

A Guide for Individuals Who Care for Persons with Dementia

Preventing Stress from Becoming Harmful



Developed by:

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Has caring for your family member or friend with dementia become overwhelming?

Do any of these quotes describe how you feel?

- "I'm like a pot ready to boil over?"*
- "I used to go out and now I am a prisoner in my own home."*
- "I feel like I am out of control."*

Caring for a person with dementia may be the most difficult and demanding work you have ever done. You may have to draw on special skills and knowledge that you never imagined you would need. Most individuals are not prepared for the devastation of dementia and the overwhelming responsibilities involved in caregiving.

Patience and tolerance are put to the test!

Caring for a person with dementia is difficult because of:

- daily ups and downs
- unexpected changes
- having to take on new tasks and roles
- loss of those special moments and connections
- fatigue that never goes away
- profound sadness of losing the essence of a loved one
- not knowing the duration of the illness

What is dementia?

- ❑ At one time, it was called senility. Now the term “dementia” is used to describe a decline in mental abilities (especially memory) or the loss of the ability to think. **It is not a normal part of aging.**
- ❑ There are many causes of dementia, some of which are reversible. These conditions are caused by medications, infections, severe depression, nutritional disorders, and chemical or hormonal imbalances (such as thyroid disease). However, many dementias (such as Alzheimer’s disease) result in permanent, progressive brain damage.
- ❑ Complete medical evaluations are important to determine the cause of mental changes and proper treatment. Even in dementias that are not reversible, treatments are available that may help manage common difficulties such as sleep disturbances, agitation and behavioral problems. Regular checkups will help maintain the person’s physical health.
- ❑ Behavioral changes in the person with dementia may be especially stressful for caregivers. The person with dementia may no longer know you. You may also find yourself caring for someone who is nothing like the person you have always known.

It is important to remember that the person with dementia does not have control over these changes!

Key point:

Older persons experiencing mental changes should have a complete medical and psychological evaluation.

What triggers your stress?

It is normal to feel overwhelmed. Caregiving is physically and emotionally demanding. The stresses of caregiving may cause you to reach your limit. Stress can result in harm to you and the person for whom you are caring.

The first step in reducing stress is to identify situations that trigger it. Many caregivers report that the following behaviors related to dementia cause stress.

Look over the list and check all the behaviors that are bothersome to you.

- repeats the same thing over and over
- hits or grabs me in a mean way
- yells or swears at me or other people
- talks or acts in sexual ways that make me uncomfortable
- keeps me up at night
- acts suspicious or accuses me of things
- clings to me or follows me around
- has bladder or bowel accidents
- wanders outside the house
- refuses to do what he/she needs to do
- other behaviors _____

Key point:

There are practical ways to help understand the causes and management of problem behaviors.

Problem behaviors may be the result of brain damage, reaction to frustration, fear, fatigue or physical illness.

Discussing these behaviors with other experienced caregivers or professionals can help you find ways of managing the situation and reducing tension.

How do you respond to the stresses and strains of caregiving?

The second step in reducing your stress is to become aware of its effect on you and how you react to stressful situations. Some stress is normal, but if you are frequently feeling the negative effects of caregiving, it may mean that things are getting too difficult.

Check any of the following feelings or reactions to stress that you often (several times a week) have.

When I am stressed because of caregiving I:

- am downhearted, sad or blue
- have more physical aches and pains
- isolate myself from others
- drink more alcoholic beverages or take more medications
- am pressured by competing responsibilities to the person I am caring for and to my family members
- question my ability to provide care
- am unable to eat or eat excessively
- list other reactions to stress

If you have checked any of the statements listed above, you may be at a point where your health and well-being are suffering. **Consider seeking help!** The Alzheimer's Association can link you with support services and help you get some relief. Telephone Helpline, support groups, information and educational programs are valuable for understanding your feelings and getting practical ideas. You also may want to discuss your situation with your doctor. It may be helpful to share with the doctor your list of feelings and stress reactions.

Are you at risk for crossing the line between caring and neglecting or mistreating?

It is important to be aware of how your reactions to stress affect the person with dementia. Harm can result from the caregiver's poor judgement, overwhelming feelings of anger and frustration, and inability to fulfill his/her responsibilities.

Harm can occur without intent.

Key point:

Caregiver strain can affect you and the person under your care. Without realizing, caregivers can be at risk for mistreating the person with dementia.

Due to the frustration and strain of caregiving, I (check all that apply):

- leave the person with dementia alone longer than I intend
- allow the person with dementia to take his/her medications without help although he/she has made mistakes in the past
- allow the person with dementia to leave home alone, even though I think he/she would get lost
- use the person's money or property for reasons other than his/her care, without permission
- yell or swear at the person with dementia
- give care in a rough way
- hit or physically lash out at the person with dementia

If you circled even one of the statements above, you may be neglecting or mistreating the person for whom you care. The more you have checked, the greater your risks of harming the person you are trying to help. This may surprise you, but you are in the **danger zone!**

You are not alone, help is available.

The stress of caring for someone with dementia may place you in a situation you never thought you would experience. You may feel that the situation is uncontrollable. Although there are many aspects of caregiving that you cannot change, you can control the way you react to stress. Recognize what triggers your stress and seek the assistance you need to make things more manageable. There are others in your community who understand and who are able to help.

Where to Find Help

There are services in the community to help reduce the strain of caregiving. In addition to the Alzheimer's Association there are other agencies that specialize in providing services to older adults and their caregivers. Services that may be useful to you include:

- home health services
- companion/chore services
- adult day care centers
- respite or time out at nursing homes or assisted living facilities
- counseling
- legal advice
- money management
- support groups and educational programs

For more information about Adult Protective Services (APS) call:

APS (216) 420-6700
WRAA PASSPORT Services (216) 621-0303

The harmful effects of caregiver stress can be prevented. Let other experienced caregivers help you through the challenges of caring for a person with dementia.

For help and support, simply call one of these agencies:

Cleveland Chapter Alzheimer's Association
(216) 721-8457

Western Reserve Area Agency on Aging
(216) 621-8030

