

Caregiving

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Caregiving is a long, hard, full time job. Caregivers are often called the "hidden victims" of Alzheimer's disease. Although changes in brain tissue only occur in the person diagnosed with having dementia, changes in behaviors, life style and demands occur in both the patient and the caregiver. It is the caregivers who must adjust, modify behaviors and adapt to the effects of the illness and how it presents in the person they love.

Sometimes the pain of seeing someone you love deteriorate is veiled by "denial." A caregiver may not be able to see how bad the person is. While this denial helps decrease the devastating feelings a person may have, it may also prevent a caregiver from initiating changes or learning new things that may eventually make caregiving easier.

Sometimes caregivers are embarrassed by a loved ones behaviors. This is understandable. It is embarrassing to see your wife walk into a room of company with her nightgown on over her clothes, or have the neighbors bring your husband home after he has slipped out the back door. Unfortunately, these behaviors are a part of the illness and are another example of needed adjustments the caregiver must make.

Why do people do it?

Some caregivers feel responsibility. Some don't feel the overpowering sense of responsibility but just fall into the role and accept it. Others feel they don't have a choice. They may ask who would do it if they didn't. How you accept the role and your feelings about caregiving do make a difference.

What to try:

Join a support group. There are many other people experiencing similar feelings of loss and embarrassment who will benefit from hearing from you, and you can learn much from them.

Learn all you can about caregiving.

Take breaks (respite) from caregiving right from the beginning. Learn to recognize your symptoms of stress and take time to relieve them.

Laugh: some of the stuff is downright funny. Consider it a gift.

Let other people help you. Assume the offers are sincere and allow others to help.

Keep relatives who are not actively involved in caregiving informed of the person's condition. Send them A.D. literature if they seem to ask obscure questions or respond inappropriately.

Attend meetings when you can and read the literature.

Plan ahead. Look at nursing homes or assisted living facilities in case you become ill and have to temporarily give up your caregiving responsibility.

Tell neighbors and friends generally about the condition and what they can expect to help ease the tension of embarrassing moments.