



A GUIDE FOR PEOPLE LIVING WITH ALS



SOCIÉTÉ DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE DU QUÉBEC
AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

als-quebec.ca



ALS GUIDE

A GUIDE TO AMYOTROPHIC
LATERAL SCLEROSIS (ALS)



SOCIÉTÉ DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE DU QUÉBEC
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LA MALADIE DE LOU GEHRIG'S DISEASE



INTRODUCTION

Receiving a diagnosis of ALS can be overwhelming. You may experience many different emotions, and you may feel the need to learn more about how this complex disease will affect you. Some people want to know as much as possible, often right after diagnosis. Others prefer to take a gradual approach as changes occur and as the need for specific information develops. Take the approach that works best for you. Family members and close friends may also wish to learn more about ALS.

The ALS Guide has been developed to provide practical information about ALS, its progression, and how people and families living with ALS can find solutions to help maintain independence. There are different versions of this guide. All of the content is the same except for the information about the local delivery of care and services, which can be different from province to province.

The purpose of the ALS Guide is to help people and families with ALS plan for the physical, emotional, and financial challenges ahead and to offer tips and support for the

day-to-day challenges of living with ALS. It is meant to complement your primary source of information – the healthcare team managing your ALS.



ACKNOWLEDGEMENTS

This ALS Guide is a project of the Federation Council of ALS Societies across Canada – Client Services Committee.

The 2019 edition of the ALS Guide in English and French is built upon the premise of previous editions of the ALS Manual, with new and exciting, up to date information.

Thank you to staff at ALS Canada who researched and wrote the majority of the content with expertise from numerous healthcare providers and people living with ALS, their caregivers and other experts.

Thank you to the Client Services Committee for their diligence and hard work in developing this Guide. Each provincial ALS Society developed content for segments specific to their region. The ALS Guide is stronger as a result of all the thoughtful feedback.

Appreciation is also given for the language editor, translators, and designer whose contributions were critical to this ALS Guide.

This guide will be updated on an ongoing basis to reflect changes about ALS, care

and treatment, research and provincial specific information.

We hope that the ALS Guide provides you and your family with helpful information.

Diana Rasmussen, Executive Director, ALS Society of Manitoba and Chair of the Client Services Committee

Lisa Droppo, Vice President, Client Services, ALS Canada and ALS Guide Project Manager.

HOW TO USE THE GUIDE

This guide is divided into seven main sections, which means you can refer easily to the information you need when you need it. You may prefer to skim through the guide or choose certain sections to read first.

It is not necessary to read the guide all at once. You may pick sections that you want to read yourself and others you want to share with family, friends, and caregivers.



While every effort has been made to provide up-to-date content at the time of publication, certain information – particularly in the area of research and clinical trials – may change faster than we can update the guide. To stay updated, please refer to the ALS Society in your province and ALS clinical specialists from time to time for new information.

Disclaimer: The information in this publication has come from sources that the ALS Society of Canada deems reliable and is provided for general information purposes only. It is not intended to replace personalized medical assessment and management of ALS. The ALS Society of Canada disclaims any liability for the accuracy thereof, and does not intend to disseminate either medical or legal advice. Throughout this publication, people with ALS are advised to consult with healthcare and legal professionals for medical and legal advice, respectively.

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1.0

MY ALS SOCIETY

WHO WE ARE



Our Name

The ALS Society of Quebec



What We Do

The ALS Society of Quebec offers a wide variety of services to families living with ALS across the province of Quebec. We:

- Provide support and referrals for people with ALS and their loved ones
- Fund research
- Raise awareness of the disease among the general public, government officials, and medical and paramedical practitioners.



Our Values

AS A MEMBER OF THE FEDERATION COUNCIL OF THE ALS SOCIETIES ACROSS CANADA, THE SOCIETY'S VALUES ALIGN WITH THOSE OF OUR NATIONAL PARTNERS AS WE AIM TO WORK WITH COMPASSION, EMPATHY, AND RESPECT THROUGH ETHICAL BEHAVIOUR.



Where We Are

5415 Paré Street, Suite 200 Mount-Royal, QC H4P 1P7

Tel: 514 725 2653

Toll free in Quebec: 1 877 725 7725

Email: info@sla-quebec.ca

Website: <http://als-quebec.ca/>

OUR CLIENT SERVICES PROGRAMS

Information



Documentation



Conferences



Internet site and online,
on-demand resources



Newsletters

Psychosocial and Community Support Programs



Orientation and
reference



Personalized support
and toll-free line



Support groups



Short-term
financial support*



Bereavement
support

Awareness, Social and Networking Activities



Social activities
and events



Online community



Professional networking
activities



Interaction with ALS
research community

Opportunities to Get Involved



Advocacy



Volunteer



Ambassador's club

* Certain conditions apply.

Information, Guidance, and Referrals



The ALS Society of Quebec welcomes individuals diagnosed with amyotrophic lateral sclerosis (ALS) or primary lateral sclerosis (PLS), and their caregivers, living in the province. We provide general information about resources offered through the healthcare system as well as community and governmental resources that are helpful to people living with ALS. We help members navigate the healthcare system, offering general information on typical care plans, including which types of services can be expected

and which professionals may be involved in our members' care. Conferences, discussion forums with specialists, and testimonials on relevant topics are offered to people with ALS, to their caregivers, and to professionals. For information on upcoming dates, topics, and locations, please consult our website at <http://als-quebec.ca/>.

The ALS Society of Quebec is committed to accompanying you every step of the way. We offer regular follow-up with families living with ALS throughout the progression of the illness with the aim of offering support and services that, in tandem with those of other organizations, help to meet your specific needs and improve your quality of life.

Support and Social Activities



Personalized support is available to all of our members throughout their journey with ALS. Whether in the form of one-on-one meetings, group gatherings, social activities, or conferences, we aim to satisfy the varying needs of our diverse members throughout the province at different locations, including some hospital-based ALS clinics, Local Community Service Centres (CLSCs), and rehabilitation centres.

Keeping in contact with our members directly helps familiarize us with our members' needs, which we believe is crucial in helping us to be responsive and remain relevant.

Community Support Program



ALS can cause unprecedented disruption in the daily lives of those touched by the illness, leaving no one spared of its' impact. Even the most prepared and adaptive families may need help at some point in time.

There are many resources and assistance programs available at the provincial, governmental and community levels that can offer support services, food security assistance, and financial aid that can help you meet your most pressing needs.

If you are in a precarious situation and do not have sufficient financial resources to meet your daily needs, speak with your health care team to evaluate whether you might be able to receive support from us. We provide a short-term **last-resort** support service, that is subject to the availability of funds. Financial assistance is time-limited and is reserved for financially and socially vulnerable families with urgent, illness-related needs that cannot be addressed by: existing health and social service networks; regional community resources; insurance coverage or government programs. If you have any questions or concerns about your situation, please contact us. We will gladly help you to explore resources and guide you through the steps that could lead to sources of support.

The request for financial aid must be made by a health care professional from the local community services centre (CLSC), Integrated Health and Social Services (University) Network (CISSS or CIUSSS) or from a long-term care centre/facility or a palliative care unit/residence.

Please note that we will not reimburse any purchases, rentals of equipment, or costs/fees related to services that are made prior to a request being sent, received and processed by the ALS Society of Quebec. Please contact us before undertaking any expenses or purchases. We are here to help you.

This support program provides last-resort, short-term assistance. Given that the ALS Society of Quebec is a non-profit community organization, our role is to help with delays and shortcomings within the health care system, not to replace or substitute any government programs. This support program is made possible through donations and grants, and varies according to the funds available.

Support for Caregivers



The ALS Society of Quebec knows that caring for someone diagnosed with a neurodegenerative disease is physically and emotionally demanding. From the outset, the Society's goal has been to help improve the quality of life of caregivers, as well as those diagnosed with ALS, by providing services to support, equip, and refer our caregiver members as needed, thus lessening the risk for injuries, exhaustion, depression, anxiety, and stress. By doing so, we help you set the stage for a less complicated grieving process.

We are an ally, an advocate, and a resourceful lifeline that ALS caregivers in Quebec can rely upon and trust. Our committed team is available to support caregivers throughout their caregiver journey at every stage of the disease. We recognize that caregivers devote an enormous amount of time, energy, focus, and financial resources to caring for loved ones with ALS, but they can't do it alone. Providing families with different options for interactive and specialized support groups, training, teleconferences, and webinars with disease-

specific information allows caregivers to break their sense of isolation and share their stories, worries, and frustrations while offering one another emotional comfort and support.

We know that when it comes to a challenging disease such as ALS, one size simply does not fit all. Each caregiver's path is unique and has its own needs and rhythm. We also strive to work with ALS caregivers on providing access to information and resources so that caregivers are better equipped to maintain their own health and have the energy, knowledge, and ability to meet the day-to-day demands, challenges, and impacts of the illness.

To see more about the ALS Society of Quebec's caregiver-specific support programs and services, such as our online learning environment, called Taking Care, please consult Section 5g: Supports and Services for Caregivers, or visit our website at <http://als-quebec.ca/support-and-services/caregiver/>.

Bereavement support for caregivers



When it comes time for a loved one's journey to end, the ALS Society of Quebec remains available to provide respectful and compassionate bereavement support. Whether a family member or friend is in search of someone to talk to, a resource, or some other kind of information, our counsellors are there to help.

If the loss of your loved one has been especially difficult and you would like to consult with a professional that is specialized in bereavement but are hesitant to because of the cost, please contact your counsellor at the ALS Society of Quebec.

2.0

ABOUT ALS

Amyotrophic lateral sclerosis (ALS), often known as Lou Gehrig's disease, is the most common form of motor neuron disease (MND).

In French, ALS is called sclérose latérale amyotrophique (SLA) or maladie de Charcot. The first full account of ALS symptoms was published in 1874 by Dr. Jean-Martin Charcot, a French neurologist and founder of the field of modern neurology.

Other less common types of MND are primary lateral sclerosis (PLS) and Kennedy's disease.

Throughout this guide, we will use the shorter abbreviation ALS to refer to ALS/MND.

2A

WHAT THE NAME MEANS

“

Amyotrophic Lateral Sclerosis stands for:

a | absence

myo | muscle

trophic | nourishment

lateral | side (referring to the spine)

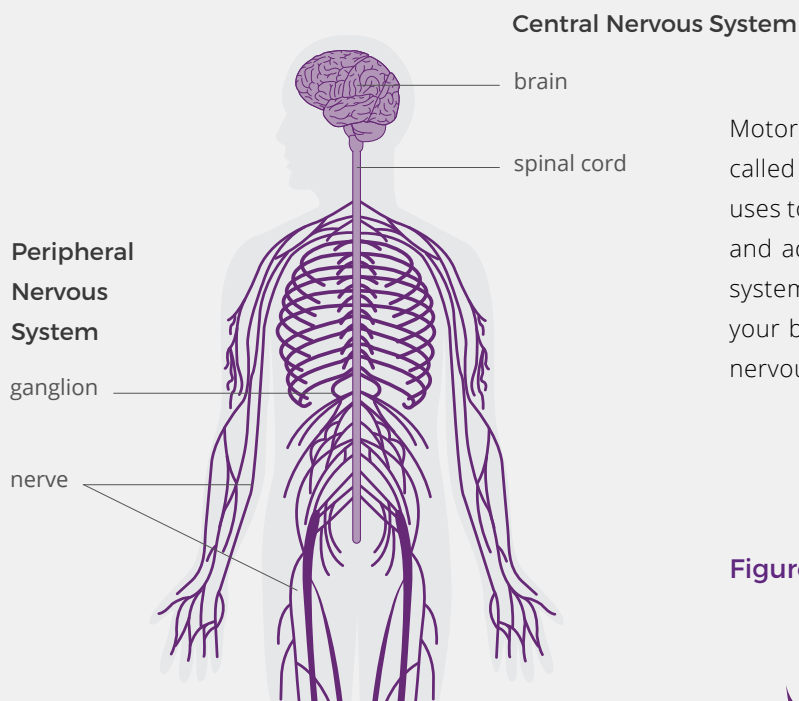
sclerosis | hardening or scarring.

2B HOW ALS AFFECTS THE BODY

ALS affects the motor neurons of your body, causing voluntary muscles to atrophy (deteriorate and weaken). Voluntary muscles are muscles that are under an individual's conscious control. These muscles include the ones in the arms, such as the biceps and triceps. The muscles of the face, neck, and tongue are also voluntary muscles that allow you to eat, support and move your head, and make facial expressions. Muscles that are not under an individual's conscious control, such as the heart muscle, are called involuntary muscles.

What are motor neurons?

Figure 1. Nervous system



Motor neurons are cells in the nervous system. They're also called nerve cells. Your nervous system is what your body uses to communicate with your muscles and organs to react and adapt to things happening around you. Your nervous system spreads across your entire body but is controlled by your brain and spinal cord, which is known as your central nervous system (Figure 1).

To be able to talk to your muscles, your nervous system uses motor neurons (Figure 2). They are like the “messengers” of your nervous system. So, if you want to move your arm, your brain will send a signal, or message, to your arm muscles using motor neurons.

Figure 2. Motor Neuron

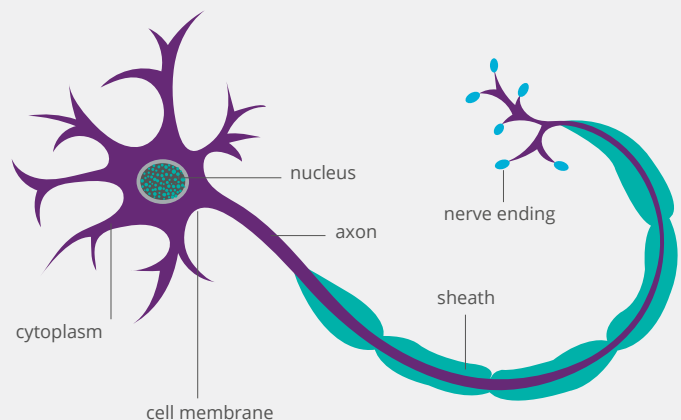
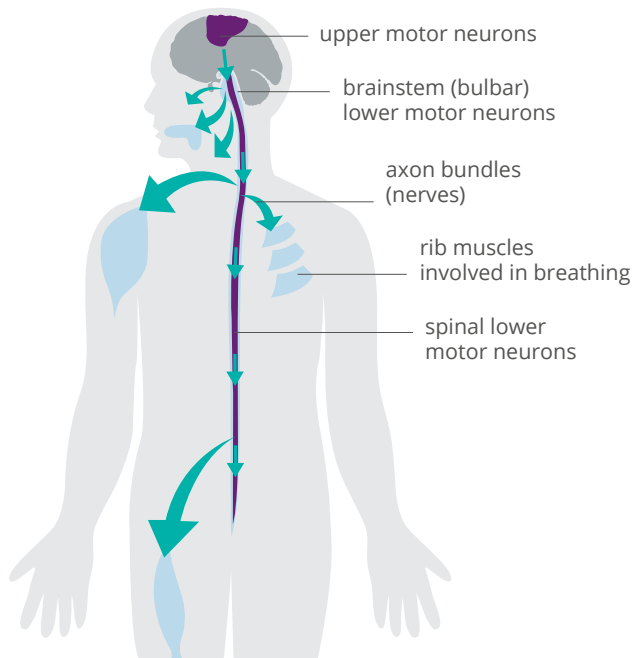
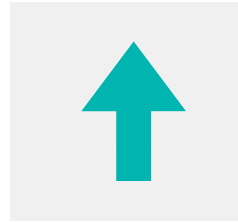


Figure 3. Upper and lower motor neurons

The two main groups of motor neurons are the upper and lower motor neurons (Figure 3).

**UPPER MOTOR NEURONS**

tell your lower motor neurons when and how to move your muscles.

**LOWER MOTOR NEURONS**

send signals directly to your muscles to tell them to move according to the directions of the upper motor neurons.

WHAT HAPPENS TO MOTOR NEURONS WITH ALS

When you have ALS, your motor neurons start to die. As they die, your brain is no longer able to send messages to your voluntary muscles telling them to move. This means your muscles atrophy. Over time, ALS spreads throughout the body and atrophies all voluntary muscles, eventually weakening muscles required for breathing and leading to respiratory problems.

ALS affects both upper and lower motor neurons. If only upper or only lower motor neurons are affected it is not ALS but a different disease.

When you have ALS/MND, your motor neurons start to die. As they die, your brain is no longer able to send the message to your voluntary muscles that they need to move a certain way.

ALS is a disease that decreases life expectancy. There are some treatments and no known cures. As a result, 80% of people with ALS have a life expectancy of two to five years after diagnosis. How fast a person loses the use of their muscles can vary significantly from person to person. Some deteriorate rapidly, while others have long periods of very slow degeneration.

ALS does not typically affect the five senses: sight, hearing, taste, smell, and touch. It also does not usually affect the heart. Recent studies have shown that some people with ALS may experience a reduced ability to smell or detect odours.

2C

HOW DO YOU GET ALS?

WHAT ARE THE RISK FACTORS?

ALS is not contagious, and you did nothing to cause it. It's not your, or anyone's, fault.

A small number (10% or less) of people have **familial** (or **hereditary**) ALS. The rest (90% or more) are **random** (or sporadic) **ALS** diagnoses. As the name "random" implies, anyone can develop ALS, including young adults and the elderly. On average, the disease tends to show the first symptoms in the mid- to early senior years. It is most commonly diagnosed between the ages of 40 and 70. ALS is diagnosed in both men and women of all ethnic and socio-economic groups.

Most of the risk factors are things you can't do anything about:

RISK FACTORS



GENETICS

For information about the genetics of ALS, please see Section 6: Research and ALS.



AGE

The risk of getting ALS increases with age.



HEREDITY

Most people with the familial form of ALS have a 50% chance of passing the disease to each child.



SMOKING

Smoking is the only environmental factor to be recognized as having a direct influence on increasing the risk of developing ALS. Studies have shown that smokers are about twice as likely to develop ALS as those who have never smoked, while those who are former smokers have a moderately increased risk.

2D DIAGNOSING ALS

The onset of ALS can be subtle and the symptoms are often overlooked until weakness is obvious enough to cause a doctor to suspect ALS. ALS is often diagnosed by ruling out other diseases and conditions first. This is because so far, there is no test specifically to diagnose ALS. Usually, the diagnosis is made by a neurologist.

Early symptoms of ALS can include the following:

- Tripping
- Dropping things
- Difficulty with simple tasks such as buttoning a shirt or turning a key
- Slurred or “thick” speech
- Muscle cramping, weakening and twitching

Some people with one or more early symptoms may simply think they are experiencing normal signs of aging.

However, as the disease progresses, muscles will continue to weaken. As it spreads throughout the body, it will become more apparent that the cause is ALS through a process of elimination.

In addition to a physical examination, the usual process of diagnosing ALS includes an electromyography (EMG) test, blood tests, magnetic resonance imaging (MRI), and other tests to search for the possible presence of other diseases that exhibit symptoms similar to those of ALS.

2E SPINAL/LIMB ONSET ALS

The most common type of ALS is spinal or limb onset ALS. As the name indicates, limbs (arms and legs) are usually the first areas to be affected. Usually, symptoms begin in either the arms or the legs, not both at once.

Symptoms of spinal/limb onset ALS

Symptoms of lower limb onset ALS include

- Tripping
- Stumbling
- Difficulty running properly
- Foot drop (foot slapping down on the ground when walking rather than rolling smoothly)

Symptoms of upper limb onset ALS include

- Less finger dexterity
- Cramping in the arm or hand
- Weaker hands
- Stiffness in the arms or hands

Both types of limb onset ALS have other symptoms that indicate whether upper or lower motor neurons are being affected first. Signs of lower motor neuron degeneration include:

- Muscle weakness and atrophy
- Involuntary twitching of muscles (known as fasciculations)
- Muscle cramps
- Weakened reflexes
- Flaccidity (decreased muscle tone)
- Difficulty swallowing
- Inability to articulate speech
- Shortness of breath at rest

Signs of upper motor neuron degeneration include

- Muscle stiffness or rigidity
- Increased or hyperactive reflexes
- Emotional lability (a decreased ability to control laughing or crying)

The sequence of symptoms and the rate of disease progression may vary from person to person.

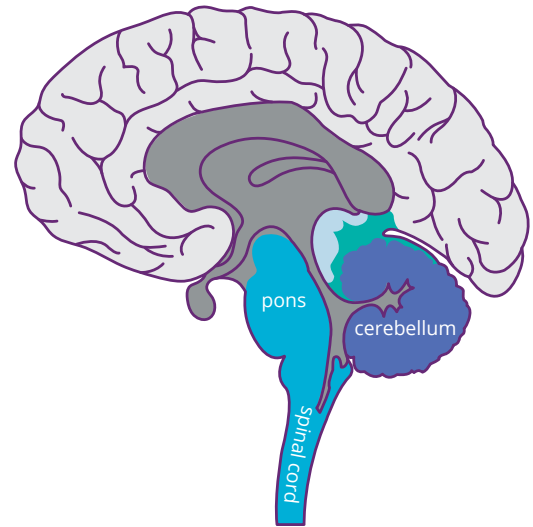
2F

BULBAR ONSET ALS

In about 20–25% of ALS cases, the muscles for speaking, swallowing, and/or breathing are the first to be affected. This is known as bulbar onset ALS. The term “bulbar” refers to the motor neurons located in the corticobulbar area of the brainstem (Figure 4), which control muscles of the face, head, and neck. Bulbar ALS often progresses faster than limb onset ALS.

In rare cases, the respiratory muscles are the first to be affected, and the disease may be classified separately as respiratory onset ALS. People with this type of ALS may be referred directly to acute respiratory care instead of to an ALS clinic or a neurologist.

Figure 4. Corticobulbar tract

**Symptoms of bulbar onset ALS****Symptoms of bulbar ALS include the following**

- Changes in voice and speech
- Harsh, hoarse, or strained voice
- Whispery voice (as a result of the vocal cords not folding as they do normally allowing more air to escape during speech)
- Poor articulation
- Less vocal range
- Quieter voice
- Spasms in muscles of the jaw, face, voice box, throat, or tongue
- Involuntary excessive laughing and crying
- Brisk jaw jerks
- Involuntary twitching in muscles of the tongue
- Vocal cord spasms causing the sensation that air cannot be moved in or out

If you have bulbar ALS, talk to your ALS clinic team about dietary changes, communication devices, speech therapy, and medications that can help maintain your quality of life.

