

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.**



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.

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.

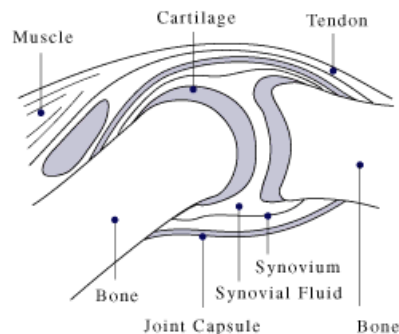
Searching for the Causes of Rheumatoid Arthritis

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:

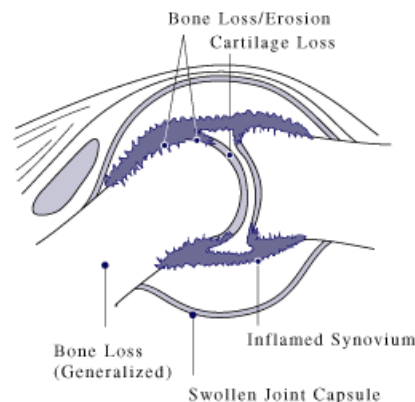
Genetic (inherited) factors

- 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
- More than one gene is involved in determining whether a person develops rheumatoid arthritis and how severe the disease will become

Normal Joint



Joint Affected by Rheumatoid Arthritis





Environmental factors	<ul style="list-style-type: none"> • Many scientists think that something must occur to trigger the disease process in people whose genetic makeup makes them susceptible to rheumatoid arthritis. • 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	<ul style="list-style-type: none"> • 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. • 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 of tools to diagnose the disease and to rule out other conditions:

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

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.**



Laboratory tests	<ul style="list-style-type: none"> • rheumatoid factor – blood antibody - Has a high false positive and negative so not conclusive • check white blood cell count – high if there is an infection • check red blood cell count to look for anemia, and a test of the erythrocyte sedimentation rate - measures inflammation in the body. • C-reactive protein - measures disease activity
X rays	<ul style="list-style-type: none"> • used to determine the degree of joint destruction • not useful in the early stages • 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	<ul style="list-style-type: none"> • need a good balance between rest and exercise – ↑rest when the disease is active and ↑exercise when in remission • Rest – helps to reduce active joint inflammation, pain and to fight fatigue <ul style="list-style-type: none"> ○ Occasional shorter rest breaks every are more helpful than long times spent in bed • Exercise – important for maintaining healthy and strong muscles, preserving joint mobility, and maintaining flexibility <ul style="list-style-type: none"> ○ helps improve sleep, reduce pain, maintain a positive attitude, and lose weight
Joint care	<ul style="list-style-type: none"> • splints to reduces pain and swelling – supports join to let it rest <ul style="list-style-type: none"> ○ usually on wrists or hands, also ankles and feet ○ should be ordered my doctor and fitted by OT or PT • assistive devices to increase function and decrease stress on joints <ul style="list-style-type: none"> ○ zipper pullers, long-handled shoe horns ○ devices to help with getting on and off chairs, toilet seats, and beds

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.**



Stress reduction emotions - fear, anger, and frustration-combined with pain and physical limitations can increase stress level	<ul style="list-style-type: none"> • regular rest periods • relaxation, distraction, or visualization exercises • exercise programs • participation in support groups • good communication with the health care team
Healthful diet no scientific evidence that any specific food or nutrient helps or harms people with rheumatoid arthritis	<ul style="list-style-type: none"> • nutritious diet with enough-but not an excess of-calories, protein, and calcium is important • careful about drinking alcoholic beverages because of possible interaction with medications
Climate	<ul style="list-style-type: none"> • Moving to a new place with a different climate usually does not make a long-term difference in a person's rheumatoid arthritis
Medications 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	<ul style="list-style-type: none"> • for pain relief • to reduce inflammation • to slow the course of the disease - disease-modifying antirheumatic drugs (DMARDs) • 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 • decrease medications during remissions
Surgery Several types of surgery are available to patients with severe joint damage and pain Goal is to improve function and ↓pain	
Joint replacement	<ul style="list-style-type: none"> • most frequently performed surgery • primarily to relieve pain and improve or preserve joint function • careful consideration with young people – may need to be replaced after time
Tendon reconstruction	<ul style="list-style-type: none"> • used most frequently on the hands • reconstructs the damaged tendon by attaching an intact tendon to it • can help to restore hand function
Synovectomy:	<ul style="list-style-type: none"> • inflamed synovial tissue is removed • seldom done on own –cannot remove all tissue • 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.

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.**



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.

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 Buffered 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 Ibuprofen Ketoprofen Naproxen	NSAIDs help relieve pain within hours of administration 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 lightheadedness; 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.

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 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, hypertension (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.

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.

<p>Methotrexate</p>	<p>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.</p>	<p>Abdominal discomfort, chest pain, chills, nausea, mouth sores, painful urination, sore throat, unusual tiredness or weakness.</p>	<p>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.</p>
<p>Sulfasalazine</p>	<p>This drug works to reduce the signs and symptoms of rheumatoid arthritis by suppressing the immune system.</p>	<p>Abdominal pain, aching joints, diarrhea, headache, sensitivity to sunlight, loss of appetite, nausea or vomiting, skin rash.</p>	<p>Doctor monitoring is important, particularly if you are allergic to sulfa drugs or aspirin, or if you have a kidney, liver, or blood disease.</p>
<p>Biologic Response Modifiers</p>	<p>These drugs selectively block parts of the immune system called cytokines. Cytokines play a role in inflammation. Long-term efficacy and safety are uncertain.</p>	<p>Increased risk of infection, especially tuberculosis. Increased risk of pneumonia, and listeriosis (a foodborne illness caused by the bacterium <i>Listeria monocytogenes</i>).</p>	<p>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.</p>
<p>Tumor Necrosis Factor Inhibitors Etanercept Infliximab Adalimumab</p>	<p>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.</p>	<p>Etanercept: Pain or burning in throat; redness, itching, pain, and/or swelling at injection site; runny or stuffy nose. Infliximab: Abdominal pain, cough, dizziness, fainting, headache, muscle pain, runny nose, shortness of breath, sore throat, vomiting, wheezing. Adalimumab: Redness, rash, swelling, itching, bruising, sinus infection, headache, nausea.</p>	<p>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.</p>

Interleukin1 Inhibitor Anakinra	This medication requires daily injections. Long-term efficacy and safety are uncertain.	Redness, swelling, bruising, or pain at the site of injection; head-ache; upset stomach; diarrhea; runny nose; and stomach pain.	Doctor monitoring is required.
Selective costimulation modulator <i>Abatacept</i>	Abatacept is given intravenously in a 30-minute infusion. It may be given alone or with DMARDs.	Cough, dizziness, headache, infections, sore throat.	Doctor monitoring is required.
CD20 antibody <i>rituximab</i>	This medication is for people whose rheumatoid arthritis has not responded to other biologic agents. It is given by two IV infusions 2 weeks apart. It is given with methotrexate.	Abdominal pain, chills/shivering, fever, headache, infection, itching.	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

Adapted (10/2012) 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. (2009)

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.**

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.

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**.

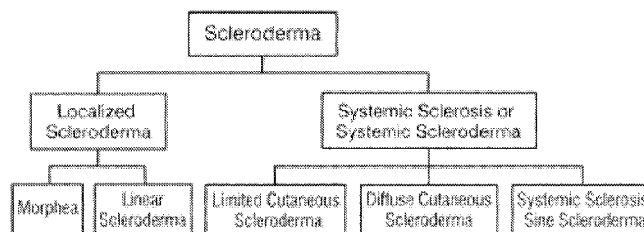
- The term rheumatic disease refers to a group of conditions characterized by inflammation and/or pain in the muscles, joints, or fibrous tissue.
- A connective tissue disease is one that affects tissues such as skin, tendons, and cartilage.

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
<p style="text-align: center;">Raynaud's Phenomenon</p> <p>More than 90 percent of people with scleroderma have this condition</p>	<ul style="list-style-type: none"> • Don't smoke! Smoking narrows the blood vessels even more and makes Raynaud's phenomenon worse. • Dress warmly, with special attention to hands and feet. • Dress in layers and try to stay indoors during cold weather. • Use biofeedback and relaxation exercises. • For severe cases, calcium channel blockers, such as nifedipine (Procardia*), can open up small blood vessels and improve circulation. • For skin sores or ulcers, an increased dose of calcium channel blockers 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.
<p style="text-align: center;">Stiff, painful joints</p> <p>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.</p>	<ul style="list-style-type: none"> • 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. • Exercise regularly. Swimming can help maintain muscle strength, flexibility, and joint mobility. • Medications: NSAIDs over the counter or rx if need stronger. • Learn to perform daily tasks, such as lifting and carrying objects or opening doors, in ways that will put less stress on tender joints.
<p style="text-align: center;">Skin problems</p> <p>When too much collagen builds up in the skin, it crowds out sweat and oil glands, causing the skin to become dry and stiff.</p>	<ul style="list-style-type: none"> • Apply oil-based creams and lotions frequently, and always right after bathing. • Apply sunscreen before going outdoors, to protect against further damage from the sun's rays. • Use humidifiers to moisten the air in the home in colder winter climates. Clean humidifiers often to stop bacteria from growing in the water. • Avoid very hot baths and showers, as hot water dries the skin. • Avoid harsh soaps, household cleaners, and caustic chemicals, if at all possible. Otherwise, be sure to wear rubber gloves when using such products. • Exercise regularly. Exercise, especially swimming, stimulates blood circulation to affected areas.
<p style="text-align: center;">Dry mouth and dental problems</p> <p>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.</p>	<ul style="list-style-type: none"> • Brush and floss teeth regularly. If hand pain and stiffness are present adaptive aids may be of help. • Have regular dental checkups. Contact the dentist immediately if experience mouth sores, mouth pain, or loose teeth. • If decay is a problem, ask the dentist about fluoride rinses or prescription toothpastes that remineralize and harden tooth enamel. • Keep mouth moist by drinking plenty of water, sucking ice chips, using sugarless gum and hard candy, and

	<p>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.</p>
<p>Gastrointestinal (GI) problems 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.</p>	<ul style="list-style-type: none"> • Eat small, frequent meals. • 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. • Avoid late-night meals, spicy or fatty foods, alcohol, and caffeine, which can aggravate GI distress. • Eat moist, soft foods, and chew them well. • For swallowing difficulties, or if the body doesn't absorb nutrients properly, a special diet may be prescribed. • 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.
<p>Lung damage: Virtually all people with systemic sclerosis have some loss of lung function.</p> <p>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).</p>	<p>Treatment for the two conditions is different:</p> <ul style="list-style-type: none"> • Pulmonary fibrosis may be treated with drugs that suppress the immune system. • Pulmonary hypertension may be treated with drugs that dilate the blood vessels. <p>To minimize lung complications, work closely with the medical team. Do the following:</p> <ul style="list-style-type: none"> • Watch for signs of lung disease, including fatigue, shortness of breath or difficulty breathing, and swollen feet. Report these symptoms to a doctor. • 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. • Get regular flu and pneumonia vaccines as contracting either illness could be dangerous for a person with lung disease.
<p>Heart problems 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.</p>	<ul style="list-style-type: none"> • Treatment ranges from drugs to surgery, and varies depending on the nature of the condition.

<p style="text-align: center;">Kidney problems</p> <p>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.</p>	<ul style="list-style-type: none"> • 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. • 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.
<p style="text-align: center;">Cosmetic problems</p> <p>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.</p>	<ul style="list-style-type: none"> • The appearance of telangiectasias may be reduced or even eliminated with the use of guided lasers. • 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:

<p>Appearance and self-esteem</p>	<p>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.</p>	<p>Effects may be minimized with proper treatment and special cosmetics – and in some cases, plastic surgery – can help conceal scleroderma's damage.</p>
<p>Self care</p>	<p>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.</p>	<p>Devices as simple as Velcro fasteners and built-up brush handles can help improve independence.</p>
<p>Family relationships</p>	<p>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.</p>	<p>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.</p>

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.**

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:

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.

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.**

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 stroke.
- 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 decubitus 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 by 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

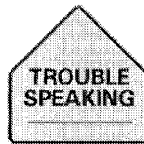
Many risk factors for stroke can be managed, some very successfully. Although risk is never zero at any age, by starting early and controlling risk factors one can lower his or her risk of death or disability from stroke.



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

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.**



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	<ul style="list-style-type: none"> • Weakens blood vessels • Increases brain damage in case of stroke 	<ul style="list-style-type: none"> • Physician recommended treatment • Insulin supplements • Diet control (control sugar intake)
High Blood Pressure (Hypertension)	<ul style="list-style-type: none"> • Most potent risk factor for stroke 	<ul style="list-style-type: none"> • Maintain proper weight • Cut down on salt and increase potassium intake • Physician prescribed medication
Cigarette Smoking	<ul style="list-style-type: none"> • Causes blockage of carotid artery - leading cause of stroke in Americans • Nicotine raises blood pressure • Makes blood thicker and more likely to clot 	<ul style="list-style-type: none"> • 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 fibrillation)	<ul style="list-style-type: none"> • Can create blood clots that may break loose and block vessels in the brain 	<ul style="list-style-type: none"> • Physician prescribed treatment including medication and surgery • Diet control (low sodium and fat)
History of Stroke or Exhibiting Warning Signs (TIA: Mini-stroke)	<ul style="list-style-type: none"> • Identify an underlying serious condition that may cause stroke • Second stroke likely to cause more damage/disability 	<ul style="list-style-type: none"> • 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.

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.**



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. ("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 weakness. 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)

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.**



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	<ul style="list-style-type: none"> ▪ Inability to control urination 	<i>Treatment:</i> Catheter; trying to urinate at regular intervals; limiting liquid, caffeine, and alcohol consumption at night; Pelvic floor muscle (Kegel) exercises
Urinary Retention	<ul style="list-style-type: none"> ▪ 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) <i>Treatment:</i> Physician prescribed medication; pantliners, waterproof underpants, or disposable adult diapers
Urinary Tract Infection (UTI)	<ul style="list-style-type: none"> ▪ Urine with a bad smell, cloudiness, blood or sediment (solid deposits). ▪ Burning when urinating ▪ Fever and chills ▪ Cramps in lower abdomen or side ▪ Pain in lower back ▪ Frequent urination 	Needs immediate treatment. See physician for antibiotics or other treatment medication
Constipation and Bowel Incontinence	<ul style="list-style-type: none"> ▪ Inability to have a regular bowel movement ▪ Inability to control release of stool 	Caused by: <ul style="list-style-type: none"> ▪ Reduced fluid intake ▪ Diet ▪ Not moving around enough ▪ Side effects from prescription drugs ▪ Being unaware of need to use the bathroom ▪ Weakness in the rectal muscle ▪ Being unable or reluctant to ask for help <i>Treatments:</i> 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)

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.**



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 one's 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 Disturbance	Symptoms	Treatment
Clinical Depression	<ul style="list-style-type: none"> ▪ A sense of hopelessness that disrupts an individual's ability to function ▪ Feeling sad or “empty” most of the time ▪ Loss of interest or pleasure in ordinary activities ▪ Fatigue ▪ Sudden trouble sleeping or oversleeping ▪ Sudden loss of appetite or weight gain ▪ Being unable to concentrate, remember or make decisions ▪ Feeling worthless or helpless ▪ Feelings of guilt ▪ Ongoing thoughts of death or suicide, suicide planning or attempts ▪ A sudden change in how easily one is annoyed ▪ Crying all the time 	<ul style="list-style-type: none"> ▪ Physician prescribed antidepressant medications ▪ Psychological counseling

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.**



Extreme Anxiety	<ul style="list-style-type: none"> ▪ An overwhelming sense of worry or fear ▪ Increased sweating/ heart rate ▪ 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 	<ul style="list-style-type: none"> ▪ Physician prescribed antidepressant medications ▪ Psychological counseling
Pseudobulbar Affect (PBA) (Uncontrolled emotions, emotional incontinence or pathologic lability)	<ul style="list-style-type: none"> ▪ Not the same as depression ▪ Unable to control emotional expression ▪ Can lead to fear, shame and isolation 	<ul style="list-style-type: none"> ▪ No treatment approved by the FDA ▪ 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	<ul style="list-style-type: none"> ▪ Move extra furniture out of the way, either to corners or another room. ▪ Clear paths to the kitchen, bedroom and bathroom ▪ Move electrical cords out of pathways ▪ Wear non-skid shoes and avoid slick surfaces ▪ Remove loose carpets and runners in hallways and stairwells or fasten them with non-skid tape ▪ Replace thick carpeting with lower pile carpeting to make wheelchair or walker movement easier ▪ Install handrails for support in going up and down stairs. Make sure they're securely fastened to the wall ▪ 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	<ul style="list-style-type: none"> ▪ Use simple cleaning products such as disposable wipes and mop heads ▪ Choose one multipurpose cleaning solution for most cleaning. ▪ Use smaller, lightweight containers, wheeled push carts and cleaning tools with long handles or extensions ▪ Working on small areas ▪ Frequent breaks

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.**

Doing Laundry	Disabilities caused by stroke can cause difficulties in keeping house, including doing the laundry	<ul style="list-style-type: none"> ▪ Move laundry machines to an easily accessible place ▪ Stackable, front-loading machines may be easier to reach and take up less space ▪ Label and make accessible detergents and laundry supplies. ▪ Machines with easy-to-read markings for wash settings ▪ Nearby table or cart at the right height to sort and fold clothes ▪ Ironing board that folds down from the wall
Using the Bathroom	Bathrooms are customarily small spaces and can pose mobility problems	<ul style="list-style-type: none"> ▪ Sturdy hand rails ▪ Grab bars in the tub or shower ▪ Non-slip flooring strips installed inside and outside of the tub ▪ Bath tub benches and toilet chairs ▪ Easy-to-use water control knobs with easily seen settings or long-handled levers ▪ An adjustable or handheld showerhead ▪ Bathing supplies that are easy to reach and use ▪ A raised toilet seat or toilet seat riser to reduce the distance and difficulty in sitting down and getting up.
Getting Dressed		<ul style="list-style-type: none"> ▪ Avoid tight-fitting sleeves, armholes, pant legs and waistlines ▪ Clothes with fasteners in the front ▪ Replace buttons, zippers and laces with Velcro fasteners. ▪ Dressing aids and adaptable clothing can be found on Internet sites and at health supply stores. ▪ Check out the following websites for adaptable clothing: <ul style="list-style-type: none"> ○ http://www.makoa.org/clothing.htm ○ http://www.professionalfit.com/
In the Kitchen	Space can be small and items hard to reach. Dangers of handling sharp and hot objects.	<ul style="list-style-type: none"> ▪ Controls at the front of the stove are easier and safer to use than the traditional back-of-the-stove controls. ▪ Push-button controls are easier to use than those that turn. ▪ Automatic shut-off controls for safety ▪ An over-the-stove mirror will help in viewing stovetop contents if cooking while seated. ▪ Keep a clear space near the stove to place a hot pot or pan quickly. ▪ Accessible oven mitts ▪ Fire extinguisher in kitchen ▪ 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).

