

## Caregiver's Guide

A person becomes a caregiver to provide for the needs of a relative or friend who is ill or disabled. The caregiver is often an adult daughter or daughter-in-law, and is often an older adult herself. The person being cared for may need help due to mental illness, memory problems, physical illness or injury, or some combination of these.



A caregiver's job can be very rewarding but may also be frustrating and stressful. Most caregivers are not specifically prepared or trained for the role. In some cases, it is a role assumed very reluctantly or because there was no other choice.

**You must be realistic about what to expect.** The following suggestions may help:

Do not put too much pressure on yourself.

Get medical information so that you understand the cause of the person's illness, his or her limitations, what symptoms to expect, and the likely course of the illness.



Often the person being cared for cannot control what he or she says or does. This is especially true for those with dementia, head injury, Huntington's disease, and those who have had a stroke. Knowing these behaviors are a symptom of the disease and not in the person's control should decrease anger, frustration, and hurt feelings.

Allow the person to be as independent as possible in his or her care, and include the person in decision-making whenever possible. Give the person limited choices when you can ("Do you want your red shirt or the blue one?"). The person may take longer to do things without help but could also find great satisfaction in taking part in his or her own care. For example, you could seat the person in front of the sink, set out the toothbrush and toothpaste, and assist only if needed. Provide cues and directions in simple steps. He or she may need



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help performing tasks in the proper order. (For example, say "Pick up your coat...put your arms in...button it up," rather than "Put on your coat.")

Always tell the person what to do, not what he or she should not do.

### **In order to cope with your new caregiver role, you may want to do several things:**

Set reasonable goals to ensure the person's comfort and safety. You also want to provide a calm atmosphere and foster the person's self-esteem and independence.

Accept that goals and care will change all the time. You must be very flexible. Become skilled at noticing changes in condition so you can report them to the person's health care provider.

Learn how to coordinate activities, delegate tasks to others when needed, and plan for the future.

Pay attention to your own physical and emotional health. Caregivers are often on duty 24 hours every day. There is little or no time to address your own mental and physical well-being. This can lead to illness or burnout if you do not take steps to prevent it. Remember, the best predictor of your loved one's continued well-being is **your** continued health and ability to care for him or her. When you take care of yourself, it is for you **and** for your loved one.



### **Here are some suggestions to help caregivers avoid burnout:**

Accept your own limitations and those of the person for whom you are caring.

Accept help from friends and family to schedule times when you can leave the home to relax or take care of your own affairs. Tell people what you need them to do, rather than wait for them to offer. For example, you might ask someone to sit with the person being cared for, to watch TV with or to read to him or her. Even if others don't do things just the way you would, as long as they do a good job, let them do it.



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Consider placing your loved one in adult day care at least 2 or 3 days a week. The facility may even provide transportation. If the person is a veteran, contact the local Veterans Affairs office and ask what benefits are available.

Learn to manage your own stress on an ongoing basis. You need to take time to relax. Get a good night's sleep by having someone else stay over sometimes to answer the nighttime calls of the person you care for.



Listen to music and sing while working in the house. The elderly respond very well to music, especially to the old tunes that bring back memories. Even those with Alzheimer's will sometimes surprise people by remembering the words to a favorite song when they can't even put together a sentence in conversation. Music will often be calming when other methods fail.

Join a caregivers' support group. Talking with others and sharing problems and solutions really helps. You are not alone in your concerns.

Look for positive experiences in caregiving. It is often a way to return many years of loving care by a parent or spouse.

If the situation calls for it, do not be reluctant to place your loved one in a nursing home or other facility. This may be an adult family home (a private home licensed by the state to care for a limited number of clients) or an assisted living facility (each person may have his or her own room but there is 24-hour care with services such as meals, laundry, housekeeping, and chore service). The move can be temporary for a few weeks or a few months. You may need to take a trip or recover from an illness. In some cases where the care required by the person is too great, permanent placement may be required.



Contact your state Division on Aging agency about counseling, social work services, and home health/chore services. Call the National Eldercare Locator hotline (1-800-677-1116) for help locating community resources for seniors including benefit issues, nursing homes, and legal help.

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Don't forget to include children to help in the care. They can do chores for you, play cards or games with the person being cared for, or just talk with him or her.



Have regular family meetings for sharing feelings and information. If possible, include the person being cared for in these talks. Use this time to make plans and to improve communication and cooperation between family members.

Use other services available in the community:

Nursing homes may offer respite beds where you can place the person you care for on a temporary basis (usually less than 2 weeks) while you take a vacation or just get time off for yourself. This is especially good for a weekend getaway or other family events such as weddings that the person you care for cannot attend. These stays usually must be privately paid for and require a doctor's orders.

Churches and fraternal groups (such as the Elks and Masons) may have volunteers to give you several hours off.

Home health agencies may have nurses and certified nursing assistants you could hire to stay with your loved one from time to time.



The caregiver's role requires a lot of time and energy. But there can be great satisfaction and joy in keeping loved ones at home and making them a part of family life. The key is keeping a balance between giving to another and caring for oneself.



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