

CARING FOR PERSONS WITH DEMENTIA

Many people are caring for an elderly parent or other loved one with dementia. This is a practical guide, in a question and answer format, designed to help caregivers assist and interact with older persons with dementia. An excellent book with detailed information is *The 36-Hour Day*, published by The Johns Hopkins University Press. A web site with additional information is www.caregiver.org.

QUESTIONS & ANSWERS

1. DEMENTIA

Q. What is dementia?

A. Essentially, dementia is mental deterioration that results in cognitive deficits, including impairment in memory.

Q. What causes dementia in some older persons?

A. One or more conditions may cause dementia in older persons. Two common dementing conditions are Alzheimer's Disease and stroke (sometimes called Vascular or Multi-Infarct Dementia).

Alzheimer's Disease is a progressive brain disease that eventually causes severe impairment in most areas of mental functioning.

EXAMPLE A person with Alzheimer's disease may have mild symptoms initially but later may not remember to use a cup for drinking or a toothbrush for brushing teeth. Eventually, the person may not recognize loved ones.

Strokes cause damage (called infarcts) to one or more parts of the brain. Strokes may severely affect one or more areas of mental and/or physical functioning and leave other areas quite unaffected.

EXAMPLE A person who has had one or more strokes may exhibit poor short term memory but excellent long term memory, difficulty expressing thoughts but an ability to think clearly, or confusion about time and place but good command of information about his or her own finances and medical conditions.

The fact that the person has a cognitive deficit does not mean that the person has no cognitive strengths. It is important to offer the person opportunities to do activities that are

possible. One woman who had very limited ability to express herself in words was still able to play a musical instrument and to coordinate her clothing and accessories very well.

Q. Is there a cure for dementia?

A. Usually no. Most dementias are irreversible. About ten to twenty percent of dementia causing illnesses are reversible.

Damage from Alzheimer's Disease and strokes is irreversible. However, there are medications that improve mental functioning in people with these conditions. There are medications that reduce the risk of future strokes. Research is ongoing to develop more effective medications for Alzheimer's Disease.

If dementia is caused by some other treatable medical condition, then there may be a cure. Causes of treatable dementia include: thyroid deficiency, hydrocephalus, vitamin deficiency, and side effects of medications. A thorough evaluation is of central importance when dementia presents, and there is not a documented cause. An example of a documented cause would be a cognitive deficit that occurs following a stroke and is consistent with what would be expected, given the area of the brain shown on a brain scan as impacted.

Q. Are people with dementia mentally ill?

A. Dementia itself is not a mental illness. However, some people with Alzheimer's Disease develop psychiatric and behavioral symptoms as part of the disease process. Also, people with dementia may have coexisting conditions, such as depression or anxiety. Psychiatric and behavioral symptoms, such as agitation, intense anxiety, and paranoid thoughts, may be treated with medications. Before concluding that a symptom requires treatment with medications, it is important to rule out other causes. A behavior, such as agitation, may have a variety of causes other than a psychiatric condition, such as, pain, hunger, constipation, or side effects of medication. If agitation is caused by pain, the solution would be to seek to identify and treat the cause of the pain.

EXAMPLE A woman who had limited communication skills due to prior strokes appeared agitated and repeatedly called out for help. Her behavior could appear, without further inquiry, to be irrational. In fact, she had a serious and painful infection. Her behavior was a rational response to her condition, given her limited communication skills.

Q. Are people with dementia competent to make decisions for themselves?

A. Some are. Some are not. A neurologist or psychiatrist can evaluate and advise regarding competency.

EXAMPLE A person with short term memory loss alone may be quite capable of making financial and personal decisions. On the other hand, a person with severe impairments in

broad areas of mental functioning may not be competent to understand relevant facts and make rational decisions.

Q. Does dementia present in the same way all the time in the affected person?

A. No. Symptoms of dementia may vary from day to day for various reasons.

EXAMPLE If a person is hospitalized, the change in routine may cause greater mental difficulties during and just after the hospital stay. When out of the normal place and routine, the person is less able to rely on the usual ways of compensating for the impairments. Also, the person may feel more anxious or depressed, thus reducing the level of mental functioning. If new medication is introduced, it may have side effects that compound problems in mental functioning.

2. DEMENTIA AND LEGAL COMPETENCE

Q. Can a person with dementia execute a valid Medical or General Power of Attorney, Living Will, or Will ?

A. The answer depends upon the type and severity of the mental impairment. If the person is not able to know what he or she is doing by signing the document, then there is a lack of the necessary capacity. If the person does know, then there may be requisite capacity even though the person may be confused about time and place. Some courts have found certain individuals with dementia, caused by stroke or Alzheimer's Disease, to have the necessary capacity and to be competent to execute such documents. Witness testimony as to what the person understood, at the time of signing, is often important. The opinion of the treating physician may also be helpful.

