).**<br>Do you have breakthrough pain—sudden, brief periods of increased pain?<br>How often do you experience BTP on an average day?<br>Do certain activities cause the pain or does it happen unexpectedly?<br>Have you ever been treated for BTP? With what medicines? | Treat BTP: Reduce or eliminate precipitating causes if possible. Optimize the ATC medication regimen. Consider multimodal strategy, including rehabilitative treatments (e.g., PT, OT, bracing) and psychological treatments (e.g., relaxation training).<br>If unrelieved BTP during opioid therapy:<br>• End of LAO dose interval? Increase LAO daily dose or shorten interval.<br>• Unpredictable BTP? Add or change SAO.<br>• Predictable BTP with pain-producing activity? Add or increase SAO dose before activity.<br>Do not exceed acetaminophen 4000 mg/24h if combination SAO is selected. |
| **Evaluate limitations on activities.**<br>What daily activities do you avoid because of pain?<br>Does pain interfere with your ability to sleep/walk/work/play?<br>How does pain affect your mood and relationships? | If daily activities are limited or prevented by mild to moderate pain:<br>• Add or increase non-drug strategies.<br>• Add or change non-opioid or adjuvant drugs, or change opioid plan.<br>If activities or sleep are limited or prevented by moderate to severe pain:<br>• Increase dose or change ATC medicine.<br>• Add or increase dose or change SAO for BTP. |
| **Treat side effects.**<br>Are you experiencing side effects from pain medicines, such as drowsiness, nausea, or itching?<br>What are you doing to decrease or prevent these side effects?<br>Are you taking something to prevent constipation?<br>Are you having side effects with other medicines or therapies? | Discuss potential side effects of all pain medicines and non-drug treatments.<br>If patient reports side effects from opioids:<br>• Use antiemetic if nauseous, antihistamine if pruritus. In selected cases, co-administration of a stimulant may reverse drowsiness or mental clouding.<br>• Prevent or treat constipation with appropriate laxatives.<br>• Change opioid selection.<br>For side effects of SAO for BTP, consider:<br>• Take side effects medication before dose.<br>• Reduce dose or change opioid.<br>• Evaluate adequacy of multimodal adjuvant pain medications.<br>Expand use of non-drug methods. |

**The goal of pain management is to treat pain until optimal relief and functional outcomes are reached.**
**If you are not having success, or are not comfortable treating pain, refer your patient to a pain specialist.**

| | |
|---|---|
| **ATC** | around-the-clock |
| **BTP** | breakthrough pain |
| **LAO** | long–acting opioid |
| **SAO** | short-acting opioid |

## RESOURCES AND INFORMATION ABOUT OPIOIDS

**Treating Patients with Opioids:**
When prescribed by a healthcare professional and taken as directed, opioids are safe, effective, and rarely lead to addiction. For more information go to www.painfoundation.org

**Definitions of Addiction, Dependence, and Tolerance:**
These terms are often confused. For more information see Definitions Related to the Use of Opioids in the Treatment of Pain: asam.org/pain/definitions2.pdf

**Evaluating Risk:**
When prescribing opioids, vulnerability to addiction should be assessed in all patients. Some problems to look for:
- A pattern of repeated non-adherence to pain treatment plan
- Absence of pain relief during gradual escalation of opioid therapy
- Lack of functional improvement

**Treating Patients at Risk for Addiction:**
To learn more about treating patients with addictive disease, see the ASPMN position statement Pain Management in Patients with Addictive Disease: www.aspmn.org/html/PSaddiction.htm

**Diversion & Abuse:**
Be mindful of the problem of diversion and abuse of opioids. To learn more about how you can care for patients with pain, while keeping your practice safe, refer to Model Guidelines for the Use of Controlled Substances for the Treatment of Pain by the Federation of State Medical Boards of the United States: www.medsch.wisc.edu/painpolicy/domestic/model.htm

**Other Resources:**
For information on treating your patients with opioids and other analgesics:
- American Pain Society's Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain. For ordering information, go to: www.ampainsoc.org/pub/principles.htm
- Guideline for the Management of Pain in Osteoarthritis, Rheumatoid Arthritis and Juvenile Chronic Arthritis: www.ampainsoc.org/pub/arthritis.htm
- AGS Guidelines for the Management of Persistent Pain in Older Persons: www.americangeriatrics.org/education/manage_pers_pain.shtml
- National Institute on Drug Abuse (NIDA): www.drugabuse.gov (search "opioids")
- Drug and Alcohol Services Information System (DASIS): www.samhsa.gov/oas/dasis.htm
- Drug Abuse Warning Network (DAWN): dawninfo.samhsa.gov

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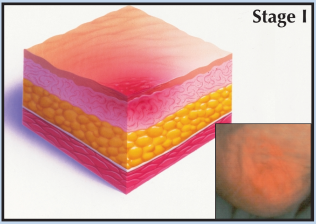
# Guidelines for Staging of Pressure Ulcers

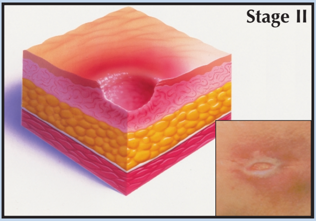
The following criteria can be used to quickly identify pressure ulcer wound stages as defined by the Wound Ostomy and Continence Nurses Society (WOCN) in their STANDARDS OF CARE (1992), the AHCPR Clinical Practice Guidelines (1994), now the Agency for Healthcare Research and Quality (AHRQ), the National Pressure Ulcer Advisory Panels (NPUAP) addition originally published in ADVANCES IN WOUND CARE (Nov/Dec 1995) and the 1998 revision of the Stage I definition by the NPUAP.



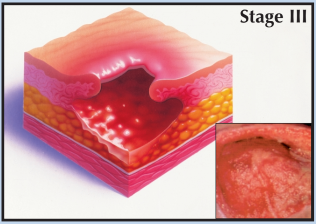
An observable pressure-related alteration of intact skin whose indicators as compared to the adjacent or opposite area on the body may include changes in one or more of the following:

Skin temperature (warmth or coolness),
Tissue consistency (firm or boggy feel) and/or
Sensation (pain, itching).

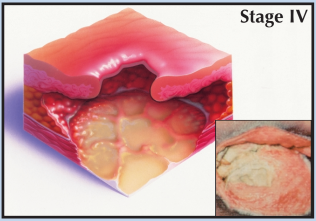
The ulcer appears as a defined area of persistent redness in lightly pigmented skin, whereas in darker skin tones, the ulcer may appear with persistent red, blue or purple hues.



Partial thickness loss of skin involving epidermis and/or dermis. The ulcer is superficial and presents clinically as an abrasion, blister, or shallow crater.



Full-thickness tissue loss involving damage to or necrosis of subcutaneous tissue that may extend down to, but not through, underlying fascia. The ulcer presents clinically as a deep crater with or without undermining of adjacent tissue.



Full-thickness tissue loss with extensive destruction, tissue necrosis or damage to muscle, bone or supporting structures (e.g. tendon, joint capsule). Undermining and sinus tracts also may be associated with Stage IV pressure ulcers.

# Guidelines for Pressure Ulcer Prevention and Treatment

| PREVENTION | STAGE I | STAGE II | STAGE III & IV |
|---|---|---|---|
| ▪ Inspect skin daily<br>▪ Cleanse skin when soiled with soap and water<br>▪ Minimize exposure to moisture from incontinence, perspiration, or wound drainage<br>▪ Moisturize dry skin<br>▪ Minimize shear and friction (observe proper positioning, transfer, turning techniques)<br>▪ Utilize skin protectants / antimicrobial ointments as moisture barrier as necessary<br>▪ Address nutritional needs<br>▪ Reposition at least every 2 hours<br>▪ Increase mobility, activity<br>▪ Use pressure reduction devices in bed, chair, wheelchair<br>▪ Relieve pressure on bony prominences<br>▪ Relieve heel pressure<br>▪ Maintain head of bed no higher than 30 degrees<br>▪ Use lifting devices<br>▪ Involve and educate consumer and/or provider<br>▪ Monitor and document interventions and outcomes | **Treatment may include:**<br>▪ Apply skin protectants / antimicrobial ointments to buttocks with each episode of incontinence.<br>**Or**<br>▪ Cleanse with Wound Cleanser, pat dry<br>▪ Cover with Transparent Film Dressing or Thin Hydrocolloid<br>▪ Change at least 2x week and PRN | **Minimal Drainage:**<br>▪ Cleanse with Wound Cleanser and apply skin protectants / antimicrobial ointments as moisture barrier to buttocks with each episode of incontinence.<br>**Or**<br>▪ Apply Skin Prep to skin area around the wound<br>▪ Apply Hydrogel sheet<br>▪ Cover with Transparent Film Dressing or Hydrocolloid dressing.<br>▪ Change 2x a week and PRN for dislodgment or leakage<br>**Or**<br>**Moderate to Heavy Drainage**<br>▪ Cleanse with Wound Cleanser<br>▪ Apply calcium alginate product to wound bed<br>▪ Apply Hydrogel ointment or Hydrogel sheet Cover with Bordered Gauze, Transparent Film Dressing, or Hydrocolloid dressing and change 2x a week and PRN | **Low Drainage**<br>▪ Irrigate wound with Wound Cleanser (4 to 15 psi)<br>▪ Apply Calcium Alginate Wound Dressing, Waterproof Foam dressing or Hydrogel to wound cavity<br>▪ Cover with a Bordered Gauze, or Hydrocolloid dressing<br>▪ Change 2x a week and PRN for dislodgment or leakage<br>**Or**<br>**Moderate to Heavy Drainage**<br>▪ Irrigate wound with Wound Cleanser (4 to 15 psi)<br>▪ Line wound bed with Calcium Alginate (rope or sheet), waterproof Foam Dressing, or Hydrogel to wound cavity<br>▪ Apply Skin Prep to skin area around the wound<br>▪ Cover with Bordered Gauze, Transparent Film Dressing, or Hydrocolloid dressing<br>▪ May frame with tape to prevent premature dislodgement<br>▪ Change 2x a week and PRN for dislodgement or leakage<br>**Stage IV Wounds**<br>▪ Consider using a hydrofiber dressing or high percentage of alginate to control exudates |

Adapted (8-07) from: http://www.dermarite.com/pressure_ulcer_protocols.html

# Pressure Ulcer Risk Assessment Scale
## (Adapted from the Braden Scale)

*NOTE: This tool would be helpful in assessing risk of bed and chairbound individuals or those with impaired ability to reposition.*

| | | | | |
|---|---|---|---|---|
| **Sensory Perception**<br>*Ability to respond meaningfully to pressure-related discomfort* | **1. Completely Limited** | **2. Very Limited** | **3. Slightly Limited** | **4. No Impairment** |
| | Unresponsive to painful stimuli, due to diminished level of consciousness or sedation<br>OR<br>limited ability to feel pain over most of body surface | Responds only to painful stimuli. Cannot communicate discomfort except by moaning or restlessness.<br>OR<br>has a sensory impairment which limits the ability to feel pain or discomfort over ½ of body | Responds to verbal commands, but cannot always communicate discomfort or the need to be turned.<br>OR<br>has some sensory impairment which limits ability to feel pain or discomfort in 1 or 2 extremities. | Responds to verbal commands. Has no sensory deficit which would limit ability to feel or voice pain or discomfort |
| **Moisture**<br>*Degree to which skin is exposed to moisture* | **1. Constantly Moist** | **2. Very Moist** | **3. Occasionally Moist** | **4. Rarely Moist** |
| | Skin is kept moist almost constantly by perspiration, urine, etc. Dampness is detected every time patient is moved or turned. | Skin is often, but not always, moist. Linen must be changed least or two or three times a day. | Skin is occasionally moist, requiring an extra linen change daily. | Skin is usually dry. Linen only requires changing at routine intervals. |
| **Activity**<br>*Degree of physical activity* | **1. Bedfast** | **2. Chairfast** | **3. Walks Occasionally** | **4. Walks Frequently** |
| | Confined to bed. | Ability to walk severely limited or non-existent. Cannot bear own weight and/or must be assisted into chair or wheelchair. | Walks occasionally during day, but for very short distances, with or without assistance. spends majority of day bed or chair. | Walks around the house at least once every 2hours during waking hours. |

| | | | | |
|---|---|---|---|---|
| **Mobility**<br>*Ability to change and control body position* | **1. Completely Immobile** | **2. Very Limited** | **3. Slightly Limited** | **4. No Limitations** |
| | Does not make even slight changes in body or extremity position without assistance. | Makes occasional slight changes in body or extremity position but unable to make frequent or significant changes independently. | Makes frequent though slight changes in body or extremity position independently. | Makes major and frequent changes in position without assistance. |
| **Nutrition**<br>*Usual food intake pattern* | **1. Very Poor** | **2. Probably Inadequate** | **3. Adequate** | **4. Excellent** |
| | Never eats a complete meal.<br>Rarely eats more than 1/3 of any food offered. Eats 2 servings or less of protein (meat or dairy products) per day. Takes fluids poorly.<br>Does not take a liquid dietary supplement. | Rarely eats a complete meal and generally eats only about 1/2 of any food offered. Protein intake includes only 3 servings of meat or dairy products per day. Occasionally will take a dietary supplement.<br>OR<br>receives less than optimum amount of liquid diet or tube feeding. | Eats over half of most meals. Eats a total of 4 servings of protein (meat, dairy products) each day. Occasionally will refuse a meal, but will usually take a supplement if offered.<br>OR<br>is on a tube feeding or TPN regimen which probably meets most of nutritional needs. | Eats most of every meal.<br>Never refuses a meal.<br>Usually eats a total of 4 or more servings of meat and dairy products. Occasionally eats between meals. Does not require supplementation. |
| **Friction and Shear**<br>*Stress and dragging on skin and tissues.* | **1. Problem** | **2. Potential Problem** | **3. No Apparent Problem** | |
| | Requires moderate to maximum assistance in moving. Complete lifting without sliding against sheets is impossible. Frequently slides down in bed or chair, requiring frequent repositioning with maximum assistance. Spasticity,contractures or agitation lead to almost constant friction. | Moves feebly or requires minimum assistance.<br>During a move, skin probably slides to some extent against sheets, chair restraints, or other devices.<br>Maintains relatively good position in chair or bed most of the time, but occasionally slides down. | Moves in bed and in chair independently and has sufficient muscle strength to lift up completely during move.<br>Maintains good position in bed or chair at all times. | |

*NOTE: Clients with a total score of 16 or less are considered to be at risk of developing pressure ulcers. (15 or 16 = low risk; 13 or 14 = moderate risk; 12 or less = high risk)*

Modified from the Braden Risk Assessment scale; © Copyright Barbara Braden and Nancy Bergstrom, 1988

NATIONAL PRESSURE
ULCER ADVISORY PANEL

# Statement on Pressure Ulcer Prevention

(1992)

## Foreword

Millions of dollars are spent annually on pressure ulcer prevention and management. An effective national approach to pressure ulcer prevention will help to meet the National Pressure Ulcer Advisory Panel's (NPUAP) goal of reducing pressure ulcer incidence by 50% by the year 2000. This monograph is designed to assist clinicians with pressure ulcer prevention.

The Agency for Health Care Policy Research, Public Health Service, U.S. Department of Health and Human Services, is developing a set of clinical practice Guidelines with the intent of assisting health care providers and patients to determine appropriate care for specific clinical conditions. The guideline on pressure ulcer prevention, *Pressure Ulcers in Adults: Prediction and Prevention*, was released May 18, 1992. A guideline for detecting and treating urinary incontinence was released earlier in 1992. A guideline on *treatment* of pressure ulcers is currently being developed. The AHCPR clinical practice guidelines are written by private-sector, multidisciplinary panels of experts. Several members of the NPUAP served on the AHCPR pressure ulcer prevention guideline panel.

In March, 1991, the NPUAP also conducted the first public critique of the proposed AHCPR pressure ulcer prevention guideline. The dissemination of guidelines for the effective prevention and management of pressure ulcers is a goal of the NPUAP. The NPUAP presents this monograph as an interpretation and summary of the AHCPR Clinical Practice Guideline *Pressure Ulcers in Adults: Prediction and Prevention.* A concise summary of specific AHCPR recommendations for pressure ulcer prevention is presented in Table 1.

## Introduction

**Pressure Ulcers** are defined as localized areas of tissue necrosis that develop when soft tissue is compressed between a bony prominence and an external surface for a prolonged period of time.

These wounds have been referred to by many names, including

- decubitus ulcers
- bedsores
- pressure sores
- dermal ulcers
- pressure ulcers

Because pressure is the critical factor in the development of these wounds, the term "pressure ulcer" is recommended to describe these lesions.

Early intervention is designed for patients at increased risk for pressure ulcer development. The principle components of early intervention are:

1. identification of at-risk individuals who need preventive interventions and of the specific factors that place them at risk
2. maintenance and improvement of tissue tolerance to injury
3. protection against the adverse effects of pressure, friction, and shear
4. reduction of the incidence of pressure ulcers through educational programs

Most pressure ulcers are preventable. However, in some cases it is unrealistic, and may even be in conflict with the overall plan of care or patient directives for a terminally ill patient, to subject the patient to aggressive preventive measures. Pressure ulcers can be an indication of the multi-system failure that accompanies the terminal stages of many disease processes. In these cases, patient comfort should be the primary goal.

Pressure ulcer incidence has been used as an indicator of the quality of patient care. Is important that incidence and prevalence of pressure ulcers be differentiated.

- **Incidence** refers to the rate at which new cases occur in a population over a given time period, such as the number of new cases per year among the patients at a long term care facility.
- **Prevalence** refers to the number of both new and old cases at any one time in the population, such as the proportion of patients in a long term care facility with pressure ulcers on a specified day--a cross-sectional view of the problem.

Because patients may develop pressure ulcers in one health care facility and then be transferred to another facility, the incidence of new pressure ulcers is a more appropriate criterion to use for quality of care assessment.

## Risk Assessment

Pressure ulcer risk assessment requires a comprehensive approach including skin assessment and evaluation of factors most commonly reported to be associated with pressure ulcer development

- immobility
- inactivity
- nutritional factors
- fecal and urinary incontinence
- decreased sensory perception

Individuals may have multiple conditions that increase their susceptibility to pressure ulceration.

Pressure ulcer risk assessment must be done systematically. An assessment tool that is validated for a specific type of patient population is recommended. There are several published pressure ulcer risk assessment instruments including the:
Braden Scale

- Gosnell Scale
- Norton Scale

Patients must be assessed for pressure ulcer risk on admission to any health care agency and reassessed periodically as their condition changes.

## Intervention

When assessment identifies pressure ulcer risk before there is overt evidence of pressure-induced injury, interventions can be implemented to reduce the risk.

Skin Care

1. Healthy skin is clean and well-hydrated. Dry skin is evidenced by roughness and scaling.
2. Skin should be washed with warm water, using a mild cleansing agent to minimize excessive dryness.
3. Excessive friction and scrubbing are contraindicated.
4. Cleansing must be done at each time of soiling and at intervals consistent with good hygiene.
5. Non-alcohol based moisturizing agents are recommended.

Although it is important to cleanse and moisturize all skin surfaces, aggressive massage has been shown to cause tissue damage, and must be avoided. Massage over bony prominences is especially likely to cause additional injury to pressure-damaged skin.

Ideally, temperature and humidity should be maintained at levels that minimize damage to the patient's skin, such as MACERATION, cracking, or decrease in blood flow to the skin.. Heat lamps should be avoided because they increase local tissue temperature and metabolic demands, dry the tissue, and may be a safety hazard.

It is important to prevent mechanical injury to the skin from friction and shearing forces during repositioning and transfer activity. The key is to have a sufficient number of personnel available to move patients. Assistive devices such as lift sheets, trapezes, transfer boards, or mechanical lifts may be useful adjunctive devices to minimize tissue injury. Mechanical injury from friction can be reduced with dry lubricants, such as cornstarch, or application of barrier dressings such as

## Transparent Films and Hydrocolloids

Pressure Reduction

Intervention to reduce pressure over bony prominences are of primary importance. Immobile patients need to be maintained in proper alignment. Attention must be focused on maintaining and/or enhancing functional ability. If not medically contraindicated, activity regimens may include physical therapy and/or occupational therapy.

A turning schedule must be established for patients who are confined to bed.. Data do not indicate how often patients should be turned to prevent ischemia of soft tissue, but two hours in a single position is the maximum duration of time recommended for patients with normal circulatory capacity.

For positioning, the "rule of 30" is used. This means that the head of the bed is elevated to 30 degrees or less (Figure 1) and the body is placed in a 30-degree laterally inclined position, when repositioned to either side (Figure 2).

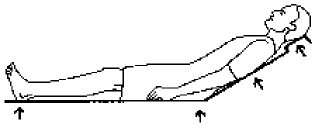


Figure 1

Figure 2

[Figures 1 and 2 adapted from J. Maklebust. Pressure ulcer update. RN, December 1991, pages 56-61. Original illustration by Jack Tandy. Used with permission.]

If the head of the bed is elevated (e.g.., for eating, watching television) beyond 30 degrees, the duration of this position needs to be limited to minimize both pressure and shear forces. In the 30 degree laterally inclined position, the patient's hips and shoulders are tilted 30 degrees from supine and pillows or foam wedges are used to keep the patient properly positioned without pressure over the trochanter or sacrum. If tolerated, the prone position may also be used.

Based on the patient's risk and mobility status, pressure reducing MATTRESS OVERLAYS or MATTRESS REPLACEMENT UNITS may need to be employed. Health care agencies must have support surface protocols that describe the specific product(s) recommended and the indications for each. Pillows and cotton blankets are simple devices that are readily available for pressure reduction. When used judiciously, they expand the weight-bearing surface by molding to the body. Pillows under the calf may be used to elevate the patient's heels off the bed surface.

Cushioning devices should be placed between the legs/ankles to maintain alignment and prevent apposition of bony prominences. Commercially available pressure-reducing mattresses include

- foam
- static air
- alternating air
- gel
- water.

A small percentage of patients may need support surfaces with greater ability to reduce pressure, shear, friction, and moisture. These products may include

- low air loss
- air-fluidized support surfaces

Patients who are chair bound for long periods of time need appropriate seating surfaces, capable of safely reducing pressure while still providing adequate stability and support. Areas at particularly high risk in the seated person include

- ischial tuberosities
- thoracic spine
- feet
- heels

Donut cushions are to be avoided because they can cause tissue ischemia. Selection of customized chair cushions requires the services of a qualified seating specialist.

For those patients who are temporarily chair bound, consideration should be given to cushions that furnish maximum pressure reduction over the ischial tuberosities, adequate support, and comfort Proper body alignment is essential for chair bound patients. Patients who are able must be instructed to reposition themselves at 15-20 minute intervals. Patients who have sufficient upper body strength should be taught to do wheelchair push-ups.

Nutrition

Nutrition is important for maintaining tissue integrity. Sufficient nutrients for individual needs must be available. Indicators of impaired nutritional status include:

- rapid weight loss
- inadequate intake
- decreased serum albumin/transferrin

For patients with inadequate nutritional intake, strategies must be employed to increase oral intake. Patients must have diets prescribed with protein and caloric content sufficient to meet metabolic needs (this assumes that there are no medical contraindications for doing so). Dietary consultation is indicated for nutritional evaluation. The diet prescription should consider patient preferences and special needs, such as a dental soft diet for and endentuous patient. Assistance with meals may include opening food containers, elevating the head of the bed to allow the patient to eat or be fed, providing an environment conducive to eating and allowing sufficient time and assistance for optimal oral intake.

When, despite these measures, patients are unable to consume adequate amounts of nutrients, tube feeding or parenteral alimentation should be considered. Patient and family preferences and the overall goals of treatment should guide these decisions.

Incontinence

Patients who are incontinent of urine and/or feces must have an adequate evaluation to identify whether reversible causes exist. Reversible causes include

- urinary tract infection
- medications
- confusion
- fecal impaction
- polyuria due to glycosuria or hypercalcemia
- restricted mobility due to restraints

A bowel training program must be instituted for spinal cord injury patients. Further evaluation and intervention should be considered if consistent with the patient's overall treatment goals. Preventing maceration of skin by managing excessive moisture can be achieved through cleansing at appropriate

## Evaluation and Documentation

The effectiveness of skin protection measures for high-risk patients must be evaluated as appropriate for the individual's condition and setting.

Adjustments in preventive measures should be made as needed. Development of Stage I pressure ulcer(s) (NON-BLANCHABLE ERYTHEMIA) is an indication for intensifying interventions, such as

- more frequent repositioning,
- use of topical skin management agents and/or dressings,
- and the use of pressure reducing devices

Documentation must be done at regular intervals and should include

- risk assessment
- skin evaluation

- therapies designed to maintain intact skin
- patient response to alterations in therapy,
- the rational for the alteration(s)
- the outcome of the skin care program

## Education of Caregivers: Patients and Families

Responsibility for pressure ulcer prevention is shared by physicians, nurses, enterostomal therapy nurses, physical and occupational therapist, nutritionists, pharmacists, administrators, patients, and patients' families. Education of these groups is an important aspect of pressure ulcer prevention. Toward that end, appropriate educational programs that provide current research-based information should be offered at periodic intervals.

Educational programs for health professionals must include:

1. Characteristics of normal, healthy skin
2. Elements of skin assessment
3. Characteristics of tissue deformation (tissue performance under mechanical loading)
4. Role of nutrition in pressure ulcer prevention
5. Pressure ulcer risk factors
6. Research-based risk assessment tools and their selection for specific populations
7. Etiology and staging of pressure ulcers
8. Proper techniques for turning, positioning, and repositioning
9. Indications and limitations of pressure-reducing devices/support surfaces
10. Indications and limitations of friction reducing products
11. Documentation of skin assessment and skin care program, including outcomes

Programs presented for patient and/or family must include:

1. Etiology of pressure ulcers
2. Inspection of skin
3. Protection of skin
4. Proper, safe cleansing techniques and agents
5. Reduction of pressure ulcer risk
6. Role of nutrition in pressure ulcer prevention
7. Need for position changes
8. Proper/correct positioning techniques.
9. Proper use of pillows and/or other pressure reducing devices.
10. Skin and other health status changes to be reported to health care professionals.