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.**



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					

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.**



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%

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.**



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						

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.**



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 1999

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.**

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 pantliners, 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.

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.

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.

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.

- 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?”

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.

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

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 your 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.

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?”

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.



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.

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.**



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	<ul style="list-style-type: none"> • Remain conscious or may experience a loss of consciousness for a few seconds or minutes • May also feel dazed or not like himself for several days or weeks after the initial injury • 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	<ul style="list-style-type: none"> • 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 • 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.

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.**



What are the Different Types of TBI?

Concussion	<ul style="list-style-type: none"> • Most minor and the most common type short loss of consciousness in response to a head injury
Skull fractures	<ul style="list-style-type: none"> • Depressed skull fracture-pieces of the broken skull press into the tissue of the brain • Penetrating skull fracture- occurs when something pierces the skull
Contusion	<ul style="list-style-type: none"> • A distinct area of swollen brain tissue mixed with blood released from broken blood vessels
Contrecoup	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Is a shearing injury which involved damage to nerve cells and loss of overall communication within the brain
Hematoma	<ul style="list-style-type: none"> • Damage to a major blood vessel in the head, or heavy bleeding into or around the brain
Anoxia	<ul style="list-style-type: none"> • A condition in which there is an absence of oxygen supply • 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	<ul style="list-style-type: none"> • Patient is unresponsive but can be aroused briefly by a strong stimulus, such as sharp pain
coma	<ul style="list-style-type: none"> • Patient is totally unconscious, unresponsive, unaware, and unarousable • Do not respond to external stimuli, such as pain or light, and do not have sleep-wake cycles. • Results from widespread and diffuse trauma to the brain • Generally is of short duration, lasting a few days to a few weeks • After this time, some patients gradually come out of the coma, some progress to a vegetative state, and others die • Have lower brain and brain stem damage
vegetative state	<ul style="list-style-type: none"> • Patients are unconscious and unaware of their surroundings, but they continue to have a sleep-wake cycle and can have periods of alertness • Often open their eyes and may move, groan, or show reflex responses • Do not have lower brain and brain stem damage • Many patients emerge from a vegetative state within a few weeks
persistent vegetative state	<ul style="list-style-type: none"> • Patients that do not emerge or vegetative state within 30 days • The longer a patient is in a PVS, the more severe the resulting disabilities will be
locked-in syndrome	<ul style="list-style-type: none"> • Patient is aware and awake, but cannot move or communicate due to complete paralysis of the body • Is caused by damage to specific portions of the lower brain and brainstem with no damage to the upper brain • Patients can communicate through movements and blinking of their eyes, which are not affected by the paralysis
brain death	<ul style="list-style-type: none"> • 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

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.**



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:

<p>Problems with cognition (thinking, memory, and reasoning)</p>	<p><u>Severe TBI</u></p> <ul style="list-style-type: none"> • Most patients with severe TBI, if they recover consciousness, suffer from cognitive disabilities, including the loss of many higher level mental skills • most common cognitive impairment is memory loss, characterized by some loss of specific memories and the partial inability to form or store new ones
	<p><u>Mild to Moderate TBI</u></p> <ul style="list-style-type: none"> • become easily confused or distracted and have problems with concentration and attention • 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 • Recovery from cognitive deficits is greatest within the first 6 months after the injury and more gradual after that
<p>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.</p>	
<p>Sensory processing (sight, hearing, touch, taste, and smell)</p>	<ul style="list-style-type: none"> • Vision problems common • may not be able to register what they are seeing or may be slow to recognize objects • 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 • TBI may develop tinnitus, a ringing or roaring in the ears • 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 • 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.

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.**



Communication
(expression and understanding)

- Common disabilities in TBI patients
- **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
- **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.
- **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
- **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
(depression, anxiety, personality changes, aggression, acting out, and social inappropriateness)

- Personality changes and behavioral problems
- Psychiatric problems that may surface include depression, apathy, anxiety, irritability, anger, paranoia, confusion, frustration, agitation, insomnia or other sleep problems, and mood swings
- 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
- Some patients' personality problems may be so severe that they are diagnosed with borderline personality disorder
- 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

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.**



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



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.

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.**



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.

Adapted (8-07) from: "Traumatic Brain Injury: Hope Through Research," NINDS. February 14, 2007 NIH Publication No. 02-2478



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.**

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.tbinc.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.tbitec.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

Brain Injury Association of America. *Guide to Selecting and Monitoring Brain Injury Rehabilitation Programs.* (800) 444-6443.

Brain Injury Association of America. (2002). *National Directory of Brain Injury Rehabilitation Services: May 2002 - May 2003.* (800) 444-6443.

Brain Injury Association of America.
What Is Brain Injury? www.biausa.org/Pages/what_is_brain_injury.html

Brain Injury Association of America. Treatment and Rehabilitation.
www.biausa.org/Pages/treatment_and_rehab.html

National Institutes of Health. (1998). *Rehabilitation of Persons with Traumatic Brain Injury.* Consensus, NIH Consensus Statement. October 26-28, 1998.

Centers for Disease Control. Traumatic Brain Injury. *Fact Sheet.* National Center for Injury Prevention and Control. www.cdc.gov/ncipc/factsheets/tbi.htm

Vaughn, S.L. & King, A. (2001). A survey of state programs to finance rehabilitation and community services for individuals with brain injury, *Journal of Head Trauma Rehabilitation*, Vol. 16, 20-33.

Fujii, D., Schaefer Hanes, S., & Kokuni, Y. (1996). Family intervention in the rehabilitation and community reintegration of individuals with brain injury, *The Journal of Cognitive Rehabilitation*, March/April, 6-10.

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 Scbold, Communications Specialist of the Brain Injury Association of America. Funded by the Archstone Foundation. September 2003. © Family Caregiver Alliance. All rights reserved.

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 your 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, Galveston, 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., Neuropsychology 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.**

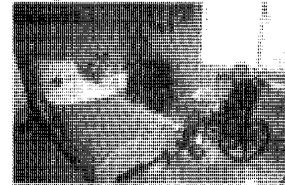


National Institute on Aging

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.

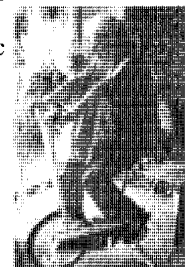
Fear of Falling

- 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.

NIH SeniorHealth

- **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.

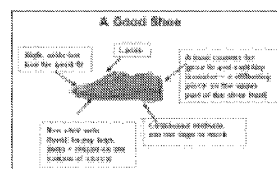
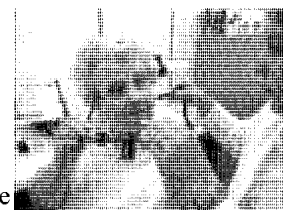
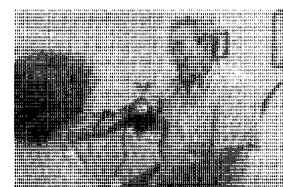
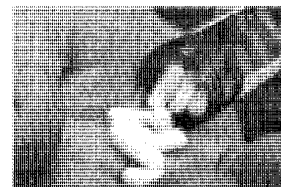
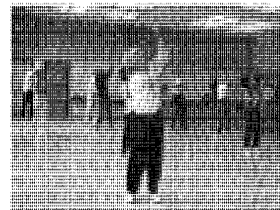
All falls should be reported to the doctor:

- 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.

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.



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.**

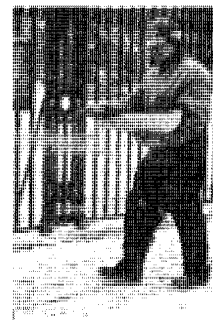
NIH SeniorHealth

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.

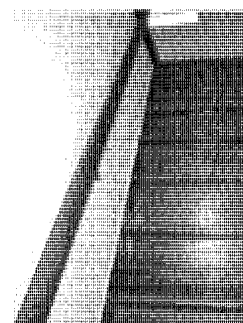
Some tips to help prevent falls outdoors are:

- 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.

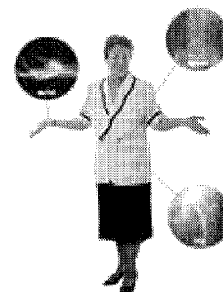
Having healthy bones won't prevent a fall, but can help prevent hip or other fractures.

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.



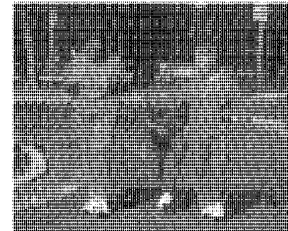
NIH SeniorHealth

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

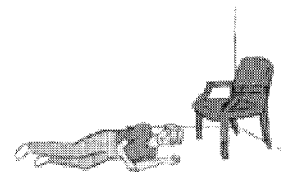
- Maintain a healthy weight.
- Being underweight increases the risk of bone loss and broken bones.

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.



NIH SeniorHealth

- 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

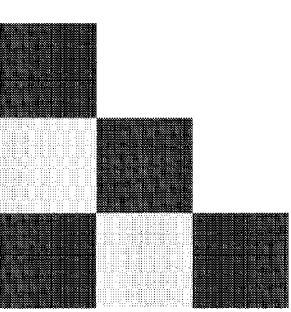
- If a patient has problems with balance or dizziness and are often alone, consider getting a personal emergency response system
 - This service, through the telephone line and provides a button or bracelet to wear at all times in the home
 - If the patient falls or needs emergency assistance for any 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

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.**



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.



What Are Ways to Prevent Falls and Related Fractures?

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

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.

What Are Ways to Prevent Falls and Related Fractures?

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

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

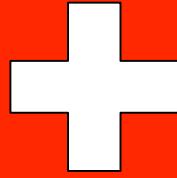
For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration at 1-888-INFO-FDA (1-888-463-6332, a toll-free call) or visit their Web site at www.fda.gov.

Vial of Life



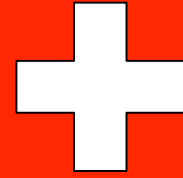
See Refrigerator
Door for medical
Information

Vial of Life



See Refrigerator
Door for medical
Information

Vial of Life



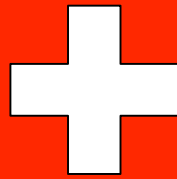
See Refrigerator
Door for medical
Information

Vial of Life



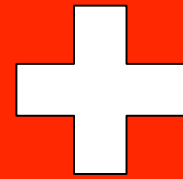
See Refrigerator
Door for medical
Information

Vial of Life



See Refrigerator
Door for medical
Information

Vial of Life



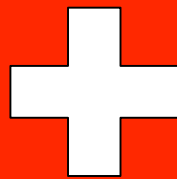
See Refrigerator
Door for medical
Information

Vial of Life



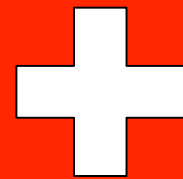
See Refrigerator
Door for medical
Information

Vial of Life



See Refrigerator
Door for medical
Information

Vial of Life



See Refrigerator
Door for medical
Information

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 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.**

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		UNABLE TO SPEAK		
List vision difficulties								UPPER LOWER		<input type="checkbox"/>		
								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

Prepared by Family Caregiver Alliance. Funded by Alameda County Area Agency on Aging. © 2003 Family Caregiver Alliance. All rights reserved.

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[®] 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 Hoeffler 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.

IHSS Training Academy

15

Elective: Medical Implications

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.**

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

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.**

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

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 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

Prepared by Family Caregiver Alliance. Funded by the California Department of Mental Health. ©2003 Family Caregiver Alliance. All rights reserved.



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 require supervision or assistance 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.

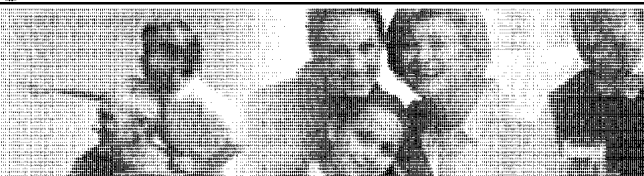
FOR MORE INFORMATION

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



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 doctor 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



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.

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



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 doc

tor 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, in-

cluding 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 design-

ation 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 incapacitated 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.medicarights.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/onourown/terms
"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

Improving Care for the End of Life (with Janice Lynch Schuster), Getty Center for Education in the Arts, 1999

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. © 2000 All Rights Reserved.

Revised 10/03/02

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

- meperidine – **Demerol**
- nonsteroidal anti-inflammatory drugs (NSAIDs) – **Naprosyn, Naproxen**

Sedative - hypnotics

- halcion – **Halcion, Triazolam**
- benzodiazepines – **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**

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.**

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®) chlorpromazine (Thorazine®) thioridazine (Mellaril®) 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.

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.**

Blood Clotting Disorders (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®) Ticlopidine (Ticlid®)	May cause bleeding in those using blood thinners/anticoagulants.
Prostate Disease/Benign Prostatic Hyperplasia (BPH)	Antihistamines chlorpheniramine (Chlor-Trimeton®) diphenhydramine (Benadryl®) hydroxyzine (Vistaril®, Atarax®) cyproheptadine (Periactin®)	May impair urination and cause obstruction in persons with BPH.
	stomach and intestinal antispasmodics dicyclomine (Bentyl®) hyoscyamine (Levsin®, Levsinex®) propantheline (Pro-Banthine®) belladonna alkaloids (Donnatal®) clidinium/chlordiazepoxide (Librax®)	May impair urination and cause obstruction in persons with BPH.
	muscle relaxants cyclobenzaprine (Flexeril®) methocarbamol (Robaxin®) carisoprodol (Soma®) oxybutynin (Ditropan®); chlorzoxazone (Paraflex®); metaxalone (Skelaxin®)	May impair urination and cause obstruction in persons with BPH.
	narcotics propoxyphene and combination products (Darvon®, Darvocet N-100®) 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 amitriptyline (Elavil®) chlordiazepoxide/amitriptyline (Limbitrol®) perphenazine/amitriptyline (Triavil®) doxepin (Sinequan®)	May impair the ability to urinate in persons with BPH.

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.**

Incontinence	alpha blockers Doxazosin (Cardura®) Prazosin (Minipress®) Terazosin (Hytrin®)	May cause incontinence by relaxing the bladder.
Constipation	Narcotic pain relievers	Will cause or worsen constipation.
	Certain antidepressants amitriptyline (Elavil®) chlordiazepoxide/amitriptyline (Limbitrol®) perphenazine/amitriptyline (Triavil®) doxepin (Sinequan®)	May worsen constipation.
	Iron products	Will cause or worsen constipation.
Dizziness/Lightheadedness or Falls	beta blockers (Tenormin®, Inderal®, Lopressor®)	May slow the heart and weakens the pumping action of the heart. May cause dizziness/lightheadedness or falls.
	Antianxiety medications diazepam (Valium®) flurazepam (Dalmane®)	May contribute to falls due to sleepiness, confusion, and other side effects.
Abnormal heart rhythms/Arrhythmias	tricyclic antidepressants amitriptyline (Elavil®) chlordiazepoxide/amitriptyline (Limbitrol®) perphenazine/amitriptyline (Triavil®) 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 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/>

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 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.**

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 (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®) methocarbamol (Robaxin®) carisoprodol (Soma®) oxybutynin (Ditropan®); chlorzoxazone (Paraflex®); 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®) chlordiazepoxide/amitriptyline (Limbitrol®) perphenazine/amitriptyline (Triavil®) 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.

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.**

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 lorazepam (Ativan®) 3 mg oxazepam (Serax®) 60 mg temazepam (Restoril®) 15 mg triazolam (Halcion®) 0.25mg 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®) chlordiazepoxide/amitriptyline (Limbitrol®) clidinium/chlordiazepoxide (Librax®) 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®) 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.