EXAMPLE In one case, a woman with Alzheimer's Disease was found to have sufficient capacity to execute a valid Will because she knew the value and contents of her estate and to whom she desired to leave that estate, even though she was confused about her current living arrangements.

3. COMMUNICATING WITH PERSONS WHO HAVE DEMENTIA

Q. In general, how should we best communicate with the person with dementia?

A. Keep in mind that, if we live long enough, we may one day have dementia and consider how we would wish to be treated. Here are a few general principles.

Have surroundings simple and well organized. Placing identifying signs on closet doors, drawers, and the bathroom door may help reduce confusion. Having favorite possessions, pictures, or paintings on display may help the person feel safe and at home. Putting a large bright sticker next to your speed dial number on the person's telephone will make it easier for the person to call you.

Establish routines. Speak calmly, slowly, and simply. Do not criticize. Instead, praise the person. Do not display impatience. Instead, adjust your pace to the pace of the person.

If the person is perceiving something incorrectly, do not argue. We are used to trusting what our brains tell us and are likely to continue that trust even when the brain is damaged and no longer sending correct information. Instead of arguing, change the topic.

Try to understand and take account of the particular problems that the person has in mental or physical functioning. Do not talk about the person to a third party as if the person is not there. The person will feel isolated and demeaned. Include the person in the discussion.

Finally, remember that communication does not always involve words. Touch is extremely important to older persons. For a family member to hug the person and hold the person's hand can convey love and affection. By conveying love, showing the person that he or she is still useful and needed, and building the person's self esteem, we can create a more accepting and loving environment that may help the person achieve the best possible functional level.

Q. How should we communicate if the person has short term memory loss?

A. If the person has short term memory loss, give frequent cues and reminders, especially as to time and place. Try talking about events from long ago. Some people are most comfortable talking about when they were raising a family or the work they once did.

EXAMPLE Say "You had a nice lunch earlier, and soon it will be time for dinner." Ask about a place where the person once lived or a job the person held some time ago.

Q. How should we communicate if the person has difficulty expressing thoughts of any length or retrieving words from memory?

A. Ask targeted questions that can be answered with a few words instead of open ended questions. A question calling for a short answer gives the person a chance to feel successful. A question calling for a long answer may cause the person to feel embarrassed and frustrated over the inability to formulate and keep in mind a lengthy answer. Also, even if the person does not speak at length, it is fine to tell the person information. Some people who have difficulty expressing themselves understand everything you say.

EXAMPLE Instead of asking "What did you have for lunch?" ask "Did you enjoy lunch?" or "Did you have ice cream today?"

Q. What should we do if the person is slow to understand, speak, or proceed with an activity?

A. Understand that the person may take longer to process what you are saying and to respond to your requests. If the person becomes distracted, reorient the person and repeat the request. Assure the person that there is no rush. Do not raise your voice or demand that the person go faster. If the person becomes anxious and tries to hurry, progress will be even more slow.

4. DEALING WITH COEXISTING PHYSICAL DISABILITIES

Q. How do we deal with physical disabilities that are present along with dementia?

A. Physical disabilities are sometimes present because of strokes, injuries from falls, and other causes. The greater the number and severity of the problems, the more difficult it is for the person to compensate for any one problem.

Keep surroundings and routines simple and consistent. Make the living area safe. Consider grab bars in the bathroom, a shower bench, carpeting rather than hard flooring, and eliminating anything with sharp edges. Providing a life line, so that the person can push a button for help, may increase safety and reduce anxiety.

Never tell the person that he or she could do better, is not trying hard enough, or must go faster. Instead, accommodate each particular problem as best you can. Success is not measured by speed. You can adjust your pace to proceed more slowly, but the person with impairments cannot adjust his or her pace to go faster. Also, give praise for what the person can do.

EXAMPLE If the person has some degree of paralysis that makes dressing difficult, consider pull over shirts with zippers rather than buttons, shoes with Velcro rather than laces, loose pants with elastic waist, and other items that are easy to handle and promote a feeling of independence and success.

5. DEALING WITH BOREDOM

Q. What if the person seems bored or engages in scratching or other repetitive actions?

A. Understand that the person may not be able to do the activities that once were fulfilling and has very little to do. Life may seem empty and boring.

If there is vision loss, reading may not be possible. Consider books on tape, radio programs, and music tapes.

If there is memory loss, the person may not be able to follow a movie plot. Consider a news program such as Headline News or reruns of a TV show the person used to enjoy.

Provide visual and auditory stimulation in the person's surroundings, such as bright colors, paintings, a calendar, pictures, and, at times, appropriate holiday decorations. Try activities that are realistic, given the problems. If possible, take the person out to lunch or

to the stores. Plan together future activities, so that the person can look forward to something positive and enjoyable. Involve the person as much as possible in the management of his or her affairs. If you handle the person's finances, discuss and have the person make as many decisions as possible. Also, ask for advice about something you are doing. People love to feel useful and valued. Even in the final days of life, the person should be as "in charge" as possible. Feeling in control reduces anxiety and promotes a content state of mind.

