

Caregiver's Guide

A caregiver is someone who provides for the needs of a relative or friend who is ill or disabled. The person being cared for may need help because of physical illness or injury, mental illness, memory problems, or some combination of these. The caregiver might be, for example, an adult daughter. Many caregivers are also caring for young children or grandchildren at the same time.

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

When you are the caregiver, you must be realistic about what to expect. The following suggestions may help:

- Get information about the person's medical problems. Information can help you better understand his or her limitations, know what symptoms to expect, and have an idea of the likely course of the condition.
- Often the person being cared for cannot control what he or she says or does. This is especially true for people who have dementia, head injury, or a stroke. Reminding yourself that the behavior is a symptom of the disease and not in the person's control may help you feel less angry, frustrated, or hurt.
- Allow the person to do as much as he or she is able to do. Include them in decision making whenever possible. Offer limited choices when you can. For example, "Do you want your red shirt or the blue one?" The person may take longer to do things without help but could also find 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 help only if help is needed. Provide cues and directions in simple steps. He or she may need help doing tasks in the right order. For example, you might say "Pick up your coat, put your arms in, and button it up," rather than just, "Put on your coat."
- Be positive. Tell the person what to do instead of what he or she should not do.

In your caregiver role, you may want to do several things:

- Set reasonable goals to ensure the person's comfort and safety. A calm atmosphere can help foster a sense of self-esteem and independence. Reminding yourself to stay calm can also lessen your own tension and frustration.
- Accept that goals and needs for care can change from day to day. You must be very flexible.
- Become skilled at noticing changes in the person's condition so you can report them to the healthcare provider.
- Learn how to coordinate activities and delegate tasks to others when needed. Try to always plan ahead.
- Pay attention to your own physical, mental, and emotional health. If you are on duty 24 hours a day, there may be little or no time to care for yourself. 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 helps you **and** your loved one.

Here are some suggestions to help you avoid burnout:

- Accept your own limitations and those of the person you are caring for.
- Ask others to help you. Accept help from friends and family. Tell people what you need them to do, rather than wait for them to offer. Sometimes people are afraid of intruding or don't know what help to offer. If help is offered but not what you need, be honest and say so. Suggest something they can do that would help. Even if others don't do things just the way you would, as long as they do a good job, let them do it.
- Make sure you keep managing your own stress. Schedule times when you can leave to relax or take care of your own affairs. For example, you might ask someone to sit with the person being cared for and watch TV or read to him or her. Get a good night's sleep by having someone else stay over sometimes to answer nighttime demands.
- Consider placing your loved one in adult day care for a few hours or days each week. The adult day care facility may provide transportation.
- If the person you are caring for is a veteran, contact the local Veterans Affairs office and ask what benefits are available.
- Listen to music and sing while working in the house. Older adults respond well to music, especially to the old tunes that bring back memories. Even people with Alzheimer's disease surprise people by remembering the words to a favorite song even though they can't 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.
- Try keeping a journal. Write down your thoughts, frustrations, and anger. Journaling can be a good way to relieve stress. Include the positive experiences of caregiving. Your journal notes, particularly the notes about good things that happen, can be a great source of comfort and joy.
- It may help to look at care giving as a way to give back many years of loving care by a parent or spouse. Know that because you did all you could while the person was alive, you will not have regrets.
- If you need to take a trip or recover from an illness, you may be able to use respite care. Someone else may provide care in your home, or you may be able to place the person temporarily in a nursing facility.
- In some cases, the care that is needed is more than you can do. The person you are caring for may need to move to a nursing facility. Moving them to such a facility may actually be the most loving thing you can do. It is likely to be hard emotionally but still may be the best choice. It may help you keep a loving relationship. One of the greatest risk factors for elder abuse is an overburdened caregiver.
- Contact your state Division on Aging agency about counseling, social work services, and home health and chore services. Call the National Eldercare

Locator hotline (1-800-677-1116) for help finding community resources for seniors and their caregivers. This may include benefit issues, nursing facilities, and activities for older adults, such as card games or conversation.

- Have regular family meetings for sharing feelings and information. If possible, include the person being cared for in these meetings. Use this time to make plans and to improve communication and cooperation among family members.
- Use other services available in the community:
 - Nursing facilities 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 are usually paid for privately and require a healthcare provider's orders.
 - Churches and other organizations may have volunteers to give you several hours off or provide other services.
 - Home health agencies may have certified nursing assistants or homemaker aides you can hire to stay with your loved one from time to time.
 - You might want to contract with a geriatric care manager. Geriatric care managers can assess needs, arrange for services in the home, help with financial management, and even take the person to medical appointments for you. They are experts about the services available in the community. No services are provided that you do not agree to. You can use their services one time, for a short time, or on an ongoing basis. The local Agency on Aging or Eldercare Locator can help you find geriatric care managers.

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 a part of family life. The key is keeping a balance between giving to another and caring for oneself.

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