

FAMILY CAREGIVING

Family Caregiving: Help and Support for Caregivers

As a caregiver, you face many responsibilities. But with the right tools and support, you can overcome challenges and make caregiving more rewarding—for both you and the person you're caring for.

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What is family caregiving?

Family caregiving is the act of providing at-home care for a relative, friend, or other loved one with a physical or mental health problem. As life expectancies increase, medical treatments advance, and more people live with chronic illnesses and disabilities, many of us find ourselves caring for a loved one at home.

Whether you're taking care of an aging parent, a disabled spouse, or looking after a sick child, providing care for a family member in need is an act of kindness, love, and loyalty. Day after day, you gift your loved one your care and attention, and improve their quality of life, even if they're unable to express their gratitude.

Whatever 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 be a good family caregiver.

With the right help and support, you can provide loving, effective care without having to sacrifice yourself in the process. And that can make family caregiving a more life-affirming experience.

New to being a caregiver?

If you're a first-time caregiver, these are some ways to begin your caregiving journey on a positive note:

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 caregivers 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'll handle the additional responsibilities of caregiving or what how your family member will cope if something happens to you. You may also stress about the future and how your loved one's condition will progress.
- → 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 being a "better" caregiver, having more patience, or accepting your situation with more composure. In the case of long distance caregiving, you may feel guilty about 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 or the goals and dreams you've had to set aside, for example). 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. But rather than try to keep your emotions bottled up, it's important to talk about them. 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. This is especially true 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're 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

It's not always easy to ask for help, even when you desperately need it. You may be afraid to impose on others, or worry that your requests 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.

- → Set aside one-on-one time to talk to your friend or family member.
- → Go over the list of caregiving needs you've drawn up.
- → Point out areas where their skills could help (maybe your brother is good at internet research, or your friend a financial whiz, for example).
- → Ask the person if they'd like to help, and if so, in what way.
- → Make 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:

- → 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 (such as the Alzheimer's Association).

Tip 3: Really connect with your loved one



Pablo Casals, the world-renowned cellist, once said, "The capacity to care is the thing which gives life its deepest significance." When handled in the right way, caring for a loved one can bring meaning and 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 can have the same effect on your loved one, too.

Even if the person you're caring for can no longer communicate verbally, it's still important to take a short time each day to focus fully on them. 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" 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.

Take care of your emotional needs

Make time to relax daily, and learn how to 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 caregiving role 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.

Caregivers have social and recreational needs, too

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



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

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.

Look after your physical health

Exercise regularly. Aim to get in at least 30 minutes of exercise, three times per week. <u>Exercise</u> is a great way to relieve stress and boost your energy. So, try to get moving, even if you're tired.

Eat right. Well-nourished bodies are more resilient and better prepared to cope with stress of busy days. Keep your energy up and your mind clear by eating nutritious meals at regular intervals throughout the day.

Avoid excessive use of alcohol and drugs. When life feels overwhelming, it can be tempting to <u>turn to</u> <u>substances</u> for relief. But in the long-run, they can make stress and anxiety worse, and even compromise the quality of your caregiving. Instead, try dealing with problems head on and find healthier ways to cope.

Get enough sleep. Shoot for six to eight hours of solid, uninterrupted sleep every night. Otherwise, your energy level, productivity, and ability to handle stress will suffer.

Maintain your own health care. Keep up with medical appointments, treatments, and prescriptions. 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 or your health service.

Services that may be available in your community include adult day care centers, home health aides, homedelivered 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 your loved one's illness or disability 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, they may be eligible for additional support services. In the U.S., for example, home health care coverage, financial support, <u>nursing home care</u>, and adult day care benefits are often available.



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 care recipient is a senior and well enough, consider <u>adult day care</u>. 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 care help might also provide limited assistance with tasks such as taking blood pressure or 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.

Use a medical alert system. When you live a distance away from the care recipient, you'll be unable to respond quickly in the event of an emergency, such as a fall or life-threatening health issue. A <u>medical alert system</u>, though, will enable your loved one to call for immediate help when they need it. By simply activating the small, wearable device, your loved one can be connected to a dispatcher to summon medical help.

Coordinate doctor and medical appointments. Try to schedule all medical appointments together, at a time when you'll be in the area. Take the time to get to know your loved one's doctors and arrange to be kept up-to-date on all medical issues via phone or email 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 their progress, manage billing, and communicate with the family.



Investigate local services. Look for local services that can offer home help, 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 monitoring in-home help for your relative.

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

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.

Find caregiver services

In the U.S. Family Care Navigator - Including eldercare services. (Family Caregiver Alliance)

Elder Care Services Search – For older adults and their carers. (The U.S. Department

of Aging)

Respite Locator – Services in U.S. and Canada. (Arch National Respite Network)

Meals on Wheels (Meals on Wheels Association of America)

UK Your Guide to Care and Support Services, including respite care. (NHS)

Meals at Home Services (UK) (Directgov)

Australia Support for Families and Carers – Resources and information. (Carers Australia)

My Aged Care – Aged care services. (Australian Government Depart of Health and

Ageing)

Meals on Wheels Australia (Meals on Wheels Australia)

New Zealand Carers New Zealand – Caregiving help, including respite care services. (Carers NZ)

Canada Programs and Services for Seniors – Including caregiving support. (Government of

Canada)

Respite Locator – Services in U.S. and Canada. (Arch National Respite Network)

Find a Meals on Wheels Location (VON Canada)

More Information



Helpful links

- **01.** For Family Caregivers: Guides and Checklists Helps family caregivers of chronically or seriously ill patients navigate home care. (Next Step in Care)
- **O2.** <u>Family Caregiver Toolbox</u> Tips and information to help caregivers care for their loved ones and themselves. (Caregiver Action Network)
- **O3.** FCA Learning Center Articles, videos, and online classes tackling a variety of caregiving challenges. (Family Caregiver Alliance)

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