## Conclusion

Adherence to the principles in this monograph will help to prevent pressure ulcer development in most high-risk patients. The NPUAP believes that pressure ulcers are a major health problem, and recommends that health care professionals adopt the following:

- Prevention is the best solution to the pressure ulcer problem.
- Pressure ulcer prevention alleviates needless human suffering and unnecessary health care costs.
- Responsibility for pressure ulcer prevention is shared by health care professionals, bedside caregivers, patients, and families.

*Source: http://www.npuap.org/positn1.htm*

# Synthetic Wound Dressings

Synthetic wound dressing deliver important characteristics of an ideal wound dressing: moisture keeping and absorbing (e.g. polyurethane foams, hydrocolloids) and moisture keeping and antibacterial (e.g. iodine-containing gels).
They consist of the following groups of products:

- vapors-permeable adhesive films
- hydrogels
- hydrocolloids
- alginates
- synthetic foam dressings
- silicone meshes
- tissue adhesives
- barrier films
- silver- or collagen-containing dressings

**Ideal wound dressing**
No single dressing is suitable for all types of wounds. Often a number of different types of dressings will be used during the healing process of a single wound. Dressings should perform one or more of the following functions:

- Maintain a moist environment at the wound/dressing interface
- Absorb excess exudate without leakage to the surface of the dressing (Exutade is a fluid rich in protein and cellular elements that oozes out of blood vessels due to inflammation and is deposited in nearby tissues.)
- Provide thermal insulation and mechanical protection
- Provide bacterial protection
- Allow gaseous and fluid exchange
- Absorb wound odor
- Be non-adherent to the wound and easily removed without trauma
- Provide some debridement action (remove dead tissue and/or foreign particles)
- Be non-toxic, non-allergenic and non-sensitizing (to both patient and medical staff)
- Sterile

## Classification of wound dressings

Synthetic wound dressings can be broadly categorized into the following types.

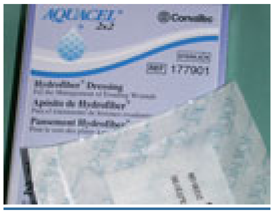
| Type | Properties |
|---|---|
| Passive products | Traditional dressings that provide cover over the wound, e.g. gauze and tulle dressings |
| Interactive products | Polymeric films and forms which are mostly transparent, permeable to water vapor and oxygen, non-permeable to bacteria, e.g. hyaluronic acid, hydrogels, foam dressings |
| Bioactive products | Dressings which deliver substances active in wound healing, e.g. hydrocolloids, alginates, collagens, chitosan |

## Wound types and dressings

The following table describes some of the many different types of wound dressings and their main properties.

| Dressing type | Properties | |
|---|---|---|
| Gauze | • Dressings can stick to the wound surface and disrupt the wound bed when removed<br>• Only use on minor wounds or as secondary dressings |  |
| Tulle | • Dressing does not stick to wound surface<br>• Suitable for flat, shallow wound<br>• Useful in patient with sensitive skin<br>• E.g. Jelonet® |  |
| Semipermeable film | • Sterile sheet of polyurethane coated with acrylic adhesive<br>• Transparent allowing wound checks<br>• Suitable for shallow wound with low exudate<br>• E.g. OpSite®, Tegaderm® |  |

| | | |
|---|---|---|
| Hydrocolloids | • Composed of carboxymethylcellulose, gelatin, pectin, elastomers and adhesives that turn into a gel when exudate is absorbed. This creates a warm, moist environment that promotes debridement and healing<br>• Depending on the hydrocolloid dressing chosen can be used in wounds with light to heavy exudate, sloughing or granulating wounds<br>• Available in many forms (adhesive or non-adhesive pad, paste, powder) but most commonly as self-adhesive pads<br>• E.g. DuoDERM®, Tegasorb® |  |
| Hydrogels | • Composed mainly of water in a complex network or fibers that keep the polymer gel intact. Water is released to keep the wound moist<br>• Used for necrotic or sloughing wound beds to rehydrate and remove dead tissue. Do not use for moderate to heavily exudating wounds<br>• E.g. Tegagel®, Intrasite® |  |
| Alginates | • Composed of calcium alginate (a seaweed component). When in contact with wound, calcium in the dressing is exchanged with sodium from wound fluid and this turns dressing into a gel that maintains a moist wound environment<br>• Good for exudating wounds and helps in debridement of sloughing wounds<br>• Do not use on low exudating wounds as this will cause dryness and scabbing<br>• Dressing should be changed daily<br>• E.g. Kaltostat®, Sorbsan® |  |

| | | |
|---|---|---|
| Polyurethane or silicone foams | • Designed to absorb large amounts of exudates<br>• Maintain a moist wound environment but are not as useful as alginates or hydrocolloids for debridement<br>• Do not use on low exudating wounds as this will cause dryness and scabbing<br>• E.g. Allevyn®, Lyofoam® |  |
| Hydrofibre | • Soft non-woven pad or ribbon dressing made from sodium carboxymethylcellulose fibers<br>• Interact with wound drainage to form a soft gel<br>• Absorb exudate and provide a moist environment in a deep wound that needs packing |  |
| Collagens | • Dressings come in pads, gels or particles<br>• Promote the deposit of newly formed collagen in the wound bed<br>• Absorb exudate and provide a moist environment | |

Different types of wounds and the different stages of a healing wound require different dressings or combinations of dressings. The following table shows suitable dressings for particular wound types.

| Wound Type | | Dressing Type |
|---|---|---|
|  | Clean, medium-to-high exudate (epithelialising) | • Paraffin gauze<br>• Knitted viscose primary dressing |
|  | Clean, dry, low exudate (epithelialising) | • Absorbent perforated plastic film-faced dressing<br>• Vapor-permeable adhesive film dressing |

| | | |
|---|---|---|
|  | Clean, exudating (granulating) | • Hydrocolloids<br>• Foams<br>• Alginates |
|  | Slough-covered | • Hydrocolloids<br>• Hydrogels |
|  | Dry, necrotic | • Hydrocolloids<br>• Hydrogels |

The dressings may require secondary dressings such as absorbent pad and bandages.

Adapted (-8-07) from: http://www.dermnetnz.org/procedures/dressings.html; http://www.surgical-tutor.org.uk/default-home.htm?specialities/plastic/dressings.htm~right; and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

| PRACTICE GUIDELINES FOR WOUND CARE | | | |
|---|---|---|---|
| **PREVENTION** | **NECROTIC/ ESCHAR/SLOUGH** | **DIABETIC/ARTERIAL VENOUS ULCERS** | **SKIN TEARS** |
| ▪ Inspect skin daily<br>▪ Cleanse skin when soiled with soap and water<br>▪ Minimize exposure to moisture from incontinence, perspiration, or wound drainage<br>▪ Moisturize dry skin<br>▪ Minimize shear and friction (observe proper positioning, transfer, turning techniques)<br>▪ Utilize skin protectants / antimicrobial ointments as moisture barrier as necessary<br>▪ Address nutritional needs<br>▪ Reposition at least every 2 hours<br>▪ Increase mobility, activity<br>▪ Use pressure reduction devices in bed, chair, wheelchair<br>▪ Relieve pressure on bony prominences<br>▪ Relieve pressure on bony prominences<br>▪ Maintain head of bed no higher than 30 degrees<br>▪ Use lifting devices<br>▪ Involve and educate consumer and/or provider<br>▪ Monitor and document interventions and outcomes | • Cleanse with a Wound Cleanser<br>• Apply Skin Prep to skin around the wound<br>• Apply Hydrocolloid dressing for autolytic debridement<br>• Change q 3-5 days and PRN for dislodgement or leakage<br>Or<br>• Apply if chemical debridement agent if 100% of wound bed is necrotic<br>• Cover with gauze. Change daily. (Do not cover with occlusive dressing)<br>• Discontinue this treatment when necrotic tissue is dissolved.<br>• Continue with moist wound healing<br>**Intact Black Heel**<br>• Relieve pressure<br>• No dressing<br>• No debridement<br>• If area opens refer to necrotic slough | **Dry Wound**<br>• Cleanse with Wound Cleanser<br>• Apply Skin Prep to skin around the wound<br>• Apply Hydrogel, cover with Transparent Film Dressing<br>Or<br>• Apply Hydrocolloid dressing<br>• May frame with tape to prevent premature dislodgement<br>• Change every 3-5 days & PRN for dislodgement or leakage<br>**Draining Wound**<br>• Cleanse with Wound Cleanser<br>• Apply Skin Prep to skin around the wound<br>• Line wound bed with Calcium Alginate (rope or sheet) – fill remaining space with gauze Cover with Transparent Film Dressing | **Skin Tears**<br>• Cleanse with Wound Cleanser & pat dry<br>• Replace attached torn skin with gauze pad / non-adhesive pad<br>• Secure with light gauze or Transparent Film Dressing<br>• May consider using Hydrocolloid alone over the skin tear as needed<br>• Change Transparent Film or Hydrocolloid 2x a week and PRN |

***Necrotic*** tissue is dead tissue. ***Eschar*** is a hard plaque covering an ulcer implying extensive tissue necrosis, infarcts, deep burns, or gangrene

Adapted (8-07): http://www.dermarite.com/wound_care.html

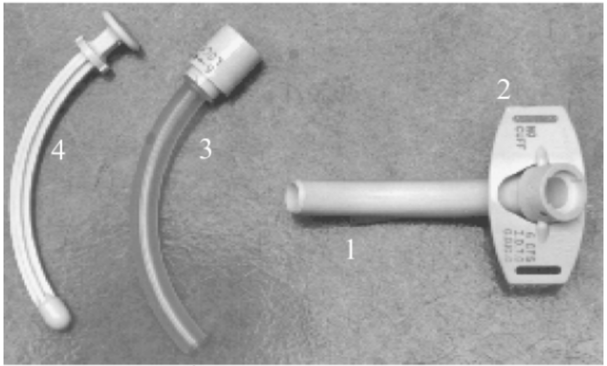
# Tracheostomy Care

A tracheostomy is a surgical opening in the trachea (windpipe) to make breathing easier. The opening is called a stoma. A tracheotomy tube is inserted in it to keep it open. Eventually, the person may be able to talk by taking a deep breath and placing a finger over the stoma.

### The Tracheotomy Tube

The tracheotomy tube consists of four parts:

1. **Outer cannula**: Part of the trach tube that is inside the windpipe.
2. **Flange/neck plate**: “Wings” on the trach tube that the ties are secured to. The flange will have the brand and size of trach tube printed on it.
3. **Inner cannula**: Part that is inside the cannula of a double cannula trach. The inner cannula may be removed for cleaning.
4. **Obturator:** Used to guide the tube into the opening when changing the trach tube.



### Changing Tracheostomy Dressings

It is very important to change tracheostomy dressings as soon as
they become soiled.

Supplies:

- Tracheostomy dressings
  NOTE: Plain sterile gauze pads should not be used to create tracheostomy dressings, as fibers that become loose may be aspirated into the airway.
- Clean tracheostomy ties or a Velcro® tracheostomy tube holder
- 1⁄2-strength hydrogen peroxide
- Dry sterile pad or towel.

Procedure:

- Remove old dressing, being careful to keep tracheostomy tube in place.
- Clean around tube at stoma site with hydrogen peroxide solution.
- Place clean tracheostomy dressing under the flange, inserted from below.
- Change tracheostomy ties as necessary.
- Change dressing as necessary.

## Skin Care

The care of the skin around the stoma site should be considered one of the more important procedures in the care of the tracheostomy. The site needs to be cleaned and dressed frequently as it heals. As the incision heals, the frequency will decrease.

Supplies:

- Cotton-tipped swabs
- Normal saline or 1⁄2-strength hydrogen peroxide.

Procedure:

- Gather all necessary supplies.
- Wash hands with soap and water.
- Inspect the site around the tracheostomy stoma for signs of skin breakdown, infection, or irritation.
- Moisten the swabs in either the peroxide solution or with normal saline.
- With a rolling motion, clean the skin area around the stoma and under the flange of the tube.
- Pat dry with a clean dry swab or pad.
- Replace tracheostomy dressing.

## Cleaning the Tracheostomy Tube

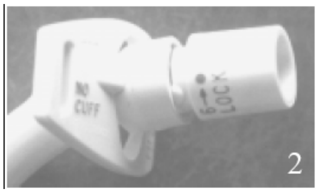
Cleaning the inner cannula of the trach tube is an important task. It should be done at least once a day, or more often if needed, to keep it clean and free of secretions.

Supplies:

- 2 bowls (margarine containers work well) or disposable cups, one for cleaning, one for rinsing.
- Hydrogen peroxide solution.
- Long pipe cleaner, cotton tipped applicator or a trach brush.
- Sterile water (see recipe for sterile water at the end of the document).

Procedure:

- Wash hands well with soap and water.
- Prepare cleaning and rinsing bowls
  - In the 1st bowl, make hydrogen peroxide solution. (Pour 1/2 cup of sterile water and 1/2 cup of hydrogen peroxide into one bowl).
  - In the 2nd bowl, pour only sterile water.
- Cough or suction if needed. This clears the airway of secretions. Take a few deep breaths.



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Cleaning the inner cannula:

1. Loosen the inner cannula.

2. Hold the outer cannula with one hand. With the other hand turn the inner cannula to your right to unlock.

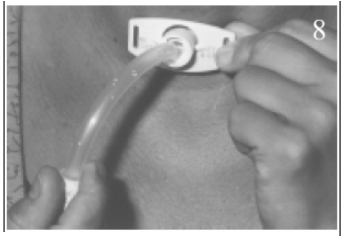
3. Remove the inner cannula by steadily pulling it down and toward your chest until it is out.

4. Place the inner cannula in the peroxide solution.

5. Use a pipe cleaner folded double, an applicator stick or trach brush to gently clean the inner cannula and to remove mucous and dried secretions.

6. Now place it in the bowl of plain sterile water and rinse well.

7. Shake off excess water. Do not dry it. Moisture will make the inner cannula slide back in easily.
8. Reinsert the inner cannula. Keep the curved portion facing downward.
9. Lock the inner cannula into position.
10. Wash bowls thoroughly and leave to dry in a clean place. If using a trach brush soak it in hydrogen peroxide, rinse with sterile water and leave to dry. Throw away pipe cleaners or applicator sticks and paper cups.
11. Wash hands.



If there are crusts or plugs in the windpipe, an eyedropper can be used to slowly drop salt water or saline down into the stoma. The person should take a deep breath as the salt water enters the windpipe. The salt water will loosen the mucus to help cough it from the lungs. A tissue or gauze should be held in front of the tracheotomy tube to wipe away the mucus as it is coughed up.

### Changing the Tracheotomy Tube

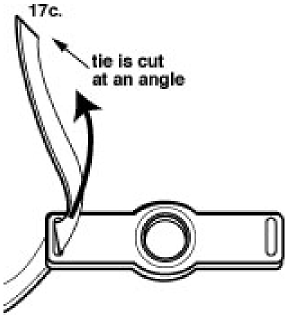
1. Wash hands thoroughly. Remove the new tracheotomy tube from the sterile pouch.
2. Remove the inner cannula and insert the obturator into the outer cannula.
3. Attach the clean trach ties to the neck plate so that the ties will be able to attach around the neck.
4. Lubricate the end of the tube and the obturator with a thin layer of water-soluble lubricant, such as KY-jelly (this can be purchased at the drug store). Do not use a lubricant that contains oil.
5. Untie the neck ties from the tracheotomy tube that is being replaced.
6. With the thumb and forefinger, grasp the neck plate. Carefully remove the entire tube in a straight downward motion. DO NOT force the tube. If you are unable to remove it contact your physician or nurse.
7. Immediately insert the new tracheotomy tube with gentle backwards pressure.
8. Remove the obturator when the new tube is in place and allow air to flow in.
9. Insert the new inner cannula.
10. Secure the trach ties around your neck.
11. Cleanse the used tube, using hydrogen peroxide and water. Store in a clean container with a lid. The tracheotomy tubes may be reused.

There should always be a replacement tracheotomy tube available in case of an emergency; the second tube can be inserted while the other is being cleaned. Then the clean tube can be used the next time the tracheotomy tube needs to be changed.

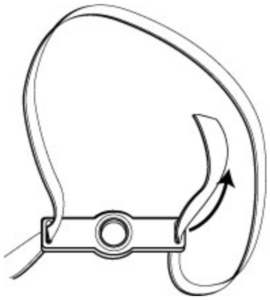
### Changing the tracheostomy tube ties

While changing the tracheostomy ties or holders, one person holds the tube in place while the other removes the old ties or holders and replaces them with new. NEVER tie tracheostomy ties with a bow. Ties should always be tied with a square knot.

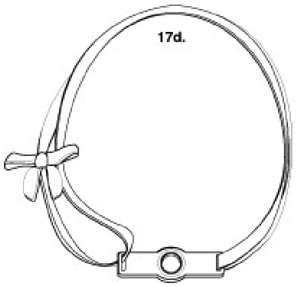
- Measure and cut a piece of tie long enough to go around the neck twice. Cut the tie at an angle so it is easier to insert the tie into the neckplate.
- Untie one side of the old tie and remove that side from the neckplate. Do not completely remove the old tie until the new one is in place and is securely fastened.



- Holding the trach tube in place, lace the tie through one hole of the neckplate, around the back of the neck, through the other hole of neckplate, and again around the back of the neck.
- Pull the tie snugly and tie a square knot on the side of the neck. There should be enough space for no more than two fingers between the tie and the neck.



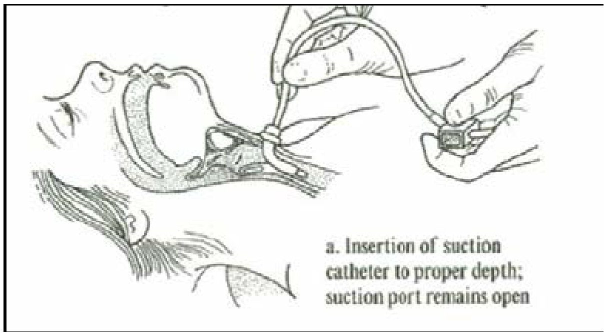
- Cut, remove and discard the old tie. If you have a cuffed trach tube, be careful not to cut the cuff balloon when removing the old trach tube tie.



## Suctioning

Supplies:

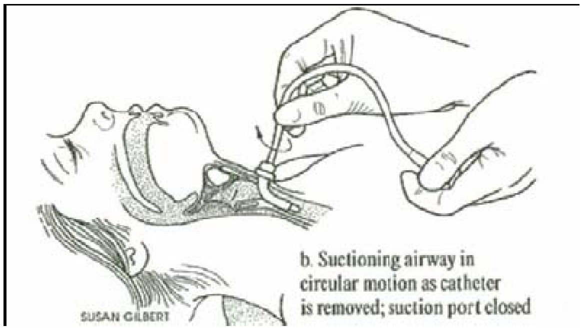
- Suction machine
- Suction catheter
- Water
- Clean plastic bag or container



a. Insertion of suction catheter to proper depth; suction port remains open

Procedure:

- Wash hands.
- Attach the right sized suction catheter to the suction machine tubing.
- Turn on the suction machine.
- Insert the catheter into the trach tube opening to the pre-measured distance. This distance will be determined by the doctor.
- Cover the thumbhole on the suction catheter with the thumb.



b. Suctioning airway in circular motion as catheter is removed; suction port closed

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- Slowly remove the catheter while rolling or twirling the catheter between the thumb and finger.
- Rinse the catheter in clean or sterile water then repeat the process until the trach tube is clear of mucus.
- Keep the catheter clean by keeping it in a clean plastic bag or container.
- Throw it away at the end of the day or if it doesn’t come clean

## Ways to add Moisture to the air

- Wear a wet gauze over the stoma. Re-wet it when it becomes dry.
- Use a humidifier in your home. Place it in the main living area during the day. Run it in the bedroom at night with the windows and door closed. Clean the water container or the humidifier daily with warm soapy water. Then add vinegar and water, let it sit for 20 minutes, empty and rinse.
- In the winter when air is dryer, place shallow pans of water on the heater or radiator.
- House plants can add moisture to the air.
- Close the bathroom door and turn on the hot water to fill the room with steam. Sit in the room and breathe deeply for 10-15 minutes.
- An ultrasonic humidifier (drugstores, discounters, etc.) can provide extra humidity in the bedroom during the cold, dry winter nights.

## Recipes for Sterile Water and Salt Water

To make sterile water:

Boil water for 15 minutes in a covered pot. Let it cool. This frees it from bacteria.
To store sterile water:

1. Place clean jars and tops in a large pan of water.
2. Heat water to boiling. Boil for 15 minutes.
3. Remove jars from water. Place on a clean towel to cool.
4. Pour sterile water into jars and seal.
5. Store in refrigerator for up to 2 days.

To make salt water:

1. Boil one pint of water in a covered pan for 20 minutes.
2. Add 1/2 teaspoon of salt and pour into a clean jar with a lid.
3. Allow the mixture to cool. Store in the refrigerator.
4. Each day, remove enough salt water for daily use. Allow it to warm to room temperature before using it. Make new salt water every three days.

Adapted (8-07) from: http://www.headandneckcancer.org/patienteducation/docs/tracheostomy.php; http://www.blankchildrens.org/documents/Trach%20Book.pdfhttp://www.tracheostomy.com/resources/pdf/TrachHandbk.pdf; http://cms.clevelandclinic.org/headandneck/body.cfm?id=159; http://www.cdha.nshealth.ca/patientinformation/nshealthnet/0244.pdf; and Potter and Perry, Basic Nursing: essentials for nursing practice, Mosby 5th edition.

# Colostomy

A colostomy is created when a portion of the large intestine is removed or bypassed. The remaining portion of the functioning large intestine (colon) is brought through the abdominal wall, creating a **stoma**. This results in a change of normal body function to allow elimination of bowel contents.

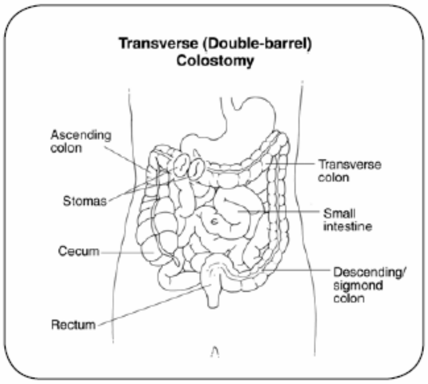
Since nutrients are absorbed in the small intestine, a colostomy does not affect the body's ability to be nourished. When a colostomy interrupts the passage of stool, storage becomes more difficult. The higher up in the colon the colostomy is made, the less time the bowel has to absorb water and the more liquid (or soft) the stool is likely to be. Therefore, a colostomy in the transverse colon will discharge a softer and more voluminous stool and will require the use of a collection pouch.

A colostomy far down in the colon, near the rectum, will discharge stool that has been in the intestine a longer time and barring the effects of illness, medications or other forms of treatment, may produce a more formed stool. Some colostomates find that they are able to pass this stool at regulated times with or without the help of irrigation (an enema through the stoma).

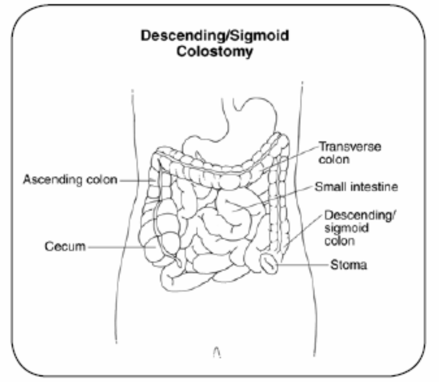
After the operation, if the rectum is intact, patients may feel urges and even have some discharge from the anal area. It may continue to secrete mucus that can be harmlessly passed whenever the urge occurs.

There are **two types of transverse colostomies**: “loop transverse colostomy” and “double-barrel transverse colostomy.”

### Transverse Colostomy

| | |
|---|---|
|  | **Indications:**<br>• Diverticulitis.<br>• Trauma (injury).<br>• Birth Defects.<br>• Cancer/descending or sigmoid colon.<br>• Bowel obstruction.<br>• Paralysis.<br>**Discharge:**<br>• Semi-solid.<br>• Unpredictable.<br>• Contains some digestive enzymes.<br>**Management:**<br>• Skin protection.<br>• Drainable pouch.<br>• Closed-end pouch for convenience or special moments. |

### Descending or Sigmoid Colostomy

| | |
|---|---|
|  | **Indications:**<br>• Cancer of rectum or sigmoid colon.<br>• Diverticulitis.<br>• Trauma (injury).<br>• Congenital defects.<br>• Bowel obstruction.<br>• Paralysis.<br>**Discharge:**<br>• Resembles normal bowel movements.<br>• Regulated in some persons, not in others.<br>**Management:**<br>• Natural evacuation or irrigation.<br>• Protective cover or closed-end pouch if regulated.<br>• If not regulated, use open-end drainable pouch. |

# Ileostomy

The end of the ileum (the lowest portion of the small intestine) is brought through the abdominal wall to form a stoma, usually on the lower right side of the abdomen. Occasionally, a temporary ileostomy is performed in order to protect and rest the colon or small intestine while it is healing.

### Standard or Brooke Ileostomy

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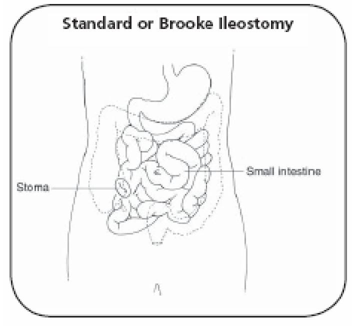
|  | **Indications:**<br>• Ulcerative Colitis<br>• Crohn’s Disease<br>• Familial Polyposis<br>• Cancer complications<br>**Discharge:**<br>• Liquid or paste consistency<br>• Unpredictable drainage<br>• Contains residual digestive enzymes<br>**Management:**<br>• Skin protection;<br>• Open-end, drainable pouch |

# Ostomy Bag Change

**Bag change:**

1. Cleanse the stoma with a warm, wet wash cloth.
2. Rinse the bag and reuse or change the bag and reattach to the appliance.