2G

ALS AND COGNITIVE CHANGES

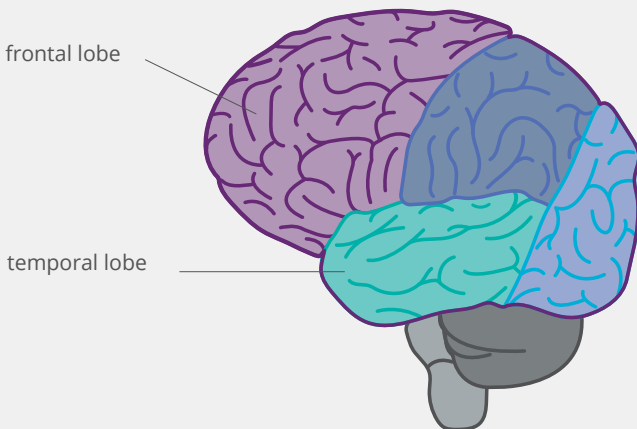
Almost half of people diagnosed with ALS will experience some level of cognitive change. Cognitive change means that the way a person thinks, knows, perceives, and understands the world around them becomes altered, which may or may not lead to differences in the way the person acts.

Most commonly, people with ALS experience only mild to moderate cognitive changes. Mild effects include alterations in planning, reasoning,

organizing, and managing life functions (or executive functions); increased apathy; changes in language (written or oral expression) and comprehension, including decreased verbal fluency and speech impairment; inattention or forgetfulness; bouts of irritability, apathy and/or anxiety and depression. Mild cognitive alterations are often recognized only through neurological testing, whereas moderate changes may be more noticeable.

Approximately 35% of patients with ALS experience clinically relevant cognitive impairment, with an additional 15% having frontotemporal dementia (ALS-FTD). There is greater complexity to the spectrum of cognitive changes detailed within the diagnostic criteria defined by Dr. Mike Strong and team. For more information, please refer to the Resource Section under ALS and Cognitive Changes.

Figure 5. Frontal and temporal lobes

**Frontotemporal dementia**

Frontotemporal dementia is a progressive brain disease involving loss of neurons in the frontal and temporal lobes of the brain (Figure 5), which are areas of the brain responsible for rational thought, impulse control, and personality. Unlike Alzheimer's disease, severe behavioural changes are usually the first signs to develop in FTD rather than memory loss, which may not occur at all.

Both FTD and ALS occurring at once is referred to as ALS frontotemporal spectrum disorder.

Signs and symptoms of frontotemporal dementia

- Restlessness
- Recurring sudden mood swings
- Loss of reasoning or problem-solving ability
- Repetitive behaviours
- Socially inappropriate behaviour
- Impulsiveness and loss of inhibitions
- Memory loss
- Balance and/or movement problems
- Problems with speech and/or language

3.0

FIRST STEPS: HELPING YOU AND YOUR FAMILY NAVIGATE THE JOURNEY

3A

REGISTER WITH YOUR LOCAL ALS SOCIETY

Provincial ALS societies provide comprehensive, accurate, and timely information about the disease and offer services and support to those living with ALS/MND (referred to here as ALS), their caregivers, and their families. Your provincial ALS Society can help you navigate the healthcare system and connect you with health and community services available in your area.

Register with your provincial society and take advantage of its services. See the “My ALS Society” section for more information.

3B

COMMUNICATING THE NEWS

You will most likely need a few days or weeks to process your diagnosis. For some people it takes longer to be able to talk about their situation, and **that’s okay**. Everyone’s experience with the disease is different.

You may be anxious about how and when to communicate the news. You may prefer to take some time to process the news yourself. You may wish to find out more about the disease, consider its long-term implications, and think about how you wish to manage things before discussing it with family and friends. That’s all okay.

But don’t wait too long. Talking with others can help you process the news yourself and can be a first step in getting emotional and practical support. If you find it hard to talk about, it may be useful to talk with a member of your ALS care team, your ALS Society representative, a friend, a co-worker, or a counsellor. They may be able to help you and your loved ones talk to each other in a way that works for you. It is most important that you have someone to talk to who will not be upset by what you are saying.

A practical strategy may be to tell a few key people and ask them to break the news to everyone else you wish to inform, once you’ve given those key people clear, accurate information.

Keep in mind, though, that your loved ones are experiencing emotional reactions to your diagnosis too, which is normal. No one should feel guilty about any of their feelings. Keeping the lines of communication open is the best way to work out feelings on both sides.

Communicating the news to children

Many people hope they can protect children from difficult situations by not explaining how bad the disease really is. But all children, no matter how old they are, should be told the truth in a way they can understand. Children, even very young ones, can pick up on emotional changes in a family.

Excluding them from the conversation can easily make them misunderstand why emotions have changed and could even make them think they did something wrong and that they are to blame. This type of thinking can be more harmful to their well-being than telling them the truth and sharing the family’s experience.

There may be signs that indicate you need to talk to your children about your diagnosis sooner rather than later. For instance, if children start asking questions about noticeable changes in your situation, appear withdrawn, or show anxiety, they need to be told what’s happening.

Even though it is important to talk to children about the disease, it's also important not to overwhelm them with information. The pace, amount, and type of information you provide will depend on how old the child is and how the disease is progressing. Many children will guide the pace at which information is given by asking questions, for example.

Starting the conversation

The words you choose are extremely important: **clear, simple, correct, and precise words are best.** This will help limit confusion and misunderstanding.

The conversation may not be easy, especially if you are trying to explain ALS to children when you yourself may not quite understand the disease. But starting an ongoing conversation with a child can have positive effects on their thinking and behaviour throughout the course of the disease.

Start the conversation by referring to things the child already knows. For example, if ALS is affecting their father's legs, you could say,

“ You know your dad has been having trouble walking lately. He has been to the doctor, who has told him he is sick. He has something called ALS and it's going to make it more and more difficult for him to walk. ”

You may want to explain more or decide that this is enough for now, but a conversation like this is a good starting point. Talking about ALS openly shows that it is something safe to talk about.

Children need to know that it is okay to ask questions and that someone will try to answer them. Children often have these major worries when a close family member is affected:

- What will happen to me if the person with ALS becomes very sick or dies?
- Who will look after me?
- Will I have to move or change schools?
- Will I have to give up my favourite activities?

They may also ask,

- What exactly does the sick person have?
- Will I catch it?
- What will happen to the sick person? Will they die?

These are all normal questions for a child to ask.

When answering a child's questions, be honest. Don't be afraid to say, "I don't know" or "the doctor doesn't know." Children do pick up when you are not being honest with them, and this can make them wonder if you are hiding something. Even if you don't know the answer, the types of questions children ask will give you some idea of what they are worried about.

Slowly, give more information about the disease and its progression. It helps a child when they feel an adult is in control. It is also important to keep reminding them that they will continue to be cared for as the family faces the challenges of ALS progression. Talking about how you plan to manage day-to-day family activities will help children feel more at ease.

If your child won't talk about it

Not asking any questions does not mean the child is not interested or not thinking about the situation. Some children may need time to process the first conversation before they ask questions. Other children may need a little coaxing to ask their questions. Some children may feel too afraid of what they will hear to ask anything.

The important thing is to establish good communication so they can come to you when they are ready. Check in with them every so often about how they are feeling and if they have any questions.

Denial is a common reaction adults have when faced with something painful and unpleasant. Children do the same. Children may hope that by not talking about it and pretending nothing is happening, things will get better or go away.

Some children may be afraid of upsetting their mom or dad by talking to them about the disease. They may find it easier to talk to someone who is not their parent or a caregiver. Having another adult to talk to, such as a friend or relative, may be a good way to encourage the child to share their thoughts and feelings. This adult can reassure them that emotional reactions are normal and healthy. They can also let the child

know not to worry about hurting their parents and encourage them to share more of their fears and worries with them.

If you have a hard time talking to children about ALS

If you, as parent or caregiver, do not feel you can talk to your children about the disease yourself, that's okay. You just need to make sure the child has someone they can talk to when they need to. A good way of doing this is to involve another person, such as a friend or a relative, in the conversation.

It's okay to cry when talking about ALS with children. It's part of your authentic reaction to what's going on and it helps reassure children that it's normal to be emotional. Just let them know why you are sad and that it is okay for them to be sad, afraid, or even angry. Tell them it's okay to talk about their feelings with you.

Children may ask questions before you are ready to initiate a conversation. They may not come to a parent with their concerns but to another adult in their life. It is therefore important to keep the following things in mind:

- Be mentally prepared to answer any questions that may come "out of the blue" or unexpectedly.
- Try to have everyone involved in the children's lives on the same page when it comes to how to communicate the news. This could include relatives, parents of close friends, teachers, and coaches. Try to be consistent with language and tone.

If you are unsure about how and when to talk to your children, seek professional advice. Your ALS healthcare team and ALS Society can support you and provide resources to help you talk to your children.

Talking about death with children and helping them grieve

Explaining to a child that someone they love is sick and will not live much longer is difficult. During this discussion you

may want to talk to children about what you believe occurs when physical death occurs. Belief in an afterlife, if that is a part of your spiritual beliefs, can provide comfort to family when faced with the death of a loved one.

When the time comes, wanting to protect your children, or yourself, from your child's grief is normal. But it is important that news of a death be shared with children, not hidden from them.

What you tell your child about death depends on how old they are and the stage of the disease. You should use simple, clear, honest terms. They should hear the words "dead" and "death." A young child's understanding of time is usually very different than an adult's, and euphemisms such as passed away, lost, and gone communicate something different to the child than they do to an adult.

You may have had an opportunity to discuss mourning or death through previous family loss or the loss of a pet. Explain these natural feelings of sadness when losing a loved one. Showing that happy memories can live on is helpful for children.

For some children, the only experience of human death they have had is the violence reported on television news or in films. They may believe that all deaths are violent. It is important that you reassure children that death from ALS is very different from what they see in the media.

A good way of helping children cope with death and grief is to let them take part in family rituals and traditional bereavement activities. This helps them understand that death is real and permanent and teaches them some valuable life experiences and coping skills.

Communicating with co-workers and employers

If you have been diagnosed with ALS and continue to work, consider what to tell your employer and co-workers, and when. This is a personal decision and depends on you and your employment situation.

Refer to Section 3h – Financial, Social, and Legal Assistance for additional information.

When to tell your employer

You should tell your employer sooner rather than later because they can be very supportive and helpful in finding

options and benefits that you may be eligible for. Ask your healthcare team for advice about talking to your employer.

Here are some things to think about when getting ready to talk to your employer:

- Are there any extended healthcare benefits you might be eligible for?
- Are you working on a project that you want to finish before telling your employer?
- Are your symptoms interfering with your ability to perform your job?
- Are you worried that your employment future would be compromised if you tell your employer?
- Does working bring meaning and quality to your life? Will you miss that if you are unable to continue working?
- Do changes need to be made to help you carry out your job duties?
- Do you have the energy to continue working?
- Do you need support to have these conversations?

IMPORTANT

In Canada employers are legally required to accommodate a person with a disability such as ALS (<http://www.canada.pch.gc.ca/eng/1448633334025>). The legislation related to employment rights for persons with disabilities varies for each province. If you have questions about the legislation in your province, please contact your ALS Society or a lawyer. Many provinces have free or subsidized legal support available to residents. It is highly recommended that you not sign anything regarding ending your employment without first seeking legal advice. You may be eligible for a severance package and benefits.

3C

STRATEGIES FOR COPING WITH ALS

There is no “right” way to deal with an ALS diagnosis. ALS progresses differently in everyone. Everyone’s family and social supports, financial circumstances, and life experiences are different. Whatever your journey may be, know that your ALS Society is here to help you every step of the way.

Your perspective

Many people will look at life with ALS as a series of losses, but it could also be a unique opportunity to bring a different meaning to your life. How you approach the course of your disease is your choice.

If you choose to bring a different meaning to your life, it can take many forms. These choices are very personal. You can learn to appreciate things in the world around you that you previously took for granted. You can take time to read, listen to music, or be part of something that gives you joy and hope. You could choose to travel depending on your financial situation. The list goes on and on. It won’t likely include everything you’ve always wanted to do, but it can include enough to give you a full and satisfying life. It all depends on your attitude and imagination.

Be positive, but do not trivialize your situation. It isn’t helpful to pretend that everything will be fine or that ALS is not a very serious condition. Focus more on what you can do than what you can’t. Live one day at a time because this can help limit the anxiety created by focusing on what’s to come. Focus on having a joyful experience every single day.

Learn as much as you can about your condition. Through social workers, psychologists, counsellors, and support groups, you can learn from those who are familiar with what you are going through. Support groups specifically allow you to share with others who have the same challenges as you, and you can learn how people living with more advanced ALS are dealing with issues you might face in the future. Your ALS Society, some hospices, and other organizations provide support groups and other types of services to help provide social and emotional support throughout the course of the disease.

Coping with grief

Grief is the outward sign of bereavement and mourning. People living with ALS often feel anticipatory grief. Anticipatory grief happens when you are considering future losses – changes in your ability to do things for yourself, giving up plans for your retirement, having to stop working, changing social roles and relationships, missing social activities, and ultimately the loss of life itself.

Allowing yourself to grieve can be beneficial. When feelings are repressed, they gain power; when they are embraced, you gain strength.

Here are some suggestions for coping with grief:

- Confront your feelings of grief by saying what they are for you.
- Talk about your feelings with others. Some feelings may be hard to share. Enlist the support of someone who is objective, accepting, empathetic, and not afraid of strong feelings. You may prefer to speak to a professional counsellor or join a support group.
- Try to resolve and forgive past wrongs.
- Make plans for the future. Deal with financial changes, tax issues, insurance, and medical and personal care choices; make a will and funeral arrangements; and so on. Although it is often difficult to confront these tasks, early preparation eases the decision-making process.
- Live in the present. Try to relax whenever possible. Enjoy and celebrate life's joys and pleasure. Mindfulness is the practice of staying in, and paying attention to, the present moment (often through meditation). It helps relieve stress and anxiety.
- Think about how you want to be remembered. Document your special memories in a journal or on audio or video recordings. Make a lasting memory for survivors to remember how you lived your life and the meaningful times you shared. Leaving your mark on the world may help you feel satisfied with a life well lived.

The grieving process is unique to each person who experiences loss. There is no script to follow or blueprint on how to grieve.

Realize that feeling grief is not a one-time thing. You will have a period of grieving each time you experience a new loss. Accept your grief, let it happen, give yourself a timeframe for grieving, and then focus on what you can still do.

Coping with daily needs

Members of your immediate family will likely become involved in assisting you with your daily care. Most people with ALS prefer to remain in their home as long as possible, and the demands on family members can be great. Your primary informal caregivers, such as your spouse or partner or your grown children, may find that your care, especially in the later stages of the disease, takes up most of their time. It is natural for them to want to do all they can to help you, but they need to stay healthy themselves and recognize when they need to take a break.

IMPORTANT

Ask other family members or friends to fill in for your primary caregiver when he or she takes regular breaks or, if possible, arrange for paid help. An ALS care team member or ALS Society representative may be able to help you identify respite services and any funding available for respite care. Some people are reluctant to ask for or receive help, but please remember that sometimes, your family caregiver or partner will need help and support, even if they don't say so.

Caregivers must continue to have lives of their own and they must take care of themselves. They need to be able to spend time in the company of friends and other family members, to pursue hobbies or activities other than caregiving, and to find quiet time alone. These periods of respite allow caregivers to recover from the stresses of caregiving and to remain effective, balanced helpers. More information on how to cope and manage as a caregiver can be found in Part 5: For Caregivers.

Dealing with friends and relatives

Your friends and relatives may want to be there for you. Allowing them to support you is a great gift you can give them. You may find that some people in your life aren't around as much as they were previously. This may hurt you and be hard to understand, but it may simply be their way of coping with your diagnosis based on their own life experiences.

You could connect friends and relatives who have become distant with your ALS Society representative, who can provide resources and support.

In contrast, some people you don't expect to see will show up time and time again.

People will often make a general offer to help, saying something like, "If you need anything, I'm here." Even though they really want to be there for you, sometimes they don't know what type of help to offer.

As the disease progresses, think of practical ways they can help – picking up the kids at extra-curricular activities, assisting with house or yard work, keeping you company, taking you to medical appointments, and so on.

Keep a list at hand to make suggestions when someone makes a general offer to help and see what that person is comfortable doing. This will turn the kind general offer into some practical, much-needed help.

3D

STRATEGIES FOR HELPING CHILDREN COPE WITH ALS

Make sure life goes on as normally as possible for children, and don't be afraid to ask others to help you make this happen. It is easy to let ALS take over your daily life, and maintaining a normal routine is important for children to feel secure and safe in times of stress. For example, make sure to keep them in the extra-curricular activities they have always done or enjoy doing, let them continue spending time with their friends regularly, and go out as a family.

Most importantly, find time to give your children love and undivided attention and to show them that life goes on.

Coping with children's feelings and reactions

It will be important to model healthy emotional behaviour in front of children and to talk about what is happening in terms of feelings as well as facts. Encourage children to talk about how they feel, to cry if they want to, and to talk about the situation to anyone with whom they feel comfortable doing so.

Don't try to hide tears or emotions: explain to your child that you are having a bad day, emotionally or physically. When you are having a good day, talk to them about that too. Sharing your emotions will help them understand their own emotions. For example,

“ Even though I don't like being sick, I love to hear the birds sing and to watch you playing in the yard – it makes me smile. ”

If your child isn't showing any emotion about the situation, understand that children may hide their feelings at times. But that does not mean they do not care or that they are not feeling anything.

When children are experiencing big changes, it is important to explain everything as fully as possible. When adults don't explain clearly to children what is happening, children don't come to understand the situation fully and often blame themselves for the sadness in the house, which can turn into strong feelings of guilt.

Aggressive behaviour and acting out are also completely normal. Children can be angry or resent the changes that illness has brought into their life, including the amount of attention taken away from them. Children may express anger directly at the person with ALS or display other attention-seeking behaviour.

Helping children cope with day-to-day changes

Children are acutely aware of “differences” among people and may be embarrassed by the changes the illness has caused. They need help understanding that although Mom’s voice sounds strange or Dad is in a wheelchair, it is still their mom or dad. Close family should be kept informed and encouraged to visit as much as possible.

Let children help with caregiving when they express the desire to do so. Being useful will make them feel involved and valuable. They do not have to help with medical care; doing more chores around the house or just reading and spending time with the person with ALS are all helpful activities that will make children feel useful. Let them also be involved in planning family activities that will include the relative with ALS. These activities also help them better understand the lifestyle changes that come with ALS.

Coping with anticipatory grief in children

As the illness progresses, many families find comfort making a special remembrance book or filming videos. Photographs and other mementos will be a reminder of happy family times, as well as a reminder to the child of how much they are loved. Older children may find that talking to the person with ALS about their plans for college, employment, or marriage can help them later, during bereavement.

3E PARTICIPATING IN THE ALS COMMUNITY

At both the national and provincial level, your ALS Society and your local community run special events, public awareness campaigns, and fundraising and advocacy activities in which you, your friends, and your family may wish to participate, such as

- ALS Awareness Month in June
- The WALK to End ALS
- Federal, provincial, or regional advocacy efforts that focus on making changes to public policy to improve the quality of life of persons affected by ALS

Advocating for support and services for people with ALS is important. Participation in your ALS Society’s activities can be very empowering. Please contact your local society to find out how you, your family, and your friends can get involved, or visit your society’s website.



3F

YOUR HEALTHCARE TEAM

Depending on where you live, a number of service providers may be working with you to manage your journey with ALS. Below is a list of possible team members you may work with. Your provincial ALS Society can also help you find additional resources.

