- Don't tease or laugh at a person with a speech disability. The ability to communicate effectively and to be taken seriously is important to all of us.

Things to Consider

- Many persons with difficulty speaking find themselves in situations where people treat them as if they are drunk, developmentally disabled, or mentally ill.
- Many persons with difficulty speaking are accustomed to being avoided, ignored, or even hung up on by phone.
- Accessibility for persons with difficulty in speech lies within your power. Your patience and communication skills are as important to someone with speech that is difficult to understand as a grab bar or a ramp is to someone who uses a wheelchair.

PERSONS OF SHORT STATURE

Things to Know

- There are 200 diagnosed types of growth related disorders that result in a person being 4 feet 10 inches or less in height.
- For an adult, being treated as cute and childlike can be a tough obstacle.

Things to Do

- Be aware of having necessary items within the person's reach to the maximum extent possible.
- Communication can be easier when people are at the same level. Persons of short stature have different preferences. You might kneel to be at the person's level; stand back so you can make eye contact without the person straining her neck (this can be hard to do in a crowded room); or sit in a chair. Act natural and follow the person's cues.

Things to Avoid

- As with people who have other disabilities, never pet or kiss a person of short stature on the head.

DEVELOPMENTAL DISABILITY (DD)

Things to Know

- Developmental Disability refers to conditions occurring before adulthood which sometimes result in below average intelligence, impaired motor functioning, or other disabling conditions.
- A low intelligence test score alone does not necessarily indicate that a person is developmentally disabled.
- What is seen by most people is behavior reflecting slow, arrested, or incomplete development before a person reaches the age of eighteen.

- Some people with developmental disabilities have a hard time using what they have learned and applying it from one setting or situation to another.
- It is important to remember that, even though someone is an adult, there are certain characteristics which are described as childish or childlike, leading to the erroneous conclusion that a person has a "mental age of 4 or 5." A person who is 30 years old with a mental age of five has had 25 more years of life experience upon which to base his or her behavior.
- Because each person with a developmental disability is an individual, there is no "overall" description one can give to alert that a person is developmentally disabled.
- Every person with a developmental disability will display characteristics differently, with varying levels of intensity.
- Not all people with developmental disabilities look disabled, nor will they act in the same way when making contact with people.
- People with developmental disabilities often rely on routine and on the familiar to manage work and daily living. Be aware that a change in the environment or in a routine may require some attention and a period of adjustment.

Things to Do

- It can be difficult for people with developmental disabilities to make quick decisions. Be patient and allow the person to take their time.
- A calm, patient attitude on your part will prove to be your most effective tool.
- Speak to the person in clear sentences, using simple words and concrete rather than abstract concepts. Help her understand a complex idea by breaking it down into smaller parts.
- Clear signage with pictograms can help a person who has developmental disabilities to find her way around.
- Be aware that a "yes" response may be inappropriately given out of fear of disapproval or in an attempt to please.
- If a person with a developmental disability is lost, be aware that residents of board and care homes may have their names printed on their clothes, collar or similar location.

Things to Avoid

- Don't use baby talk or talk down to people who have developmental disabilities.
- Gauge the pace, complexity, and vocabulary of your speech according to theirs.
- People with developmental disabilities may not have any speech, or may have very limited speech.
- Avoid frightening a person with developmental disabilities, as they may be unable to respond because of fear. They may, however, respond to questions, especially those requiring a "yes" or "no" answer.

Things to Consider

- Remember that the person is an adult and, unless you are informed otherwise, can make her own decisions.
- Medication may slow their speech or reactions, or cause them to walk in a manner which arouses suspicion.
- People with developmental disabilities may be anxious to please. During an interview, the person may tell you what she thinks you want to hear. In certain situations, such as law enforcement or a doctor's examination, it can have grave consequences if your interview technique is not effective. Questions should be phrased in a neutral way to elicit accurate information. Verify responses by repeating each question in a different way.

CEREBRAL PALSY (CP)

Things to Know

- Cerebral Palsy is a condition that results from damage to the central nervous system before birth, or early in life.
- “Cerebral" refers to the brain and "Palsy" to a disorder of movement or posture. It is neither progressive nor communicable, and has little or no relation to intelligence.
- Cerebral Palsy is characterized by an inability to fully control motor functions. A person with Cerebral Palsy may have spasms; involuntary movement; disturbance of gait or mobility; seizures; abnormal sensation and perception; impairment of sight, hearing, or speech; and mental retardation.

Things to Do

- A person who may appear to be drunk, sick or have a medical emergency might in fact have CP or another disability. Get the facts before acting on your first impression, whether the situation is business, social or law enforcement.

Things to Avoid

- Do not make assumptions about the intelligence of persons with Cerebral Palsy.
- Many people with CP have slurred speech and involuntary body movements.
- Your impulse may be to discount what they have to say, based on their appearance. Monitor your responses and interact with the person as you would with anyone else.

Things to Consider

- Over a half million people in the United States have Cerebral Palsy. Many are wheelchair users and you may refer to the previous section concerning wheelchairs for additional information.

TOURETTE SYNDROME

Things to Know

- People with Tourette syndrome may make vocalizations or gestures such as tics that they cannot control.
- A small percentage of people with Tourette syndrome involuntarily say ethnic slurs or obscene words.
- A person with Tourette syndrome will benefit from the understanding and acceptance others.

Things to Do

- If a person with Tourette makes vocalizations during a conversation, simply wait for her to finish, then calmly continue.

Things to Consider

- The more the person tries to contain these urges, the more the urges build up. It may be helpful for a person with Tourette to have the option to leave the meeting or conversation temporarily to release the build-up in a private place.

EPILEPSY (SEIZURE DISORDER)

Things to Know

- Epilepsy is a symptom of a disorder of the central nervous system occurring either as a result of head trauma or as a condition present from birth, which may result in seizures.
- Epilepsy is not a disease, nor is it progressive, related to intelligence, or necessarily related to another disability.
- One person in a hundred has epilepsy; however, 80% of those diagnosed will have good control of seizures through medication.
- Be aware that beepers and strobe lights can trigger seizures in some people.
- There are three seizure patterns. The Grand Mal convulsion consists of a loss of consciousness, stiffening, muscle rigidity and spasms. The Petit Mal seizure may not be readily recognized, as it usually consists of a lapse of from 5-25 seconds and gives the appearance of daydreaming or staring. The Psychomotor seizure may be seen only as staring or confusion, dizziness or fear, or other behavior such as lip smacking or erratic arm movements.

Things to Do

- At the scene of a seizure, your best action would be to keep the person from getting injured by removing objects from the area which might cause injury (chairs, tables, etc.).
- If the person is still unconscious after a seizure, turn him or her on their side, with the face downward.

- When a seizure has ended, the person may feel disoriented and embarrassed.
- Try to ensure that he has privacy to collect himself.

Things to Avoid

- Do not restrain the movements of a person having a seizure.
- Do not put anything between the teeth.
- Do not give the person anything to drink.

Things to Consider

- Medical aid for epilepsy is usually not necessary unless a seizure lasts longer than 15 minutes.
- The person may not remember what has happened, and may require your assistance for a short period of time while getting reoriented.
- Seizures usually draw a crowd of onlookers. This is an excellent opportunity to set an example for others by your conduct, and educate the uninformed as to successful intervention techniques.

AUTISM

Things to Know

- Autism is a severely, incapacitating, lifelong developmental disability that appears during the first three years of life.
- In its broad definition, autism or autistic-like symptoms occur in about five out of every thousand children.
- Autism is four times more common in males than in females, and is found throughout the world in families of all racial, ethnic and social backgrounds. Symptoms of autism include:
  - Slow development or lack of physical, social, and learning skills.
  - Immature rhythm of speech and limited understanding or use of words.
  - Abnormal responses to sensations: sight, hearing, touch, pain, balance, smell, taste, etc. Abnormal ways of relating to people, objects and event.

Things to Do

- Quite often, when you come into contact with people with autism, they will be in their neighborhood or where family or friends are near.
- There are no hard and fast rules for dealing with people who have autism. Be aware of the symptoms of autism.
- A calm, persistent approach should work best.

Things to Avoid

- Resist the natural tendency to counter aggression or non-compliance with physical control, since merely touching someone with autism might cause them to flee.
- Attempting to confine a person who is autistic might cause great fear and resistance.

Things to Consider

- At first glance, the actions of persons with autism may seem to be hostile, antagonistic, bizarre or drug-induced.
- People with autism sometimes feel pain when others would not, and at other times feel no pain.
- Your attention may be drawn to people who are autistic by their "odd" behavior.
- People with autism may show a fascination with something inanimate (especially wheels or circular objects), walk into traffic without looking, or be engaged in other aggressive or self-injurious behavior.

PSYCHIATRIC DISABILITIES (MENTAL ILLNESS)

Things to Know

- People with psychiatric disabilities may at times have difficulty coping with the tasks and interactions of daily life.
- The disorder may interfere with their ability to feel, think, and relate to others.
- Most people with psychiatric disabilities are not violent.
- The biggest obstacle is societal attitudes about mental illness.
- Mental Illness covers a broad range of psychiatric disabilities such as schizophrenia, manic depression, severe depression, and most anxiety disorders.
- Some of these mental illnesses can be treated with medicine but, because they do not recognize that they are ill, people who have mental illness frequently stop taking their medication.

Things to Do

- Stress can affect the person's ability to function. Try to keep the pressure of the situation to a minimum.
- In a crisis, stay calm and be supportive as you would with anyone. Ask how you can help, and find out if there is a support person who can be sent for. If appropriate, you might ask if the person has medication that he needs to take.
- Call for professional assistance if necessary.

Things to Avoid

- Resist the natural tendency to counter aggression or non-compliance with physical control, since merely touching someone with a mental disability might cause them to flee or react violently.
- Tones of voice, actions, or appearance which are threatening to a person with a mental disability could trigger an unexpected or unwanted reaction.

Things to Consider

- Neurological disorders and the broad range of mental illnesses present challenges for medical professionals, family members, friends, and the people affected by the disabilities.
- Your interactions and conversations with people who have such disabilities may be frustrating or unnerving at times.
- By remaining calm, friendly, and helpful you should be able to attain your objective despite the complications which are involved.
- People who have psychiatric disabilities have varying personalities and different ways of coping with their disability. Some may have trouble picking up on social cues; others may be super-sensitive. One person may be very high energy, while someone else may appear sluggish. Treat each person as an individual. Ask what will make him most comfortable and respect his needs to the maximum extent possible.

ALZHEIMER'S DISEASE

Disabilities which do not manifest themselves with physical symptoms can present unexpected complications when interacting with anyone you do not know. What might be considered a "normal" conversation could change without warning or apparent cause.

Things to Know

- Alzheimer's disease normally affects people who are older.
- Childlike characteristics or symptoms may suddenly appear, and memory loss is the most common sign that Alzheimer's disease is present.
- People who have Alzheimer's disease often wander away from their residences, and may have very plausible explanations of where they think they are going.

TRAUMATIC BRAIN INJURY (TBI)
ACQUIRED BRAIN INJURY (ABI)

Head injuries can occur in accidents which sometimes appear minor. A person with a TBI may not recognize that their characteristics or actions change when the injury's symptoms are manifested. Even if there are normally no signs of a TBI present, a sudden change in speech pattern or volume, a burst of anger, or an indecipherable sentence could be an indication that a head injury has occurred.

Things to Know

- People with brain injury may have a loss of muscle control or mobility that is not obvious. For example, a person may not be able to sign her name, even though she can move her hand.
- A person with a brain injury may have poor impulse control. The person may make inappropriate comments and may not understand social cues or "get" indications that she has offended someone. In her frustration to understand, or to get her own ideas across, she may seem pushy. All of these behaviors arise as a result of the injury.
- A person with a brain injury may be unable to follow directions due to poor short-term memory or poor directional orientation. She may ask to be accompanied, or she may use a guide dog for orientation, although she does not appear to be mobility impaired.
- The person may have trouble concentrating or organizing her thoughts, especially in an over-stimulating environment, like a crowded movie theater or transportation terminal. Be patient. You might suggest going somewhere with fewer distractions.

Things to Do

- Head injuries can be so varied that there are no easy rules for dealing with the symptoms they cause.
- Be alert for unusual characteristics, actions or phrases; if they present, assume that there may be some type of disability present.
- If you are not sure that the person understands you, ask if she would like you to write down what you were saying.
- A calm, friendly approach works best while interacting with anyone.

Things to Avoid

- Resist the natural tendency to counter aggression or non-compliance with physical control, since merely touching someone with a head injury might cause them to flee or react violently.
- Tones of voice, actions, or appearance which are threatening to a person with a head injury could trigger an unexpected or unwanted reaction.

Things to Consider

- Neurological disorders and the broad range of head injuries present challenges for medical professionals, family members, friends, and the people affected by the disabilities.
- Your interactions and conversations with people who have such disabilities may be frustrating or unnerving at times.
- By remaining calm, friendly, and helpful you should be able to attain your objective despite the complications which are involved.

HIDDEN DISABILITIES

Not all disabilities are apparent. A person may have trouble following a conversation, may not respond when you call or wave to them, may make a request that seems strange to you, or may say or do something that seems inappropriate. The person may have a hidden disability, such as low vision, a hearing impairment, a learning disability, traumatic brain injury, mental retardation, or mental illness. Don't make assumptions about the person or their disability. Be open-minded.

A WORD ABOUT CONFIDENTIALITY

You may really care or you may just be curious about a person with a disability who is in crisis, suddenly ill, or does not "show" for unexplained reasons. In spite of your concern, please respect the privacy of a person with a disability. Allow him to discuss his situation if and when he feels comfortable doing so.

LEARNING MORE

Lack of knowledge or misinformation may lead you to shy away from interacting with persons with certain disabilities. Preconceptions about mental illness, AIDS, Cerebral Palsy, Tourette syndrome, Alzheimer's disease and other disabilities often lead to a lack of acceptance by those around the person. Remember that we are all complex human beings; a disability is just one aspect of a person. Learning more about the disability may alleviate your fears, and can pave the way for you to see the person for who they really are. Keep practicing, and enjoy the experience.

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WORKING WITH VISUALLY IMPAIRED CONSUMERS IN IHSS

Aid codes for blind aid are "20", "26", "28", etc.

- Best corrected vision for statutory blindness 20/200 or visual field <15°

Most common causes of blindness:

- Lack of oxygen and other delivery impairments at birth
- Macular degeneration (degenerative blemishes on the retina), which results in "tunnel vision"
- Glaucoma (increased pressure and hardening of the eyeball)
- Diabetes (diabetic retinopathy)
- Cataract (lens becomes opaque) – now often corrected or improved by surgery
- Retinal detachment (retina is light-sensitive cells at back of eyeball. If they detach from the optic nerve, visual image cannot reach the brain.)
- Diseases of the cornea

Things to Know

- Most persons who are blind have some sight, rather than no sight at all.
- Many people who are blind are mobile and independent. Some people who are blind view blindness not as a disability as much as an inconvenience.
- While many people who are blind can use Braille, the majority of persons who are blind do not.
- A person may have a visual disability that is not obvious. Be prepared to offer assistance – for example – in reading when asked.

Things to Do

- Introduce yourself. Identify who you are and what your job or role is. Be sure to introduce any others who are with you.
- If you have met before, remind consumer of the context; as they won't have the visual cues to jog their memory.
- Be descriptive when giving directions. Saying "over there" has little meaning to someone who cannot see you point.
- Always ask someone if they need your assistance and how you can assist them.
- Lead someone who is blind only after they have accepted your offer to do so. Allow them to hold your arm, rather than you holding them. It is important to let people with vision impairments control their movements.
- Many techniques are used as tools for independence, but individuals with disabilities use only things that work for them.
- If the person has a guide dog, walk on the side opposite the dog. As you are walking, describe the setting, noting any obstacles, such as stairs ("up" or "down") or a big crack in the sidewalk.
- If you are going to give a warning regarding a hazard, be specific. Shouting, "Look out!" does not tell the person if he should stop, run, duck or jump.
- Remember to describe sights or objects from their perspective, not yours. Tell them when you have brought new items into their environment, describing what they are and, most importantly, where you have put them.

- Offer to read written information.
- If you need to leave a person who is blind, inform him first.

Things to Avoid

- Do not move items (furniture, personal items) after their position has been learned by the person. This can be frustrating and, in some cases, dangerous for the person with a disability.
- Do not use references that are visually oriented like "over there near the green plant."
- Don't touch the person's cane or guide dog. The dog is working and needs to concentrate. The cane is part of the individual's personal space. If the person puts the cane down, don't move it. Let him know if it's in the way.

Things to Consider

- Persons who are blind have more often been told what to do rather than asked what they would prefer doing. This attitude is not acceptable towards any person.

People with Low Vision

Things to Know

- Persons with low vision may not be wearing dark glasses or using a cane and therefore are not easily identifiable.
- A person with low vision may need written material in large print.
- It is easiest for most people with low vision to read bold white letters on a black background.

Things to Do

- Ask the person what size and type font they prefer to read.
- Remember that you can use a copy machine to enlarge print.
- Good lighting is very important.
- Have a simple (drug store brand) magnifying glass available.
- Use a thick point black marker when writing down information. Check with the person to determine what size to write letters/numbers so they can see it.
- Keep walkways clear of obstructions.

Things to Avoid

- Avoid using all uppercase letters because it is more difficult for people with low vision to distinguish the end of a sentence.
- Do not move items (furniture, personal items) after their position have been learned by the person. This can be frustrating and, in some cases, dangerous for the person with a disability.

Assessment of home care needs of the blind and vision-impaired:

- Legal blindness covers a wide range of vision. Don't assume about consumer capabilities.
    - Ask consumer how much vision they do have.
    - As in any IHSS interview, carefully observe the consumer to determine their abilities. Do not assume complete blindness or helplessness.

  - Allow the consumer to describe his/her vision and how it impacts function.
  - Examples might be to hand them a pen, if they do not reach for it then tell them you are handing them a pen and that you will need them to sign their name.
  - Always look directly at the consumer as you or they are speaking and note if they respond to your movements, smiles etc.