**Complete appliance change:**

1. Set out your equipment within easy reach. You will need: adhesiver remover, skin protector, wafer, pencil, measuring guide, stomahesive paste, plastic bags, washcloth, clean towel, new pouch, scissors.
2. Empty bag, if needed.
3. Gently remove the appliance.
4. Wash the stoma and surrounding skin with a warm, wet wash cloth using plain water. If soap is used, rinse thoroughly.
5. Pat skin dry thoroughly.
6. Keep the hair around the stoma shaved.
7. If you notice changes in the skin around the stoma, contact your nurse or physician for instructions.
8. Measure the stoma to check for changes in stoma size. The hole in the appliance should be the same size as the stoma. This protects the surrounding skin from the excoriating effects of urine or stool.
9. Place the appliance around the stoma so the base of the stoma is hugged by the opening of the skin barrier or pouch. Firmly hold the appliance in place for a few seconds so the heat of your body will seal the barrier to the skin surrounding the stoma.
10. Reapply the bag. Check to be sure that it is securely attached.

**What Do I Need To Report to My Physician?**

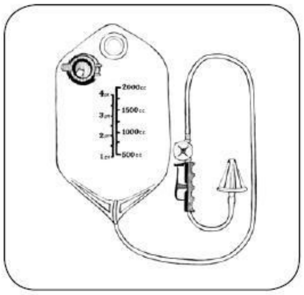
- A normal stoma is pink or red, moist, may bleed at times and does not have sensation. Call your physician if you experience the following:
- Unusual change in stoma or your stoma turns blue or black.
- The skin around the stoma appears red, swollen or excoriated (or chafed)
- Excessive bleeding (blood in pouch with each emptying of bag) or continuous bleeding at juncture of stoma and skin.
- Cramps lasting 2-3 hours or nausea/vomiting
- Severe watery discharge lasting more that 5-6 hours (colostomy only).
- You have a temperature over 1000F

For more Patient Fact Sheets, see the Greenwich Hospital web site at www.greenhosp.org and click on Patients & Visitors, then Patient Education Rev. 7/04

# Colostomy Irrigation

Irrigation is only suitable for patients with end colostomies. This technique can be used to avoid wearing a pouch, although a small cap or pouch may be advisable if there is a risk of leakage.

Bathroom facilities are needed as it may take up to an hour to complete irrigation.



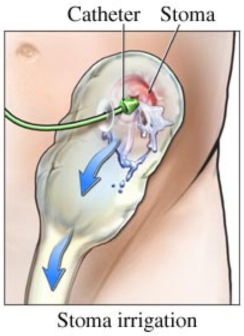
Irrigation system

This technique should be performed every 1 to 3 days at a convenient time. A special irrigating set and cone is used.

The colostomy plug can be used following irrigation.

**Procedure**

1. Choose a time of day when there will be no interruptions.
2. Irrigation may be more satisfactory if it follows a meal or hot/warm drink.
3. Instill 1,000 cc (one quart) of lukewarm (not hot) water into the irrigating container.
4. Hang the container at such a height that its bottom will be at the level of the shoulder when seated.
5. Patient should sit up straight on the toilet or on a chair next to the toilet.
6. Attach the adjustable belt to the plastic irrigation sleeve and place the bottom end of the sleeve in the toilet bowl.
7. Wet or lubricate the end of the cone with water or water-soluble surgical lubricant.
8. To remove air bubbles from the tubing, release the clamp on the tubing and let a small quantity of water escape into the sleeve. Reclamp the tubing, insert the cone into the colostomy to a snug fit, but do not apply too much force. Reminder: the insertion of the cone would be a Paramedical Service. Again, release the clamp on the tubing and allow the water to flow in.
9. The water must go in slowly. The water flow can be slowed or stopped by shutting the clamp or pressing the walls of the tube together. It takes about five to ten minutes to drip in 1000 cc of water. Hold the cone in place for at least an additional 15 seconds. This flow adjustment would also be a Paramedical Service.
10. The amount of water needed is individual. Begin with 1000 cc and adjust to obtain successful returns.
11. The patient should not experience cramps or nausea while the water flows in. Both these symptoms indicate a flow that is too rapid, too much water, or water that is too cold. Once the water has been instilled, a bowel movement-type cramp may precede the return of the water and stool. (there may be some nausea the first time.)
12. Remove the cone and attach the irrigation sleeve over the stoma. Returns will come in spurts over a period of approximately 45 minutes. As soon as the major portion of stool has been expelled, the bottom of the irrigating sleeve may be clipped to the top with a clasp. This allows the patient may move around, bathe or anything else to pass the time.
13. A squirt of gas may indicate completion, or a quiet appearance of the stoma may be a sign. In time the patient will learn the signs that all the water and stool has been expelled.



# Urostomy

Urostomy is one of a number of surgical procedures that detour, or divert, urine away from a diseased or defective bladder. The bladder is either bypassed or removed, and the urine is passed from the body through a surgically created opening called a stoma. You will not have voluntary control of the urine that comes out through the stoma, therefore a collection pouch will be fitted for your individual needs.

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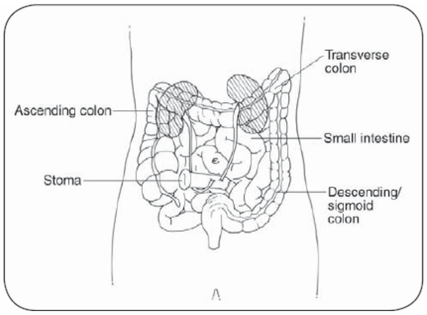
| <br> | **Indications**<br>• Cancer of bladder<br>• Neurologic dysfunction<br>• Birth defects<br>• Chronic inflammation of bladder<br>**Discharge**<br>• Urine<br>• Some mucus<br>• Continuous drainage<br>**Management**<br>• Skin protection<br>• Drainable, valve-end pouch<br>• Adaptable to night drainage |

### Urostomy Management

**Pouching systems:**
Successful pouching system should provide the following:

- Security with a good leak-proof seal, lasting for 3 to 7 days
- Skin protection
- Be inconspicuous
- Easy to apply and to remove

There are one and two piece pouching systems.

This information is presented to inform IHSS social workers about common paramedical techniques and personal care tasks related to medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. There are different acceptable ways to perform many procedures. This information represents information gained from sources as listed at the end of the document. **All IHSS assessments should be individualized; all paramedical services must be consistent with time and frequency specified by the consumer's physician.**

During the day the pouch is emptied as needed. At nighttime a length of flexible tubing can be attached to the drain valve and attached to a drainage bag. Many people find a bedside drainage unit preferable to getting up during the night and emptying the pouch.

## Changing the Pouching System

Many people prefer to change the pouch in the morning before anything has been ingested. If not then it is good to wait at least one-to-two hours after ingestions of fluids so that urine is not dribbling on the skin.

The pouch may be changed while sitting, standing or lying down. The best position is one that allows for the best view of the stoma and is the easiest when making a change. Some people stand facing the toilet so the urine, dripping from the stoma may be caught in the toilet. When changing while sitting in a wheelchair, it is helpful to have the person slide their buttocks toward the front of the chair and recline.

If someone is changing their own pouch using a mirror will help them center the pouch over the stoma. And some people find it helpful to use rolled gauze or paper towels to absorb dibbling urine from the stoma.

**General steps** for pouch change – every person will individualize this process over time.

- Have all equipment ready and on hand.
- Wash hands
- Empty bags before removing
- Prepare new wafer by cutting hole to size. This may need to wait until the stoma is exposed if it is a new stoma and is changing in size.
- Remove old wafer and bag and discard
- Clean skin around the stoma and pat dry with a clean towel. Area must be dry before applying new appliance wafer
- Prepare skin for new wafer by applying stoma adhesive as indicated.
- Apply new wafer and bag.
- Wash hands when finished.

## Emptying the Pouch

Since bacteria multiply rapidly in urine, it is important to empty the pouch at regular intervals. During the day, the pouch will probably need to be emptied every 2 to 4 hours or more often if the person drinks a lot of fluids. The volume of urine could jeopardize the pouch seal. It is a good idea to empty the pouch when it is 1/3 to 1/2 full. Simply open the valve and drain into an appropriate receptacle usually directly into the toilet.

Adapted (8-07) from: http://www.cancer.org/docroot/CRI/content/CRI_2_6x_Urostomy.asp; and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

# Two-Piece Pouching System

Ostomy Care Tips

## How to apply skin barrier and pouch

### Collect supplies

- Skin barrier, pouch, gauze or tissue, water.
- Other supplies which *may* be needed include: scissors, pen, measuring guide, **Adapt** paste or skin barrier ring and pouch clamp.

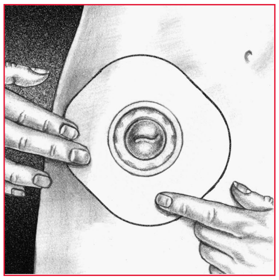


Figure 1

### Prepare the skin barrier and pouch

For a **cut-to-fit skin barrier**:

- Draw the pattern of the stoma onto the backing of the skin barrier. If you know your stoma size, identify the correct circle on the cutting guide.
- **Cut the skin barrier** to the correct size.
- If using a drainable pouch, apply pouch clamp or close **Lock 'n Roll** closure (see other side).
- If using a urostomy pouch, make sure the urostomy valve is in the closed position. The teardrop indicator should face your body.
- **Remove and discard the backing** from the skin barrier.
- **Apply Adapt Paste or Adapt Barrier Ring** to sticky side of skin barrier next to stoma opening (optional).

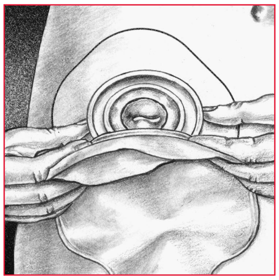


Figure 2

### Remove used pouching system

- Gently **peel the adhesive** away from the skin, beginning at the top and working downward.
- Properly **dispose** of used pouch and barrier. Do not flush down the toilet. Disposal bags are provided with the New Image pouches for convenient disposal.

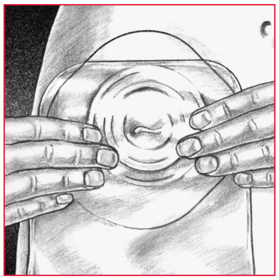


Figure 3

### Clean and dry your skin thoroughly

### Apply the new pouching system

- **Center opening of the skin barrier** over the stoma.
- **Apply barrier** and gently press until it is touching the skin at all points (Figure 1).
- **Attach pouch** to skin barrier by engaging the lower edges of the pouch flange and skin barrier flange (Figure 2).
- **Press the two flanges together.** A series of "clicks" will confirm you are doing it correctly (Figure 3). No more "clicks" means the pouch is secured.
- Gently press the barrier against your skin for about 30 seconds (heat and pressure help activate the adhesive).

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Attention to Detail. Attention to Life.

## Guidelines

- Empty pouch when 1/3 full of discharge or gas. Do not allow the pouch to overfill.
- If leakage occurs, do not reinforce with tape. Change the pouch and skin barrier.
- Change barrier and pouch every _____ days (as recommended by your healthcare provider).
- If using a **Flextend** extended wear barrier, the use of Skin Gel Wipes or other brands of skin preps are not recommended as they may reduce the weartime of the Flextend extended wear skin barrier.
- For more information, refer to the New Image instructions in the skin barrier box.
- If you have any questions regarding your care, contact your Wound, Ostomy and Continence Nurse (WOC or ET Nurse) or healthcare professional at: ____________________
- To obtain necessary supplies contact: ____________________

## List of products

| Products | Stock No | Size |
|---|---|---|
| **New Image** Two-Piece Skin Barrier | ____________ | ________ |
| **New Image** Two-Piece Pouch | ____________ | ________ |
| Other products | ____________ | ________ |

## Additional Instructions

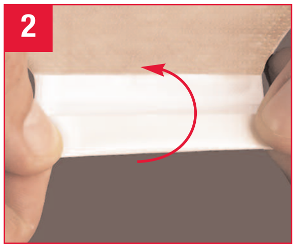
____________________

____________________

## Using the Lock ’n Roll Closure

1

2



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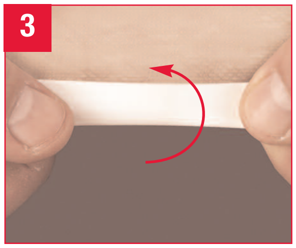

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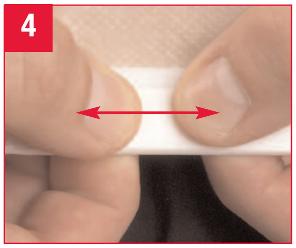

**To Close.** (steps 1-3) Fold up pouch tail three times up towards the outer side of the pouch until the plastic fasteners meet.

**To Seal.** (step 4) Press firmly from the center to the outer edges along the closure strip and **Feel the Seal!**

**To Drain:** Pinch (squeeze) the sides of the pouch tail.

**To Clean:** Clean the inside of the pouch tail with a tissue.

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Libertyville, IL 60048 USA
1.800.323.4060

**www.hollister.com**

# Intermittent Self-Catheterization

**What is self catheterization?**

Intermittent self-catheterization is a safe and effective method of completely emptying the bladder at regular intervals.

Catheterization is removing urine from the bladder by placing a tube in the bladder. This is done when the bladder doesn't empty on its own, when a bladder leaks urine, or when very high pressures have developed in the bladder. It is important to prevent a urinary tract infection. Extra urine in the bladder can grow germs. Over time, chronic infections and high bladder pressures can damage the kidneys.

Self catheterization is not difficult and will not hurt the bladder if directions are followed.

Self-catheterization should be done every 3 to 8 hours, or as recommended by the physician. Never stop self-catheterization unless instructed by a physician.

The following may be an indication that it is time to catheterize:

- Distended bladder
- Feeling of fullness
- Restlessness
- Perspiration
- Chills
- Headache

**How to clean the catheter**

- Always wash hands before and after procedure.
- Wash catheter after use in warm soapy water.
- Run tap water through the catheter. Place the catheter on a paper towel to air dry.
- Alternating catheters is a good idea.
- Replace the catheter in a clean container.
- Catheters should be discarded when they begin to lose their flexibility, or become brittle or discolored.
- An option to cleaning the catheter is to soak it in a solution of 1 part vinegar to 3 parts tap water once each week to keep urine crystals from forming inside the catheter.

## Equipment

- Catheter
- A container to carry the catheter.
- Cotton balls moistened with soap and water.
- Water soluble lubricant - K-Y® Jelly or Lubifax®
  (Do not use mineral oil or petroleum lubricant).

## Procedure

- Prepare equipment.
- Wash hands with soap and water.
- Urinate if possible.
- May be done standing, sitting or lying down, whichever is easiest.
- Remove catheter from clean container.
- Lubricate the catheter end that will be going into the urethra. Lubricant must be water-soluble.
- **Males** — Hold penis up with one hand and cleanse the tip with a cotton ball moistened with soap and water. Wash in a circular motion starting at the urethra and working outward. Holding the penis upward, gently insert the catheter through the external opening of the urinary tract (external meatus). Once one half length of the catheter has passed through external meatus, lower the penis and slide the catheter the rest of the way into the bladder until urine flows.
- **Females** — Spread labia and lift up. Cleanse the urethral opening using downward strokes, front to back, with a cotton ball soaked with soap and water. Spread labia apart and gently inset the catheter into the urethra in and upward and backward direction approximately 2 inches, until urine flows.
- Allow the bladder to empty completely.
- To remove the catheter, slowly rotate it as it is withdrawn. Stop each time more urine drains.
- To completely remove the catheter pinch off the end and pull it out. This will prevent urine from flowing back into the bladder.
- Check for any unusual odor and/or cloudy hazy urine. Be aware of any changes that need to be reported to the physician.

## Remember

- Catheterize regularly, every 3 to 8 hours to keep urine volumes low.
- Do not skip a catheterization for any reason.
- Always wash hands before and after the procedure.
- Fluid intake is directly related to urine output and the frequency of catheterization. Normal intake is six to eight 8-ounce glasses per day.
- If the catheter is accidentally dropped and cannot be washed properly, it may be wiped off to remove any possible grit and then used to catheterize.
- It is more important to empty the bladder; there is a greater chance of getting an infection from a full bladder than an unwashed catheter.

**Call the doctor with** any of the following symptoms:

- Cloudy or dark urine
- Blood in urine
- Nausea or vomiting
- Chills or fever
- Flank pain
- Lethargy
- Frequency of urination
- Urgency
- Painful urination
- Swelling or redness around urethral opening
- Change in smell of urine
- Noticeable decrease in the amount of urine
- Unusual discharge from urethra or around catheter
- Sudden pain or bleeding when inserting the catheter
- Inability to keep urine volume within recommended amount
- Inability to urinate of presence of abdominal distention

### Sterilization of Urinary Catheters

If catheters are re-used, it is important to clean them between uses. Below is one accepted method for cleaning re-used intermittent catheters:

### Supplies

- Resealable freezer bags
- Tupperware or similar plastic or metal container with a cover
- 70% isopropyl (rubbing) alcohol

### Procedure

1. Rinse catheter with tap water for 30 seconds.
2. Place catheter on paper towel to dry for one hour.
3. After it is dry, place it in a container with the alcohol for five minutes. Make sure that the entire catheter is covered with alcohol.
4. Store catheter in freezer bag without rinsing off the alcohol.
5. Just prior to using the catheter, rinse it with tap water (If there is well water, it is probably better to use distilled water).
6. If the catheter is not used within seven days of soaking it in the alcohol, remove it from the freezer bag and soak it again.
7. Freezer bags may be re-used until they show signs of wear or begin to leak.
8. Several catheters may be soaking in alcohol at one time, but store each one in a separate freezer bag.
9. Discard the alcohol from the container once a month and fill with a fresh supply. Keep the container of alcohol covered between uses.

A 1:4 mixture of household bleach with tap water or betadine solution with tap water in a 1:2 solution may also be used. The research that has been done using these two solutions is not as thorough as that done with the alcohol.

It is no longer recommended to use a microwave oven to sterilize urinary catheters. The studies that showed sterilization of catheters with the microwave technique were made of latex. Non-latex catheters have not become sterile when microwaved.

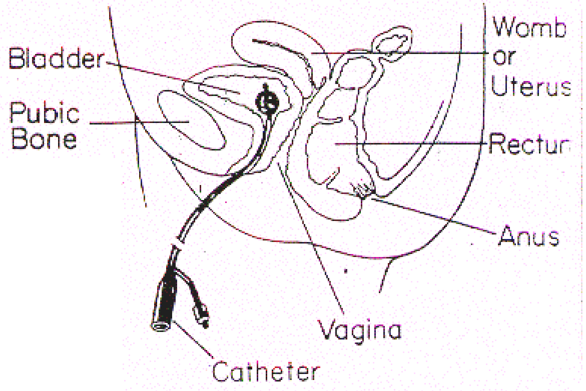
Adapted (8-07) from: http://www.ucof.com/files/IntermittentSelfCath.pdf ; http://www.cincinnatichildrens.org/health/info/urinary/home/self-cath-male.htm#explanation#explanation; and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

# Indwelling Catheter

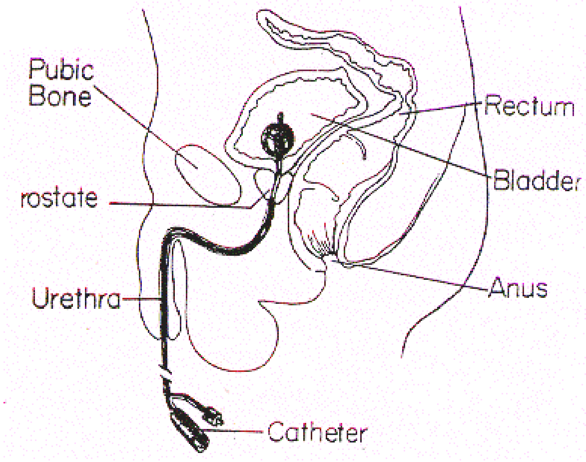
Any catheter which is inserted into the bladder and allowed to remain in the bladder is called an indwelling catheter.

A common type of indwelling catheter is a Foley catheter which is a closed, sterile system inserted into the urethra to allow the bladder to drain. A Foley catheter has a balloon attachment at one end. After the Foley catheter is inserted, the balloon is filled with sterile water. The filled balloon prevents the catheter from leaving the bladder.

Female Urinary Tract with Catheter in Place



Male Urinary Tract with Catheter in Place



The indwelling catheter is used for persons with urinary incontinence that is caused by obstruction (blockage in the urethra) or urinary retention (incomplete bladder emptying) that cannot be treated with other methods like with surgery, medications. It is also used in very sick persons where the incontinence interferes with monitoring of urinary output and in terminally ill or severely impaired persons for whom moving is painful.

An indwelling catheter is also used in persons with skin irritation or pressure ulcers (Stage 3 or 4) that are caused by incontinence. Catheters are also used in situations when a person is homebound, lives alone and a family member or a caregiver is not available to help.

**Care of an indwelling catheters**

- Care will vary. The usual practice is to change them every 4-5 weeks. This changing schedule is based on insurance reimbursement allowance. Persons who have problems with leakage, blockage (encrustations) might do better if their catheters were changed more often. If there is any concern the person may have a bladder infection, the entire catheter and system should be changed and a specimen for urine culture taken from the newly inserted catheter system.
- Always wash hands before and after touching the catheter or drainage bag.

This information is presented to inform IHSS social workers about common paramedical techniques and personal care tasks related to medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. There are different acceptable ways to perform many procedures. This information represents information gained from sources as listed at the end of the document. **All IHSS assessments should be individualized; all paramedical services must be consistent with time and frequency specified by the consumer's physician.**

- Wash the skin around the catheter with soap and water every day and after each bowel movement.
- Prevent kinks or loops in the catheter and tubing which might stop the flow of urine. Do not clamp the catheter or drainage tube.
- Urine must always drain "downhill", so keep the urine drainage bag below the level of the bladder at all times. This allows the urine to drain by gravity and will prevent the urine from flowing back into the bladder.
- Anchor the catheter securely to the thigh by using an anchor strap, but do not pull the catheter tightly. Leave some "slack" on the catheter to prevent pressure in the bladder.
- Empty the drainage bag at least every 4 to 8 hours or if it becomes filled before four hours. Do not touch the end of the drainage spout.
- If the tubing becomes disconnected, clean the ends with an alcohol pad and reconnect immediately.
- Indwelling catheters are attached to drainage bags, overnight or leg. An overnight bag is a bag with a long tube that is used during the night. The bag should be hung over the side of the bed below the level of the catheter so that the urine will flow easily.
- A leg bag is a smaller collection bag for use at home or when the person goes out of the house. The smaller bag is easy to hide under clothing. The care of both bags is the same

### Common Catheter Problems

**Burning or spasms** – Feeling a "burning" or "spasms" when urine passes through the catheter. This is a normal reaction, and there is no cause for alarm. These "spasms" may cause some urine to leak out around the catheter. A mild pain killer or medication to relieve the spasms may be prescribed. This may also indicate that the catheter needs to be changed.

**Falling out** -- Catheters falling out unexpectedly is common. The person may pull out the catheter by mistake, it may fall out because of too much tension on the catheter or because of bladder spasms. The balloon may still be in place when the catheter falls out.

**Catheter leakage or bypass** -- Leakage of urine around the catheter happens in most persons. Leakage may be due to involuntary bladder spasms (detrusor hyperreflexia or overactive bladder), infection, the catheter or balloon size being too large, or the bladder is irritated from catheter use.

The general belief is if the catheter is leaking then a larger size should be used but this will only worsen the problem. Remember a catheter may occasionally leak. There is no reason to be alarmed unless the catheter leaks continuously or if there is no urine in the drainage bag.

**Catheter blockage or obstruction** -- Obstruction or blockage is the result of the formation of encrustations which is caused by the collection of bacteria, crystallization of protein, or mucus plugs. Another common problem is encrustation of the catheter tip with calculous material causing blockage of the urine flow. This encrusted material is a combination of calcium, phosphorus, magnesium, uric acid and protein debris. This occurs more frequently when the pH of the urine is alkaline.

Obstruction of the catheter is the primary reason for frequent catheter changes. If this is occurs, the person should drink more liquids or consider acidifying the urine by taking ascorbic acid (vitamin C) 500-1000mg per day. If the catheter does become blocked do not disconnect the system and irrigate the catheter unless there is a doctor's order. If this is not ordered and the catheter stops draining, call the doctor.

**Catheter infection** -- Use of indwelling catheters over months and years causes bacteriuria (germs in the urine) and infection. Bacteriuria develops in most persons within 2 - 4 weeks after the catheter is inserted. Bacteria (germs) may enter the bladder either by traveling up from the bag to the bladder from inside the catheter system or outside on the surface of the system.

Notify the doctor if any of the following occurs:

- The urine has a strong odor, becomes cloudy or gets red. The urine coming through the catheter should be light yellow. There may be occasional blood clots.
- Chills, fever above 99.4 F, lower back pain, and/or leakage around the catheter.
- There is swelling at site where the catheter is inserted.
- The catheter is not draining any urine.

Adapted (8-7) from: http://www.seekwellness.com/incontinence/manage.htm; http://calder.med.miami.edu/pointis/indwelling.html; and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

# Condom Catheter

**What is it?**

Condom catheters are a useful and simple device for the control and treatment of urinary incontinence in males.

The condom catheter is a condom like device that is placed over the penis. A condom catheter allows the person to empty their bladder without using a urinal, bedpan, or toilet. A drainage tube is attached to the condom that allows the urine to pass into a urinary storage bag. The bag's contents can be emptied into the toilet.

There are several different external condom catheters available. They are made from latex rubber, polyvinyl, or silicone that are attached on the shaft of the penis by several different methods; a double-sided adhesive, latex inflatable cuff, jockey's type strap, or foam strap. They are then attached to urine drainage bags by a tube. Do not use a latex catheter if the person is allergic (phonetics) to latex. Do not use adhesive tape. Always read and follow the directions given with the catheter when putting on, taking off, and throwing away the catheter.