TEAM/ SUPPORT PERSON	ROLE	HOW THEY CAN HELP YOU
ALS Society in your province or region	<ul style="list-style-type: none"> ALS societies provide a multitude of support mechanisms, including interaction with others who have ALS. Each province has unique programs to help you maintain your quality of life. 	You are not alone. Connect with your ALS Society and bring hope to life.
Multidisciplinary Clinics		
ALS/MND clinics	<ul style="list-style-type: none"> Most provinces have ALS clinics. Many clinics have a multidisciplinary team of specialists that work together to help you cope with mobility, breathing, speech, and nutrition challenges. 	<ul style="list-style-type: none"> If you aren't a patient at one of these clinics yet, ask your neurologist or family physician for a referral. The ALS clinic's nurse coordinator or your ALS Society's representative may be able to help you arrange travel for a clinic appointment.
Physicians		
Family doctor or healthcare team	<ul style="list-style-type: none"> Your doctor's role may include <ul style="list-style-type: none"> Making necessary referrals to, and consulting with, other healthcare providers to best manage your care Signing forms and benefits applications Your family doctor or healthcare team will rely on specialists and therapists associated with an ALS clinic for consultations and advice. Depending on your region and access to specialists, your family doctor or healthcare team may play a larger role throughout your illness. 	Your doctor can... <ul style="list-style-type: none"> access resources from the ALS Society that could benefit you request a copy of the patient guide or other information made available by the ALS Society continue to manage pre-existing conditions and provide general medical care assess regularly to maintain continuity of care
Neurologist		
	<ul style="list-style-type: none"> Your family doctor or healthcare team will refer you to a neurologist, a specialist in diseases of the nervous system. The neurologist is the one who will confirm an ALS diagnosis and after diagnosis conduct regular follow-up. 	Your neurologist can... <ul style="list-style-type: none"> outline treatment options – ask which are best for you work with you to identify specific needs and concerns – they may be able to refer you to therapists answer questions about ongoing research and clinical trials for which you might be eligible

TEAM/ SUPPORT PERSON	ROLE	HOW THEY CAN HELP YOU
Palliative care physician and team		
	<ul style="list-style-type: none"> • Palliative care is delivered by a doctor or team with special training focused on pain management and other care aimed at improving comfort and quality of life for patients with life-limiting illness. • They are trained in talking with patients about care decisions, including end-of-life issues. 	<ul style="list-style-type: none"> • Your palliative care physician or team can help you with pain and symptom management.
Physiatrist		
	<ul style="list-style-type: none"> • A physiatrist is a medical doctor specializing in physical and rehabilitative medicine. • They evaluate the extent of disability and gauge your level of muscle function. • Based on these findings, the physiatrist may design your treatment plan. • A physiatrist will consult with therapists concerning orthoses (devices worn to support weak joints) and other equipment. 	<p>Your physiatrist...</p> <ul style="list-style-type: none"> • may know about supportive treatments – they can recommend something that works for you • can work with you to identify strategies to help you maintain maximum function and quality of life
Gastroenterologist		
	<ul style="list-style-type: none"> • A gastroenterologist is a physician who specializes in managing the digestive system. • This includes every organ involved in digestion, from the mouth to the colon. 	<p>Your gastroenterologist...</p> <ul style="list-style-type: none"> • oversees overall nutritional care • inserts and assesses feeding tubes
Respirologist		
	<ul style="list-style-type: none"> • A respirologist is a medical doctor who specializes in care for the respiratory system. • They assess respiratory function. 	<p>Your respirologist can...</p> <ul style="list-style-type: none"> • care for you if you have a respiratory infection • answer your questions and concerns when you are interested in mechanical ventilation (equipment to help you breathe) • answer questions about other respiratory aids, such as suction units and cough assist machines

TEAM/ SUPPORT PERSON	ROLE	HOW THEY CAN HELP YOU
Nurse clinician		
	<ul style="list-style-type: none"> • A nurse clinician analyzes assessment data, formulates nursing goals, and draws up and implements a care plan for the person with ALS. • They will ensure you are as comfortable as possible. 	<p>Your nurse clinician can...</p> <ul style="list-style-type: none"> • explain healthcare terminology and techniques that you don't understand • advise you about care decision-making and encourage and promote decision-making by you and your family • inform you about community organizations that can help you or that may be of interest to you – nurse clinicians are often a liaison between the healthcare system and the community • refer you to specialists you may need to see
Allied Health Professionals		
Occupational therapist	<ul style="list-style-type: none"> • The occupational therapist (OT) develops strategies that enable you to continue to carry out daily activities safely and efficiently. • The OT is generally most concerned with fine motor function (e.g., hand use) and how movement will affect function. • If you haven't already seen an OT, ask your healthcare team to refer you for an assessment. 	<p>Your OT can...</p> <ul style="list-style-type: none"> • evaluate your positioning and seating requirements, so tell them what does and doesn't feel comfortable • help you choose and access devices to help you move and communicate, along with other assistive devices – they can guide you to what is best for you • teach you about exercise, positioning, correct body mechanics for lifting and transferring, and the use of assistive devices – they can give instructions on these topics to you, family members, and caregivers • instruct you on energy conservation and time management techniques • provide information about modifications to your home and other environments to enhance mobility and safety

TEAM/ SUPPORT PERSON	ROLE	HOW THEY CAN HELP YOU
Physiotherapist	<ul style="list-style-type: none"> • A physical therapist/physiotherapist (PT) develops strategies that enable you to continue to carry out daily activities safely and efficiently. • The PT is generally most concerned with gross motor (large-muscle) function and with how ALS is affecting your movement. • Your PT will work with your respirologist on your breathing. 	<p>Your physiotherapist...</p> <ul style="list-style-type: none"> • will provide a detailed analysis of abnormal movement (e.g., gait analysis – how you walk) • helps you optimize your strength, function, and comfort • can design and monitor a therapeutic exercise program when appropriate • can assist with breathing management • provides training in energy conservation and time management techniques
Dietitian/ nutritionist	<ul style="list-style-type: none"> • A Dietitian or nutritionist's primary role is to keep your quality of life as high as possible by ensuring that you maintain safe and adequate nutrition and hydration to prevent life-threatening nutritional deficits. • The Dietitian may work with the speech-language pathologist. 	<p>Your Dietitian/nutritionist...</p> <ul style="list-style-type: none"> • may assess your ability to feed yourself or to administer your own tube feedings • evaluates nutritional status and offers strategies for maximizing nutritional intake • can recommend changes in food texture and consistency • can recommend different methods of food preparation • can suggest substitutes for hard-to-manage foods • can recommend manageable meal sizes and frequency
Respiratory therapist	<ul style="list-style-type: none"> • A respiratory therapist (RT) generally devises strategies to optimize remaining breathing muscle function and reduce discomfort. • The RT will institute a program of chest care if necessary. • In some locations, the RT may help you with exercises to promote airway clearance and cough techniques. 	<p>Your RT can...</p> <ul style="list-style-type: none"> • evaluate your pulmonary function • help you maintain pulmonary hygiene (airway clearance) • provide suggestions for managing decreasing breathing function • offer information on body positioning, energy conservation, relaxation, and compensatory techniques to improve breath support for eating and speaking • set up a home ventilation program if appropriate • make suggestions about a course of action for when respiratory failure occurs

TEAM/ SUPPORT PERSON	ROLE	HOW THEY CAN HELP YOU
Social worker	<ul style="list-style-type: none"> The social worker's role includes both practical assistance and emotional support to help you and your family cope with everyday life. 	<p>Your social worker...</p> <ul style="list-style-type: none"> can provide emotional support and counselling and refer you to appropriate service agencies if ongoing support is required understands the emotional impact of ALS and can assist with psychological adjustments that come with the diagnosis can provide information about community resources and help you access them may be able to provide information on legal and financial issues and help you access these resources in your community can help you set short- and long-range goals and make plans to meet future care needs
Speech-language pathologist	<ul style="list-style-type: none"> A speech-language pathologist provides advice on techniques and strategies to allow you to continue to communicate throughout your life. 	<p>Your speech-language pathologist can...</p> <ul style="list-style-type: none"> evaluate your motivation and potential for learning new techniques evaluate functional abilities, such as oral motor function, cognitive-linguistic function (including reasoning, social language skills and memory), augmentative communication function (including need for communication aids to add on to speech), and swallowing function determine the most efficient communication method for you train you and your family on techniques for effective communication and energy conservation provide advice on safe eating, drinking, and swallowing techniques

TEAM/ SUPPORT PERSON	ROLE	HOW THEY CAN HELP YOU
Pastoral care	<ul style="list-style-type: none"> • A minister, priest, rabbi, chaplain, imam, or other pastoral care worker can provide guidance and spiritual support throughout your illness. 	<p>Your pastoral care provider can...</p> <ul style="list-style-type: none"> • listen and empathize if you want to talk about your concerns • assist in making decisions • provide spiritual support during emotional or physical crises • advocate for those who have no voice • reassure you that life has meaning and facilitate spiritual reflection • assist your family after your death
Psychologist or Counsellor	<ul style="list-style-type: none"> • A psychologist or counsellor can provide you with emotional or psychological support. 	<p>Your counsellor or psychologist can..</p> <ul style="list-style-type: none"> • provide counselling and a safe space where you can express your feelings and emotions • provide specific emotional and psychological support for various phases of disease progression

Types of care



In-home care such as nursing or personal support, may become necessary at some point for many families living with ALS. In-home care assists with personal care, medical care, or even household management for someone with ALS. Nursing and other home healthcare services may be purchased directly by an individual, covered by private insurance plans, or publicly funded.



Hospice palliative care is aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, advanced illness or are bereaved. The goal of palliative care is to provide comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. Palliative care can take place in the individual's home, at a long term facility, in a hospital, or in a special hospice facility.



Respite care offers temporary, substitute living arrangements or special care in the home for people who need care, in order to provide a brief period of relief or rest for the family members or others who are the ill person's regular caregivers.



Long-term care homes are places where people can live and receive 24-hour nursing care and daily support for a range of cognitive or physical conditions.

3G

PLANNING FOR YOUR ILLNESS

The list of things you need to do when you are diagnosed with ALS/MND can be long and both physically and emotionally exhausting. Plan to also include positive and personal items, such as taking a trip that you've always wanted to do, attending your weekly book club, or getting a massage.

IMPORTANT

Note that you don't need to do everything at once, and other people can help you cross things off your list. Making a list and a schedule, and assigning responsibility for different tasks, will lift a weight off your shoulders. It will help reassure you that you aren't forgetting anything and that you have help. There will be weeks when you have energy and support to cross many things off of your list. Other weeks, your energy or emotional reserves may be low. If you are ahead in your planning, take a week off. Only do one thing a day or a week; just move forward.

List of Things to Consider

- Register with your local Local Community Service Centre (CLSC).
- Apply for a disability parking permit from your local government Société de l'assurance automobile or for adapted transport: <https://saaq.gouv.qc.ca/en/persons-mobility-impairment/>
- Apply for the Disability Pension under the Quebec Pension Plan if necessary.
- Obtain a medical alert card from the ALS Society of Québec; It can be useful for telling others about your condition, in the event you are unable to speak. For further information, please call the ALS Society of Quebec at 514-725-2653 or 1 877 725-7725, ext. 105 or email at info@sla-quebec.ca
- Talk with your physician about whether to contact your car insurance provider as your auto insurance coverage may not be valid, following your diagnosis. The Société de l'Assurance Automobile du Québec (SAAQ) must be notified of changes in medical status within 30 days of such change. Driving sometimes requires fast foot and hand reactions. Enquire about a driving test service in your community that can certify your current abilities for insurance purposes.
- Anticipate home adaptations for the future and consider involving an occupational therapist to discuss changes such as wheelchair ramps, bathroom set-up for safety, or wider doorways. You may need to consider a move. This may not need to be done immediately but planning and thinking about these issues in advance will reduce later stress. You can contact your local CLSC to discuss the possibility of home adaptation.
- Read sections on legal, financial, and end-of-life issues. Include action items and a time frame to deal with them in your plan.



ONLINE RESOURCES AND FORMS FOR PLANNING AND BENEFITS

- [ONLINE: Advance Care Planning documents are often available at no charge through your provincial government.](#)
- [ONLINE: Sample healthcare directive created specifically for palliative care](#)
- [ONLINE: Advance care directive workbook and form](#)
<http://www.advancareplanning.ca/resource/quebec/>
<http://www.advancareplanning.ca/what-is-advance-care-planning/>
- [Issues and Opinions: Advance Care Planning in ALS. Muscle and Nerve, 24: 1706-1709.](#)

Additional resources regarding advance care planning:

My Protection Mandate (previously known as Mandate in Case of Incapacity)

A Protection Mandate is an official document in which you, as an adult in full possession of your faculties, designate someone or several people to look after you or your property in the event that you become temporarily or permanently incapable of doing so yourself.

http://www.curateur.gouv.qc.ca/cura/en/outils/publications/mon_mandat.html

Contact information: 514 873-4074; 1 800 363-9020

You can read more about Protection Mandates on Éducaloi's website, as seen here:

- <https://www.educaloi.qc.ca/en/capsules/incapacity-being-unable-care-yourself-or-your-affairs>
- <https://www.educaloi.qc.ca/en/capsules/protection-mandates-naming-someone-act-you>

Advance Medical Directives

Advance Medical Directives are a written statement, made by persons 18 and over who are able to express their will, which indicates the medical care you accept or refuse to receive in the event you become incapable of consenting to healthcare in specific situations.

<http://www.ramq.gouv.qc.ca/en/citizens/health-insurance/advance-directives/Pages/advance-medical-directives.aspx>

You can read more about Advance Medical Directives on the following websites:

- Portail Santé Mieux-Être <http://sante.gouv.qc.ca/en/programmes-et-mesures-daide/directives-medicales-anticipees/demarche/>
- INESSS (Institut national d'excellence en santé et en services) https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/OrganisationsSoins/Depliant_niveaux-de-soins_ENG_20170111.pdf

3H

FINANCIAL, SOCIAL, AND LEGAL ASSISTANCE

On top of coping with the day-to-day challenges of living with a progressive illness like ALS/MND, financial and legal planning can seem overwhelming. However, it is very important to consider these aspects of life for you and your loved ones. A family member or friend may be able to help you get organized or do some research.

The progression of the disease has both direct and indirect costs. The indirect costs can include the loss of income not only for the person living with ALS/MND, but also for a family member if they take on the caregiving role. The impact of lost income, and additional costs on top of lost wages, increases the challenge of making quality of life decisions for people living with ALS/MND and their families.

Employment after an ALS diagnosis

If you continue to work after an ALS diagnosis, one thing to consider is when and what to tell your employer. See section 3b for things to think about when communicating the news to your employer.

Factors to consider before leaving work:

If you are thinking about leaving your job, here are things to keep in mind before you go. It is highly recommended that you do not sign anything regarding your termination without first getting legal advice. You may be eligible for severance packages and benefits. For example, do you have access to or meet the eligibility requirements for benefits like:

- Private Pension
- Extended Health Care
- Short Term Disability
- Long Term Disability
- Banked Sick Time
- Medical Employment Insurance
- Canada Pension Plan/Quebec Pension Plan
- Compassionate Care Benefits (for your caregiver see Part 4: For Caregivers)

Do you have financial supports like:

- RRSPs
- Savings
- Investments

If you have any questions about what government programs and benefits you may be eligible for, please contact your social worker or your ALS Society representative.

Insurance considerations

If you are having trouble getting information about your policy or getting living benefits, contact the help line at the Canadian Life and Health Insurance Association: in Montreal (514) 845-9004 ; Toll Free 1-888-295-8112 Health insurance coverage or visit their website at <https://www.clhia.ca/>

If you have health insurance coverage, you may want to maximize on the benefits of your plan. Here are things to keep in mind regarding accessing your health benefits through your plan:

- Keep a record of the name, phone number, identification and group number of your insurance plan
- If you have more than one insurance plan, or your spouse or common-law partner has an insurance plan under which you are covered, determine which policy is primary and which is secondary. Getting confused with this may result in billing mistakes.
- Contact your insurance company directly, and ask specific questions about your benefits.
- Ask if your policy offers case management. Case managers either work for the insurance company or are contracted by them to monitor and advocate for clients whose costs are high or who have complicated needs. They are often helpful in gaining access to little-known insurance benefits, and reducing your overall out-of-pocket expenses. Case management can be activated at various stages of your illness, depending on how your insurance company has defined the benefit.

IMPORTANT

Your doctor may be asked to write a letter of medical necessity and complete specific forms to verify your medical condition and eligibility for whatever item or service is being requested.

Life insurance: Living benefits

Some life insurance companies offer a “living benefit” feature to people living with a terminal disease, enabling them to receive a portion of their life insurance paid to them in advance, during the years before their death. If you are interested in getting living benefits:

- You should talk to a lawyer or accountant about all the financial implications.
- You or your lawyer should talk to your insurance agent. Not all living benefits are the same.

If you are having trouble getting information about your policy or getting living benefits, contact the help line at the Canadian Life and Health Insurance Association: in Montreal (514) 845-9004; Toll Free 1-888-295-8112.

IMPORTANT

There are organizations that buy life insurance policies from people who are terminally ill in return for a certain amount of cash immediately, usually substantially less than the death claim value of the policy. The person with a life insurance policy names the organization as a beneficiary and gives up all rights under the policy. When the person dies, the organization will receive the full value of the policy.

Many U.S. firms actively try to recruit Canadian policy-holders. Talk to your lawyer or the Canadian Life and Health Insurance Association before becoming involved with such organizations.

Driving

Speak with your ALS clinic or family physician about whether you are safe to continue driving. A driving test may be required to verify your current abilities. Know that you must notify your provincial automobile association of changes to your medical status within 30 days of such change.

Ask your local health care provider or your occupational therapist about services to test your driving, but note that the legislation pertaining to driving safety varies from province to province. In Quebec, you can contact the Société de l'assurance automobile (SAAQ) to ask about the test requirements by contacting the help line: in Montreal (514) 873-7620 ; Toll Free number 1-800-361-7620, or visiting their website at <https://saaq.gouv.qc.ca/en/drivers-licences/state-health-licence/your-state-of-health-has-changed/mobile/page/>

Property insurance

If you have specialized equipment and/or have made modifications or renovations to your home as the result of your diagnosis, you may need additional property insurance. Review your current plan and speak with an insurance representative

to ensure coverage or if you have any questions regarding car or home insurance. Check with your ALS Society for other programs in your province that may help you.

Social Services

The Quebec Government funds home and community care services, which are carried out by the Local Community Service Centre (CLSC). These services may include common health and social services, preventive or medical services to the population of its territory, rehabilitation and reintegration services, and public health activities. They may also include respite care, personal support worker hours and access to other allied professionals such as social workers, occupational therapists, physiotherapists, and nutritionists.

To find out more about the services your CLSC offers, contact them at 514 644-4545 for the Montreal area or 1 877 644-4545 (toll free). People with a hearing or speech impairment may call at 1 800 361-9596 (toll free). You may also find your CLSC webpage here: <http://sante.gouv.qc.ca/en/repertoire-ressources/clsc/> At times, you may be referred to an Integrated Health and Social Services Centre (CISSS) and Integrated University Health and Social Services Centres (CIUSSS) which also ensure accessibility, continuity and quality of services for people in their territory.

Each community also offers unique social support that is carried out by various non-profit organizations. Please speak with a social worker or a healthcare professional from your CLSC to find out what social supports from other non-profit organizations may be available near you. You may also communicate with a psychosocial counsellor from the ALS Society of Quebec at 514-725-2653 or 1 877-725-7725 (toll free), who can refer you to community supports in your geographic region.

Legal considerations

With an ALS diagnosis, it may be helpful for you to consult a lawyer, notary, chartered accountant, or financial specialist to discuss possible legal changes, such as the following:

Planning for the future

You will need to ask your lawyer or an equivalent specialist about changes that need to be made to:

Powers of Attorney: This is a document that allows an

adult to appoint an individual to make decisions regarding their financial and legal affairs on their behalf. The power of attorney can be one or more persons, and can take those actions that you give them the right to take on your behalf, when you cannot physically do so yourself (i.e., due to travel, scheduling problems, distance, physical disability, etc...). You must be an adult (18 or over) and have the mental ability to give someone a power of attorney. The powers associated with Powers of Attorney vary between provinces. Check with your social worker or ALS Society representative for the relevant provincial legislation.

You can read more about the power of attorney on Éducaloi's website: <https://www.educaloi.qc.ca/en/capsules/powers-attorney>

Wills and Estates

- **Estate Planning:** estate planning is the process by which you begin to get your financial affairs in order. This can include the creation of a will, examining assets and liabilities, and setting up trusts. Estate planning may also document what your wishes are, you have passed away.
- **Last Will and Testament:** A will is a legal document that provides instructions to your loved ones on how some of your belongings and liabilities are to be distributed once you have passed. To get your will ready, you need to:
 - Make a list of your belongings and liabilities including additional taxes due on your death
 - Determine who your beneficiaries will be (spouse, children, relatives, friends, charities, etc)
 - Consider tax reduction strategies, such as donations to charities
 - Choose your estate trustee, such as your spouse or trusted friend
 - Formalize and validate the will according to your provincial or territorial legislation. Generally, the normalities include dating the will and having the maker of the will (the 'testator') sign in the presence of two witnesses, who should not be beneficiaries under the will. The witnesses must also sign the document in the presence of the testator and each other. To avoid future confusion, only one copy of the will should be signed.
- Appoint an executor of your Will and estate. An executor will collect the assets of the estate, pay taxes and any other liabilities, and distribute your assets according to the terms of the will
- Note: The official term for **an estate** in **Quebec** law is **"succession"**.
- Note: the official term for **an executor** in **Quebec** law is **"liquidator"**.

In Quebec, three types of wills exist: notarial wills, wills made in the presence of witnesses, and holograph wills. Each type of will is created differently and must follow different rules. The type of will that is best for you depends on your individual needs and financial situation. No matter which will you choose, as long as you follow the specific rules related to it, it will ensure your wishes are respected.

You can read more about all three types of wills and related rules on Éducaloi's website: <https://www.educaloi.qc.ca/en/capsules/wills>

1. Notarial wills: are written by notaries, and thus involve a fee. Notaries will ensure to consider your financial situation, your wishes, as well as those of your family.
 2. Wills made in the presence of witnesses: must be signed in front of two witnesses together at the same time. This type of will can be prepared by a lawyer, which thus involves a fee, but can also be free if you don't use a lawyer. However, the will must be probated (made official) after you die, which involves a cost.
 3. Holograph wills: are the most simple kind of will because there are only two requirements: they must be handwritten, and they must be signed by the person making the will. There are no costs associated with this type of will, however, these wills must be probated (made official) after you die, which involves a cost.
- **Using Your Will to Make a Charitable Gift:** Many people choose to make provisions in their Will to contribute a special bequest to a cause close to their heart. Bequests allow people to name a charity of their choice as a beneficiary, and to make a financial contribution from their estate to the charity that is often far greater than would have been possible during their lifetime. A legacy is defined as a gift made in a will.

Provincially, these may vary. Please contact your ALS Society as they may be able to direct you to the appropriate resource.

Pensions

Private Pensions

If you are in a company or other group pension plan, find out about any changes that might be made to your plan as a result of an ALS diagnosis. To make sure that you get your full entitlement, ask your lawyer or your pension provider the following questions:

- Can you receive some of your pension before age 65, if you are disabled and unable to work?
- Will payments be made to your spouse if you are no longer alive?

To minimize tax on death, you may want to make sure that your spouse is the beneficiary of your pension plan; otherwise your pension plan's value will be part of your estate and subject to probate fees. Information on eligibility for tax programs can be found on the Revenue Canada website: <http://www.cra-arc.gc.ca/disability/>.

Quebec Disability Pension Plan

Persons with ALS may qualify for a disability pension in Quebec. To be eligible for a disability pension under the Quebec Pension Plan you must:

- Be under 65 years of age
- Have a severe and permanent disability recognized by the Quebec Pension Plan's (QPP) team of medical professionals
- Have stopped working because of your medical condition
- Have contributed sufficiently to the Québec Pension Plan

If you would like to find out more about your eligibility for a disability pension in Quebec, please visit the government's website: https://www.rrq.gouv.qc.ca/en/programmes/regime_rentes/prestations_invalidite/Pages/admissibilite_ri.aspx or contact them at 1 800 463-5185

What if I am already retired and receiving the Quebec Pension Plan (QPP)?

Between age 60 and 65

Retirement pension beneficiaries age 60 to 65 who are not eligible for a disability pension can receive an additional

amount for disability if they become disabled and are unable to do any type of full-time work.

To be eligible for the additional amount for disability, you must meet the following 4 requirements:

- 1. You must have a disability deemed to be severe and permanent by QPP medical advisors**
- 2. You must have contributed sufficiently to the Québec Pension Plan**
- 3. You must be under age 65**
- 4. The time period for cancelling your retirement pension has expired**

If you have been receiving a retirement pension for less than 18 months, you can apply for a disability pension. You will have to prove that you became disabled no later than 6 months after the first payment of your retirement pension. If your application for a disability benefits is accepted, you will have 2 months to cancel your retirement pension application.

At age 65 and over

At age 65 the disability pension will automatically be replaced by a retirement pension. The amount of the retirement pension will be reduced.

You may also be eligible for an Old Age Security pension paid by the federal government. However, you must file an application.

Read more about this here: https://www.rrq.gouv.qc.ca/en/retraite/rrq/Pages/calcul_rente.aspx

Ways to minimize taxes

There are a number of ways to effectively manage your tax situation resulting in greater after-tax income. Talk to your accountant and/or financial advisor about your options.

