Dementia: Caring for Someone with Progressive Dementia

What is progressive dementia?

Progressive dementia is the gradual loss of mental functions such as the ability to think, reason, remember, and plan. Dementia is caused by damaged brain cells. A stroke, brain tumor, head injury, or disease, such as Alzheimer's or Huntington's disease, can damage brain cells. Dementia is more common in older adults.

People with dementia have trouble with things such as:

- Putting thoughts into words or responding to others
- Understanding complex information
- · Reading and writing
- · Learning new things, for example, remembering directions to new places
- · Remembering how to do things, such as how to cook something
- Remembering things that just happened or things that have just been said
- Concentrating and paying attention
- · Organizing, reasoning, and solving problems.

In the early stages of dementia, people can follow routines that are familiar to them. As the disease continues, people have serious problems with thinking, judgment, and the ability to do everyday activities. In time, people may be totally dependent on others for care. Their personality also changes.

What should I do as a caregiver?

If you are caring for a person with dementia in your home:

- Keep routines and the surroundings as much the same as possible. Try to understand their past experiences and habits. Make current routines as much like the past as possible.
- Only do for them the things that they can no longer do.
- Find and remove home hazards, such as throw rugs or poor lighting.
- Allow lots of time for communication.
- · Speak slowly and simply. Repeat or rephrase your message.
- · Ask questions that can be answered with yes or no.
- Listen to what the person with dementia is saying. Try to understand the feeling behind the person's words. Don't argue with the content of the person's thought. Agree with the feeling.
- Give choices, but limit the number of choices to two. Multiple choices can be hard for people with dementia to handle. Simple choices can sometimes help to guide behavior. If they resist cleaning up, ask, "Do you want to wipe your chin or shall I?" instead of asking, "Can I wipe your chin?"

- Reduce distractions. For example, reduce background noise by turning off the radio or TV when you need to talk to the person, or when they must accomplish a task like eating a meal.
- Don't plan complicated trips. Short day trips to familiar places can be fun. Long-distance travel is tiring and disorienting.
- · Help the person give up driving.
- · Try to limit the number of new people that are around at any one time.
- · Celebrate what they can do well. Don't focus on what they cannot do.

How should I respond to a problem behavior?

Remember that problem behavior, such as arguing, pacing, wandering, or resisting personal care, is a symptom of the disease. Don't take it personally. Change the way you respond, rather than trying to change the behavior. People with dementia usually do not know that their behavior is inappropriate. The way you respond can have a calming effect or make the situation worse. Do not try to argue or explain what is happening. Rather, divert their attention, stay calm, and reassure them.

Change any routines that may have started the behavior. Plan events to be at the best time of the day for the person with dementia. During stressful activities provide frequent breaks. Offer snacks or return to a nonstressful familiar activity.

Change the surroundings if you think it may prevent a problem behavior from happening. For example, a person who wanders may need several types of locks installed on doors or a bolt put up higher than expected.

When people with dementia cannot control unwanted behaviors, divert them to something else. For example, say, "Let's do this now, over here," rather than trying to tell them why they shouldn't do something.

If the person with dementia seems to get worse over a few days, with more disruptive and confused behavior, they may be getting sick. As a caregiver, you should make sure that the person with dementia sees their healthcare provider for a checkup. If you notice something particular about the behavior change – for example, it might be urinating in the wrong place more often – tell the healthcare provider. Your information helps the provider decide what testing to do.

What help is available?

Caring for a person with dementia can be a big challenge. It can affect family life, careers, finances, and your mental and physical health.

Find people who can help you. Nurses, adult day care, or adult protective services may be available in your area. They may include visiting services. Counseling may help you cope with problems. Don't be shy about asking for help from friends or your spiritual community.

When a family cannot keep caring for someone with dementia, other options include residential care, such as nursing facilities.

For suggestions on ways for families to deal with dementia in loved ones, contact the Alzheimer's Association at 800-272-3900 or visit their Web site at http://www.alz.org. The local Area Agency on Aging, which may be called something slightly different in your area, can also provide information about available services. If you have trouble finding the phone number for your local Area Agency on Aging, call the toll-free Eldercare Locator phone number: 1-800-677-1116.

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