- Ask the consumer about adaptations to the home and adaptive training they may have received. (Example: stove knobs marked in braille)
  - What kind?
  - How much mobility training?
  - Have they developed their own systems or do they use tools which allow them to complete some tasks?
  - Those with intensive schooling are often Braille capable and very adept to getting around.
  - Those who are blind from birth may have mental health issues overlay basic blindness or experience isolation due to never having sight.
  - Those with late or adult onset tend to have a slower diminution of sight, allowing time to adapt.
  - Those new to the loss may have some depression and may not yet availed themselves of training nor be aware of what is available to them.

- Community resources:
  - Department of Vocational Rehabilitations
  - OCB
  - Living Skills Centers
  - Guide dogs
  - Special mobility training
  - Non-profit organization serving the blind
  - Special services from utilities
  - Large print books

- Explore other health problems and their impact on functioning.

- IHSS Tasks – Some things to consider:
  - Domestic: Examine floors and counter surfaces for sign of vermin too small for consumer to see, crumbs, grease or mold. Check refrigerators for spoiled food.
  - Meals & Cleanup: Same as above. Explore for vermin. They currently may be cooking out of necessity. Make sure that this can be done safely.
  - Laundry: Observe spots and stains on clothing and linens. Consumers often have trouble with use of bleach, pre-spotting, coordination of colors, storing clothing in matching sets to facilitate dressing.
  - Dressing: How is clothing stored? Are clothes stored in matching styles, colors? Consumers feel seams to determine right-side out and label to tell back from front. These are some of the skills taught in the training programs.
  - Feeding: Consumers rely on things being in place. Ask what system they are currently using for their meals.
  - Bathing and Grooming: Most men use an electric razor. Observe hairstyle as a factor in grooming time. Provider may need to do set-ups.

  - Accompaniment to MD Visits: Can be approved only for consumers who need physical assistance. Many impaired persons are adept at using public transportation.
  - Paramedical: Can be involved with administration of insulin injections/ testing.
  - Setting up medi-sets can be helpful. For low vision consumers, have they asked their pharmacy to provide large print prescriptions?

- Determine if adaptive items are used by the consumer to facilitate independence for any of the above tasks. If not and consumer is interested, refer to a low vision living skills center.

Other Resources

- The Pub 13 Rights and Responsibilities Pamphlet is available in large print, Braille and in audio versions. www.cdss.ca.gov/civilrights/PG594.htm
- CDSS website: Handbook and services for the visually impaired. http://www.cdss.ca.gov/cdssweb/PG1941.htm

6: Cultural Resources

CULTURAL IMPLICATIONS

Cultural Implications for IHSS Assessment:

1. Any general cultural awareness does not fit every situation. If there are any concerns, the consumer should be consulted.

2. Most cultural beliefs are influenced by culture, age, and length of time in the U.S.

3. Culture can be defined as the integrated patterns of behaviors that include language, thoughts, communications, actions, customs, beliefs, values, and/or institutions of racial, ethnic, religious, and/or social groups.

4. Culture is only one of a number of influences on behaviors in the face of illness and other life transitions.

5. Culturally appropriate care includes sensitivity to issues related to race, gender, sexual orientation, social class, economic situation, age, and disability.

6. It is important that the social worker understand their own cultural context and influences so he/she can be aware of their own cultural filters.

7. Knowledge allows you to move forward to assess your consumers with awareness and sensitivity.

8. Having knowledge about a specific cultural/ethnic group does not ensure cultural appropriateness; however, without knowledge and understanding, being culturally appropriate most likely will not occur.

9. Stereotyping – one makes an assumption about a person based on group membership without learning whether or not the individual in question fits that assumption.

10. Generalizing – begins with an assumption about a group but leads to a quest for further information as to whether the assumption fits the individual.

Cultural Variations in Communication:

- Conversational style and pacing
  - Silence is interpreted differently by different cultures. In some, it is a sign of respect, while in others a person will find you rude or even interpret silence as a "no" response.
  - Styles of answers can be different in cultures ranging from blunt and to the point to indirect and storytelling styles.
  - In some cultures, directness, insistence and emphasis can look like anger to others.

- Eye contact
  - Avoiding eye contact has many reasons and can be easily misinterpreted.

- Personal space
    - There are many different comfort levels. In some cultures, standing close is comfortable and in others giving ample space is important for personal comfort.

- Touch
    - Different parts of the body are taboo in different cultures such as touching the head and feet. In addition, it is important to be conscientious about gender differences in comfort with touch. In some cultures, there is great sensitivity regarding opposite gender caregivers.

- Time orientation
    - Differences include being strictly oriented to clock time versus embracing personal and subjective time. The importance of being 'on time' can vary.

Adapted from *Culture and Clinical Care.* Edited by J. Lipson and S. Dibble, UCSF Nursing Press, 2005.

ATTRIBUTES, KNOWLEDGE, AND SKILLS NECESSARY FOR THE SOCIAL WORKER TO DEVELOP CULTURAL COMPETENCY

Attributes:

- genuineness, accurate empathy, non-possessive warmth and a capacity to respond
- flexible to a range of possible solutions
- acceptance of ethnic differences between people
- willingness to work with consumers of different ethnic groups
- articulation/clarification of the worker's personal values, stereotypes, and biases about their own and other's ethnicity/social class
- resolution of feelings about one's own professional image in a field that is systematically oppressed and may exclude people of color or other differences

Knowledge of:

- culture (history, values, traditions, family systems, artistic expressions) of cultural group
- the impact of class and race on behavior, attitudes, and values
- help seeking behaviors of consumers
- the role of language, speech patterns, and communication styles
- the impact of social service policies on consumers
- resources that can be utilized and how to access them
- recognizing ways that professional values may conflict with or accommodate the needs of minority consumers
- power relationships within the community, agency, or institution and their impact on the consumer

Skills:

- techniques for learning about culture
- ability to communicate accurate information on behalf of the consumer
- ability to openly discuss cultural differences and respond to culturally based cues
- ability to assess the meaning that ethnicity has for individual consumers
- ability to differentiate between the symptoms of intrapsychic stress and stress arising from the social structure
- interviewing techniques that are culturally sensitive
- ability to utilize the concepts of empowerment on behalf of the consumer and community
- ability to recognize and combat racism, racial stereotypes, and myths in individuals and institutions
- ability to evaluate new techniques, research, and knowledge as to its validity and applicability in working with cultural differences

How to do this:

- Skills and knowledge are gained through education, training, practice and self-reflection.
- Personal attributes can be developed through exposure to the positive aspects of minority cultures.
- Knowledge and skills must be coupled with a willingness to let consumers determine their own future, within program parameters.

Adapted from *Toward a Culturally Competent System of Care* by T. Cross, B. Bazron, K. Dennis, M. Isaacs, March 1989.

USING AN INTERPRETER

Many times, assessments are conducted by a social worker who is fluent in the consumer's language. But at times, you have to conduct an assessment or other interactions with a consumer and/or provider through an interpreter. The consumer has the right to choose who his/her interpreter is, but if the consumer needs assistance, it is important to select someone who is certified or otherwise has been arranged for by the county.

There are several techniques you may employ when using an interpreter. While behaviors may vary by cultural group, demonstrating respect is recognized and valued by all people. When using an interpreter, consider the following strategies:

- Even if it is the wish of the consumer, do not use a child under the age of 18 as an interpreter except in extenuating circumstances when requested to do so by the consumer and when no other interpreter is available. For additional information, see ACL 06-20, ACL 03-56 and MPP Section 21-115.16.
- Before the interview begins, inform the interpreter that you need him/her to translate all that the consumer says and to say to the consumer all of what you say.
- Always display professionalism and let the consumer know you are interested in their situation by being polite and formal.
- Ask the interpreter to use the consumer's own words as much as possible.
- Ask the interpreter to refrain from inserting his/her own ideas or interpretations, and from omitting information.
- When communicating with the consumer through an interpreter, look directly at the consumer when you speak, not at the interpreter.
- Address questions to the consumer, not the interpreter.
- Observe the consumer's non-verbal communication, such as facial expressions, voice intonations, and body movements.
- Avoid raising your voice in an attempt to clarify your statements.
- Do not use hand gestures to emphasize statements; they may prove to be culturally insulting or even frightening.
- Use simple, nontechnical language and avoid using acronyms.
- Do not use slang.
- Check the consumer's understanding and accuracy by asking him/her to repeat the message or instructions in his/her own words with help from the interpreter.
- Provide instruction in the proper sequence and discuss one topic at a time.
- Avoid using double negatives.
- Avoid using leading questions that may encourage the consumer to say what he thinks you want to hear.
- Whenever appropriate, ask open-ended questions rather than questions requiring a "yes" or "no" response.

21-115 PROVISION FOR SERVICES TO APPLICANTS AND RECIPIENTS WHO ARE NON-ENGLISH SPEAKING OR WHO HAVE DISABILITIES 21-115

(Continued)

HANDBOOK CONTINUES

In the example above, one full time Spanish-speaking worker in any program would satisfy the requirements for all programs, provided that the worker would be available to interpret for the other two programs.

HANDBOOK ENDS HERE

.15 When the percentage of non-English cases in a program and/or location is less than five percent, the agency shall ensure that effective bilingual services are provided. This requirement may be met through utilization of paid interpreters, qualified bilingual employees, qualified employees of other agencies or community resources.

.16 Applicants/recipients may provide their own interpreter; however, the CWD shall not require them to do so. Only under extenuating circumstances or at the specific request of the applicant/recipient shall a CWD allow a minor (under the age of 18 years) to temporarily act as an interpreter. This provision does not apply to interpretive services for persons who are deaf.

.2 Forms and other written material required for the provision of aid or services shall be available and offered to the applicant/recipient in the individual's primary language when such forms and other written material are provided by CDSS. When such forms and other written material contain spaces (other than "for agency use only") in which the CWD is to insert information, this inserted information shall also be in the individual's primary language.

.3 Each CWD shall ensure that administrative practices do not have the effect of denying non-English speaking persons and individuals with disabilities equal access to and participation in the available programs and activities.

.4 Auxiliary Aids

.41 CWDs shall provide auxiliary aids and services to persons who are deaf or hearing impaired, or persons with impaired speech, vision or manual skills where necessary to afford such persons an equal opportunity to participate in, and enjoy the benefits and services of programs or activities. Auxiliary aids and services may include brailled material, taped text, qualified interpreters, large print materials, telecommunication devices for the deaf (TDDs) and other effective aids and services for persons with impaired hearing, speech, vision or manual skills. Compliance with this section can be accomplished through use of volunteer services from community organizations and individuals who are able to provide prompt effective services without undue delays using qualified interpreters.

.42 CWDs shall provide an opportunity for individuals with disabilities to request auxiliary aids and services of their choice. CWDs shall give primary consideration to the requests of individuals with disabilities.

4

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY ARNOLD SCHWARZENEGGER, *Governor*

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

June 30, 2006

ALL COUNTY LETTER NO. 06-20

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order or Settlement Agreement
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS

TO: ALL COUNTY WELFARE DIRECTORS
ALL COUNTY CIVIL RIGHTS COORDINATORS

SUBJECT: INTERPRETIVE SERVICES

The purpose of this All-County Letter (ACL) is to remind counties of their continued obligation to comply with the California Department of Social Services (CDSS) Manual of Policies and Procedures (MPP) Division 21 regulations regarding the provision of effective language services to all applicants/recipients in their primary language. The provision of effective language services shall be prompt, without undue delay. These requirements apply regardless of whether the county provides an interpreter (qualified bilingual employees, paid interpreters, qualified employees of other agencies, or use of community resources) or the applicant/recipient chooses to provide his/her own interpreter.

Counties must comply with MPP Section 21-107 regarding the dissemination of information and ensure that applicants/recipients are advised of their right to free interpretive services. It is always the county's obligation to affirmatively offer interpretive services (Section 21-115.15). Once the county has been informed that the applicant/recipient needs an interpreter, the county must offer and provide an interpreter at each client contact. The county's obligation to provide interpretive services may be met using a variety of methods, which may include bilingual staff, county interpreters, and contracted interpreters (including language line).

Applicants/recipients may use their own interpreter, but must not be compelled or encouraged to do so (Section 21-115.16). Before applicants/recipients decide to use their own interpreter, the county is required to advise them at initial intake and at each redetermination of (1) the right to free interpretive services; (2) potential problems of using the client's own interpreter, including the possibility of ineffective communication, inaccurate interpretation, and the need to disclose private information to the interpreter; (3) the availability of county-provided interpretive services, whether or not a client chooses to provide his own interpreter; and (4) the right to accept county-provided interpretive services at any time, even when a client-provided interpreter is present.

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If the applicant/recipient chooses to provide his or her own interpreter, but at any time informs the county that he or she wishes to utilize the county-provided interpreter, the county must provide free interpretive services, without undue delay. The county *shall not* conduct substantive, program-related conversations with the applicant/recipient until qualified interpretive services are available.

The county may allow a minor to temporarily act as interpreter only at the request of the applicant/recipient, or under other extenuating circumstances. The county must document the use of a minor and the reason(s) for it in the case record. Examples of extenuating circumstances warranting the temporary use of a minor as interpreter include, but are not limited to:

- The County Welfare Department (CWD) telephones or visits the applicant/recipient's home for initial contact and finds a non-English or limited-English speaking client, while a minor in the home speaks English. Under these circumstances, the CWD contact may use the minor as an interpreter only to determine the language of the client and to schedule a date and time to return with a county provided interpreter. When the matter is time sensitive, the county is encouraged to use a telephone interpreter.

- A non-English or limited-English speaking applicant/recipient enters the CWD with a minor child who speaks English and the county does not immediately have access to a county provided interpreter in the applicant/recipient's primary language. Under these circumstances, the minor may only be used as a temporary interpreter to schedule a date and time to return to the CWD when a county provided interpreter will be available. When the matter is time sensitive, the county is encouraged to use a telephone interpreter.

- When a CWD employee encounters a health and safety issue such as a car accident or crime scene, where immediate communication is imperative, a minor may be used temporarily until a qualified interpreter arrives at the scene or communicates with the applicant/recipient via telephone, cell phone, etc.

In all instances, the use of a minor as the applicant's/recipient's interpreter should be temporary, only until a county interpreter is made available.

In addition to providing free interpretive services, the county must document the following in the case record file for each contact with the applicant/recipient:

- The county offered free interpretive services;

- Who provided the interpretive services;

- The county informed the applicant/recipient of potential problems for ineffective communication when using the applicant's/recipient's own interpreter;
- The county offered county-provided interpretive services if the applicant/recipient provided interpreter is not available;
- A minor temporarily acting as an interpreter did so at the specific request of the applicant/recipient or there were other extenuating circumstances, with an explanation of those circumstances;
- The applicant/recipient signed a consent for the release of information when using his or her own interpreter;
- The county informed the applicant/recipient of his/her right to accept county-provided interpretive services at any time, even when a client provided interpreter is present. (Section 21-115.16; 116.22 through .24)

If you have any questions regarding this letter, you may contact the Civil Rights Bureau at (916) 654-2107, or toll free at 1-866-741-6241.

Sincerely,

Original Document Signed By:

TOM LEE
Acting Deputy Director
Human Rights and Community Services Division

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY Gray Davis, *Governor*

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order or Settlement Agreement
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS - Policy Clarification

October 29, 2003

ALL COUNTY LETTER NO. 03-56

TO: ALL COUNTY WELFARE DIRECTORS
ALL CIVIL RIGHTS COORDINATORS

SUBJECT: REQUIREMENTS FOR LANGUAGE SERVICES

REFERENCE: MANUAL OF POLICIES AND PROCEDURES, DIVISION 21

This ACL serves to clarify the responsibilities of County Welfare Departments under California Department of Social Services (CDSS) regulations in providing effective language services with respect to six areas: 1) Bilingual Staffing, 2) Interpreter Services, 3) Minors Used as Interpreters, 4) Use of Translated Forms, Notices and Materials, 5) Informing Signs, and 6) Documentation.

1. Bilingual Staffing: Pursuant to Manual of Policies and Procedures (MPP) Division 21-115.1, counties are required to have qualified and certified bilingual public contact staff who speak the languages spoken by a substantial number of clients and who serve those non- or limited-English-speaking clients, including clients who use American or other sign language. A substantial number is five percent of the clients served in a program at an office.

   For example, in the local office of a county where clients are applying for and/or receiving Food Stamps and seven percent of those clients speak Tagalog, seven percent of the public contact staff in each job classification in the Food Stamp Program in that office must be certified Tagalog-speaking staff to serve the Tagalog-speaking clients. Counties may have different percentages of non-English-speaking staff at each separate office, and the number of bilingual staff must be determined for each separate office. In addition, counties must measure the substantial number by individual language, not language groups (i.e., Southeast Asian languages).

2. Interpreter Services: Pursuant to MPP Division 21-115.15 and .16, when a non- or limited-English-speaking client population is less than a substantial number (less than five percent) in a program at a location, counties must offer and provide interpreter services, upon request, in the language the client has specified for oral communication. This means that if a client comes to the office, is contacted by telephone, or is visited in his or her home, and speaks limited or no English, and has requested an interpreter, an interpreter must be provided. For example, in a county with a small Russian-speaking population where bilingual staffing is not required, when a Russian-speaking client's child is removed from her home as a result of alleged abuse, and the client requests an interpreter, the county is required to provide a Russian-speaking interpreter when communicating with the client—by phone or in person.

   Interpreter services can be provided in person or by phone using a bilingual staff person who is acting as an interpreter, a contracted interpreter, an interpreter from an outside agency, or a family member or friend.

3. Minors Used as Interpreters: Pursuant to MPP Division 21-115.16, counties are prohibited from using minor children as interpreters except temporarily under extenuating circumstances or at the specific request of the client. Extenuating circumstances may include using a minor child to determine the language of the adult so that an appropriate interpreter or bilingual staff person could be called, or when the adult is experiencing a medical emergency.