Income splitting

Income splitting is when the income of the higher income earners in a family gets attributed to lower income earners ("splitting" the income), reducing the tax rates of the higher income earner and increasing (or not changing) the tax rates of the lower income earner. There are many ways to do this, including:

- Contributing to your spousal RRSP

- Having the higher income earner pay for all the household expenses
- Contributing to an RESP
- Sharing CCP payments
- If you have a business, paying a reasonable salary to your spouse, common-law partner, or children
- Pension Income Splitting

For more ideas on income splitting, please visit <http://www.taxplanningguide.ca/tax-planning-guide/section-2-individuals/income-splitting-family-members/>

Guide for Quebec, Ottawa, and Edmonton: <http://en.planiguide.ca/>

Tax on Deemed Disposition of Assets on Death

At the date of death, the Canada Revenue Agency (CRA) requires one tax return for income earned to the date during the year, and to account for the tax that is applicable on all increased value of the deceased person's properties and other assets. There are certain tax-free "roll over" provisions for property left to a spouse, or spousal trust. Also, dividend-paying shares may incur a double tax unless appropriate action is taken.

Be sure to seek advice from a professional accountant on these matters.

Probate Fees

When the will is validated with a Certificate of Appointment of Estate Trustee with a Will, the Estate Court charges a tax rate that varies from province to province. Probate fees are decreased by reducing the amount of the estate, such as making life insurance payable to a spouse instead of to the estate. In Quebec, a notarial will has the advantage of not having to be probated after you die. This is done in court (Justice Québec) or by a notary, the total cost usually being about \$1000 to probate.

Tax-effective Wills

There are many estate planning alternatives:

- Naming a spouse as a beneficiary to all life insurance and pension plans
- Multiple testamentary trusts
- An exclusive spousal trust
- Trustee powers to authorize actions to minimize tax

- Bequests to a voluntary organization

If substantial amounts are involved, it is probably wise to consult with a professional estate planning accountant or planning lawyer.

Provincial Government of Quebec (Revenu Québec) Benefits and Tax Credit Programs

Assistive Device Programs

The Ministry of Health and Social Services in Quebec has put in place the Aides à la vie quotidienne (AVQ) and Aide à la vie domestique (AVD) program to help Quebecers who are living with a disability have access to all sorts of customised equipment to help them accomplish daily and home living activities.

For example, you can get help with bed posture, a transfer chair or a bathtub seat. Please contact your local healthcare professional, from your CLSC or other health institutions, to find out about the equipment that may be accessible or available in your territory.

National Program for Home Ventilator Assistance (NPHVA)

The National Program for Home Ventilator Assistance (NPHVA) has been at the forefront of quality respiratory care for ALS patients across the province of Quebec. They are dedicated to providing quality respiratory services and equipment in the comfort of your own home, and support people with neuromuscular disorders who have specialized respiratory needs. They additionally provide service support remotely through their telehealth services. Read more on their website: <http://www.nphva.ca/>

Office des personnes handicapées du Québec (OPHQ)

If you need help with your living expenses due to living with ALS, you may be eligible for governmental programs in Quebec. If you need information, advice, support or guidance on how to access government programs and services, you can communicate with OPHQ. They are a government agency with unique expertise in the social participation of people with disabilities. They can also provide you with information about your rights and remedies. For more information, please visit: <https://www.ophq.gouv.qc.ca/> (Website in French only)

Social Solidarity Program

If you are living with financial limitations, know that you may be eligible for the Social Solidarity Program. For more information, please visit: <http://www.emploi.quebec.gouv.qc.ca/en/citizens/obtaining-financial-assistance/social-assistance-and-social-solidarity-programs/>

Dental Care

For dental coverage, please contact your private group insurance, your employee benefit dental plan, or the RAMQ health insurance for dental services, as described here <http://www.ramq.gouv.qc.ca/en/citizens/health-insurance/healthcare/Pages/dental-services.aspx>

Prescription Drug Insurance

If you are permanently living in Quebec, you may have access to two types of insurance plans: the public plan that is administered by the Régie de l'assurance maladie du Québec (RAMQ), and a private plan (group insurance or employee benefit plans).

For more information on the prescription drug insurance plans, please visit: <http://www.ramq.gouv.qc.ca/en/citizens/prescription-drug-insurance/Pages/description.aspx>

You may also contact your private insurance provider to find out more on the costs that may be covered for your drugs prescriptions.

Residential Adaptation Assistance Program

Funded by the government of Quebec, the Quebec housing corporation (SHQ) promotes citizens access to adequate housing conditions. This specific program provides financial support for adapting your home. For more information, please visit: http://www.habitation.gouv.qc.ca/english/detail_du_programme_english/programme/residential_adaptation_assistance_program.html

You may also contact your local CLSC for further information.

Federal tax credits and benefits

The following are some of the credits, benefits, and programs the federal government offers. Check with your accountant or go to the CRA website to see which may apply to you.

- **Disability tax credit.** The disability tax credit is a non-refundable credit for eligible individuals or their

representatives. It reduces your income tax payable. The eligibility requirements are available on the CRA website (<http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/dtc/menu-eng.html>).

- **Medical expenses tax credit.** You can claim some of your uninsured medication, devices, and treatments for the medical expense tax credit. For more details on this credit, visit the CRA website (http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins300-350/330-331/menu-eng.html#hw_clm).
- **Disability supports deduction.** You may be able to deduct from your income taxes the costs of disability support, including personal care attendants' expenses. For more information on the disability supports deduction, visit the CRA website (<http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins206-236/215-eng.html>).
- **Federal Excise Gasoline Tax Refund Program.** If you are unable to take public transit safely, you may be eligible for a tax refund on the gas you buy. For more details on this refund, visit the CRA website (<http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/xcs-tx-eng.html>).
- **Goods and services tax exemption.** As a person living with ALS you may not have to pay GST on certain things, such as hospital parking, medical devices, home-delivered meals, and specially equipped motor vehicles. For more details on this tax exemption, visit the CRA website (<http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/gsthst-tpstvh-eng.html>).
- **Home accessibility expenses credit.** If you have renovated your home to make it more accessible and comfortable for you, you may be able to claim expenses for building materials, fixtures, equipment rentals, building plans, and permits. For more details on this tax credit, visit the CRA website (http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins360-390/398/398-eng.html#lgb_ndvdl).
- **Home Buyers' Plan.** The Home Buyers' Plan is a federal program that allows you to withdraw up to \$35,000 in a calendar year from your RRSP to buy or build an accessible home. For more information on this plan, visit the CRA website (<http://www.cra-arc.gc.ca/hbp/>)

4.0

LIVING WITH ALS

4A OVERVIEW

ALS/MND (referred to here as ALS) will change the way your body functions but not everyone experiences the same changes and not all will happen at the same time. As you move forward after your diagnosis, remember that this is your life, and when it comes to planning your care and how you wish to live, it's your decision.

As ALS progresses it is helpful to be aware of the changes that may happen so that you know what to expect and can seek appropriate support to manage them. You are your most valuable advocate. Ask questions of your healthcare team. The goal should be to understand what is happening to you so you can make informed decisions. If you need to seek a second opinion, do so.

Reach out to your local ALS Society. It is there to support you. Be specific about what resources you need, and try to have resources and support in place before you need them. Your situation will change and so will your needs. If you need more or clearer information, don't be afraid to ask.

In the face of the anxiety, anger and grief, be kind to yourself.

Common symptoms of ALS

This section is a brief overview of the types of changes you may experience. Most of these topics are covered in detail later in the chapter.

Muscle weakness

Muscle wasting, or atrophy, is a key feature of ALS. Atrophy is a result of the inability of the motor neurons to communicate with the muscles of the body, leading to muscle weakness, atrophy, and stiffness.

- **Muscle fasciculations** are often seen early in ALS. Fasciculation is the involuntary twitching of muscles. It can be seen happening under the skin.
- **Muscle cramping** is a common symptom and can result in pain, posture imbalance, or falling. Cramps can be relieved by keeping the affected muscles warm and by stretching the muscles. Contact your doctor if cramping is frequent or severe.
- **Mobility** is negatively affected over time as muscles weaken and stiffen. You may have difficulty walking and you may notice changes in your posture.

- You may experience **difficulty gripping or holding small objects**, such as a pen or cutlery.

PLEASE NOTE

Supports and devices are available to help you maintain your independence even as ALS progresses.

Problems eating and swallowing

Weakness of the throat and mouth muscles can cause difficulty in chewing and swallowing. It can also cause coughing during or after eating or drinking. Adjusting the way you eat and drink, such as eating more slowly, taking smaller bites, maintaining an upright posture, and adapting your diet (with the help of a dietitian) to make healthy, safe choices are all useful strategies.

- **Saliva** may build up in the mouth because of difficulty swallowing, and this can cause drooling. Your doctor can recommend ways to treat this, including medications and suction devices.

- **Increased coughing** can result from irritation in the throat but can be managed through changes in diet, such as avoiding dry, flaky food or food that is too thin or runny.
- **Weak and ineffective cough** can result from weakness of the abdominal muscles, the muscles of the throat and muscles of the diaphragm. This can cause mucus build up in the breathing passages since they are no longer easily cleared by coughing. Your physiotherapist or respiratory therapist can teach you about assistive cough techniques.
- **Choking** may occur if you are experiencing difficulty swallowing. Changing the way you eat and what you eat can help reduce the risk of food getting stuck in the throat. It is a mistaken assumption that people with ALS die from choking. In fact, choking is a manageable symptom and most people with ALS die peacefully.

Trouble speaking

In a small percentage of people with ALS, the muscles involved in speaking and swallowing are among the first to be affected. This is called bulbar onset ALS. For many people, though, speech is affected in the later stages of ALS.

Communication aids ranging from no-tech to high-tech are available to assist those who have difficulty speaking. A speech-language pathologist can assess changes in your speech and suggest strategies to help you use your natural speech for as long as possible while also introducing other means of communication.

Fatigue

Muscle weakness, cramps and fatigue make daily activities more difficult. Activities may take more time and effort than before. This extra work can make people with ALS feel tired and exhausted. In addition, the lower calorie intake and dehydration that can come with ALS can result in fatigue.

An important way to combat fatigue is to conserve energy for important and meaningful activities that you really want to do. You can also learn to do things in ways that use less energy. An occupational therapist can help plan a suitable daily routine and provide strategies for conserving energy. This is covered in more detail in Section 4c – Mobility and Independence.

Constipation

People with ALS may experience constipation. This may be due to dietary changes, reduced fluid intake, or lack of mobility. A dietitian can help you find ways to add more dietary fibre and your doctor can prescribe medication if the problem persists. The ALS Society of Canada website offers a fact sheet on constipation that includes tips on how to manage it.

Sleep problems

Difficulty falling or staying asleep is common in people with ALS. Poor sleep may be due to an inability to move easily during the night, which can result in sleeping in the same uncomfortable position for many hours. Special beds are available that help an immobile person sleep. In addition, satin sheets and nightwear can help you turn over. Relaxation exercises may help you get to sleep. Medication, if required, must be prescribed by your doctor because certain sedatives negatively affect breathing and should be used with caution.

Involuntary emotions (emotional lability)

Some people with ALS experience excessive crying or laughing that does not match their actual emotions. This is called emotional lability (or “pseudobulbar affect”). If you experience this symptom, your doctor can prescribe medicine to help control it.

With ALS you may experience anxiety, sadness, anger, and disbelief. These reactions are all normal. Acknowledging and trying to understand what you are feeling is the first step in managing your emotions.

Cognitive and behavioural changes

It is now known that about half of people with ALS may experience some cognitive changes (meaning the way you think, behave, and process information). Mild cognitive changes may include inattention and forgetfulness, bouts of irritability, slower thinking, or mood swings.

While some mild cognitive changes may be noticeable, this does not necessarily indicate that cognitive abilities will worsen as the disease progresses.

Parts of your body that will not be affected by ALS

ALS does not affect every part of your body or every function.

- **Your senses** of smell, taste, touch, sight, and hearing are generally not affected. You may have slight changes to your sense of taste, smell or skin hypersensitivity.
- **Bowel functions** are usually unaffected by ALS, other than challenges posed by decreased mobility, such as constipation. A few people with ALS have diarrhea. Discuss changes in bowel habits with your doctor.
- **Sexual desire and function** may not be affected, though you may experience anxiety or self-consciousness due to changes in your body, which may affect your sex life. Physical limitations due to weakness, discomfort, or fatigue can affect intimacy. Your emotional state, such as feelings of sadness, may also have an effect on sexual desire. There are ways to preserve intimacy with your partner; speak with your doctor, a sex therapist, or your ALS Society representative for more information.

Approved Treatment for ALS

Riluzole, the first drug approved for use in the treatment of ALS, has been shown to slow the progression of ALS and increase survival for 3-6 months in some patients. If you would like more information on Riluzole, please consult your neurologist.

In October 2018, Health Canada approved Radicava (edaravone) for the treatment of ALS in Canada, which is an important and hopeful milestone for the ALS community. Radicava is only the second ALS therapy to be approved by Health Canada and the first in nearly 20 years. Radicava was approved by the FDA in May 2017 for use in ALS patients in the United States.

The role of complementary therapies

Complementary and alternative healthcare refers to practices that complement conventional medicine if used in combination.

These treatments and therapies include massage, meditation, and reflexology. They may be covered under some private or group insurance plans if prescribed and/or delivered by a registered physiotherapist.

- **Massage and touch therapies** can be relaxing and comforting, helping to warm limbs and improve circulation. Modifications in massage technique are often required for someone with ALS and should be done with medical consultation.

- **Reflexology** is based on the theory that massaging and pressing certain points in the feet will affect the whole body and bring about relaxation.
- **Shiatsu**, which means “finger pressure,” is a Japanese touch therapy. Shiatsu techniques include massages with fingers, thumbs, feet, and palms.
- **Aromatherapy** is a massage technique that uses specific fragrant oils to further aid relaxation.
- The **TENS machine** stimulates muscles through electronic impulses and is used by physiotherapists. TENS stands for transcutaneous (“through the skin”) electrical nerve stimulation.
- **Meditation** can help you clear your mind and achieve a relaxed and revitalized state.

If you are thinking of trying any complementary or alternative healthcare treatments, it is important that you consult with your doctor first and that you seek a licensed, accredited practitioner for complementary therapy. Refer to Part 6 – ALS and Research for more information on alternative therapies.



Marijuana/Cannabis for Medical Use

Marijuana or cannabis products may help alleviate a few of the symptoms of ALS, according to some studies published by the American Journal of Hospital and Palliative Care. More studies are underway to confirm the effects, if any. Consult your doctor if you would like further information.

Natural healthcare products are herbs, vitamins, minerals, and homeopathic treatments. While these products may promise treatment, it is important to note that unlike pharmaceutical drugs, natural healthcare products (with the important exception of vitamins) do not undergo extensive controlled clinical research. Scientifically, we know very little about their effects on the human body.

Your doctor can help you decide whether any natural health products will be helpful or harmful in your case.

For more information, refer to the fact sheet which can be found on the ALS Society of Canada website.

4B

4B TOOLS FOR STAYING ON TRACK

This section includes charts for keeping track of some of the many details you will be managing through the course of your illness. Keeping records also makes it easier for others to help you manage information and schedules.

Personal Information

Record your details here and keep in a safe place as it contains confidential information.

Name _____ **Date of Birth** _____

Contact Information

Address _____

Home Telephone _____ **Cell Number** _____

Email _____ **Health Card #** _____

Private Insurance Plan Group and Policy # _____

Date of ALS/MND Diagnosis _____

Type of ALS:

- Familial ALS
 Sporadic ALS
 Kennedy's disease
 Primary lateral sclerosis
 Don't know

Form of ALS:

- Limb Onset
 Bulbar Onset
 Don't know

Household**Lives with**

Name/s _____ Relationship _____

Dependants

Name/s _____ Relationship _____

Informal Caregivers (family, friends, or neighbours)

Name/s _____ Phone/Email Address _____

Professional Contacts

TITLE/ORGANIZATION	NAME	CONTACT DETAILS (address, phone, email)
ALS Society		
Family doctor		
Neurologist		
ALS clinic		
Palliative care physician/team		
Physiatrist		
Respirologist		
Nurse		
Community care coordinator		
Occupational therapist		
Physiotherapist		
Speech-language pathologist		
Respiratory therapist		
Dietitian		
Social worker		
Psychologist/Counsellor		
Other contacts:		

About me

Use this section to tell people about your individual needs, what foods you prefer, what signals you use to communicate, and so on.

4C**MOBILITY AND INDEPENDENCE**

ALS progresses differently for everyone but will at some point affect your ability to be independent and to perform daily tasks easily. You may start to feel as if you can no longer participate in the things you enjoy. How you approach this is your choice. Focus on staying positive about all the things you can do today and on the supports available to help you stay independent and active even as the disease progresses.

Working with an occupational therapist and a physiotherapist familiar with ALS will help you find ways to stay as functionally mobile as possible so that you can continue to do your everyday activities.

How ALS may affect your mobility

In ALS the motor neurons die and this causes muscle weakness and stiffness, leading to difficulty moving your limbs. You may find that you need to make an extra effort to do everyday activities such as getting out of bed or carrying groceries.

When the limb muscles become weak, the associated joints are no longer used to their full capacity. You may start to feel stiffness in these joints.

Occasionally there may be tightening of the muscles – called spasticity – resulting from the muscles flexing and extending. This can cause muscle stiffness and pain.

You may experience these other changes in mobility:

- Mild leg and foot swelling
- Muscle cramps
- Discomfort when sitting, particularly in your lower back, shoulders, and neck
- Difficulty gripping or holding objects, such as a pen or cutlery
- Difficulty walking

If you start to experience changes in mobility, consult with your ALS healthcare team, which includes your doctor, occupational therapist, and physiotherapist. They will guide you on ways to

stay safe and mobile. Your healthcare team can also provide options to manage the symptoms associated with joint stiffness and reduced mobility.

Some of the key things to think about and discuss include exercise, injury prevention, and use of assistive devices.

The role of exercise

Exercise has been shown to have a positive impact on people living with ALS, both emotionally and physically. Exercise can ease the discomfort of joint stiffness and muscle inactivity and boost enjoyment of life. That said, it is important to remember that exercise will not strengthen muscles that have been weakened by ALS. Once a muscle has atrophied, the change cannot be reversed.

The purpose of exercise for people with ALS is to:

- Maintain the strength and flexibility of muscles not affected by ALS
- Maintain the flexibility of muscles that have weakened
- Maintain joint flexibility
- Help manage pain and stiffness due to spasticity
- Increase muscle tone

If you would like to participate in exercise, it is important to remember these points:

- Everyone with ALS should have an exercise program tailored to their individual needs and abilities.
- Exercise programs should be designed by an occupational therapist or a physiotherapist to ensure you are doing the right kind and amount of exercises for you. Your occupational therapist or physiotherapist will demonstrate the exercises so you know how to perform them correctly.
- Ask for diagrams of the exercises to help you and your caregivers remember the techniques.
- Exercise should not cause pain, excessive fatigue, or shortness of breath. If you experience any of these, stop and consult your doctor.

Types of exercise recommended in ALS

Four types of exercise may be considered for people with ALS. Each is discussed in more detail below:

1. **Flexibility training:** stretching and exercises to increase your range of motion
2. **Strengthening:** low to moderate resistance exercises, such as those done with a resistance band (e.g., Thera-Band)
3. **Aerobic:** moderate exercise for large muscle groups, such as stationary cycling, swimming, or walking
4. **Balance training** with a physiotherapist

It is important to **perform all exercises in moderation**. Let your fatigue level guide you and listen to your body. Keep in mind that day-to-day activities such as cleaning and cooking count as exercise!

IMPORTANT

If you find that your prescribed exercises tire you, talk to your physio- or occupational therapist. They can make changes to your program that will eliminate the risk of fatigue. Similarly, none of your exercises should cause pain or soreness. If you experience pain or soreness during or after exercising, stop and talk to your physiotherapist or occupational therapist. It may be that you are not doing the exercise correctly, or perhaps your exercise program needs to be adjusted.

Flexibility training. Range-of-motion (ROM) exercises are movements designed to stretch and loosen your joints. People with ALS need to move each affected joint every day to prevent joint stiffening. ROM exercises also prevent “frozen shoulder” and contractures (contractures are abnormal shortening of muscles or other tissues) and help decrease spasticity.

ROM exercises are usually done in a certain order – you start and complete exercises that move joints of one limb before you do exercises for another joint and another limb.

There are three ways of doing ROM exercises:

- **Active exercise:** You do ROM exercises without any help, when your muscles can do the full movement.
- **Active-assisted exercise:** If you can no longer move through a ROM exercise on your own you may have someone assist with the exercises, or you may be shown a way to do a self-assisted ROM exercise.
- **Passive exercise:** If your muscles can no longer do the movements at all a helper completes the ROM exercise for you by lifting and moving your limbs. Passive exercises work the joints but not the muscles. Your therapist can train your caregiver(s) to do these exercises with you.

Loss of muscle strength is gradual and as the disease progresses the type of ROM exercises you will need will likely change. You may also find that you can do some exercises actively, some with assistance, and others only passively. Your physio- or occupational therapist will modify your exercise program accordingly.

Strengthening exercise. Strengthening exercises are done using weights and resistance equipment. Low to moderate strengthening exercises can be helpful, but intense strengthening exercises are not recommended and can be harmful.

Aerobic recreational exercise. If you enjoy activities like walking, stationary cycling, and especially swimming, continue with them for as long as you are able to safely. If you experience cramping or fatigue, do not continue the exercise until you have consulted your doctor or therapist. Your physio- or occupational therapist will help make adaptations to both the activity and to any equipment to help you continue these activities while minimizing risk of injury even as your abilities change.

Balance training with a therapist. Balance exercises help your posture and balance and may include such activities as balancing on one foot or walking in a straight line. Exercises may also include elements of yoga and tai chi.

Falling

Falls can be a problem for people with ALS. Falling may be a result of leg weakness leading to foot drop, weakness of the arms or neck that can affect balance, or stiffening of limbs making them harder to control.

As someone living with ALS, you wish to maintain your independence as long as you can, while staying safe. As limbs weaken and stiffen, the risk of falls increases and you may require mobility aids to reduce your risk.

A discussion with your occupational or physiotherapist about **mobility assistive devices** can guide you to the correct equipment so you can remain both active and safe.

If you find yourself falling, it is better to drop straight down than to fall forward or backward. Falling straight down will help to avoid a head injury. The most important thing to do once you are down is to get sitting upright. The best way to do this depends on what muscles you can still use. If you still have enough arm and hand strength, you can hold on to something firm, like furniture, and pull yourself up into a chair. **Your occupational therapist or physiotherapist can help teach you about safe practices in the event of a fall.**

You may need some help getting up. You may need just a little help from one person, or the help of two people to get you into a chair or wheelchair. If you have shoulder weakness, be careful that those helping you do not pull on your arms, which could hurt weak joints.

