

# Family Caregiving

## Finding Caregiver Support and Making Caregiving More Rewarding



As a family caregiver for an ailing parent, child, spouse, or other loved one, you're likely to face a host of new responsibilities, many of which are unfamiliar or intimidating. At times, you may feel overwhelmed and alone. But despite its challenges, caregiving can also be extremely rewarding. And there are a lot of ways you can make the caregiving process easier and more pleasurable for both you and your loved one. These tips can help you get the support you need while caring for someone you love in way that can benefit both of you.

### What is family caregiving?

As life expectancies increase, medical treatments advance, and increasing numbers of people live with chronic illness and disabilities, more and more of us find ourselves caring for a loved one at home. Whether you're taking care of an aging parent, a handicapped spouse, or looking after a child with a physical or mental illness, providing care for a family member in need is an act of kindness, love, and loyalty. Day after day, you gift your loved one with your care and attention, improving their quality of life, even if they're unable to express their gratitude.

Regardless of your particular circumstances, being a family caregiver is a challenging role and likely one that you haven't been trained to undertake. And like many family caregivers, you probably never anticipated this situation. However, you don't have to be a nursing expert, a superhero, or a saint in order to be a good family caregiver. With the right help and support, you can be an effective, loving caregiver without having to sacrifice yourself in the process. And that can make family caregiving a more rewarding experience—for both you and your loved one.

## New to family caregiving?

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**Learn as much as you can** about your family member's illness or disability and how to care for it. The more you know, the less anxiety you'll feel about your new role and the more effective you'll be.

**Seek out other caregivers.** It helps to know you're not alone. It's comforting to give and receive support from others who understand exactly what you're going through.

**Trust your instincts.** Remember, you know your family member best. Don't ignore what doctors and specialists tell you, but listen to your gut, too.

**Encourage your loved one's independence.** Caregiving does not mean doing everything for your loved one. Be open to technologies and strategies that allow your family member to remain as independent as possible.

**Know your limits.** Be realistic about how much of your time and yourself you can give. Set clear limits, and communicate those limits to doctors, family members, and other people involved.

## Family caregiving tip 1: Accept your feelings

Caregiving can trigger a host of difficult emotions, including anger, fear, resentment, guilt, helplessness, and grief. It's important to acknowledge and accept what you're feeling, both good and bad. Don't beat yourself up over your doubts and misgivings. Having these feelings doesn't mean that you don't love your family member—they simply mean you're human.

### What you may feel about being a family caregiver

- **Anxiety and worry** - You may worry about how you will handle the additional responsibilities of caregiving and what will happen to your family member if something happens to you. You may also fear what will happen in the future as your loved one's illness progresses.
- **Anger or resentment** - You may feel angry or resentful toward the person you're caring for, even though you know it's irrational. Or you might be angry at the world in general, or resentful of other friends or family members who don't have your responsibilities.
- **Guilt** - You may feel guilty for not doing more, being a "better" caregiver, having more patience, accepting your situation with more equanimity, or in the case of long distance caregiving, not being available more often.
- **Grief** - There are many losses that can come with caregiving (the healthy future you

envisioned with your spouse or child; the goals and dreams you've had to set aside). If the person you're caring for is terminally ill, you're also dealing [with that grief](#).

Even when you understand why you're feeling the way you do, it can still be upsetting. In order to deal with your feelings, it's important to talk about them. Don't keep your emotions bottled up; find at least one person you trust to confide in, someone who'll listen to you without interruption or judgment.

### **Tip 2: Find caregiver support**

Even if you're the primary family caregiver, you can't do everything on your own, especially if you're caregiving from a distance (more than an hour's drive from your family member). You'll need help from friends, siblings, and other family members, as well as from health professionals. If you don't get the support you need, you'll [quickly burn out](#)—which will compromise your ability to provide care.

But before you can ask for help, you need to have a clear understanding of your family member's needs. Take some time to list all the caregiving tasks required, making it as specific as possible. Then determine which activities you are able to perform (be realistic about your capabilities and the time you have available). The remaining tasks on the list are the ones you'll need to ask others to help you with.