**Putting on a condom catheter**

The following are general guidelines for using a condom catheter. If the instructions that came in the box with the catheter are different from these, follow those instructions.

- Gather the following items:
    - Waterproof pad or bath towel.
    - Bowl of warm water, soap, washcloth, and hand towel.
    - Correct size of condom catheter (small, medium, large, extra large).
    - Velcro, tape, or other kind of sheath holding material.
    - Urine bag with tube.
- Place the waterproof pad or bath towel under the person if working in a chair or in bed.
- Wash the penis using soap and water. Rinse and dry carefully.
- Trim any pubic hair that may cause discomfort if it got caught in the condom or may prevent the condom being fitted securely.
- Inspect the penis to make sure it does not have any broken or reddened skin.
- Wash, rinse, and dry hands.

- Hold penis at a 90° angle from the body. Gently roll the condom over the penis. Leave 1 to 2 inches of the condom catheter at the end of the penis.
- Wrap the sheath holder around the condom at the base of the penis. Do not wrap the sheath holder too tightly because this may stop blood from going to the penis.
- Connect the condom catheter to the tube of the urine bag.
- Make sure the condom is not twisted where it attaches to the catheter.
- If you are using a small leg bag, use the catheter leg strap that came with the kit to secure the urine bag to the leg just below the knee. Leave some slack in the tube so the catheter will not be pulled when the leg moves.

**How often should the condom catheter be changed?**
Condom catheters should be changed every day or at least every other day.

### Hygiene and caregiver tips

### Keep skin clean: preventing infection

- Always clean the penis before applying a condom catheter and after taking it off.
- Make sure the skin does not show any signs of damage such as sores or cuts.
- Sometimes the adhesive that secures the urinary condom device into place around the base of the penis can cause irritation.
- If the skin shows signs of skin breakdown the device should not be reapplied until the skin heals properly.
- Remember, urine is an irritant to the skin and regular cleaning of any leakage is very important. Barrier creams should not be used on or near the penis as this may cause the urinary condom to slip off or leak.

### Cleaning the bag

- Clean urine bag with soap and water at least once a week if it is reused. If the urine bags are reused, have two of them. This allows use of the clean one while the other is being washed and stored.
- Procedure:
    - Rinse the old bag with warm water.
    - Fill the bag with one part white vinegar to three parts tap water. Let the bag sit with the water and vinegar in it for 30 minutes.
    - Empty, rinse, and air dry the bag.
    - When the bag is dry, store it in a clean plastic storage bag until later use.

Adapted (8-07) from:
http://www.healthtouch.com/bin/EContent_HT/cnoteShowLfts.asp?fname=02528&title=HOW+TO+CARE+FOR+YOUR+CONDOM+CATHETER+&cid=HTHLTH; http://alzheimers.about.com/od/practicalcare/a/condom_catheter.htm?p=1; http://www.seekwellness.com/incontinence/manage.htm; and Potter and Perry, Basic Nursing: essentials for nursing practice, Mosby 5th edition.

# Chest Percussion and Postural Drainage

Chest percussion is the manual pounding or clapping to loosen secretions. Postural drainage relates to the positioning of a person to drain and remove secretions from particular areas of the lungs. The specific positions involved in postural drainage allow different lobes to drain.

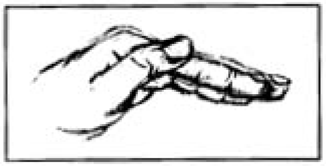
These techniques are used at intervals on people who have conditions that produce a great deal of sputum, such as cystic fibrosis, bronchiectasis, and lung abscess. The techniques may also be used when a person cannot cough up sputum effectively, as may happen with older people, people who have muscle weakness, and people recovering from surgery, an injury, or a severe illness.

Postural drainage cannot be used for people who are unable to tolerate the position required, are taking anticoagulation drugs, have recently vomited up blood, have had a recent rib or vertebral fracture, or have severe osteoporosis. Postural drainage also cannot be used for people who are unable to produce any secretions (because when this happens, further attempts at postural drainage may lower the level of oxygen in the blood).

Postural drainage and percussion (PD & P) is a time-consuming process. The average length of time to perform a treatment is 30 minutes.

Hand position for postural drainage:

- Bend your hand at your knuckles, and keep your fingers and thumb together. Form a "cup" with your hand.

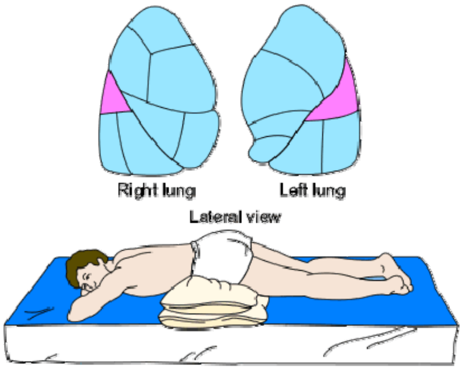


Clap the back or chest with a cupped hand quickly and rhythmically. This loosens the mucus, allowing it to drain. Bend the hand at the wrist and form a cup. During the clapping, there should hear a hollow "popping" sound. If the sound is more of a slapping sound, the hand is not cupped enough. Clapping is safe over the ribs, but do not clap over the middle back, spine, or female breasts. Do not clap directly on the skin; always cover the area with thin clothing or a cloth. Follow this procedure for each position.

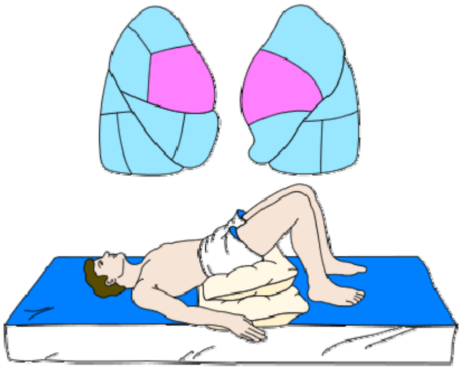
**How much force to use while clapping,** and how long you clap, depends on the person. Consider the following:

- Watch for the signs of pain and discomfort. If present, the clapping force may be too much.
- Is mucus coming up? If not, there may need to be more force.

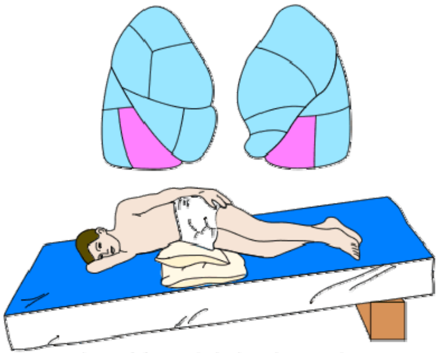
Postural drainage involves a patient assuming various positions to facilitate the flow of secretions from various parts of the lung into the bronchi, trachea and throat so that they can be cleared and expelled from the lungs more easily. The diagram below shows the correct positions to assume for draining different parts of the lung.



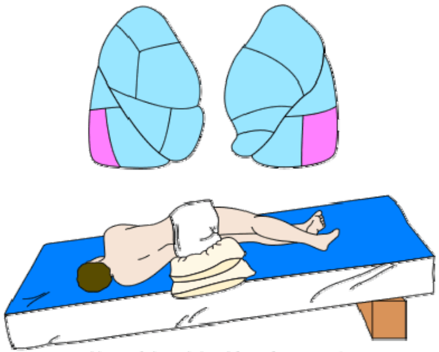
Lower lobes, superior segments



Upper lobes, anterior segment



Lower lobes, anterior basal segment



Upper lobes, lateral basal segment

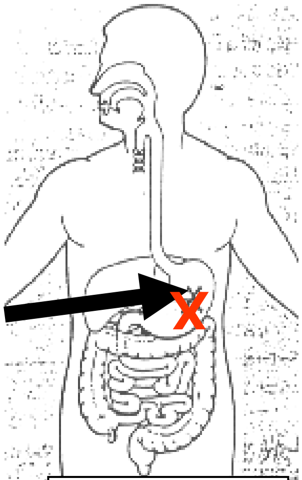
Adapted (08-07) from: http://www.merck.com/mmhe/sec04/ch040/ch040i.html; http://headtotoe.apta.org/kbase/as/ug1720/how.htm; http://www.cystic-l.org/handbook/html/physical_therapy.htm; http://connection.lww.com/products/smeltzer9e/imagebank.asp; and Potter and Perry, Basic Nursing: essentials for nursing practice, Mosby 5th edition.

# Feeding Tubes

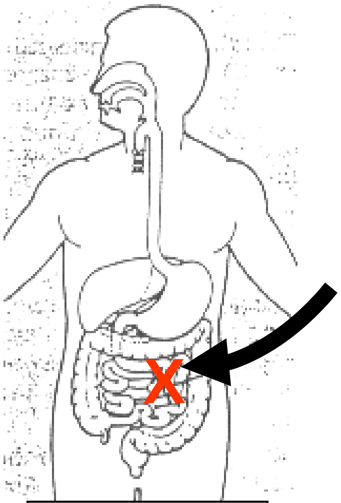
## Feeding Tubes placed through the abdominal wall include:

- Gastrostomy Tube (G-Tube)
- Jejunostomy Feeding Tube (J-Tube)

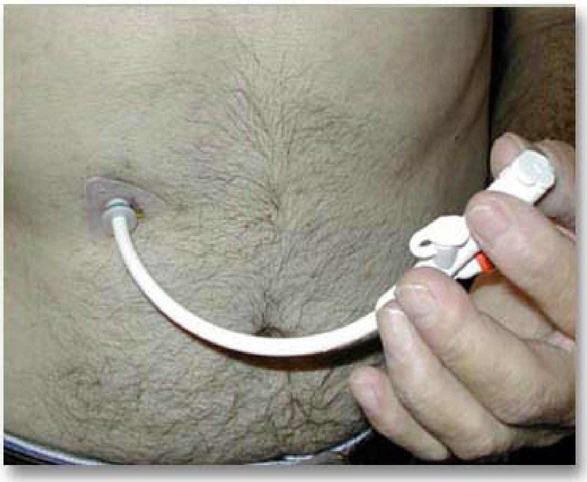
**Procedure:** Gastrostomy tubes are the preferred method of artificially feeding and hydrating patients over the long term. Gastrostomies, first practiced on humans in 1875, involve the surgical insertion of plastic tubes into the stomach through the abdominal wall. The most common type is the **percutaneous endoscopic gastrostomy (PEG) tube**. It is placed endoscopically: the patient is sedated, and an endoscope is passed through the mouth and esophagus into the stomach. The position of the endoscope can be visualized on the outside of the patient's abdomen because it contains a powerful light source. A needle is inserted through the abdomen, visualized within the stomach by the endoscope, and a suture passed through the needle is grasped by the endoscope and pulled up through the esophagus. The suture is then tied to the end PEG tube that will be external, and pulled back down through the esophagus, stomach, and out through abdominal wall. The insertion takes about 20 minutes. The tube is kept within the stomach either by a balloon on its tip (which can be deflated) or by a retention dome which is wider than the tract of the tube. J-tubes, are similar to G-tubes, but are much less commonly used. J-tubes feed into the upper intestines rather than into the stomach. With both G-tubes and J-tubes, a track forms between the skin and the stomach wall over time (much like the track that forms in the ear lobe a few months after ordinary ear piercing). The tube can be relatively comfortable after the incision heals.



**Gastrostomy Tube (G-Tube) or PEG tube**



**Jejunostomy Feeding Tube (J-Tube)**



Exterior view

Interior view

### Care of the patient and the tube

### Immediately after placement

- Greater care is required during the first week the tube is in place
- The area around the wound must be kept thoroughly clean and covered with clean, gauze.
- During this period of time the tube may occasionally pull away from the abdominal wall, resulting in leakage around the insertion site.
- Leakage may also occur if the stoma site becomes enlarged.
- Excessive tension may cause the tube to be pulled out prematurely.
- ***Should the tube accidentally come out*** it must be reinstated by the physician within twenty-four hours or the incision will begin to heal, and new surgery may be required. The tube is marked at the point where it should be level with the incision and should be checked daily to make sure that it is still properly in place. Excessive tension on the tube may also result in pressure necrosis (death of an area of tissue) of the interior abdominal wall.

### Feeding the patient

- It is imperative that the caregiver or patient thoroughly washes their hands with soap and water before preparing formula or having contact with the tube.
- The tube should be checked to make sure it is not blocked.
- The formula administered at room temperature.
- The patient should be upright, no less than thirty degrees, to minimize the risk of regurgitation and aspiration, and
- They should be kept upright for thirty to sixty minutes after feeding.

- To prevent complications (abdominal cramping, nausea and vomiting, gastric distension, diarrhea, aspiration), food should be infused slowly.
- It may take more than an hour to administer one feeding session, as the drip mechanism is kept at very slow settings
- Maintaining slow infusion speed and upright position should be monitored, but the patient does not need to be continuously monitored during the feeding.

### Continuous feeding

- A feeding pump is set up and connected to the tube.
- The formula is infused over a prescribed period of time into the patient.
- The risk for aspiration is decreased because less formula is given during a more prolonged period of infusion.

### Drip- feeding (gravity method)

- Using an attached bag system by which food is allowed to drip slowly into the tube though “gravity feeding.”
- With this technique, there is greater freedom in that feedings can be done anywhere, at any interval, and medications may be administered through the tube utilizing this method.
- Feedings are usually performed every four to six hours.

### Tube Patency

- The tube is very narrow, and commercial tube feeding formulas such as Ensure, are designed so that they will not clog the tube; they are not too thick and do not leave a residue.
- Most formulas are designed to have water added to them to ensure that the patient is receiving enough dietary water, and to further thin the formula for ease of use.
- Tubes should be flushed with water before and after feeding during intermittent delivery, and every 4 to 8 hours during continuous feeding. Multiple water flushings with the syringe will ensure a free flowing system.
- The placement of noncommercial formulas or foods into the tube is highly discouraged, as there is a greater likelihood that they will contribute to clogging.

### Bloating

- May experience bloating either before or after feeding.
- If this occurs, the stomach and intestinal tract should be decompressed. Removing the adapter feeding cap from the tube and allowing the tube to be open to air can easily accomplish this.
- Encouraging the patient to cough will also facilitate decompression.

## Oral Care

- Scrupulous oral care is imperative in preventing problems, and must be attended to frequently, especially in patients who are provided with total nutritional support through the feeding tube. Oral care should be done at least after each feeding. If the patient has very dry mucus membranes or sores in the mouth it should be done several times a day.
- Daily brushing of the patient's teeth, gums and tongue must be performed.
- The patient's lips should be routinely moistened, and if necessary, lubricated with petroleum jelly to prevent cracking.

## Skin care

- The incision area must be observed daily for redness, swelling, necrosis or pus like drainage, and
- The skin must also be cleaned daily.
- It helps to routinely apply an antibacterial ointment such as Neosporin to the insertion site after cleaning to prevent infections.

The lifespan of the feeding tube is about six months. When the tubing begins to wear, it may pull away from the stomach wall and cause leakage near the insertion point. The replacement process is relatively simple, and usually does not involve another endoscopic procedure. Typically, the tubing is merely pulled out through the stomach site and then replaced with a new catheter. This would be done by the doctor.

## Possible complications of Gastrostomies:

- Wound infections and painful insertion sites (where the tube passes though the skin), hemorrhaging and splitting open of the incision site.
- Inflammation of the stomach lining (peritonitis), stomach wall perforation and other related stomach and stomach wall defects, diarrhea, gastrointestinal bleeding, bowel obstruction, nausea, vomiting, reflux, fluid overload.
- Aspiration of feeding formula into the lungs, leading to aspiration pneumonia.
- Some patients may be confused and irritated -- physically and/or emotionally -- about the purpose of the stomach tube and its associated apparatus. Patients suffering from dementia may need to be very closely supervised so they do not pull out the tube.

## Nasogastric (NG) Tube

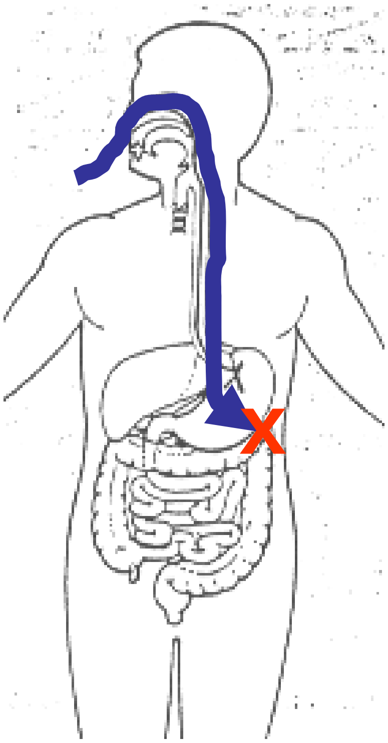
**Procedure:** Feeding by NG tube is the most common mode of delivering feeding formulas directly to the stomach for patients who need assistance in the **short term**. The insertion of an NG tube involves the passing of a flexible plastic tube, lubricated with a tasteless jelly, up through the nostril, then down through the back of the throat and into the stomach. NG tubes are rarely used for incompetent patients.

### Care of the patient and the tube

- Feeding is most often continuous with NG tubes to prevent overfilling of the stomach and prevent aspirations.

Note: If the patient starts coughing or choking during a feeding the feeding should be stopped. Noisy or "wet" respirations can indicate that liquid is impinging on the airway and could indicate the patient is aspirating feeding contents. This can be liquid that is actually aspirated into the airway or that merely penetrates the airway and then is expelled.

- Tube Placement should be check by inserting a bolus of air with a syringe and listening to stomach for a “woosh” before each feeding.
- Oral care is very important as the tube placement makes nose breathing difficult and mouth breathing creates dry mucus membranes.
- Watch or skin breakdown at the nostril.



## Possible complications of NG Tubes:

- The process of NG tube insertion can be quite uncomfortable, and even painful, especially when the tube hits the upper portion of the nasal cavity (when the individual doing the insertion must force the tube to make the downward turn toward the throat). Then, as the tube passes down past the esophagus it often causes a gag reflex that can result in vomiting.
- For confused patients, tube insertion can be frightening. Even after the tube has been placed, it can be irritating and frightening to the demented patient, close supervision will be needed to prevent them from tampering with the tube.
- If formula is introduced into the stomach too rapidly, diarrhea, regurgitation, aspiration, or vomiting can result.
- If the NG tube becomes dislodged (or if the patient vomits), gastric contents can be aspirated into the lungs, leading to the development of **aspiration pneumonia**.

Adapted (8-07) from: What is a feeding tube? http://huntingtondisease.tripod.com/feedingtubes/id1.html; Tube feeding in the elderly http://www.postgradmed.com/issues/2004/02_04/dharmarajan.htm; Tube feeding http://www.oralcancerfoundation.org/dental/tube_feeding.htm and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

# Using a Feeding Tube to Give Medications

**General rules** for delivering medications via enteral feeding tubes include the following:

- If the patient is able to take medications by mouth, the oral route is preferred over administration via the feeding tube. Some consumers may be able to take oral meds, but still need tube feeding for nutritional support.
- If the tube must be used, use liquid medications if at all possible.
- Flush the tube before and after the medication is administered with 30 ml of water.
- Dilute liquid medications with at least 30 ml of water to decrease osmolality (concentration of particles).
- Medications should never be added directly to the feeding formulation. The potency, stability, and availability of the medication as well as the stability of the enteral formulation cannot be ensured.
- If liquid medications are not available, check to see that the tablet medication can be crushed. Sublingual (under the tongue), enteric-coated or sustained release medication (names ending in XR, XL, XT, CD, EL, ER, SR) cannot be crushed.
- Administer each medication separately to avoid drug-drug incompatibilities, and flush the tube well between with 15-30 ml of water.
- Consider the timing of the medication; check to see whether it should be given on an empty or full stomach.
- Provide exact information about tube location to the dispensing pharmacist in order to best provide the correct dosage form. Use only water to flush tubes, as cranberry juice or cola may actually promote tube occlusion.

## Step-by-Step Procedure for Administering Medications through a Feeding Tube

1. Use a syringe no smaller than 30 ml to avoid excessive pressure and potential tube rupture.
2. Verify tube placement by pulling back on plunger until you see stomach contents. Do not discard this fluid by push back into stomach. If no fluid comes back have the consumer shift a little and try again. If you cannot confirm placement do not give medications, and call the doctor.
3. Prepare medication by diluting liquid medication with 30 ml of water or by crushing tablets with a mortar and pestle to a fine powder and mix with water.
4. Connect syringe to medication port on tube or to end of tube if medication port is not available, and gently push in medication.

5. When several medications are to be administered, all medications should be given separately and the tube flushed with at least 5mL of water after each dose.
6. Flush tube well following all medications to keep tube open, and reconnect feeding bag, or close off tube as indicated.

Adapted (8-07) from: http://www.ascp.com/publications/tcp/1999/jan/tubes.shtml#fig1;http://healthlinks.washington.edu/nutrition/section5.html; and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

# Nebulizer

A nebulizer with an attached inhaling apparatus

In medicine, a nebulizer is a device used to administer medication to people in forms of a liquid mist to the airways. It is commonly used in treating cystic fibrosis, asthma, and other respiratory diseases.

Also called "atomizers", they pump air or oxygen through a liquid medicine to turn it into a vapor, which is then inhaled by the patient.

As a general rule, doctors generally prefer to prescribe inhalers for their patients, not only because these are cheaper and more portable, but are often less potent and carry less risk of side effects. Nebulizers, for that reason, **are usually reserved only for serious cases of respiratory disease, or severe attacks**.

Newer, compact ultrasonic nebulizers are also available. These nebulizers, such as the Omron MicroAir series, use vibrating micro-mesh to produce the vapor. Nebulizers of this variety are rather expensive, and the micro-mesh is very delicate and sensitive to dust and debris.

**Use and Attachments**

Nebulizers usually accept their medicine in the form of a concentrated liquid, sometimes viscous. These medicines are frequently steroids, and the reason they are inhaled instead of ingested is to limit their effect to the lungs and respiratory system only. Otherwise, that amount of steroid saturated throughout the body would be toxic. This liquid is loaded into the machine for use.

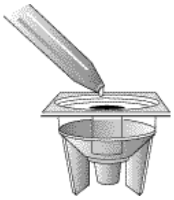
Bronchodilators such as Albuterol are often used.

Usually, the vaporized medicine is inhaled through a tube-like mouthpiece, similar to that of an inhaler. This has the added benefit of increasing portability, as well as allowing surrounding air to mix with the medicine, decreasing the unpleasantness of the vapor. The inhaling apparatus, however, is sometimes replaced with a standard rubber face mask, similar to that use for inhaled anesthesia, for ease of use with young children or the elderly.

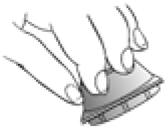
After use with steroids, the person who used the nebulizer must rinse his or her mouth because those steroids can cause yeast infection of the mouth (thrush). This is not true for bronchodilators; however, patients may still wish to rinse their mouths due to the unpleasant taste of many bronchdilating drugs.

**Giving a treatment:**
The following steps are recommended when giving a treatment. However, always consult the patient’s physician for specific instructions.

1. Gather supplies needed, including:
    - medication to be nebulized
    - nebulizer set (nebulizer cup, mouthpiece or mask, tubing to connect to nebulizer machine)

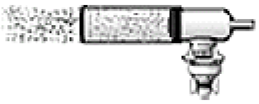


2. Place the nebulizer on a flat surface (i.e., table or the floor).
3. Plug the unit into a wall outlet.
4. Connect the air tubing to the nebulizer machine.

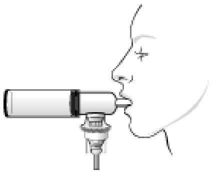


5. Put the medication into the nebulizer cup and screw the cap on securely.

6. Connect the other end of the air tubing to the nebulizer cup.
7. Connect the mouthpiece or face mask to the nebulizer cup.
8. Turn the machine on.



9. Check to make sure a fine mist of medication is coming through the face mask or mouthpiece.



10. Mouthpiece:
    - Place the mouthpiece in the patient’s mouth with the lips sealed around the mouthpiece.
    - Encourage the patient to take slow deep breaths in and out of their mouth. The mist should "disappear" with each breath.

11. Face mask:
    - Place the mask over the patient's mouth and nose. The adjustable elastic band may be used to hold the mask in place.
    - Encourage the patient to take deep breaths in and out for the duration of the treatment.

12. The patient should sit up straight on a comfortable chair

13. Encourage the patient to continue slow, deep breaths until all the medication in the nebulizer cup is gone. (about seven to 10 minutes). Tapping the sides of the nebulizer cup can help to ensure all medication is given.

14. Turn the nebulizer off.

15. If included in the patient's treatment plan:
    - Take peak flow measurements; obtain these before the treatment starts and after the treatment is completed. (see more about peak flow measurement at below.)
    - Have the patient take several deep breaths and cough. S/he should continue coughing and try to clear any secretions that might be in the lungs; coughing the secretions into a tissue and disposing of it properly.

**After each treatment:**

1. Disconnect the nebulizer cup from the tubing.
2. Open the cup and wash all pieces in a mild dish soap and water. (Do not wash or rinse the tubing.)
3. Rinse all pieces.
4. Air dry on a clean towel.
5. Store the dried nebulizer cup and tubing in a plastic bag.
6. Once a week rinse the nebulizer cup in a vinegar/water solution, after washing.

**Note:**

- Stay near the patient throughout the nebulizer treatment.
- If the patient should vomit becomes dizzy or feel "jittery," or have a severe coughing spell during the treatment, stop the treatment, let them rest for a few minutes, then resume the treatment. Then if these symptoms continue with future treatments, inform the appropriate health care provider.
- Check the filter on the nebulizer machine once a week. When it becomes discolored, replace with a new filter.
- Always keep a spare nebulizer kit at home.

### Storing

- Cover the compressor with a clean cloth when not in use. Keep it clean by wiping it with a clean, damp cloth as needed.
- Do not put the air compressor on the floor either for treatments or for storage.
- Medications should be stored in a cool, dry place. Check them often. If they have changed color or formed crystals, throw them away and replace them with new ones.