6. DEALING WITH CONFUSION AND ANXIETY

Q. What should we do if the person seems anxious, upset or difficult for no obvious reason?

A. Keep in mind that confusion and anxiety in older persons may intensify at night, a phenomenon called "sundowning." It may help to have a light on at night so the person can see enough to be better oriented. Also, soft music may be a calming influence. Generally, people are helped by the presence of familiar items. If the person exhibits confusion or anxiety, start by orienting and reminding. If the person persists in saying something that is incorrect, ordinarily do not argue. Instead, change the topic. The person may shift attention to what you say and become more relaxed and cooperative.

EXAMPLE Say "It is evening, and you are in your room after having your dinner." If the person says it is morning and time for breakfast, do not argue. This may only cause greater distress. Try to change the topic. You might compliment the person about some good quality the person displays, such as "Your hair looks nice today" or "You have such a great sense of humor so much of the time."

Q. What if the person has trouble learning new things?

Sometimes people with dementia have difficulty learning anything that is new to them. Try explaining a new process simply several times. If possible, compare to something the person knew in the past.

EXAMPLE One woman told her family that she needed to pay the beautician for each visit to the nursing home beauty shop, even though the required procedure was that the beauty shop charge would be entered on the nursing home monthly bill. Her family explained the billing method and compared it to the way meals used to be entered on a monthly bill at a club the woman belonged to years ago. The woman was able to learn the nursing home billing process because of the comparison to a past similar process.

Q. What if the person says "Help me" and is not specific?

A. First orient the person as to time and place. Do not ask the person what is wrong or what do you want, as this may only increase distress if the person cannot elaborate. Instead, ask a few questions that call for short answers. This may assure the person that you care about them.

EXAMPLE “Are you warm enough ?” or “Do you need help to get to the bathroom?” or “Do you have any pain?” As you leave, assure that you will see the person soon.

Q. What if the person says “I want to go home”?

A. Often this does not mean the person wants to go to a house in which he or she once lived. What it may mean is that the person wants to feel comfortable and safe, as was the case in the past.

EXAMPLE Do not say “You are never going home.” This might cause the person to feel that he or she will never feel comfortable or safe again. Instead, try “You have a nice place here for right now , and we enjoy having you here.”

Q. What if a woman says her deceased husband visited that day?

A. She may simply be expressing a wish. Another possibility is that she is thinking about the possibility of dying and thinking about loved ones who have died. Finally, she may have forgotten that her husband has died. At times for her the memory of her husband alive may be stronger than the memory that he has died.

EXAMPLE In any event, do not tell her that he is dead and can never visit. This may only cause shock and grief, as if she were hearing the news for the first time. If she asks “Where is my husband?” say “ I haven’t seen him” or try “It would be nice to see him” or “How wonderful to have a long, happy marriage.” These comments are positive and comforting to the woman. A mother told her daughter that Dad (who was deceased) would be coming for dinner. The daughter responded that Dad would come if he could, but it would not be possible that evening.

7. DEALING WITH YOUR OWN FRUSTRATION, ANGER, OR FATIGUE

Q. What should you do if you have expressed your frustration or anger to the person with dementia?

A. Caregivers are often horrified at the anger and frustration they feel at times. Such feelings are a common experience for caregivers. Express your feelings, not to the person with dementia, but to a trusted confidant. Realize that it can be difficult to care for a person with dementia and that even a good person may become impatient at times. No one is perfect. If you have said something in frustration or anger to the person, catch yourself as quickly as possible and say that you are sorry. Try not to feel guilty or to reproach yourself. Turn the conversation in a positive direction. Let the person know that you enjoy visiting, so that the person does not come to feel that he or she is a burden. You might also praise the person and express your pride in the person’s accomplishments and efforts.

Q. What should you do to manage your feelings of frustration, anger, or fatigue?

If you are a family member involved in the care of the person with dementia, be sure that you take regularly scheduled breaks. If the person is living in an assisted living or nursing facility, and you become frustrated during visits, try taking a break for a few days or having shorter visits. If you are providing care in the person's home or your home, arrange for alternate care givers and services, as needed. Check into services available in your local community that are designed to help caregivers, such as, informational seminars and support groups. It is important to take care of yourself and do things you enjoy, e.g., take walks, go for a swim, see a movie, or engage in social activities.

There are risks in pushing yourself, rather than pacing yourself, in your care giving role. Caregiver syndrome is a debilitated condition brought on by unrelieved, constant caring for a person with a chronic illness or dementia. Depression and/or physical illness can result from trying to push yourself past your emotional limits. Keeping yourself well will enable you to be effective in your care giving role.

†This pamphlet was prepared by Patricia Horan Latham, J.D., a Washington, DC attorney, and Jean Posner, M.D., a Baltimore, Maryland neuropsychiatrist. We thank Cynthia Walker, J.D., and Patricia Quinn, M.D., for their comments and appreciate the valuable input we received from families of persons with dementia.