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.**

methyldopa (Aldomet®) 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®) 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®) hyoscyamine (Levsin®, Levsinex®) propantheline (Pro-Banthine®) belladonna alkaloids (Donnatal®) 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®) diphenhydramine (Benadryl®) hydroxyzine (Vistaril®, Atarax®) cyproheptadine (Periactin®) promethazine (Phenergan®) tripelennamine (PBZ®) 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.

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.**

Actifed C® Poly-Histine CS® Bromfed DM® Ambenyl® Novahistine DH® Polyhistine DM® 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 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/>

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.**

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 persons. 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.

References

Cipolle, R. J., Strand, L. M., & Morley P. C. (1998). *Pharmaceutical Care Practice*. New York: McGraw Hill.

Hanlon, J. T., et al. (1997). Adverse drug events in high risk older outpatients. *Journal of the American Geriatric Society*, 45, 945-948.

National Alliance for Caregiving, AARP. (1997, June). *Family caregiving in the U.S.: findings from a national survey*.

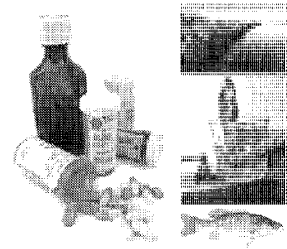
Travis, S. S., et al. (2003). Development of the family caregiver medication administration hassles scale. *The Gerontologist*, 43, 360-368.

Williams, R.D. (1997, September/October). Medication and older adults. *FDA Consumer*.

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. © 2004 Family Caregiver Alliance. All rights reserved.

Pharmaceutical Waste: Disposing of Unwanted Medications

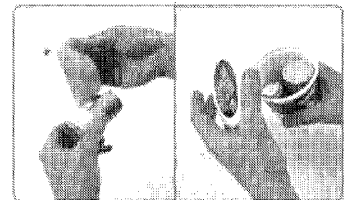
Expired or unwanted prescription or over-the-counter medications from households have traditionally been disposed of by flushing them down the toilet or a drain. Although this method of disposal prevents immediate accidental ingestion, it can cause pollution in wastewater, which has been demonstrated 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 marker.
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.



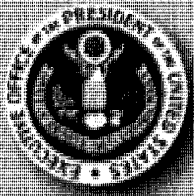
Managing Other Types of Pharmaceutical Waste

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.

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.**



Proper Disposal of Prescription Drugs

Office of National Drug Control Policy | February 2017

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.





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.

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.**



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.

	<ul style="list-style-type: none"> • 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.
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.
	<ul style="list-style-type: none"> • 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.

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.**



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.
<ul style="list-style-type: none"> • 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 	
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 .
<p>Repetitive stress injuries are muscular conditions that result from repeated motions performed in the course of normal work or other daily activities. They include:</p> <ul style="list-style-type: none"> • 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 	
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 .

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.**



<p>Other painful disorders affecting the skin include:</p> <ul style="list-style-type: none"> • vasculitis, or inflammation of blood vessels • other infections, including herpes simplex • skin tumors and cysts • tumors associated with neurofibromatosis, a neurogenetic disorder. 	
<p>Sports injuries</p>	<p>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.</p>
<p>Spinal stenosis</p>	<p>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.</p>
<p>Surgical pain</p>	<p>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.</p>
<p>Temporomandibular disorders</p>	<p>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.</p>
<p>Trauma</p>	<p>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.</p> <p>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.</p>
<p>Vascular disease or injury</p>	<p>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</p>

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.**



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:

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.

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.**



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.
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.
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.
Chemoneucleolysis	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.
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.

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.**



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.
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. 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.

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.**



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.
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. (Rest, Ice, Compression, and Elevation)	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.

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.**

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)*

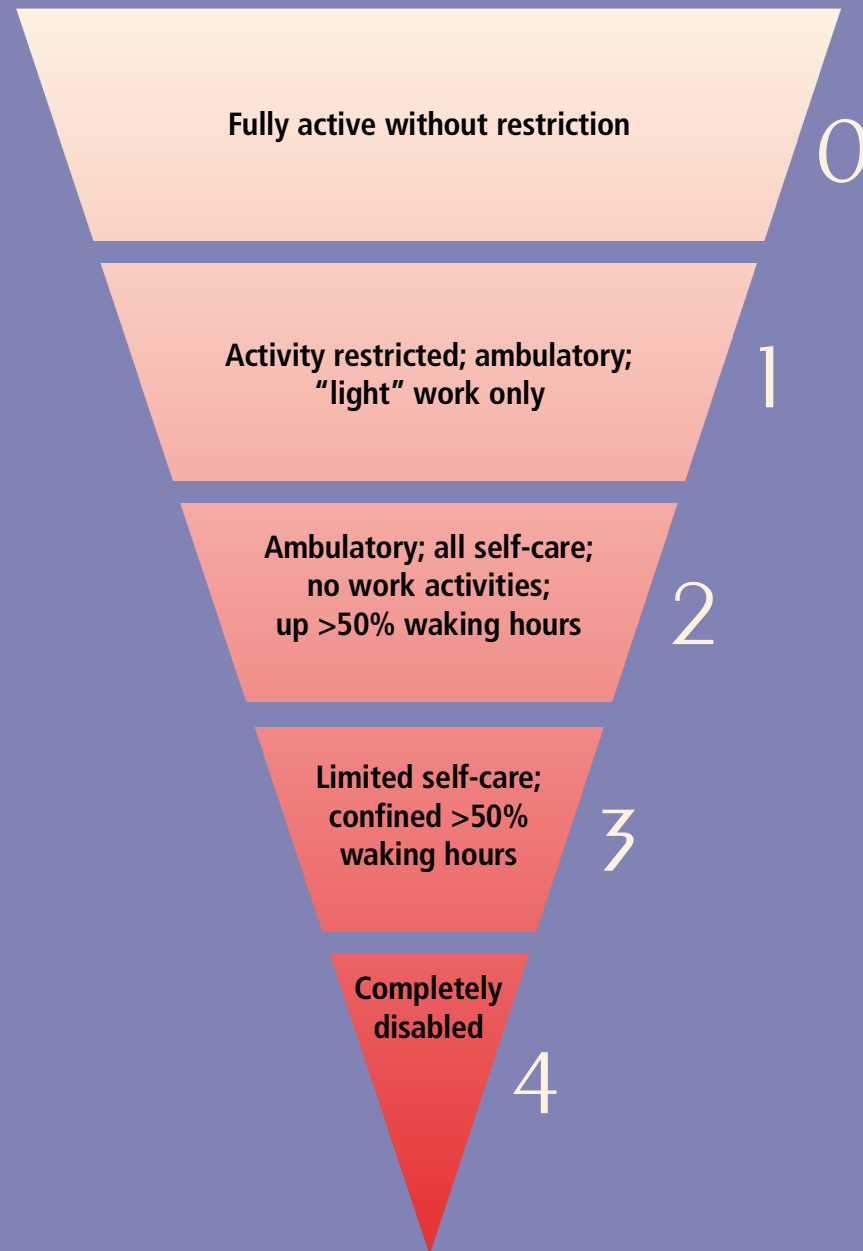
The information is presented to inform IHSS social workers about medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

The 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.**

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.

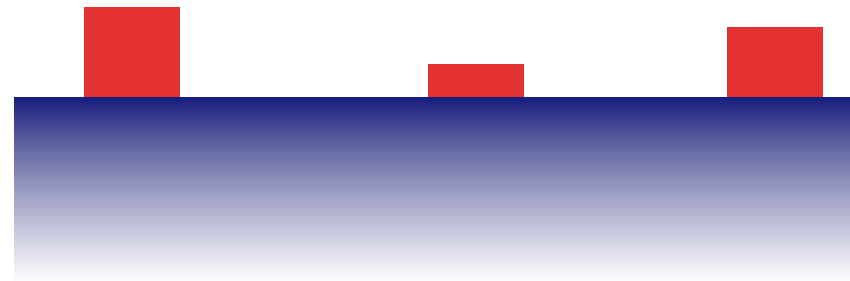


American Pain Foundation • 201 N. Charles St., Suite 710
Baltimore, MD 21201-4111 • 1-888-615-PAIN(7246)
info@painfoundation.org • www.painfoundation.org

The American Pain Foundation is solely responsible for the content, and maintains editorial control, of all materials and publications it produces. We gratefully acknowledge those who support our work. This publication was underwritten with an unrestricted educational grant from Cephalon, Inc.

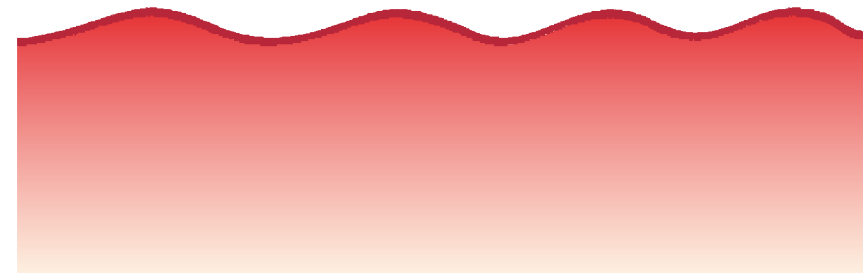
CHRONIC PAIN:

INTERMITTENT, PERSISTENT, BREAKTHROUGH



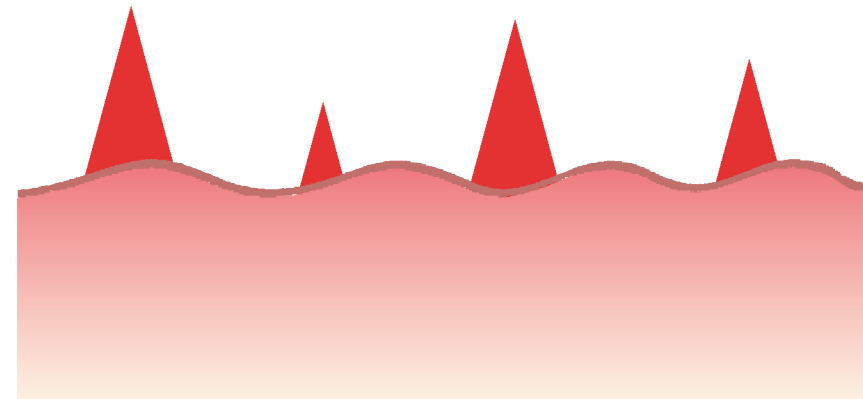
Intermittent Pain

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

Talk to your patients about their pain.

- Where is the pain located?
- What does it feel like (e.g., sharp, dull, burning)?
- When did it begin? How long does it last?
- What makes it better? What makes it worse?

Ask about current treatments.

- What medicines are you taking to relieve pain (prescription, over-the-counter)? What is the dose?
- What other pain relief methods do you use (e.g., acupuncture, heat/cold, massage, home remedies)?
- When do you use these medications and methods and how well do they work?

Rate pain intensity and get details.

- What is your level of pain most of the time (0-10 scale)?
- When is your pain the worst/best?
- What is your pain level when you rest? During movement?

Get details about breakthrough pain (BTP).

- Do you have breakthrough pain—sudden, brief periods of increased pain?
- How often do you experience BTP on an average day?
- Do certain activities cause the pain or does it happen unexpectedly?
- Have you ever been treated for BTP? With what medicines?

Evaluate limitations on activities.

- What daily activities do you avoid because of pain?
- Does pain interfere with your ability to sleep/walk/work/play?
- How does pain affect your mood and relationships?

Treat side effects.

- Are you experiencing side effects from pain medicines, such as drowsiness, nausea, or itching?
- What are you doing to decrease or prevent these side effects?
- Are you taking something to prevent constipation?
- Are you having side effects with other medicines or therapies?

SUGGESTIONS FOR MANAGING YOUR PATIENTS' PAIN

Accept your patients' reports of pain.
Assess chronic pain as part of each visit.
Look for causes of pain.
Ask about any history of substance abuse or addiction.
Treat pain until optimal relief and functional outcomes are reached.

Develop a treatment plan that relates directly to the pain assessment findings. For prescribing medicines, consider using guidelines (see resources).
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.

Evaluate need for multimodal pain treatment. That may include NSAIDs, opioids, adjuvants such as anticonvulsants or antidepressants, and/or non-drug therapies.
Among non-drug strategies consider rehabilitative and behavioral therapies. 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.

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).
If unrelieved BTP during opioid therapy:

- End of LAO dose interval? Increase LAO daily dose or shorten interval.
- Unpredictable BTP? Add or change SAO.
- Predictable BTP with pain-producing activity? Add or increase SAO dose before activity.

Do not exceed acetaminophen 4000 mg/24h if combination SAO is selected.

If daily activities are limited or prevented by mild to moderate pain:

- Add or increase non-drug strategies.
- Add or change non-opioid or adjuvant drugs, or change opioid plan.

If activities or sleep are limited or prevented by moderate to severe pain:

- Increase dose or change ATC medicine.
- Add or increase dose or change SAO for BTP.

Discuss potential side effects of all pain medicines and non-drug treatments. If patient reports side effects from opioids:

- Use antiemetic if nauseous, antihistamine if pruritus. In selected cases, co-administration of a stimulant may reverse drowsiness or mental clouding.
- Prevent or treat constipation with appropriate laxatives.
- Change opioid selection.

For side effects of SAO for BTP, consider:

- Take side effects medication before dose.
- Reduce dose or change opioid.
- Evaluate adequacy of multimodal adjuvant pain medications.

Expand use of non-drug methods.

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

Developed in collaboration with:

Micke A. Brown, BSN, RN
American Pain Foundation
Baltimore, Maryland

Debra B. Gordon, MS, RN, CS
University of Wisconsin Hospital & Clinics
Madison, Wisconsin

Claudia Campbell, BSN, RN, CCRN
Intermountain Healthcare
Salt Lake City, Utah

Diane B. Loseth, MSN, RN
Yale-New Haven Hospital
New Haven, Connecticut

Patrick J. Coyne, MSN, APRN, BC
Medical College of Virginia Hospitals
Virginia Commonwealth University Health Systems
Richmond, Virginia

Christine Miaskowski, PhD, RN, FAAN
University of California, San Francisco
San Francisco, California

APF Board reviewers:

James N. Campbell, MD
Johns Hopkins University
Medical Center
Baltimore, Maryland

Scott M. Fishman, MD
UC Davis Medical Center
Sacramento, California

Russell Portenoy, MD
Beth Israel Medical Center
New York, New York

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

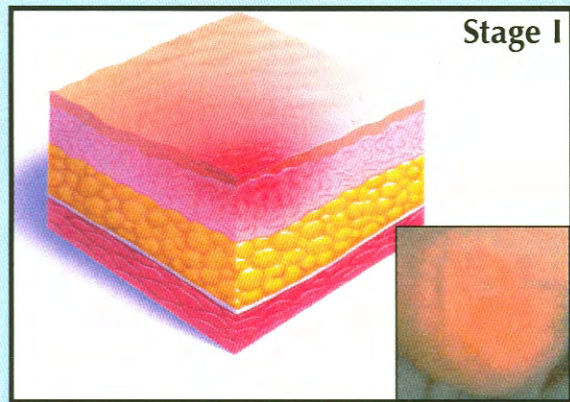
BTP breakthrough pain

LAO long-acting opioid

SAO short-acting opioid

Guidelines for Staging of Pressure Ulcers

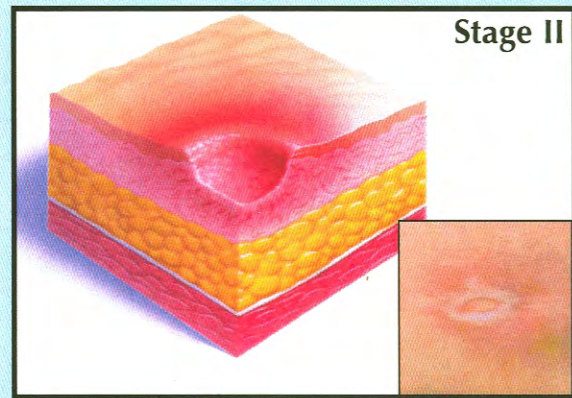
The following criteria can be used to quickly identify pressure ulcer wound stages as defined by the Wound Ostomy and Continence Nurses Society (WOCN) in their STANDARDS OF CARE (1992), the AHCPN Clinical Practice Guidelines (1994), now the Agency for Healthcare Research and Quality (AHRQ), the National 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.



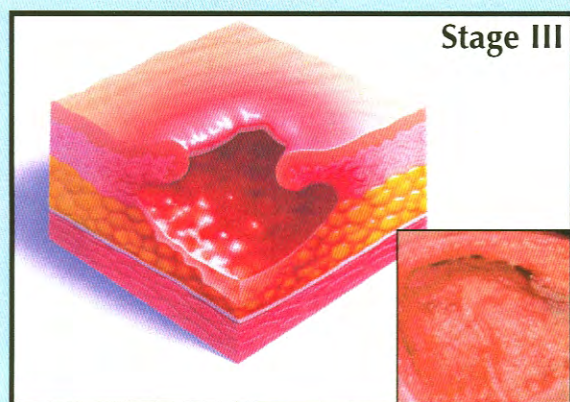
An observable pressure-related alteration of intact skin whose indicators as compared to the adjacent or opposite area on the body may include changes in one or more of the following:

Skin temperature (warmth or coolness),
Tissue consistency (firm or boggy feel) and/or
Sensation (pain, itching).