### **Asking family and friends for help**

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It's not always easy to ask for help, even when you desperately need it. Perhaps you're afraid to impose on others or worried that your request will be resented or rejected. But if you simply make your needs known, you may be pleasantly surprised by the willingness of others to pitch in. Many times, friends and family members want to help, but don't know how. Make it easier for them by:

- Setting aside one-on-one time to talk to the person
- Going over the list of caregiving needs you previously drew up
- Pointing out areas in which they might be of service (maybe your brother is good at Internet research, or your friend is a financial whiz)
- Asking the person if they'd like to help, and if so, in what way
- Making sure the person understands what would be most helpful for both you and the caregiving recipient

### **Other places you can turn for caregiver support include:**

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- Your church, temple, or other place of worship
- Caregiver support groups at a local hospital or online

- A therapist, social worker, or counselor
- National caregiver organizations
- Organizations specific to your family member's illness or disability

### Tip 3: Really connect with your loved one

Pablo Casals, the world-renowned cellist, said, "The capacity to care is the thing that gives life its deepest significance and meaning." When handled in the right way, caring for a loved one can bring pleasure—to both you, the caregiver, and to the person you're caring for. Staying calm and relaxed and taking the time each day to really connect with the person you're caring for can release hormones that boost your mood, reduce stress, and trigger biological changes that improve your physical health. And it has the same effect on your loved one, too.

Even if the person you're caring for [can no longer communicate verbally](#), it's important to take a short time to focus fully on him or her. Avoid all distractions—such as the TV, cell phone, and computer—make eye contact (if that's possible), hold the person's hand or stroke their cheek, and talk in a calm, reassuring tone of voice. When you connect in this way, you'll experience a process that lowers stress and supports physical and emotional well-being—for both of you—and you'll experience the "deepest significance and meaning" that Casals talks about.

### Tip 4: Attend to your own needs

If you're distracted, burned out, or otherwise overwhelmed by the daily grind of caregiving, you'll likely find it difficult to connect with the person you're caring for. That's why it's vital that you don't forget about your own needs while you're looking after your loved one. Caregivers need care, too.

Emotional needs of family caregivers

**Take time to relax daily**, and learn how to regulate yourself and de-stress when you start to feel overwhelmed. As explained above, one way to achieve this is to really connect with the person you're caring for. If that isn't possible, employ your senses to effectively [relieve stress in the moment](#), and return to a balanced state.

**Talk with someone** to make sense of your situation and your feelings about it. There's no better way of relieving stress than spending time face-to-face with someone who cares about you.

**Keep a journal.** Some people find it helpful to write down their thoughts and feelings to help them see things more clearly.

**Feed your spirit.** Pray, meditate, or do another activity that makes you feel part of something greater. Try to find meaning in both your life and in your role as a caregiver.

**Watch out for signs of depression, anxiety, or burnout** and seek professional help if needed.

### Social and recreational needs of family caregivers

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**Stay social.** Make it a priority to [visit regularly with other people](#). Nurture your close relationships. Don't let yourself become isolated.

**Do things you enjoy.** Laughter and joy can help keep you going when you face trials, stress, and pain.

**Maintain balance in your life.** Don't give up activities that are important to you, such as your work or hobbies.

**Give yourself a break.** Take regular breaks from caregiving, and give yourself an extended break at least once a week.

**Find a community.** Join or reestablish your connection to a religious group, social club, or civic organization. The broader your support network, the better.

### Physical needs of family caregivers

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**Exercise regularly.** Try to get in at least 30 minutes of exercise, three times per week. [Exercise](#) is a great way to relieve stress and boost your energy. So get moving, even if you're tired.

**Eat right.** Well-nourished bodies are better prepared to cope with stress and get through busy days. Keep your energy up and your mind clear by [eating nutritious meals](#) at regular intervals throughout the day.

**Avoid alcohol and drugs.** It can be tempting to [turn to substances](#) for escape when life feels overwhelming, but they can easily compromise the quality of your caregiving. Instead, try dealing with problems head on and with a clear mind.

**Get enough sleep.** Aim for an average of eight hours of [solid, uninterrupted sleep](#) every night. Otherwise, your energy level, productivity, and ability to handle stress will suffer.

**Keep up with your own health care.** Go to the doctor and dentist on schedule, and keep up with your own prescriptions or medical therapy. As a caregiver, you need to stay as strong and healthy as possible.

### Tip 5: Take advantage of community services

Most communities have services to help caregivers. Depending on where you live, the cost may be based on your ability to pay or covered by the care receiver's insurance. Services that may be available in your community include adult day care centers, home health aides, home-delivered meals, respite care, transportation services, and skilled nursing.

**Caregiver services in your community.** Call your local senior center, county information and referral service, family services, or hospital social work unit for contact suggestions. Advocacy groups for the disorder your loved one's suffering from may also be able to recommend local services. In the U.S., contact your local Area Agency on Aging for help with caring for older family members.