It is also important that caregivers do not hurt themselves while helping you. If they cannot help you up by themselves, they need to make you comfortable where you are until another person is available to help. Ask your therapist to teach you and your caregiver(s) the best way to recover from falls.

Preventing injuries

Preventing joint pain and stiffness

Joint pain and stiffness happen when you can't move yourself and spend too long in one position. This can be very uncomfortable for both the skin and the joints. Arrange a schedule with your caregivers so they can move you into a new position every couple of hours during the day and also turn you at night.

Some people with ALS find that using a sheepskin, an "egg crate" or foam mattress, a gel mattress pad, or an alternating pressure air mattress improves their comfort in bed. Your occupational or physiotherapist can provide information on options and help you decide what to try.

Preventing injury during assisted transfers

An assisted transfer is when someone, such as your caregiver, physically moves you from one spot to another – for example, from the bed into a chair. Assisted transfers can be done with or without equipment.

Assisted transfers are a leading cause of caregiver injury when proper body mechanics are not used. Body mechanics involves standing and using one's body properly and making best use of one's strength when moving someone – thus avoiding injury. Poor transfer techniques also increase the risk of harm for the person being moved. Ask your occupational or physiotherapist to show you and your caregivers safe transfer techniques.

Your physio- or occupational therapist can provide information on different transfer devices such as lifts. It is important to always learn and practise transferring with a therapist before trying it on your own.

Assistive equipment to aid transfers

The following are some of the devices that can make your life easier:

- **Lift chairs.** Weakened leg muscles may make it difficult to get out of regular chairs. Motorized lift chairs help gradually lift a person to a standing position or ease them into a sitting position without causing injury.
- **Ceiling lifts.** Ceiling lifts are used to help move a person between bedroom, bathroom, and living areas. A rail is installed in the ceiling and an attached sling is used to lift the person. Ceiling lifts should be installed by professionals familiar with assistive mobility equipment.
- **Portable floor lifts.** Portable floor lifts, such as Hoyer lifts, use a sling to lift the person up and can be easily rolled around. With a portable lift, the person is placed

comfortably in the sling, lifted, moved to a new location, and then eased out of the sling.

- **Stair glides.** Stair glides provide a way to transfer from one level of a home to another. They use a track fastened to the wall side of a stairway. An automated chair moves up and down the track. Stair glides require the person being transferred to have safe sitting balance and the ability to transfer on and off the automated chair. Stair glides should be professionally installed by an expert familiar with assistive transfer equipment.
- **Porch lifts.** Porch lifts may be used if it is not possible to have a wheelchair ramp installed from your home's door to ground level.

Bathroom Supports and Transfers

If you have weakened leg muscles or limited mobility as a result of ALS, the following equipment may be useful:

- **Versaframe.** Also called toilet safety frames, these devices with sturdy armrests are used to help provide stability and balance when using the toilet.
- **Stationary commode.** This device provides height adjustability and grip to aid safe toilet use.
- **Wheeled commode/wheeled shower commode chairs.** These portable chairs provide a safe seat for washing and bathing and help you use the toilet safely.
- **Bath lift.** This power-operated lift raises and lowers you in and out of the tub.
- **Tub transfer bench.** This device assists in manual transfer of someone into and out of a bathtub.

Mobility aids and how they can help

Mobility aids are assistive equipment that help you stay mobile and independent for as long as possible while keeping you safe from falls and related injuries. They include canes, walkers, wheelchairs, and scooters.

Starting to use mobility aids is a gradual process. You should start talking with your doctor, occupational therapist, or physiotherapist early on about your mobility needs, the

type of mobility devices that may help you, and the assistive equipment available to you.

Few people are eager to use mobility aids and this is natural. Try to think of them as tools to help you stay independent and get around. They will also help you conserve energy.

The time to start using a device will depend on the progression of the disease. Here are some questions to keep in mind when considering using a mobility aid or changing the device you use to a more supportive one:

- Do you often need another person to help you to rise from a seated position?
- Do you stumble and fall a lot?
- Are you fatigued when you walk?
- Do you avoid outings because you are afraid of injuring yourself or becoming too fatigued?

If you answer "yes" to any of these questions, it might be time to consider using an aid at least some of the time. The type of aid you use will depend on your needs.

Determining what you need requires an assessment from an occupational therapist or physiotherapist who will assess your needs and situation and help find the best fit and accessories.

Because ALS is progressive, you may need different mobility aids for varying periods of time.

Canes, walkers and orthoses

Canes may be recommended only at an early stage of ALS because they require adequate upper-body and arm strength to use safely. Walkers provide greater stability than canes and are available as standard and wheeled. People with ALS often prefer wheeled walkers because the device does not need to be lifted manually, thus conserving your energy.

Orthoses are devices attached to the body to support weak joints and support correct positioning. People with ALS may be recommended cervical (neck) collars, wrist or hand splints, or ankle-foot orthoses. Ankle-foot orthoses may be recommended if you experience ankle fatigue while walking or have trouble lifting your foot (that is, if you have foot drop).

Wheelchairs

Many people with ALS will find themselves needing a wheelchair at some point. No one is eager to use a wheelchair and this is perfectly natural but a wheelchair should be viewed as **an opportunity to remain independent** and continue to do the things that are important to you, such as visiting loved ones, shopping, or moving around in your home. A wheelchair will also help you conserve energy – many everyday tasks can be accomplished while seated in a wheelchair, thus reducing the need for frequent transfers.

- **Transport wheelchairs** are useful for people who cannot walk long distances. They are basic and provide minimal postural support. Their advantage is that they are inexpensive and portable and can be transported easily in cars and airplanes.
- **Manual wheelchairs** are usually less expensive than power wheelchairs and many can be folded easily, making them a portable option. Manual wheelchairs come with several functions, such as recline and tilt, headrests, elevating leg rests, seat height adjustments, and appropriate seat cushions to support prolonged sitting.
- **Power wheelchairs** are more expensive and often provide features such as tilt-in-space seating systems (where the seat and backrest move simultaneously, maintaining the angle of seat to backrest) thus helping relieve pressure and pain. Multiple drive controls are available to allow individuals with different degrees of strength to control the chair (e.g., through hand, head, chin, or foot movements). Power wheelchairs can also be equipped with augmentative communication devices. These chairs are large and not easily portable and may require modifications to both your home and standard vehicle.

Your occupational therapist will help you decide the most appropriate wheelchair for your current needs and determine the required fit for you. This may also include any additional features and accessories you may need. You will likely need different types of chairs as your ALS progresses. It is therefore a good idea to try to borrow or rent chairs you may need for shorter durations and save your resources for more expensive equipment later, if required.

Please access the ALS Society in your province to inquire about an equipment program to get you the devices you need. Together, you, your healthcare team, and the ALS Society can help you adapt to mobility changes and maintain independence for as long as possible.

ENERGY CONSERVATION

Fatigue is very common in people with ALS and results from progressive muscle weakness. You can limit the effect of fatigue through energy conservation techniques such as these:

- Optimize your environment: rearrange furniture to make a more accessible space, remove things you don't really need in your home, and consider moving your bedroom to a more accessible floor.
- Replace regular utensils with specially weighted and balanced utensils and plates with non-skid bottoms and elevated edges. This minimizes the effort used for people with hand and finger weakness. Use utility carts to push heavy items rather than lifting them.
- Keep everyday items at waist level so you can reach them without standing or bending.
- Sit rather than stand for most tasks, especially those that take longer than five minutes.
- Ask for help if you feel tired.
- Plan your tasks and take regular scheduled breaks.
- Save your most important tasks for the time of day when you feel your best.

For more information on energy conservation techniques, talk to your occupational therapist or physiotherapist.

Travelling with ALS

Yes, you can travel if you have ALS. Planning and booking ahead of time can help you find accessible accommodation and transport to meet your needs. Keep the following in mind when planning to travel:

- List and discuss beforehand the specifics of what you may need with the travel agent, tour operator, or organization(s) and services you are using during your trip.
- Ensure that you have checked any requirements for travelling with equipment – during air travel, for instance.
- Check your equipment to ensure that everything is in good working order before you depart.
- Allow for extra time and arrive early at your destination.
- Keep a list of organizations that may be able to assist you or provide useful information at your destination. For example, the provincial ALS Society or if travelling overseas, the national or local ALS or MND associations at your destination.
- Check with your insurance company regarding your insurance coverage and any possible restrictions.

Hotel facilities

If your mobility is limited and you are using a mobility device like a wheelchair, call hotels at your destination ahead of time to find out if they have accessible rooms. If they do, **ask what the accessible features of the room are.** Be very specific about what you need because people understand “accessible” differently. For example, a room may be designed for a wheelchair to move around, but not have an adapted bathroom with a roll-in shower or other accessible features.

Some places are very accessible to people who use assistive devices, but others are not. Here are some questions to ask the hotel

- What are the hotel’s accessible features? For instance, does it have accessible parking? What about ramp access to the entrance? Is there an elevator to reach upper floors?
- What are the room’s accessible features?
- Does the bathroom have a roll-in-shower, or a bathtub? Is there a shower chair?

- Is the shower chair attached to the wall or is it a wheeled chair?
- Does the bathroom and shower area have grab-bars?
- Are the doorways wide and is there enough space to manoeuvre around the room and bathroom?
- How high is the bed? Hotel beds may be higher than regular beds, making it more difficult to transfer from a wheelchair

Source: Muldoon, Emma “Simple tips for booking the best wheelchair accessible hotels” Rick Hansen Foundation, 18 July 2016, <https://www.rickhansen.com/news-stories/blog/simple-tips-booking-best-wheelchair-accessible-hotels>

Air travel

You may think flying is not possible when you have ALS, but airports and airlines have become more accessible for people with disabilities. Here are a few things to know and think about if you are considering flying:

- **Wheelchairs to and from the plane:** Most airports or airlines provide wheelchairs in the terminal that you can use to get to and from the plane. Make sure to call the airline and let them know in advance that you will need one.
- **Flying with a caregiver:** If you need to be accompanied by a caregiver, make sure to get the proper documentation signed by your doctor because some airlines allow a caregiver (whom they call an “attendant” or “personal support”) to fly with you at a discounted rate.
- **Other services:** Some airlines provide other services to people with disabilities, including special meals.

When enquiring about reservations, **make sure the airline can accommodate your requirements.** In particular, if you need to use a non-invasive ventilator while travelling, contact the airline **before** booking a trip to find out if they permit the device to be used in-flight. You may need to contact the device manufacturer to see if they have a sticker you can affix to the device indicating it meets aircraft safety requirements.

Car travel

Some families with ALS purchase a wheelchair-accessible (barrier-free) van for everyday use as well as for road-trip vacations. Keep in mind that you must be assessed and trained in the use of hand controls by a driver rehabilitation specialist before you are legally able to drive a hand-controlled vehicle.

Many taxi companies and vehicle rental businesses call their vehicles wheelchair accessible. But this may mean only that they can accommodate a foldable manual wheelchair, not an electric wheelchair. Check in advance whether the company you are considering using can accommodate your specific equipment and requirements **before** booking.

There are companies that rent out barrier-free converted vans for extended road trips or to use on arrival at your destination.

Check with your local Canadian or American Automobile Association (CAA or AAA) or destination Visitors' Bureau to find other resources that may be available at your destination.

Public transit

Many larger cities offer accessible public transit for people with mobility impairments. Accessible public transit typically consists of specially equipped buses or taxis licensed by the municipality to carry passengers. Note that buses and taxis may require that you book an appointment for pick-up. Larger cities may also have subways that are accessible by elevator. Check with your provincial ALS Society for public transit options in your area.

The Intercity Bus Code of Practice is designed to remove barriers to access for travellers with disabilities when using scheduled intercity bus services in Canada. This Code is a voluntary commitment by intercity bus service operators to serve people with disabilities in a safe, dignified manner. More information is available here <http://www.tc.gc.ca/eng/policy/acc-accf-guidetoaccessibility-2949.htm>.

Most trains can accommodate wheelchairs up to a certain size and can assist with priority boarding. A support person may travel at a discounted rate if required to accompany someone who cannot travel alone. To receive such a discount, your support person will likely require a medical certificate completed by a doctor.

Support resources while you're away

If you are travelling to another part of Canada, make sure you know how to contact the ALS Society office closest to your destination for information on the services and equipment it provides in case you need them.

For travel in Quebec, also check <http://www.keroul.qc.ca>.

Similarly, if you are travelling in the United States, contact the

nearest ALS Association (ALSA) chapter. For an ALSA chapter list, visit www.alsa.org.

If you are travelling abroad, check the ALS/MND International Alliance website for information on associations by country at www.ALSMNDAlliance.org.

Additional information that may be useful while you're travelling is available here:

- <http://www.AccessToTravel.gc.ca>
- <https://www.disabled-world.com/travel/canada/carriage.php>

A final note on mobility

Your mobility and your need for assistive devices will likely change over time. Your ALS healthcare team, particularly your occupational therapist and physiotherapist, can help you plan for changes and adaptations ahead of time. Advance planning will help make transitions smoother and will promote comfort, safety, and independence.



4D

SWALLOWING, NUTRITION, AND ORAL HEALTH

As someone with ALS you may experience difficulty swallowing. This can make it harder for you to drink and eat. Trouble swallowing usually happens gradually, and with some changes to your diet and the way you eat and drink you can continue to enjoy your meals for some time.

How ALS affects eating

How swallowing works

Swallowing is a complex process involving several nerves and muscles working in a perfectly timed sequence. Normally, the jaw, lips, and tongue keep food and liquids in your mouth when you chew. Chewing mixes food with saliva, making it easier to swallow. The tongue then pushes the food to the back of the mouth and into the throat, triggering the swallowing reflex.

Two things happen when you swallow: 1) The voice box (larynx) closes, blocking the windpipe so that food and liquid do not enter the breathing system, and 2) your throat muscles contract and push food down the esophagus to the stomach.

How ALS affects swallowing

ALS can affect the muscles of the jaw, mouth, and throat, leading to difficulty swallowing. This problem may affect up to 80% of people with ALS.

In addition, ALS can affect the limbs, making it harder for you to use your hands to manoeuvre food to your mouth.

In 20-25% of ALS cases, the muscles for speaking, swallowing, and breathing are the first to be affected. This is known as bulbar onset ALS.

What you can expect

If your condition is affecting your ability to swallow, you may experience some of these symptoms:

- Leaking of food or liquid from your mouth or nose
- Difficulty chewing or trying to swallow
- Coughing or needing to clear your throat during or after eating and drinking

- Feeling unable to clear your throat or mouth
- The sensation of food stuck in your throat
- A wet-sounding or gurgly voice

You also may not feel interested in eating and may avoid eating with other people. You may feel frustrated, embarrassed, or anxious about eating. **Many people living with ALS have problems swallowing – you are not alone.**

Who can help

It is important to discuss changes in swallowing and eating with your doctor or another member of your care team so you can be referred to the right specialists. Some of the key healthcare providers who may help you manage your eating and drinking include the following:

- A **dietitian** will provide advice on adapting your diet and ensuring proper nutrition. They will help you develop a plan to meet current and future nutritional needs.
- An **occupational therapist** can provide advice on posture and adaptive equipment, such as modified utensils.
- A **respiratory therapist** can teach you how to avoid choking and gagging during eating and drinking.
- A **speech-language pathologist** may assess your swallowing and offer strategies to help you adapt your eating and drinking techniques and decrease your risk of aspiration (see also Section 4g on Speech and Communication).

Swallowing assessments usually involve the speech-language pathologist observing how you eat and drink small samples of food and liquids, sometimes with different textures. They may ask questions about your experience eating and drinking at home, such as what foods and drinks cause coughing or difficulty clearing your throat.

Your speech-language pathologist may need to know more about what is happening inside your throat when you swallow and may recommend an x-ray called a modified barium swallow videofluoroscopic swallowing study (VFSS). In this procedure, you will eat and drink small amounts of food and drink containing barium, which is a substance that can be seen on x-rays. A VFSS is useful in identifying swallowing problems, for testing whether different positions and different strategies make swallowing safer, and for finding out what foods are safest for you to swallow.

IMPORTANT

You and your caregiver should take a recognized first aid course with a focus on identifying signs of airway obstruction or blockage (choking) and should know how to respond to such a situation. Your caregivers should know how to do the Heimlich manoeuvre on a choking person. For information on course locations, contact your provincial ALS Society (als.ca/guide-provincial), local Red Cross Society (www.RedCross.ca), or St. John Ambulance branch (www.sja.ca).

Making eating and drinking safer

Coughing, gagging, and the risk of food “going down the wrong way” (aspiration) can reduce the pleasure of eating and drinking for someone with ALS.

Although everyone with ALS has different challenges, these are some common ways to make eating easier and safer:

- Eat and drink slowly and avoid rushing.
- Sit upright while eating and if you can, for up to 30 minutes after eating (this will help prevent heartburn).
- Ask your occupational therapist about adapted feeding equipment and utensils.
- Take food and drink separately.
- Concentrate on eating and avoid distractions.
- Avoid speaking when eating.
- Use a straw (if recommended by your speech-language pathologist).
- Avoid very dry food as well as thin, runny meals.
- Avoid tipping your head back.

Changing your diet

Our enjoyment of food directly affects our quality of life. Adapting your diet and the way you eat and drink will help you maintain a balanced diet, get proper hydration, consume enough calories, and still enjoy food. Meals are also a time to

connect with loved ones, and taking steps such as preparing appropriate foods, taking the right precautions and, if needed, getting additional support to help with feeding can make mealtime less stressful and more enjoyable. Opting for a feeding tube may also be beneficial.

Changing the consistency of the food you eat may make it easier to swallow. Start with soft food served with gravy or sauce. Incorporate thick liquids like milkshakes and smoothies. If these foods are difficult or painful to eat, consider pureed or blended foods such as puddings and custards. Thickeners such as yogurt, ground rice, or flour can be added to food.



YES

Creamy soups, crustless buttered toast, scrambled or poached eggs, casseroles



NO

Hot spicy food, dry meats, fruits with tough skin, popcorn, nuts, pizza, food with mixed consistencies (e.g., cereal with milk), dry, crumbly foods (e.g., dry muffin, dry toast)

Choose calorie-rich foods or add butter, cream, or healthy oils when cooking. Your nutritional needs remain high, and there are many things you can do to avoid becoming undernourished.

Your dietitian can offer advice on many topics:

- The best ways to cook food
- Easy-swallow recipes
- Foods to avoid and what to substitute
- Commercial thickeners
- Nutritional supplements

Please follow the recommendations of your healthcare team.

The Resource Section at the back of this guide includes a list of cookbooks. You can also visit the MDA (ALS Division) website and view or download *Meals for Easy Swallowing*: https://www.mda.org/sites/default/files/publications/Meals_Easy_Swallowing_P-508.pdf

Using a feeding tube

Your ALS care team (which includes your doctor and dietitian/nutritionist) may recommend that you get a feeding tube.

A feeding tube can supplement what you are able to eat so that you can get enough nutrition and fluids. It may be a good idea to have a feeding tube placed before you need to use it so you can get comfortable with it. It is also recommended that you have a feeding tube fitted before you lose a lot of weight or before your breathing capacity is very low.

Even though the idea of a feeding tube may be scary, it can make life easier by allowing you to get the food and liquids you need to keep strong. A feeding tube also helps you conserve your energy – as ALS progresses it takes more energy to eat a meal.

A feeding tube may be beneficial if

- Your weight decreases 15% below your normal weight. Your dietitian can tell you what your normal weight should be.
- It takes more than an hour to eat your meal or you find eating too fatiguing.
- Eating is no longer pleasurable.
- The risk of aspirating food or drink (having it go down the wrong way) is increasing.
- Eating or drinking leads to frequent choking or frequent throat clearing.

A feeding tube may not be suitable for you if the risks outweigh the benefits. Your doctor will assess your risks and benefits.

Feeding tube insertion

The feeding tube, also called a percutaneous endoscopic gastrostomy, or PEG, tube, gets its name from how and where it is inserted into the body. The tube is inserted into your stomach through your abdominal wall in a simple 30-minute procedure done under sedation. It is a fairly routine procedure.

Feedings through the tube can start about 24 hours after the procedure and are based on a prescribed plan developed by your care team. Because your eating abilities will change over time, your tube-feeding requirements will likely increase as well. Your dietitian and other members of your care team will adapt your nutritional plans accordingly.

Some common concerns about feeding tubes are addressed briefly below:

- **Will I have to stop eating by mouth if I get a PEG tube?** No. In many cases, continuing to have some solids and liquids by mouth depends on whether you are able to do so without choking. Your dietitian/nutritionist and neurologist will monitor your swallowing and advise you accordingly.
- **Will my appearance change with a PEG tube?** The tube is inserted into your stomach through the abdominal wall. It may protrude a little bit and you may want to avoid tight-fitting tops or shirts to be more comfortable. The tubing can be tucked inside trousers and skirts. The PEG tube does not go through the nose and down the throat.
- **Can I get the feeding tube inserted later if I don't need it now?** It is recommended that PEG insertion be done sooner rather than later for someone with ALS. The reason is that breathing capacity declines as the disease progresses and the respiratory muscles weaken. Because PEG insertion is usually done under sedation, a certain amount of breathing capacity is required. If your breathing capacity is less than what's required, PEG insertion may either need to be done under local anesthetic (you will be completely awake, but the area will be "frozen") or ruled out completely because of the risks involved.
- **Will having a PEG tube slow down the progression of ALS?** Having a feeding tube will not slow the progression of ALS. Feeding tubes help improve your quality of life by making meal times less stressful and ensuring that you're getting enough nutrition.
- **What if I still don't want a feeding tube?** That's okay; it is your decision. Whatever you decide, don't forget to document your choice in your personal healthcare directive and share a copy with your doctor.
- **What if I opt for a feeding tube and change my mind later on?** You always have the right to consent to or refuse care. You may choose to request the feeding tube be removed or refuse to be fed through the tube at any time.

Learning about the options available to you will help you make a well-informed choice about what will work for you. Discuss your nutritional goals with your ALS care team. If you

decide to have a feeding tube, your doctor will refer you to a gastroenterologist.

For additional information on feeding (PEG) tubes, what to consider when deciding whether to get one, and useful tips on care and maintenance, refer to the ALS Canada fact sheet on PEGs available online.