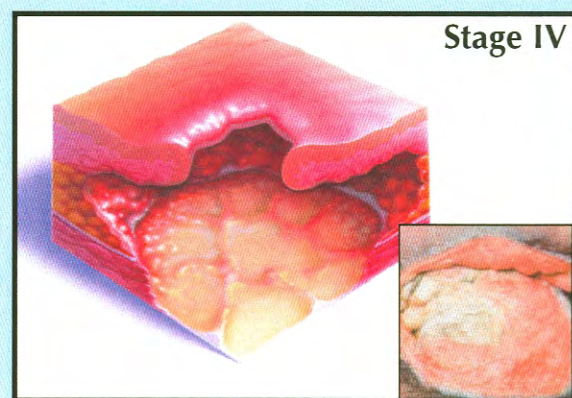
The ulcer appears as a defined area of persistent redness in lightly pigmented skin, whereas in darker skin tones, the ulcer may appear with persistent red, blue or purple hues.



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
<ul style="list-style-type: none"> ▪ Inspect skin daily ▪ Cleanse skin when soiled with soap and water ▪ Minimize exposure to moisture from incontinence, perspiration, or wound drainage ▪ Moisturize dry skin ▪ Minimize shear and friction (observe proper positioning, transfer, turning techniques) ▪ Utilize skin protectants / antimicrobial ointments as moisture barrier as necessary ▪ Address nutritional needs ▪ Reposition at least every 2 hours ▪ Increase mobility, activity ▪ Use pressure reduction devices in bed, chair, wheelchair ▪ Relieve pressure on bony prominences ▪ Relieve heel pressure ▪ Maintain head of bed no higher than 30 degrees ▪ Use lifting devices ▪ Involve and educate consumer and/or provider ▪ Monitor and document interventions and outcomes 	<p>Treatment may include:</p> <ul style="list-style-type: none"> ▪ Apply skin protectants / antimicrobial ointments to buttocks with each episode of incontinence. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> ▪ Cleanse with Wound Cleanser, pat dry ▪ Cover with Transparent Film Dressing or Thin Hydrocolloid ▪ Change at least 2x week and PRN 	<p>Minimal Drainage:</p> <ul style="list-style-type: none"> ▪ Cleanse with Wound Cleanser and apply skin protectants / antimicrobial ointments as moisture barrier to buttocks with each episode of incontinence. <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> ▪ Apply Skin Prep to skin area around the wound ▪ Apply Hydrogel sheet ▪ Cover with Transparent Film Dressing or Hydrocolloid <p>Change 2x a week and PRN for dislodgment or leakage</p> <p style="text-align: center;">Or</p> <p>Moderate to Heavy Drainage</p> <ul style="list-style-type: none"> ▪ Cleanse with Wound Cleanser ▪ Apply calcium alginate product to wound bed ▪ Apply Hydrogel ointment or Hydrogel sheet ▪ Cover with Bordered Gauze, Transparent Film Dressing, or Hydrocolloid dressing and change 2x a week and PRN 	<p>Low Drainage</p> <ul style="list-style-type: none"> ▪ Irrigate wound with Wound Cleanser (4 to 15 psi) ▪ Apply Calcium Alginate Wound Dressing, Waterproof Foam dressing or Hydrogel to wound cavity ▪ Cover with a Bordered Gauze, or Hydrocolloid dressing ▪ Change 2x a week and PRN for dislodgment or leakage <p style="text-align: center;">Or</p> <p>Moderate to Heavy Drainage</p> <ul style="list-style-type: none"> ▪ Irrigate wound with Wound Cleanser (4 to 15 psi) ▪ Line wound bed with Calcium Alginate (rope or sheet), waterproof Foam Dressing, or Hydrogel to wound cavity ▪ Apply Skin Prep to skin area around the wound ▪ Cover with Bordered Gauze, Transparent Film Dressing, or Hydrocolloid dressing ▪ May frame with tape to prevent premature dislodgement ▪ Change 2x a week and PRN for dislodgment or leakage <p>Stage IV Wounds</p> <ul style="list-style-type: none"> ▪ 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

IHSS Training Academy
Elective: Medical Implications



IHSS Training Academy
Elective: Medical Implications

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.**



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.

	1. Completely Limited	2. Very Limited	3. Slightly Limited	4. No Impairment
<p>Sensory Perception</p> <p><i>Ability to respond meaningfully to pressure-related discomfort</i></p>	<p>Unresponsive to painful stimuli, due to diminished level of consciousness or sedation OR limited ability to feel pain over most of body surface</p>	<p>Responds only to painful stimuli. Cannot communicate discomfort except by moaning or restlessness. OR has a sensory impairment which limits the ability to feel pain or discomfort over ½ of body</p>	<p>Responds to verbal commands, but cannot always communicate discomfort or the need to be turned. OR has some sensory impairment which limits ability to feel pain or discomfort in 1 or 2 extremities.</p>	<p>Responds to verbal commands. Has no sensory deficit which would limit ability to feel or voice pain or discomfort</p>
<p>Moisture</p> <p><i>Degree to which skin is exposed to moisture</i></p>	<p>1. Constantly Moist</p> <p>Skin is kept moist almost constantly by perspiration, urine, etc. Dampness is detected every time patient is moved or turned.</p>	<p>2. Very Moist</p> <p>Skin is often, but not always, moist. Linen must be changed least or two or three times a day.</p>	<p>3. Occasionally Moist</p> <p>Skin is occasionally moist, requiring an extra linen change daily.</p>	<p>4. Rarely Moist</p> <p>Skin is usually dry. Linen only requires changing at routine intervals.</p>
<p>Activity</p> <p><i>Degree of physical activity</i></p>	<p>1. Bedfast</p> <p>Confined to bed.</p>	<p>2. Chairfast</p> <p>Ability to walk severely limited or non-existent. Cannot bear own weight and/or must be assisted into chair or wheelchair.</p>	<p>3. Walks Occasionally</p> <p>Walks occasionally during day, but for very short distances, with or without assistance. spends majority of day bed or chair.</p>	<p>4. Walks Frequently</p> <p>Walks around the house at least once every 2hours during waking hours.</p>

	1. Completely Immobile	2. Very Limited	3. Slightly Limited	4. No Limitations
Mobility <i>Ability to change and control body position</i>	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.
	1. Very Poor	2. Probably Inadequate	3. Adequate	4. Excellent
Nutrition <i>Usual food intake pattern</i>	Never eats a complete meal. 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. 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. OR 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. OR is on a tube feeding or TPN regimen which probably meets most of nutritional needs.	Eats most of every meal. Never refuses a meal. Usually eats a total of 4 or more servings of meat and dairy products. Occasionally eats between meals. Does not require supplementation.
	1. Problem	2. Potential Problem	3. No Apparent Problem	
Friction and Shear <i>Stress and dragging on skin and tissues.</i>	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. During a move, skin probably slides to some extent against sheets, chair restraints, or other devices. 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. 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

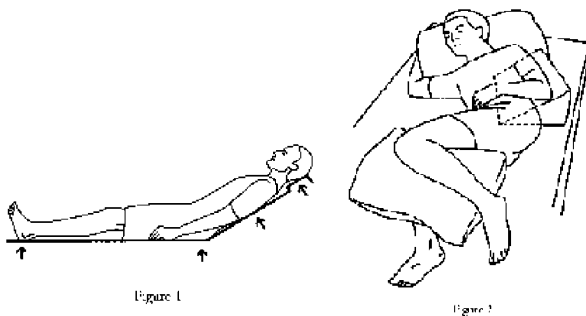
Transparent Films and Hydrocolloids

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).



[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 an edentulous 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 rationale 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 (Exudate 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	<ul style="list-style-type: none"> ● Dressings can stick to the wound surface and disrupt the wound bed when removed ● Only use on minor wounds or as secondary dressings 	
Tulle	<ul style="list-style-type: none"> ● Dressing does not stick to wound surface ● Suitable for flat, shallow wound ● Useful in patient with sensitive skin ● E.g. Jelonet® 	
Semipermeable film	<ul style="list-style-type: none"> ● Sterile sheet of polyurethane coated with acrylic adhesive ● Transparent allowing wound checks ● Suitable for shallow wound with low exudate ● E.g. OpSite®, Tegaderm® 	

<p>Hydrocolloids</p>	<ul style="list-style-type: none"> ● 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 ● Depending on the hydrocolloid dressing chosen can be used in wounds with light to heavy exudate, sloughing or granulating wounds ● Available in many forms (adhesive or non-adhesive pad, paste, powder) but most commonly as self-adhesive pads ● E.g. DuoDERM®, Tegaserb® 	
<p>Hydrogels</p>	<ul style="list-style-type: none"> ● Composed mainly of water in a complex network or fibers that keep the polymer gel intact. Water is released to keep the wound moist ● Used for necrotic or sloughing wound beds to rehydrate and remove dead tissue. Do not use for moderate to heavily exuding wounds ● E.g. Tegagel®, Intrasite® 	
<p>Alginates</p>	<ul style="list-style-type: none"> ● 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 ● Good for exudating wounds and helps in debridement of sloughing wounds ● Do not use on low exudating wounds as this will cause dryness and scabbing ● Dressing should be changed daily ● E.g. Kaltostat®, Sorbsan® 	

<p>Polyurethane or silicone foams</p>	<ul style="list-style-type: none"> ● Designed to absorb large amounts of exudates ● Maintain a moist wound environment but are not as useful as alginates or hydrocolloids for debridement ● Do not use on low exudating wounds as this will cause dryness and scabbing ● E.g. Allevyn®, Lyofoam® 	
<p>Hydrofibre</p>	<ul style="list-style-type: none"> ● Soft non-woven pad or ribbon dressing made from sodium carboxymethylcellulose fibers ● Interact with wound drainage to form a soft gel ● Absorb exudate and provide a moist environment in a deep wound that needs packing 	
<p>Collagens</p>	<ul style="list-style-type: none"> ● Dressings come in pads, gels or particles ● Promote the deposit of newly formed collagen in the wound bed ● 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
	<p>Clean, medium-to-high exudate (epithelialising)</p>	<ul style="list-style-type: none"> ● Paraffin gauze ● Knitted viscose primary dressing
	<p>Clean, dry, low exudate (epithelialising)</p>	<ul style="list-style-type: none"> ● Absorbent perforated plastic film-faced dressing ● Vapor-permeable adhesive film dressing

	<p>Clean, exudating (granulating)</p>	<ul style="list-style-type: none"> ● Hydrocolloids ● Foams ● Alginates
	<p>Slough-covered</p>	<ul style="list-style-type: none"> ● Hydrocolloids ● Hydrogels
	<p>Dry, necrotic</p>	<ul style="list-style-type: none"> ● Hydrocolloids ● 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.



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.**

PRACTICE GUIDELINES FOR WOUND CARE

PREVENTION	NECROTIC/ ESCHAR/SLOUGH	DIABETIC/ARTERIAL VENOUS ULCERS	SKIN TEARS
<ul style="list-style-type: none"> ▪ Inspect skin daily ▪ Cleanse skin when soiled with soap and water ▪ Minimize exposure to moisture from incontinence, perspiration, or wound drainage ▪ Moisturize dry skin ▪ Minimize shear and friction (observe proper positioning, transfer, turning techniques) ▪ Utilize skin protectants / antimicrobial ointments as moisture barrier as necessary ▪ Address nutritional needs ▪ Reposition at least every 2 hours ▪ Increase mobility, activity ▪ Use pressure reduction devices in bed, chair, wheelchair ▪ Relieve pressure on bony prominences ▪ Relieve pressure on bony prominences ▪ Maintain head of bed no higher than 30 degrees ▪ Use lifting devices ▪ Involve and educate consumer and/or provider ▪ Monitor and document interventions and outcomes 	<ul style="list-style-type: none"> • Cleanse with a Wound Cleanser • Apply Skin Prep to skin around the wound • Apply Hydrocolloid dressing for autolytic debridement • Change q 3-5 days and PRN for dislodgement or leakage <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Apply if chemical debridement agent if 100% of wound bed is necrotic • Cover with gauze. Change daily. (Do not cover with occlusive dressing) • Discontinue this treatment when necrotic tissue is dissolved. • Continue with moist wound healing <p>Intact Black Heel</p> <ul style="list-style-type: none"> • Relieve pressure • No dressing • No debridement • If area opens refer to necrotic slough 	<p>Dry Wound</p> <ul style="list-style-type: none"> • Cleanse with Wound Cleanser • Apply Skin Prep to skin around the wound • Apply Hydrogel, cover with Transparent Film Dressing <p style="text-align: center;">Or</p> <ul style="list-style-type: none"> • Apply Hydrocolloid dressing • May frame with tape to prevent premature dislodgement • Change every 3-5 days & PRN for dislodgement or leakage <p>Draining Wound</p> <ul style="list-style-type: none"> • Cleanse with Wound Cleanser • Apply Skin Prep to skin around the wound • Line wound bed with Calcium Alginate (rope or sheet) – fill remaining space with gauze • Cover with Transparent Film Dressing 	<p>Skin Tears</p> <ul style="list-style-type: none"> • Cleanse with Wound Cleanser & pat dry • Replace attached torn skin with gauze pad / non-adhesive pad • Secure with light gauze or Transparent Film Dressing • May consider using Hydrocolloid alone over the skin tear as needed • 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



IHSS Training Academy
Elective: Medical Implications

18

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.**

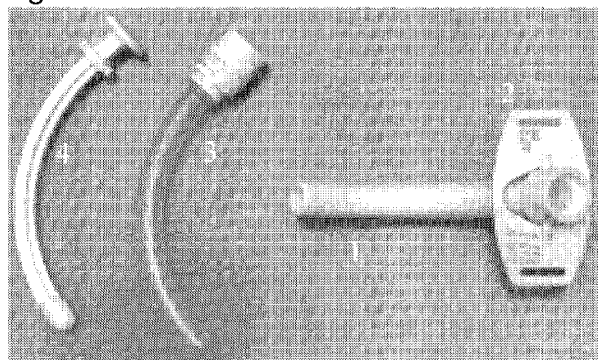
Tracheostomy Care

A tracheostomy is a surgical opening in the trachea (windpipe) to make breathing easier. The opening is called a stoma. A tracheostomy 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 Tracheostomy Tube

The tracheostomy 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.

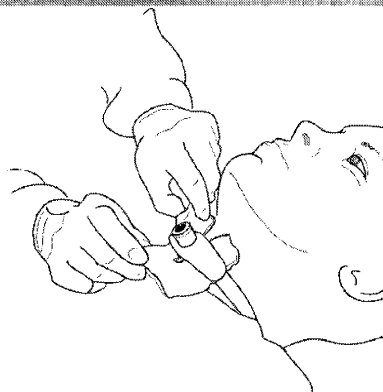


Changing Tracheostomy Dressings

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).

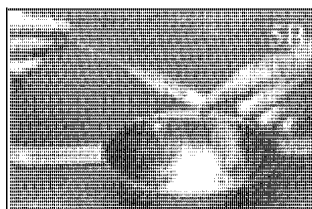
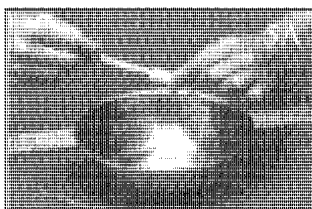
Procedure:

- 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.

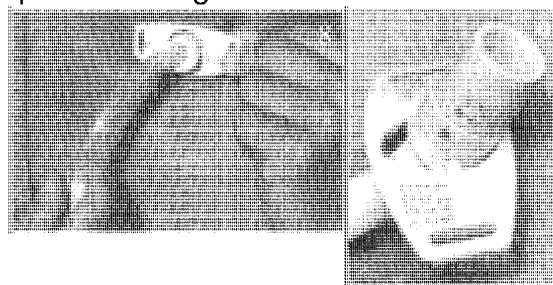


Cleaning the inner cannula:

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

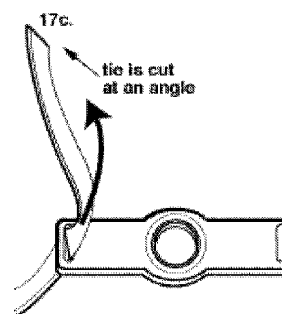
1. Wash hands thoroughly. Remove the new tracheotomy tube from the sterile pouch.
2. Remove the inner cannula and insert the obturator into the outer cannula.
3. Attach the clean trach ties to the neck plate so that the ties will be able to attach around the neck.
4. Lubricate the end of the tube and 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.

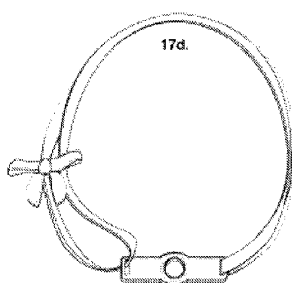
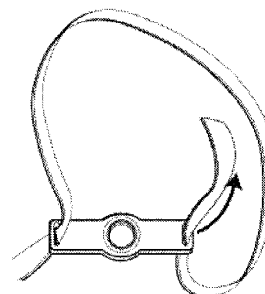
Changing the tracheostomy tube ties

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.