4. Use of Translated Documents: Pursuant to MPP Division 21-115.2, when a county uses a form, notice or other written material required by CDSS in the county's delivery of services, benefits and programs, and that translated form, notice or other written material has been provided by CDSS, the county must use the translated form, notice or material when serving a non- or limited-English-speaking client.

   This rule regarding use of translated written materials provided by CDSS applies regardless of the number of non- or limited-English-speaking clients who are served by the county. For example, in a county with less than 5 percent Chinese-speaking clients, the Application for Social Services (SOC 295) that has been translated into Chinese by CDSS must be provided in Chinese to the Chinese-speaking applicants. The same rule applies whether Chinese is less than 5 percent or 5 percent or more: When the translated document is a required form and is provided by CDSS, counties must provide the translated form.

   In addition, if using a translated notice of action, any added information that is unique to the recipient of the notice must be in the language of the client. This means that an explanation of the action that is not printed on the notice must be in the language of the notice. If the notice of action is translated into a non-English language, the informing notice on the reverse side (NA Back) must also be in the translated language.

5. Informing Signs: Pursuant to MPP 21-107.211 and .212, counties must post a sign that informs clients that they may request assistance in their primary language. That requirement can be met by using the Pub 86 poster "Everyone is Different, but Equal Under the Law." However, counties are encouraged to also post separate "I Speak" posters inviting non-English-speaking clients to easily identify their language.

   In addition to the signs offering translation services, if a particular county office serves a substantial number of clients who speak a non-English language, all directional and instructional signs must be translated and posted in that particular language. For example, if a county office that serves a substantial number of Spanish-speaking clients posts a sign stating "Employment Classes Every Thursday at 6 p.m.," the county must also have a sign in Spanish stating "Clases de Empleo Cada Jueves a las 6 p.m."

6. Documentation: Pursuant to MPP Division 21-116.2, counties are required to ask clients their preferred language for oral and written communication and document the preferred language(s) in the client's file. Once known, the county is then required to document the following information or actions regarding language services in a client's file:

   a. Client's acceptance or refusal of written material in his/her language after asking the client's preference.
   b. How bilingual services are provided. If, for example, a bilingual staff person is used, it must be documented in the file.
   c. Temporary use of a minor as an interpreter, and the circumstances requiring temporary use of the minor.
   d. That the county informed a client providing his or her own interpreter of the potential problems for ineffective communication.
   e. Client consent to the release of information to the interpreter if the county uses an interpreter other than a county employee.

   This documentation is assessed when the Civil Rights Bureau does its periodic compliance review. In addition, if a client complains that he or she did not receive appropriate language services, this documentation could provide evidence of the client's preferred language for oral and written communication and that language services were provided.

Each of these important areas related to effective language services is addressed in the civil rights compliance reviews which take place according to MPP Division 21-201. Staff and manager interviews, site visits and case file reviews are performed to determine full compliance with the requirements of state regulations.

If you have questions about translated forms, notices, or materials, you may contact Language Services, at (916) 445-6778, or go to the Language Services web page at http://www.dss.cahwnet.gov/cdssweb/FormsandPu_274.htm. If you have questions regarding this letter, you may contact Christine Webb-Curtis, Chief, Civil Rights Bureau, at (916) 654-2107.

Sincerely,

Original Document Signed By

JEANNE RODRIGUEZ
Deputy Director
Human Resources Management Division

alzheimer's association

basics of alzheimer's disease

What it is and what you can do

the compassion to care, the leadership to conquer

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what is alzheimer's disease?

Alzheimer's (AHLZ-high-merz) is a disease of the brain that causes problems with memory, thinking and behavior. It is not a normal part of aging.

Alzheimer's gets worse over time. Although symptoms can vary widely, the first problem many people notice is forgetfulness severe enough to affect their ability to function at home or at work, or to enjoy lifelong hobbies.

The disease may cause a person to become confused, lost in familiar places, misplace things or have trouble with language.

It can be easy to explain away unusual behavior, especially for someone who seems physically healthy. Instead, seek a diagnosis as early as possible.

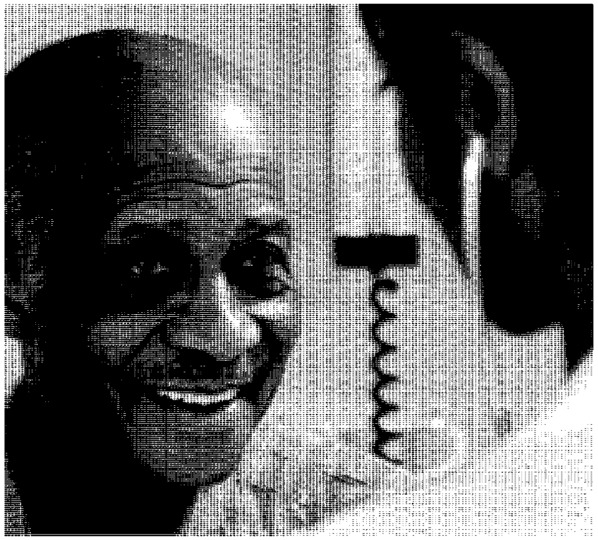
***Basics of Alzheimer's Disease* is intended for anyone who would like to learn more about this disease and related dementias.**

1. when memory loss is a warning sign

Many people worry about becoming more forgetful as they grow older. Our brains change as we age, just like the rest of our bodies.

Most of us eventually notice some slowed thinking and problems remembering certain things. However, serious memory loss, confusion, and other major changes in the way our minds work are not a typical part of aging.

Many conditions can disrupt memory and mental function. Symptoms may improve when the underlying cause is treated.



Contact the Alzheimer's Association if you need assistance finding a doctor with experience evaluating memory problems.

Possible causes of memory problems include:

- Depression
- Medication side effects
- Excess alcohol use
- Thyroid problems
- Poor diet
- Vitamin deficiencies
- Certain infections
- Alzheimer's disease and related dementias

Anyone experiencing significant memory problems should see a doctor as soon as possible. Methods for early diagnosis are improving dramatically, and treatment options and sources of support can improve quality of life.

An early diagnosis helps individuals receive treatment for symptoms and gain access to programs and support services. It may also allow them to take part in decisions about care, living arrangements, money and legal matters.

What's the difference?

Signs of Alzheimer's/dementia	Typical age-related changes
Poor judgment and decision making	Making a bad decision once in a while
Inability to manage a budget	Missing a monthly payment
Losing track of the date or the season	Forgetting which day it is and remembering later
Difficulty having a conversation	Sometimes forgetting which word to use
Misplacing things and being unable to retrace steps to find them	Losing things from time to time

2. 10 warning signs of alzheimer's disease

It may be hard to know the difference between a typical age-related change and the first sign of Alzheimer's disease. Ask yourself: Is this something new? For example, if the person was never good at balancing a checkbook, struggling with this task is probably not a warning sign. But if his or her ability to balance a checkbook has changed significantly, it is something to share with a doctor.

Some people recognize changes in themselves before anyone else does. Other times, friends and family are the first to notice changes in the person's memory, behavior or abilities.

To help identify problems early, the Alzheimer's Association has created a list of warning signs for Alzheimer's. Individuals may experience one or more of these signs in different degrees.

1. Memory loss that disrupts daily life

One of the most common signs of Alzheimer's disease, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; and increasingly needing to rely on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own.

What's a typical age-related change?
Sometimes forgetting names or appointments, but remembering them later.

2. Challenges in planning or solving problems

Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

What's a typical age-related change?
Making occasional errors when balancing a checkbook.

3. Difficulty completing familiar tasks at home, at work or at leisure

People with Alzheimer's disease often find it hard to complete daily tasks. Sometimes, people have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game.

What's a typical age-related change?
Occasionally needing help to use the settings on a microwave or to record a television show.

4. Confusion with time or place

People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

What's a typical age-related change?
Getting confused about the day of the week but figuring it out later.

5. Trouble understanding visual images and spatial relationships

For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast, which may cause problems with driving.

What's a typical age-related change?
Vision changes related to cataracts.

alzheimer's association®

KNOW the
10 SIGNS
EARLY DETECTION MATTERS

6. New problems with words in speaking or writing

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock").

What's a typical age-related change?
Sometimes having trouble finding the right word.

7. Misplacing things and losing the ability to retrace steps

A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.

What's a typical age-related change?
Misplacing things from time to time, and retracing steps to find them.

8. Decreased or poor judgment

People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.

What's a typical age-related change?
Making a bad decision once in a while.

If you notice any of these warning signs, please see a doctor. Doctors' ability to diagnose Alzheimer's disease and related dementias is improving dramatically.

9. **Withdrawal from work or social activities**
A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

What's a typical age-related change?
Sometimes feeling weary of work, family and social obligations.

10. **Changes in mood and personality**
The mood and personality of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

What's a typical age-related change?
Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Note: Mood changes with age may also be a sign of some other condition. Consult a doctor if you observe any changes.

3. alzheimer's disease and other types of dementia

Dementia (dih-MEN-shuh) is a general term for the loss of memory and other intellectual abilities serious enough to interfere with daily life. Alzheimer's is the most common form of dementia.

More than 5 million Americans have Alzheimer's disease. That includes 13 percent of those over age 65 and nearly 50 percent of those 85 and older. By 2050, the number of individuals with the disease may reach 16 million. Because 70 percent of those with Alzheimer's live at home, its impact extends to millions of family members, friends and caregivers.

Other types of dementia

Alzheimer's accounts for 60 to 80 percent of dementia cases. Other disorders that can cause memory loss, confusion and other symptoms associated with dementia include:

Vascular dementia, often considered the second most common type of dementia, refers to impairment caused by reduced blood flow to parts of the brain. One type may develop after a single major stroke blocks blood flow to a large area of brain tissue. Another kind, formerly called multi-infarct dementia, can occur when a series of very small strokes clog tiny arteries. Individually, these strokes are too minor to cause significant symptoms, but over time their combined effect becomes noticeable.

Vascular dementia symptoms can be similar to Alzheimer's disease. They include problems with memory and confusion and difficulty following instructions. In some cases, the impairment associated with vascular dementia can occur in "steps" rather than in the slow, steady decline usually seen in Alzheimer's.

Mixed dementia is a condition in which Alzheimer's disease and one or more other dementias occur together. Evidence shows that this type of dementia is much more common than once believed.

Parkinson's disease affects control of movement, resulting in tremors, stiffness and impaired speech. Many individuals with Parkinson's also develop dementia in later stages of the disease.

Dementia with Lewy bodies often starts with wide variations in attention and alertness. Individuals affected by this illness often experience visual hallucinations as well as muscle rigidity and tremors similar to those associated with Parkinson's disease.

Physical injury to the brain caused by an automobile accident or other trauma can damage or destroy brain cells and cause symptoms of dementia such as behavioral changes, memory loss and other cognitive difficulties.

Huntington's disease is an inherited, progressive disorder that causes irregular movements of the arms, legs and facial muscles; personality changes; and a decline in the ability to think clearly.

Creutzfeldt-Jakob disease (CJD) (CROYZ-felt YAH-kob) is a rare, rapidly fatal disorder that impairs memory and coordination and causes behavior changes. Recently, variant Creutzfeldt-Jakob disease (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by mad cow disease.

Frontotemporal dementia is a term describing several conditions (such as Pick's disease and primary progressive aphasia) in which front and side areas of the brain are especially affected. Personality and behavior changes are often the first symptoms.

Normal pressure hydrocephalus (NPH) is caused by a buildup of fluid in the brain. The cause of most cases is unknown. Symptoms include difficulty walking, memory loss and inability to control urine. NPH can sometimes be corrected with surgery to drain the excess brain fluid.

Mild cognitive impairment (MCI) is a term some doctors use to describe a situation in which a person may have problems with memory or another thinking skill that is serious enough to show up on tests, but not severe enough to interfere with daily life. Research has shown that individuals with MCI have an increased risk of progressing to Alzheimer's disease, especially when their main area of difficulty involves memory. But a diagnosis of MCI does not always mean the person will develop Alzheimer's.

4. how alzheimer's affects the brain

The changes that take place in the brain begin at the microscopic level long before the first signs of memory loss.

What goes wrong in the brain

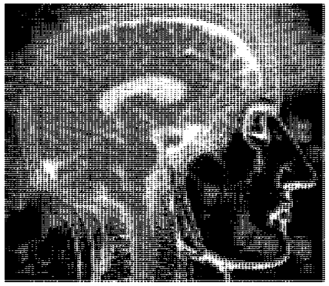
The brain has 100 billion nerve cells (neurons). Each nerve cell connects to many others to form communication networks. In addition to nerve cells, the brain includes cells specialized to support and nourish other cells.

Groups of nerve cells have special jobs. Some are involved in thinking, learning and memory. Others help us see, hear and smell. Still others tell our muscles when to move.

Brain cells operate like tiny factories. They receive supplies, generate energy, construct equipment and get rid of waste. Cells also process and store information and communicate with other cells. Keeping everything running requires coordination as well as large amounts of fuel and oxygen.

Scientists believe Alzheimer's disease prevents parts of a cell's factory from running well. They are not sure where the trouble starts. But just like a real factory, backups and breakdowns in one system cause problems in other areas. As damage spreads, cells lose their ability to do their jobs and, eventually, die.

Take a closer look



Learn how Alzheimer's affects the brain and its functions — take our interactive brain tour at alz.org/brain.

The role of plaques and tangles

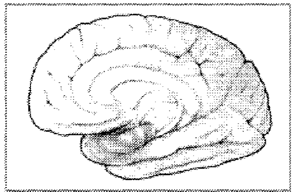
The brains of individuals with Alzheimer's have an abundance of plaques and tangles. Plaques are deposits of a protein fragment called beta-amyloid that build up in the spaces between nerve cells. Tangles are twisted fibers of another protein called tau that build up inside cells.

Though autopsy studies show that most people develop some plaques and tangles as they age, those with Alzheimer's tend to develop far more. They also tend to develop them in a predictable pattern, beginning in the areas important for memory before spreading to other regions.

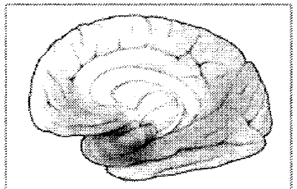
Scientists do not know exactly what role plaques and tangles play in Alzheimer's disease. Most experts believe that they somehow play a critical role in blocking communication among nerve cells and disrupting processes the cells need to survive.

The destruction and death of nerve cells causes memory failure, personality changes, problems in carrying out daily activities and other symptoms of Alzheimer's disease.

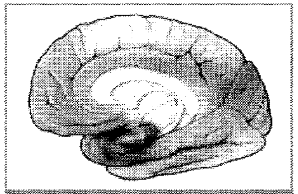
How Alzheimer's spreads in the brain



Plaques and tangles begin in brain areas involved in memory.



They gradually spread to other areas.



Eventually much of the brain is affected.

Illustrations:

Alzheimer's Disease
Education and Referral Center,
a service of the
National Institute on Aging

5. causes and risk factors

While scientists know that Alzheimer's disease involves the failure of nerve cells, why this happens is still unknown. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's.

Age

The greatest known risk factor for Alzheimer's disease is increasing age. Most individuals with the illness are 65 and older. One in eight people in this age group has Alzheimer's. Nearly half of people age 85 and older have Alzheimer's.

Family history and genetics

Another risk factor is family history. Research has shown that those who have a parent, brother or sister with Alzheimer's are more likely to develop the disease than individuals who do not have a first-degree relative with Alzheimer's. The risk increases if more than one family member has the illness.

Scientists have identified three genes that *guarantee* individuals will develop Alzheimer's, but only a very small percentage of people with Alzheimer's (about 1 percent) carry these genes. The ε4 form of the gene apolipoprotein E (APOE-ε4) is carried by about 25 percent of individuals and increases the risk of developing Alzheimer's, *but does not guarantee* that individuals will develop the disease. Experts believe the vast majority of cases of Alzheimer's are caused by a complex combination of genetic and nongenetic influences.

Latinos and African-Americans at risk

Research shows that older Latinos are about one-and-a-half times as likely as older whites to have Alzheimer's and other dementias. Older African-Americans are about twice as likely to have Alzheimer's and other dementias as older whites. The reason for these differences is not well understood, but researchers believe that higher rates of vascular disease in these groups may also put them at greater risk for developing Alzheimer's. A growing body of evidence suggests that risk factors for vascular disease — including diabetes, high blood pressure and high cholesterol — may also be risk factors for Alzheimer's.

Other risk factors

Age, family history and genetics are all risk factors we can't change. Research is beginning to reveal clues about other risk factors that we may be able to influence. There appears to be a strong link between serious head injury and future risk of Alzheimer's. It's important to protect your head by buckling your seat belt, wearing your helmet when participating in sports and fall-proofing your home.

One promising line of research suggests that strategies for overall healthy aging may help keep the brain healthy and may even offer some protection against Alzheimer's. These measures include eating a healthy diet, staying socially active, avoiding tobacco and excess alcohol, and exercising both body and mind.

Some of the strongest evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by many conditions that damage the heart and blood vessels. These include heart disease, diabetes, stroke, high blood pressure and high cholesterol. Work with your doctor to monitor your heart health and treat any problems that arise.

Studies of donated brain tissue provide additional evidence for the heart-head connection. These studies suggest that plaques and tangles are more likely to cause Alzheimer's symptoms if strokes or damage to the brain's blood vessels are also present.

Aluminum

During the 1960s and 1970s, aluminum emerged as a possible suspect in causing Alzheimer's disease. This suspicion led to concerns about everyday exposure to aluminum through sources such as cooking pots, foil, beverage cans, antacids and antiperspirants. Since then, studies have failed to confirm any role for aluminum in causing Alzheimer's. Almost all scientists today focus on other areas of research, and few experts believe that everyday sources of aluminum pose any threat.