### Peak Flow Measurement:

The peak expiratory flow rate measures how fast a person can breath out (exhale) air. It is one of many tests that measure the how well the airways work.

This test requires a peak expiratory flow monitor, a small hand-held device with a mouthpiece at one end and a scale with a moveable indicator (usually a small plastic arrow).

- Breathe in as deeply as possible.
- Blow into the instrument's mouthpiece as hard and fast as possible.
- Do this 3 times, and record the highest flow rate.

Adapted (8-07) from: http://www.schneiderchildrenshospital.org/peds_html_fixed/peds/respire/handheld.htm ; Wikipedia, the free encyclopedia http://en.wikipedia.org/wiki/Nebulizer ; Home nebulizer treatment http://www.cchs.net/health/health-info/docs/0300/0352.asp?index=4297 ;

# Standing Frames

A standing frame (also known as a stand, stander, standing technology, standing aid, standing device, standing box, tilt table) is assistive technology used by a child or adult who uses a wheelchair for mobility. A standing frame provides alternative positioning to sitting in a wheelchair by supporting the person in the standing position. Standing frames are used for the medical benefits, but also to increase independence, mobility, and self-esteem.

Users include people with disabilities such as Paraplegic & Quadriplegic Spinal Cord Injuries, Muscular Dystrophy, Multiple Sclerosis, Traumatic Brain Injury, Cerebral Palsy, Spina Bifida, Stroke, ALS, and more...

Several options exist for achieving a standing position:

- **tilt tables** allow patients to lie flat on a bed and bring them to a stand after straps are added. The tables are tilted to the upright position either manually or by gas spring or electric power.
- **standing frames**, uses straps to hold up the person; lifting to the standing position may be achieved either by the patients pulling themselves up or with a hoist where straps are placed under the bottom and back. The lifting hoist can be either manual or electric.
- **“sit to stand”** method, is most common. The person sits on a device that can be moved to the upright position. The seat and back in the sitting position become the support in the upright position.

Systems for moving to the upright position are either electrical or manual with hydraulic assistance.

**Health Benefits of Standing**

Individuals who rely on a wheelchair for mobility should also look to a standing device or standing frame as a way prevent the secondary complications that often result from prolonged use of a wheelchair. Weight-bearing exercise like standing stretches muscles and increases stamina so users increase their confidence. Moving weight to the legs by standing offers an important method of relieving pressure from the bottom, the most common site of pressure ulcers.

## Medical Benefits of Standing

The most widely accepted medical benefits of standing include:

- Prevention of contractures (ankles, knees, and hips)
- Improvement of range of motion (spine, hips, knees and ankles)
- Reduction in spasticity
- Prevention or reversal of osteoporosis and resultant hypercalciuria
- Improvement of renal function, drainage of the urinary tract, and reduction in urinary calculi
- Prevention of pressure ulcers through changing positions
- Improvement in circulation as it related to orthostatic hypotension
- Improvement in bowel function
- Normalization of respiratory function

Other specific reasons that people stand include:

- Facilitation of a natural symmetrical standing posture
- Development & improvement of upper body balance & strength
- Alleviation of pain caused by prolonged or inappropriate position
- Development of standing tolerance & endurance
- Lessening progressive scoliosis
- Maintenance of bone density

## Psychological Benefits of Standing

Although funding sources rarely recognize the psychological benefits of standing, they can be some of the most important reasons to stand, especially for kids. Clinicians, parents, also recommend standing for the psychological benefits, including:

- Increase independence & self-image
- Being active and mobile while standing
- Be more alert
- Increase cognition
- Enhance social development & interactions with peers
- Participate in activities that are meant to do standing up
- Increase activities of daily living
- Be more vocal & responsive
- Look peers in the eye
- Give & get hugs easier
- Encourage inclusion in school
- Decrease fatigue from inactivity
- Help prevent depression

Adapted (8-07) from: http://en.wikipedia.org/wiki/Standing_frame; http://www.southwestmedical.com/Standing_Frames/482c0; http://people.howstuffworks.com/shepherd-center4.htm; and http://www.hmetoday.com/issues/articles/2000-03_04.asp

# Normal Vital Sign Values

**Respiratory Rate:**

| | |
|---|---|
| Newborns | Average 44 breaths per minute |
| Infants | 20-40 breaths per minute |
| Preschool children | 20-30 breaths per minute |
| Older children | 16-25 breaths per minute |
| Adults | 12 to 20 breaths per minute |

**Heart Rate:**

| | |
|---|---|
| newborn | 120-160 beats per minute |
| 0-5 months | 90-140 beats per minute |
| 6-12 months | 80-140 beats per minute |
| 1-3 years | 80-130 beats per minute |
| 3-5 years | 80-120 beats per minute |
| 6-10 years | 70-110 beats per minute |
| 11-14 years | 60-105 beats per minute |
| 14+ years | 60-100 beats per minute |

**Blood Pressure –Adult:**

| **Category** | **Systolic (top number)** | **Diastolic (bottom number)** |
|---|---|---|
| Normal | Less than 120 | Less than 80 |
| Prehypertension | 120–139 | 80–89 |
| High blood pressure | | |
| Stage 1 | 140–159 | 90–99 |
| Stage 2 | 160 or higher | 100 or higher |

**Blood Pressure – Pediatric:**

| **Age** | **Boys** | | **Girls** | |
|---|---|---|---|---|
| | **Normal** | **High** | **Normal** | **High** |
| 1 | < 103/54 | >= 106/58 | < 103/56 | >= 107/60 |
| 2 to 3 | < 109/63 | >= 113/67 | < 106/65 | >= 110/69 |
| 4 to 5 | < 112/70 | >= 116/74 | < 109/70 | >= 113/74 |
| 6 to 7 | < 115/74 | >= 119/78 | < 113/73 | >= 116/77 |
| 8 to 10 | < 119/78 | >= 123/82 | < 118/76 | >= 122/80 |
| 11 to 12 | < 123/79 | >= 127/83 | < 122/78 | >= 133/90 |
| 13 to 14 | < 128/80 | >= 132/84 | < 125/80 | >= 136/92 |
| 15 to 17 | < 136/84 | >= 140/89 | < 128/82 | >= 132/86 |
| Over 18 | same as adults | | | |

# MEDICAL ABBREVIATIONS: TERMS AND MEANINGS

| | | |
|---|---|---|
| **A** | | |
| **AAA** | Abdominal aortic aneurysm | Balooning of the abdominal aorta, that exceeds the normal diameter by more than 50% |
| **Abd** | Abdomen | The front of the body, below the chest and above the groin |
| **ACLS** | Advanced cardiac life support | Resuscitation including CPR, medications and defibrillation |
| **ACS** | Acute coronary syndrome | Sudden obstruction of blood flow to the heart |
| **ADD** | Attention Deficit Disorder | Hyperactivity |
| **ADL** | Activities of daily life | Personal care services |
| **A-fib** | Atrial fibrillation | Abnormal heart rhythm (cardiac arrhythmia) which involves the two small, upper heart chambers (the atria) |
| **AIDS** | Acquired immune deficiency syndrome | Disease of the immune system resulting from infection with HIV (human immunodeficiency virus) |
| **AKA** | Above knee amputation | Removing diseased leg above the knee |
| **ALL** | Acute lymphocytic leukemia | Malignant disease of the blood forming cells |
| **AMA** | Against medical advice | Patient leaves hospital before doctor is ready to release |
| **ALS** | Amyotrophic Lateral Sclerosis (Lou Gehrig's disease) | Progressive, fatal, neurodegenerative disease |
| **Amb** | Ambulate | Walk |
| **AODM** | Adult onset diabetes mellitus | Type 2 diabetes mellitus |
| **AP** | Anteroposterior | From front to back |
| **ARF** | Acute Renal Failure | Rapid loss of renal function due to damage to the kidneys |
| **AROM** | Active range of motion or artificial rupture of membranes | Active range of motion means that the patient is moving a limb to improve flexibility; artificial rupture of membranes means the amniotic sac is broken by the physician to induce labor |
| **AS** | Aortic stenosis | Narrowing of the aortic valve of the heart |
| **ASA** | Aspirin (acetylsalicylic acid) | An over the counter pain reliever |
| **ASHD** | Arteriosclerotic Heart Disease | Heart disease due to hardening of the arteries |
| **AV** | Arteriovenous | From artery to vein, for example, for dialysis |
| **Ax** | Axillary | Referring to the armpit |
| **B** | | |
| **BCP** | Birth control pills | Pills taken cyclically by a woman to prevent pregnancy |
| **BKA** | Below knee amputation | Self explanatory |
| **BM** | Bowel movement | The excretion of feces |
| **BMI** | Body mass index | The measurement of the proportion of fat in a body |
| **BP** | Blood Pressure | Level should be 130/80 or lower |
| **BPH** | Benign prostatic hypertrophy | Non-cancerous enlargement of the prostate gland |
| **BPM** | Beats per Minute | How fast the heart pumps |
| **BR** | Bed rest | Stay in bed to recuperate |
| **BS** | Blood Sugar | The measure of glucose in the blood |
| **BS** | Bowel sounds, breath sounds, blood sugar | Characteristic sounds of lungs or intestines heard with stethoscope; level of glucose in blood |
| **BX** | Biopsy | The removal of tissue from the body and examination under a microscope to rule out cancer |

# MEDICAL ABBREVIATIONS: TERMS AND MEANINGS

| | | |
|---|---|---|
| **C** | | |
| **c̄** | With | Self explanatory |
| **CA** | Cancer, carcinoma | Irregular growth of cells in an organ. |
| **CABG** | Coronary artery bypass graft | Surgical repair of clogged arteries of the heart |
| **CAD** | Coronary artery disease | Clogged arteries of the heart |
| **CAPD** | Continuous ambulatory peritoneal dialysis | Cleansing of the blood by inserting a solution into the belly, and when removed, the solution has absorbed blood waste products for a person whose kidneys are not working |
| **CBC** | Complete blood count | A diagnostic blood test which shows the specific number of each type of blood cell |
| **CCU** | Coronary care unit | A unit of the hospital specializing in care of those who have had a heart attack |
| **CHD** | Coronary Heart Disease | Narrowing or disease of the arteries supplying the heart |
| **CHF** | Congestive Heart Failure | Failure of the pumping action of the heart resulting in fluid retention, swelling, shortness of breath, etc |
| **CHI** | Closed head injury | A trauma to the head, causing injury to the brain |
| **CNS** | Central nervous system | The spinal column and nerves branching out of it |
| **C/O** | Complaining of | Self explanatory |
| **COPD** | Chronic obstructive pulmonary disease | Chronic bronchitis emphysema |
| **CPR** | Cardiopulmonary resuscitation | Intermittent pressure to the chest and mouth-to-mouth resuscitation in an effort to start the heart beating again and minimize brain damage |
| **CR** | Complete remission | Total recovery |
| **CRF** | Chronic renal failure | Slowly progressive loss of renal function over a period of months or years |
| **CRI** | Chronic renal Insufficiency | Condition in which the kidneys gradually lose their ability to perform their primary functions, |
| **CV** | Cardiovascular | The heart and circulatory system |
| **CVA** | Cardiovascular accident | Stroke |
| **CXR** | Chest x-ray | An x-ray of the chest, lungs, heart, large arteries, ribs, and diaphragm |
| **D** | | |
| **DBP** | Diastolic blood pressure | Blood pressure between heart beats – the second number listed in blood pressure reports |
| **DC** | Discontinue | Stop |
| **DH** | Developmental history | Description of the times when a person reaches certain milestones such as crawling, walking, being toilet trained, etc. |
| **DI** | Diabetes insipidis | Lack of antidiuretuc hormone results in abnormal fluid loss |
| **DJD** | Degenerative joint disease | Osteoarthritis |
| **DKA** | Diabetic ketoacidosis | Severe complication of type 1 diabetes when it is out of control |
| **DM** | Diabetes Mellitus | Decrease or absence of insulin production in the body |
| **DNR** | Do not resuscitate | If a person’s heart stops beating, medical staff have been instructed not to attempt to save the person’s life |
| **DOB** | Date of birth | Self explanatory |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

| | | |
|---|---|---|
| **DRSG** | Dressing | Bandages |
| **DVT** | Deep venous thrombosis | blood clot in large veins usually of leg or pelvis |
| **DWI** | Diffusion weighted image | A type of MRI imaging technique |
| **Dx** | Diagnosis | The clinical definition of what's wrong with the patient |
| **E** | | |
| **ECASA** | Enteric coated aspirin | Aspirin coated that melts in the intestine rather than the stomach to prevent damage to the esophagus and stomach lining |
| **ECG** | Electrocardiogram | A test of the electrical impulses that make the heart beat |
| **ED** | Emergency department | Of a hospital |
| **EDC** | Expected date of confinement | Date baby is due |
| **EEG** | Electroencephalogram | Test of electrical impulses of the brain |
| **EENT** | Ears, eyes, nose, throat | Self explanatory |
| **EKG** | Electrocardiogram | A test of the electrical impulses that make the heart beat |
| **EMG** | Electromyogram | Electrical testing of muscles |
| **ENT** | Ear, nose, throat | Self explanatory |
| **EOB** | Edge of bed | Self explanatory |
| **EOM** | Extraocular movements | movement of eyes related to muscles of orbit |
| **ER** | Emergency room | Of the hospital |
| **ERSD** | End Stage Renal Disease | Kidney failure |
| **ET** | Endotracheal | within the trachea, usually a tube placed for ventilation |
| **ETOH** | Alcohol | That one drinks |
| **EUA** | Examination under anesthesia | Self explanatory |
| **ext** | External | Self explanatory |
| **F** | | |
| **FB** | Foreign body | Self explanatory |
| **FBS** | Fasting blood sugar | A blood test after fasting at least 10 hours to determine the blood glucose level.  The level should be between 90 and 130.  Blood sugar levels 1 to 2 hours after the start of a meal should be less than 180. |
| **FH** | Family history | Self explanatory |
| **fob** | Foot of bed | Self explanatory |
| **FSBS** | Finger stick blood sugar | Pricking a finger with a lancet to test the glucose level in the blood |
| **F/U** | Follow-up | Self explanatory |
| **FUO** | Fever of unknown origin | Self explanatory |
| **fx** | Fracture | A broken bone |
| **G** | | |
| **GB** | Gallbladder | A gland that helps digest fats |
| **GC** | Gonorrhea | A sexually transmitted disease |
| **GE** | Gastroenterostomy | Artificial opening into the gastrointestinal tract |
| **GERD** | Gastro-esophageal Reflux Disease | Heart burn |
| **GH** | Growth hormone | Self explanatory |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

| | | |
|---|---|---|
| **GI** | Gastro-intestinal | Related to the digestive tract |
| **gluc** | Glucose | Blood sugar |
| **GTT** | Glucose tolerance test | A test of the body's ability to metabolize glucose in which a bolus of glucose is administered and blood levels are measured hourly for a period of time |
| **gtt** | Drop | Dosage of medicine given by eyedropper |
| **GU** | Genitourinary | The sexual and urinary tracts |
| **GYN** | Gynecologic | Related to the female sexual organs and tracts |
| **H** | | |
| **h** | Hour(s) | Self explanatory |
| **HA** | Headache | Self explanatory |
| **HAV** | Hepatitis A virus | Hepatovirus – causes an acute infectious disease of the liver |
| **HBP** | High Blood Pressure | Self explanatory |
| **HBV** | Hepatitis B virus | A contagious liver disease caused by the Hepatitis B virus |
| **HCT** | Hematocrit | Blood test that measures the number and the size of red blood cells |
| **HCV** | Hepatitis C virus | Virus causing a blood-borne, infectious, viral disease |
| **HCVD** | Hypertensive cardiovascular disease | High blood pressure |
| **HDL** | High density lipoprotein cholesterol | "Bad" cholesterol. |
| **HGB** | Hemoglobin | A protein in red blood cells that carries oxygen |
| **HIV** | Human immune deficiency virus | A person with HIV is carrying the virus that causes AIDS, but may not be symptomatic |
| **H/O** | History of | Self explanatory |
| **HOB** | Head of bed | Self explanatory |
| **HOH** | Hard of hearing | Self explanatory |
| **HPI** | History of present illness | Self explanatory |
| **HR** | Heart Rate | The speed the heart beats. |
| **hr(s)** | Hour(s) | Self explanatory |
| **HRT** | Hormone replacement therapy | Estrogen or estrogen with progesterone to treat the symptoms of menopause |
| **hs** | At bedtime | Self explanatory |
| **ht** | Height | Self explanatory |
| **HTN** | Hypertension | High blood pressure |
| **Hx** | History | Self explanatory |
| **I** | | |
| **IADLs** | Instrumental Activities of Daily Living | Domestic and Related services |
| **IBD** | Inflammatory bowel disease | Group of inflammatory conditions of the large intestine and, in some cases, the small intestine |
| **IBS** | Irritable bowel disease | A complex disorder of the lower intestinal tract. It is mainly characterized by a pattern of symptoms that is often worsened by emotional stress |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

| | | |
|---|---|---|
| **ICU** | Intensive care unit | A unit of the hospital where patients are at high risk of death |
| **IDD** | Insulin Dependent Diabetes | Type 1 diabetes and some with type 2 – insulin injections are necessary, usually twice a day |
| **IM** | Intramuscular | An injection site |
| **int** | Internal | Self explanatory |
| **I&O** | Intake and output | The measure of liquid ingestion and excretion |
| **IV** | Intravenous | In the vein |
| **IVF** | Intravenous fluid | Fluid dripped into the vein |
| **J** | | |
| **JODM** | Juvenile onset diabetes mellitus | Usually type 1 diabetes – onset under the age of 30 |
| **JVD** | Jugular venous distension | Abnormal dilation of the large veins in the neck |
| **K** | | |
| **KVO** | Keep vein open | A low rate of flow in an intravenous line to maintain the line by giving the least amount of fluid |
| **L** | | |
| **L** | Left | Self explanatory |
| **LA** | Left atrium | Part of the heart |
| **LBP** | Lower back pain | Self explanatory |
| **LDL** | Low density lipoprotein cholesterol | “Good” cholesterol. |
| **LE** | Lower extremity | The leg |
| **LFD** | Low fat diet | A diet low in fat |
| **LFT** | Liver function test | Blood tests of liver enzymes in the blood which indicate health of the liver tissue |
| **LLE** | Left lower extremity | Left leg |
| **LLL, LUL** | Left lower lobe, left upper lobe | Of the lung |
| **LLQ, LUQ** | Left lower quadrant, left upper quadrant | Of the abdomen |
| **LOC** | Level of consciousness | Degree of alertness, ability to respond to external stimuli |
| **LOF** | Loss of fluid | Loss of fluid from the body through excretion, sweating, bleeding, etc |
| **LP** | Lumbar puncture (spinal tap) | Diagnostic procedure that is done to collect a sample of cerebrospinal fluid (CSF) |
| **LUE** | Left upper extremity | Left arm |
| **LV** | Left ventricular | Large, muscular chamber of the heart that pumps blood out to the body |
| **M** | | |
| **MA** | Mental age | IQ translated into functional comparison |
| **MAE** | Moves all extremities | Able to move arms and legs |
| **MAP** | Mean Arterial Pressure | Average pressure in the arterial system |
| **MAR** | Medication administration record | Calendar of drugs given at specified times |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

| | | |
|---|---|---|
| **MDI** | Metered dose inhaler | A device that administers specified dose of medication through the mouth to the lungs |
| **MDR** | Minimum daily requirement | The least amount of a vitamin or mineral required for health |
| **Meds** | Medications | Prescriptions and over the counter drugs |
| **MI** | Myocardial infarction | Heart attack |
| **MICU** | Medical Intensive Care Unit | Hospital unit that provides care for those at high risk of death |
| **MOM** | Milk of magnesia | An over the counter medicine to cure constipation |
| **MRA** | Magnetic resonance angiogram | A type of MRI scan which shows blood vessels |
| **MRI** | Magnetic resonance imaging | A type of imaging which uses magnetic waves and is based on proton vibration in the tissues |
| **MRSA** | Methicillin resistant staphylococcus aureus | A specific strain of the Staphylococcus aureus bacterium that has developed antibiotic resistance to all penicillins, including methicillin |
| **MUD** | Matched unrelated donor | Self explanatory |
| **MVI** | Multi-vitamin | Vitamin dietary supplement |
| **N** | | |
| **NA or N/A?** | Not applicable | Self explanatory |
| **Na** | Sodium | A chemical element.  Too much of it can cause water retention in the tissues (edema) and high blood pressure |
| **NAD** | No active disease | Self explanatory |
| **NC** | Nasal cannula | Device for administering oxygen through the nose |
| **NG** | Nasogastric | Going from nose to the stomach |
| **NIBP** | Noninvasive blood pressure | taking blood pressure with a cuff, not an arterial line |
| **NIDDM** | Non-insulin dependent diabetes mellitus | Someone with type 2 diabetes who can control blood sugar levels with diet and exercise alone |
| **NKDA** | No known drug allergies | Self explanatory |
| **NPO** | Nothing by mouth | No food or liquid by mouth.  Often a person who is scheduled for surgery will be ordered NPO after midnight to prevent inhaling vomit |
| **NS** | Normal saline | Saline that is isotonic (same concentration as) body fluids |
| **NSICU** | Neurosurgery intensive care unit | Hospital unit that provides care for people who are not recovering from surgery but are at high risk of death |
| **NSR** | Normal sinus rhythm | Normal electrical conduction in the heart |
| **N&T** | Nose and throat | Self explanatory |
| **NTG** | Nitroglycerin | A drug to control the rhythm of the heart |
| **N/V** | Nausea and Vomiting | Self explanatory |
| **NWB** | Non weight bearing | Self explanatory |
| **O** | | |
| **$O_2$ sat** | Oxygen saturation | Measures the percentage of hemoglobin binding sites in the bloodstream occupied by oxygen |
| **OA** | Osteoarthritis | Wear-and-tear condition that may develop during aging, sometimes called degenerative joint disease |
| **OB** | Obstetrics | Prenatal care |
| **OBS** | Organic brain syndrome | General term, referring to physical disorders (usually not psychiatric disorders) that cause decreased mental function |

# MEDICAL ABBREVIATIONS: TERMS AND MEANINGS

| | | |
|---|---|---|
| **OCD** | Obsessive compulsive disorder | Anxiety disorder characterized by recurrent thoughts, feelings, ideas or sensations (obsessions) or behaviors that makes a person feel driven to perform (compulsions) |
| **OG** | Oral gastric | Related to the mouth and digestive tract |
| **OOB** | Out of bed | Self explanatory |
| **ORIF** | Open reduction and internal fixation | A surgery to repair the fracture-frequently, metal rods, screws or plates are used to repair the bone |
| **OT** | Occupational therapy | The matching of DMEs and wheelchairs to a patient’s condition and the teaching of adaptive techniques to perform ADLs |
| **OTC** | Over the counter | A drug that can be purchased without a prescription |
| **P** | | |
| **P** | Pulse | The heart beat |
| **p** | After | Self explanatory |
| **PA** | Pulmonary artery | Carries blood from the heart to the lungs |
| **PACU** | Post anesthesia care unit | Self explanatory |
| **PAO** | Pulmonary artery pressure | Pressure in the pulmonary artery |
| **PCA** | Patient controlled analgesia | A pain pill that is taken when the patient feels it’s time |
| **PCN** | Penicillin | Widely used antibiotic |
| **PCP** | Pneumocystitis carinii pneumonia | Common pneumonia type in HIV infected persons |
| **PD** | Progressive disease | A chronic disease that gets worse over time |
| **PE** | Pulmonary embolism | A blockage of an artery in the lungs by a blood clot, fat, air or clumped tumor cells |
| **PET** | Positron-emission tomography | Nuclear medicine medical imaging technique which produces a three dimensional image or map of functional processes in the body |
| **PF** | Peak flow | Fastest rate of air travel when forcing breath out, used to test asthmatics |
| **PFT** | Pulmonary function tests | A test of the lung capacity |
| **PID** | Pelvic inflammatory disease | An infection of the pelvic region outside organs |
| **PIH** | Pregnancy induced hypertension | High blood pressure as a result of pregnancy |
| **PMH** | Past medical history | Self explanatory |
| **PMP** | Previous menstrual period | Self explanatory |
| **po** | By mouth | Self explanatory |
| **PROM** | Passive range of motion | The movement of a joint by another (usually a PT) to improve flexibility |
| **prn** | As needed, as the occasion arises | Self explanatory |
| **PRO** | Protein | Self explanatory |
| **PSA** | Prostate specific antigen | blood test which is elevated in prostate cancer |
| **PT** | Physical therapy | Exercises and massage to improve strength and range of motion |
| **pt** | Patient | Client/consumer |
| **PUD** | Peptic ulcer disease | Ulcers/ erosions of the stomach or small intestine |
| **PVC** | Premature ventricular contraction | Premature heartbeats originating from the ventricles |
| **PVD** | Peripheral vascular disease | Diseases of blood vessels outside the heart and brain |

