

Caregiving: Some General Suggestions

(From The 36 Hour Day by Nancy L. Mace, MA, and Peter V. Rabins, MD, MPH)

Be Informed. The more you know about the nature of the diseases that cause dementia, the more effective you will be in devising strategies to manage behavioral symptoms. The behavioral symptoms you have to cope with will vary with the specific disease the person has, so it helps to have an accurate diagnosis.

Share your concerns with the person who has dementia. When a person is only mildly to moderately impaired, he can take part in managing his problem. You may be able to devise memory aids that will help him remain independent. People whose impairments are mild may benefit from counseling that can help them accept and adjust to their limitations. If the person does not recognize the problem accept his point of view.

Try to solve your most frustrating problems one at a time. Families tell us that the day-to-day problems often seem to be the most insurmountable. Getting Mother to take her bath or getting supper prepared, eaten, and cleaned up can become daily ordeals. *If you are at the end of your rope, single out one thing that you can change to make life easier and work on that.* Sometimes changing small things makes a bit difference.

Get enough rest. One of the dilemmas families often face is that the caregiver may not get enough rest or may not have the opportunity to get away from his caregiving responsibilities. This can make the caregiver less patient and less able to tolerate irritating behavioral symptoms. If things are getting out of hand, ask yourself if this is happening to you. If so, you may want to focus on finding ways to get more rest or more frequent breaks from your caregiving responsibilities. We recognize that this is difficult to arrange.

Use your common sense and imagination; they are your best tools. Adaptation is the key to success. If a thing cannot be done one way, ask yourself if it must be done at all. For example, if a person can eat successfully with his fingers but cannot appropriately use a fork and spoon, don't fight the problem; serve as many finger foods as possible. Accept changes. If the person insists on sleeping with his hat on, this is not harmful; go along with it. Cognitive losses are uneven: accept what does not seem logical.

Maintain a sense of humor; it will get you through many crises. The person who has dementia is still a person. He needs and enjoys a good laugh, too. You may both be able to laugh when something goes wrong. Sharing your experiences with other families to help you. Surprisingly, these groups of families often find their shared experiences funny as well as sad.

Try to establish an environment that allows as much freedom as possible but also offers the structure that people who have dementia need. Establish a regular, predictable, simple routine for meals, medication, exercising, bedtime, and other activities. Do things the same way and at the same time each day. If you establish regular routines, the person may gradually learn what to expect. Change routines only when they aren't working. Keep the person's surroundings reliable and simple. Leave furniture in the same place. Put away clutter.

Have an ID necklace or bracelet made for the person who has dementia. Include on it the nature of his disease (for example, "memory impaired") and your phone number. This is one of the single most important things you can do. Many people who have dementia get lost or wander away at one time or another, and an ID can save you hours of frantic worry. Stores that sell monogrammed items may make these, or your drugstore may sell them. Your local chapter of the Alzheimer's Association may be able to tell you where to purchase an ID necklace or bracelet.

Telephones and GPS devices that can help you find a lost person are also available from phone providers and other companies.

Keep the person active but not upset. Families often ask if retraining, reality orientation, or keeping active will slow or stop the course of the disease. They may ask if being idle hastens the course of the disease. Some people who have dementia become depressed, listless, or apathetic. Families often wonder whether encouraging such as person to do things will help him to function better.

Activity helps to maintain physical well-being and may help to prevent other illnesses and infections. Being active helps the impaired person continue to feel that he is involved in the family and that his life has meaning.

It is clear that people who have illnesses that cause dementia cannot learn as well as before because brain tissue has been damaged or destroyed. It would be unrealistic to expect them to learn new skills. However, some individuals can learn simple tasks or facts if they are repeated often enough. Some people who feel lost in a new place eventually “learn” their way around.

At the same time, too much stimulation, activity, or pressure to learn may upset the person who has dementia, may upset you, and may accomplish nothing. The key to this is balance:

1. Accept that lost skills are gone for good (the woman who has lost the ability to cook will not learn to fix a meal). But do know that repeatedly and gently giving information that is within the person’s abilities will help him function more comfortably (the person going into a strange day care setting will benefit from frequent reminders of where he is).
2. Know that even small amounts of excitement—visitors, laughter, changes—can upset the person who has dementia. But do plan interesting, stimulating things within his capabilities—a walk, visiting one old friend.
3. Look for ways to simplify activities so that a person can continue to be involved within the limits of his abilities (the woman who can no longer fix a whole meal may still be able to peel the potatoes).
4. Look for things the person is still able to do and focus on them. A person’s intellectual abilities are not all lost at once. Both of you will benefit from carefully assessing what he can still do and making the best use of those abilities. For example, *Mrs. B often cannot remember the words for things she wants to say, but she can make her meaning clear with gestures. Her daughter helps her by saying, “Point to what you want.”*
5. Consider having a trained person come to the home to visit the person who has dementia or trying a group program such as an adult day care. Day care often offers the right level of stimulation for some people and gives you time off as well.
6. While you may want to try activities and games that are “memory enhancing”, give priority to keeping the person who has dementia calm and comfortable. For example, if a memory game upsets the person, you may decide to stop using it.