Oral health

Muscle weakness in ALS can affect your ability to swallow, leading to food or mucus staying in your mouth. Weakness may also affect your ability to brush your teeth. All of this means that oral hygiene is very important to prevent complications such as tooth decay or gum disease.

Taking care of your teeth and mouth

It is important to continue to brush your teeth regularly to maintain your oral health. This is true even if you are using a feeding tube.

If you have weakness in your arms and hands, opt for an electric toothbrush with soft bristles that will take over some of the work of brushing for you. Suction toothbrushes that help remove plaque or mucus buildup are also an option. Electric or manual flossing aids help get to hard-to-reach areas of your mouth.

If you have difficulty swallowing, you may worry about choking on toothpaste. Using non-foaming toothpaste, which dissolves so you don't have to rinse or spit, will help. Choose a toothpaste that contains fluoride to protect your teeth from bacteria.

Other devices that may be worth considering include oral irrigators (which provide a stream of water to remove plaque and food debris between teeth), dental wipes (which can be useful if it becomes difficult to tolerate a toothbrush in your mouth), and bite blocks (which help keep your mouth open, protecting your fingers).

If you have excessive saliva buildup or suffer from a dry mouth

Saliva is produced in the mouth and helps keep your mouth moist to chew, taste, and swallow food. It is also helpful in preventing tooth decay and gum disease because it contains certain chemicals that protect tooth enamel.

In people with ALS, weakened tongue and throat muscles may

make it difficult to easily swallow saliva, leading to a buildup in the mouth. This can make it uncomfortable to sleep and can even lead to choking.

Although home remedies and over-the-counter medications are available to help with saliva buildup, they may sometimes cause a dry mouth. It is useful to consult your doctor about your concerns so they can help find the right solution for you. Your doctor may prescribe medication or a suction machine.

Suction machines are used to remove fluids such as secretion and mucus from body cavities. Breathing muscles weaken in ALS and the ability to cough may weaken as well resulting in mucus or phlegm buildup. Doctors or members of your health care team may prescribe a portable suction machine for people to easily remove secretions and mucus from the airways and help breathing.

If you experience a dry mouth, the following tips may be useful:

- Take frequent small sips of water or milk.
- Use a vaporizer (make sure it is cleaned weekly with vinegar and water).
- Oral rinses and artificial saliva replacement sprays (check with a pharmacist).

See your dentist

You still need to get regular dental checkups. If accessing the dental facility becomes difficult, your dentist or a social worker can refer you to a community dental service that could arrange checkups at your home.

For more information on oral health, the following websites may be helpful:

- **Dental Hygiene Canada**
<http://www.dentalhygienecanada.ca>
- **Canadian Dental Association**
https://www.cda-adc.ca/en/oral_health/index.asp
- **Ontario Dental Hygienist Association Facts – Oral care for seniors** <https://odha.on.ca/wp-content/uploads/2016/08/ODHA-Facts-seniors.v2.pdf>

4E

SPEECH, COMMUNICATION AND ASSISTIVE DEVICES

ALS and your ability to communicate

ALS affects muscles of the tongue, lips, and throat, along with those used in breathing. As muscles gradually weaken, you may notice the following changes when you speak:

- Change in voice quality (hoarseness, volume, or pitch changes; “nasal” tone; strained voice)
- Stiffness or difficulty moving mouth and jaw
- Soft, faint speech
- Slow or slurred speech

Manage these changes

Speech impairment can be scary, difficult to accept, and frustrating for you and for your caregivers, family, and friends. It is important to remember that speech impairment and loss of speech is gradual and there are several strategies you can use to continue to communicate.

As the muscles involved in speech weaken, keep these tips in mind:

- Carry a notepad with pen or an erasable whiteboard or erasable slate to write your messages.
- Work out hand signals for frequently used phrases with your immediate family.
- Work out non-verbal yes or no signals (using eye blinks or head movements).
- Make a list of commonly used questions and requests that someone can go through until you indicate yes or no.
- Pause between phrases and rest often. Conserve energy and avoid fatigue.

If you are caring for someone with ALS, consider these useful strategies:

- Ask one question at a time.
- Try to frame questions so that they need only a yes or no answer.
- Ask the person if it is ok for you to guess part of their message.

- Be patient.
- Don't simplify sentences when you speak – impaired speech does not mean impaired understanding.
- Don't speak too loudly or too slowly – impaired speech does not mean impaired hearing.

It is best to plan ahead so both you and your caregivers are aware of the options available to you. Remember, you can continue to be an active participant in both your family and your community even as ALS progresses.

The role of your speech-language pathologist

A speech-language pathologist, sometimes called a speech-language therapist, with experience in ALS and augmentative and alternative communication will assess, monitor, and guide you as you manage your speech and communication.

Augmentative and alternative communication

Augmentative and alternative communication (AAC) is any kind of communication other than speech. Although the same systems can be used for both augmentative and alternative communication, augmentative is the term used when someone can still speak a bit but needs help to do so. Alternative is the term used when someone can't speak and must rely on other communication options.

The AAC solutions that work best for you depend on your unique situation. A discussion with your speech-language pathologist about your current and future needs will help determine the right assistive communication devices for you.

These are some “no-tech” solutions:

- Take a full breath before speaking.
- Speak slowly, using short sentences, and pause between words.
- Identify the topic before you go into detail.
- Make the environment as “communication friendly” as possible. For example, reduce background noise such as the TV or radio and make sure the listener can see you when you speak.
- Agree on gestures for commonly used words.

The following are some low-tech solutions:

- **Writing boards** and erasable slates can be used while hand grip is strong.
- **Communication boards** use letters, words, or images – various designs are available, along with options to create your own. If you are unable to point your fingers, someone can assist by scanning their finger across the board until you signal the right choice (by blinking, for instance). You can use different communication boards for various scenarios, such as one for daily life, one for socializing, and another for TV watching, etc.
- **Devices using pre-programmed messages** can store up to 32 messages on a single display with each display created for an individual topic. Devices can usually accommodate six to eight topics.
- Hands-free **speaker phones or smartphones** activated by voice (e.g., Siri or Samsung S voice commands, etc.) can support telephone communication.
- **Bells, intercoms, or buzzers** can get your caregiver's attention when they are not in view. An inexpensive option would be a simple wireless doorbell system.
- **Voice amplification devices** can enhance the volume of your voice and are useful if you speak clearly but softly, if speaking loudly enough is fatiguing, or if you need to speak in an environment with a lot of background noise.

If there are times you are likely to be home alone, you may want to apply for an emergency response service. These devices are small transmitter boxes with an emergency button that when pressed sends a signal to the service about you and your medical condition. The service will then call the emergency contacts you provided when you registered with the service. You can apply to this service by purchase of an emergency response device or payment of a monthly fee.

You may be able to use some of these high-tech solutions:

- **Speech generating devices** (SGDs) work either by using digitized speech (messages and words you have recorded

previously), synthesized (artificial) speech, or a combination of both. SGDs can be controlled with your fingers, eye movements, head movements, switches, joysticks, and/or a mouse.

- **Text-to-speech programs** convert speech into text for emails and letters.
- **Rate enhancement programs**, such as word completion, word prediction, and commonly used words.

Computer-based systems, including laptops, smartphones, e-readers, and tablets, can incorporate many of these communication support programs along with options for built-in customization.

One such example is eye-gaze control technology which allows people with limited motor movement to use eye movements to operate a laptop, computer or speech-generating device. Eye gaze computer systems are specially designed and rely on eye movement for activation via a camera which is placed below a computer monitor to track retina movement. Software is loaded onto the computer and allows the user to have full access to the computer by simply moving their eyes around the screen.

Depending on where you live, your local ALS Society may offer communication aids or funding assistance to help you acquire them.

IMPORTANT

It is important to understand that communication does not have to stop simply because your hands have become weak and typing and writing are no longer possible.

Message banking and voice banking

Message banking is an easy method that involves recording common expressions in your own voice. You can record greetings, words of affection, your favourite phrases, frequent requests, and more. Message banking can be done through an application (app) downloaded on a computer or smartphone. These recorded messages can later be played as audio files on a computer or through a speech generating device.

Voice banking is a detailed process that allows you to record an extensive list of phrases and sentences to create speech samples that are then used to duplicate and create a customized synthesized voice that sounds similar to your voice. This voice can be imported into an SGD, enabling it to “speak” any message you enter.

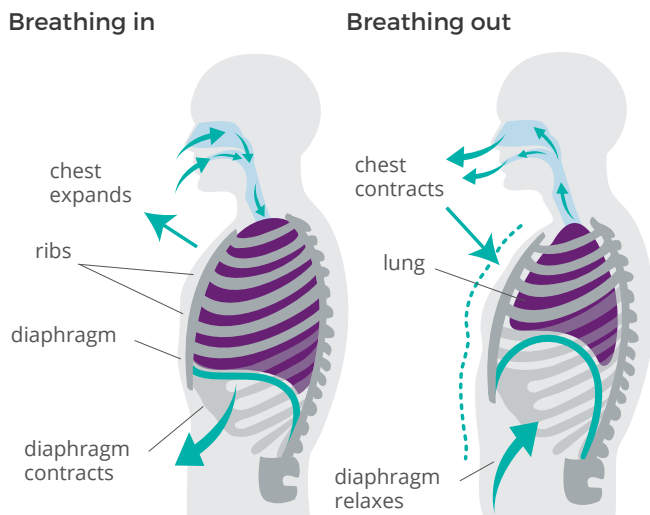
For more information, discuss these technologies with a speech-language pathologist or augmentative and alternative communication clinic.

4F BREATHING

ALS can affect the muscles that help you breathe. This is usually something that happens in the later stages of the disease, but it can occur early on in some cases. You may start to notice changes in your breathing or it may be that difficulty in breathing comes to light when a lung infection develops.

What happens during breathing and coughing

Figure 4. Breathing



Our respiratory system consists of our lungs and a series of air passages leading to the lungs. The entire breathing mechanism is defined by two processes:

- **Inhalation:** taking in oxygen-rich air, which is then carried around the body to enable us to function

- **Exhalation:** sending out carbon-dioxide-rich air

We use quite a few muscles to breathe, including the diaphragm and the intercostal muscles. The diaphragm (located beneath the lungs) and the intercostal muscles (located between the ribs) tighten, or contract, to pull air into the lungs. When these muscles relax, air is forced out of the lungs.

When we cough, the throat and voice box (larynx) close and the diaphragm contracts. This builds pressure inside the chest. Next, the voice box muscles relax, allowing the high-pressure air to escape and with it any irritants, foreign particles, or phlegm. Coughing helps clear food or drink that may have “gone down the wrong way” and entered the windpipe (this is known as aspiration).

What happens to breathing and coughing in ALS

When the breathing muscles weaken, you may feel breathless. Your ability to cough may also weaken and with it your ability to expel phlegm and mucus.

You may experience these symptoms:

- Shortness of breath with activity such as carrying a load or climbing stairs or even at rest or without exertion
- Excess mucus buildup and difficulty clearing mucus or phlegm
- Feeling tired and sleepy during the day
- Morning headaches
- Feeling breathless while lying flat
- Disturbed sleep or insomnia
- Nightmares

If you notice any of these symptoms, consult your doctor for a referral.

A skilled professional such as a respirologist or respiratory therapist can assess and monitor your respiratory function and help train you and your family on deep breathing exercises and assisted cough techniques.

Managing breathing changes

You can take steps to stay healthy as you navigate breathing and coughing changes:

- Consider getting vaccinated against pneumonia and flu. Avoid coming in contact with people who have a cough, cold, or flu.
- Avoid allergens and make sure your home is regularly dusted. An air purifier with a HEPA filter can help keep the air free of particles that irritate your airways.
- Don't smoke – it reduces lung capacity and can increase phlegm.
- Be careful using alcohol or sedatives because they may increase your risk of aspiration.
- Practice good oral hygiene. An overgrowth of oral bacteria can lead to respiratory infections.
- Learn deep breathing exercises, which can help reduce the risk of lung infections and can compensate for weakened muscles. Ask your respiratory therapist to demonstrate an exercise routine that suits you.
- Learn assisted cough techniques, which help reduce excess mucus buildup. A trained professional such as a respiratory therapist or a physiotherapist can teach you and your caregivers these techniques.

Deep Breathing Exercise

1. **Sit at a table hunched slightly with your weight supported on your hands or elbows. This position expands the rib cage by allowing your shoulder and neck muscles to assist in breathing.**
2. **Breathe in deeply and hold the breath for a few seconds. Exhale.**
3. **Repeat a few times.**

What your respiratory care team can do

Depending on where you live, your breathing needs may be managed by a team that may include a respirologist, a respiratory therapist, a physiotherapist, and/or an occupational therapist. Your team will likely do some of the following to support you:

- Perform tests to check your breathing function. Tests are often done at the early stage of ALS to help establish a starting point for how your lungs are performing (called

a baseline measure). This measure can then be used to track your lung performance and support needs over time. Commonly performed tests include the following:

- **Forced vital capacity (FVC).** This measures how forcefully you can breathe air out. If your lips are weak, you will be given a lip seal mouthpiece or mask to get a more accurate measurement.
- **Maximum inspiratory force (MIP).** This measures the force of the muscles as you breathe in.
- **Maximum expiratory force (MEP).** This measures the force of the muscles as you breathe out.
- **Blood oxygen saturation.** This is a measure of the level of oxygen in your blood (this may be tested through a sensor clipped to your finger, a method called pulse oximetry).
- Teach and demonstrate assisted coughing techniques and deep breathing exercises.
- Prescribe medications, if required.
- Identify treatment and therapy options that are suitable for you.
- Provide information and answer any questions you may have so you can make informed choices about your care.

IMPORTANT

The treatment and therapy options recommended for you will be based on your unique needs and situation. Your doctor will discuss your options with you. Sometimes a palliative care physician or team may talk with you about care decisions, including certain end-of-life issues.

Ventilation is one option you may be offered. The section below deals briefly with some types of ventilation.

For more information, refer to the ALS Canada fact sheet on Ventilation available online.

Ventilation

What is ventilation?

When the breathing muscles become weak and unable to fully expand the lungs, you may require assistance to breathe. This support may come through a machine called a ventilator. Ventilation can relieve symptoms associated with weakness of respiratory muscles but does not slow the progression of ALS. You may use either non-invasive or invasive ventilation.

In **non-invasive ventilation** a machine supports your own breathing by boosting the amount of air you take in. This is done through a mask over the nose or nose and mouth. A bilevel positive airway pressure (BiPAP) ventilator is often used. This machine provides two levels of air pressure: higher pressure for when you inhale and lower for when you exhale.

Non-invasive ventilation is easier and more comfortable than invasive ventilation and the associated care is often simple. The use of non-invasive ventilation is usually started at night. As your breathing support needs increase over time, a volume ventilator with a mouth piece may be recommended for daytime use. Volume ventilators deliver a pre-set air volume and allow for passive exhalation.

When someone requires non-invasive ventilation for more than 16 hours per day, it may be time to switch to invasive ventilation.

With **invasive (mechanical) ventilation**, a tube is inserted into your windpipe through the neck (in a procedure called a tracheostomy) and connected to a ventilator machine that assists with breathing.

The decision to use invasive ventilation or not must be **yours**. It is best to understand the full implications of invasive ventilation before arriving at your decision. There may be several factors to consider, including these:

- Who will assist you? Invasive ventilation requires 24-hour support from trained caregivers.
- What are the financial implications, including health insurance coverage?
- In what circumstances would mechanical ventilation be acceptable to you?



IMPORTANT

It is important to plan ahead and discuss your ventilation options early on with your healthcare team and your family. You should decide whether you would wish to go forward with invasive ventilation (should the need arise at a later stage) ahead of time and communicate your wishes in an advance care plan or personal healthcare directive. Your doctor should have a copy of the directive. Information on how to prepare your advance care plan can be found here: <http://www.advancecareplanning.ca/what-is-advance-care-planning/>

Advance care planning is covered in this guide in Section 4h, Advance Care and End of Life.

Remember, you can change your mind about what works for you at any stage.

Funding assistance for ventilators

Your provincial Ministry of Health may fund programs for residents with a long-term disability. Check with your provincial ALS Society for more information.

Your doctor may be asked to complete specific forms to verify your medical condition and eligibility for whatever item or service you are requesting.

Travelling if you have breathing problems

- Always consult your doctor before making any plans to travel. Your healthcare team may assess your fitness and suitability for travel and offer advice on how to manage symptoms while you are away.
- If you plan to travel by air, before you book call your airline and check whether you are allowed to take non-invasive ventilators on board. You may need medical forms signed by your doctor in order to take certain equipment on the plane.
- If you cannot travel alone and need a caregiver to accompany you, you and your doctor may need to complete forms to secure a discounted airfare for your support person.

See Section 4c, Mobility and Independence, for more information.

4G

COGNITIVE CHANGES

Mild to moderate cognitive changes will be experienced by almost half of people diagnosed with ALS. Up to 20% of people with ALS develop severe cognitive changes that are known as ALS-frontotemporal dementia (ALS-FTD).

Diagnosis, treatment, and prognosis

ALS-FTD is diagnosed through tests done by a specialist or sometimes at an ALS multidisciplinary clinic. Unfortunately, these cognitive changes can't be cured, but they may be managed with psychotropic medications. Psychotropic medications are used to help balance moods and behaviours in people with cognitive impairments.

People with both ALS and severe cognitive impairment may have shorter lifespans than those with ALS alone as a result of disease mechanisms we don't understand very well. In some cases a shorter lifespan may be because the person is less likely to choose life-prolonging procedures as a result of their reduced understanding of their ever-changing needs.

What do I do if I start to experience cognitive changes?

- You may have to make decisions about healthcare and finances early in the disease's progression, soon after you start to experience these changes.
- You may want to assign a power of attorney for when you can no longer make decisions for yourself.
- Ask family, friends, and caregivers to use straightforward language and speak slowly and directly
- Encourage caregivers to create a calm and orderly environment around you. Your healthcare professionals should be able to help with the small environmental changes needed to suit the symptoms you are experiencing.

4H RELATIONSHIPS AND INTIMACY

Sexual intimacy is an important part of life. ALS does not usually affect the ability and desire to have sex.

However, you may have physical limitations such as muscle weakness, joint stiffness, or discomfort that may negatively affect your sexual life. You may feel anxious, sad, or easily tired. You may be worried about how your body appears to your partner or you may be focusing all your efforts on everyday survival. The emotional toll of ALS can reduce sexual desire and arousal and create feelings of loneliness and negative self-image. Often, your partner is your primary caregiver and they may be feeling lonely and exhausted.

What you can do

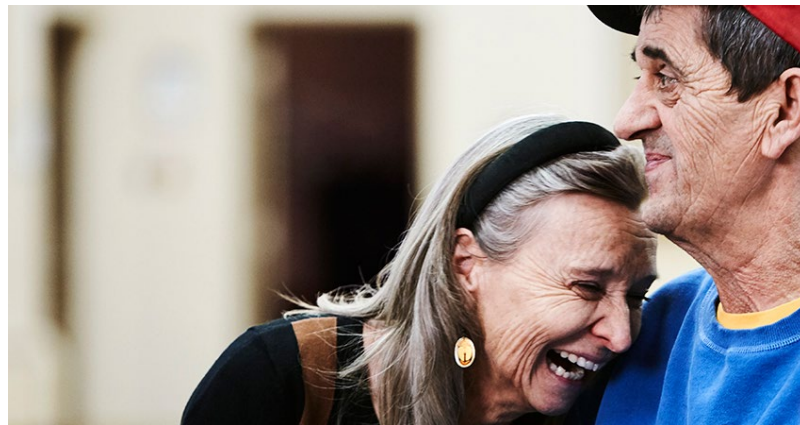
There are ways to increase intimacy between you and your partner.

- Explore different sexual techniques and the use of assistive devices to accommodate muscle weakness and limited mobility. Sexual aids are available online and through specialty shops.
- Emphasize other expressions of intimacy. Many forms of touching can be pleasurable and comforting. Hugging, kissing, and cuddling are ways you and your partner can express affection and intimacy.
- Allow role flexibility, having your partner play a more active role.
- Schedule time for intimacy. Set aside “adult time” (if there are young children in the family) at a time during the day when you are likely to be less fatigued.
- Alter your living environment to provide adequate privacy.
- Respect each other’s wishes and boundaries.

It is important to communicate openly with your partner about your sexual desires and need for intimacy. For instance, you may be worried about appearing less attractive, while your partner may be worried about hurting you. Discuss your worries and let them share theirs with you. Open communication lets you both know what works and what doesn’t for your relationship.

If you have questions or concerns, speak with your doctor or another member of your care team. The members of your healthcare team may not raise the subject of sexuality themselves for fear of causing offence or appearing intrusive, so do ask for help if you need it. Your doctor can refer you to a sexual health practitioner. In addition, your occupational therapist, physiotherapist, or social worker can help answer some specific questions.

You could consult a sex therapist for information and resources. A list of therapists specializing in sexuality/sex therapy can be found on the Canadian Association for Marriage and Family Therapy website (www.camft.ca).



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END OF LIFE AND ADVANCE CARE PLANNING

The end of life is unavoidable. People with ALS may experience progressive changes to their body that bring thoughts of death to the forefront. Accepting that our time is limited and precious can help us focus on things that matter – for example, family or personal goals. It can also motivate us to make a difference in our lives and in the lives of those around us.

Planning for the end of life in a well-thought-out way can make for a peaceful death and provide comfort to loved ones.

Approaching the end of life

A diagnosis of ALS can feel overwhelming. It may seem as if the future is no longer certain and priorities and goals may change drastically. In medical terms, the end of life is the stage in a person's life when death is expected within a short time, barring use of life-sustaining interventions.

It is normal to initially feel a sense of denial and later on anger, anxiety, and sadness. Over time, with the functional changes associated with ALS, accepting that life is coming to an end may become less difficult. It is worth remembering that you may feel a sense of acceptance on some days and anger or grief on others. There is no linear timeline of how anyone should feel.

Talking about the end of life is difficult. Most people have a strong survival instinct and the prospect of death is not something anyone likes to contemplate. Discussing death may make you or others uncomfortable. You may also worry that this discussion might upset family or caregivers.

It is nevertheless important to start communicating with loved ones about the end of your life and to begin to plan for this. Thinking about these matters provides a certain feeling of control over the future because you can plan and settle many things concerning your personal affairs and final stage of life. Having someone organize a gathering or celebration before someone's passing is also a way for family and friends to celebrate their loved one's life while they're still around.

Here are some suggestions for starting the conversation with your family about end-of-life planning:

- Find a quiet time and place to talk.
- Consider talking to just one or two people at a time.