6. how to find out if it's alzheimer's disease

People with memory loss or other possible Alzheimer's warning signs may find it hard to recognize they have a problem and may resist following up on their symptoms. Signs of dementia may be more obvious to family members or friends.

The first step in following up on symptoms is finding a doctor with whom a person feels comfortable. (The Alzheimer's Association can help find the right one.)

There is no single type of doctor that specializes in diagnosing and treating memory symptoms or Alzheimer's disease. Many people contact their regular primary care physician about their concerns. Primary care doctors often oversee the diagnostic process themselves.

In many cases, the doctor may refer the patient to a specialist such as a:

- Neurologist who specializes in diseases of the brain and nervous system
- Psychiatrist who specializes in disorders that affect mood or the way the mind works
- Psychologist with special training in testing memory and other mental functions

There is no single test that proves a person has Alzheimer's. The workup is designed to evaluate overall health and identify any conditions that could affect how well the mind is working.

Experts estimate that a skilled physician can diagnose Alzheimer's with more than 90 percent accuracy. Physicians can almost always determine that a person has dementia, but it may sometimes be difficult to determine the exact cause.

Steps to diagnosis include:

Understanding the problem

Be prepared for the doctor to ask:

- What kind of symptoms have been occurring
- When they began
- How often they happen
- If they have gotten worse

Reviewing medical history

The doctor will interview the person being tested and others close to him or her to gather information about current and past mental and physical illnesses. It is helpful to bring a list of all the medications the person is taking. The doctor will also obtain a history of key medical conditions affecting other family members, especially whether they may have or had Alzheimer's disease or related disorders.

Evaluating mood and mental status

Mental status testing evaluates memory, ability to solve simple problems and other thinking skills.

This testing gives an overall sense of whether a person:

- Is aware of symptoms
- Knows the date, time and where he or she is
- Can remember a short list of words, follow instructions and do simple calculations

The doctor may ask the person his or her address, what year it is or who is serving as president. The individual may also be asked to spell a word backward, draw a clock or copy a design. The doctor will also assess mood and sense of well-being to detect depression or other illnesses that can cause memory loss and confusion.

Physical exam and diagnostic tests

A physician will:

- Evaluate diet and nutrition
- Check blood pressure, temperature and pulse
- Listen to the heart and lungs
- Perform other procedures to assess overall health

Blood and urine samples will be collected and other laboratory tests may be ordered. Information from these tests can help identify disorders such as anemia, infection, diabetes, kidney or liver disease, certain vitamin deficiencies, thyroid abnormalities, and problems with the heart, blood vessels or lungs. All of these conditions may cause confused thinking, trouble focusing attention, memory problems or other symptoms similar to dementia.

Neurological exam

A doctor, sometimes a neurologist specializing in disorders of the brain and nervous system, will closely evaluate the person for problems that may signal brain disorders other than Alzheimer's.

The physician will also test:

- Reflexes
- Coordination
- Muscle tone and strength
- Eye movement
- Speech
- Sensation

The doctor is looking for signs of small or large strokes, Parkinson's disease, brain tumors, fluid accumulation on the brain and other illnesses that may impair memory or thinking.

The neurological exam may also include a brain imaging study. The most common types are magnetic resonance imaging (MRI) or computed tomography (CT). MRIs and CTs can reveal tumors, evidence of small or large strokes, damage from severe head trauma or a buildup of fluid. Researchers are studying other imaging techniques so they can better diagnose and track the progress of Alzheimer's. Medicare will cover a positron emission tomography (PET) scan as an aid in diagnosis in certain cases.

7. when the diagnosis is alzheimer's

Once testing is complete, the doctor will make an appointment to review results and share his or her conclusions. A diagnosis of Alzheimer's reflects a doctor's best judgment about the cause of a person's symptoms, based on the testing performed.

You may want to ask the doctor:

- *Why* the diagnosis is Alzheimer's
- *Where* the person may be in the course of the disease
- *What* to expect in the future

Find out if the doctor will manage care going forward and, if not, who will be the primary doctor. The doctor can then schedule the next appointment or provide a referral.

Alzheimer's disease is life-changing for both the diagnosed individual and those close to him or her. While there is currently no cure, treatments are available that may help relieve some symptoms. Research has shown that taking full advantage of available treatment, care and support options can make life better.

Consider:

- How to provide increasing levels of care as the disease progresses
- How the individual and family members will cope with changes in the person's ability to drive, cook and perform other daily activities
- How to ensure a safe environment

It is also important to begin making legal and financial plans. A timely diagnosis often allows the person with dementia to participate in this planning. The person can also decide who will make medical and financial decisions on his or her behalf in later stages of the disease

To learn more about planning for the future, contact the Alzheimer's Association or visit alzheimersnavigator.org to create a customized action plan of information, support, and community resources.

8. stages of the disease

Alzheimer's disease gets worse over time. Experts have developed "stages" to describe how a person's abilities change from normal function through advanced Alzheimer's.

It's important to keep in mind that stages are general guides, and symptoms vary greatly. Every person is unique, but there are some common patterns of the illness. Those with Alzheimer's live an average of four to eight years after diagnosis, but some live as long as 20 years.

This seven-stage framework is based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

Reliable support

Your local Alzheimer's Association chapter can connect you with the resources you need to cope with the challenges of Alzheimer's. Many chapters also provide special programs tailored to their communities, including services for African-Americans, Asian-Americans, Latinos, rural residents and those who live alone.

Our 24/7 Helpline (800.272.3900) operates around the clock to provide information, referral and care consultation by master's-level professionals in 170 languages.

Stage 1: No impairment

Normal function

The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms.

Stage 2: Very mild decline

May be normal age-related changes or the earliest signs of Alzheimer's

The individual may feel that he or she is having memory lapses — forgetting familiar words or the location of everyday objects. But no symptoms can be detected during a medical exam or by friends, family or co-workers.

Stage 3: Mild cognitive decline

Early-stage Alzheimer's may be diagnosed in some, but not all, individuals at this point

Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common difficulties at this stage include:

- Noticeable problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Noticeably greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

Stage 4: Moderate cognitive decline

Mild or early-stage Alzheimer's

At this point, a careful medical interview should be able to detect clear-cut problems in several areas:

- Forgetfulness of recent events
- Impaired ability to perform challenging mental arithmetic (e.g., counting backward from 100 by 7s)
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills or managing finances
- Forgetfulness about one's own personal history
- Becoming moody or withdrawn, especially in socially or mentally challenging situations

Stage 5: Moderately severe cognitive decline

Moderate or mid-stage Alzheimer's

Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer's may:

- Be unable to recall their own address or phone number or the high school or college they attended
- Become confused about where they are or what day it is
- Have trouble with less challenging mental arithmetic (e.g., counting backward from 40 by subtracting fours)
- Need help choosing proper clothing for the season or occasion
- Still remember significant details about themselves and their family
- Continue to eat or use the toilet unassisted

Stage 6: Severe cognitive decline

Moderately severe or mid-stage Alzheimer's

Memory continues to worsen, personality changes may take place and individuals need significant help with daily activities. The person may:

- Lose awareness of recent experiences as well as their surroundings
- Remember their own name but have difficulty with their personal history
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver
- Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet
- Experience major changes in sleep patterns — sleeping during the day and becoming restless at night
- Need help handling details of the toilet (e.g., flushing the toilet, wiping or disposing of tissue properly)
- Have increasingly frequent trouble controlling their bladder or bowels
- Experience major personality and behavioral changes, including suspiciousness and delusions (e.g., believing the caregiver is an impostor) or compulsive, repetitive behavior like hand-wringing or tissue shredding
- Tend to wander or become lost

Wandering

Six out of 10 people with Alzheimer's disease will wander and become lost. If not found within 24 hours, up to half of those who wander risk serious injury or death.

Medic Alert® + Alzheimer's Association Safe Return® is a 24-hour emergency response service that provides assistance when a person with dementia becomes lost or has a medical emergency. Alzheimer's Association Comfort Zone® is a comprehensive Web-based location management system that allows families to monitor a person with Alzheimer's.

Visit alz.org/safety to learn more.

Stage 7: Very severe cognitive decline

Severe or late-stage Alzheimer's

In the final stage of this disease, individuals lose the ability to respond to the environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases.

At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing is impaired.

9. treating the symptoms

Currently, there is no cure for Alzheimer's and no way to stop the underlying death of brain cells. But drugs and non-drug treatments may help with both cognitive and behavioral symptoms.

A comprehensive care plan for Alzheimer's disease:

- Considers appropriate treatment options
- Monitors treatment effectiveness as the disease progresses
- Changes course and explores alternatives as necessary
- Respects individual and family goals for treatment and tolerance for risk

Cognitive symptoms

FDA-approved treatments

Two types of drugs are currently approved by the U.S Food and Drug Administration (FDA) to treat cognitive symptoms of Alzheimer's disease.

The first type, cholinesterase (KOH-luh-NES-ter-ays) inhibitors, prevents the breakdown of acetylcholine (a-SEA-til-KOH-lean), a chemical messenger important for memory and learning. By keeping levels of acetylcholine high, these drugs support communication among nerve cells.

Three cholinesterase inhibitors are commonly prescribed:

- Donepezil (Aricept®), approved in 1996 to treat mild-to-moderate Alzheimer's, and in 2006 for the severe stage
- Rivastigmine (Exelon®), approved in 2000 for mild-to-moderate Alzheimer's
- Galantamine (Razadyne®), approved in 2001 for mild-to-moderate stages

The second type of drug works by regulating the activity of glutamate, a different messenger chemical involved in information processing:

- Memantine (Namenda®) is the only currently available drug in this class

The effectiveness of both types of treatments varies from person to person. While they may temporarily help symptoms, they do not slow or stop the brain changes that cause Alzheimer's to become more severe over time.

Vitamin E

Doctors sometimes prescribe vitamin E for cognitive symptoms of Alzheimer's disease. One large federally funded study showed that vitamin E slightly delayed loss of ability to carry out daily activities and placement in residential care.

Scientists think that vitamin E may work because it is an antioxidant (an-tee-OX-uh-dent), a substance that may protect cells from certain kinds of chemical wear and tear.

No one should use vitamin E to treat Alzheimer's disease except under the supervision of a physician. The doses used in the federal study were relatively high, and vitamin E can negatively interact with other medications, including those prescribed to prevent blood from clotting.

Key Terms

Symptoms

Cognitive: Symptoms that affect memory, awareness, language, judgment and ability to plan, organize and carry out other thought processes.

Behavioral: A group of additional symptoms that occur to at least some degree in many individuals with Alzheimer's. In early stages, people may experience personality changes such as irritability, anxiety or depression. In later stages, individuals may develop sleep disturbances; wandering impulses; agitation (physical or verbal aggression, general emotional distress, restlessness, pacing, shredding paper or tissues, yelling); delusions (firmly held belief in things that are not real); or hallucinations (seeing, hearing or feeling things that are not there).

Treatments

FDA-approved: Medication approved by the U.S. Food and Drug Administration (FDA) that specifically treats a symptom of Alzheimer's disease.

Non-drug: A strategy other than medication that helps relieve a symptom of Alzheimer's disease.

Behavioral symptoms

Many find behavioral changes to be the most challenging and distressing effect of Alzheimer's disease. These include anxiety, agitation, aggression and sleep disturbances. They can have an enormous impact on care and quality of life for individuals living in both family situations and long-term residential care.

As with cognitive symptoms of Alzheimer's, the chief underlying cause of behavioral and psychiatric symptoms is the progressive damage to brain cells. Other possible causes of behavioral symptoms include:

- **Drug side effects**
  Side effects from prescription medications may be at work. Drug interactions may occur when taking multiple medications for several conditions.
- **Medical conditions**
  Symptoms of infection or illness, which may be treatable, can affect behavior. Pneumonia or urinary tract infections can bring discomfort. Untreated ear or sinus infections can cause dizziness and pain.
- **Environmental influences**
  Situations affecting behavior include moving to a new private residence or residential care facility; misperceived threats; or fear and fatigue from trying to make sense of a confusing world.

There are two types of treatments for behavioral symptoms: non-drug treatments and prescription medications. Non-drug treatments should be tried first.

Non-drug treatments

Steps to developing non-drug treatments include:

- Identifying the symptom
- Understanding its cause
- Changing the caregiving environment to remove challenges or obstacles

Identifying what has triggered behavior can often help in selecting the best approach. Often the trigger is a change in the person's environment, such as:

- New caregivers
- Different living arrangements
- Travel
- Admission to a hospital

- Presence of houseguests
- Being asked to bathe or change clothes

Because people with Alzheimer's gradually lose the ability to communicate, it is important to regularly monitor their comfort and anticipate their needs.

Prescription medications

Medications can be effective in managing some behavioral symptoms, but they must be used carefully and are most effective when combined with non-drug strategies. Medications should target specific symptoms so that response to treatment can be monitored. Prescribing any drug for a person with Alzheimer's is medically challenging. Use of drugs for behavioral and psychiatric symptoms should be closely supervised.

Behavior: Some Tips for Caregivers

Create a calm, safe environment that may be better suited for the person's abilities:

- Eliminate clutter, noise, glare and excessive background noise
- Develop soothing rituals with regular daily routines, comforting objects, gentle music and a reassuring touch
- Provide opportunities for exercise and satisfying activities geared to the person's abilities
- Monitor personal comfort: ensure a comfortable temperature and check regularly for pain, hunger, thirst, constipation, full bladder, fatigue, infection and skin irritation
- Be sensitive to frustration about expressing wants and needs
- Rather than argue or disagree, redirect the person's attention
- Simplify tasks and routines
- Avoid open-ended questions; ask yes or no questions instead
- Allow enough rest between stimulating events, such as visits from friends or neighbors
- Use labels to cue or remind the person
- Equip doors and gates with safety locks
- Remove guns

10. hope for the future

The Alzheimer's Association is the largest nonprofit funding resource for Alzheimer's research. Since 1982, we have awarded over $292 million to more than 2,000 research investigations worldwide.

When Alois Alzheimer first described the disease in 1906, a person in the United States lived an average of about 50 years. Few people reached the age of greatest risk. As a result, the disease was considered rare and attracted little scientific interest.

That attitude changed as life span increased and scientists began to realize how often Alzheimer's strikes people in their 70s and 80s. The Centers for Disease Control and Prevention recently estimated average life expectancy to be 78.5 years.

Today, Alzheimer's is at the forefront of biomedical research, with 90 percent of what we know discovered in the last 20 years. Some of the most remarkable progress has shed light on how Alzheimer's disease affects the brain. Better understanding of its impact may lead to better ways to treat it.

Clinical studies drive progress

Although many ideas about Alzheimer's treatment and prevention begin in the laboratory, the final stage of testing involves clinical (human) studies. New treatments are evaluated in humans only if laboratory tests and animal studies show good results.

In early clinical studies, a treatment is tested for safety in a small group of volunteers. Later studies, involving thousands of participants, test how well the treatment works. Hundreds of researchers are currently exploring potential methods of treating and preventing Alzheimer's in dozens of studies around the globe.

Choosing to participate in a clinical trial is an important personal decision. Treatment studies typically last at least several months, and prevention research can run for years. Most treatment studies require the involvement of a caregiver as well as the person with the disease. And joining a study is not a surefire way to get an experimental drug, as most studies randomly assign participants to receive either the drug or an inactive treatment, called a placebo. Still, many people find hope and comfort in participating. Others are motivated knowing that they are helping future patients by contributing to medical research.

Visit alz.org/trialmatch to learn more about Alzheimer's Association TrialMatch®, a clinical studies matching service that connects individuals living with Alzheimer's, caregivers, healthy volunteers and physicians with current Alzheimer's-related clinical trials.

New directions in treatment and prevention

One promising target is beta-amyloid (BAY-tuh AM-uh-loyd). This protein fragment builds up into the plaques considered one hallmark of the disease. Researchers have developed several ways to clear beta-amyloid from the brain or prevent it from forming. Experimental drugs that zero in on beta-amyloid are now being tested.

Many other new approaches to treatment are also under investigation worldwide. We don't yet know which of these strategies may work, but scientists say that, with the necessary funding, the outlook is good for developing treatments that slow or stop Alzheimer's.

While there is no known way to prevent Alzheimer's disease, research suggests that the steps people take to maintain brain health may also reduce the risk of Alzheimer's. Eating a low-fat diet rich in fruits and vegetables, exercising regularly, and staying mentally and socially active may all help protect the brain.

Some of the strongest evidence links brain health to heart health. This connection makes sense, because the brain is nourished by one of the body's richest networks of blood vessels, and the heart is responsible for pumping blood through these blood vessels to the brain. It's especially important for people to do everything they can to keep weight, blood pressure, cholesterol and blood sugar within recommended ranges to reduce the risk of heart disease, stroke and diabetes.

11. we can help

The Alzheimer's Association is the trusted resource for reliable information, education, referral and support to the millions of people affected by the disease, their families and caregivers, and healthcare professionals.

- Our nationwide network of more than 70 chapters is the core of our support lifeline.
- Our 24/7 Helpline, **800.272.3900**, provides information, referrals and care consultation in more than 170 languages and dialects.
- Our website, **alz.org**, provides comprehensive information about Alzheimer's disease and how the Association can help those affected.
- Our online Safety Center, **alz.org/safety**, features information, tips and resources to assist you with safety inside and outside of the home, wandering and getting lost, and driving and dementia.
- Our support groups, conducted at hundreds of locations nationwide, provide people with Alzheimer's and their families a confidential, open forum to share concerns and receive support.
- ALZConnected (**alzconnected.org**), powered by the Alzheimer's Association, is a social networking community that connects people with Alzheimer's, their caregivers and others affected by the disease.
- Alzheimer's Association Alzheimer's Navigator™ (**alzheimersnavigator.org**) is an online assessment program that creates customized action plans and works in conjunction with Alzheimer's Association Community Resource Finder (**communityresourcefinder.org**), an online search engine for locating community programs, services and resources.
- Educational workshops led by trained professionals on topics such as caregiving, brain health, Alzheimer's basics and living with dementia, as well as a number of free e-learning courses available at **elearning.alz.org**.
- The Alzheimer's Association Green-Field Library is the nation's largest resource center devoted to Alzheimer's disease and dementia.