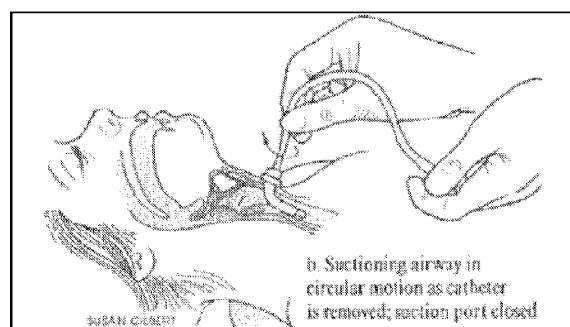
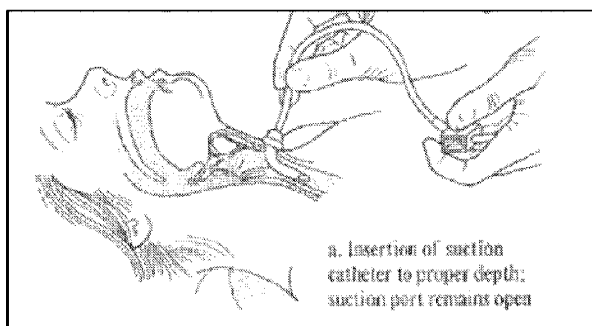
Suctioning

Supplies:

- Suction machine
- Suction catheter
- Water
- Clean plastic bag or container

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.
- 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.pdf> <http://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.

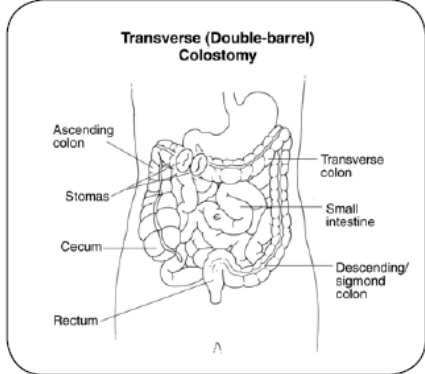
Since nutrients are absorbed in the small intestine, a colostomy does not affect the body's ability to be nourished. When a colostomy interrupts the passage of stool, storage becomes more difficult. The higher up in the colon the colostomy is made, the less time the bowel has to absorb water and the 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

	<p>Indications:</p> <ul style="list-style-type: none"> • Diverticulitis. • Trauma (injury). • Birth Defects. • Cancer/descending or sigmoid colon. • Bowel obstruction. • Paralysis. <p>Discharge:</p> <ul style="list-style-type: none"> • Semi-solid. • Unpredictable. • Contains some digestive enzymes. <p>Management:</p> <ul style="list-style-type: none"> • Skin protection. • Drainable pouch. • Closed-end pouch for convenience or special moments.
---	---

Descending or Sigmoid Colostomy

	<p>Indications:</p> <ul style="list-style-type: none"> • Cancer of rectum or sigmoid colon. • Diverticulitis. • Trauma (injury). • Congenital defects. • Bowel obstruction. • Paralysis. <p>Discharge:</p> <ul style="list-style-type: none"> • Resembles normal bowel movements. • Regulated in some persons, not in others. <p>Management:</p> <ul style="list-style-type: none"> • Natural evacuation or irrigation. • Protective cover or closed-end pouch if regulated. • 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

	<p>Indications:</p> <ul style="list-style-type: none"> • Ulcerative Colitis • Crohn's Disease • Familial Polyposis • Cancer complications <p>Discharge:</p> <ul style="list-style-type: none"> • Liquid or paste consistency • Unpredictable drainage • Contains residual digestive enzymes <p>Management:</p> <ul style="list-style-type: none"> • Skin protection; • 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 than 5-6 hours (colostomy only)
 - You have a temperature over 100°

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

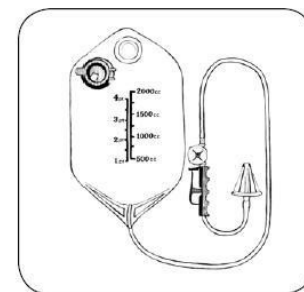
Colostomy Irrigation

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.

This technique should be performed every 1 to 3 days at a convenient time. A special irrigating set and cone is used.

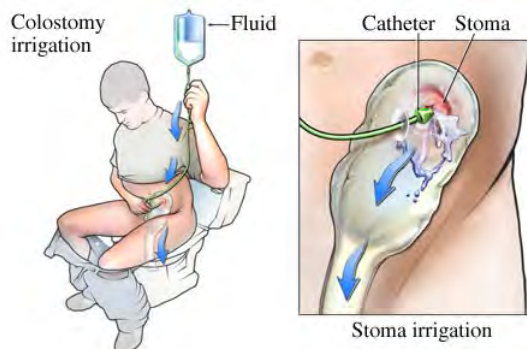
The colostomy plug can be used following irrigation.



Irrigation system

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.

	<p>Indications</p> <ul style="list-style-type: none"> • Cancer of bladder • Neurologic dysfunction • Birth defects • Chronic inflammation of bladder <p>Discharge</p> <ul style="list-style-type: none"> • Urine • Some mucus • Continuous drainage <p>Management</p> <ul style="list-style-type: none"> • Skin protection • Drainable, valve-end pouch • 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.

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 dribbling 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.

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).

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.

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).

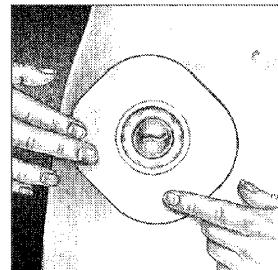


Figure 1

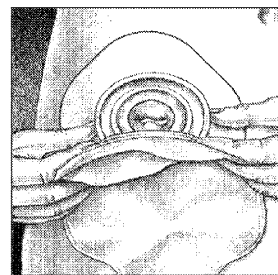


Figure 2

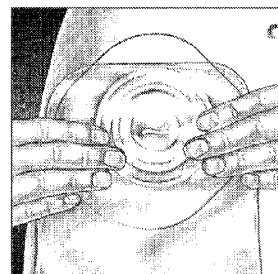


Figure 3



Attention to Detail. Attention to Life.

Guidelines

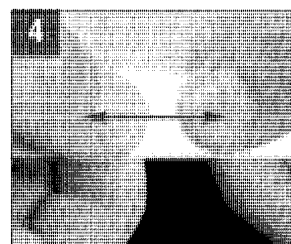
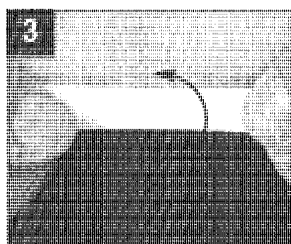
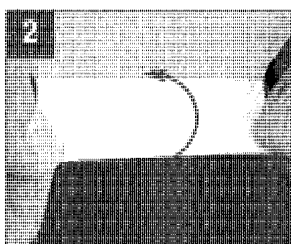
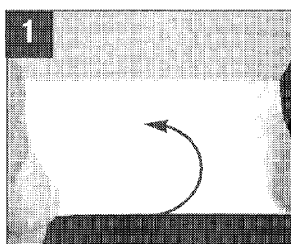
- Empty pouch when 1/3 full of discharge or gas. Do not allow the pouch to overfill.
- If leakage occurs, do not reinforce with tape. Change the pouch and skin barrier.
- Change barrier and pouch every _____ days (as recommended by your healthcare provider).
- If using a **Flexend** extended wear barrier, the use of Skin Gel Wipes or other brands of skin preps are not recommended as they may reduce the wear time of the Flexend 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	_____	_____

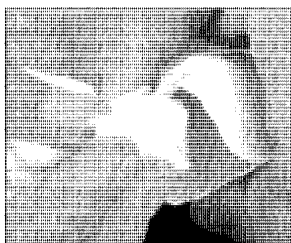
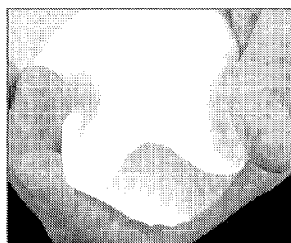
Additional Instructions

Using the Lock 'n Roll Closure



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.



Hollister Incorporated
2000 Hollister Drive
Libertyville, IL 60048 USA
1.800.323.4060

OSTOMATES FOOD REFERENCE CHART

For individuals who have had ostomy surgery, it is important to know the effects of various foods on ileal output. The effects may vary with the remaining portion of functioning bowel.

Listed below are some general guidelines of the effects of foods after ostomy surgery. Use trial and error to determine your individual tolerance. Do not be afraid to try foods that you like, just try small amounts.

Stoma Obstructive

Apple peels
Cabbage, raw
Celery
Chinese vegetables
Corn, whole kernel
Coconuts
Dried fruit
Mushrooms
Oranges
Nuts
Pineapple
Popcorn
Seeds

Gas Producing

Alcoholic bev.
Beans
Soy
Cabbage
Carbonated bev.
Cauliflower
Cucumbers
Dairy products
Chewing gum
Milk
Nuts
Onions
Radishes

Odor Producing

Asparagus
Baked Beans
Broccoli
Cabbage
Cod liver oil
Eggs
Fish
Garlic
Onions
Peanut butter
Some vitamins
Strong cheese

Color Changes

Asparagus
Beets
Food colors
Iron pills
Licorice
Red Jello®
Strawberries
Tomato sauces

Constipation Relief

Coffee, warm/hot
Cooked fruits
Cooked vegetables
Fresh fruits
Fruit juices
Water
Any warm or hot beverage

Increased Stools

Alcoholic bev.
Whole grains
Bran cereals
Cooked cabbage
Fresh fruits
Greens, leafy
Milk
Prunes
Raisins
Raw vegetables
Spices

Odor Control

Buttermilk
Cranberry juice
Orange juice
Parsley
Tomato juice
Yogurt

Diarrhea Control

Applesauce
Bananas
Boiled rice
Peanut butter
Pectin supplement (fiber)
Tapioca
Toast

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 or 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.

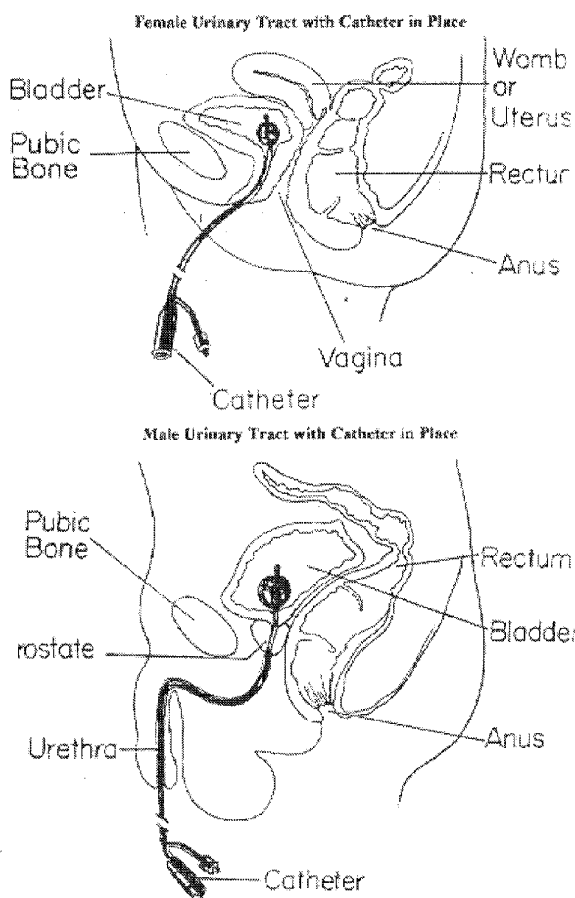
A common type of indwelling catheter is a Foley catheter which is a closed, sterile system inserted into the urethra to allow the bladder to drain. A Foley catheter has a balloon attachment at one end. After the Foley catheter is inserted, the balloon is filled with sterile water. The filled balloon prevents the catheter from leaving the bladder.

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.



- 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 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.



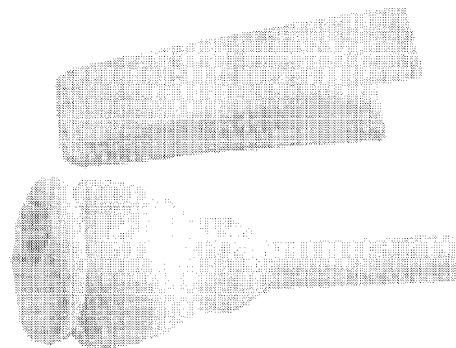
This information is presented to inform IHSS social workers about common paramedical techniques and personal care tasks related to medical conditions. It is not meant to contradict any information the consumer may receive from their personal physician. There are different acceptable ways to perform many 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.**

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=HHLTH; 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.

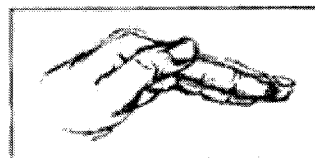
These techniques are used at intervals on people who have conditions that produce a great deal of sputum, such as cystic fibrosis, bronchiectasis, and lung abscess. The techniques may also be used when a person cannot cough up sputum effectively, as may happen with older people, people who have muscle 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.

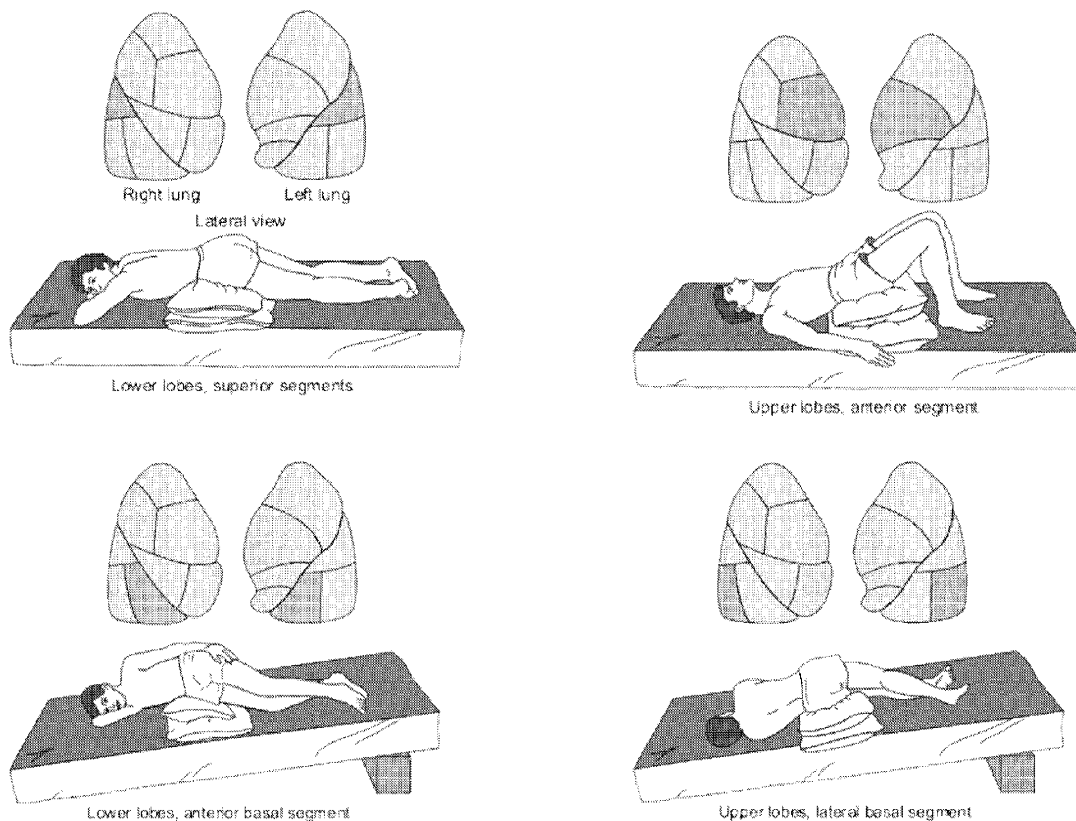


Clap the back or chest with a cupped hand quickly and rhythmically. This loosens the mucus, allowing it to drain. Bend the hand at the wrist and form a cup. During the clapping, there should hear a hollow "popping" sound. If the sound is more of a slapping sound, the hand is not cupped enough. Clapping 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.



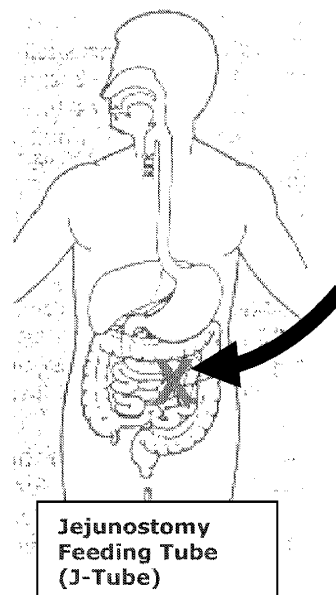
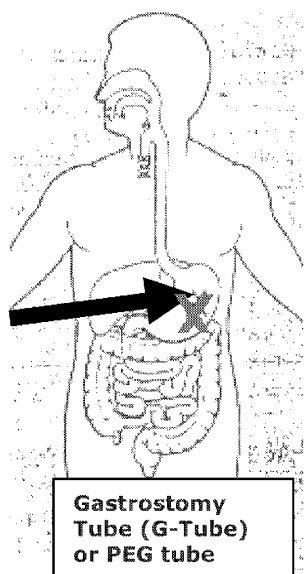
Adapted (08-07) from: <http://www.merck.com/mmhe/sec04/ch040/ch040i.html>; <http://headtoe.apta.org/kbase/as/ug1720/how.htm>; http://www.cystic-l.org/handbook/html/physical_therapy.htm; <http://connection.lww.com/products/smeltzer9e/imagebank.asp>; and Potter and Perry, Basic Nursing: essentials for nursing practice, Mosby 5th edition.

