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Together to End Stroke®

Self-Care for Caregivers

American Stroke Association





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Caregiving in the U.S.

Caregivers can be spouses, adult children, parents, other family members or friends. As a caregiver, you make many sacrifices for your loved ones while providing essential long-term support.

- An estimated 53 million Americans 18 and older provide unpaid help and support to older adults or individuals with chronic or disabling conditions.
- The value of this unpaid work is estimated at around \$306 billion yearly. This is almost double the cost shared by cost of home health care (\$43 million) and nursing home care (\$155 million).
- About two-thirds of caregivers are female.
- Most caregivers are not prepared for their roles and provide care with little to no support.
- More than one-third of caregivers continue to provide intense care while experiencing poor health themselves.
- It's no surprise that emotional, mental, and physical health problems arise among many caregivers.





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What Are the Responsibilities of Caregivers?

There is no job description that explains all that caregivers do. Each caregiver's responsibilities vary with the unique needs of the person they care for. Role changes and new skills may be needed. For stroke survivors, common caregiving duties may include:

- Helping with personal care, such as bathing, dressing, toileting, grooming.
- Assisting with moving about, such as walking or wheelchair transfers.
- Running errands and providing transportation.
- Managing financial, legal and business affairs.
- Monitoring behavior to ensure safety.
- Managing housework and making meals.





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What Are the Responsibilities of Caregivers?

- Coordinating health care needs, such as scheduling appointments or specialist visits.
- Helping manage relationships and communication with the health care team.
- Helping with medications and watching for side effects.
- Helping the survivor maintain learned rehab skills and working to improve them.
- Providing emotional support.
- Managing relationships with friends and family.
- Encouraging the survivor to continue working toward their recovery and to be as independent as possible.





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What Is Caregiver Burnout?

Caregiver burnout is caused by long-term stress. This can affect your physical, emotional and mental well-being.

You become overwhelmed trying to meet the constant demands of your caregiving role. This can have a negative effect on how you care for yourself and your loved one.

Many caregivers don't take time to care for themselves, and they begin to show signs of caregiver burnout. Your health and well-being benefit your loved one as well as you.





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Signs of Caregiver Burnout

Caregivers are often under a lot of stress. Watch out for signs of burnout, including:

- Denial about your loved one's condition.
- Anger toward the person you're caring for.
- Social withdrawal from friends and activities you enjoy.
- Angst about caregiving responsibilities.
- Depression and anxiety.
- Exhaustion and lack of energy to do things.
- Losing control physically or emotionally.
- Trouble sleeping.
- Difficulty concentrating.
- Unhealthy behaviors, such as drinking or smoking too much.

Long-term stress can lead to health problems.
If you're experiencing any of these warning signs, take
steps to get your life back into balance.



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How Can I Avoid Burnout?

Take things one day at a time. You can take steps to avoid caregiver burnout by:

- Learning more about your loved one's condition and how to manage it.
- Discussing your feelings with a friend or joining a support group for caregivers.
- Finding out what caregiving resources are available in your community.
- Asking for and accepting help from others.
- Using day care or respite care so you can take time for yourself.





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- Using relaxation techniques such as meditation, yoga or breathing exercises.
- Taking care of yourself by eating well, exercising and getting plenty of rest.
- Making health care appointments and check-ups for yourself.
- Focusing on the positive aspects of caregiving.
- Talking to a counselor or therapist, if needed.

You are not alone. Ask and accept help.

How Can I Avoid Burnout?





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Practical Tips for Self-Care

Here are tips to try to make things run more smoothly:

- Make meals ahead. Pick one day and prepare all or some of your meals for the week. Defrost and heat meals during your busiest days.
- Arrange outside transportation for your loved one. Ask your insurance company or other community resources if there are other transportation options.
- Use a pill organizer. If your loved one takes more than one pill per day, this can save five to 10 minutes.





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Practical Tips for Self-Care

- **Make to-do lists.** Being organized helps you stay on task and avoid wasting time, for instance by making extra trips to the store.
- Stay focused and set time limits. If you don't get something done, add it to a list for another day.
- Find and use resources in your community for patients and caregivers.
- Ask for help — and accept it when it's offered!





