

CAREGIVERS & EPILEPSY

Caring for someone with a chronic condition such as epilepsy can be overwhelming and stressful. There may be day-to-day demands, such as making sure medications are taken on time, giving first aid during seizures, and going to appointments with health care providers. Some people need “hands on” help or support from family or caregivers 24/7. Caregivers may need to make sure their loved ones have access to education and other support for legal and financial issues. When family members/caregivers are the main decision makers and managers, tasks can seem endless. It is critical that caregivers take proper care of themselves, too. Here are a few tips to help caregivers stay well and be at their best.



Recognize symptoms of overload and burnout

It's important to recognize the symptoms of caregiver overload or burnout before they become too severe and cause physical problems.

- ▶ Isolation from friends, family, and other loved ones
- ▶ Loss of interest in activities that were previously enjoyed
- ▶ Feelings of sadness, irritability, and hopelessness
- ▶ Changes in sleep habits, appetite, and weight
- ▶ More likely to get sick
- ▶ Intense physical and emotional fatigue (exhaustion)
- ▶ Chronic stress or anxiety



Understand the causes

- ▶ **Demands:** Caring for others can be physically, mentally, and emotionally demanding.
- ▶ **Overlap of roles:** The role as caregiver adds to a current roles as parent, spouse, partner, offspring, sibling, or friend. The caregiver may need to help with different activities several times each day, such as physical, occupational, or speech therapies.
- ▶ **Unmet expectations:** Some caregivers expect their performance to improve the health and happiness of the patient when this is not always possible.
- ▶ **Loss of control:** Seizures and other problems are often unpredictable, leading to a feeling of loss of control.
- ▶ **Unreasonable demands:** When someone is not well, they may have unreasonable demands out of their own frustration and anger with having epilepsy.

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Managing caregiver overload

Steps to help prevent and treat caregiver burnout and physical or emotional exhaustion:

- ▶ **Talk to friends.** Find someone you trust, such as a friend, a coworker, or a neighbor to talk about your feelings and frustrations. Parents of a child with epilepsy may find it helps to talk to other parents in similar situations.
- ▶ **Have realistic goals.** Accept when you need help in caring for your loved one and take action by asking for and accepting offers of help from others. Be realistic about your loved one's health, but maintain hope. Stay in touch with the epilepsy care team and make sure you have the latest facts and treatment options.
- ▶ **Nurture yourself.** Plan free time for yourself, even if it is a few hours on a regular basis.
- ▶ **Seek professional help.** Most therapists, social workers, and members of the clergy or church are trained to counsel people who face physical and emotional difficulties or challenges.
- ▶ **Use respite care services.** Respite care provides short-term relief for primary caregivers. These can give you a brief or longer break from your activities.
- ▶ **Know your limits.** Take a real check of your personal situation. Recognize and accept if you are overloaded or emotionally stressed.
- ▶ **Manage your expectations.** Don't try to do everything. Simplify your meals, extracurricular activities, and holidays.
- ▶ **Learn about the illness of your loved one.** The more you know about the illness, the more effective you will be caring for or helping your loved one.
- ▶ **Develop skills to overcome challenges.** Remember to emphasize positive things. Use relaxation techniques, such as mindfulness, yoga, or deep breathing to help you cope with day-to-day challenges.
- ▶ **Laugh.** Your sense of humor can help you deal with the stress of each day.
- ▶ **Practice healthy habits.** Maintain your well-being by eating healthy foods, exercising, and getting enough sleep.
- ▶ **Accept your feelings.** Having negative feelings—frustration or anger—about your responsibilities or the person you are caring for is normal and human.
- ▶ **Foster and prioritize your primary relationships.** Do something fun with a loved one 5-10 minutes a day or 1 day a month.
- ▶ **Join a support group.** Sharing your feelings with others in the same situation can help you manage stress, find sources of help, and decrease feelings of frustration or isolation.
- ▶ **Consult your doctor.** If you already suffer from stress and depression, seek medical help.



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Explore other sources of help if you're feeling overloaded

Overload and burnout can be prevented. Consider the following resources:

- ▶ Home help and respite services are agencies that provide in-home help and nurses for short-term care.
- ▶ Day care for adults are programs that offer a place for your loved one to socialize, perform various activities, and receive medical help and other services.
- ▶ Nursing homes or other institutions provide residential places on a temporary basis to provide caregivers with a respite from their responsibilities.
- ▶ Private services may be available from professionals to help coordinate care needs.
- ▶ Other support services for the caregiver include support groups and other programs that can help caregivers “recharge batteries” and meet other people who are facing similar situations, find more information, and locate additional sources.



Remember that the Epilepsy Foundation can help you find the information and help you need.

FOR MORE INFORMATION

- ▶ Parents as Caregivers: epilepsy.com/for-parents-caregivers
- ▶ National Institute on Aging Respite Care Resources: nia.nih.gov/health/what-respite-care