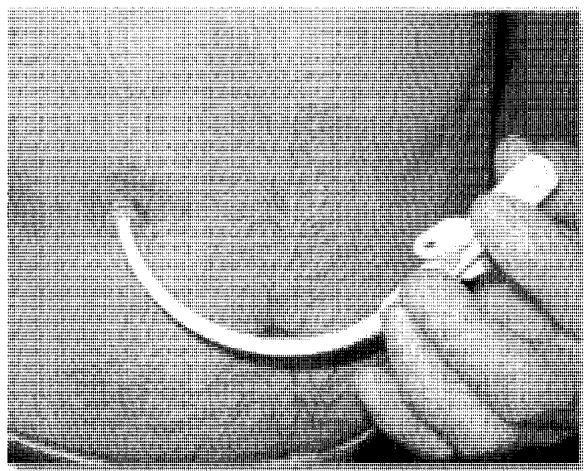
Feeding Tubes

Feeding Tubes placed through the abdominal wall include:

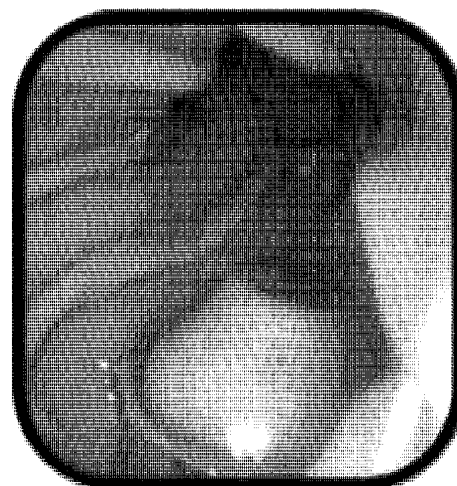
- Gastrostomy Tube (G-Tube)
- Jejunostomy Feeding Tube (J-Tube)

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.





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 through “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 through 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

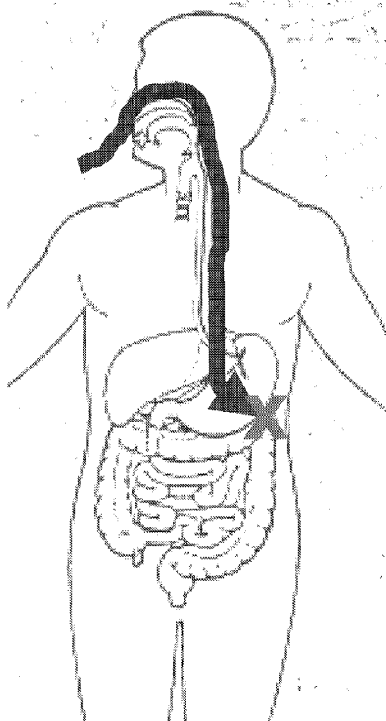
Procedure: Feeding by NG tube is the most common mode of delivering feeding formulas directly to the stomach for patients who need assistance in the **short term**. The insertion of an NG tube involves the passing of a flexible plastic tube, lubricated with a tasteless jelly, up through the nostril, 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:

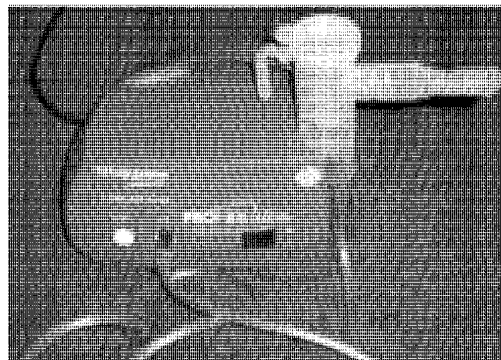
<http://www.ascp.com/publications/tcp/1999/jan/tubes.shtml#fig1>; <http://healthlinks.washington.edu/nutrition/section5.htm>; and Potter and Perry, *Basic Nursing: essentials for nursing practice*, Mosby 5th edition.

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 bronchodilating 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.

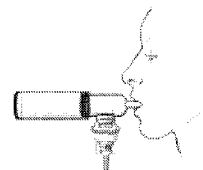
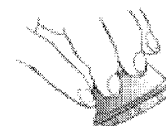
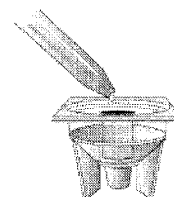
7. Connect the mouthpiece or face mask to the nebulizer cup.

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

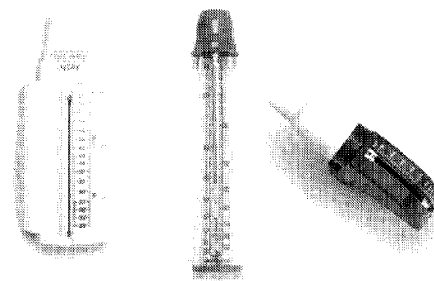
- Cover the compressor with a clean cloth when not in use. Keep it clean by wiping it with a clean, damp cloth as needed.
- Do not put the air compressor on the floor either for treatments or for storage.
- Medications should be stored in a cool, dry place. Check them often. If they have changed color 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



101 Hints to "Help-with-Ease" for Patients with Neuromuscular Disease



A Do-It-Yourself Owner's Guide

101 Hints to "Help-with-Ease" for Patients with Neuromuscular Disease

Irwin M. Siegel, M.D.
Patricia Casey, M.S., OTR/L

Irwin M. Siegel, M.D.
Patricia Casey, M.S., OTR/L

Published as an educational service of the Muscular Dystrophy Association - USA
Research and Program Services Department.
© 1996, 2005 by the Muscular Dystrophy Association
Updated 03/07

PREFACE

This little booklet was written to assist patients with neuromuscular disease in handling their tasks of daily living. All the hints it contains have been field-tested and proven useful. Most were suggested by patients or their families. Only a few have been gleaned from the literature. In this sense, the pamphlet, like the Heloise books, is truly a do-it-yourself owner's manual. Usually, "Help-With-Ease" hints don't require any special tools or equipment. Most of the gadgets described can be easily made with materials at hand in the ordinary household or purchased at a grocery, hardware or fabric store or ordered from readily available self-help catalogs.

We hope these hints will help you and your caregivers tend to your daily tasks of eating, grooming, dressing, sitting, transferring, communicating, getting around, using the toilet, working, recreating, traveling, shopping and sleeping.

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.**

1-19: DRESSING

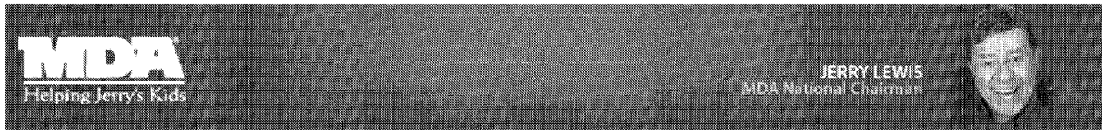
1.	Velcro closures make buttoning and donning shoes easier than using buttons, snaps or shoestrings. Velcro buttons and strips are available at fabric stores. Velcro tabs can be sewn to shoes at a brace shop or shoe repair shop. Ready-made velcro closure tennis shoes are usually found at discount department stores.
2.	Large bib overalls are excellent garb for young people in wheelchairs. They slip off easily to facilitate using the toilet. A front opening is available in some styles for use with male urinals. Elastic-waisted exercise clothing (i.e., sweat pants and running suits) is easier to push down and pull up. A 22-inch zipper can be sewn into the front seam and extended down the leg to allow plenty of room for the use of a urinal.
3.	A double bias tape loop (one attached to a belt loop, the other encircling the wrist) makes it easier to lift and lower a pair of trousers when at least one-hand support is needed to stand after using the toilet.
4.	Ventilation under plastic braces is improved by wearing fishnet panty hose. This practical apparel is especially useful in the summer.
5.	A simple pushing or pulling aid to help bring clothing closer to you from the bed, dresser drawer or closet, without reaching, can be made from a wire coat hanger custom bent at either or both ends. Be careful with a sharp end. Wrap the ends with masking tape or slip a soft pencil eraser on the end to help avoid tearing clothing and to provide a better grip.
6.	A circular key ring can be attached to a zipper tab that has a hole in it, allowing fingers or thumb to easily grasp the tab and close the zipper. Sticky zippers will slide easily if rubbed with the lead from a lead pencil.
7.	Buttoning can be eased by using elastic loops for buttonholes and sewing buttons on with elastic thread. The center of each button (front and back) can be touched with clear nail polish to seal the threads and make the button stay on longer. This works especially well with buttons on cuffs. Buttons can also be fastened to buttonholes for appearance and velcro patches placed on the back for closure.
8.	Although a gentleman's pre-knotted necktie can be adapted with an elastic band, a plastic or metal clip glued or sewn on the back of the knot might be easier to place on a buttoned collar.
9.	Tube socks (socks without heels that stretch to fit the foot) are easy for a child or adult to put on. Socks with a little Orlon in them are also easier to put on for winter wear than socks made of 100 percent wool.
10.	A foot that stiffens downward so much that it's hard to get a shoe on can be more easily slipped into a shoe if the back of the shoe is cut vertically and loosely laced. A tennis shoe can be adapted by sewing a zipper down the side. Any shoe repair shop can modify a pair of shoes in this fashion.
11.	When a child has difficulty telling the right shoe from the left, draw half an animal on each so the two halves make a whole animal when placed side by side.
12.	For the little girl who often puts her dress on backwards, provide a reminder to help her do it right, such as pinning a colorful bow to the front of the dress.
13.	Heavy fishing line pulled through zipper tabs and tied in a loop (the knot can be sealed by melting it with the heat from a lighted match) makes it easier to pull the zipper closed. This idea works especially well on men's or women's slacks. The loop is invisible and also washes well.



14.	A gastrostomy tube can be covered easily with body-size stockinette tubing. This will protect clothing from getting soiled by the tube. A 10- to 12-inch-wide piece is cut and slipped over the head and arms. Ask your clinic orthotist to give you some.
15.	Leaving your leg braces in the shoes provides an instant shoe horn which may help when slipping the shoes and braces onto your feet.
16.	Don't try to trim plastic braces by yourself. Even using a sharp tool to carve the plastic can cause it to weaken.
17.	Always use shoes that have the same heel height as those worn when your leg braces were fitted. If you don't your feet and ankles may be tilted up or down, which will throw you off balance. Also check the sole on tennis shoes. Some brands have soft cushion bubbles on the soles that can make you unsteady. Look for firm, flat soles.
18.	If one side of the body is weaker, it takes less effort to dress this side first. For example, put the weaker arm into the shirt sleeve first, the stronger arm next. Whenever possible, sit while dressing so you can safely rest as needed.
19.	If you have difficulty buttoning a shirt or blouse, get a larger size, keep it buttoned all the time and put it on as if it were a pullover shirt.

20-25: COMMUNICATING

20.	When speaking is a problem, a doodle board can be used. Some types are the Magna Doodle, Etch-A-Sketch and Magic Slate. These handy devices make it unnecessary to carry a pencil and pad. Small electronic models are also available. Look for memory organizers with simple functions that will write out a word, phrase or sentence on the screen. These instruments are relatively legible, portable and inexpensive.
21.	Large felt tip pens are more easily handled than the average ball-point model. Large-diameter ball-point pens are available at office supply stores, at checkout counters in many drug stores, discount stores, etc.
22.	Pieces cut from a common kitchen sink foam sponge or even some rubber bands wrapped around a pencil/pen make it easier to grip. Many small pen/pencil grips are available at office warehouse stores. Inexpensive, too!
23.	A small rubber ball can be punctured so a pencil can be forced through. This makes an excellent grip for a pencil or other writing implement. A small lazy Susan turntable on the desk top for pens, tape, paper clips, etc., makes them easier to reach.
24.	Many children with poor hand control can learn to write well on a typewriter or computer keyboard. The youngster who is clever with numbers can do many accounting tasks on a small calculator.
25.	When hands are too weak to turn the pages of a book but neck strength and control remain, an excellent head-centered turner can be fashioned by attaching a pencil-thin wooden dowel, approximately 18 inches long, to the center of the brim of a tightly fitting cap or sunshade. A soft pencil eraser slipped over the end of the dowel can provide friction for turning the page. Mouthsticks and commercial pointers are also available if this doesn't work.



26-36: SITTING, TRANSFERRING AND MOBILITY

26.	An effective transfer board can be fashioned from a length of hardwood which is sanded, waxed and highly polished. Both ends should be beveled. This is a project for someone at your house who likes to work with wood.
27.	Transfers and gait can be assisted by using a wide, securely buckled belt around the patient's waist, which is then grasped to support him/her during transfer or steady him/her while walking. However, special gait belts are often inexpensive, usually under \$10 at a medical supply store.
28.	A king-size satin pillow case is an excellent aid to use as a drawsheet for transfer or turning in bed.
29.	Because of its height, a bar stool is a good seat for the patient with weak hip and/or knee extensors. Look for one with a wide leg base. You might also want one with a back and armrests. When rising from a chair with arm covers, the covers can be kept from slipping by laying a sheet of art foam (available at art supply stores) between the cover and the arm rest of the chair. A terry cloth washcloth will also work.
30.	Leverage can be increased when moving in bed by using arm elevators constructed with lightweight, wide-based wooded blocks to which dowel handles have been fixed.
31.	Football receiver gloves afford a better grip on the handrail when climbing or descending stairs. Baseball or biking gloves are not quite as good.
32.	When traveling, an airline wheelchair can be rented for negotiating narrow doors and passageways.
33.	Radio waves can cause unintended motion of power wheelchairs or scooters. Take caution using CB radios or cellular phones when your wheelchair power is on. Also be aware of the location of radio transmitters such as radio or TV stations and two-way radios. Try to avoid driving near them.
34.	A heavy rope, knotted at 12-inch intervals and slung from a secure tree branch, can be used for support to help a child with weak legs practice walking outside in the back yard.
35.	Low-cut pile carpeting without padding is safer to walk on than heavy shag or throw rugs and makes wheelchair mobility at home easier to manage.
36.	A lightweight bicycle helmet is comfortable for head protection with children prone to falling. A homemade head protector made of cloth strips filled with closed-cell foam padding sewn to circle and cross the top of the head is also effective.

37-50: RECREATING

37.	Many libraries will deliver or mail books to your home. Check with your local library for information.
38.	Gardening can be aided by using a length of plastic tubing as a conduit to plant seeds when seated in a wheelchair.
39.	The dimples on a rubber thimble provide friction to help turn the pages of a book or magazine.

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.**



40.	For fishermen who have difficulty retrieving a line, several devices are available, including a vest with a lightweight harness which holds the fishing rod in an aluminum tube with a locking feature. Also obtainable is an electronic fishing reel featuring a four-speed control with two manual and two electronic settings.
41.	A spring-loaded billiard cue is available for billiards or pool players who lack strength enough to handle the standard cue.
42.	If you want to play a stringed instrument (guitar, banjo, ukulele, etc.) but have weak hands and wrists, a soft glove can be modified by gluing individual plastic picks onto the fingers, adding a Velcro strap (for quick sizing) at the wrist and opening the thumb area for easy removal. The glove facilitates plucking and strumming stringed instruments by moving the fingers in a clawing manner, either separately or together.
43.	For those who sew, a small magnet glued to the end of a yardstick makes an effective "retriever" for dropped pins and needles.
44.	The Department of Transportation, Office of Consumer Affairs, 400 7th Street, SW, Washington, DC, 20590 (202/366-2220) distributes an excellent booklet, "New Horizons for the Air Traveler with a Disability," which details one's rights as a disabled person. It is free on request.
45.	"Paddle-minton" is badminton-like game using a short paddle which is easy to handle from a wheelchair. The game's birdie is modified so as not to fly fast or high. The birdie's speed can be adjusted by tying the feathers together for faster play or spreading them apart to slow its flight.
46.	The "Quad-Bee" frisbee has two adaptive thumb clips allowing someone with upper extremity weakness to hold and throw the device.
47.	Hand control in children can be developed with games utilizing rings placed around pegs. Pegs can be made from an old broomstick or other small dowels nailed or glued to a flat board. Rings can be fabricated from the plastic holders found on soda pop or beer cans or cardboard rings can be cut from a cylindrical oatmeal box or a paper towel tube.
48.	Wheelchair archery is made easier for persons with weak arms by using a straight arm splint on the arm that holds the bow and a hook fashioned to the other hand to pull the bowstring. Archery may help correct spinal curvature. The arm pulling the string should be on the side that has the more prominent curve of the spine.
49.	A secure seat for a small child's use on a seesaw can be fashioned from half of a plastic bucket or a section of an automobile tire. Tape the edges with duct tape for safety.
50.	A thick board can be slotted to hold a hand of playing cards for those whose grasp is weak. Ask your handy woodworking friend to make this simple but useful gadget for you.

51-52: HOUSEKEEPING

51.	When bending is a problem in cleaning lower cabinets or appliances, they can be reached with a good spray cleaner. An O'Cedar Light N' Thirsty mop can be used to wipe the surface clean, after allowing the spray to set a few minutes.
52.	When fingers are too weak to grasp a broom or mop handle firmly, a leather or cloth loop can be placed over the handle and pulled with the forearm.