**Caregiver support for veterans.** If your care recipient is a veteran in the U.S., home health care coverage, financial support, nursing home care, and adult day care benefits may be available. Some Veterans Administration programs are free, while others require co-payments, depending upon the veteran's status, income, and other criteria.

**Your family member's affiliations.** Fraternal organizations such as the Elks, Eagles, or Moose lodges may offer some assistance if your loved one is a longtime dues-paying member. This help may take the form of phone check-ins, home visits, or transportation.

**Community transportation services.** Many communities offer free or low-cost transportation services for trips to and from medical appointments, day care, senior centers, and shopping malls.

**Adult day care.** If your senior loved one is well enough, consider the possibility of adult day care. An adult day care center can provide you with needed breaks during the day or week, and your loved one with some valuable diversions and activities.

**Personal care services.** Help with activities of daily living, such as dressing, bathing, feeding, or meal preparation may be provided by home care aides, hired companions, certified nurse's aides, or home health aides. Home health aides might also provide limited assistance with tasks such as taking blood pressure or offering medication reminders.

**Health care services.** Some health care services can be provided at home by trained professionals such as physical or occupational therapists, social workers, or home health nurses. Check with your insurance or health service to see what kind of coverage is available. Hospice care can also be provided at home.

**Meal programs.** Your loved one may be eligible to have hot meals delivered at home by a Meals on Wheels program. Religious and other local organizations sometimes offer free lunches and companionship for the sick and elderly.

### Tip 6: Provide long-distance care

Many people take on the role of designated caregiver for a family member—often an older relative or sibling—while living more than an hour’s travel away. Trying to manage a loved one’s care from a distance can add to feelings of guilt and anxiety and present many other obstacles. But there are steps you can take to prepare for caregiving emergencies and ease the burden of responsibility.

**Set up an alarm system for your loved one.** Because of the distance between you, you won’t be able to respond in time to a life-threatening emergency, so subscribe to an electronic alert system. Your loved one wears the small device and can use it to summon immediate help.

**Manage doctor and medical appointments.** Try to schedule all medical appointments together, at a time when you’ll be in the area. Make the time to get to know your loved one’s doctors and arrange to be kept up-to-date on all medical issues via the phone when you’re not in the area. Your relative may need to sign a privacy release to enable their doctors to do this.

**Use a case manager.** Some hospitals or insurance plans can assign case managers to coordinate your loved one’s care, monitor his or her progress, manage billing, and communicate with the family.

**Investigate local services.** When you’re not there, try to find local services that can offer home help services, deliver meals, or provide local transportation for your loved one. A geriatric care manager can offer a variety of services to long-distance caregivers, including providing and monitoring in-home help for your relative.

**Schedule regular communication with your loved one.** A daily email, text message, or quick phone call can let your relative know that they’re not forgotten and give you peace of mind.

**Arrange telephone check-ins** from a local religious group, senior center, or other public or nonprofit organization. These services offer prescheduled calls to homebound older adults to reduce their isolation and monitor their well-being.

## Where to turn for help

### Family caregiving services in the U.S.

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[Find Help in Your Community](#) - Connects families to community-based resources for senior care. (Eldercare Locator)

# HelpGuide

[Healthfinder](#) - Find health care and other services near you. (U.S. Department of Health and Human Services)

## Family caregiving services in other countries

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[Your Guide to Care and Support](#) - NHS services available to UK carers of disabled children and adults, including respite care. (NHS)

[My Aged Care](#) - Information on contacts and services available to assist you with ageing and aged care issues in Australia, including home care services for seniors. (Australian Government Department of Health and Ageing)

[Resources for Seniors](#) - Information on services for seniors in Canada, including in-home support. (Government of Canada)

## Find meals on wheels services

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[Meals on Wheels: Find a U.S. Program](#) (Meals on Wheels Association of America)

[Meals at Home Services \(UK\)](#) (Directgov)

[Meals on Wheels Australia](#) (Meals on Wheels Australia)

[Find a Meals on Wheels Location in Canada](#) (MealCall)

## Recommended reading

[For Family Caregivers: Guides and Checklists](#) - Helps family caregivers of chronically or seriously ill patients navigate home care. (Next Step in Care)

[Family Caregiver Toolbox](#) - Tips and information to help caregivers care for their loved ones and themselves. (Caregiver Action Network)

[FCA Learning Center](#) - Articles, videos, and online classes tackling a variety of caregiving challenges. (Family Caregiver Alliance)

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