Alzheimer's Association Educational Materials

Whether you're an individual with Alzheimer's, a caregiver, health professional or someone who wants to learn more about the disease, the Alzheimer's Association can help. Visit **alz.org** or call **800.272.3900** to request our consumer education materials that provide information about all aspects of Alzheimer's.

Popular Titles Include:

For individuals with Alzheimer's

- *If You Have Alzheimer's Disease: What you should know, what you should do*
- *Younger-Onset Alzheimer's: I'm too young to have Alzheimer's disease*

For Spanish-speaking audiences

- *The Latino Family and Alzheimer's Disease: A bilingual telenovela*
- *If You Have Alzheimer's Disease: What you should know, what you should do*

For African-American audiences

- *Staying Strong: Stress relief for the African-American caregiver*
- *Is It Alzheimer's or Just Signs of Aging? 10 signs every African-American should know*

For caregivers

- *Behaviors*
- *Communication*
- *Activities at Home*
- *End-of-Life Decisions*
- *Caregiver Stress*
- *Legal Plans*
- *Money Matters*

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alzheimer's association®

behaviors

How to respond when dementia causes unpredictable behaviors

the compassion to care, the leadership to conquer®

how should i handle erratic behaviors?

Alzheimer's disease and related dementias can cause a person to act in different and unpredictable ways. Some individuals with Alzheimer's become anxious or aggressive. Others repeat certain questions or gestures. Many misinterpret what they hear.

These types of reactions can lead to misunderstanding, frustration and tension, particularly between the person with dementia and the caregiver. It is important to understand that the person is not acting that way on purpose.

Behavior may be related to:

- **Physical discomfort**
  Illnesses or medication
- **Overstimulation**
  Loud noises or a busy environment
- **Unfamiliar surroundings**
  New places or the inability to recognize home
- **Complicated tasks**
  Difficulty with activities or chores
- **Frustrating interactions**
  Inability to communicate effectively

The Alzheimer's Association offers suggestions for handling behaviors such as:

Use this three-step approach to help identify common behaviors and their causes:

1. Examine the behavior

- What was the behavior? Was it harmful to the individual or others?
- What happened just before the behavior occurred? Did something trigger it?
- What happened immediately after the behavior occurred? How did you react?
- Could something be causing the person pain?
- Consult a physician to identify any causes related to medications or illness.

2. Explore potential solutions

- What are the needs of the person with dementia? Are they being met?
- Can adapting the surroundings comfort the person?
- How can you change your reaction or your approach to the behavior? Are you responding in a calm and supportive way?

3. Try different responses

- Did your new response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

1. aggression

Aggressive behaviors may be verbal (shouting, name calling) or physical (hitting, pushing). These behaviors can occur suddenly, with no apparent reason, or can result from a frustrating situation. Whatever the case, it is important to try to understand what is causing the person to become angry or upset.

How to respond:

Try to identify the immediate cause
Think about what happened right before the reaction that may have triggered the behavior.

Rule out pain as a source of stress
Pain can cause a person with dementia to act aggressively.

Focus on feelings, not facts
Rather than focusing on specific details, consider the person's emotions. Look for the feelings behind the words or actions.

Don't get upset
Be positive and reassuring. Speak slowly in a soft tone.

Limit distractions
Examine the person's surroundings, and adapt them to avoid other similar situations.

Try a relaxing activity
Use music, massage or exercise to help soothe the person.

Shift the focus to another activity
The immediate situation or activity may have unintentionally caused the aggressive response. Try something different.

2. anxiety or agitation

A person with Alzheimer's may feel anxious or agitated. He or she may become restless and need to move around or pace. Or, the person may become upset in certain places or focused on specific details.

How to respond:

Listen to the frustration
Find out what may be causing the anxiety, and try to understand.

Provide reassurance
Use calming phrases. Let the individual know you are there.

Involve the person in activities
Try using art, music or other activities to help engage the person so he or she can relax and be distracted from anxiety.

Modify the environment
Decrease noise and distractions, or relocate.

Find outlets for energy
The person may be looking for something to do. Take a walk, or go for a car ride.

3. confusion

A person with Alzheimer's may not recognize familiar people, places or things. He or she may forget relationships, call family members by other names or become confused about where home is. The purpose of common items, such as a pen or fork may also be forgotten. These situations are difficult for caregivers and require patience and understanding.

How to respond:

Stay calm
Although being called by a different name or not being recognized can be painful, try not to make your hurt apparent.

Respond with a brief explanation
Don't overwhelm the person with lengthy statements and reasons. Instead, clarify with a simple explanation.

Show photos and other reminders
Use photographs and other thought-provoking items to remind the person of important relationships and places.

Offer corrections as suggestions
Avoid explanations that sound like scolding. Try "I thought it was a fork," or "I think he is your grandson Peter."

Try not to take it personally
Remember, Alzheimer's disease causes your friend or family member to forget, but your support and understanding will continue to be appreciated.

4. repetition

A person with Alzheimer's may do or say something over and over again — like repeating a word, question or activity. In most cases, he or she is probably looking for comfort, security and familiarity.

The person may also pace or undo what has just been done. These actions are rarely harmful to the person with Alzheimer's, but can be stressful for the caregiver.

How to respond:

Look for a reason behind the repetition
Try to find out if there is a specific cause or trigger for the behavior.

Focus on the emotion, not the behavior
Rather than reacting to what the person is doing, respond to how he or she is feeling.

Turn the action or behavior into an activity
If the person is rubbing his or her hand across the table, provide a cloth and ask for help with dusting.

Stay calm, and be patient
Reassure the person with a calm voice and gentle touch.

Provide an answer
Give the person the answer that he or she is looking for, even if you have to repeat it several times. It may help to write it down and post it in a prominent location.

Engage the person in an activity
The individual may simply be bored and need something to do. Provide structure and engage the person in a pleasant activity such as taking a walk or working on a puzzle together.

Use memory aids
If the person asks the same questions over and over, offer reminders that are meaningful to the individual like notes, clocks, calendars or photographs.

Accept the behavior, and work with it
If it isn't harmful, don't worry about it. Find ways to work with it.

5. suspicion

Memory loss and confusion may cause a person with Alzheimer's to perceive things in new, unusual ways. Individuals may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. Sometimes a person may also misinterpret what he or she sees and hears.

How to respond:

Don't take offense
Listen to what is troubling the person, and try to understand that reality. Then be reassuring, respond to the feeling and let the person know you care.

Don't argue or try to convince
Allow the individual to express ideas. Acknowledge his or her opinions.

Offer a simple answer
Share your thoughts with the individual, but keep it simple. Don't overwhelm the person with lengthy explanations or reasons.

Switch the focus to another activity
Engage the individual in an activity, or ask for help with a chore.

Duplicate any lost items
If the person often searches for a specific item, have several available. For example, if the individual is always looking for his or her wallet, purchase two of the same kind.

6. wandering and getting lost

It's common for a person with dementia to wander and/or become lost. In fact, more than 60 percent of individuals with Alzheimer's will wander at some point. They may try to go home when already there or attempt to recreate a familiar routine, such as going to school or work.

How to respond:

Encourage activity
Keeping the person with Alzheimer's active and engaged will discourage wandering behavior by reducing anxiety and restlessness. Involve the person in daily activities such as doing dishes, folding laundry or preparing dinner.

Inform others
Make sure friends, family and neighbors know that the person has Alzheimer's and that wandering may occur.

Make the home safe
Install deadbolt or slide-bolt locks on exterior doors, and limit access to potentially dangerous areas. Never lock the person with dementia in a home unsupervised.

Sign up for MedicAlert® + Alzheimer's Association Safe Return® and Alzheimer's Association Comfort Zone®
MedicAlert + Safe Return is a 24-hour, nationwide emergency response service for individuals with dementia who wander or have a medical emergency. Comfort Zone is a Web application that allows family members to monitor a person's location. Visit alz.org/safety to learn more about these services.

For more information about dementia and safety, visit alz.org/safety.

7. trouble with sleep

People with dementia may have problems sleeping or experience changes in their sleep schedule. Scientists don't completely understand why these sleep disturbances occur. As with changes in memory and behavior, sleep changes somehow result from the impact of Alzheimer's on the brain.

How to respond:

Make a comfortable environment
The person's sleeping area should be at a comfortable temperature. Provide nightlights and other ways to keep the person safe, such as appropriate door and window locks. Discourage watching television during periods of wakefulness at night.

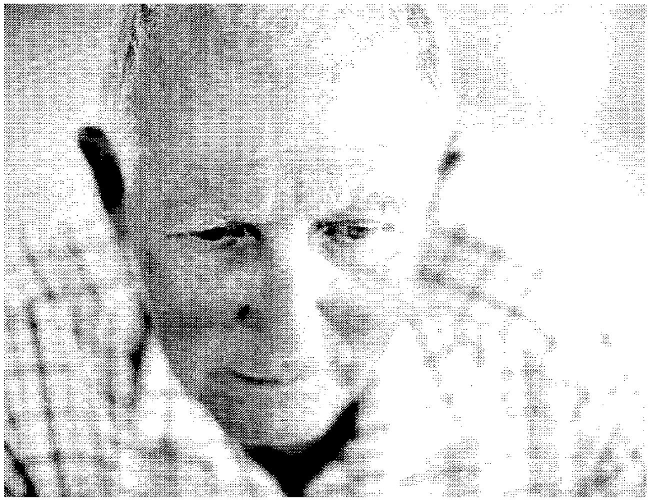
Maintain a schedule
As much as possible, encourage the person with dementia to adhere to a regular routine of meals, waking up and going to bed. This will allow him or her to sleep more restfully at night.

Talk to a doctor
Discuss sleep disturbances with a doctor to help identify causes and possible solutions. Most experts encourage the use of non-drug measures rather than medication.

Avoid stimulants
Alcohol, caffeine and nicotine can all affect ability to sleep. Avoid them as much as possible to promote better sleep at night.

10 quick tips
responding to behaviors

1. Remain flexible, patient and calm.
2. Explore pain as a trigger.
3. Respond to the emotion, not the behavior.
4. Don't argue or try to convince.
5. Use memory aids.
6. Acknowledge requests, and respond to them.
7. Look for the reasons behind each behavior.
8. Consult a physician to identify any causes related to medications or illness.
9. Don't take the behavior personally.
10. Share your experiences with others.



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alz.org/care

The Alzheimer's and Dementia Caregiver Center provides information and resources, including:

- **Alzheimer's Navigator™** — create customized action plans.
- **Community Resource Finder** — find the local resources you need.
- **ALZConnected™** — connect with other caregivers who can relate to your situation.
- **Care Team Calendar** — invite friends, family members and neighbors to sign up for caregiving responsibilities.

800.272.3900

The Alzheimer's Association 24/7 Helpline

- Confidential consultation by master's-level clinicians.
- Referrals to local programs and services.

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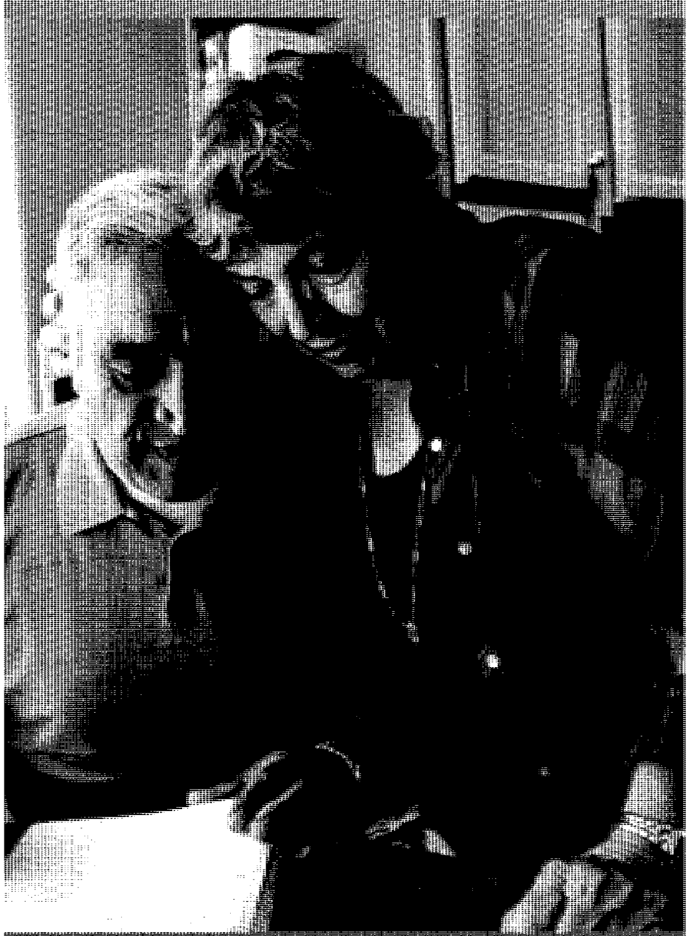
communication

Best ways to interact with a person with dementia



the compassion to care, the leadership to conquer

communication and dementia

Alzheimer's disease and related dementias can gradually diminish a person's ability to communicate. Not only do people with dementia have more difficulty expressing thoughts and emotions, they also have more trouble understanding others. The ability to exchange our ideas, wishes and feelings is a basic need.

Communication is:

- Sending and receiving messages.
- How we relate to each other.
- An important part of our relationships.
- A way to express who we are.
- More than talking and listening.
- About attitude, tone of voice, facial expressions and body language.

Changes in communication

Changes in the ability to communicate are unique to each person. A caregiver may recognize differences in the person with dementia such as:

- Difficulty finding the right words.
- Using familiar words repeatedly.
- Inventing new words to describe familiar things.
- Easily losing train of thought.
- Difficulty organizing words logically.
- Reverting to speaking in a native language.
- Using curse words.
- Speaking less often.
- Relying on gestures more than speaking.

A number of physical conditions and medications can affect a person's ability to communicate. Consult your doctor when you notice major changes.

The Alzheimer's Association recommends ways to better communicate with a person with dementia. Inside, you'll find tips for the following:

1. helping a person communicate

Communicating with a person with dementia requires patience and understanding. Above all, you must be a good listener.

To help a person communicate:

Be patient and supportive
Let the person know you're listening and trying to understand what is being said.

Show your interest
Keep good eye contact. Show the person that you care about what he or she is saying.

Offer comfort and reassurance
If he or she is having trouble communicating, let the person know that it's OK. Encourage the person to continue to explain his or her thoughts.

Give the person time
Let the person think about and describe whatever he or she wants. Be careful not to interrupt.

Avoid criticizing or correcting
Don't tell the person what he or she is saying is incorrect. Instead, listen and try to find the meaning in what is being said. Repeat what was said if it helps to clarify the thought.

Avoid arguing
If the person says something you don't agree with, let it be. Arguing usually only makes things worse.

Offer a guess
If the person uses the wrong word or cannot find a word, try guessing the right one. If you understand what the person means, you may not need to give the correct word. Be careful not to cause unnecessary frustration.

Encourage unspoken communication
If you don't understand what is being said, ask the person to point or gesture.

Limit distractions
Find a place that's quiet so you won't be interrupted. The surroundings should support the person's ability to focus on his or her thoughts.

Focus on feelings, not facts
Sometimes the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may provide clues.

2. best ways for you to communicate

As dementia progresses, communication can become more and more challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person may be.

While a person with dementia may not always respond, he or she still requires and benefits from continued communication. When communicating with him or her, it's especially important to choose your words carefully.

To best communicate:

Identify yourself
Approach the person from the front. Tell the person who you are.

Call the person by name
This is not only courteous, it also helps orient the person and gets his or her attention.

Use short, simple words and sentences
Don't overwhelm the person with lengthy requests or stories. Speak in a concise manner. Keep to the point. In some cases, slang words may be helpful.

Speak slowly and clearly
Be aware of speed and clarity when speaking.

Give one-step directions
Break down tasks and instructions into clear, simple steps. Give one step at a time.

Ask one question at a time
Don't overwhelm or confuse the person with too many questions at once.

Patiently wait for a response
The person may need extra time to process what you said. Give the person the time and encouragement he or she needs to respond.

Repeat information or questions
If the person doesn't respond, wait a moment. Then ask again. Ask the question in the same way, using the same words as before.

Turn questions into answers
Try providing the solution rather than the question. For example, say "The bathroom is right here," instead of asking, "Do you need to use the bathroom?"

Avoid confusing expressions
If you tell the person to "Hop in!" he or she may take that as a literal instruction. Describe the action directly to prevent confusion. "Please come here. Your shower is ready."

Avoid vague statements
Instead of saying "Here it is!" try saying, "Here is your hat."

Emphasize key words
Stress the words in a sentence that you want to draw attention to, like "Here is *your coffee*."

Turn negatives into positives
Instead of saying, "Don't go there," say, "Let's go here."

Give visual cues
To help demonstrate the task, point or touch the item you want the individual to use. Or, begin the task for the person.

Avoid quizzing
Reminiscing may be healthy, but avoid asking, "Do you remember when ... ?" Refrain from saying things like, "You should know who that is."

Give simple explanations
Avoid using complex logic and reasoning. Instead give clear and concise responses.

Write things down
Try using written notes as reminders, if the person is able to understand them. A written response may also help when a spoken one seems too confusing.

Treat the person with dignity and respect
Avoid talking down to the person or talking as if he or she isn't there.

Be aware of your tone of voice

- Speak slowly and distinctly.
- Use a gentle and relaxed tone — a lower pitch is more calming.
- Convey an easygoing, non-demanding manner of speaking.
- Be aware of your feelings and attitude — you may be communicating through your tone of voice, even when you don't mean to.

Pay special attention to your body language

- Always approach the person from the front.
- Avoid sudden movements.
- Keep good eye contact; if the person is seated or reclining, get down to that level.
- Be aware of your stance to avoid sending a negative message.
- Use positive, friendly facial expressions.
- Use nonverbal communication like pointing, gesturing or touching.