53-61: SLEEPING OR RESTING

53.	Friction is decreased for changing sleep position by using satin or nylon sheets and/or pajamas. But, be careful when sitting on the side of the bed as you will slip quite easily when trying to transfer to your wheelchair or commode.
54.	A heavy belt or strap tied to the bedposts or a bed frame is a simple way to gain leverage to turn yourself from side to side.
55.	For the couple who want a double bed where only one requires a hospital bed, an extra long (80") twin bed can be attached side by side to an electric hospital bed. Order an electric hospital bed that has no headboard (80"), then a king-size headboard can be attached to both beds.
56.	Washable synthetic sheepskin padding or commercial eggcrate foam can be placed under a fitted sheet for more comfort when lying down. Any of a variety of inflatable camping mattresses serve the same purpose.
57.	A U-shaped travel neck pillow can be used to support the neck while lying flat or reclining in bed or in a lounge chair.
58.	Fiberfill or down comforters are lighter and warmer than wool or acrylic blankets. It's easier to move underneath or to lift them.
59.	Covers tented over a straight-back chair at the end of the bed will free your feet and legs while keeping you warm. Using bed corner garters to secure the blanket edges to the mattress is an inexpensive way of keeping them securely tucked. They can be found in the bedding department of discount stores.
60.	To easily identify and retrieve a house key from a ring of keys, drill a second hole near the edge of the key so it will hang off center on the key ring or use a plastic key end cover, available at your hardware store.
61.	Long body pillows can be used to prop the back for side lying, preventing you from rolling backward. They can also be placed between your knees to decrease pressure and propped to reduce hip contracture.

62-68: GROOMING

62.	An empty half-gallon plastic cylindrical container makes a handy floating support for the head and neck to allow shampooing while the bather is reclined in a tub. Avoid overly hot water when bathing, since it causes fatigue.
63.	For a "dry shampoo," sprinkle cornstarch or baby powder lightly on oily hair and brush it out. Pull a nylon stocking over the brush bristles and brush vigorously to remove more dirt and restore the sheen to your hair.
64.	Cylindrical foam can be purchased in yard lengths and attached or wrapped for extending or enlarging the handle of a razor, comb, toothbrush or other grooming tool. One end of a flat wooden coat hanger can be drilled to accept a pick-type comb. This device provides a light and easily handled comb extension.
65.	Liquid soap containers are convenient to use when attached to the bathroom or shower wall. You don't have to handle a slippery bar of soap or bottle of shampoo or hair conditioner. Make a slit and pocket in a thick sponge to hold a flat bar of soap. When you wash just squeeze the sponge to get the suds.

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.**



66.	A toothbrush can be adapted for use by weak hands/wrists by cutting the middle rows of bristles down to half their height. With this modification the front and back of the teeth are brushed by the high front and back bristles while the tops are cleaned by the shortened middle bristles. Such a toothbrush can also be purchased through an appliance catalog, as can an electric-powered model suitable for those lacking the strength or agility to brush their teeth. Look for one with a rotary brush. It's easier to hold in front of your mouth.
67.	A washcloth mitten is easier for some folks to use than a regular washcloth for washing oneself or the dishes.
68.	A nail clipper and file combination can be mounted on a sturdy board, eliminating the need for thumb or pinch strength when using these implements.

69-73: TOILETING

69.	Use baby wipes instead of toilet tissue. They are easier to hold and you feel (and are) cleaner when you finish using them.
70.	Serenity Security Pads worn at night can decrease the number of times you have to use the bathroom. They can also be worn on long car trips.
71.	A piece of semi-flexible plastic (like that used to make small pocket rulers) can be employed to fold toilet tissue for use. The tissue is wrapped around two-thirds of the length of the plastic (no sharp edges please), and the remainder used as an extension handle. Another way to provide an extension for cleaning yourself with toilet paper is to wrap the tissue around the working end of a pair of ordinary kitchen tongs.
72.	Easy access to and egress from a bathroom can be provided by removing the door (and even part of the door-frame) and hanging an opaque shower curtain instead. This ends the difficulty of opening and closing the door without sacrificing privacy. Offset hinges can also be used to widen the doorway without removing the door.
73.	A Texas condom catheter for men or boys who can't control their urine or are in situations where it's inconvenient to use the toilet can be prescribed by your physician. It's attached with double-sided adhesive tape to avoid leaking and fastened to a leg bag for urine collection. The long connection hose (for the leg bag) can be clamped at the end and placed over a urinal or toilet edge, thus eliminating the need for a leg bag. The condom can be reused if carefully washed in plain soap and water.

74-90: EATING

74.	A moistened paper towel placed under your plate will keep it from slipping on a formica tabletop.
75.	The diameter of eating utensil handles can be increased with cylindrical foam (available as pipe insulation at the hardware store).
76.	Wide-handled plastic mugs are easier to lift when all four fingers can be placed inside the handle. This way a firm grasp isn't needed to hold and tip the cup toward the mouth. An inexpensive sip-a-mug can be purchased at most drugstores or supermarkets. This is a light plastic mug with a contoured handle which also serves as a straw.
77.	Lightweight plastic bowls are easier to handle than glass or ceramic dishes. A rubber mesh mat will keep them from slipping on the counter or in the lap.

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.**



78.	A sport-type plastic drink container often has a hole containing a straw in its cover which eases/allows access to its contents.
79.	Annoying phlegm can be decreased by limiting the ingestion of dairy foods, but be sure to get your daily calcium quotient in other ways. Citrus juice can "cut" thick saliva.
80.	Suck ice chips before eating if you have difficulty swallowing. It helps desensitize the gag reflex.
81.	Chewing licorice just before eating decreases the appetite because it dulls taste buds. Be careful not to overdo this. Too much licorice can decrease your serum potassium level.
82.	Where swallowing is difficult, a package of frozen peas placed on the front of the neck may prove of assistance by relaxing muscle spasm.
83.	When food gathers in the back of the mouth, tip the chin downward, not upward, to improve ingestion.
84.	A little Oscar's meat tenderizer (MSG) on the back of the tongue will help to break up thick saliva and aid swallowing.
85.	A damp dish towel wrapped around the base of a bowl will keep it from slipping on a smooth counter.
86.	A simple portable aid to help get the hand to the mouth can be made with any forearm support such as a flat length of wood or even split bamboo (with several slips of velcro tacked on to secure the arm) and attached in the middle on both sides with a pin to two large dowels which are fixed to a heavy wooden base. This forearm prop can be placed on a table where it acts like a seesaw, lifting the hand to the mouth when the elbow is dropped.
87.	A disposable plastic cup with a space cut out along the rim to fit about a child's nose will allow the youngster to drink in a better, more controlled position with his chin forward, rather than having to bend his head back.
88.	A child having trouble controlling a cup with one hand can often do better if it's fitted with two handles. This adapted cup is listed at low cost in ADL catalogs or you can ask a local potter to make one for you if a ceramic mug will not be too heavy to lift.
89.	An "octopus" soap holder which has multiple suction supports makes an effective plate, glass or cup stabilizer. This gadget can be purchased in most grocery stores.
90.	An extra-long plastic straw can be used to eliminate the need to lift a glass when drinking.

91-101: EXERCISING AND MANAGING CONTRACTURES

91.	Tight heel cords can be treated while a young child rides a rocking horse by fitting the horse with stirrups so that the feet will be stretched up to a more normal position as he/she rocks.
92.	Contractures can be measured by folding a piece of paper to match the angle of the joint, tracing the folded edge onto a second sheet and measuring it with a protractor. By keeping a record of the degree of contracture, the caregiver can see progress and is more likely to keep working hard at stretching exercises to correct the contractures.

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.**



93.	Balancing exercises are important because loss of balance can result in a fall with possible injury. Holding on to someone while standing on each foot alone is a simple way to improve balance.
94.	A foot board (one-half- to three-quarter-inch plywood padded with a blanket will do) for support at the foot of the bed to keep the feet propped at the ankles during sleep, helps prevent ankle contractures. Of course, this means you must be able to sleep on your back with both feet against the board. You could, however, be side-lying with at least one foot against the board for some effect.
95.	If your heels feel sore while you're lying on your back, place a small pillow under your calves to relieve heel pressure. This same technique can be used during the day when you prop up your feet to reduce swelling. Tender heels can be toughened by patting them with a moist teabag at night. When the tea dries, the tannic acid it contains will act to harden (and slightly discolor) the skin. Passive stretching of the knee can be accomplished by placing the calves on a pillow supported by a hassock or kitchen chair. In this way, your heels aren't resting on the supporting surface and there is no heel pressure that might reduce local vascular circulation.
96.	Hand exercises can be fun. Try learning sign language and playing "shadow puppets." Or squeeze the poles of a toy that makes an articulated animal go loop-de-loop. Fingers are exercised comfortably by squeezing a washcloth or sponge in a basin of warm water.
97.	Exercising with your child can be made entertaining by strapping a small bell or flag to the arm or leg so that it will ring or flap when the child moves.
98.	The easiest way to stretch heel cord contractures is to stand at arm's length from a wall and place your hands on the wall. Lean toward the wall, bending your elbows, while keeping the heels flat on the floor and the knees straight, and attempt to touch the wall with your chest. If this is too hard you can start with your feet closer to the wall, or bend one knee at a time.
99.	When a child is seated, his feet should always be supported. A box or large book will do. Dangling feet are more prone to develop contractures.
100.	Simple breathing exercises can be performed by blowing through a straw, blowing up balloons or blowing a ping pony ball on a tabletop or other flat surface. Playing a harmonica, kazoo or other wind instrument is a pleasant way to exercise the lungs.
101.	Excessive heat will increase symptoms in those with myasthenia gravis. Swimming in a cool pool is the best exercise for these patients. Cool foods and drink are also easier to swallow. Emotional stress, even positive stress, increases weakness in this disease and should be avoided. That's right, you can have too much fun!

Dr. Irwin M. Siegel co-directs several Chicago-area MDA clinics. He is the author of The Clinical Management of Muscle Disease, Muscle and Its Diseases, and The Clinical I, a collection of vignettes and essays.

Patricia Casey is an occupational therapist serving four Chicago clinics. She is also active in local ALS clinical programs and drug studies. Ms. Casey has published numerous scientific articles on the role of occupational therapy in the management of neuromuscular diseases.

Used by permission of the Muscular Dystrophy Association of the United States.

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.**

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	Ballooning 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		
c	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 insipidus	Lack of antidiuretic 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		
O₂ 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		
s	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 organs 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.

RESOURCE LIST

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>

American Academy of Allergy, Asthma, and Immunology

555 East Wells Street, Suite 1100

Milwaukee, WI 53202-3823

(800) 822-2762

<http://www.aaaai.org>

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>

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 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

American Academy of Orthopaedic Surgeons

P.O. Box 1998
Des Plaines, IL 60017-1998
(800) 824-BONE (2663)
www.aaos.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

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

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.jdrf.org

American Behçet's Disease Association

P.O. Box 19952
Amarillo, TX 79114
(800) 7-BEH CET (723-4238)
www.behcets.com

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
nadffmail@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 of 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.nlm.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) <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.nlm.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 *NIH Senior Health* (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

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

National Fibromyalgia Partnership

P.O. Box 160
Linden, VA 22642-0160
(866) 725-4404
Fax: (866) 666-2727
mail@fmpartnership.org
www.fmpartnership.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

lifoptions@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

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

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

Kidney Friendly Comfort Foods

Shire US Inc.
Wayne, PA 19087
(866) 896-6152
www.fosrenol.com/Consumers/Resources/CookBooks.aspx

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

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) 459-5900 or (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 NIH Senior Health 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 Plaines, 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 *NIH Senior Health* (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

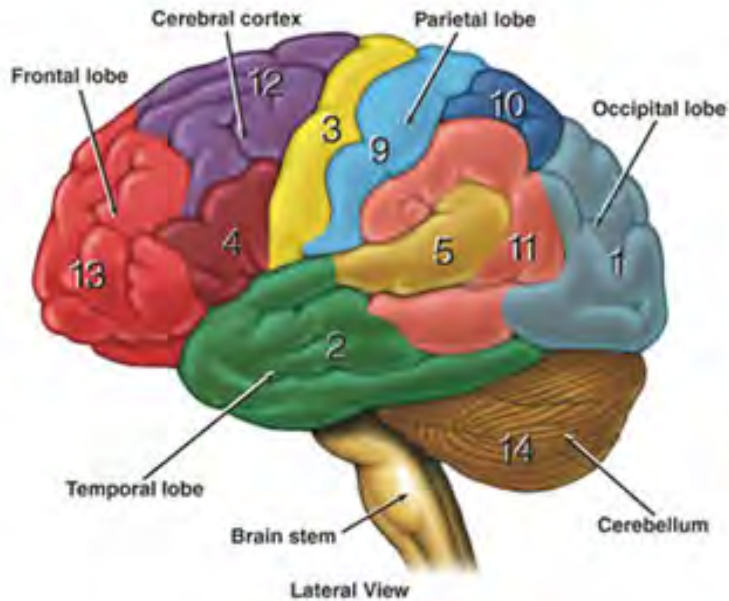
Anatomy and Functional Areas of the Brain

Functional Areas of the Cerebral Cortex

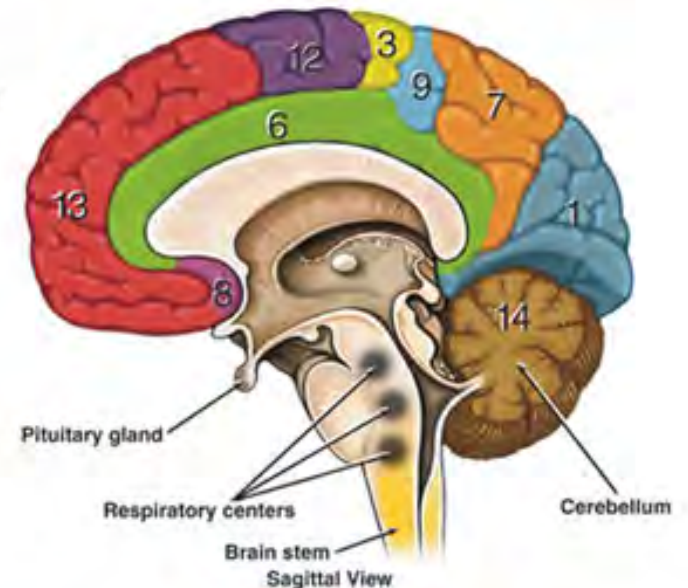
- 1 Visual Area:**
Sight
Image recognition
Image perception
- 2 Association Area:**
Short-term memory
Equilibrium
Emotion
- 3 Motor Function Area:**
Initiation of voluntary muscles
- 4 Broca's Area:**
Muscles of speech
- 5 Auditory Area:**
Hearing
- 6 Emotional Area:**
Pain
Hunger
"Fight or flight" response
- 7 Sensory Association Area:**
- 8 Olfactory Area:**
Smelling
- 9 Sensory Area:**
Sensation from muscles and skin
- 10 Somatosensory Association Area:**
Evaluation of weight, texture,
temperature, etc. for object recognition
- 11 Wernicke's Area:**
Written and spoken language comprehension
- 12 Motor Function Area:**
Eye movement and orientation
- 13 Higher Mental Functions:**
Concentration
Planning
Judgment
Emotional expression
Creativity
Inhibition

Functional Areas of the Cerebellum

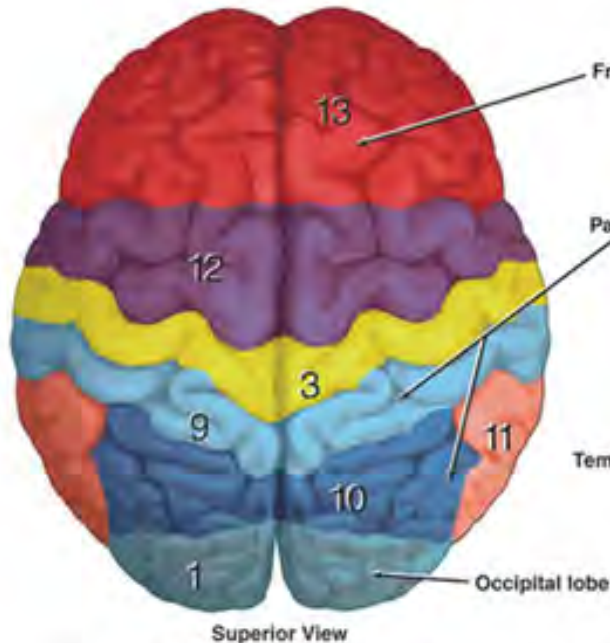
- 14 Motor Functions:**
Coordination of movement
Balance and equilibrium
Posture



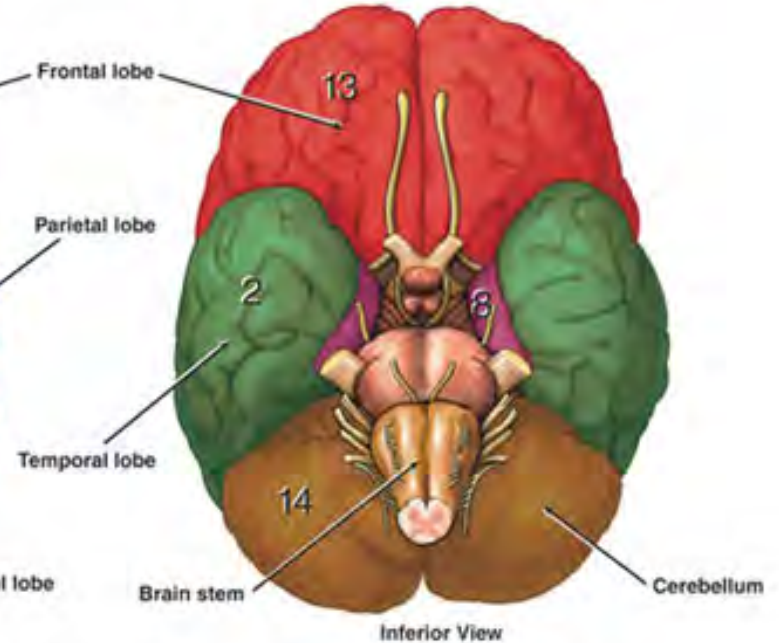
Lateral View



Sagittal View



Superior View



Inferior View

IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
Alzheimer's	Alzheimer's is the most common form of dementia among older people, which initially involves the parts of the brain that control thought, memory, and language.	<ul style="list-style-type: none"> • People with Alzheimer's live an average of eight years after diagnosis, although some people may live for as many as 20 years after being diagnosed. • To help people understand the changes that occur as the disease progresses, Alzheimer's is broken into stages: early, middle and late. • At the later stages, the person has lost most of their ability to function normally. • The development of symptoms will differ from person to person, and that each stage will gradually progress over a period of years. 	<ul style="list-style-type: none"> • It is also usual for people with Alzheimer's to have "good days" and "bad days." For example, a person with early-stage Alzheimer's may not show any symptoms one day; the next day he or she may have trouble remembering his/her name or finding the milk in the refrigerator. • A person with Alzheimer's may engage in behaviors that put themselves at risk in the middle stage, but is unlikely to function well enough in the late stages to engage in such behaviors. • In the middle stage, it may take an extraordinarily long time to perform such tasks as bathing and shampooing a person with Alzheimer's because of their fear of water. • The person may be unable to select clothing and/or to dress self; may be resistant to change clothing.
Asthma	Asthma is a chronic disease of the respiratory system in which the airway occasionally constricts, becomes inflamed, and is lined with excessive amounts of mucus, often in response to one or more triggers.	<ul style="list-style-type: none"> • Inflammation makes the airways very sensitive, and they tend to react strongly to things that the patient is allergic to or find irritating. • When the airways react, they get narrower, and less air flows through to the lung tissue. • This causes symptoms like wheezing (a whistling sound when you breathe), coughing, chest tightness, and trouble breathing, especially at night and in the early morning. • Triggers include allergens such as animal dander, molds, dust and pollen, and irritants such as smoke, perfumes and cold air. Other triggers can be medications, foods, or chemicals. • Asthma cannot be cured, but most people with asthma can control it so that they have few and infrequent symptoms and can live active lives. 	<ul style="list-style-type: none"> • If the disease is under control, most people will have few limitations. • During attacks, the patient may have difficulties with exertion and exercise. • Heavy cleaning may be appropriate to dustproof the bedroom. • It may be appropriate to make an exception to the Domestic Time per Task standard in order to keep the home dustproof and free from dust mites. • Having asthma alone may not be a basis for needing Domestic services; the consumer could wear a dust mask and perform needed laundry and house cleaning.