- Make a list of the topics you wish to discuss. It may be one or two things to start with, but you can build on it in later discussions, or you may already have a full list of things you want to plan for.
- You can start by talking about things that matter to you most. A good resource is the card game activity Go Wish, which gives you an easy way to talk about what's important to you. To learn more go to www.GoWish.org.
- You could start with one aspect, such as what flowers or music you would like at your funeral, for example, and then take the conversation further.
- You could discuss what further information you and your caregivers may need to help you make decisions.
- You should agree to revisit this topic once more information has been gathered and you are closer to making your decisions.

Palliative care

Palliative care is about taking care of the needs of someone with a life-limiting illness to improve their quality of life.

For someone with ALS, palliative care includes managing pain and other symptoms as well as helping with emotional, psychological, and spiritual needs. The quality of life of the ill person is maintained by looking after the wellbeing of both the individual and their family. Palliative care therefore includes respite care, which provides temporary rest or a break for the regular caregiver for a few hours or days.

The Difference Between Palliative Care and End-of-Life Care

- Palliative care provides comfort and relieves distress for someone with a life-shortening illness, such as ALS.
- Palliative care aims to improve quality of life and is provided by healthcare teams and specialist palliative care services.
- End-of-life care addresses the needs of anyone in the final stage of life, providing support to help them live as long as possible and as comfortably as possible and to die with dignity. End-of-life care includes palliative care.

Advance care planning

Advance care planning is a process of consideration, communication, and planning by an individual along with their family, friends, caregivers, and healthcare team about their values and wishes for a time when they no longer have the ability to make or communicate decisions about their care.

As someone with ALS, you should try to discuss your advance care plans early on – first with loved ones and then with your healthcare team. Later on, communication may become challenging so it is best to gather information and make informed choices well ahead of time. It is also important to document your wishes and to communicate them to loved ones and your healthcare team.

Creating your advance care directive

Essentially, you and your loved ones should gather information about, discuss, and make plans for end-of-life care and for dealing with bereavement. End-of-life care choices are often documented in an advance care directive.

An **advance care directive** also called a **personal directive** or a **healthcare directive** in some provinces is a document prepared when you are still able to make your own decisions. It expresses your wishes for medical and non-medical care for a time in the future when you may be unable to speak for yourself.

An advance care directive is not a legal requirement but there are several reasons why you should consider taking the time to create one. An advance care directive can help others decide on your treatment if you are unable to communicate at some point. It can also help your family understand and support the decisions that you would have made yourself.

If you do not have an advance care directive in place, others may not know your wishes and you may be subjected to medical interventions that you would not want. On the other hand, you may prefer to opt for all available treatment and want that documented in your advance care directive.

Preparing an advance care directive has five steps:

1. Gather information. Think about what is important to you and what you value most in life. Think about what you would like the last few days or weeks of your life to be like, if you could plan them today. Talk to your doctor and your

healthcare team. Discuss the medical interventions and choices available to you. You can also seek information about the dying process from a specialist in palliative care.

- 2. Talk about choices.** Discuss your choices and decisions with your loved ones (family and close friends) and your healthcare team. Decisions may be based on personal preferences, financial resources, caregiver support, religious beliefs, and your perceived quality of life. Remember that you can change your mind at any point.
- 3. Prepare the directive.** See below for details.
- 4. Inform the appropriate people and provide copies.** You should provide copies of your advance care plan to your healthcare team and to your substitute decision-maker. A substitute decision-maker is someone you appoint to make healthcare decisions on your behalf when you are unable to do so or are unable to communicate your decisions.
- 5. Revisit your decisions.** Every few months, talk to your doctors and re-evaluate your decisions and plans. Communicate and document any changes you want to make.

What the advance care directive covers

The advance care directive may cover the following:

- Your choice of where you want to be cared for (e.g., at home, hospital, or hospice) and where you would prefer to be when you are at the end of your life.
- Religious or spiritual beliefs you want to be incorporated in your care.
- Who you would like providing personal care.
- Treatments you may or may not want, such as a feeding tube, mechanical ventilation, or tracheostomy (a surgical opening in your neck to aid breathing). This may also include medical treatment for infections, such as antibiotics.
- Instructions for how you want to be cared for in an emergency (see below).
- Whether you would like to donate organs, brain or spinal cord after death either to people in need or to research (research suggests that some people with ALS may be considered suitable donors if they satisfy medical eligibility criteria; speak to your neurologist if you would like to learn more about this).

Is an Advance Care Plan/Healthcare Directive Legally Binding?

The Canadian Medical Association's Policy on Advanced Care Planning (2017) reports that the legality of advance care plans varies across Canada:

"The term 'advance care directive' has different [...] legal authority across Canada. For example in British Columbia an advance directive is a written legal document that provides a mechanism for capable patients to give directions about their future healthcare once they are no longer capable. [...] In Ontario, on the other hand, 'advance directive' is a generic non-legal term referring to oral, written or other forms of communication. [...] In Quebec, advance directives are legally binding."

You have the right to decide the type of medical care acceptable to you during the course of living with ALS, including during the end stage. Just as you decide about using a feeding tube or ventilator as your illness progresses, it is you who will decide whether to suspend or stop these treatments.

Your advance care directive should cover three major medical interventions:

- **Resuscitation.** You may or may not wish to be resuscitated in the event of respiratory failure. A Do Not Resuscitate (DNR) order means that you do not wish to undergo cardiopulmonary resuscitation (CPR) or any form of advanced cardiac life support if you stop breathing or if your heart stops beating. A DNR order is a legal document and you can ask your doctor about how to obtain one if you wish.
- **Life-extending interventions.** These include feeding tubes and mechanical ventilation. You may or may not choose to continue using a feeding tube or mechanical support for your breathing to extend your life.
- **Pain management.** How you would like any pain controlled should also be part of your advance care directive.

IMPORTANT

If you chose not to opt for certain interventions (such as mechanical ventilation), it is a good idea to document what you want to do if and when symptoms occur as a result of not having that intervention. For instance, if you don't want mechanical ventilation, state what you want done to manage breathlessness – would you be satisfied with non-invasive ventilation such as a BiPAP machine? What would be your medical plan to manage respiratory infections such as pneumonia?

You may wish to communicate in writing where you want to spend your last weeks or days. Many people prefer to spend their last moments in the comfort of their own homes. You should discuss this with your family and consider factors such as your family's ability to cope, your homecare situation, and any financial implications before deciding.

You may also wish to write down the kind of environment you want around you near the end, such as music choices, candles or scents, and who should be there – specific family members, pets, and caregivers, for example.

End-of-life resources

You can find additional information through these resources:

- An excellent resource is the Quality End-of-life Care Coalition of Canada. This group of over 36 national organizations is concerned about quality end-of-life care for all Canadians. www.qelccc.ca/
- Another excellent resource on advance care planning is the Speak Easy Program. www.AdvanceCarePlanning.ca/
- A useful booklet on patients' rights in Canada can be found online on the End-of-Life Planning website. This booklet also covers the right to an assisted death: https://elplanning.ca/wp-content/uploads/2016/04/patient-rights-booklet_2016_elpc1.pdf

Medical Assistance in Dying

On February 6, 2015, the Supreme Court of Canada struck down the ban on medical assistance in dying (MAiD) for patients meeting specific eligibility requirements. On June 17, 2016, the Federal Parliament of Canada passed Bill C-14, establishing the legislation to regulate the practice of MAiD. Talk to your healthcare provider if you would like more information.

Information regarding province-specific laws and regulations can be found on the Government of Canada website:

English www.canada.ca/en/health-canada/services/medical-assistance-dying.html

French www.canada.ca/fr/sante-canada/services/aide-medicale-mourir.html

The book *Living with Life Threatening Illness: A Guide for Patients, their Families and Caregivers* by Kenneth Doka, a leading authority, covers end-of-life issues. Other videos and books are listed in the Resource Section of this guide.

Find province-specific information on advance care plans at the links below:

Alberta: The term used in Alberta is personal directive.

- <https://www.alberta.ca/decision-making-healthcare-planning.aspx>
- <https://myhealth.alberta.ca/alberta/pages/advance-care-planning-topic-overview.aspx>

British Columbia: <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning>

Quebec: The term used in Quebec is advance medical directive.

- <http://sante.gouv.qc.ca/en/programmes-et-mesures-daide/directives-medicales-anticipees/demarche/>
- Details about the Quebec Act Respecting End-of-Life Care can be found here: <http://sante.gouv.qc.ca/en/programmes-et-mesures-daide/loi-concernant-les-soins-de-fin-de-vie/>

- The Institut national d'excellence en santé et en services sociaux (INESSS) has also made the following pamphlet on advance medical directives: https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/OrganisationsSoins/Depliant_niveaux-de-soins_ENG_20170111.pdf

Manitoba: The term used in Manitoba is healthcare directive.

- <http://www.gov.mb.ca/health/livingwill.html>

Newfoundland and Labrador: The term used in Newfoundland and Labrador is advance healthcare directive.

- https://www.cssd.gov.nl.ca/publications/pdf/seniors/ahcd_booklet.pdf

New Brunswick: The term used in New Brunswick is advance healthcare directive.

- http://www2.gnb.ca/content/gnb/en/departments/health/patientinformation/content/advance_health_care_directives.html

Nova Scotia: The term used in Nova Scotia is personal directive.

- <https://novascotia.ca/just/pda/>

Ontario: The term used in Ontario is advance care plan.

- <https://www.speakupontario.ca>

Prince Edward Island: The term used in PEI is healthcare directive.

- http://www.gov.pe.ca/forms/pdf/2797.pdf?_ga=1.153991742.763754036.1454519248

Saskatchewan: The term used in Saskatchewan is healthcare directive.

- <http://www.rqhealth.ca/department/advance-care-planning/advance-care-planning>



Appointing a Power of Attorney for Personal Care

Giving someone your power of attorney for personal care* allows that person to make decisions on your behalf concerning your personal care and your medical treatment if you are not able to make your wishes known. For instance, even if you prepared an advance care directive, a particular medical situation may arise that was not covered in your plan. The person who has your power of attorney for personal care is your substitute decision-maker.

A power of attorney for personal care is a legal document. It is important that the individual you choose as your substitute decision-maker understands your wishes and is prepared to act on your behalf.

*Called a representation agreement in British Columbia; personal directive in Alberta, Nova Scotia, and Northwest Territories; protection mandate in Quebec; and power of attorney in Ontario, New Brunswick, and Saskatchewan. This legislation does not exist in other provinces and territories.

Adapted from "Who Will Speak for You? Advance Care Planning Kit," available online at www.AdvanceCarePlanning.ca.

Bereavement planning

It is beneficial for the family and close friends of a dying person to identify resources that will help them deal with the feelings of grief and loss they will experience on the passing of their loved one. A few resources are mentioned below.

- Coping with Grief, a booklet published by the ALS Society of Canada, is available through your provincial ALS Society. This booklet covers anticipatory grief and strategies to overcome grief.
- This Guide contains a section for caregivers on dealing with bereavement.
- Emotional and psychological from mental health practitioners such as grief counsellors, from faith leaders, or from hospice organizations can help in healing.
- Peer support through others who have gone through a similar experience can help. Your provincial ALS Society may be able to connect you with other bereaved ALS caregivers to meet as a group or one on one to support each other.

Leaving a legacy

Planning for the end of your life involves thinking about what kind of legacy you would like to leave. You may choose to tell your life story and recount special memories that will serve as a tangible reminder and memorial to who you are, your beliefs and values, and how you lived your life.

- If you can type or use specialized computer software you may prefer to write the story of your life.
- If your speech is good, you could ask a friend or family to videotape your stories as you recount them.
- A good resource to guide you through the process is "A Guide to Recalling and Telling Your Life Story," available for purchase through the Hospice Foundation of America (www.HospiceFoundation.org).
- Free printable templates for creating for your life story can be found at the <http://www.LegacyProject.org/activities/lifestory.pdf>

5.0 FOR CAREGIVERS

5A WHO CAREGIVERS ARE AND WHAT THEY DO

A caregiver is any person who provides regular physical and/or emotional support to a person with an illness to ensure they continue to enjoy the best possible quality of life. Caregivers are usually adults, and they may be paid, such as personal support workers and nurses, or unpaid, such as a spouse, an adult child, or a parent.

Caregivers for a person with ALS/MND (referred to here as ALS) may

- Give medication
- Manage the appointment schedule
- Accompany the person with ALS to appointments
- Manage transportation
- Assist the person with ALS when they need to change position or transfer
- Bathe the person with ALS and provide other personal hygiene care
- Dress the person
- Help with feeding including tube feeding
- Ensure the comfort of the person, for example by scratching an itch, applying or removing braces, and adding or removing layers of clothing or blankets
- Provide feeding (PEG) tube care
- Provide tracheostomy care
- Take on additional household tasks and roles, perhaps those previously carried out by the person with ALS, such as cooking (which may include preparing special food), cleaning, managing finances, running errands, driving, providing child care, etc.

If you are a family member, it may seem strange to call yourself a caregiver. You may see yourself as no more than a person helping a loved one in need. However, in the eyes of the health and social care systems, if you provide care and support to someone living with ALS, you are a caregiver.

Primary caregivers

Though many people can provide care for a person with ALS, there is usually someone who is the primary caregiver. In some cases, a person can have more than one primary caregiver.

A primary caregiver is the main contact for the care of the person with ALS. They tend to provide most of the care for the person and/or supervise the care provided. Primary caregivers may also be the main support for the person with ALS as they make decisions, and may take over making decisions if the person they are caring for becomes unable to communicate their wishes. This transition can be formalized in legal documents, such as a mandate in case of incapacity or a power of attorney.

Young caregivers

Young caregivers are those under age 18 who help to care for the person with ALS. As much as possible, young caregivers should not be primary caregivers. Being a primary caregiver is demanding and it is important that young people continue living their lives as normally as possible. However, in some situations, no adult can provide care to the person with ALS, and a young person may end up having the responsibility of being the primary caregiver.

Things to think about when becoming a caregiver

Caregiving can be a positive and rewarding experience, a heavy and demoralizing experience, anything in between, or a combination. As much as the care may be needed, there are often physical and mental health consequences to caregiving because caregivers tend to prioritize the needs of their loved one over their own.

You have the right to think about what you want to do – or not do – as a caregiver. You are allowed to ask yourself

- What kinds of tasks would I want to do?
- What kinds of tasks am I not comfortable doing, or not able to do?
- How will I make time to eat well, exercise, and get to my own appointments?
- How will I make sure I have time to relax?

As you enter your role as a caregiver, it can be helpful to think about these things ahead of time to make sure you maintain your own health.

You may want to give time to your relationship with the person you are caring for outside of being a caregiver, whether the person is your spouse, parent, child, or friend. Getting people to support you by doing daily tasks can give you room to fulfill your other role, such as scheduling someone to help with feeding so you can share mealtimes together.

Think about family members, friends, and neighbours you can involve in the care process. Make a list of anyone who has offered to help and think about ways they can help or ask them to offer specific examples of how they are willing and able to contribute. Examples include organizing meals, managing appointments, managing medications, helping with laundry, managing the flow of equipment in and out of the house, or being the point person for all the people who have offered to help. You can also have a family meeting to discuss everyone's strengths and to figure out how the tasks can be shared based on those strengths.

In the beginning, you may find that you don't need much help. But establishing how others can be involved early on can be reassuring and make life a little easier for you.

5B YOU ARE NOT ALONE

You may feel lost and alone facing the challenges of caring for a person living with ALS. You may not know anyone else who is or has been in a similar role.

If you feel like this, it is important to remember that you are not alone. Even though every caregiver's experience is different, others are experiencing this challenging role as well. Nearly three out of every ten Canadians are family caregivers. In fact, it is estimated that 80% of home care in Canada is provided by informal caregivers, including family, friends, and neighbours.

Your provincial ALS Society may have supports geared toward caregiving, such as support groups, one-on-one support from a counsellor, financial support, or respite services, and the society may be able to connect you with other community services for caregivers. They may also be able to connect you with another caregiver who is experiencing similar challenges for mutual peer support.

Online supports also exist. The following websites provide information and/or host forums where people can share and discuss different topics:

- <https://elizz.com/>

5C

RECOGNIZING AND UNDERSTANDING COMMON CAREGIVER EMOTIONS

Caregivers experience many different emotions and it is important to understand that this is common and normal. Some feelings you may not even know how to explain or describe. Here are a few of the feelings you may have, plus ways to cope with them.

Ambivalence

Ambivalence is when you have mixed feelings about something. You may feel that you both want to – and don't want to – do the things you are doing. One day you may feel happy and motivated to help, and the next you may feel you wish you didn't have to.

Being ambivalent about caregiving is completely normal. Everyone who looks after someone has these feelings sometimes. Whenever you feel the swing of emotions, remember that no feeling lasts forever and that no feeling is bad or makes you a bad person.

Denial

Denial is when you refuse to believe something is true. When you first hear about your loved one's ALS diagnosis, you may believe it is a mistake, that it will change, or that your loved one will get better.

Denial actually serves a purpose: it's one way people protect themselves from information that is too much to handle at once. For some, the truth of the situation may seep in over time, and for others, denial may stay until the end. Not everyone experiences denial.

With ALS diagnoses, denial happens frequently and is normal. However, the longer you deny the existence of the disease, the more difficult it becomes to care for the person with ALS and to adapt to their daily needs and changes.

By learning to live with the disease and facing the challenges head on, you may find it easier to cope with the demands of caregiving. If you are having a hard time digesting the news of the diagnosis and what it means, speaking with a social worker or psychologist can help.

Anger

Anger is a very common, normal emotion among ALS caregivers. Anger is marked by strong feelings of unhappiness, irritability, and hostility. You may feel angry at the situation, wonder what happened that caused the person to develop the disease, or wonder if they – or you – did anything wrong. You may be angry that it is happening to you and that the person with ALS is completely dependent on your help. Remember that neither you nor anyone else did anything to cause the ALS. It is not anyone's fault.

When you become angry toward something or someone, leave the room to prevent those feelings from getting worse. This is not about bottling up your anger, but instead giving yourself an opportunity to take a breath and consider the best strategy for managing your anger.

One strategy is talking with your loved one about how and what you feel when you become angry. This can help them know how to react to your emotions when you become angry. If this strategy does not seem appropriate, consider sharing your feelings with friends, family, or your family doctor, who all understand your situation.

Often when dealing with anger, a release of emotions is helpful. Find a safe way to let it out that works for you: take a brisk walk around the block, laugh, listen to music, or vent to a friend. Remember, there is nothing wrong with feeling angry.

If your anger concerns you, consider speaking with a social worker or psychologist for help in dealing with it.

Resentment

Resentment is similar to anger, but is more bitter and personal. It is the feeling of anger directed toward someone or something that you believe has done you wrong. It is common for ALS caregivers to feel resentful. You may have had to give up a lot to be a caregiver. You may feel the role is taking over your life and sense of self and that you have no time for yourself anymore.

Resentment can be a sign of impending burnout. It means you need to take some time to take care of yourself. Don't be afraid to ask for help from your healthcare team, family members, or friends. Taking some time for yourself can really help your health and wellbeing.

Guilt

Guilt happens when you feel you have done something wrong. You may feel guilty that you are healthy and the person with ALS is ill. You may worry that you are not a good enough caregiver or that you can't get to everything on your to-do list. You may feel guilt when you have thoughts about not wanting to be a caregiver. You may feel guilty that you are not spending enough time with friends and family. You may feel that when you take some time for yourself, your loved one is left with another caregiver who may not be as experienced as you are, and so on.

Guilt is very common among caregivers. Take some time to think back on how much you do as a caregiver. Take note of the different tasks you accomplish in a day. Realizing how much you are doing can give perspective to your guilt. Be open about your feelings and communicate with others about what you are feeling. The guilt you feel toward a situation is often different from how others perceive what is happening. Think about what you would say to a friend in your situation. Recognize that you have a right to your own health and wellbeing.

Loneliness

Loneliness happens when you feel isolated and alone. Caregivers of people with ALS often feel lonely, especially as the disease progresses. You may feel that caregiving is taking over your life. The more the disease progresses and your loved one's mobility and speech become impaired, leaving the house may become increasingly difficult, making you feel trapped in your own home.

If you feel like this, it is important to remember that you are not alone. Your ALS Society may have supports to help you. Ask your friends and family to visit you. Connect with other caregivers in person, via phone, or online.

Anxiety and fear

Anxiety and fear often go hand in hand. Anxiety is the feeling of worry and unease about something or some situation. Fear is the feeling that something terrible is going to happen. Anxiety and fear are normal feelings among caregivers. This is likely the first time you have been in this role. You likely don't know what to expect or how things will turn out.

Learn as much as you can. Read about the disease and how to care for someone with it. Learn from others who have been through it; talk to your ALS Society representative. Having more knowledge can calm your mind. Also, don't be afraid to ask for help from your loved one's healthcare team. They may be able to provide the information you need and teach you valuable skills that settle some of your anxieties and fears about caring for someone with ALS.

Helplessness

Since ALS has no effective treatment or cure and its symptoms continuously worsen, caregivers often feel that they can't really help their loved one, especially as the tasks become more demanding.

Take a moment to think about all the responsibilities you've taken on as a caregiver. You may doubt that you are doing enough, but remember that you are doing it. Remember that you are not superhuman and that you can't do it all. You are doing the best you can.

Take control where you can. For some, that means planning and organization, thinking about what's coming, and setting up supports ahead of time. For others, it means thinking about hope, maximizing the quality of life, and having a beautiful moment and a laugh every day.

If you need support or are unsure about how to do something, don't hesitate to contact your ALS Society or members of your loved one's healthcare team. They can teach you useful skills for caring for someone with ALS.

5D

COMPASSION FATIGUE

Compassion fatigue occurs when caregivers begin to feel the pain and suffering of the people they care for. Caregivers with compassion fatigue start to lose their sense of self and give more compassion than they receive, meaning they are no longer able to feel that their work is valued. As a result, caregivers “burn out,” leaving them with feelings of deep physical and emotional exhaustion.

People experiencing compassion fatigue have a hard time maintaining a healthy balance of concern and objectivity and find it hard to come out of the downward spiral. Many people experiencing compassion fatigue will push themselves harder, eventually reaching rock bottom.

Compassion fatigue can be experienced by anyone close to a person with ALS, especially those who are very motivated to make a difference in the lives of anyone they feel is suffering. Those most at risk of compassion fatigue are primary caregivers and close family members and friends.

Signs of compassion fatigue

A person with compassion fatigue may experience disruptions in job performance or personal relationships, deterioration in their home life, or a change in personality. Compassion fatigue can also lead to an overall decline in general physical and mental health.