3. people with hearing limitations

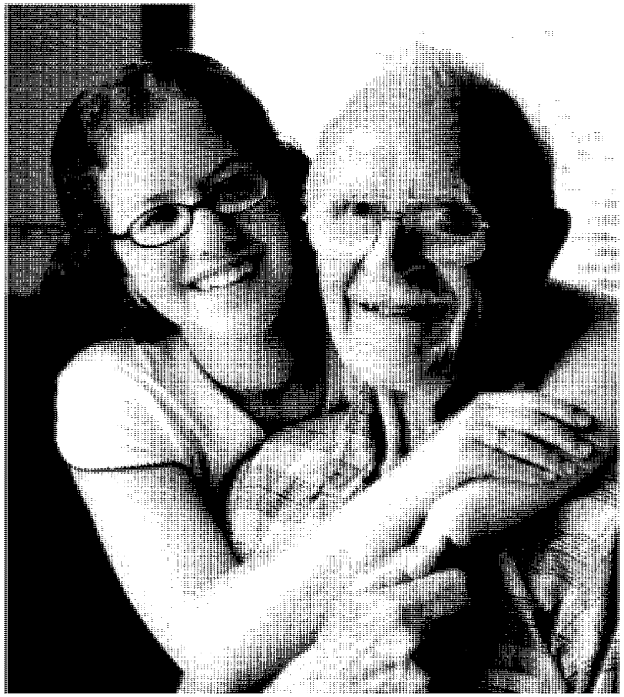
If the person has difficulty hearing:

- Approach the person from the front.
- Speak to him or her face to face.
- Get the person's attention by saying his or her name, and give a gentle touch.
- Speak slowly and clearly.
- Use a lower tone of voice.
- Use nonverbal communication like pointing, gesturing or touching.
- Write things down, if needed.
- If he or she has a hearing aid, encourage the person to wear it. Check the battery often.

4. people with vision limitations

If the person has difficulty seeing:

- Avoid startling the person with loud noises or sudden movements.
- Identify yourself as you approach the person.
- Tell the person of your intentions before you begin.
- Use large-print or audiotape materials, if available.
- If he or she has glasses, encourage the person to wear them. Keep them clean and have the prescription checked regularly.



10 quick tips

better communication

1 Be calm and supportive.

2 Focus on feelings, not facts.

3 Pay attention to tone of voice.

4 Address the person by his or her name.

5 Speak slowly and use short, simple words.

6 Ask one question at a time.

7 Avoid vague words and negative statements.

8 Don't talk about the person as if he or she isn't there.

9 Use nonverbal communication, like pointing or gesturing.

10 Be patient, flexible and understanding.

alzheimer's association®

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's®.

For information and support, contact the Alzheimer's Association:

800.272.3900
alz.org

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FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

Fact Sheet: Caregiver's Guide to Understanding Dementia Behaviors

Caring for a loved one with dementia poses many challenges for families and caregivers. People with dementia from conditions such as Alzheimer's and related diseases have a progressive *brain* disorder that makes it more and more difficult for them to remember things, think clearly, communicate with others, or take care of themselves. In addition, dementia can cause mood swings and even change a person's personality and behavior. This Fact Sheet provides some practical strategies for dealing with the troubling behavior problems and communication difficulties often encountered when caring for a person with dementia.

Ten Tips for Communicating with a Person with Dementia

We aren't born knowing how to communicate with a person with dementia—but we can learn. Improving your communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness.

1. **Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.

2. **Get the person's attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have her attention; address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.

3. **State your message clearly.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If she doesn't understand the first time, use the same wording to repeat your message or question. If she still doesn't understand, wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns or abbreviations.

4. Ask simple, answerable questions. Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, *"Would you like to wear your white shirt or your blue shirt?"* Better still, show her the choices—visual prompts and cues also help clarify your question and can guide her response.

5. Listen with your ears, eyes and heart. Be patient in waiting for your loved one's reply. If she is struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately. *Always strive to listen for the meaning and feelings that underlie the words.*

6. Break down activities into a series of steps. This makes many tasks much more manageable. You can encourage your loved one to do what he can, gently remind him of steps he tends to forget, and assist with steps he's no longer able to accomplish on his own. Using visual cues, such as showing him with your hand where to place the dinner plate, can be very helpful.

7. When the going gets tough, distract and redirect. When your loved one becomes upset, try changing the subject or the environment. For example, ask him for help or suggest going for a walk. *It is important to connect with the person on a feeling level, before you redirect.* You might say, *"I see you're feeling sad—I'm sorry you're upset. Let's go get something to eat."*

8. Respond with affection and reassurance. People with dementia often feel confused, anxious and unsure of themselves. Further, they often get reality confused and may recall things that never really occurred. *Avoid trying to convince them they are wrong.* Stay focused on the feelings they are demonstrating (which are real) and respond with verbal and physical expressions of comfort, support and reassurance. Sometimes holding hands, touching, hugging and praise will get the person to respond when all else fails.

9. Remember the good old days. Remembering the past is often a soothing and affirming activity. Many people with dementia may not remember what happened 45 minutes ago, but they can clearly recall their lives 45 years earlier. Therefore, *avoid asking questions that rely on short-term memory*, such as asking the person what they had for lunch. Instead, try asking general questions about the person's distant past—this information is more likely to be retained.

10. Maintain your sense of humor. *Use humor whenever possible, though not at the person's expense.* People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

Handling Troubling Behavior

Some of the greatest challenges of caring for a loved one with dementia are the personality and behavior changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. It also helps to not take things personally and maintain your sense of humor.

To start, consider these ground rules:

We cannot change the person. The person you are caring for has a brain disorder that shapes who he has become. When you try to control or change his behavior, you'll most likely be unsuccessful or be met with resistance. It's important to:

- *Try to accommodate the behavior, not control the behavior.* For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.
- *Remember that we* ***can*** *change our behavior or the physical environment.* Changing our own behavior will often result in a change in our loved one's behavior.

Check with the doctor first. Behavioral problems may have an underlying medical reason: perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem.

Behavior has a purpose. People with dementia typically cannot tell us what they want or need. They might do something, like take all the clothes out of the closet on a daily basis, and we wonder why. It is very likely that the person is fulfilling a need to be busy and productive. *Always consider what need the person might be trying to meet with their behavior—and, when possible, try to accommodate them.*

Behavior is triggered. It is important to understand that all behavior is triggered—it doesn't occur out of the blue. It might be something a person did or said that triggered a behavior or it could be a change in the physical environment. *The root to changing behavior is disrupting the patterns that we create.* Try a different approach, or try a different consequence.

What works today, may not tomorrow. The multiple factors that influence troubling behaviors and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all. The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Get support from others. You are not alone—there are many others caring for someone with dementia. Call your local Area Agency on Aging, the local chapter of the Alzheimer's Association, a Caregiver Resource Center or one of the groups listed below in *Resources* to find support groups, organizations and services that can help you. Expect that, like the loved one you are caring for, you will have good days and bad days. Develop strategies for coping with the bad days (see the FCA Fact Sheet, *Dementia, Caregiving and Controlling Frustration*).

The following is an overview of the most common dementia-associated behaviors with suggestions that may be useful in handling them. You'll find additional resources listed at the end of this Fact Sheet.

Wandering

People with dementia walk, seemingly aimlessly, for a variety of reasons, such as boredom, medication side effects or to look for "something" or someone. They also may be trying to fulfill a physical need—thirst, hunger, a need to use the toilet or exercise. Discovering the triggers for wandering are not always easy, but they can provide insights to dealing with the behavior.

- Make time for regular exercise to minimize restlessness.
- Consider installing new locks that require a key. Position locks high or low on the door; many people with dementia will not think to look beyond eye level. Keep in mind fire and safety concerns for all family members; the lock(s) must be accessible to others and not take more than a few seconds to open.
- Try a barrier like a curtain or colored streamer to mask the door. A "*stop*" sign or "*do not enter*" sign also may help.
- Place a black mat or paint a black space on your front porch; this may appear to be an impassable hole to the person with dementia.
- Add "child-safe" plastic covers to doorknobs.
- Consider installing a home security system or monitoring system designed to keep watch over someone with dementia. Also available are new digital devices that can be worn like a watch or clipped on a belt that use global positioning systems (GPS) or other technology to track a person's whereabouts or locate him if he wanders off..
- Put away essential items such as the confused person's coat, purse or glasses. Some individuals will not go out without certain articles.
- Have your relative wear an ID bracelet and sew ID labels in their clothes. Always have a current photo available should you need to report your loved one missing. Consider leaving a copy on file at the police department or registering the person with the Alzheimer's Association Safe Return program (see *Resources*).
- Tell neighbors about your relative's wandering behavior and make sure they have your phone number.

Incontinence

The loss of bladder or bowel control often occurs as dementia progresses. Sometimes accidents result from environmental factors; for example, someone can't remember where the bathroom is located or can't get to it in time. If an accident occurs, your understanding and reassurance will help the person maintain dignity and minimize embarrassment.

- Establish a routine for using the toilet. Try reminding the person or assisting her to the bathroom every two hours.
- Schedule fluid intake to ensure the confused person does not become dehydrated. However, avoid drinks with a diuretic effect like coffee, tea, cola, or beer. Limit fluid intake in the evening before bedtime.
- Use signs (with illustrations) to indicate which door leads to the bathroom.
- A commode, obtained at any medical supply store, can be left in the bedroom at night for easy access.
- Incontinence pads and products can be purchased at the pharmacy or supermarket. A urologist may be able to prescribe a special product or treatment.
- Use easy-to-remove clothing with elastic waistbands or Velcro^{O} closures, and provide clothes that are easily washable.

Agitation

Agitation refers to a range of behaviors associated with dementia, including irritability, sleeplessness, and verbal or physical aggression. Often these types of behavior problems progress with the stages of dementia, from mild to more severe. Agitation may be triggered by a variety of things, including environmental factors, fear and fatigue. Most often, agitation is triggered when the person experiences "control" being taken from him.

- Reduce caffeine intake, sugar and junk food.
- Reduce noise, clutter or the number of persons in the room.
- Maintain structure by keeping the same routines. Keep household objects and furniture in the same places. Familiar objects and photographs offer a sense of security and can suggest pleasant memories.
- Try gentle touch, soothing music, reading or walks to quell agitation. Speak in a reassuring voice. Do not try to restrain the person during a period of agitation.
- Keep dangerous objects out of reach.
- Allow the person to do as much for himself as possible—support his independence and ability to care for himself.
- Acknowledge the confused person's anger over the loss of control in his life. Tell him you understand his frustration.

- Distract the person with a snack or an activity. Allow him to forget the troubling incident. Confronting a confused person may increase anxiety.

Repetitive speech or actions (perseveration)

People with dementia will often repeat a word, statement, question or activity over and over. While this type of behavior is usually harmless for the person with dementia, it can be annoying and stressful to caregivers. Sometimes the behavior is triggered by anxiety, boredom, fear or environmental factors.

- Provide plenty of reassurance and comfort, both in words and in touch.
- Try distracting with a snack or activity.
- Avoid reminding them that they just asked the same question. Try ignoring the behavior or question and distract the person into an activity.
- Don't discuss plans with a confused person until immediately prior to an event.
- You may want to try placing a sign on the kitchen table, such as, "*Dinner is at 6:30*" or "*Lois comes home at 5:00*" to remove anxiety and uncertainty about anticipated events.
- Learn to recognize certain behaviors. An agitated state or pulling at clothing, for example, could indicate a need to use the bathroom.

Paranoia

Seeing a loved one suddenly become suspicious, jealous or accusatory is unsettling. Remember, what the person is experiencing is very real to them. It is best not to argue or disagree. This, too, is part of the dementia—try not to take it personally.

- If the confused person suspects money is "missing," allow her to keep small amounts of money in a pocket or handbag for easy inspection.
- Help them look for the object and then distract them into another activity. Try to learn where the confused person's favorite hiding places are for storing objects, which are frequently assumed to be "lost." Avoid arguing.
- Take time to explain to other family members and home-helpers that suspicious accusations are a part of the dementing illness.
- Try nonverbal reassurances like a gentle touch or hug. Respond to the feeling behind the accusation and then reassure the person. You might try saying, "I see this frightens you; stay with me, I won't let anything happen to you."

Sleeplessness/Sundowning

Restlessness, agitation, disorientation and other troubling behavior in people with dementia often get worse at the end of the day and sometimes continue throughout the night. Experts believe this behavior, commonly called *sundowning,* is caused by a combination of factors, such as exhaustion from the day's events and changes in the person's biological clock that confuse day and night.

- Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.
- Watch out for dietary culprits, such as sugar, caffeine and some types of junk food. Eliminate or restrict these types of foods and beverages to early in the day. Plan smaller meals throughout the day, including a light meal, such as half a sandwich, before bedtime.
- Plan for the afternoon and evening hours to be quiet and calm; however, *structured, quiet activity is important*. Perhaps take a stroll outdoors, play a simple card game or listen to soothing music together.
- Turning on lights well before sunset and closing the curtains at dusk will minimize shadows and may help diminish confusion. At minimum, keep a nightlight in the person's room, hallway and bathroom.
- Make sure the house is safe: block off stairs with gates, lock the kitchen door and/or put away dangerous items.
- As a last resort, consider talking to the doctor about medication to help the agitated person relax and sleep. Be aware that sleeping pills and tranquilizers may solve one problem and create another, such as sleeping at night but being more confused the next day.
- It's essential that you, the caregiver, get enough sleep. If your loved one's nighttime activity keeps you awake, consider asking a friend or relative, or hiring someone, to take a turn so that you can get a good night's sleep. Catnaps during the day also might help.

Eating/Nutrition

Ensuring that your loved one is eating enough nutritious foods and drinking enough fluids is a challenge. People with dementia literally begin to forget that they need to eat and drink. Complicating the issue may be dental problems or medications that decrease appetite or make food taste "funny." The consequences of poor nutrition are many, including weight loss, irritability, sleeplessness, bladder or bowel problems and disorientation.

- Make meal and snack times part of the daily routine and schedule them around the same time every day. Instead of three big meals, try five or six smaller ones.
- Make mealtimes a special time. Try flowers or soft music. Turn off loud radio programs and the TV.
- Eating independently should take precedence over eating neatly or with "proper" table manners. Finger foods support independence. Pre-cut and season the food. Try using a straw or a child's "sippy cup" if holding a glass has become

difficult. Provide assistance only when necessary and allow plenty of time for meals.

- Sit down and eat with your loved one. Often they will mimic your actions and it makes the meal more pleasant to share it with someone.
- Prepare foods with your loved one in mind. If they have dentures or trouble chewing or swallowing, use soft foods or cut food into bite-size pieces.
- If chewing and swallowing are an issue, try gently moving the person's chin in a chewing motion or lightly stroking their throat to encourage them to swallow.
- If loss of weight is a problem, offer nutritious high-calorie snacks between meals. Breakfast foods high in carbohydrates are often preferred. On the other hand, if the problem is weight gain, keep high-calorie foods out of sight. Instead, keep handy fresh fruits, veggie trays and other healthy low-calorie snacks.

Bathing

People with dementia often have difficulty remembering "good" hygiene, such as brushing teeth, toileting, bathing and regularly changing their clothes. From childhood we are taught these are highly private and personal activities; to be undressed and cleaned by another can feel frightening, humiliating and embarrassing. As a result, bathing often causes distress for both caregivers and their loved ones.

- Think historically of your loved one's hygiene routine – did she prefer baths or showers? Mornings or nights? Did she have her hair washed at the salon or do it herself? Was there a favorite scent, lotion or talcum powder she always used? Adopting—as much as possible—her past bathing routine may provide some comfort. Remember that it may not be necessary to bathe every day—sometimes twice a week is sufficient.
- If your loved one has always been modest, enhance that feeling by making sure doors and curtains are closed. Whether in the shower or the bath, keep a towel over her front, lifting to wash as needed. Have towels and a robe or her clothes ready when she gets out.
- Be mindful of the environment, such as the temperature of the room and water (older adults are more sensitive to heat and cold) and the adequacy of lighting. It's a good idea to use safety features such as non-slip floor bath mats, grab-bars, and bath or shower seats. A hand-held shower might also be a good feature to install. Remember—people are often afraid of falling. Help them feel secure in the shower or tub.
- Never leave a person with dementia unattended in the bath or shower. Have all the bath things you need laid out beforehand. If giving a bath, draw the bath water first. Reassure the person that the water is warm—perhaps pour a cup of water over her hands before she steps in.
- If hair washing is a struggle, make it a separate activity. Or, use a dry shampoo.

- If bathing in the tub or shower is consistently traumatic, a towel bath provides a soothing alter-native. A *bed* bath has traditionally been done with only the most frail and bed-ridden patients, soaping up a bit at a time in their beds, rinsing off with a basin of water and drying with towels. A growing number of nurses in and out of facilities, however, are beginning to recognize its value and a variation—the "*towel* bath"—for others as well, including people with dementia who find bathing in the tub or shower uncomfortable or unpleasant. The towel bath uses a large bath towel and washcloths dampened in a plastic bag of warm water and no-rinse soap. Large bath-blankets are used to keep the patient covered, dry and warm while the dampened towel and washcloths are massaged over the body. For more information, see the book *Bathing Without a Battle,* (details in the *Recommended Reading* section below), or visit www.bathingwithoutabattle.unc.edu/main_page.html.

