



ALS & Caregiver Self-Care

A Les Turner ALS Foundation Guide for Caregivers

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

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ALS & caregiver self-care

Caregivers can live fulfilling lives with the right support. Making sure you meet your own physical and emotional needs will help both you and your loved one with ALS. In this guide, you will find information on symptoms and causes of caregiver burnout as well as ways to prevent and deal with burnout.

Taking care of yourself

Self-care strategies:



Exercise daily



Get good quality sleep



Spend some time outdoors



Eat a well-balanced diet



Talk to someone about what you are going through—support groups are great for this!



Participate in mind-body practices like yoga, meditation, and deep breathing exercises



Journal



Take short breaks throughout the day



Stay connected with friends and family



Plan something to look forward to

“ Many caregivers feel like they are failing their loved one by not doing enough each day, and this is normal. Everyone has different capabilities. Once you accept your limitations as a caregiver and realize you are doing the best you can, you will be able to focus on more important things.

-Steve

“ Self-care can mean a lot of things. Everyone's self-care is different. Find your happy place. Whatever peace you had before ALS, find some of that. A little goes a long way.

-Kelly

Professional and community support



Develop a support system

Having practical and emotional support will improve your well-being and prevent burnout.



Reach out to your Support Services Coordinator

Les Turner ALS Foundation's Support Services Team is here to support you every step of the way.



Talk with a mental health professional

Speaking with a mental health professional can help you process what you are going through and identify skills to manage the challenges of caregiving.



Explore home health, respite and hospice care

Talk to your ALS care team and insurance company about how professionals can provide you with caregiver training, short breaks (respite care), and end of life care.



Hiring a caregiver

Prior to contacting caregiver agencies or independent caregivers, we encourage you to spend time creating a list of your needs, preferences, and expectations for care. For more information, visit: [Tips for Hiring a Caregiver](#).

Social media groups

Caregivers have told us that social media community groups have helped them tremendously. Check out some of the most well-liked Facebook groups:

- [ALS - Patient and Caregiver Tips for Everyday Living](#)
- [ALS Support Group](#)
- [This is ALS](#)
- [Familial \(Hereditary, Genetic\) ALS/MND Support Group](#)
- [ALS Equipment Donations](#)
- [Traveling with ALS](#)
- [ALS Clinical Trials and Research](#)



I surround myself with good friends and family that understand (to the extent they can) the journey we are on. I set boundaries, and now we have a core group of friends and family that are faithful to us and are life-giving, not life-draining.

Caregivers only support group

The Les Turner ALS Foundation's Caregivers Only group offers a time to talk about issues caregivers face in a non-judgmental, accepting atmosphere without their loved one living with ALS being present. Caregivers often share a common experience; life has become so tumultuous that they often feel exhausted, overwhelmed, and hungry for emotional comfort. Together, with the guidance and encouragement of a devoted facilitator, caregivers can find the strength to persevere. And, by feeling heard and understood, caregivers become more equipped to face another day with new coping strategies.

To find out more, visit:
lesturnerals.org/support-groups

How to effectively ask for help

Asking for and accepting outside help can be hard for both the person with ALS and yourself. However, it is not feasible for you to take on all the responsibilities of caregiving by yourself. Being honest about when you need help will not only prevent burnout but will also allow you to continue to provide the best quality of care to your loved one. Most of the time people want to help, but they don't know how!

- 1 —
- 2 —
- 3 —

Have a list of small things ready for when people ask what they can do to help



Give clear, specific instructions on what you want done and how you want it done



Match skills and abilities to needs: If someone loves to cook, ask them to help with a meal

“ **Mary, since you are going to the store can you please pick up some milk, eggs, and trash bags for me, please?**

“ **Sarah, can you please help us with dinner on Monday night? We know you love to cook and would really appreciate the help!**



Don't be afraid to ask several people for help - there are more people out there who want to help than you think.

Caregiver burnout

Burnout occurs when you are physically, emotionally, and mentally exhausted. Stress related to caregiving can compromise your physical and psychological health if not managed appropriately.

