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## What it means to be a caregiver

*Luciana Cramer, Educator and Care Special-*

Caregiver: a person who gives care. It is such a self-descriptive, widely used and recognizable term. Have you ever thought about what it really means to be a caregiver? More specifically, what does it mean to be a **caregiver for a loved one with dementia?**

Family caregivers are those who step in to assist in performing necessary tasks that a loved one is no longer able to perform alone. These tasks vary, including assistance with practical matters, such as handling insurance, paying bills or coordinating with family and friends; assistance with physical care – bathing, dressing, eating and taking medication; and assistance with emotional care – facilitating activities, providing companionship and love.

Family caregivers may provide hands-on, direct care, or long-distance supervision and managerial care – yes, long-distance caregivers are caregivers too!

In dementia care, the need for assistance begins long before full-blown dementia sets in. A patient with mild cognitive impairment (MCI) or in the early stages of dementia, although able to make decisions, may need help with organizing schedules, monitoring finances and keeping a social calendar. A close relative, most often a spouse or adult child, may offer help, not fully realizing that this is the very start of a caregiving relationship. Some caregivers work as a team: mother and daughter assisting dad; siblings working together to assist mom. But in a majority of cases there is a single caregiver who takes over most care responsibilities.

As dementia progresses, patient's needs become more personable and more time consuming. Dementia often causes changes in personality and communication skills that caregivers find unsettling. Physical and emotional needs become more demanding and



a caregiver will need to utilize help from external resources, such as family members, friends, professional caregivers and community organizations. While a family caregiver may be able to manage complete assistance in the early stages of dementia, in the later stages it is not possible to provide care alone without serious safety risks for both patient and caregiver.

Identifying exactly when care responsibilities become too demanding is one of the biggest challenges for caregivers of dementia patients. Dementia generally progresses gradually, in small increments, over the course of several years. And so do the tasks of caregiving. Given the incremental nature of dementia caregiving, the caregiver may not recognize the point where the toll grows too high and exceeds safety levels.

Caregivers should be aware of all the stresses they are under. There are **physical** stresses related to the exertion of providing assistance with personal needs, hygiene, housekeeping, lifting and cleaning. There are **financial** stresses given that dementia costs are estimated to be three times as much as other conditions. There are **environmental** stresses. The home must be modified to attend to the unique needs of dementia patients, and companion caregivers may find themselves living in uncomfortable settings. There is also the **social** stress, given that dementia leads to isolation, and the

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## Tips

### 10 Symptoms of Caregiver Stress

1. Denial about the disease and its effect on the person who's been diagnosed.
2. Anger at the person with Alzheimer's or others, anger that no cure exists or that people don't understand what's happening.
3. Social withdrawal from friends and activities that once brought pleasure.
4. Anxiety about facing another day and about the future.
5. Depression that begins to break your spirit and affects your ability to cope.
6. Exhaustion that makes it nearly impossible to complete necessary daily tasks.
7. Sleeplessness caused by a never-ending list of concerns.
8. Irritability that leads to moodiness and triggers negative responses and actions.
9. Lack of concentration that makes it difficult to perform familiar tasks.
10. Health problems that begin to take a mental and physical toll.

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caregiver often becomes isolated too, without the benefit of the companionship that existed in the relationship with the patient prior to the onset of dementia. And finally there is **emotional** stress, of juggling multiple responsibilities and suffering the effects of social isolation while experiencing every stage of grief at once, every day, month after month... with no end in sight.

Given the prolonged extent of caregiving, the high demands of dementia care and the stresses caregivers live under, it is no wonder that dementia caregivers are among the most stressed people in the world and have elevated risks of developing certain health conditions, such as high blood pressure, anxiety, shingles, heart attack and, most ironically, Alzheimer's disease.

The Alzheimer's Association suggests caregivers who want to minimize their risks of burning out or becoming ill observe the following guidelines:

**1. Find time for yourself.** Take advantage of respite care so you can spend time doing something you enjoy. Respite care provides caregivers a temporary rest from caregiving, while the person with Alzheimer's continues to receive care in a safe environment. Visit [alz.org/care](http://alz.org/care) to learn more about respite care.

**2. Know what community resources are available.** Contact the Alzheimer's Association or use our online Community Resource Finder ([alz.org/communityresourcefinder](http://alz.org/communityresourcefinder)) to find Alzheimer's care resources in your community. Adult day programs, in-home assistance, visiting nurses and meal delivery are just some of the services that can help you manage daily tasks.

**3. Become an educated caregiver.** As the disease progresses, new caregiving skills may be necessary. The Alzheimer's Association offers programs to help you better understand and cope with the behaviors and personality changes that often accompany Alzheimer's. Visit the Alzheimer's and Dementia Caregiver Center at [alz.org/care](http://alz.org/care) to learn more and access care training resources, including free e-learning workshops.

**4. Get help and find support.** Seek the support of family, friends and people who can relate to your situation. Use our online Care

Team Calendar ([alz.org/carecalendar](http://alz.org/carecalendar)) to organize family and friends who want to help. Our 24/7 Helpline (800.272.3900), ALZConnected® online social networking community ([alzconnected.org](http://alzconnected.org)) and local support groups are good sources for finding comfort and reassurance. If stress becomes overwhelming, seek professional help.

**5. Take care of yourself.** Watch your diet, exercise and get plenty of rest. Making sure that you stay healthy will help you be a better caregiver.

**6. Manage your level of stress.** Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, change in appetite). Note your symptoms. Use relaxation techniques that work for you, and talk to your doctor.

**7. Accept changes as they occur.** People with Alzheimer's change and so do their needs. They may require care beyond what you can provide on your own. Becoming aware of community resources — from home care services to residential care — should make the transition easier. So will the support and assistance of those around you.

**8. Make legal and financial plans.** Plan ahead. Consult a professional to discuss legal and financial issues including advance directives, wills, estate planning, housing issues and long-term care planning. Involve the person with Alzheimer's and family members when possible. Use Alzheimer's Navigator™ ([alz.org/alzheimersnavigator](http://alz.org/alzheimersnavigator)) to help assess your needs and create a customized action plan.

**9. You're doing your best.** Know that the care you provide makes a difference and you are doing the best you can. You may feel guilty because you can't do more, but individual care needs change as Alzheimer's progresses. You can't promise how care will be delivered, but you can make sure that the person with Alzheimer's is well cared for and safe.

**10. Visit your doctor regularly.** Take time to get regular checkups, and be aware of what your body is telling you. Pay attention to any exhaustion, stress, sleeplessness or changes in appetite or behavior. Ignoring symptoms can cause your physical and mental health to decline.