Additional Problem Areas

- Dressing is difficult for most dementia patients. Choose loose-fitting, comfortable clothes with easy zippers or snaps and minimal buttons. Reduce the person's choices by removing seldom-worn clothes from the closet. To facilitate dressing and support independence, lay out one article of clothing at a time, in the order it is to be worn. Remove soiled clothes from the room. Don't argue if the person insists on wearing the same thing again.
- Hallucinations (seeing or hearing things that others don't) and delusions (false beliefs, such as someone is trying to hurt or kill another) may occur as the dementia progresses. State simply and calmly your perception of the situation, but avoid arguing or trying to convince the person their perceptions are wrong. Keep rooms well-lit to decrease shadows, and offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard. Distractions may help. Depending on the severity of symptoms, you might consider medication.
- Sexually inappropriate behavior, such as masturbating or undressing in public, lewd remarks, unreasonable sexual demands, even sexually aggressive or violent behavior, may occur during the course of the illness. Remember, this behavior is caused by the disease. Talk to the doctor about possible treatment plans. Develop an action plan to follow before the behavior occurs, i.e., what you will say and do if the behavior happens at home, around other adults or children. If you can, identify what triggers the behavior.
- Verbal outbursts such as cursing, arguing and threatening often are expressions of anger or stress. React by staying calm and reassuring. Validate your loved one's feelings and then try to distract or redirect his attention to something else.
- "Shadowing" is when a person with dementia imitates and follows the caregiver, or constantly talks, asks questions and interrupts. Like sundowning, this behavior often occurs late in the day and can be irritating for caregivers. Comfort the

person with verbal and physical reassurance. Distraction or redirection might also help. Giving your loved one a job such as folding laundry might help to make her feel needed and useful.

- People with dementia may become uncooperative and resistant to daily activities such as bathing, dressing and eating. Often this is a response to feeling out of control, rushed, afraid or confused by what you are asking of them. Break each task into steps and, in a reassuring voice, explain each step before you do it. Allow plenty of time. Find ways to have them assist to their ability in the process, or follow with an activity that they can perform.

Credits and Recommended Reading

Bathing Without a Battle, by Ann Louise Barrick, Joanne Rader, Beverly Hoeffer and Philip Sloane, (2002), Springer Publishing, (877) 687–7476.

Caring for a Person with Memory Loss and Confusion: An Easy Guide for Caregivers, (2002), Journeyworks Publishing, Santa Cruz, CA, (800) 775–1998.

Communicating Effectively with a Person Who Has Alzheimer's, (2002), Mayo Clinic Staff, *www.mayoclinic.com/invoke.cfm?id=AZ00004*

Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease,(1996), Alzheimer's Association, Chicago, IL, (800) 272–3900.

Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease, (1996), Alzheimer's Association, Chicago, IL, (800) 272–3900.

The Validation Breakthrough: Simple Techniques for Communicating with People with "Alzheimer's-Type Dementia," Naomi Feil , 2nd Edition 2002, Health Professions Press, Baltimore, MD, (410) 337–8539.

Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses, A. Robinson, B. Spencer, and L.White, (2001), Eastern Michigan University, Ypsilanti, MI, (734) 487–2335.

For More Information

Family Caregiver Alliance
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Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating health conditions that strike adults.

FCA Publications

Practical Skills Training for Family Caregivers, Mary A. Corcoran, 2003, Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, CA 94104, (800) 445–8106. *www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=954*

FCA Fact Sheets. All Family Caregiver Alliance Fact Sheets are available free online. Printed versions are $1.00 for each title—send your requests to FCA Publications, 180 Montgomery St., Suite 1100, San Francisco, CA 94104. For the full list, see: *www.caregiver.org/caregiver/jsp/publications.jsp?nodeid=345*

FCA Fact Sheet: *Dementia, Caregiving and Controlling Frustration*

FCA Fact Sheet: *Taking Care of YOU: Self-Care for Family Caregivers*

FCA Fact Sheet: *Hiring In-Home Help*

FCA Fact Sheet: *Community Care Options*

Other Web Sites

Alzheimer's Disease Education and Referral (ADEAR) Center
(800) 438-4380
www.alzheimers.org

This service of the National Institute on Aging offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and research related to Alzheimer's disease.

Eldercare Locator
(800) 677–1116
www.eldercare.gov

This service of the Administration on Aging offers information about and referrals to respite care and other home and community services offered by state and Area Agencies on Aging.

Alzheimer's Association Safe Return Program
(800) 272–3900
www.alz.org/SafeReturn

A nationwide program that identifies people with dementia who wander away and returns them to their homes. For a $40 registration fee, families can register their loved one in a national confidential computer database. They also receive an identification bracelet or necklace and other identification and educational materials.

This fact sheet was prepared by Family Caregiver Alliance in cooperation with California's statewide system of Caregiver Resource Centers. Reviewed by Beth Logan, M.S.W., Education and Training Consultant and Specialist in Dementia Care. Funded by the California Department of Mental Health. *FS-CGTU20050610.*

8: Documentation

THE WRONG AND THE BETTER WAY TO

DOCUMENT

When thinking about, "How do I document this case," always paint a solid picture of need so that others who review the case will be able to understand the need for services and hours authorized. This solid picture should always identify the consumer's functional impairments and the risk they pose to the consumer, and should spell out how In-Home Supportive Services will reduce the risk. In addition, remove all judgmental comments; instead, simply report observed behaviors and environmental conditions.

Here are a few examples that reflect two different ways to document FI ranking and/or hours authorized. The "better way" examples are often abbreviated versions of appropriate documentation. Documentation should always include information about the FI ranking and the hours authorized:

Wrong way: "The consumer needs Meal Preparation services."
Better way: "Consumer has congestive heart failure, which causes her to become short-of-breath, with minor exertion. As a result, she is only able to prepare a light breakfast (she states she has more energy in the morning), and needs meal preparation services for lunch and dinner."

[NOTES: Here the second example presents a description of functioning, but is missing information regarding types of meals and time required to prepare the meals and number of days a week needed.]

Wrong way: "Consumer's house is filthy."
Better way: "During the home visit, I observed animal feces on the floor in several places. Consumer's couch appeared stained, and had the odor of urine emanating from it. I noticed a pile of unwashed dishes in the kitchen sink, and a layer of black mold in the bathroom sink."

[NOTES: Here the "better way" presents facts and detailed observations; the statement, as originally written, could be an expression of the worker's judgment based on her own standards of cleanliness and does not provide information regarding how the social worker came to this conclusion.]

Wrong way: "Consumer needs one hour per week for Ambulation."
Better way: "During the home visit, I observed consumer attempting to ambulate. His gait appeared unsteady – he nearly fell twice during the visit – and he stated that he is afraid to walk unassisted. Consumer stated that he spends approximately 8-9 minutes per day, getting to and from the bedroom, bathroom and kitchen. This is equivalent to 1 hour per week for Ambulation."

[NOTES: MPP 30-757.14(k) defines Ambulation as, "consisting of assisting the recipient with walking or moving the consumer from place to place inside the home..." Based on the information, this consumer would also need assistance to and from the car for medical appointments. It should be evaluated and addressed here.]

Wrong way: "Consumer no longer needs Bathing services."
Better way: "Telephone call from consumer. She stated that her broken wrist is completely healed, and that her orthopedic surgeon removed her arm-cast today. She further stated that she is now bathing for herself, unassisted. Bathing services removed as of this date."

> *[NOTES: In this case, the consumer stated no further need for Bathing services, but the removal of a cast does not, per se, mean that the consumer can return to the former functioning level immediately. The worker would need additional information about the consumer's functioning now before eliminating Bathing. It is possible that the orthopedic surgeon will prescribe a regimen of physical therapy to regain functioning in the consumer's hand. If the fracture was in the consumer's dominant hand, then it is probable that the consumer will still need assistance with Bathing and Dressing until full functioning is regained.]*

Wrong way: "Consumer needs total care. Maximum hours authorized."
Better way: "Consumer has Multiple Sclerosis, and she spends the entire day in bed. She requires assistance with all ADLs and IADLs because she lacks the physical strength and endurance to perform any Domestic and Related Services or Personal care."

> *[NOTES: Here the "better way" presents a description of functioning, and its connection to the specific types of services needed to address the impairment. Good documentation would also address hours of service needed. The social worker should not assume that all consumers who need care in most or all areas of IHSS would need maximum hours. Appropriate questions should be asked to determine specific tasks, amount of time, and frequency needed.]*

Wrong way: "Consumer needs Protective Supervision."
Better way: "According to the physician's evaluation on a SOC 821, the consumer has a diagnosis of dementia from Alzheimer's disease and a history of wandering in the street, unable to recognize danger."

> *[NOTES: Here the physician's evaluation suggests elements of the consumer's behavior and cognitive limitations that could assist the SW in concluding that Protective Supervision is warranted. However, a full evaluation should be done by the SW, using the Protective Supervision criteria found in MPP 30-757.17 et seq. Additional information should be gathered about current behavior that consumer exhibits that places him/her at risk for injury, hazard or accident. Additionally, information should be solicited from others involved in the care of the consumer such as involved family members, the Regional Center, Mental Health, Day Care Centers, schools, etc.]*

Wrong way: "Consumer was uncooperative."
Better way: "Three months ago, I suggested to consumer that the local Senior Center would be a resource for him, for both socialization and daily lunches. To date, he continues to state a feeling of isolation; however he has not contacted the Senior Center yet."

> *[NOTES: The "better way" describes the consumer's statements and actions and the social worker's efforts to resolve some of the issues identified during the home visit; the "wrong way" suggests uncooperativeness. Consumers have the right to refuse services, and not to follow the SW's suggestions. While, from the SW's perspective, going to the Senior Center could reduce social isolation, the social worker should determine if there are other issues that can be resolved such as of transportation.]*

HEY, HEY, HEY, READ ALL ABOUT IT!

IHSS Social Workers are Documenting! Documenting! Documenting!

Documentation is important in each and every one of our IHSS cases; it allows the reader to have a visual picture of what took place while the social worker was in the home, and what has transpired since the home visit. This is important when, and if, the case is transferred to another worker or another county. It lays a foundation, which a consumer's history is built on. Case narrative is the readers visual picture of what has been going on with the consumer, his/her family dynamics, living environment, provider history and any changes in the consumer's health conditions.

Documentation / Narrative will be a valuable resource to you when you need to fall back on certain dates and times that a particular incident took place. It can be anything from a consumer being hospitalized, to a consumer alleging abuse by a caretaker. (Remember however, narrative alone is not enough if there is an allegation of abuse, you must also cross-report any abuse to APS/Law Enforcement on a SOC 341).

When documenting your case it is simple, just pretend that you work for the local news paper, no it is not the Daily Planet, it is the "IHSS" or the "Independent Helping Services Sentinel". Sentinel means "Look out, or Guard" which is the job of each social worker to look out for the best interest of their consumer, and guard them against possible fraud, or neglect. As a reporter for the Sentinel, it is your job to be accurate, grab the reader's attention and tell a story that will allow your reader to be there with you.

Remember you are a star reporter, the Clark Kent of Social Services, you may not have a cape, and phone booths are really hard to find these days, but you have something more powerful, and that is you are a social worker. You are providing services to the elderly and dependent adult allowing them to remain in their own home as long as possible. So what you need to do to insure safety, and insure that your consumer is receiving the appropriate services, is simple, just follow the rules of journalism: Who, What, When, Where, How, and Why. So grab your mighty pen, which can write faster than a speeding bullet, okay maybe not faster, but pretty quickly, and practice the following:

Who is calling you?	The client, doctor, family member, Lois Lane, or a friend?
What are they calling you about?	Need a new provider, changes in their medical conditions, no longer in the home, hospitalized, can't find a phone booth or just needing information about other community resources that may be available to them.
When did the incident occur?	Was it today, yesterday, last week, last year or will it be sometime in the future.
Where was the client when it occurred?	In her own home, in the hospital or racing a locomotive.
How has this affected the client?	Emotionally, physically, financially? Did the provider quit, or has consumer hired a new provider.
Why did this happen?	Was it because of the consumer, the provider, a family member? Was it because of bills were not being paid, or because of theft?

*Remember the importance of documentation: "If it isn't documented it did not happen."

State Hearings:
When going to a State Hearing, it is important that you have completed an assessment tool, covering each area of service, and documented the home visit. The State Hearing Judge will rely on documented information from your case, and testimony from you, the consumer, and other witnesses. If you did not document certain events, and the consumer denies that you addressed these issues, it will be a case of "he said, she said" and the Judge usually will err on the side of the consumer. So for better results on those rare occasions when you have a case that is appealed by a consumer, you need to make sure that your documentation is accurate, filed appropriately in your case, and that it allows the reader reviewing your case to build a visual picture of what transpired during your home visit, and how you came up with your assessments, and the hours you granted or denied.

If you follow the simple rules of journalism, who knows-one day when a new social worker comes down the road and picks up one of your cases they may say "Wow who was that Super Social Worker?!!!!!!!"

NARRATIVE GUIDE

(Note: This is only a guide. Each case should be reviewed on a case-by-case basis and documented according to your specific findings and county procedures.)
Remember to always address: ***Who? What? When? Why? How?***

1. Reason for the interaction (annual reassessment, client request because of recent hospitalization, etc).
2. Age of consumer.
3. Current living arrangement (note who else is present during the interview).
4. Condition of the home (cleanliness, cluttered, odors, unkempt, lifestyle choice).
5. Consumer's general attitude and condition during the interview (ability to understand and answer questions).
6. Consumer's diagnosis (past and present).
7. Observations noted at the time of the home visit.
8. Consumer's current functional capabilities/limitations.
9. A summary supporting any changes to Functional Index Ranking.

Example:

Prior notes indicate the consumer was able to walk or move around inside the house without assistance. Due to a recent hip surgery and failure to show any significant improvement and the fact the consumer can no longer walk or move around the house without being at risk of falling and/or injury, the consumer currently requires assistance with ambulation.
Or
Prior notes indicate the recipient had hip surgery 6 months ago with significant medical improvement. It was observed that the consumer is now able to stand, walk, and move around inside the house without any limitations. The consumer does not require assistance walking or moving around inside the house.

10. Complete name of alternative resources and/or voluntary services and hours provided.
11. Description and justifications for Protective Supervision needs or changes.
12. Description and justifications for Paramedical needs or changes.
13. If it was established at the prior home visit that Paramedical services were temporary, a review and notation should be documented in the summary regarding the continuance or denial of the current Paramedical services.

DOCUMENTATION EXAMPLES

Meal Prep: *Rank 5* – Clt. post CVA – R (dominant) side paralysis – IP must cut meat in bite-sized pieces daily – 5 min. extra per day – 7.58 hrs./wk.

Reason for Assistance: Clt. is post CVA – R (dominant) side paralysis

Daily Needs:
Breakfast – 10 minutes – mostly eats oatmeal, toast, coffee or juice
Lunch – 20 minutes – eats soups or stew
Dinner – 35 minutes – mostly grilled meat, fish or poultry, some type of vegetables and potato

Shared Living Exceptions: Clt. lives alone for now but plans to move in with daughter.

Additional information to document exception: IP must cut meat, fish or poultry and vegetables into bite-sized pieces.

Meal Cleanup: *Rank 5* – Extra time needed b/c of clt.'s spasticity. IP has to clean up many spills following each meal. 10 min. breakfast; 15 min. lunch and dinner = 4.67 hrs./wk.

Reason for Assistance: Clt. has cerebral palsy.

Daily Needs:
Breakfast – 10 minutes
Lunch – 15 minutes
Dinner – 15 minutes

Shared Living Exceptions: Clt. lives with a live-in provider; Clt. and IP did not agree to have need for related services prorated.

Additional information to document exception: Due to clt.'s spasticity, there are many spills to clean up following each meal.

Bowel & Bladder: *Rank 3* – Clt. uses urinal and commode. Needs 9 min./daily = 1.05 hrs./wk.

Reason for Assistance: Shortness of breath

Daily Needs: 9 min./daily
2 min. X 3 daily to empty and rinse urinal = 6 min./daily
3 min. X 1 to empty and clean commode after bowel movement = 3 min./daily

Additional information to document exception: Clt. uses urinal for bladder care and commode for bm. Able to wipe self after bm.

Feeding: *Rank 2* – Clt. severely depressed and will not eat without constant encouragement – 6 meals/day b/c she can't eat much at a time. Needs 15 min./meal = 10.5 hrs./wk.

Reason for Assistance: Severe depression; will not eat without constant encouragement.

Daily Needs:
15 min. each meal, 6 meals

Additional information to document exception: 6 meals because clt. can't eat much at a time.

Bed Bath: *Rank 3* – Clt. sponge bathes b/c wheelchair won't fit into bathroom. Can bathe self once basin and supplies are brought to her and returned. Bathes 3x/wk. Needs 10 min./ daily = .5 hrs./wk.

Reason for Assistance: Wheelchair-bound.

Clt. needs 3 times per week @ 10 minutes each time.

Additional information to document exception: Can wash, rinse and dry body once basin and supplies are brought to her.

Bathing: *Rank 4* – Clt. can't reach feet from shower bench. Needs help w/ shampoo b/c arthritis of shoulders. Able to clean dentures. 3 showers/wk @ 15 min. ea. = .75 hrs./wk.

Reason for Assistance: Severe arthritis of shoulders and unable to reach feet from shower bench.

Clt. needs IP help in shampooing and applying conditioner, combing hair, soaping and rinsing from legs to feet while in the shower – 3 times per week @ 15 minutes each time.

Additional information to document exception: Able to clean dentures. Able to reach most of body parts. Nails done at the nearby nail salon.

Dressing: *Rank 2* – Clt. can dress self but needs wardrobe advice b/c of his developmental disability. Time needed = 0 hrs./wk.

Reason for Assistance: Can dress self but due to cognitive impairment, needs prompting on clothing selection. Clt. needs verbal assistance in selecting appropriate clothes.

Additional information to document exception: No need to document exception since Rank 2 and 0 hours are not an exception.

Repositioning and Rubbing Skin: *Rank N/A* – Clt. needs help on and off stationary bike in home 2x/day @ 1 min. ea. = .47 hrs./wk.

Reason for Assistance: Clt. is heavy and has poor balance. Bike ride is for circulation problems.

Client need to ride bike 2 times daily; 1 min. on and 1 min. off = 4 min./daily

Additional information to document exception: Once on the bike, Clt. able to pedal (very little resistance).