# MEDICAL ABBREVIATIONS: TERMS AND MEANINGS

| | | |
|---|---|---|
| **Q** | | |
| **QC** | Quality control | Measuring results of care |
| **R** | | |
| **R** | Right | Self explanatory |
| **RA** | Rheumatoid arthritis | Chronic, inflammatory autoimmune disorder that causes the immune system to attack the joints |
| **RBC** | Red blood cell (erythrocyte) | Part of the blood that carries oxygen through the body |
| **RBS** | Random blood sugar | Testing of blood glucose levels randomly throughout the day |
| **RDA** | Recommended daily allowance | The amount of a vitamin or mineral that is recommended for optimal health |
| **RHF** | Right heart failure | A condition in which the right side of the heart loses its ability to pump blood efficiently. Also called, Congestive heart failure - right-sided. |
| **RLE** | Right lower extremity | Right leg |
| **RLL, RUL, RML** | Right lower lobe, right upper lobe, right middle lobe | Of the lung |
| **RLQ, RUQ** | Right lower quadrant, right upper quadrant | Of the abdomen |
| **R/O** | Rule out | Many diagnoses are made by ruling out other diseases that create the symptoms |
| **ROM** | Range of motion | Movement of a joint to improve flexibility |
| **ROS** | Review of systems | Part of history and physical in which questions are asked to look for problems in organ systems other than the chief complaint |
| **RR** | Respiratory rate or respirations | Measurement of the number of inhalations in a period of time |
| **r/t** | Related to | Self explanatory |
| **RTC** | Return to clinic | Self explanatory |
| **RUE** | Right upper extremity | Right arm |
| **RV** | Right ventricle | The lower right chamber of the heart that receives deoxygenated blood from the right atrium and pumps it under low pressure into the lungs via the pulmonary artery. |
| **Rx** | Prescription treatment | Self explanatory |
| **S** | | |
| **s̄** | Without | Self explanatory |
| **SARS** | Severe acute respiratory syndrome | A contagious lung infection |
| **SBP** | Systolic blood pressure | Blood pressure when the heart beats (the first number in listed in blood pressure) |
| **SCC** | Squamous cell carcinoma | A form of cancer of the carcinoma type that may occur in many different organs, including the skin, mouth, esophagus, prostate, lungs, and cervix. |
| **SH** | Social history | Self explanatory |
| **SICU** | Surgical Intensive Care Unit | A hospital unit where people in unstable conditions go for care following surgery |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

| | | |
|---|---|---|
| **SL** | Sublingual | Under the tongue |
| **SLE** | Systemic lupus erythematosus | Disease in which the body makes abnormal antibodies against various orgasm and tissues |
| **SO** | Significant other | Partner |
| **SOB** | Shortness of Breath | Self explanatory |
| **SOP** | Standard of Practice | Self explanatory |
| **S/P** | Status post | Self explanatory |
| **SQ** | Subcutaneous | Under the skin |
| **S&S** | Signs and symptoms | Self explanatory |
| **SVI** | Stroke volume index | Measure of cardiac function |
| **SVT** | Supraventricular tachycardia | Rhythm of the heart in which the origin of the electrical signal is either the atria or the AV node |
| **Sx** | Symptoms | Self explanatory |
| **T** | | |
| **TAB** | Therapeutic abortion | Self explanatory |
| **TB** | Tuberculosis | A contagious lung disease |
| **TENS** | Transcutaneous electrical nerve stimulation | Works to decrease pain perception and may be used to control acute and chronic pain |
| **TF** | Tube feedings | Nutrition provided via non oral route |
| **THP** | Total hip replacement | A surgical procedure that re-forms the hip joint |
| **TIA** | Transient ischemic attack | Mini-stroke |
| **TKR** | Total knee replacement | A surgical procedure that re-forms the knee joint |
| **TLC** | Total lung capacity | Total volume of air that can be held in the lungs |
| **TMJ** | Tempromandibular joint | Joint in front of the ear which articulates the mandible (jaw bone) with the skull |
| **TPN** | Total parenteral nutrition | Highly concentrated fluid nutrition given through the vein |
| **TPR** | Temperature, pulse, respirations | Vital signs |
| **T (Temp)** | Temperature | Normal is 98.6° |
| **TV** | Tidal volume | Volume of air during each breath in normal respiration |
| **TX** | Treatment | Self explanatory |
| **U** | | |
| **UA** | Urine analysis | Lab exam of urine to determine if there is an infection, if there is blood in the urine, and if the minerals levels are balanced |
| **UCHD** | Usual childhood diseases | Refers to diseases which most children have had such as chickenpox |
| **UDS** | Urine drug screen | Test of the urine to determine whether a person is abusing drugs |
| **UE** | Upper extremity | Arm |
| **UGI** | Upper gastrointestinal | Esophagus and stomach |
| **UO** | Urine output | Amount of urine passed in a specified time |
| **URI** | Upper Respiratory Infection | A cold with a cough |
| **US** | Ultrasound | Imaging technique using sound waves |
| **UTD** | Up to date | Self explanatory |
| **UTI** | Urinary Tract Infection | Bladder or kidney infection |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

| | | |
|---|---|---|
| **V** | | |
| **VD** | Venereal disease | A sexually transmitted disease such as syphilis or gonorrhea |
| **VO** | Verbal order | Instructions given to a patient verbally – not written |
| **VO2** | Oxygen consumption | Amount of oxygen used by cells |
| **VS** | Vital signs | Temperature, pulse and blood pressure |
| **VT** | Ventricular tachycardia | Abnormally fast contraction of the heart |
| **W** | | |
| **WB** | Whole blood | Blood as it is removed from a person including all cells, plasma |
| **WBC** | White blood cell (count) | The amount of white blood cells in a blood test.  An elevated level indicates the body is fighting an infection |
| **W/C** | Wheelchair | Self explanatory |
| **WDL** | Within defined limits | Test result is within previously identified high and low values |
| **w/n** | Well nourished | Self explanatory |
| **WNL** | Within normal limits | test result or exam is within acceptable range for normal |
| **wt** | Weight | Self explanatory |
| **Y** | | |
| **YO** | Years old | Self explanatory |

# MEDICAL ABBREVIATIONS: TERMS AND MEANINGS

## Medication Administration Times

| | |
|---|---|
| ac | **Before meals** |
| ad lib | **As desired / needed** |
| ASAP | **As soon as possible** |
| b.i.d. or BID | **Twice daily** |
| h.s. or HS | **At bedtime (hour of sleep)** |
| NOC | **Nighttime** |
| pc or P.C. | **After meals** |
| p.r.n. or PRN | **As needed** |
| q or Q | **Every** |
| q AM | **Every morning** |
| q hr | **Every hour** |
| q.d. or QD | **Every day** |
| q.i.d. or QID | **Four times a day** |
| qn | **Every night** |
| q.o.d. or QOD | **Every other day** |
| q (Q) 1°, 2°, 3°, 4°, 6°, 8°, or 12°, etc | **Every 1, 2, 3, 4, 6, 8, 12 hours. (Concept is based on a day and administering on a routine sequential basis to maintain therapeutic blood levels.)** |
| stat or STAT | **Immediately!** |
| t.i.d. or TID | **Three times daily** |

## Medication Administration Routes

| | | | |
|---|---|---|---|
| a.d. or A.D. | **Right ear** | NGT | **Nasogastric tube** |
| a.s. or A.S. | **Left ear** | od or O.D. | **Right eye** |
| a.u. or AU | **each ear or both ears** | os or O.S. | **Left eye** |
| HHN | **Hand held nebulizer** | ou or O.U. | **Each eye or both eyes** |
| I.D. | **Intradermal route** | po or P.O. or PO | **By mouth** |
| I.M. or IM | **Intramuscular route** | P.R. or PR | **By rectum** |
| I.T. | **Intrathecal route** | SQ, sub q, subcut | **Subcutaneous route** |
| I.V. or IV | **Intravenous route** | SL or s.l. | **Sublingual route** |
| IVP | **Intravenous push** | S & S | **Swish and swallow** |
| IVPB | **Intravenous piggyback** | V or P.V. | **Vaginal route** |

# MEDICAL ABBREVIATIONS:  TERMS AND MEANINGS

# RESOURCE LIST

## Alzheimer's (AD)

To learn about support groups, services, research centers, getting involved in studies, and publications about AD, contact the following:

**Alzheimer's Disease Education and Referral (ADEAR) Center**
P.O. Box 8250
Silver Spring, MD  20907–8250
(800) 438–4380
www.alzheimers.nia.nih.gov
This service of the NIA offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to AD. Staff answer telephone, e-mail, and written requests and make referrals to local and national resources.

**Alzheimer's Association**
225 North Michigan Avenue, Suite 1700
Chicago, IL  60611–7633
(800) 272–3900
www.alz.org
This nonprofit association supports families and caregivers of patients with AD and funds research. Chapters nationwide provide referrals to local resources and services, and sponsor support groups and educational programs.

**American Health Assistance Foundation**
22512 Gateway Center Drive
Clarksburg, MD  20871
(800) 437–2423
(301) 948–3244
www.ahaf.org
eberger@ahaf.org
Provides emergency financial assistance to Alzheimer's disease patients and their caregivers.

**Eldercare Locator**
**(**800) 677–1116
www.eldercare.gov
This service of the Administration on Aging, funded by the Federal Government, provides information and referrals to respite care and other home and community services offered by State and Area Agencies on Aging.

**Family Caregiver Alliance (FCA)**
180 Montgomery Street, Suite 1100
San Francisco, CA  94104
(415) 434–3388
(800) 445–8106
www.caregiver.org
info@caregiver.org
Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating brain disorders that strike adults.

**National Academy of Elder Law Attorneys (NAELA)**
1604 North Country Club Road
Tucson, AZ 85716
(520) 881–4005
www.naela.com
NAELA publishes consumer information on estate planning and has an online database of Elder Law Attorneys.

**Alzheimer's Disease International**
www.alz.co.uk/alzheimers

**Alzheimer Society of Canada**
www.alzheimer.ca

**Dementia Advocacy and Support Network**
www.dasninternational.org

# Asthma

**National Library of Medicine**
MedlinePlus
8600 Rockville Pike
Bethesda, MD 20894
(888) FIND–NLM (346-3656)
(301) 594–5983
http://medlineplus.gov

**Allergy & Asthma Network/Mothers of Asthmatics**
2751 Prosperity Avenue, Suite 150
Fairfax, VA 22031
(800) 878–4403 or (703) 641–9595
http://www.aanma.org

**American Academy of Allergy, Asthma, and Immunology**
555 East Wells Street, Suite 1100
Milwaukee, WI 53202–3823
(800) 822–2762
http://www.aaaai.org

**Asthma and Allergy Foundation of America**
1233 20th Street, NW, Suite 402
Washington, DC 20036
(800) 7–ASTHMA (727–8462)
http://aafa.org

# Autoimmunity

Various parts of the NIH provide information on different aspects of autoimmune diseases. Many nonprofit organizations have patient resources, local chapters, and support groups. The patient’s doctor is the best resource to give details about their medical condition.

*National Institutes of Health*

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
1 AMS Circle
Bethesda, MD 20892–3675
(301) 495–4484 or
(877) 22–NIAMS (226–4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
www.niams.nih.gov

**National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK**) National Diabetes Information Clearinghouse (NDIC)
1 Information Way
Bethesda, MD 20892–3560
(301) 654–3327 or
(800) 860–8747
ndic@info.niddk.nih.gov
www.niddk.nih.gov

# RESOURCE LIST

**NIH Clinical Center Patient Recruitment Office**
(800) 411–1222
TTY: 866–411–1010
prpl@mail.cc.nih.gov
http://clinicalstudies.info.nih.gov/

**National Institute of Allergy and Infectious Diseases**
Office of Communications
Building 31, Room 7A25 31
Center Drive, MSC 2520
Bethesda, MD 20892–2520
(301) 496–5717
www.niaid.nih.gov/publications
and
www.niaid.nih.gov/clintrials/default.htm
(for clinical trials information)

**National Institute of Neurological Disorders and Stroke**
Office of Communication and Public Liaison
P.O. Box 5801
Bethesda, MD 20824
(301) 496–5751 or
(800) 352–9424
braininfo@ninds.nih.gov
www.ninds.nih.gov

**Office of Rare Diseases**
6100 Executive Boulevard
Room 3B01, MSC 7518
Bethesda, MD 20892–7518
(301) 402–4336
http://rarediseases.info.nih.gov

*Other Resources Sponsored by the U.S. Department of Health and Human Services*

**Combined Health Information Database**
http://chid.nih.gov

**National Health Information Center**
(301) 565–4167 or
(800) 336–4797
Health Finder: www.healthfinder.gov

*Other Organizations*

**American Academy of Dermatology**
P.O. Box 4014
Schaumburg, IL 60168–4014
(847) 330–0230 or
(888) 462–DERM (3376)
Fax: (847) 330–0050
www.aad.org

**American Academy of Orthopaedic Surgeons**
P.O. Box 1998
Des Plaines, IL 60017–1998
(800) 824–BONE (2663)
www.aaos.org

**American College of Rheumatology**
1800 Century Place, Suite 250
Atlanta, GA 30345
(404) 633–3777
Fax: (404) 633–1870
acr@rheumatology.org
www.rheumatology.org

**American Behçet's Disease Association**
P.O. Box 19952
Amarillo, TX 79114
(800) 7–BEHCET (723–4238)
www.behcets.com

**American Liver Foundation**
75 Maiden Lane, Suite 603
New York, NY 10038
(800) GO–LIVER (465–4837) or
(800) 4HEP–USA (443–7872)
info@liverfoundation.org
www.liverfoundation.org

**Crohn's and Colitis Foundation of America**
National Headquarters
386 Park Avenue South, 17th Floor
New York, NY 10016–8804
(800) 932–2423
www.ccfa.org

**Juvenile Diabetes Research Foundation International**
120 Wall Street
New York, NY 10005–4001
(212) 785–9500 or
(800) JDF–CURE (533–2873)
Fax: (212) 785–9595
info@jdrf.org
www.jdf.org

# RESOURCE LIST

**American Autoimmune Related Diseases Association**
22100 Gratiot Avenue
East Detroit, MI  48021
Literature requests: (800) 598–4668
Phone: (586) 776–3900
Fax: (586) 776–3903
aarda@aol.com
www.aarda.org

**American Diabetes Association**
Attn: National Call Center
1701 North Beauregard Street
Alexandria, VA  22311
Phone: (800) DIABETES (342–2383)
www.diabetes.org

**Arthritis Foundation**
P.O. Box 7669
Atlanta, GA  30357
(404) 872–7100 or
(800) 568–4045
www.arthritis.org

**Guillain-Barré Syndrome Foundation International**
P.O. Box 262
Wynnewood, PA  19096
(610) 667–0131
Fax: (610) 667–7036
info@gbsfi.com
www.guillain-barre.com

**Lupus Foundation of America, Inc.**
2000 L Street, N.W., Suite 710
Washington, DC  20036
(202) 349–1155 or
(800) 558–0121
info@lupus.org
www.lupus.org

**Myasthenia Gravis Foundation of America**
1821 University Avenue W., Suite S256
St. Paul, MN  55104
(651) 917–6256 or
(800) 541–5454
Fax: (651) 917–1835
mgfa@myasthenia.org
www.myasthenia.org

**The Myositis Association**
1233 20th Street, N.W., Suite 402
Washington, DC  20036
(202) 887–0088
Fax: (202) 466–8940
tma@myositis.org
www.myositis.org

**National Alopecia Areata Foundation**
14 Mitchell Boulevard
San Rafael, CA  94903 or
P.O. Box 150760
San Rafael, CA  94915–0760
(415) 472–3780
Fax: (415) 472–5343
info@naaf.org
www.naaf.org

**National Adrenal Diseases Foundation**
505 Northern Boulevard
Great Neck, NY  11021
(516) 487–4992
nadfmail@aol.com
www.medhelp.org/nadf
**National Multiple Sclerosis Society**
733 Third Avenue, 6th Floor
New York, NY  10017–3288
(212) 986–3240 or
(800) 344–4867
Fax: (212) 986–7981
info@nmss.org
www.nmss.org

**International Pemphigus Foundation**
1540 River Park Drive, Suite 208
Sacramento, CA  95815
(916) 922–1298
Fax: (510) 527–8497
pemphigus@pemphigus.org
www.pemphigus.org

**National Vitiligo Foundation**
700 Olympic Plaza Circle, Suite 404
Tyler, TX  75701
(903) 595–3713
Fax: (903) 593–1545
info@nvfi.org
www.nvfi.org

**National Organization for Rare Disorders**
P.O. Box 1968
Danbury, CT  06813-1968
(203) 744–0100 or
(800) 999–6673
TDD: 203–797–9590
orphan@rarediseases.org
www.rarediseases.org

# RESOURCE LIST

**National Psoriasis Foundation**
6600 SW 92nd Avenue, Suite 300
Portland, OR  97223–7195
(503) 244–7404 or
(800) 723–9166
Fax: 503–245–0626
getinfo@psoriasis.org
www.psoriasis.org

**Scleroderma Foundation**
300 Rosewood Drive, Suite 105
Danvers, MA  01923
(978) 463–5843
Info line: (800) 722–HOPE (4673)
Fax: (978) 463–5809
sfinfo@scleroderma.org
www.scleroderma.org

**Scleroderma Research Foundation**
220 Montgomery Street, Suite 1411
San Francisco, CA  94104
(415) 834–9444 or
(800) 441–CURE (2873)
Fax: (415) 834–9177
info@sclerodermaresearch.org
www.sclerodermaresearch.org

**Sjögren's Syndrome Foundation**
6707 Democracy Boulevard, Suite 325
Bethesda, MD  20817
(301) 530–4420 or
(800) 475–6473
Fax: (301) 530–4415
www.sjogrens.org

**Spondylitis Association of America**
P.O. Box 5872
Sherman Oaks, CA  91413
(800) 777–8189
info@spondylitis.org
www.spondylitis.org

**S.L.E. Lupus Foundation**
330 Seventh Avenue, Suite 1701
New York, NY  10001
(212) 685–4118 or
(800) 74–LUPUS (745–8787)
Fax: (212) 545–1843
lupus@lupusny.org
www.lupusny.org

**Thyroid Foundation of America, Inc.**
One Longfellow Place, Suite 1518
Boston, MA  02114
(800) 832–8321
Fax: (617) 534–1515
info@allthyroid.org
www.allthyroid.org

**Vasculitis Foundation**
P.O. Box 28660
Kansas City, MO  64188–8660
(800) 277–9474
Phone/Fax: (816) 436–8211
vf@vasculitisfoundation.org
www.vasculitisfoundation.org

## Cerebral Palsy (CP)

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

**BRAIN**
P.O. Box 5801
Bethesda, MD  20824
(800) 352–9424
http://www.ninds.nih.gov

# RESOURCE LIST

**Information also is available from the following organizations:**

**United Cerebral Palsy (UCP)**
1660 L Street, NW
Suite 700
Washington, DC  20036
(202) 776–0406 or (800) USA–5UCP (872–5827)
Fax: (202) 776–0414
national@ucp.org
http://www.ucp.org
Works to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through our commitment to the principles of independence, inclusion and self-determination.

**March of Dimes Birth Defects Foundation**
1275 Mamaroneck Avenue
White Plains, NY  10605
(914) 428–7100 or (888) MODIMES (663–4637)
Fax: (914) 428–8203
askus@marchofdimes.com
http://www.marchofdimes.com
Works to improve the health of babies by preventing birth defects and infant mortality through programs of research, community services, education, and advocacy.

**Children's Neurobiological Solutions (CNS) Foundation**
1726 Franceschi Road
Santa Barbara, CA  93103
(866) CNS–5580 (267-5580) or (805) 965–8838
info@cnsfoundation.org
http://www.cnsfoundation.org
National, non-profit organization whose mission is to accelerate the development of brain repair therapies and cures by supporting cutting-edge collaborative research on brain damage due to childhood illness, injury, or any other cause. Provides information and resources for families and health care providers.

**Regional Center**
There are 21 Regional Centers in California that have the mandate to provide services to all Californians who have one of five diagnoses that had an onset date before the age of 18:  mental retardation, cerebral palsy, epilepsy, autism, and a handicap similar to mental retardation that is substantially handicapping and has an onset before the age or 18.  Regional Centers provide case management and purchase services.

**United Cerebral Palsy (UCP) Research & Educational Foundation**
1660 L Street, NW
Suite 700
Washington, DC  20036
(202) 973–7140 or (800) USA–5UCP (872–5827)
Fax: (202) 776–0414
national@ucp.org
http://www.ucpresearch.org
Provides grants for research and training on causes and prevention of cerebral palsy and on improving the quality of life of persons with cerebral palsy.

# RESOURCE LIST

**Pathways Awareness Foundation** [For Children With Movement Difficulties]
150 N. Michigan Avenue
Suite 2100
Chicago, IL  60601
(312) 893–6620 or (800) 955–CHILD (2445)
Fax: (312) 893–6621
friends@pathwaysawareness.org
http://www.pathwaysawareness.org
National non-profit organization dedicated to raising awareness about the value of early detection, early therapy, and inclusion for infants and children with movement differences.

**Easter Seals**
230 West Monroe Street
Suite 1800
Chicago, IL  60606-4802
(312) 726–6200 or (800) 221–6827
Fax: (312) 726–1494
info@easterseals.com
http://www.easterseals.com
Provides services to help children and adults with disabilities and/or special needs as well as support to their families. Supports the National AgrAbility Project, a program for farmers, ranchers, and farmworkers with disabilities.

**Children's Hemiplegia and Stroke Association (CHASA)**
4101 West Green Oaks Boulevard, Ste. 305
PMB 149
Arlington, TX  76016
(817) 492–4325
info437@chasa.org
http://www.hemi-kids.org
Nonprofit organization that offers support and information to families of children who have hemiplegia due to stroke or other causes. Sponsors a number of programs for families, offers support groups and information about research studies, and sponsors conferences and a childhood stroke awareness campaign.

## Chronic Obstructive Pulmonary Disease (COPD)

**COPD Learn More, Breathe Better** (NHLBI) http://www.nhlbi.nih.gov/health/public/lung/copd/index.htm

**Chronic Obstructive Pulmonary Disease (COPD)** (American Academy of Family Physicians) http://familydoctor.org/online/famdocen/home/articles/706.html

**COPD** (Chronic Obstructive Pulmonary Disease) *Interactive Tutorial* (Patient Education Institute) - Requires Flash Player  Also available in Spanish http://www.nlm.nih.gov/medlineplus/tutorials/copd/htm/index.htm

**Chronic Obstructive Pulmonary Disease Fact Sheet** *NIH* (National Heart, Lung, and Blood Institute) - Links to PDF http://www.nhlbi.nih.gov/health/public/lung/other/copd_fact.pdf

**American Lung Association**
**(**800) LUNG–USA (586–4872)
http://www.lungusa.org

# RESOURCE LIST

## Cirrhosis

**American Liver Foundation (ALF)**
75 Maiden Lane, Suite 603
New York, NY 10038–4810
(800) GO–LIVER (465–4837),
(888) 4HEP–USA (443–7872),
or (212) 668–1000
Fax: (212) 483–8179
info@liverfoundation.org
www.liverfoundation.org

**Hepatitis Foundation International**
504 Blick Drive
Silver Spring, MD 20904–2901
(800) 891–0707 or (301) 622–4200
Fax: (301) 622–4702
hfi@comcast.net
www.hepfi.org

**United Network for Organ Sharing**
P.O. Box 2484
Richmond, VA 23218
(888) 894–6361 or (804) 782–4800
www.unos.org

## Congestive Heart Failure (CHF)

**Heart Failure** (MedlinePlus) http://www.nlm.nih.gov/medlineplus/heartfailure.html

**Congestive Heart Failure** *Interactive Tutorial* (Patient Education Institute) - Requires Flash Player
http://www.nlm.nih.gov/medlineplus/tutorials/congestiveheartfailure/htm/index.htm

**Heart Failure** *NIHSeniorHealth* (National Institute on Aging) http://nihseniorhealth.gov/heartfailure/toc.html

**Heart Failure** *NIH* (National Heart, Lung, and Blood Institute)
http://www.nhlbi.nih.gov/health/dci/Diseases/Hf/HF_WhatIs.html

## Coronary Artery Bypass Grafting (CABG)

**Coronary Artery Disease** (Diseases and Conditions Index)
http://www.nhlbi.nih.gov/health/dci/Diseases/Cad/CAD_WhatIs.html

**Heart Attack** (Diseases and Conditions Index)
http://www.nhlbi.nih.gov/health/dci/Diseases/HeartAttack/HeartAttack_WhatIs.html

**NHLBI-Related Public Interest Organizations** http://www.nhlbi.nih.gov/public/grouplist.htm

**Your Guide to Living Well With Heart Disease**
http://www.nhlbi.nih.gov/health/public/heart/other/your_guide/living_well.htm

**Coronary Artery Bypass Surgery** (MedlinePlus)
http://www.nlm.nih.gov/medlineplus/coronaryarterybypasssurgery.html

# RESOURCE LIST

## Diabetes

**American Association of Diabetes Educators**
100 West Monroe, Suite 400
Chicago, IL  60603–1922
(800) 338–3633
Diabetes Educator Access Line:
(800) TEAMUP4 (832–6874)
Fax: (312) 424–2427
aade@aadenet.org
www.diabeteseducator.org

**American Diabetes Association**
National Call Center
1701 North Beauregard Street
Alexandria, VA  22311–1742
(800) DIABETES (342–2383)
Fax: (703) 549–6995
askADA@diabetes.org
www.diabetes.org

**American Foundation for Urologic Disease**
1128 North Charles Street
Baltimore, MD  21201
(800) 242–2383 or (410) 468–1800
admin@afud.org
www.afud.org

**American Heart Association**
7272 Greenville Avenue
Dallas, TX  75231–4596
(800) AHA–USA1 (242–8721)
Fax: 214–369–3685
www.americanheart.org

**American Podiatric Medical Association**
9312 Old Georgetown Road
Bethesda, MD  20814–1698
(800) FOOT–CARE (366–8227) or
(301) 571–9200
Fax: 301–530–2752
askapma@apma.org
www.apma.org

**Centers for Disease Control and Prevention**
National Center for Chronic Disease
Prevention and Health Promotion
Division of Diabetes Translation
Mail Stop K-10
4770 Buford Highway, NE.
Atlanta, GA  30341–3717
(800) CDC–DIAB (232–3422)
Fax: (301) 562–1050
diabetes@cdc.gov
www.cdc.gov/diabetes

**Juvenile Diabetes Research Foundation International**
120 Wall Street
New York, NY  10005–4001
(800) 533–2873
Fax: (212) 785–9595
info@jdrf.org
www.jdrf.org

**Lower Extremity Amputation Prevention Program**
HRSA/BPH/DPSP
4350 East-West Highway, 9th floor
Bethesda, MD  20814
(888) 275–4772
www.bphc.hrsa.gov/leap

**National Diabetes Education Program**
1 Diabetes Way
Bethesda, MD  20892–3600
(800) 438–5383
Fax: (703) 738–4929
www.ndep.nih.gov

**National Digestive Diseases Information Clearinghouse**
2 Information Way
Bethesda, MD  20892–3570
(800) 891–5389
Fax: (703) 738–4929
nddic@info.niddk.nih.gov
digestive.niddk.nih.gov/about/index.htm

**National Heart, Lung, and Blood Institute Health Information Center**
P.O. Box 30105
Bethesda, MD  20824–0105
(301) 592–8573
Fax: (301) 592–8563
nhlbiinfo@nhlbi.nih.gov
www.nhlbi.nih.gov

**National Institute of Diabetes and Digestive and Kidney Diseases**
National Diabetes Information Clearinghouse
1 Information Way
Bethesda, MD  20892
(800) 860–8747
http://diabetes.niddk.nih.gov/

# RESOURCE LIST

**National Institute of Neurological Disorders and Stroke**
Brain Resources and Information Network (BRAIN)
P.O. Box 5801
Bethesda, MD 20824–5801
(800) 352–9424
Fax: (301) 402–2186
www.ninds.nih.gov

**National Kidney and Urologic Diseases Information Clearinghouse**
3 Information Way
Bethesda, MD 20892–3580
(800) 891–5390
Fax: (703) 738–4929
nkudic@info.niddk.nih.gov
kidney.niddk.nih.gov

**Pedorthic Footwear Association**
7150 Columbia Gateway Drive, Suite G
Columbia, MD 21046–1151
(800) 673–8447 or
(410) 381–7278
Fax: (410) 381–1167
www.pedorthics.org

**Weight-control Information Network**
1 WIN Way
Bethesda, MD 20892–3665
(877) 946–4627
Fax: (202) 828–1028
win@info.niddk.nih.gov
www.win.niddk.nih.gov

**Diabetes Teachers** (nurses, dietitians, pharmacists, and other health professionals) To find a diabetes teacher near, call the American Association of Diabetes Educators toll-free at (800) 832–6874.

