

CAREGIVERS AND SERIOUS ILLNESS



Do you regularly provide care to a family member, neighbor, or friend with a serious illness? Do you help them with tasks like grocery shopping, cleaning their home, or getting dressed? Do you need information about providing this care or a short break from doing it? If you answered “yes” to any of these questions, you are likely a family caregiver. “Family” can be people related to us or those we choose to call family.

Caregiver Responsibilities

When a family member has a serious illness, you may help with health care decision-making, medical procedures and care, and daily activities. You may buy and prepare food; manage finances, legal work, and insurance; provide transportation; do housework; handle your loved one’s former responsibilities, such as child care; and provide help with daily activities like bathing and eating.

If your family member has a brain disease like Alzheimer’s disease or another type of dementia, mental health problems, or a brain injury, you may have even more responsibilities. These can include complex tasks and the most basic human tasks. People with dementia get progressively worse over time so that you may provide more and more help, until the person is totally dependent on you.

As a caregiver, you need clear information and directions about your loved one’s condition and health care needs. Getting this information from health care providers is very important during major changes, like leaving a hospital or nursing home. Having conversations with your loved one about treatment choices and making plans for care is important.

Getting Help

You may feel good about helping your family through serious illness and from having close connections with them. However, caring for a family member’s physical, mental, and emotional needs can take a toll on you. You may experience distress, anxiety, depression, exhaustion, and worsening of your own physical and emotional well-being. As a result of these types of stress, your health can suffer.



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You are likely to need help from other family members, friends, and care providers, and should be able to ask for what you need from others. For example, you may have a family member or friend who could help manage finances and insurance benefits by taking on those tasks. Another person might be able to relieve you by agreeing to stay with the ill family member and providing you with a break. This kind of care is sometimes called “respite care.”

When your loved one needs medically related home health care, Medicare, Medicaid, Veterans Health Administration benefits, and private insurance plans often pay for it. You can ask doctors and nurses for referrals to home health agencies. Caregivers also can ask doctors, nurses, and home health agencies for training in carrying out complex medical tasks.

You might be able to get help from your state’s Medicaid program. Most states provide some Medicaid coverage of care at home for people with low incomes or few

assets. Community agencies often provide long-term services and supports that people can pay for privately. If your loved one is a Veteran, you may be able to get assistance from the Department of Veterans Affairs. If a seriously ill person has symptoms, such as pain, or side effects from medicines, palliative or comfort teams may be available. If the person is dying, hospice is an option.

When a family member has a serious illness, you can ask for help in understanding what it will take to meet the needs of your loved one. Help can come from health care providers, your local Area Agency on Aging, and support groups. These local groups often have caregiver training programs that can help you cope with your responsibilities.



Resources

Eldercare Locator

U.S. Administration on Aging

Find local community service organizations and programs in your area

<http://www.eldercare.gov>

National Respite Locator

Find respite services in your community

<http://archrespite.org/respitelocator>

Healthfinder.gov

Basic tips and strategies for caregivers

http://www.healthfinder.gov/HealthTopics/Category/everyday-healthy-living/mental-health-and-relationship/get-support-if-you-are-a-caregiver#the-basics_1

Long-Distance Caregiving: Twenty Questions and Answers

National Institute on Aging at the National Institutes of Health

<http://www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving-0>

Additional Resources for Caregivers of Veterans:

VA Caregiver Support Website

<http://www.caregiver.va.gov>

VA Caregiver Support Line

1-855-260-3274

VA Geriatrics and Extended Care

http://www.va.gov/GERIATRICS/Guide/LongTermCare/Home_and_Community-Based_Services.asp