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Providing care for a stroke survivor can be very rewarding. But it also can be stressful and frustrating, especially if you are new to that role. Some community resources can help:

- **Adult day care:** Professional supervision of adults in a social setting during the day.
- **Adult foster homes:** Supervised care in approved (licensed) private homes.
- **Caregiver support services:** Support groups and like programs, where you can find support and connect with others with similar experiences.

Is There Assistance for Caregivers?





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- Home health care: In-home, part-time medical services ordered by a health care professional.
- Homemaker and personal care support: Supervised, trained people who help prepare meals and do household chores.
- Meal programs: These include Meals on Wheels, a federally sponsored nutrition program and other local options.
- Private care: Professionals who specialize in assessing current needs, coordinating and providing care and services.
- Respite care: Provides short-term relief for caregivers. It can be for a few hours, days or even weeks. Care may be provided at home, in a health care setting or in adult day care.

Is There Assistance for Caregivers?





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Support and Training for Caregivers

Administration on Aging

eldercare.acl.gov | 800-677-1116

Helps connect you to services for older adults and families in your area.

Family Caregiver Alliance (FCA)

caregiver.org | 800-445-8106

Works to improve the quality of life for family caregivers and the people who receive their care. FCA provides information, education and support for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.

Caregiver Action Network (CAN)

caregiveraction.org | 855-227-3640

Works to improve the quality of life for those who care for their loved ones. CAN provides education, peer support and resources to family caregivers across the country for free.

211 Network

211.org

More than 200 agencies across the U.S. are staffed by trained and compassionate specialists who can help you access the best local resources and services to address any need, including housing, food, transportation and health care.



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Support Services Provided by the ASA

In an instant, a stroke can change a survivor's and their loved ones' lives. Whether it's in person, online or on the phone, the American Stroke Association is here to support you.

- **Stroke Connection e-news** is a trusted monthly newsletter supporting stroke survivors, their families and caregivers. Sign up at StrokeConnection.org.
- **Support Network** is an online community of survivors and caregivers who know what you're going through and can help you find your footing on the path to better health. Join at stroke.org/SupportNetwork.
- Our **Stroke Support Group Finder** tool can help you find a list of support groups near you at Stroke.org/SupportGroup.
- The **Stroke Family Warmline** connects you with trained specialists who can provide helpful information, steer you to local services or just listen. Call 888-4-STROKE (888-478-7653).





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Coping Techniques

Set aside personal time every day.

Energize yourself with exercise, meditation, prayer and play. As little as five or 10 minutes can help.





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Breathe.

Deliberately taking a breath helps restore you physically, mentally, emotionally and spiritually. When you practice deep, steady breathing, you can release emotional tension and calm your mind. Get started by trying to breathe consciously and deeply when you:

- Wait on the telephone.
- Get tense.
- Sit at a red light.
- Stand in line.

Coping Techniques





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Coping Techniques

Renew your commitment.

In the middle of a difficult day, it's easy to lose sight of what inspires you to be a caregiver. Pause and ask yourself, "Why do I do this?" Make a list of your reasons. Revisiting those reasons may provide just the energy you need to be a more inspired and committed caregiver.





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Keep a gratitude journal.

Each day write down three to five things for which you're grateful. You'll be making an inventory of all that you have — instead of what you don't have. Find a convenient time to do this, like bedtime. Some people find the evening meal a good time because it involves family members.

Coping Techniques





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Go on a retreat.

This could be a weekend or an afternoon when you distance yourself from caregiving and just relax.

Coping Techniques





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Coping Techniques

Join a support group.

Connect with others with similar experiences, learn helpful information and get support.





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Group Discussion



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What are some things I can do for myself to practice self-care?





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How can I find caregiver support groups in my area?





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**Where can I find someone to sit
with my loved one a few hours a day?**





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What organizations support caregivers?





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For more resources,
visit **stroke.org/caregivers**

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