**Recognized Diabetes Education Programs** (teaching programs approved by the American Diabetes Association) To find a program nearby, call (800) DIABETES (342–2383) or look at its Internet home page at www.diabetes.org and click on "Diabetes Info."

**Dietitians** To find a dietitian nearby, call The American Dietetic Association's National Center for Nutrition and Dietetics at (800) 366–1655 or look at its Internet home page at www.eatright.org and click on "Find a Dietitian.

## Fibromyalgia

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
National Institutes of Health
1 AMS Circle
Bethesda, MD 20892–3675
(877) 22–NIAMS (226-4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov

**National Center for Complementary and Alternative Medicine**
National Institutes of Health
P.O. Box 7923
Gaithersburg, MD 20898–7923
(888) 644–6226
TTY: (866) 464–3615
Fax: (866) 464–3616
info@nccam.nih.gov
www.nccam.nih.gov

**American College of Rheumatology/Association of Rheumatology Health Professionals**
1800 Century Place, Suite 250
Atlanta, GA 30345–4300
(404) 633–3777
Fax: (404) 633–1870
www.rheumatology.org

**Advocates for Fibromyalgia Funding, Treatment, Education, and Research**
P.O. Box 768
Libertyville, IL 60048–0766
(847) 362–7807
Fax: (847) 680–3922
info@affter.org
www.affter.org

# RESOURCE LIST

**Fibromyalgia Network**
P.O. Box 31750
Tucson, AZ  85751–1750
(800) 853–2929
www.fmnetnews.com
National Fibromyalgia Association
2200 North Glassell Street, Suite A
Orange, CA  92865
(714) 921–0150
www.fmaware.org

**National Fibromyalgia Partnership**
P.O. Box 160
Linden, VA  22642–0160
(866) 725–4404
Fax: (866) 666–2727
mail@fmpartnership.org
www.fmpartnership.org

**Arthritis Foundation**
1330 West Peachtree Street, Suite 100
Atlanta, GA  30309
(404) 872–7100 or
(800) 568–4045
or call your local chapter
(To find your local chapter, check your phone directory or visit the foundation's Web site.)
www.arthritis.org

# Hypertension (HTN)

**High Blood Pressure** NIH (National Heart, Lung, and Blood Institute)
http://www.nhlbi.nih.gov/health/dci/Diseases/Hbp/HBP_WhatIs.html

**High Blood Pressure** (MedlinePlus)
http://www.nlm.nih.gov/medlineplus/highbloodpressure.html

**Your Guide to Lowering High Blood Pressure** (interactive Web site)
http://www.nhlbi.nih.gov/hbp/index.html

**Interactive Tutorial on Hypertension** (Patient Education Institute)
http://www.nlm.nih.gov/medlineplus/tutorials/hypertension/htm/index.htm

**High Blood Pressure: Things You Can Do to Help Lower Yours** (American Academy of Family Physicians)
Also available in Spanish
http://familydoctor.org/online/famdocen/home/common/heartdisease/risk/092.html

**American Heart Association**
National Center
7272 Greenville Avenue
Dallas, TX  75231
AHA: (800) AHA–USA–1
or (800) 242–8721

# RESOURCE LIST

## Joint Replacement

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
1 AMS Circle
Bethesda, MD  20892–3675
(301) 495–4484 or (877) 22–NIAMS (226–4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov
The NIAMS, a part of the Department of Health and Human Services' National Institutes of Health, leads the Federal Government research effort in arthritis and other diseases that affect the muscles, bones, joints, and skin. The NIAMS supports research and research training throughout the United States, as well as on the NIH campus in Bethesda, Maryland. The NIAMS Office of Communications and Public Liaison provides health and research information for the public through the NIAMS Information Clearinghouse.

**Office of Medical Applications of Research (OMAR) National Institutes of Health**
Building 31, Room 1B03
31 Center Drive, MSC 2082
Bethesda, MD  20892–2082
(301) 496–5641
http://odp.od.nih.gov/omar
OMAR is the focal point for assessing medical practice and state of the science on behalf of the medical community and the public. It works closely with NIH Institutes or Centers to assess, translate, and disseminate the results of biomedical research that can be used in the delivery of health services to the public. Several consensus statements on joint replacement surgery are available on its Web site.

**MedlinePlus**
www.medlineplus.gov
MedlinePlus is the National Library of Medicine's Web site for consumer health information.

**American Academy of Orthopaedic Surgeons (AAOS)**
P.O. Box 2058
Des Plaines, IL  60017
(800) 824–BONE (2663)
www.aaos.org
The academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed stamped envelope to the address above or visit the AAOS Web site.

**American College of Rheumatology**
1800 Century Place, Suite 250
Atlanta, GA  30345
(404) 633–3777
Fax: (404) 633–1870
www.rheumatology.org
This association provides referrals to doctors and other health professionals who treat arthritis and other rheumatic diseases that may lead to joint replacement surgery. The association also provides educational materials and guidelines.

# RESOURCE LIST

**Arthritis Foundation**
1330 West Peachtree Street, Suite 100
Atlanta, GA 30309
(404) 872–7100 or
(800) 568–4045
or your local chapter listed in the telephone book
www.arthritis.org
The Arthritis Foundation is the major voluntary organization devoted to supporting research into arthritis and other rheumatic diseases and providing education and other services to people with rheumatic diseases. This foundation publishes free pamphlets, and local chapters provide many services in the community, such as exercise classes, self-help courses, and support groups.

## Kidney Failure

**American Association of Kidney Patients**
3505 East Frontage Road, Suite 315
Tampa, FL 33607
(800) 749–2257 or
(813) 636–8100
Fax: (813) 636–8122
info@aakp.org
www.aakp.org

**American Kidney Fund**
6110 Executive Boulevard, Suite 1010
Rockville, MD 20852
(800) 638–8299 or
(301) 881–3052
Fax: (301) 881–0898
helpline@akfinc.org
www.akfinc.org

**Life Options/Rehabilitation Resource Center**
c/o Medical Education Institute, Inc.
414 D'Onofrio Drive, Suite 200
Madison, WI 53719
(800) 468–7777
Fax: (608) 833–8366
lifeoptions@MEIresearch.org
www.lifeoptions.org
www.kidneyschool.org

**National Hospice and Palliative Care Organization**
1700 Diagonal Road, Suite 625
Alexandria, VA 22314
(800) 658–8898
caringinfo@nhpco.org
www.caringinfo.org
www.nhpco.org

**National Kidney Foundation**
30 East 33rd Street
New York, NY 10016
(800) 622–9010 or
(212) 889–2210
info@kidney.org
www.kidney.org

**Polycystic Kidney Disease Foundation**
9221 Ward Parkway, Suite 400
Kansas City, MO 64114–3367
(800) PKD–CURE (753–2873) or
(816) 931–2600
Fax: (816) 931–8655
pkdcure@pkdcure.org
www.pkdcure.org

**United Network for Organ Sharing**
P.O. Box 2484
Richmond, VA 23218
(888) 894–6361
www.unos.org

# RESOURCE LIST

**Additional Reading**

If you would like to learn more about kidney failure and its treatment, you may be interested in reading

**AAKP Patient Plan**

This is a series of booklets and newsletters that cover the different phases of learning about kidney failure, choosing a treatment, and adjusting to changes.
American Association of Kidney Patients
3505 East Frontage Road, Suite 315
Tampa, FL 33607
(800) 749–2257
info@aakp.org
www.aakp.org

**Medicare Coverage of Kidney Dialysis and Kidney Transplant Services**
Publication Number CMS–10128
U.S. Department of Health and Human Services
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244–1850
(800) MEDICARE (633–4227)
TDD: (877) 486–2048
www.medicare.gov/publications/pubs/pdf/esrdcoverage.pdf

**National Kidney Foundation (NKF) Patient Education Brochures**
(includes materials based on NKF's Dialysis Outcomes Quality Initiative)
National Kidney Foundation, Inc.
30 East 33rd Street, Suite 1100
New York, NY 10016
(800) 622–9010 or
(212) 889–2210
www.kidney.org

Newsletters and Magazines

**Family Focus Newsletter**
*(published quarterly)*
National Kidney Foundation, Inc.
30 East 33rd Street, Suite 1100
New York, NY 10016
(800) 622–9010 or (212) 889–2210
www.kidney.org

**For Patients Only** *(published six times a year)*
ATTN: Subscription Department
18 East 41st Street, 20th Floor
New York, NY 10017–6222

**Renalife** (published quarterly)
American Association of Kidney Patients
3505 East Frontage Road, Suite 315
Tampa, FL 33607
(800) 749–2257
Email: info@aakp.org
www.aakp.org

# RESOURCE LIST

## Books

***Bowes and Church's Food Values of Portions Commonly Used***
Eighteenth Edition
Jean A.T. Pennington and Judith S. Douglass
J.P. Lippincott Co. 2004
ISBN: 0-7817-4429-6

***The Complete Book of Food Counts***
Seventh Edition
Corinne T. Netzer
Dell Publishing Co. 2005
ISBN: 0-440-24123-5

## Brochures

***Nutrition and Hemodialysis***
National Kidney Foundation
30 East 33rd Street
New York, NY 10016
(800) 622–9010 or (212) 889–2210

***How to Increase Calories in Your Renal Diet***
National Kidney Foundation
30 East 33rd Street
New York, NY 10016
(800) 622–9010 or (212) 889–2210

## Cookbooks

These cookbooks provide recipes for people on dialysis:

***The Renal Gourmet***
Mardy Peters
ISBN: 0-9641730-0-X
Emenar Incorporated
13n625 Coombs Road
Elgin, IL 60123
Fax: (847) 741–8696
webmaster@kidney-cookbook.com
www.kidney-cookbook.com

***Southwest Cookbook for People on Dialysis***
Developed by the El Paso Chapter Council on Renal Nutrition and the
National Kidney Foundation of Texas, Inc.
Published by a grant from Amgen Inc.
www.epogen.com/patient/pdf/southwest_cookbook.pdf

***Creative Cooking for Renal Diets***
Cleveland Clinic Foundation
ISBN: 0-941511-00-6
Senay Publishing
P.O. Box 397
Chesterland, OH 44026
(866) 648–2693
jsenay@adelphia.net
www.patientsupport.net/patsupport/renal-diet-cookbooks.htm

***Creative Cooking for Renal Diabetic Diets***
Cleveland Clinic Foundation
ISBN: 0-941511-01-4
Senay Publishing
P.O. Box 397
Chesterland, OH 44026
(866) 648–2693
jsenay@adelphia.net
www.patientsupport.net/patsupport/renal-diet-cookbooks.htm

***Kidney Friendly Comfort Foods***
Shire US Inc.
Wayne, PA 19087
(866) 896–6152
www.fosrenol.com/Consumers/Resources/CookBooks.aspx

***Cooking for David***
Culinary Kidney Cooks
P.O. Box 468
Huntington Beach, CA 92648
(714) 842–4684
Eric.Brooks@CulinaryKidneyCooks.com
www.culinarykidneycooks.com

## More Online Information

The American Association of Kidney Patients provides an online nutrition counter at www.aakp.org/brochures/nutrition-counter.
The National Kidney Foundation offers many fact sheets for patients with kidney disease at www.kidney.org on the Internet.

# RESOURCE LIST

**About the Kidney Failure Series**

The publications of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Kidney Failure Series can help learn about the specific issues you will face.

**Booklets**

- Eat Right to Feel Right on Hemodialysis
  http://kidney.niddk.nih.gov/kudiseases/pubs/eatright/
- Kidney Failure: Choosing a Treatment That's Right for You
  http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/index.htm
- Kidney Failure Glossary
  http://kidney.niddk.nih.gov/kudiseases/pubs/glossary/index.htm
- Treatment Methods for Kidney Failure: Hemodialysis
  http://kidney.niddk.nih.gov/kudiseases/pubs/hemodialysis/index.htm
- Treatment Methods for Kidney Failure: Peritoneal Dialysis
  http://kidney.niddk.nih.gov/kudiseases/pubs/peritoneal/index.htm
- Treatment Methods for Kidney Failure: Transplantation
  http://kidney.niddk.nih.gov/kudiseases/pubs/transplant/index.htm

**Fact Sheets**

- Amyloidosis and Kidney Disease
  http://kidney.niddk.nih.gov/kudiseases/pubs/amyloidosis/
- Anemia in Kidney Disease and Dialysis
  http://kidney.niddk.nih.gov/kudiseases/pubs/anemia/
- Financial Help for Treatment of Kidney Failure
  http://kidney.niddk.nih.gov/kudiseases/pubs/financialhelp/
- Hemodialysis Dose and Adequacy
  http://kidney.niddk.nih.gov/kudiseases/pubs/hemodialysisdose/
- Kidney Failure: What to Expect
  http://kidney.niddk.nih.gov/kudiseases/pubs/expect/
- Peritoneal Dialysis Dose and Adequacy
  http://kidney.niddk.nih.gov/kudiseases/pubs/peritonealdose/
- Renal Osteodystrophy
  http://kidney.niddk.nih.gov/kudiseases/pubs/renalosteodystrophy/
- Vascular Access for Hemodialysis
  http://kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess/

# Systemic Lupus Erythematosus (Lupus)

**National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse**
**NIAMS/National Institutes of Health**
1 AMS Circle
Bethesda, MD  20892-3675
(301) 495–4484 or (877) 22–NIAMS (226-4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov/

The National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse is a public service sponsored by the NIAMS that provides health information and information sources. The clearinghouse provides information on lupus. Fact sheets, additional information, and research updates can also be found on the NIAMS Web site at www.niams.nih.gov.

# RESOURCE LIST

**Clinicaltrials.gov**
The Department of Health and Human Services' National Institutes of Health, through its National Library of Medicine, has developed ClinicalTrials.gov to provide patients, family members, and members of the public current information about clinical research studies. You can search for trials by disease, location, treatment, or by funding organization at the Web site clinicaltrials.gov.

**American College of Rheumatology (ACR)**
**Association of Rheumatology Health Professionals**
1800 Century Place, Suite 250
Atlanta, GA 30345
(404) 633–3777
Fax: (404) 633–1870
www.rheumatology.org
The American College of Rheumatology (ACR) is an organization of doctors and associated health professionals who specialize in arthritis and related diseases of the bones, joints, and muscles. The Association of Rheumatology Health Professionals, a division of ACR, aims to enhance the knowledge and skills of rheumatology health professionals and to promote their involvement in rheumatology research, education, and quality patient care. The association also works to advance and promote basic and continuing education in rheumatology for health professionals who provide care to people with rheumatic diseases.

**Alliance for Lupus Research, Inc. (ALR)**
28 West 44th Street, Suite 1217
New York, NY 10036
(212) 218–2840 or (800) 867–1743
www.lupusresearch.org
The Alliance for Lupus Research, Inc. (ALR), is a nonprofit organization devoted exclusively to the support of promising research for the prevention, treatment, and cure of lupus. Through accelerated, focused, goal-oriented research programs, the ALR aims to promote basic and clinical sciences to achieve major advances leading to a better understanding of the causes of lupus.

**American Autoimmune Related Diseases Association (AARDA)**
22100 Gratiot Avenue
East Detroit, MI 48021
(586) 776–3900 or (800) 598–4668
aarda@aarda.org
www.aarda.org
The American Autoimmune Related Diseases Association (AARDA) is the only national nonprofit voluntary health agency dedicated to bringing a national focus and collaborative effort to the over 100 known autoimmune diseases through education, awareness, research, and patient services. By collaborating with the National Coalition of Autoimmune Patient Groups (NCAPG), AARDA supports legislative advocacy for autoimmune disease patients. AARDA provides free patient education information, physician and agency referrals, forums and symposia, and a quarterly newsletter.

**Arthritis Foundation**
P.O. Box 7669
Atlanta, GA 30357–0669
(404) 872–7100 or (800) 568–4045 or your local chapter (listed in the telephone directory)
www.arthritis.org
The Arthritis Foundation is the major voluntary organization devoted to supporting arthritis research and providing educational and other services to individuals with arthritis. It publishes free pamphlets and a magazine for members on all types of arthritis. It also provides up-to-date information on research and treatment, nutrition, alternative therapies, and self-management strategies for patients with lupus and other autoimmune diseases. Chapters nationwide offer exercise programs, classes, support groups, physician referral services, and free literature. For more information, call your local chapter, listed in the white pages of the phone book, or contact the Arthritis Foundation at the above address.

# RESOURCE LIST

**Lupus Clinical Trials Consortium, Inc. (LCTC)**
47 Hulfish Street, Suite 442
Princeton, NJ 08540
(609) 921–6670
The LCTC is a nonprofit organization that encourages the identification and testing of promising new therapies for lupus. It provides infrastructure support grants to certain academic institutions to support their clinical research activities; encourages lupus clinical researchers from those institutions to share their expertise; supports and conducts educational efforts to show the need for lupus clinical research; and disseminates scientific insights to advance the discovery of new lupus therapies.

**Lupus Foundation of America (LFA), Inc.**
2000 L Street, N.W., Suite 710
Washington, DC 20036
(202) 349–1155 or (800) 558–0121
www.lupus.org
The LFA assists local chapters in providing services to people with lupus, works to educate the public about lupus, and supports lupus research. Through a network of more than 500 branches and support groups, the chapters provide education through information and referral services, health fairs, newsletters, publications, and seminars. Chapters provide support to people with lupus, their families, and friends through support group meetings, hospital visits, and telephone help lines.

**Rheuminations, Inc.**
221 East 48th Street, Ground Floor
New York, NY 10017
(212) 593-5180
Fax: (212) 593–5181
www.dxlupus.org
Rheuminations, Inc. is a private, nonprofit foundation committed to funding excellence in medical research to achieve a better understanding of the causes of lupus and to bring new treatments to market; to educate and to empower those who live with lupus and those who care for them; to establish a higher level of public awareness about the disease.

**SLE Foundation, Inc.**
330 Seventh Avenue, Suite 1701
New York, NY 10001
(212) 685–4118 or (800) 74–LUPUS (745–8787)
www.lupusny.org
The foundation supports and encourages medical research to find the cause and cure of lupus and improve its diagnosis and treatment. It also provides a wide variety of services to help patients with lupus and their families. In addition, this voluntary organization conducts a broad-based public education program to raise awareness of lupus and increase understanding of this serious, chronic, autoimmune disease.

## Multiple Sclerosis (MS)

National Institute of Neurological Disorders and Stroke, Brain Resources and Information Network
**BRAIN**
P.O. Box 5801
Bethesda, MD 20824
(800) 352–9424
http://www.ninds.nih.gov

# RESOURCE LIST

**Information also is available from the following organizations:**

**Clearinghouse on Disability Information**
Special Education & Rehabilitative Services Communications & Customer Service Team
550 12th Street, SW, Rm. 5133
Washington, DC 20202–2550
(202) 245–7307 (202) 205–5637 (TTD)
Fax: (292) 245–7636
http://www.ed.gov/about/offices/list/osers

**Multiple Sclerosis Association of America**
706 Haddonfield Road
Cherry Hill, NJ 08002
(856) 488–4500 or (800) 532–7667
Fax: (856) 661–9797
msaa@msaa.com abednar@msassociation.org
www.msassociation.org
National, non-profit organization dedicated to enhancing the quality of life for those affected by multiple sclerosis. Provides ongoing support and direct services to individuals with MS and their families and works to promote a greater understanding of the needs and challenges of those who face physical obstacles.

**International Essential Tremor Foundation**
P.O. Box 14005
Lenexa, KS 66285–4005
(913) 341–3880 or (888) 387–3667
Fax: (913) 341–1296
staff@essentialtremor.org
http://www.essentialtremor.org
Provides educational information, funds research in tremor disorders, and offers services and support to individuals diagnosed with essential tremor, their families, and health care providers. Information and support includes a quarterly newsletter, support groups, and physician information and referrals.

**Multiple Sclerosis Foundation**
6350 North Andrews Avenue
Ft. Lauderdale, FL 33309–2130
(954) 776–6805 or (888) MSFOCUS (673–6287)
Fax: (954) 351–0630
support@msfocus.org
http://www.msfocus.org
Dedicated to helping people with MS, the Multiple Sclerosis Foundation offers a wide array of free services including: national toll-free support, educational programs, homecare services, support groups, assistive technology programs, publications, a comprehensive website, and more programs to improve the quality of life for those affected by MS.

**National Rehabilitation Information Center (NARIC)**
4200 Forbes Boulevard
Suite 202
Lanham, MD 20706–4829
(301) 459–5900or (301) 459–5984 (TTY) (800) 346–2742
Fax: (301) 562–2401
naricinfo@heitechservices.com
http://www.naric.com

# RESOURCE LIST

**National Multiple Sclerosis Society**
733 Third Avenue
6th Floor
New York, NY  10017–3288
(212) 986–3240 or (800) 344–4867 (FIGHTMS)
Fax: (212) 986–7981
nat@nmss.org
http://www.nationalmssociety.org
Funds research, helps families stay together, provides accurate and up-to-date information, helps with employment issues, offers free counseling, runs self-help groups, advocates for people with disabilities, and provides referrals to medical professionals.

**National Ataxia Foundation (NAF)**
2600 Fernbrook Lane North
Suite 119
Minneapolis, MN  55447–4752
763) 553–0020
Fax: (763) 553–0167
naf@ataxia.org
http://www.ataxia.org
(Encourages and supports research into the hereditary ataxias, a group of chronic and progressive neurological disorders affecting coordination. Sponsors chapters and support groups throughout the U.S.A. and Canada. Publishes a quarterly newsletter and educational literature on the various forms of ataxia.

**National Organization for Rare Disorders** (NORD)
P.O. Box 1968
(55 Kenosia Avenue)
Danbury, CT  06813–1968
(203) 744–0100 Voice Mail (800) 999–NORD (6673)
Fax: (203) 798–2291
orphan@rarediseases.org
http://www.rarediseases.org
Federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

**Accelerated Cure Project for Multiple Sclerosis**
300 Fifth Avenue
Waltham, MA  02451
(781) 487–0008
Fax: (781) 487–0009
info@acceleratedcure.org
http://www.acceleratedcure.org
National nonprofit organization dedicated to the creation and execution of a plan to cure MS by determining its causes. Developing a multi-disciplinary blood, tissue, and data bank.

**American Autoimmune Related Diseases Association**
22100 Gratiot Avenue
Eastpointe
East Detroit, MI  48201–2227
(586) 776–3900 or (800) 598–4668
Fax: (586) 776–3903
aarda@aarda.org
http://www.aarda.org
National organization that works to alleviate suffering and the socioeconomic impact of autoimmunity. Dedicated to the eradication of autoimmune diseases through fostering and facilitating collaboration in the areas of education, research, and patient services.

# RESOURCE LIST

## Osteoarthritis

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
National Institutes of Health
1 AMS Circle
Bethesda, MD  20892–3675
(301) 495–4484 or
(877) 22–NIAMS (226–4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov
NIAMS provides information about various forms of arthritis and other rheumatic diseases, and other bone, muscle, joint, and skin diseases. It distributes patient and professional education materials and refers people to other sources of information. Additional information and updates can also be found on the NIAMS Web site.

**NIH Osteoporosis and Related Bone Diseases~National Resource Center**
2 AMS Circle
Bethesda, MD  20892–3676
(202) 223–0344 or (800) 624–BONE
TTY: (202) 466–4315
Fax: (202) 293–2356
www.niams.nih.gov/bone
The NIH Osteoporosis and Related Bone Diseases~National Resource Center provides patients, health professionals, and the public with an important link to resources and information on metabolic bone diseases. The mission of NIH ORBD~NRC is to expand awareness and enhance knowledge and understanding of the prevention, early detection, and treatment of these diseases as well as strategies for coping with them. The center provides information on osteoporosis, Paget's disease of bone, osteogenesis imperfecta, primary hyperparathyroidism, and other metabolic bone diseases and disorders.

**American Academy of Orthopaedic Surgeons (AAOS)**
P.O. Box 1998
Des Plaines, IL  60017
(847) 823–7186 or
(800) 824–BONE (2663)
Fax: (847) 823–8125
www.aaos.org
The academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed stamped envelope to the address above or visit the AAOS Web site.