Transfer: *Rank 3* – Clt. needs boost to get up and elbow support to sit down. Transfers 8x/day @ 1 min. in each direction = 1.87 hrs./wk.

Reason for Assistance: 94 years old; history of falling and dizziness; diagnosed with osteoporosis.

Clt. needs boost to get up and elbow support to sit_down 8 times per day @ 1 min. in each direction (4 times per day bed to wheelchair; 4 times per day wheelchair to couch).

Additional information to document exception: Clt. is 85 lbs., 5'5', very frail and scared of falling again.

Prosthetics: *Rank N/A* – Clt. can take meds if put into mediset. Needs 1x/wk. @ 10 min. = .40 hrs./wk. (Total Need) .17 hrs./wk. (Authorized Need)

Reason for Assistance: Poor eyesight and forgetful.

Clt. needs IP to prep meds in the mediset weekly @ 10 min./wk.

Additional information to document exception: Clt. takes meds 3 times a day. IP reminds clt. once a day while IP is at home providing other IHSS hours. (Insignificant amount of time so no extra would be authorized.) Daughter volunteers to call 2 times a day to remind clt. to take meds. (Phone calls = 1 min. each call; 14 min./wk. = .23 wk. SOC 450 form on file to show .23 min./wk. as Alternative Resources.)

Ambulation: *Rank 3* – Clt. able to walk with walker but needs elbow support down stairs in morning and up at night @ 12 min. ea. = 2.80 hrs./wk.

Reason for Assistance: Unsteady on feet; able to walk with walker but needs elbow support negotiating the stairs.

Clt. needs elbow support down stairs in the morning and going upstairs at night and once in the middle of the day when clt. naps and/or showers.

4 times/day @ 3 min. each time = 12 min./daily

Additional information to document exception: All bedrooms are on the second floor. (4 bed, 3 bath; full bath second floor and ½ bath first floor)

9: Day 2 Slides

Assessment and Authorization:
Day 2

Authorization of Services

When Authorizing Services

- IHSS operates under a “safety” standard, not a “comfort” standard.
- MPP 30-761.25 states: *“no services shall be determined to be needed which the consumer is able to perform in a safe manner without an unreasonable amount of physical or emotional stress.”*

Authorizing Services

- Consider functional rankings first.
- Break service up into components.
- Ask about the frequency and duration of each task.
- Consult existing regulatory guidelines.
- Document exceptions.
- Think critically – “What is the need?”
- Consider “good days” and “bad days.”
- Consider that at reassessment, functional rankings may change.

HTG Legislative Objectives

- HTG development is a key element of the Quality Assurance Initiative to:
  - Promote accurate and consistent service authorizations statewide
  - Facilitate equity in service authorizations

HTG Statutory Basis

- Collaborative effort:
  - CDSS, counties, advocates, consumers, providers and other interested stakeholders.
- Provide a tool for county workers:
  - Defines the scope of tasks.
  - Specifies a range of time *normally* required.
  - Provides criteria to assist in determining when an individual's service need falls outside the range.

Services Not Affected by HTGs

Line	SERVICES
AA	Domestic Services
BB	Preparation of Meals
CC	Meal Clean Up
DD	Routine Laundry, Etc.
EE	Shopping for Food
FF	Other Shopping & Errands
GG	Heavy Cleaning
HH	Respiration
I I	Bowel & Bladder Care
JJ	Feeding
KK	Routine Bed Baths
LL	Dressing
MM	Menstrual Care
NN	Ambulation
OO	Moving in and out of Bed (Transfer)
PP	Bathing, Oral Hygiene, Grooming
QQ	Rubbing Skin, Repositioning, Etc.
RR	Care and Assistance with Prosthesis
SS	Accompaniment to Medical App't.
TT	Accompaniment to Alt. Resources
UU	Remove Grass, Weeds, Rubbish
VV	Remove Ice, Snow
WW	Protective Supervision
XX	Teaching & Demonstration
YY	Paramedical Services
ZZ	Meal Allowance

Hourly Task Guidelines

The regulations were implemented for cases after September 1, 2006 for all assessments and reassessments.

Line	SERVICES
AA	Domestic Services
BB	Preparation of Meals
CC	Meal Clean Up
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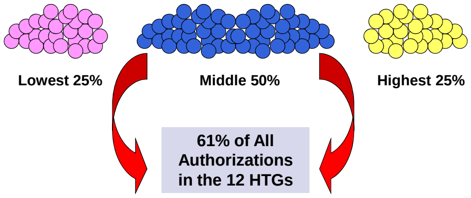
HTG Development Process

Time Ranges

- Range needed to reflect the norm
- Process
  - Standards reviewed from other states
  - Interviews with providers and consumers
- CMIPS data most reliable
  - Total Needs of all 360,000 active consumers
  - Interquartile statistical measurement used

HTG Development – Time Ranges

The **Interquartile** is the central half of the values when arraying all values in order from the smallest to the largest.



Lowest 25%

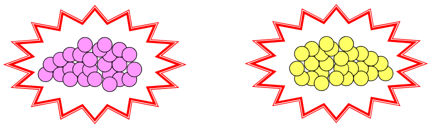
Middle 50%

Highest 25%

61% of All Authorizations in the 12 HTGs

HTG Development – Time Ranges

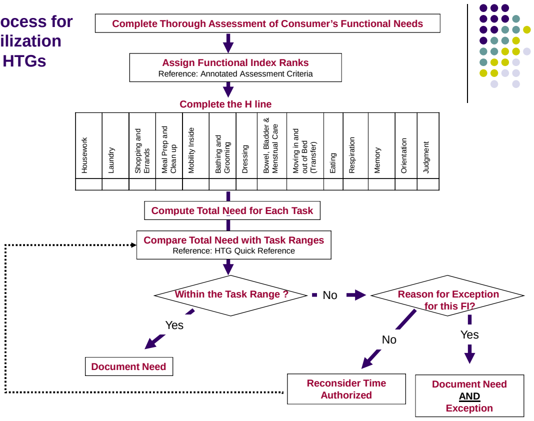
Those outside the range represent unusual or extra ordinary cases…



HTG Core Elements

- Do not replace the individualized assessment process.
- HTG ranges relate to the consumer's FI.
- No individual can have a range of time applied unless the time range meets his/her needs.
- When individual assessment indicates a need for time different than the HTG range, the different amount of time (exception) shall be authorized up to the allowable program limits (195/283 caps).
- The need for the authorized service level shall be documented in the case file.

Process for Utilization of HTGs



Complete Thorough Assessment of Consumer's Functional Needs

Assign Functional Index Ranks
Reference: Annotated Assessment Criteria

Complete the H line

Housework	Laundry	Shopping and Errands	Meal Prep and Clean up	Mobility Inside	Bathing and Grooming	Dressing	Bowel, Bladder & Menstrual Care	Moving in and out of Bed (Transfer)	Eating	Respiration	Memory	Orientation	Judgment

Compute Total Need for Each Task

Compare Total Need with Task Ranges
Reference: HTG Quick Reference

Within the Task Range ?

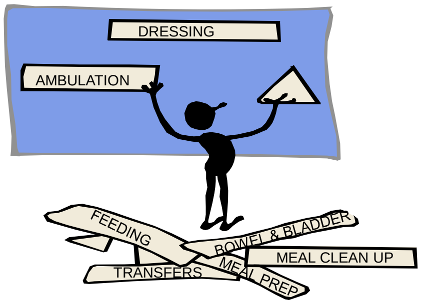
Yes → Document Need

No → Reason for Exception for this FI?

No → Reconsider Time Authorized

Yes → Document Need AND Exception

Exercise:
Category Definitions



Bowel and Bladder Care

“Bowel and bladder” care does not include insertion of enemas, catheters, suppositories, digital stimulation as part of a bowel program, or colostomy irrigation. These tasks are assessed as **“paramedical services”** specified at Section 30-757.19.

Meal Cleanup

Does not include **general** cleaning of the refrigerator, stove/oven, or counters and sinks. These services are assessed under **“domestic services”** in Section 30-757.11.

Meal Cleanup

- For meal cleanup, a recipient who has been determined able to wash breakfast/lunch dishes and utensils and only needs the provider to cleanup after dinner would require time based on the provider performing cleanup of the dinner meal only.
- A recipient who has less control of utensils and/or spills food frequently may require more time to cleanup.

Feeding

- "Feeding" tasks include assistance with reaching for, picking up, and grasping utensils and washing/drying hands before and after feeding.
- "Feeding" tasks do not include cutting food into bite-sized pieces or pureeing food, as these tasks are assessed in "preparation of meals" services specified at Section 30-757.131.

Bathing, Oral Hygiene, and Grooming

"Bathing, oral hygiene, and grooming" does not include getting to and from the bathroom. These tasks are assessed as mobility under **"ambulation"** services specified at Section 30-757.14(k).

Repositioning and Rubbing Skin *does not include:*

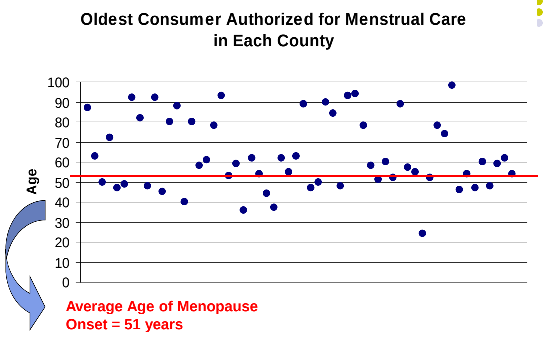
- Care of pressure sores (skin and wound care). This task is assessed as a part of "paramedical" services specified at Section 30-757.19.
- Ultra violet treatment (set up and monitor equipment) for pressure sores and/or application of medicated creams to the skin. These tasks are assessed as a part of "assistance with prosthetic devices" specified at Section 30-757.14(i).

Transfer *does not include:*

- Assistance on/off toilet. This task is assessed as a part of "bowel and bladder" care specified at Section 30-757.14(a).
- Changing the recipient's position to prevent skin breakdown and to promote circulation. This task is assessed as a part of "repositioning and rubbing skin" specified at Section 30-757.14(g).

Menstrual Care

- In assessing "menstrual" care, it may be necessary to assess additional time in other service categories specified in this section, such as "laundry," "dressing," "domestic," or "bathing, oral hygiene, and grooming."
- In assessing "menstrual" care, if the recipient wears diapers, time for menstrual care should not be necessary. This time would be assessed as a part of "bowel and bladder" care.



Average Age of Menopause Onset = 51 years

Use of Guidelines

- Functional Index ranking should be a key contributing factor, but not the only factor in determining amount of time per task.
- Services provided are subject to time guidelines unless the consumer's needs require an exception to the guideline.

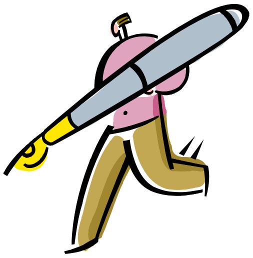
HTG Exceptions

- Assessed needs for services are outside of the HTGs.
- Result – consumer receiving more or less time.
- Because assessed needs are individualized, exceptions are **expected**.

HTG Exceptions

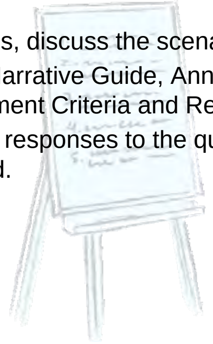
- Exceptions cannot be made due to inefficiency or incompetence of the provider.
- All exceptions must be documented in the case file.

HTG Exceptions



- *Document in a way that clarifies the need*
- *State **<u>why</u>** more or less time is necessary for **both** safety **and** maintenance of independence*

Exercise: Documenting Needs



- In groups, discuss the scenarios.
- Utilize Narrative Guide, Annotated Assessment Criteria and Regulations.
- Prepare responses to the questions provided.

Variable Assessment Intervals

Variable Assessment Intervals: 18-Month Option

- Does not apply to IHSS Plus Option cases.
- County may extend the time for reassessment for up to 6 months beyond the 12-month period.
- This should be done only on a case-by-case basis.
- Reason for extension must be documented.

Variable Assessment Intervals: Less than 12 Months

- Need for supportive services is expected to decrease in less than 12 months.
- At intake, consumer has a condition that is likely to improve over time.
- Consumer has surgery or an acute medical condition.
- Anticipated changes in living situation.
- Unsure of stability of situation.

Universal Precautions

MPP 30-757-.(A)1

- Protective practices necessary to ensure safety and prevent the spread of infectious diseases.
- Should be used by anyone providing service which may include contact with blood or body fluids.
- Should include protective barriers such as gloves or facemask.

Infectious Diseases

- Blood-borne:
  - HIV
  - Hepatitis B, Hepatitis C
  - Other blood-borne pathogens (bacteria and viruses that can cause disease in humans)
- Skin / Wound
  - Staph and Methicillin-resistant *Staphylococcus Aureus* (MRSA)
- Fecal
  - Hepatitis A
  - Parasites
  - Bacterial Dysentery

How Germs or Pathogens Can Enter the Body

- Open sores
- Abrasions
- Acne
- Cuts and burns
- Damaged or broken skin such as sunburn or blisters
- Dry, chapped, cracked or peeling hands
- Cat scratches and scrapes
- Open or torn hangnails
- Mucus membranes
- Sexually transmitted

Barriers Should Be Used For Protection . . .

- Gloves
- Protective outer layer
- Mask
- Resuscitation bags
- Sharps disposal

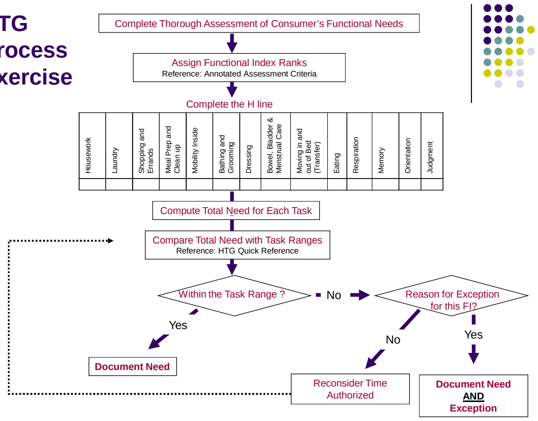
Universal Precautions and Clean Techniques

should be applied to…

all body fluids

of all consumers!

HTG Process Exercise



Complete Thorough Assessment of Consumer's Functional Needs

Assign Functional Index Ranks
Reference: Annotated Assessment Criteria

Complete the H line

Housework	Laundry	Shopping and Errands	Meal Prep and Clean up	Mobility Inside	Bathing and Grooming	Dressing	Bowel, Bladder & Menstrual Care	Moving in and out of Bed (Transfer)	Eating	Respiration	Memory	Orientation	Judgment

Compute Total Need for Each Task

Compare Total Need with Task Ranges
Reference: HTG Quick Reference

Within the Task Range ?

Yes

Document Need

No

Reason for Exception for this FI?

No

Reconsider Time Authorized

Yes

Document Need
AND
Exception

HTG Process Exercise

HTG Process Exercise

- **Identify reasons for FI ranking given**
- **Identify service hours and exceptions**
- **Give clear indication of REASON for exception (↑ or ↓ HTG) for a consumer with this FI**

Service Category FI	Hours	Exception? Y / N
1.		
2.		
3.		
4.		

Thanks For Your Participation!

10: Hourly Task Guidelines

HTG DEVELOPMENT PROCESS

Statutory Basis

SB 1104 mandates CDSS to create Hourly Task Guidelines:

SEC. 43. Section 12301.2 is added to the Welfare and Institutions Code, to read:
12301.2. (a) (1) The department, in consultation and coordination with county welfare departments and in accordance with Section 12305.72, shall establish and implement statewide hourly task guidelines and instructions to provide counties with a standard tool for consistently and accurately assessing service needs and authorizing service hours to meet those needs.
(2) The guidelines shall specify a range of time normally required for each supportive service task necessary to ensure the health, safety, and independence of the recipient. The guidelines shall also provide criteria to assist county workers to determine when an individual's service need falls outside the range of time provided in the guidelines.
(3) In establishing the guidelines the department shall consider, among other factors, adherence to universal precautions, existing utilization patterns and outcomes associated with different levels of utilization, and the need to avoid cost shifting to other government program services. During the development of the guidelines the department may seek advice from health professionals such as public health nurses or physical or occupational therapists.
(b) A county shall use the statewide hourly task guidelines when conducting an individual assessment or reassessment of an individual's need for supportive services.
(c) Subject to the limits imposed by Section 12303.4, counties shall approve an amount of time different from the guideline amount whenever the individual assessment indicates that the recipient's needs require an amount of time that is outside the range provided for in the guidelines. Whenever task times outside the range provided in the guidelines are authorized, the county shall document the need for the authorized service level.
(d) The department shall adopt regulations to implement this section by June 30, 2006. The department shall seek input from the entities listed in Section 12305.72 when developing the regulations.

12305.72. The department shall convene periodic meetings in which supportive services recipients, providers, advocates, IHSS provider representatives, organizations representing recipients, counties, public authorities, nonprofit consortia, and other interested stakeholders may receive information and have the opportunity to provide input to the department regarding the quality assurance, program integrity, and program consistency efforts required by Sections 12305.7 and 12305.71. The program development activities that shall be covered in these meetings shall include, but are not limited to:
...
(b) Development and implementation of statewide hourly supportive services task guidelines as provided in Section 12301.2.

Tasks

CDSS met with County representatives, consumers, providers, advocates, public authority representatives, and other interested parties. The group evaluated the 25 IHSS tasks and ruled out the tasks that were not amenable to task guidelines. Specifically, the four tasks of *Domestic*, *Laundry*, *Shopping* and *Errands* were excluded from the implementation efforts because Time Task guidelines already exist for those tasks. *Heavy Cleaning* was excluded because it's a task that, when authorized, is only authorized for one month and because the need is more a function of the degree of dirt that needs to be cleaned and clutter that needs to be removed. *Respiration* was excluded because it covers many