

# CARING FOR YOURSELF: INFORMATION FOR CAREGIVERS

People living with ALS require increasing levels of care as their disease progresses. Most of the time, responsibility for personal care is taken on by caregivers such as family and friends.

Caring for a person with ALS is an important but demanding role. It can be stressful and emotionally exhausting. Caregivers may be at risk for stress-related health problems, burnout, and compassion fatigue, and can be at increased risk when they experience a lack of support, isolation, or financial difficulties. There are ways to help reduce these risks.

It is important for caregivers to feel well supported and when possible, take time for self-care.



## What are the signs of caregiver stress?

Caregivers may exhibit the following signs of stress. The person living with ALS may also experience a number of these same signs.

- Denial about ALS and its effect on the person living with it
- Anger at the person with ALS and others
- Social withdrawal
- Anxiety about the future
- Depression and hopelessness
- Exhaustion and lack of energy
- Resentment and frustration
- Difficulty sleeping, such as insomnia or nightmares
- Frequent crying
- Difficulty concentrating
- Health problems, like weight gain or loss, increased susceptibility to flus and infections, or chronic health problems like backaches, headaches, and high blood pressure.



## What is compassion fatigue?

Compassion fatigue is a form of burnout in a person's ability to care for others. When a person is caring for someone over an extended period of time, they can become emotionally and physically exhausted. This can lead to a diminished ability to empathize or feel compassion for others.

They may continue to perform their duties but become emotionally disengaged.

This documented phenomenon is common in caring professions, like nursing and paramedics but can also be experienced by primary caregivers.

Compassion fatigue can be reduced. Good self-care practices are the first line of defense against compassion fatigue. Being able to take a break from caring for others is important. Caregivers may wish to look into respite care options; your ALS clinic or ALS Society may be able to recommend options.

## WHAT YOU CAN DO

Caring for someone with ALS can be challenging. Here are some things that may help.

- Develop a self-care routine. For example, you may find it helpful to engage in activities such as exercise, meditation, connecting with friends and family, or alternatively taking some time alone.
- If you believe you are suffering from compassion fatigue, know that you are not alone. There may be services available in your community that can provide you with practical help and emotional support.
- You may want to consider reaching out to family, friends or a health care professional for support.
- Plan for future care needs.



It is important for caregivers to attend to their emotional and physical needs. If a caregiver does not take care of themselves, it will become increasingly difficult to care for their loved one.

## SUMMARY

- Caring for someone with ALS is not easy, and it is important to know the signs of caregiver stress and compassion fatigue.
- There are helpful strategies, such as engaging in regular self-care activities, asking for help, accessing community services
- Your provincial ALS Society is here to help. We can connect you with practical support in your area.

## RESOURCES

- “For Caregivers,” Chapter 5 of the ALS Guide (pages 68-73), [www.als.ca/guide](http://www.als.ca/guide)
- <https://www.canada.ca/en/public-health/services/reports-publications/responding-stressful-events/self-care-caregivers.html>
- <https://ontariocaregiver.ca/find-support-2/>
- <https://www.webmd.com/healthy-aging/sharing-the-load>

## KNOW THAT WE ARE HERE TO HELP

The ALS Society of Canada can assist in connecting people and families living with ALS in Ontario to support services, equipment, and ALS clinics. We also invest in the most promising Canadian ALS research, advocate federally and provincially for the needs of people affected by ALS, and provide information to empower Canadians affected by the disease. Learn more at [www.als.ca](http://www.als.ca) where you can also find more resources in the “What is ALS?” section.

If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region.

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