**American College of Rheumatology**
1800 Century Place, Suite 250
Atlanta, GA  30345
(404) 633–3777
Fax: (404) 633–1870
www.rheumatology.org
This association provides referrals to doctors and health professionals who work on arthritis, rheumatic diseases, and related conditions. It also provides educational materials and guidelines for the treatment of osteoarthritis.

# RESOURCE LIST

**American Physical Therapy Association**
1111 North Fairfax Street
Alexandria, VA 22314–1488
(703) 684–2782 or
(800) 999–APTA (2782)
Fax: (703) 684–7343
www.apta.org
This association is a national professional organization representing physical therapists, allied personnel, and students. Its objectives are to improve research, public understanding, and education in the physical therapies.

**Arthritis Foundation**
P.O. Box 7669
Atlanta, GA 30357-0669
(404) 872–7100 or
(800) 568–4045 or your local chapter
(listed in the telephone directory)
www.arthritis.org
This is the major voluntary organization devoted to arthritis. The foundation publishes free informational brochures on various types of arthritis, including osteoarthritis, as well as a monthly magazine for members that provides up-to-date information on all forms of arthritis. The foundation also can provide addresses and phone numbers for local chapters and physician and clinic referrals.

## Osteoporosis

**NIH Osteoporosis and Related Bone Diseases~National Resource Center (NIH ORBD~NRC)**
2 AMS Circle
Bethesda, MD 20892–3676
(202) 223–0344 or (800) 624–BONE (2663)
TTY: (202) 466–4315
Fax: (202) 293–2356
NIAMSBoneInfo@mail.nih.gov
www.niams.nih.gov/bone
The NIH Osteoporosis and Related Bone Diseases~National Resource Center (ORBD~NRC) provides patients, health professionals, and the public with an important link to resources and information on osteoporosis and other metabolic bone diseases. The mission of NIH ORBD~NRC is to expand awareness and enhance knowledge and understanding of the prevention, early detection, and treatment of these diseases as well as strategies for coping with them. The center has a wide range of publications on osteoporosis, including “Bone Health and Osteoporosis: A Report of the Surgeon General” and an accompanying booklet written for the general public. Fact sheets on osteoporosis include more detailed information on topics such as prevention of falls and fractures, calcium supplements, exercise, quality-of-life issues, and osteoporosis in men and various ethnic groups. Fact sheets on bone health and osteoporosis are also available in Spanish and Chinese. These and other fact sheets are available by mail and on the center’s Web site, which also provides links to other sources of information on osteoporosis.

# RESOURCE LIST

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
National Institutes of Health
1 AMS Circle
Bethesda, MD  20892–3675
(301) 495–4484 or (877) 22–NIAMS (226–4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
NIAMSinfo@mail.nih.gov
www.niams.nih.gov
The NIAMS leads the Federal research effort on osteoporosis and related bone diseases. NIAMS distributes patient and professional educational materials about osteoporosis and can refer people to other sources of information. Through its Web site, NIAMS also provides information about current research related to osteoporosis, as well as health information about the disease. “Kids and Their Bones,” a publication produced jointly by NIAMS and the NIH Osteoporosis and Related Bone Diseases~National Resource Center, is available on the NIAMS Web site and by mail.

**National Institute on Aging (NIA) Information Center**
P.O. Box 8057
Gaithersburg, MD  20898–8057
(800) 222–2225
TTY: (800) 222–4225
www.nia.nih.gov
The National Institute on Aging (NIA), a part of the National Institutes of Health, has a book and video about exercise for older people. For more information and a free publications list, write or call the NIA Information Center. In consultation with NIAMS, NIA has also provided information about the prevention and treatment of osteoporosis on the NIHSeniorHealth Web site (www.nihseniorhealth.gov), a joint effort of NIA and the National Library of Medicine (NLM).

**American Academy of Orthopaedic Surgeons (AAOS)**
P.O. Box 2058
Des Plaines, IL  60017
(800) 824–BONE (2663)
www.aaos.org
The academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist’s scope of practice includes disorders of the body’s bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed stamped envelope to the address above or visit the AAOS Web site.

**American Geriatrics Society (AGS)**
The Empire State Building
350 Fifth Avenue, Suite 801
New York, NY  10118
(212) 308–1414
Fax: (212) 832–8646
info@americangeriatrics.org
www.americangeriatrics.org
The American Geriatrics Society (AGS), a national nonprofit organization, is the premier professional organization of health care providers dedicated to improving the health and well-being of all older adults. Through its Web site, it provides information to geriatrics health care professionals, the public, and other concerned individuals dedicated to improving the health, independence, and quality of life of all older people. The AGS provides educational materials on fall prevention, osteoporosis, and bone health for patients and health professionals on its Web site.

# RESOURCE LIST

**American Society for Bone and Mineral Research (ASBMR)**
2025 M Street, NW, Suite 800
Washington, DC  20036-3309, USA
(202) 367–1161
Fax: (202) 367–2161
asbmr@asbmr.org
www.asbmr.org
The American Society for Bone and Mineral Research (ASBMR) is a professional scientific and medical society established to bring together clinical and experimental scientists involved in the study of bone and mineral metabolism. ASBMR encourages and promotes the study of this expanding field through annual scientific meetings; an official journal, the Primer on the Metabolic Bone Diseases and Disorders of Mineral Metabolism; and advocacy and interaction with government agencies and related societies.

**National Osteoporosis Foundation (NOF)**
1232 22nd Street, NW
Washington, DC 20037–1292
(202) 223–2226
Fax: (202) 223–2237
www.nof.org
The National Osteoporosis Foundation (NOF) is the leading nonprofit, voluntary health organization dedicated to promoting lifelong bone health in order to reduce the widespread prevalence of osteoporosis and associated fractures, while working to find a cure for the disease through programs of research, education, and advocacy. NOF provides information and resources on osteoporosis for patients and the public. It also provides resources and professional relations and education programs on the disease for health professionals.

**Food and Drug Administration**
(888) 463–6332
http://www.fda.gov

## Pain

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

**BRAIN**
P.O. Box 5801
Bethesda, MD  20824
(800) 352–9424
http://www.ninds.nih.gov
Information also is available from the following organizations:

**National Institute of Dental and Craniofacial Research (NIDCR)**
National Institutes of Health, DHHS
31 Center Drive, Room 5B-55
Bethesda, MD  20892
(301) 496–4261
nidcrinfo@mail.nih.gov
http://www.nidcr.nih.gov

# RESOURCE LIST

**American Chronic Pain Association (ACPA)**
P.O. Box 850
Rocklin, CA  95677–0850
(916) 632–0922 or (800) 533–3231
Fax: (916) 632–3208
ACPA@pacbell.net
http://www.theacpa.org
Provides self-help coping skills and peer support to people with chronic pain. Sponsors local support groups throughout the U.S. and provides assistance in starting and maintaining support groups.

**American Council for Headache Education**
19 Mantua Road
Mt. Royal, NJ  08061
(856) 423–0258 or (800) 255–ACHE (2243)
Fax: (856) 423–0082
achehq@talley.com
http://www.achenet.org
Non-profit patient-health professional partnership dedicated to advancing the treatment and management of headache and to raising public awareness of headache as a valid, biologically-based illness.

**National Headache Foundation**
820 N. Orleans
Suite 217
Chicago, IL  60610–3132
(312) 274–2650 or (888) NHF–5552 (643–5552)
Fax: (312) 640–9049
info@headaches.org
http://www.headaches.org
Non-profit organization dedicated to service headache sufferers, their families, and the healthcare practitioners who treat them. Promotes research into headache causes and treatments and educates the public.

**National Foundation for the Treatment of Pain**
P.O. Box 70045
Houston, TX  77270
(713) 862–9332
Fax: (713) 862–9346
NFTPain@cwo.com
http://www.paincare.org
Not-for-profit organization dedicated to providing support for patients who are suffering from intractable pain, their families, friends and the physicians who treat them. Offers a patient forum, advocacy programs, information, support resources, and direct medical intervention.

**Mayday Fund [For Pain Research]**
c/o SPG
136 West 21st Street, 6th Floor
New York, NY  10011
(212) 366–6970
Fax: (212) 366–6979
mayday@maydayfund.org
http://www.painandhealth.org
The Mayday Pain Project works to increase awareness and to provide objective information concerning the treatment of pain.

# RESOURCE LIST

**American Pain Foundation**
201 North Charles Street
Suite 710
Baltimore, MD  21201–4111
(888) 615–PAIN (7246)
Fax: (410) 385–1832
info@painfoundation.org
http://www.painfoundation.org
Independent non-profit information, education, and advocacy organization serving people with pain. Works to improve the quality of life for people with pain by raising public awareness, providing practical information, promoting research, and advocating the removal of barriers and increased access to effective pain management.

**Arthritis Foundation**
1330 West Peachtree Street
Suite 100
Atlanta, GA  30309
(800) 568–4045 or
(404) 872–7100 or (404) 965–7888
Fax: (404) 872–0457
help@arthritis.org
http://www.arthritis.org
Volunteer-driven organization that works to improve lives through leadership in the prevention, control, and cure of arthritis and related diseases. Offers free brochures on various types of arthritis, treatment options, and management of daily activities when affected.

## Parkinson’s Disease (PD)

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

**BRAIN**
P.O. Box 5801
Bethesda, MD  20824
(800) 352–9424
http://www.ninds.nih.gov
Information also is available from the following organizations:

**American Parkinson Disease Association**
135 Parkinson Avenue
Staten Island, NY  10305–1425
(718) 981–8001 or (800) 223–2732 Calif: (800) 908–2732
Fax: (718) 981–4399
apda@apdaparkinson.org
http://www.apdaparkinson.org
Dedicated to funding Parkinson's disease research. Offers comprehensive medical information and extensive public/professional education and support services.

# RESOURCE LIST

**Parkinson Alliance**
P.O. Box 308
Kingston, NJ 08528–0308
(609) 688–0870 or (800) 579–8440
Fax: (609) 688–0875
admin@parkinsonalliance.org
http://www.parkinsonalliance.org
Raises and distributes money for the most promising research leading to a cure for Parkinson's disease. Partners with the Tuchman Foundation to ensure that every dollar donated by individuals and all net proceeds of events go directly to research. The Alliance is also devoted to improving quality of life within the DBS-STN community through an affiliated resource, www.DBS-STN.org.

**National Parkinson Foundation**
1501 N.W. 9th Avenue
Bob Hope Road
Miami, FL 33136–1494
(305) 243–6666 or (800) 327–4545
Fax: (305) 243–5595
contact@parkinson.org
http://www.parkinson.org
Provides research, patient services, clinical studies, public and professional education, and physician referrals at over 60 locations and through a nationwide network of chapters and support groups

**Michael J. Fox Foundation for Parkinson's Research**
Grand Central Station
P.O. Box 4777
New York, NY 10163
(212) 509–0995
http://www.michaeljfox.org
Dedicated to advancing a cure for Parkinson's disease by identifying promising research and raising funds for research support.

**Parkinson's Action Network (PAN)**
1025 Vermont Avenue, NW
Suite 1120
Washington, DC 20005
(800) 850–4726 or (202) 638–4101
Fax: (202) 638–7257
info@parkinsonsaction.org
http://www.parkinsonsaction.org
Non-profit education and advocacy organization that serves as a voice for the Parkinson's community by fighting for promising research that will produce effective treatments and a cure.

**Parkinson's Disease Foundation (PDF)**
1359 Broadway
Suite 1509
New York, NY 10018
(212) 923–4700 or (800) 457–6676
Fax: (212) 923–4778
info@pdf.org
http://www.pdf.org
National nonprofit organization that supports Parkinson's disease research, patient education, and public advocacy programs.

# RESOURCE LIST

**Parkinson's Institute**
1170 Morse Avenue
Sunnyvale, CA  94089–1605
(408) 734–2800 or (800) 786–2958
Fax: (408) 734–8522
http://www.thepi.org
Non-profit organization conducting patient care and research activities in the neurological specialty area of movement disorders.

**Parkinson's Resource Organization**
74-090 El Paseo
Suite 102
Palm Desert, CA  92260–4135
(760) 773–5628 or (310) 476–7030 or (877) 775–4111
Fax: (760) 773–9803
info@parkinsonsresource.org
http://www.parkinsonsresource.org
Helps families affected by Parkinson's by offering emotional and educational support programs, publishing a monthly newsletter about quality of life and family issues, providing information and referral services, promoting advocacy and public awareness, and providing respite for family caregivers.

**WE MOVE (Worldwide Education & Awareness for Movement Disorders)**
204 West 84th Street
New York, NY  10024
(212) 875–8312 or (866) 546–3136
Fax: (212) 875–8389
wemove@wemove.org
http://www.wemove.org
WE MOVE provides movement disorder information and educational materials to physicians, patients, the media, and the public.

**Bachmann-Strauss Dystonia & Parkinson Foundation**
Mt. Sinai Medical Center One Gustave L. Levy Place
P.O. Box 1490
New York, NY  10029
(212) 241–5614
Fax: (212) 987–0662
Bachmann.Strauss@mssm.edu
http://www.dystonia-parkinsons.org
Non-profit foundation that supports patients, family members, researchers, clinicians, and volunteers working in partnership to find better medical treatments and a cure for dystonia and Parkinson's disease.

## Peripheral Arterial Disease (PAD)

**Peripheral Arterial Disease** NIH (National Heart, Lung, and Blood Institute)
http://www.nhlbi.nih.gov/health/dci/Diseases/pad/pad_what.html

**Stay in Circulation: Take Steps to Learn About PAD**
http://www.nhlbi.nih.gov/health/public/heart/pad/index.html

**Peripheral Arterial Disease Coalition**
http://www.padcoalition.org/wp/

# RESOURCE LIST

**Peripheral Vascular Disease** (American Heart Association)
http://www.americanheart.org/presenter.jhtml?identifier=4692

**Peripheral Arterial Disease** (Mayo Foundation for Medical Education and Research)
http://www.mayoclinic.com/health/peripheral-arterial-disease/DS00537

**Peripheral Arterial Disease (PAD) and Limb Loss** (Amputee Coalition of America)
http://www.amputee-coalition.org/easyread/fact_sheets/dysvascular-ez.html

## Rheumatoid Arthritis (RA)

**National Institute of Arthritis and Musculoskeletal and Skin Diseases**
National Institutes of Health
1 AMS Circle
Bethesda, MD 20892–3675
(301) 495–4484 or
(877) 22–NIAMS (226–4267)
Fax: (301) 718–6366
TTY: (301) 565–2966
niamsinfo@mail.nih.gov
http://www.niams.nih.gov/
The National Institute of Arthritis and Musculoskeletal and Skin Diseases provides information about various forms of arthritis and rheumatic diseases. It distributes patient and professional education materials and also refers people to other sources of information.

**The National Institute of Allergy and Infectious Diseases**
National Institutes of Health
Building 31, Room 7A50
31 Center Drive, MSC 2520
Bethesda, MD 20892–2520
(301) 496–5717
Fax: (301) 402–0120
www.niaid.nih.gov
The National Institute of Allergy and Infectious Diseases conducts and supports research that strives to understand, treat, and ultimately prevent the myriad infectious, immunologic, and allergic diseases that threaten hundreds of millions of people worldwide. The Institute's mission is driven by a strong commitment to basic research and the understanding that the fields of immunology, microbiology, and infectious disease are related and complementary.

**National Center for Complementary and Alternative Medicine**
NCCAM Clearinghouse
P.O. Box 7923
Gaithersburg, MD 20898–7923
(301) 519–3153 or
(888) 644–6226
Fax: (866) 464–3616
TTY: (866) 464–3615
www.nccam.nih.gov
The National Center for Complementary and Alternative Medicine is dedicated to exploring complementary and alternative healing practices in the context of rigorous science, training complementary and alternative medicine researchers, and disseminating authoritative information to the public and professionals.

# RESOURCE LIST

**American Academy of Orthopaedic Surgeons (AAOS)**
P.O. Box 2058
Des Plains, IL  60017
(800) 824–BONE (2263)
www.aaos.org
The Academy provides education and practice management services for orthopaedic surgeons and allied health professionals. It also serves as an advocate for improved patient care and informs the public about the science of orthopaedics. The orthopaedist's scope of practice includes disorders of the body's bones, joints, ligaments, muscles, and tendons. For a single copy of an AAOS brochure, send a self-addressed, stamped envelope to the address above or visit the AAOS Web site.

**American College of Rheumatology**
1800 Century Place, Suite 250
Atlanta, GA  30345
(404) 633–3777
Fax: (404) 633–1870
www.rheumatology.org
The College provides referrals to rheumatologists and physical and occupational therapists who have experience working with people who have rheumatoid arthritis. The organization also provides educational materials and guidelines.

**Arthritis Foundation**
P.O. Box 7669
Atlanta, GA  30357–0669
(404) 872–7100 or (800) 568–4045 or your local chapter, listed in the telephone directory
www.arthritis.org
The Arthritis Foundation is the major voluntary organization devoted to supporting arthritis research and providing educational and other services to individuals with arthritis. The Foundation publishes a free pamphlet on rheumatoid arthritis and a magazine for members on all types of arthritis. It also provides up-to-date information on research and treatment, nutrition, alternative therapies, and self-management strategies. Chapters nationwide offer exercise programs, classes, support groups, physician referral services, and free literature.

## Scleroderma

**National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**
National Institutes of Health
1 AMS Circle
Bethesda, MD  20892–3675
(301) 495–4484 or (877) 22–NIAMS (226–4267)
TTY: (301) 565–2966
Fax: (301) 718–6366
NIAMSInfo@mail.nih.gov
www.niams.nih.gov
NIAMS provides information about various forms of arthritis and other rheumatic diseases, as well as other bone, muscle, joint, and skin diseases. It distributes patient and professional education materials and refers people to other sources of information. Additional information and updates can also be found on the NIAMS Web site.

**American Academy of Dermatology**
P.O. Box 4014
Schaumburg, IL  60168–4014
(888) 462–DERM (3376)
Fax: (847) 240–1859
www.aad.org
This national professional association for dermatologists publishes a pamphlet on skin conditions and can also provide physician referrals.

# RESOURCE LIST

**American College of Rheumatology**
1800 Century Place, Suite 250
Atlanta, GA  30345
(404) 633–3777
Fax: (404) 633–1870
www.rheumatology.org
This association provides referrals to doctors and health professionals who work on arthritis, rheumatic diseases, and related conditions. It also provides educational materials and guidelines.

**Scleroderma Foundation**
300 Rosewood Drive, Suite 105
Danvers, MA  01923
(978) 463–5843 or (800) 722–HOPE (4673)
(8:30 a.m.–5:00 p.m. ET, Monday–Friday)
Fax: (978) 463–5809
sfinfo@scleroderma.org
www.scleroderma.org
This voluntary organization publishes information on scleroderma and funds research. It also offers patient education seminars, support groups, physician referrals, and information hotlines.

**Scleroderma Research Foundation**
220 Montgomery Street, Suite 1411
San Francisco, CA  94104
(415) 834–9444 or (800) 441–CURE (2873)
Fax: (415) 834–9177
www.srfcure.org
The foundation's goal is to find a cure for scleroderma by funding and facilitating the most promising, highest quality research and by placing the disease and its need for a cure in the public eye. The foundation distributes patient handbooks and a twice yearly, research-related newsletter.

**Arthritis Foundation**
P.O. Box 7669
Atlanta, GA  30357–0669
(404) 872–7100 or (800) 568–4045 or call your local chapter (listed in the telephone directory)
www.arthritis.org
This is the main voluntary organization devoted to all forms of arthritis and rheumatic diseases. The foundation offers free information about scleroderma on its Web site.

## Stroke

**National Institute of Neurological Disorders and Stroke**
**Brain Resources and Information Network (BRAIN)**
P.O. Box 5801
Bethesda, MD  20824
(800) 352–9424
http://www.ninds.nih.gov

**American Stroke Association: A Division of American Heart Association**
7272 Greenville Avenue
Dallas, TX  75231–4596
(888) 4STROKE (478–7653)
Fax: (214) 706–5231
strokeassociation@heart.org
http://www.strokeassociation.org

# RESOURCE LIST

**National Stroke Association**
9707 East Easter Lane; Suite B
Centennial, CO  80112–3747
(303) 649–9299 or
(800) STROKES (787–6537)
Fax: (303) 649–1328
info@stroke.org
http://www.stroke.org

**National Rehabilitation Information Center (NARIC)**
4200 Forbes Boulevard; Suite 202
Lanham, MD  20706–4829
(301) 459–5900 or (301) 459–5984 (TTY)
(800) 346–2742
Fax: (301) 562–2401
naricinfo@heitechservices.com
http://www.naric.com

**Stroke Clubs International**
805 12th Street
Galveston, TX  77550
(409) 762–1022
strokeclubs@earthlink.net

**Easter Seals**
230 West Monroe Street
Suite 1800
Chicago, IL  60606–4802
(312) 726–6200 or (800) 221–6827
Fax: (312) 726–1494
info@easterseals.com
http://www.easterseals.com

**National Aphasia Association**
350 Seventh Avenue
Suite 902
New York, NY  10001
(212) 267–2814 or (800) 922–4NAA (4622)
Fax: (212) 267–2812
naa@aphasia.org
http://www.aphasia.org

**American Speech-Language-Hearing Association (ASHA)**
10801 Rockville Pike
Rockville, MD  20852–3279
(800) 638–8255
(301) 571–0457
actioncenter@asha.org
http://www.asha.org

## Traumatic Brain Injury (TBI)

For more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's Brain Resources and Information Network (BRAIN) at:

**BRAIN**
P.O. Box 5801
Bethesda, MD  20824
(800) 352–9424
http://www.ninds.nih.gov
Information also is available from the following organizations:

**Acoustic Neuroma Association**
600 Peachtree Parkway
Suite 108
Cumming, GA  30041
(770) 205–8211 or (877) 202–0239
Fax: (770) 205–0239 or (877) 202–0239
info@anausa.org
http://www.anausa.org
Provides information and support to patients diagnosed with or treated for acoustic neuroma or other benign tumors affecting the cranial nerves.

# RESOURCE LIST

**Brain Injury Association of America, Inc.**
8201 Greensboro Drive
Suite 611
McLean, VA 22102
(703) 761–0750 or (800) 444–6443
Fax: (703) 761–0755
FamilyHelpline@biausa.org
http://www.biausa.org
Non-profit organization dedicated to people with brain injury and their families. Offers research, education, and advocacy programs through a national office, network of state affiliates, support groups, and a helpline.

**Brain Trauma Foundation**
523 East 72nd Street
8th Floor
New York, NY 10021
(212) 772–0608
Fax: (212) 772–0357
http://www.braintrauma.org
Nationwide organization devoted to improving the outcome of traumatic brain injury patients. Focuses on the acute phase of traumatic brain injury (TBI) and methods to improve chances of a meaningful recovery. The Foundation works to improve the care of TBI patients from the scene of injury to the emergency room and ICU through guidelines development, professional education, quality improvement, and clinical research.

**Family Caregiver Alliance/ National Center on Caregiving**
180 Montgomery Street
Suite 1100
San Francisco, CA 94104
(415) 434–3388 or (800) 445–8106
Fax: (415) 434–3508
info@caregiver.org
http://www.caregiver.org
Supports and assists families and caregivers of adults with debilitating health conditions. Offers programs and consultation on caregiving issues at local, state, and national levels. Offers free publications and support online, including a national directory of publicly funded caregiver support programs.

**National Stroke Association**
9707 East Easter Lane
Suite B
Centennial, CO 80112–3747
(303) 649–9299 or (800) STROKES (787–6537)
Fax: (303) 649–1328
info@stroke.org
http://www.stroke.org
National non-profit organization that offers education, services and community-based activities in prevention, treatment, rehabilitation and recovery. Serves the public and professional communities, people at risk, patients and their health care providers, stroke survivors, and their families and caregivers.

**National Rehabilitation Information Center (NARIC)**
4200 Forbes Boulevard
Suite 202
Lanham, MD 20706–4829
(301) 459–5900 or (301) 459–5984 (TTY) or (800) 346–2742
Fax: (301) 562–2401
naricinfo@heitechservices.com
http://www.naric.com

# RESOURCE LIST

**National Institute on Disability and Rehabilitation Research (NIDRR)**
U.S. Department of Education Office of Special Education and Rehabilitative Services
400 Maryland Avenue, S.W.
Washington, DC  20202–7100
(202) 245–7460 or (202) 245–7316 (TTY)
http://www.ed.gov/about/offices/list/osers/nidrr

## Falls Risk

**NIH Osteoporosis and Related Bone Diseases~National Resource Center**
2 AMS Circle
Bethesda, MD  20892–3676
(202) 223–0344 or
(800) 624–BONE (2663)
TTY: (202) 466–4315
Fax: (202) 293–2356
NIAMSBoneInfo@mail.nih.gov
www.niams.nih.gov/bone

**National Institute on Aging (NIA)**
Building 31, Room 5C27
31 Center Drive, MSC 2292
Bethesda, MD  20892
(301) 496–1752 or
(800) 222–2225
TTY: (800) 222–4225
Fax: (301) 496–1072
niainfo@nia.nih.gov
www.nia.nih.gov

**Don't Let a Fall Be Your Last Trip: Who's at Risk?** (American Academy of Orthopaedic Surgeons)
http://orthoinfo.aaos.org/brochure/thr_report.cfm?Thread_ID=21&topcategory=Injury%20Prevention

**Why Do We Fall?**  (American Academy of Otolaryngology--Head and Neck Surgery)
http://www.entnet.org/healthinfo/balance/fall.cfm

**Falls and Fractures** NIH (National Institute on Aging) http://www.niapublications.org/agepages/falls.asp  Also available in Spanish

**Falls and Older Adults** NIHSeniorHealth (National Institute on Aging) http://nihseniorhealth.gov/falls/toc.html

**What Are Ways to Prevent Falls and Related Fractures?** Easy-to-Read NIH (National Institute of Arthritis and Musculoskeletal and Skin Diseases) http://www.niams.nih.gov/bone/hi/ff_falls_prevention.htm

**San Diego's Fall Prevention video**
http://sandiego.networkofcare.org/aging/library/fall_prevention.cfm