

FIRST STEPS AFTER AN ALS DIAGNOSIS

Receiving an ALS diagnosis is devastating for all involved. It is normal to feel lost, frightened and unsure of what to do next or who to turn to.

Although an ALS diagnosis is difficult to come to terms with, know that you, your friends, and your family are not powerless and not alone. You can take steps to help navigate this experience and to start a plan that will allow you to feel less overwhelmed. This fact sheet offers some first steps you can take if you or your loved one has been diagnosed with ALS.

Learn about the disease.

You or your family may find it helpful to learn about ALS. It is important to note that navigating the internet can be overwhelming as not all websites provide reliable information. Your ALS Clinic and ALS Canada (or your provincial ALS Society) can help direct you to the right resources.

ALS Canada has many useful resources that can help you learn more about ALS, including our website (www.als.ca), our fact sheets, and the ALS Guide (www.als.ca/guide).

Recognize your own emotions.

- Receiving an ALS diagnosis for yourself and/or for your loved one.
- Feelings of anger, denial, frustration, fear and sadness are all normal among people diagnosed with ALS and their friends and families.
- Some people may become depressed or experience anxiety following an ALS diagnosis. Speak with your doctor or a mental health professional if your feelings become overwhelming.

Recognize that ALS is a progressive disease.

- ALS can affect your life in different ways.
- Symptom progression can affect basic abilities such as speaking, swallowing, moving, and breathing.
- Family, friends and home care services may be available to assist with daily activities.
- Assistive equipment may improve quality of life for both the patient and the caregiver.

Access supports and services.

- It may help to share your feelings with someone you trust. This may be a family member, a good friend, a support group, a spiritual leader, or your contact at ALS Canada or provincial ALS Society.
- Personal caregivers to people living with ALS often report feeling isolated and lonely. If you are a personal caregiver, it will be important to stay connected to the people around you.
- It is important to recognize that ALS can affect the whole family, and lead to feelings of isolation, depression and anxiety. If you are experiencing these feelings, please reach out to a member of your healthcare team for guidance.

PLAN AHEAD.

ALS is an individual disease and every person with ALS experiences different symptoms and progression. It is advisable to plan ahead whenever possible, and while the topics can be difficult to consider there can also be peace of mind in making decisions. You and your family may need support from health care professionals to assist with planning for your future needs.



- An advance care plan is a document you can create to let people know what kind of health and personal care you would want in the future. Preparing one is a process of reflection and communication. Visit www.advancecareplanning.ca to learn more.
- Consider how you will manage your financial, legal and medical decisions. You may want to designate a substitute decision maker or Power of Attorney.

SEEK CAREGIVING HELP.

- You may want to consider accessing home care services in your community. These services are not only useful for people diagnosed with ALS but can provide much-needed support to family or friends caring for you at home.
- Your ALS Society can help you find out what home and community care services are available locally. This includes respite services, which allow a caregiver to rest and take care of him or herself.
- It can be difficult to accept help; however, some friends and family may want to support you.

SELF-CARE FOR FAMILY AND CAREGIVERS.

- It is just as important to care for yourself when you are in a caregiving role.
- Caregivers are at risk for burnout, including mental and physical health problems resulting from stress.
- Our “Caring for yourself” fact sheet at www.als.ca/factsheets provides more information for caregivers to feel well-supported.

WORK WITH YOUR HEALTH CARE TEAM.

- There is currently no cure for ALS, but treatments may help reduce some of the symptoms and improve quality of life.
- You can discuss these options with your health care team at your ALS Clinic.

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 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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