

Quick reference guide

By Your Side: First Steps After an ALS Diagnosis

ALS QUEBEC

Receiving an ALS diagnosis is a deeply overwhelming experience. It is completely normal to feel a wide range of emotions, to be in shock, or to feel unsettled in the face of uncertainty.

You are not alone.

ALS Quebec is an organization dedicated to providing personalized support to people living with ALS and to their family. Our team is here to answer your questions, listen with compassion, and offer psychosocial support, financial assistance, as well as activities and resources tailored to your reality.

Our commitment is to guide you through every stage of the disease, offering human-centered support that adapts to your needs and respects your pace.

While the following list is not exhaustive, its purpose is to guide you through your first steps in understanding, adapting to, and managing ALS, and to support you during this period of transition.

THINGS TO CONSIDER AFTER RECEIVING AN ALS DIAGNOSIS

- ☐ Confirm with your neurologist that a request has been submitted to [open a file at your local CLSC](#), and obtain the contact information needed to follow up.
- ☐ Keep a record of your medical appointments. You can also use the space provided for this purpose on [page 41 of the ALS Guide](#).
- ☐ Contact the Société de l'assurance automobile du Québec ([SAAQ](#)) if you hold a driver's [licence](#). If necessary, a healthcare professional will need to [complete a form](#) confirming the diagnosis in order to request a disabled parking permit.
- ☐ Add the ALS Quebec medical ID card to your official identification. This card helps explain your condition quickly if necessary. To get one, contact your support counsellor.
- ☐ Become part of the ALS Quebec community:
 - Register with our organization, if you haven't already
 - Schedule a call or videoconference with a support counsellor
 - Join our ALS 101 Workshops to better understand and navigate life with ALS
 - Subscribe to our [newsletter](#) to receive tips, updates, and resources

ALS RESEARCH AND CLINICAL TRIALS IN QUEBEC

Research brings significant hope to the ALS community. Quebec is home to one of the country's most respected scientific communities. To learn more about current research projects and recent advances:

- [ALS resources](#)
- [Research overview](#)

Clinical trials are available to test new treatments. If you're interested in participating, talk to your doctor or visit the [Clinical trials Quebec \(CTQ\)](#) website to find ongoing trials. If needed, you can also access [personalized support services](#) to help guide you through the process.

ORGANIZATIONS OFFERING SUPPORT AND GUIDANCE

[ALS Quebec](#): Contact us at 514 725-2653 or toll-free at 1-877-725-7725. Our team of support counsellors is here to answer your questions. We offer a wide range of services, including personalized support, financial assistance, information on available resources, and help navigating the healthcare system.

[Info-Social 811](#): A free and confidential phone service offering quick access to a psychosocial support professional – for you or a loved one. Just dial 811.

[L'Appui](#): An organization dedicated to improving the quality of life of caregivers by supporting them in their daily lives and helping them access the full range of available resources. Phone: 1-855-852-7784

GOVERNMENT PROGRAMS

[Programs for Coping with a Loss of Independence](#): A range of resources grouped into several categories: health and social services, housing, employment, legal support, home care, transportation, tax credits, and financial assistance.

[Tax Measures for People with Disabilities and Their Caregivers](#)

HOW TO ADAPT YOUR HOME?

Discover a series of [short videos](#) created in collaboration with an occupational therapist. These clips offer practical advice on how to adapt your living space, increase comfort, and better manage your energy in your everyday routine.

HOW TO USE 911 IF YOU HAVE SPEECH DIFFICULTIES

If you have a speech impairment, you can use the Text with 9-1-1 (T9-1-1) service, available in most regions of Quebec, including major urban areas.

Here's how to access it:

- Register with your [wireless service provider](#).
- Make sure your mobile device is compatible. You can find a list of supported devices on your [provider's website](#).
- For more information, including a list of municipalities where the service is available, visit the official website: [Text with 9-1-1](#).

Need More Information?

Contact one of our support counsellors:

☎ **514-725-2653, ext. 105**

☎ **Toll-free: 1-877-725-7725, ext. 105**

✉ **info@sla-quebec.ca**

Visit our [website](#) to learn more about ALS, explore available resources, and discover our services, support programs, and activities.