Stages of caregiver burnout

Dr. James R. Sherman, in his book *Preventing Caregiver Burnout*, describes three stages of caregiver burnout:



Frustration

You become frustrated or disappointed over your loved one's deteriorating condition. You might question why your quality of care isn't producing positive results. It might be hard to accept that your quality of care has nothing to do with your loved one's mood or disease progression.



Isolation

You may begin to feel lonely and struggle to maintain a sense of purpose in working hard to provide care. You may feel criticized or underappreciated by the person you are caring for and by other family members.



Despair

You begin to feel helpless and have difficulty concentrating at this stage. You may neglect your well-being and lose interest in things you previously enjoyed. You may struggle to provide care effectively.

Common causes of burnout



Multiple roles

Caring for a loved one is likely just one of many roles that you have in your life. Trying to balance multiple roles such as a job, parenting, and caring for someone with ALS can be stressful and lead to burnout.



Heavy workload

Taking on too many responsibilities can lead to a workload that is too heavy for you to handle.



Financial pressure

Paying for medical bills, equipment and other treatments can make you feel overwhelmed.



Lack of alone time

It is common to have not enough time alone. People may be in and out of your home, supporting you and the person with ALS.

Common causes of burnout *cont.*



Unrealistic expectations

Setting too many goals and believing that you have to be perfect can cause you to become discouraged and want to give up completely.



Lack of support

While you may have people helping you with certain aspects of caregiving, you may feel you have little support in other areas.

Symptoms of caregiver burnout



High levels of stress or anxiety



Irritability



Changes in appetite, weight, or both



Disturbances in sleep patterns



Emotional, physical, and mental exhaustion



Emotional withdrawal



Loss of interest in activities you previously enjoyed



Feeling hopeless



Neglecting your own needs



Physical symptoms such as headaches, body aches and stomach aches



Difficulty coping with everyday tasks

Caregiver abuse

Caregiver abuse often takes the form of manipulation, verbal abuse, and/or emotional abuse. Caregiver abuse can be difficult to talk about, but your ALS care team is there for you and can help you come up with solutions to manage your particular situation.

Resources for caregivers

Veterans Affairs assistance for family caregivers

U.S. military veterans are twice as likely to develop ALS compared to non-veterans. Veteran Affairs (VA) offers benefits such as disability and caregiver compensation; grants for home and vehicle modifications; medications and supplies; and home health care and equipment. To learn more, visit: [va.gov](https://www.va.gov).

The Paralyzed Veterans of America (PVA) specialize in providing navigation services for veterans. You can reach their website at: [pva.org](https://www.pva.org).

Family caregivers provide essential support in caring for veterans. The VA recognizes the importance of family caregivers and has an assistance program for caregivers. To learn more, visit: [caregiver.va.gov](https://www.caregiver.va.gov)

Apps for caregivers

SimpliHere

SimpliHere provides a mobile application that simplifies caregiving for those impacted by ALS and other neurodegenerative diseases through communicating, managing daily life, and staying connected.

Lotsa Helping Hands

Lotsa Helping Hands allows you to coordinate help via a calendar and communicate updates on the go.

Safe at Home

Safe at home allows you to connect to all monitor and sensor devices to keep you informed of your loved one's safety.

CaringBridge

CaringBridge is designed to rally your family and friends together, to offer you support when and how you need it. You can also share health updates, photos and videos with the people who care about you.

My Home Helper

My Home Helper is designed to help you find assistance with the jobs you need done at home.

Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, lesturnerals.org/resources.

My ALS Decision Tool™

If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options. To learn more, visit: alsdecisions.org.

**MY ALS
DECISION
TOOL**

ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research, visit: alslearningseries.org.

**ALS
LEARNING
SERIES**

My ALS Communication Passport to Quality Care

My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit: lesturnerals.org/passport.

**MY ALS
COMMUNICATION
PASSPORT
TO QUALITY CARE**

Support Groups

We facilitate support groups to provide people living with ALS, their caregivers and family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS. To find out more, visit: lesturnerals.org/support-groups.