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.

IHSS TRAINING ACADEMY

ELECTIVE: MEDICAL IMPLICATIONS

QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
<p>Cerebral Palsy (CP)</p>	<p>CP is an umbrella term encompassing a group of non-progressive, non-contagious neurological disorders that cause physical disability in human development, specifically the human movement and posture.</p>	<p>It is caused by abnormalities inside the brain that disrupt the brain's ability to control movement and posture. In some cases of cerebral palsy, the cerebral motor cortex has not developed normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage is not repairable and the disabilities that result are permanent.</p> <p>Patients with cerebral palsy exhibit a wide variety of symptoms, including:</p> <ul style="list-style-type: none"> • lack of muscle coordination when performing voluntary movements (ataxia); • stiff or tight muscles and exaggerated reflexes (spasticity); • walking with one foot or leg dragging; • walking on the toes, a crouched gait, or a "scissored" gait; • variations in muscle tone, either too stiff or too floppy; • excessive drooling or difficulties swallowing or speaking; • shaking (tremor) or random involuntary movements; and • difficulty with precise motions, such as writing or buttoning a shirt. <p>Some people with cerebral palsy also have other medical disorders, including mental retardation, seizures, impaired vision or hearing, and abnormal physical sensations or perceptions.</p> <p>Sixty-five (65%) to ninety (90%) of children with cerebral palsy live into their adult years.</p>	<ul style="list-style-type: none"> • Functional abilities can be severe and wide ranged. • The symptoms of cerebral palsy differ in type and severity from one person to the next, and may even change in an individual over time so careful reassessment of function is important. • Consider whether the consumer has spasticity that justifies extra time for Domestic and/or Laundry (due to excessive spilling during meals). • If the consumer has difficulty swallowing, extra feeding time is probably justified. • Consumers with CP are likely to be depressed.

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.**

**IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET**

Disease / Condition	Definition	Characteristics	Functional Considerations
<p>Chronic Obstructive Pulmonary Disease (COPD)</p>	<p>COPD is a lung disease in which the lungs are damaged, making it hard to breathe. In COPD, the airways—the tubes that carry air in and out of your lungs—are partly obstructed, making it difficult to get air in and out. In the U.S., COPD includes emphysema and chronic bronchitis.</p>	<p>Cigarette smoking is the most common cause of COPD. Most people with COPD are smokers or former smokers. Breathing in other kinds of lung irritants, like pollution, dust, or chemicals, over a long period of time may also cause or contribute to COPD.</p> <p>The signs and symptoms of COPD include:</p> <ul style="list-style-type: none"> • cough • sputum (mucus) production • shortness of breath, especially with exercise • wheezing (a whistling or squeaky sound when you breathe) • chest tightness <p>Extreme weakness and loss of exercise tolerance is an outcome of COPD.</p>	<ul style="list-style-type: none"> • Because symptoms usually don't appear until the later stages of COPD, most diagnosed patients will have functional limitations. • Functional limitations are most often related to exercise intolerance and shortness of breath. • Spacing activities and conserving energy are helpful in maximizing functional abilities. • The consumer will probably need to avoid exertion. For some consumers, even getting dressed may be too exerting. • If the consumer uses oxygen continuously, s/he may be able to reheat meals prepared in advance in a microwave. • The condition will become worse over time.
<p>Cirrhosis</p>	<p>Cirrhosis is a consequence of chronic liver disease characterized by replacement of liver tissue by fibrotic scar tissue, leading to progressive loss of liver function. It is most commonly caused by alcoholism and hepatitis C, but has many other possible causes.</p>	<p>Many people with cirrhosis have no symptoms in the early stages of the disease. However, as scar tissue replaces healthy cells, liver function starts to fail and a person may experience the following symptoms:</p> <ul style="list-style-type: none"> • exhaustion • fatigue • loss of appetite • nausea • weakness • weight loss • abdominal pain • spider-like blood vessels (spider angiomas) that develop on the skin <p>Complications of cirrhosis are serious and caused by the buildup of toxins in the system and backup of blood flow through the vessels leading to the liver.</p>	<ul style="list-style-type: none"> • People who have cirrhosis can have very low energy affecting all ADLs and IADLs. • Consumers who are experiencing low energy and fatigue may need a significant amount of IHSS services. • Consider need for referral for family issues related to condition, especially if still drinking. • If the consumer states they are having sticky, black stools, it could be an indication of bleeding. They should be strongly encouraged to see their MD immediately.

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.

**IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET**

Disease / Condition	Definition	Characteristics	Functional Considerations
Congestive Heart Failure (CHF)	CHF is a condition in which the heart cannot pump enough blood throughout the body. The heart cannot fill with enough blood or pump with enough force, or both.	<p>Heart failure develops over time as the pumping action of the heart gets weaker. It can affect the right, the left, or both sides of the heart. Heart failure does not mean that the heart has stopped working or is about to stop working. It means that the heart is not able to pump blood the way that it should.</p> <p>The weakening of the heart's pumping ability causes:</p> <ul style="list-style-type: none"> • Blood and fluid to "back up" into the lungs • The buildup of fluid in the feet, ankles, and legs • Tiredness and shortness of breath 	<ul style="list-style-type: none"> • ADLs and IADLs can be greatly affected as the disease progresses. • Shortness of breath, fatigue, and edema can create low endurance. • Fatigue, weakness and shortness of breath may be the primary causes of dependency for IHSS services. • It is a progressive disease, so impairment is likely to worsen over time.
Coronary Artery Bypass Grafting (CABG)	CABG surgery creates new routes around narrowed and blocked arteries, allowing sufficient blood flow to deliver oxygen and nutrients to the heart muscle.	<p>Arteries or veins from elsewhere in the patient's body are grafted from the aorta to the coronary arteries to bypass atherosclerotic narrowings and improve the blood supply to the coronary circulation supplying the myocardium (heart muscle).</p> <p>The goals of having CABG are to:</p> <ul style="list-style-type: none"> • Improve quality of life and decrease angina and other symptoms of CAD, • Resume a more active lifestyle . • Improve the pumping action of the heart if it has been damaged by a heart attack, • Lower the chances of a heart attack (in some patients, such as those with diabetes), and • Improve chances of survival. <p>Full recovery from traditional CABG may take 6 to 12 weeks or more. Less recovery time is needed for nontraditional CABG.</p>	<ul style="list-style-type: none"> • Post operatively limitations will be extensive. • Recovery should take 6-12 weeks, though is dependent upon pre-surgery conditions and complications. • Cognitive issues are common after heart-lung bypass, but should subside after several months. • A person who has had CABG may require an increase in services following surgery, but is likely to become more functional following full recovery from surgery. Therefore, it may be appropriate to authorize time-limited services.

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.

IHSS TRAINING ACADEMY

ELECTIVE: MEDICAL IMPLICATIONS

QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
<p>Diabetes</p>	<p>Diabetes is a metabolic disorder characterized by hyperglycemia (high blood sugar) and other signs.</p>	<ul style="list-style-type: none"> • Decrease or absence of insulin production in the body. • Type 1 – must take insulin shots • Type 2 – may be controlled with diet, oral medications or insulin shots <ul style="list-style-type: none"> ○ Heart disease ○ Stroke ○ Kidney disease ○ Neuropathies ○ Retinopathies ○ Gastroparesis ○ Urologic • Healthy diet and exercise are important to control the disease and prevention of complications. 	<ul style="list-style-type: none"> • For most patients newly diagnosed, primary functional issues will be medication management, diet management and exercise. • Other limitations will relate to system failures. • Meal prep issues – Diabetic diet is healthy eating; unlikely to require extra prep time. <ul style="list-style-type: none"> ○ Good questions to ask may include: What is the diet? Does the consumer eat snacks? If a consumer cannot prepare meals (is a Rank 4 or 5), does s/he have a provider every day? If not, consider a referral to the Public Authority or other resource – perhaps Meals on Wheels can augment meal prep to meet the need. Restaurant Meals Allowance may also be an alternative. • Bathing, oral hygiene and grooming – <ul style="list-style-type: none"> ○ Drying skin, especially between the toes, and application of lotion to the feet, but not between the toes, is important. • If the consumer has open, non-healing sores, a doctor may want to order Paramedical care. • Urination – The consumer may have frequent urination requiring an increase in Bowel and Bladder care. If the consumer cannot get to the toilet/urinal/commode fast enough, there may be the need to make an exception to Domestic and Laundry. • Exercise is important for controlling blood sugar levels. • Common Paramedical services – <ul style="list-style-type: none"> ○ Glucometer blood testing and charting. ○ Insulin injection. ○ Filling syringes for consumer to inject. • Consumers who are experiencing complications may require frequent visits to primary physicians and/or specialists.

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.

IHSS TRAINING ACADEMY

ELECTIVE: MEDICAL IMPLICATIONS

QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
Fibromyalgia	Fibromyalgia is a chronic syndrome (constellation of signs and symptoms) characterized by diffuse or specific muscle, joint, or bone pain, fatigue, and a wide range of other symptoms.	<p>The defining symptoms of Fibromyalgia are chronic, widespread pain and tenderness to light touch, and usually moderate to severe fatigue.</p> <p>In addition to pain and fatigue, people who have Fibromyalgia may experience:</p> <ul style="list-style-type: none"> ○ sleep disturbances, ○ morning stiffness, ○ headaches, ○ irritable bowel syndrome, ○ painful menstrual periods, ○ numbness or tingling of the extremities, ○ restless legs syndrome, ○ temperature sensitivity, ○ cognitive and memory problems (sometimes referred to as "fibro fog"), or ○ a variety of other symptoms. <p>Fibromyalgia is often referred to as an "invisible" illness or disability due to the fact that generally there are no outward indications of the illness or its resulting disabilities.</p>	<ul style="list-style-type: none"> ● Fibromyalgia can affect every aspect of a person's life due to pervasive and persistent chronic pain. ● Expect that the consumer may have cycles of good days and bad days. ● Individuals suffering from invisible illnesses in general often face disbelief or accusations of malingering or laziness from others that are unfamiliar with the syndrome and therefore may be defensive during the assessment. ● Fibromyalgia is a chronic condition, but is not progressive.
Kidney Failure	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.	<p>Causes of kidney failure include:</p> <ul style="list-style-type: none"> ○ Diabetic Nephropathy ○ High Blood Pressure ○ Glomerular Diseases ○ Inherited and Congenital Kidney Diseases ○ Poisons and trauma ○ Over-the-counter medicines <ul style="list-style-type: none"> ● 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. 	<ul style="list-style-type: none"> ● 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.**

**IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET**

Disease / Condition	Definition	Characteristics	Functional Considerations
Lupus	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.	<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ Joints ○ Skin ○ Kidneys ○ Heart ○ Lungs ○ Blood vessels ○ Brain 	<ul style="list-style-type: none"> • 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).
Multiple Sclerosis (MS)	MS is a chronic, inflammatory, demyelinating disease that affects the central nervous system.	<p>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.</p> <p>MS will cause impaired mobility and disability in more severe cases.</p> <p>Clinically categorized as:</p> <ul style="list-style-type: none"> • Relapsing-remitting (RR) • Chronic progressive MS <ul style="list-style-type: none"> ○ Primary-progressive (PP) ○ Secondary-progressive (SP) ○ Progressive-relapsing (PR) • Benign • Malignant 	<ul style="list-style-type: none"> • 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.

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.

IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
Osteoarthritis	Osteoarthritis is the most common type of arthritis, and is seen especially among older people. Sometimes it is called degenerative joint disease or osteoarthritis. People with osteoarthritis often have joint pain and reduced motion.	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.	<ul style="list-style-type: none"> • 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.
Osteoporosis	Osteoporosis is a disease marked by reduced bone strength leading to an increased risk of fractures or broken bones.	<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> ○ 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. 	<ul style="list-style-type: none"> • 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.

IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
<p>Parkinson's Disease (PD)</p>	<p>PD is a degenerative disorder of the central nervous system that often impairs the sufferer's motor skills and speech.</p>	<ul style="list-style-type: none"> • The four primary symptoms of PD are: <ul style="list-style-type: none"> ○ 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: <ul style="list-style-type: none"> ○ 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. 	<ul style="list-style-type: none"> • 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.

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.

IHSS TRAINING ACADEMY

ELECTIVE: MEDICAL IMPLICATIONS

QUICK FACTS SHEET

Disease / Condition	Definition	Characteristics	Functional Considerations
<p>Peripheral Arterial Disease (PAD)</p>	<p>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.</p>	<ul style="list-style-type: none"> ● 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 (CLL) – in the advanced stages of PAD, blood flow to one or both legs can be completely or mostly blocked. CLL 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. <p>Major risk factors for developing PAD include:</p> <ul style="list-style-type: none"> ● Smoking. Smoking is more closely related to developing PAD than any other risk factor. ● Diabetes. ● Other diseases and conditions such as: <ul style="list-style-type: none"> ○ 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 	<ul style="list-style-type: none"> ● 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.
<p>Rheumatoid Arthritis (RA)</p>	<p>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.</p>	<ul style="list-style-type: none"> ● It has several special features that make it different from other kinds of arthritis. Characterized by: <ul style="list-style-type: none"> ○ 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. 	<ul style="list-style-type: none"> ● 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.**

**IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET**

Disease / Condition	Definition	Characteristics	Functional Considerations
Scleroderma	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.	<p>Scleroderma is called both a rheumatic disease and a connective tissue disease.</p> <ul style="list-style-type: none"> • 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. <p>Side effects include:</p> <ul style="list-style-type: none"> ○ 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 	<p>Expect possible effect in the following areas:</p> <ul style="list-style-type: none"> • 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.
Stroke	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.	<ul style="list-style-type: none"> • 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 stroke. • Risk factors include: Diabetes, high blood pressure, cigarette smoking, cardiovascular disease. • Disabilities related to stroke vary depending upon the severity of the "attack". 	<p>Functional needs will be related to disabilities common after stroke such as:</p> <ul style="list-style-type: none"> • 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 decubitus 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. <ul style="list-style-type: none"> ○ 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.**

**IHSS TRAINING ACADEMY
ELECTIVE: MEDICAL IMPLICATIONS
QUICK FACTS SHEET**

Disease / Condition	Definition	Characteristics	Functional Considerations
<p>Traumatic Brain Injury (TBI)</p>	<p>Traumatic injuries to the brain, also called intracranial injury, or simply head injury, occurs when a sudden trauma causes brain damage.</p>	<p>The damage can be:</p> <ul style="list-style-type: none"> • focal - confined to one area of the brain - or • diffuse - involving more than one area of the brain. <p>TBI can result from:</p> <ul style="list-style-type: none"> ○ 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 <p>A TBI can cause problems with arousal, consciousness, awareness, alertness, and responsiveness.</p> <p>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.</p> <p>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).</p>	<ul style="list-style-type: none"> • 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. <ul style="list-style-type: none"> ○ 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.
<p>Falls</p>		<p>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.</p> <ul style="list-style-type: none"> ○ 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. 	<ul style="list-style-type: none"> • 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.**