One of the most apparent signs is a feeling of tension and preoccupation with the individual who has ALS and with their disease. Other signs of compassion fatigue include the following:

- Avoidance or numbing of your feelings
- Avoidance of certain thoughts or situations
- Memory gaps
- Pattern of tiredness even with a good night’s sleep
- Difficulty sleeping or experiencing bad dreams
- Increased absenteeism or use of sick days
- Emotional exhaustion from too much caring
- Loss of interest in previously enjoyed activities
- Difficulty making decisions

- Loss of self-esteem
- Anger, irritability, or depression
- Trouble finding hope or happiness
- Multi-tasking to save time
- Reduced productivity at work and at home
- Compromised self-care

The phases of compassion fatigue

Many caregivers experiencing compassion fatigue move through four phases:

- **The zealot phase:** The caregiver is highly committed, involved, and available, putting in extra hours and volunteering to help.
- **The irritability phase:** The caregiver begins to cut corners or avoids contact with the ill person. The caregiver may daydream or become distracted and distant.
- **The withdrawal phase:** The caregiver loses enthusiasm, develops a “thick skin,” and may complain of stress or fatigue. The line between the person with ALS and the caregiver begins to blur.
- **The “zombie” phase:** Hopelessness turns to rage; other caregivers seem incompetent. The caregiver develops disdain for the person with ALS and for other loved ones and becomes distant and impatient. Activities that the caregiver once enjoyed are no longer enjoyable.

5E REDUCING CAREGIVER STRESS AND COMPASSION FATIGUE

There are many ways you can reduce the stress and fatigue you may be feeling. Try various methods, talk with your loved one's healthcare team and other resources, and find strategies that work for you.

Use a care journal

One of the most useful strategies for reducing caregiver stress is using a journal to keep track of appointments, medication, all the different healthcare professionals, and any other information relevant to the situation. The numerous appointments and the amount of information being given to you can be overwhelming, especially in the beginning. The best way to make caregiving more manageable is to keep track of everything in a journal.

Learn as much as you can...then pass it on

Learning about ALS and about different care strategies will prepare you for the caregiver role. Understanding how the disease will affect the person will help you to stay close to them and adapt to the changes.

Sharing this information with your family and friends will help them understand what is happening and will better prepare them to help and support you.

Be realistic about the disease...and about yourself

Even though it is not easy, be realistic about the disease and how it affects people. ALS is a progressive disease. The person you are caring for will develop more and more debilitating symptoms over time. Once you take in this information, it will be easier for you to adjust your expectations.

Caring for someone takes time and energy. There will be limits to what you can do. You will have to decide what is most important to you – time with the person you are caring for, time for yourself, or a tidy house, for example. There is no right answer; only you know what matters most at any given moment.

Besides making choices, you will have to set limits on what you can do in a day. It may be hard to admit you can't do it

all, or to say no, but you may have to. Be realistic and think carefully about how much you can do by yourself and where you need help.

Get help

Access the programs and services available to help you with things like household chores and caregiving tasks. Connect with these services as soon as possible. Your local ALS Society can assist in finding them in your community. Figure out what kind of help you need, and let people know. Remember, you are not alone.

It can be hard to ask for help, but you will need the assistance of family and friends. Accepting help is not a sign of weakness. You will likely find that your family and friends are more than happy to give you a hand.

From time to time, they can help with household chores and daily tasks, such as running errands and preparing meals. They can also keep the person with ALS company for a couple of hours while you run some errands or take some time for yourself.

Make a list of activities that others can help you with. That way, when they approach you to offer their help, you can easily pick something on the list they can do.



Accept and share your feelings

When caring for someone, you will have many mixed feelings. On a given day, you may feel content, angry, guilty, happy, sad, embarrassed, afraid, and helpless. Although these feelings may be confusing and hard to handle, they are neither good nor bad, but normal. “Negative” feelings do not mean you are not a good caregiver; they mean you are human. Know that you are doing the best you can.

If your feelings start to have a bigger impact on your life than you would like, consulting with a social worker, psychologist, or your family doctor can help you better understand and manage your emotions. It is helpful to share your feelings with others. Find someone you are comfortable with and talk about how you feel or what is troubling you. This person may be a close friend, a family member, someone you met at an ALS support group, a member of your spiritual or cultural community, or a healthcare professional. Sharing your feelings, especially with a trained professional, can help you manage them and keep them from undermining your caregiver role. Other options might include keeping a journal, writing a letter that may or may not be sent, listening to music, exercising, doing art, doing demolition or other work with your hands.



Reflect, look for the good, and plan for the future to gain perspective

If you find that you’re doubting yourself and what you’re doing, take a step back and think about all the work you’re doing. Acknowledge that any effort, no matter how small, is always good. Taking a few minutes to meditate, do deep breathing exercises, or reflect on a positive memory or on why you chose to care for your loved one can help you maintain a positive perspective.

Your outlook can really affect the way you feel. Even though it may seem as if there aren’t any, look for positive things around you. Look for ways your loved one with ALS can keep exercising their physical and mental skills. Work to make every day count. There will continue to be times that are special and worthwhile.

Stay in the present. Anticipating your loss and looking ahead to what’s to come can be draining and sad. Many families try to take the “one day at a time” approach and make the most of every day to enjoy life as much as they can.

That said, planning for the future can help relieve stress. While the person with ALS is able, review their financial status and plans as needed. Choices related to future health and personal care decisions should be thought about, discussed, and written down. These plans should include an alternate caregiving plan in case you become unable to continue providing care.

5F**TAKING CARE OF YOURSELF**

You have probably heard that you can't help others if you don't help yourself. Taking care of yourself may be the last thing on your to-do list when you are caring for someone living with ALS, but it is important that you devote some time to allow yourself to recover and not lose your sense of self outside of your caregiving role.

Your own health is key. Do not ignore it. Do not wait until you are too exhausted to take care of yourself. Remember to schedule your own medical and dental appointments to monitor and maintain your health. What you will find is that when you put yourself first once in a while, you will come back more refreshed and ready to face the challenges of caregiving. It's good for you and it will make you a better caregiver to your loved one.

Many caregivers feel that by taking care of themselves, they are neglecting their loved one. Many others are so tired from their caregiving duties that they don't feel they have the energy to look after themselves. If these common struggles resonate with you, speak with a social worker or your counsellor at the ALS Society to work on getting the support you need to maintain your health and wellbeing.

Below are some ways to take care of yourself and find time away from caregiving.

Eat well and stay active

Even though it may sound like a cliché, making sure you eat proper balanced meals will help you maintain your energy. Eating well when other things have priority can be difficult. One strategy is to cook multiple large meals in advance and freeze them. Another strategy is to pick simple, quick recipes that are easy to prepare, such as popular four- or five-ingredient recipes. When people ask what they can do to help, have someone prepare food for you, not just for the person you're caring for.

Caregiving can be physically demanding and the idea of adding additional exercise to your routine may seem ridiculous. But exercise has been shown, time and time again, to improve

mood and wellbeing and to reduce stress. For you, exercise may mean working out at a gym, following home workout videos in your living room, or simply going for a brisk walk or bike ride. The level of exercise you engage in is your choice, but taking the time to separate yourself from caregiving and to do something for yourself through exercise will do you a world of good.

Relax and recharge

Take some time to relax throughout the week. Let non-urgent chores wait. Make sure you get enough sleep at night. If you find this difficult because of nighttime care activities, try to find time for a short nap during the day.

Respite care is very important because it gives you an opportunity to create a plan of care for yourself, something many caregivers overlook. Respite care gives you a much-needed break from the daily care you provide for your loved one – it can be a few hours or a few days at a time. You can take this time to meet a friend, visit a library or museum, go to the movies, attend a support group... anything that's for you. Respite services may be available during the day or at night; speak with your provincial ALS Society for more information on services available in your area.

Hobbies and activities

If you have a hobby or pursue an activity that interests you, don't give it up completely because of caregiving. If someone else can come and provide care for the person with ALS a few hours a week, take that time to focus on your own interests. You may also find a new hobby that doesn't require you to leave the home, such as sewing, do-it-yourself projects, writing, taking an online course, and so on. Don't let your interests disappear when you become a caregiver.

Keep in touch

It is very easy to lose touch with your friends and community when you're caring for someone with ALS. Use technology such as video calling, email, and social media to keep in touch with them, to follow what's happening in other people's lives, and to stay connected.

5G

SUPPORTS AND SERVICES FOR CAREGIVERS

Your ALS Society

The ALS Society of Quebec knows that caring for someone diagnosed with a neurodegenerative disease is physically and emotionally demanding. From the outset, the Society's goal has always been to help improve the quality of life of caregivers, as well as those diagnosed with ALS, by providing services to support, equip and refer our caregiver members as needed, thus lessening the risk for injuries, exhaustion, depression, anxiety, stress. By doing so, we help you set the stage for a less complicated grieving process. We are an ally, an advocate, and a resourceful lifeline that ALS caregivers in Quebec can rely upon and trust.

Our committed team is available to support caregivers throughout their caregiver journey at every stage of the disease. We recognize that caregivers devote an enormous amount of time, energy, focus and financial resources caring for loved ones with ALS, but they can't do it alone. We take great pride in empowering families living with ALS by:

- offering reliable information about ALS
- being present at multidisciplinary ALS clinics
- guiding families to navigate the healthcare system and referring them to specialized community services and resources
- providing technical/financial aid and respite programs
- organizing social/networking activities that provide opportunities to connect with other caregivers and families touched by ALS.

By offering the expertise of psychosocial counsellors who provide one-on-one support, in-person meetings, telephone contact and e-mail follow-up, a helping hand is never far away. Providing families with different options for interactive and specialized support groups, training, teleconferences, and webinars regarding disease specific information facilitates opportunities for caregivers to break their sense of isolation, share their stories, worries and frustrations while offering one another emotional comfort and support. We know that when it comes to a challenging disease such as ALS, one size simply does not fit all. Each caregiver's path is unique and has its own needs and rhythm.

Becoming a member of the ALS Society of Quebec allows

caregivers to have access to a full range of personalized support and information that are often not available in the healthcare network. Signing up is easy and allows caregivers to stay up to date regarding information, activities and support groups.

To learn more please visit our website at: <http://als-quebec.ca/support-and-services/caregiver/>

Or please contact us directly for any questions you may have, or information and support you may need:

Amyotrophic Lateral Sclerosis Society of Quebec

5415 Pare, suite 200, Mount-Royal, QC H4P 1P7

Phone: 514 725-2653

Toll Free in Quebec: 1 877 725-7725

Fax: 514 725-6184

Email: info@sla-quebec.ca

We also strive to work together with ALS caregivers on providing access to information and resources so that ALS caregivers are better equipped to maintain their health and have the energy, knowledge and ability required to meet the day to day demands, challenges and impacts of the illness. Recently, the ALS Society of Quebec has developed and incorporated a caregiver dedicated on-line virtual learning environment, called Taking Care. The aim of this virtual library is to facilitate access to helpful tips, relevant topics and practical advice in the form of online reading resources, audio podcasts and teleconferences, video capsules and webinars. All content is accessible on-demand and is available for access when the time is right for the caregiver, in the comfort of their home. In order to further expand the offer of support to ALS caregivers across the province, the ALS Society of Quebec has partnered with other community government organizations/resources so that ALS caregivers across the province of Quebec can be well supported, no matter what region of the province they live in.

From health organizations funded by the Government of Quebec

The first step for someone recently diagnosed with ALS and their caregiver is to register at your Local Community Service Centre (CLSC) in order to meet with a healthcare professional who will guide you and your loved one toward appropriate services in your region/territory.

Across Quebec, CLSC provide:

- Common health and social services

- Preventive or medical services to the population of its territory
- Rehabilitation and reintegration services
- Public health activities

Each CLSC offers various supports and services for caregivers, such as respite programs and homecare resources. To locate the CLSC that covers services in your area, please visit the government website at the following link: <http://sante.gouv.qc.ca/en/repertoire-ressources/clsc/>

At times, you may be referred to an Integrated Health and Social Services Centre (CISSS) and Integrated University Health and Social Services Centres (CIUSSS) which also ensure accessibility, continuity and quality of services for people in their territory.

CISSS and CIUSSS' are reference points where people can go in case of health or psychosocial problems. There, they can receive appropriate services or be directed to another resource of the territorial services network.

To find your CISSS or your CIUSSS, consult: <http://sante.gouv.qc.ca/en/repertoire-ressources/votre-cisss-ciuuss/>

Portail Santé mieux-être is a Quebec-government website with useful information on healthcare access. It can also help you find health care services in your region.

L'APPUI Pour Les Proches Aidants D'Aînés

Another step that may be of help for ALS caregivers living within the province of Quebec is to communicate with L'APPUI, a non-profit organization, that was created in 2009 to help improve the quality of life of those providing care to older adults by facilitating their daily tasks and ensuring that they take full advantage of available resources. Each region across the province has a regional L'APPUI office.

L'APPUI also offers a "Caregiver Support" helpline that operates every day from 8 a.m. to 8 p.m. "Caregiver Support" is a free and confidential phone consultation, information and referral service for the caregivers of older adults, as well as friends and family, practitioners and health care professionals.

L'APPUI professional counsellors are on hand to:

- **LISTEN TO YOU** with care and compassion
- **INFORM YOU** with clear, accurate and up-to-date information
- **REFER YOU** to local resources and services that meet your needs

Caregivers can call to receive one-on-one support from counsellors who help them identify their needs and available services in their region. If you would like to communicate with a L'APPUI counsellor, please call their free and confidential phone consultation line at 1-855-852-7784 (8LAPPUI).

For more information on L'APPUI and the resources that may be available in your particular region, please visit their website: <https://www.lappui.org/en>

RANQ -Regroupement des aidants naturels du Québec (French only)

Created in 2000, Regroupement des Aidants Naturels du Quebec (RANQ) brings together local and regional associations, groups and organizations that work towards improving the life conditions of caregivers. By protecting the caregiver's rights and interests, as well as those of the community organizations that support them, The RANQ's mission is to raise awareness, provide support and promote the needs of caregivers in Quebec. To learn more: <http://ranq.qc.ca/>

Resources for Helping Children and Youth

When a family member is diagnosed with ALS, children may have many questions and concerns about the person they know and love. To help families affected by ALS, the ALS Society of Canada has published four guide booklets destined for parents, children, teens and schools. They provide valuable answers and information to help address the questions and concerns that children and teens may have when facing this disease. The booklets can be used as tools to assist your family when talking or sharing information or personal feelings about ALS. You may also want to share this information with other key people involved in your children's lives, such as coaches and teachers.

- Helping Children Cope with ALS—A Parental Information Guide
- When Someone Special has ALS—A Booklet for Children
- When Your Parent has ALS—A Booklet for Teens
- Talking With Young People About ALS—For Schools

If you have limited access to the internet and would like a copy of the booklets, please contact the ALS Society of Quebec directly by phone at 1-877-725-7725 and we will be pleased to send you a copy of the guide/booklet that is of interest to you.

Below are a few additional resources that can also help you through this journey:

- KidsGrief.ca (or <http://deuildeenfants.ca/>) is a free online resource that helps parents support their children when someone in their life is dying or has died. It equips parents with the words and confidence needed to help children grieve life's losses in healthy ways.
- **Deuil-Jeunesse** (French only): Is an organization that supports young people and families who are experiencing serious illness, death or death of a loved one, or loss due to parental separation, abandonment or adoption. They work with youth themselves, their parents and their families through distinct means including awareness, support, information and intervention. They also offer their expertise to organizations, professionals and stakeholders, both in Quebec and internationally. For more details visit: <http://www.deuil-jeunesse.com/accueil>

All requests for assistance for the province of Quebec must be made by calling the head office, in Quebec City toll-free at 1-855-889-3666 or 418-624-3666.

- **NOVA West Island Camp Carousel** a circle of support is a weekend bereavement camp for children and youth. For more information visit their website at <https://www.novawi.org/copie-de-soutien-au-deuil-enfants>.
- **Camp Erin® Montreal** also offers a free weekend bereavement camp for children and teens ages 6 to 17, who are experiencing grief from a death of someone close to them. For more information visit <http://www.ymywha.com/camperin/> or call 514-737-6551 x 264.

Bereavement and Grief Resources for Adults

- **Canadian Virtual Hospice**

An online information and support resource on palliative and end-of-life care, loss and grief. http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support.aspx

- **MyGrief.ca (English only)**

MyGrief.ca can help you understand grief and work through some of the difficult issues you may be facing. MyGrief.ca has been developed by a team of national and international grief experts together with people who have experienced significant loss in their own lives. This resource is not meant to replace professional counselling or other health care services, and is free for Canadian users.

- **Tel-Écoute/Tel-Aînés Call Center**

Continuing to assist any person who is mourning the death of a loved one, the helpline previously managed by La Maison Monbourquette maintains the same telephone number and is available from 10am to 10pm – 365 days / year and is free. FREE HELP LINE : 1 888 LE DEUIL (533 3845)

Provincial Government of Quebec (Revenu Québec) Benefits and Tax Credits Programs

The Government of Quebec has different tax credits and benefit programs. Know that if you are an informal caregiver, you or the person you are caring for may qualify for the following tax credits and benefits:

- Amount for Dependants
- Independent Living Tax credit for Seniors
- Non-Refundable Tax Credit for Medical Expenses
- RRSP Withdrawals for a Person with a Functional Impairment
- Recognition of Volunteer Respite Services
- Tax Credit for Caregivers
- Tax Credit for Respite of Caregivers
- Work Premium Tax Credits

For more detailed and up to date information about general tax credits, please visit the Revenu Québec website at: <https://www.revenuquebec.ca/en/citizens/tax-credits/>

Tax Credit for Caregivers

You can claim a refundable tax credit for caregivers if you are in one of the following situations:

- You are the caregiver of your elderly spouse who is unable to live alone.
- You provide housing for an eligible relative.
- You live with an eligible relative who is unable to live alone.

To claim the tax credit for caregivers, you must meet certain conditions, including both of the following:

- You were resident in Québec on December 31 in the year covered by the claim.
- No one, other than your spouse, is claiming any of the following with respect to you:
 - an amount for a child under 18 enrolled in post-secondary studies, an amount transferred by a child 18 or over enrolled in post-secondary studies or an amount for dependants
 - an amount for expenses for medical services not available in your area
 - an amount for medical expenses

For more information regarding this tax credit, please visit the Revenu Québec website at: <https://www.revenuquebec.ca/en/citizens/your-situation/informal-caregivers/tax-credit-for-caregivers/>

Tax Credit for Caregivers of a Spouse

You can claim a refundable tax credit if all three of the following conditions are met:

- Your spouse was 70 or older at the end of the year covered by the claim.
- Your spouse had a severe and prolonged impairment in mental or physical functions that rendered him or her unable to live alone, as certified by a physician.
- Your spouse lived with you for at least 365 consecutive days (including at least 183 days in the year covered by the claim).

Note: You or your spouse must have owned, rented or sublet the dwelling in which you lived together. This dwelling must not be located in a private seniors' residence or a public network facility.

Tax Credit for Caregivers Housing an Eligible Relative

You can claim a refundable tax credit for each eligible relative housed by you in a dwelling provided you or your spouse owned, rented or sublet the dwelling. The eligible relative in question must not own, rent or sublet your dwelling.

Eligible relative housed by more than one person

If the eligible relative has a severe and prolonged impairment in mental or physical functions, he or she can be housed by both you and another relative. In this case, you may have to share the credit with the other caregiver.

Credit for Caregivers Cohabiting with an Eligible Relative

You can claim a refundable tax credit for each eligible relative who cohabited with you in a dwelling, provided the relative or the relative's spouse owned, rented or sublet the dwelling. Note: Only the person who is the relative's primary caregiver is eligible to claim the credit.

To learn more about these tax credits for caregivers please consult the Revenu Québec website at: <https://www.revenuquebec.ca/en/citizens/tax-credits/tax-credit-for-caregivers/>

Tax Credit for Respite of Caregivers

Since 2008, if you are a caregiver, you may be entitled to a refundable tax credit for expenses incurred to obtain specialized respite services. Caregivers may claim a refundable tax credit for the expenses incurred to obtain specialized respite services for the care and supervision of a person with a significant disability (refer to the definition below):

Person with a significant disability (definition) is a person who;

- is at least 18 years of age at the time the expenses are incurred;

- ordinarily lives with the individual;
- cannot be left without supervision because of the disability;
- has a severe and prolonged impairment in physical or mental functions or receives palliative care.

To claim the tax credit, an individual must have been resident in Quebec on December 31 of the taxation year; and have paid expenses to obtain specialized respite services for the care and supervision of a person with a significant disability. To learn more about this particular tax credit please visit the Government of Quebec website at: <http://www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/aines/Pages/credit-impot-repit-aidant.aspx>

Revenu Québec offers secure online services. If internet access is not an option, telephone services for benefit inquiries and other

general information can be accessed as follows:

Before accessing your file, Revenu Québec will confirm your identity in order to preserve the confidentiality of the information your file contains. Please have **two of the following documents** on hand when you call: (If you do not have the documents on hand, they may not be able to answer your question)

- your most recent notice of assessment; your most recent notice of determination;
- your most recent income tax return; any other notice that we recently sent you.

Please consult the following table for the contact telephone number for Revenu Québec which is based on the type of information required and where you are calling from:

Telephone Numbers and Service Hours by Subject

<ul style="list-style-type: none"> • General information • Income tax • Your tax file • Change of address • Notice of assessment • Direct deposit • Assistance program for individuals in business • Etc. 		<ul style="list-style-type: none"> • Advance payments <ul style="list-style-type: none"> • Tax credit for childcare expenses • Tax credit for home-support services for seniors • Work premium tax credits • Solidarity tax credit and RL-31 slips • Tax credit for the treatment of infertility • Shelter allowance program • Québec education savings incentive 	
Québec City	418 659-6299	Québec City	418 659-6299
Montréal	514 864-6299	Montréal	514 864-6299
Elsewhere in Canada or the United States	1 800 267-6299 (toll-free)	Elsewhere in Canada or the United States	1 800 267-6299 (toll-free)
Service Hours	Monday to Friday: 8:30am – 4:30pm	Service Hours	Monday to Friday: 8:30am – 4:30pm
Persons with a hearing/speech impairment			
	Montréal		514 873-4455
	Elsewhere		1 800 361 -3795 (toll-free)

Notice to Persons with Disabilities

Revenu Québec strives to offer quality services that are tailored to your needs. For example, certain documents are available in alternate formats, and we can provide special assistance if required, all free of charge.

For additional details please visit their accessibility information <https://www.revenuquebec.ca/en/policies-and-instructions/accessibility/>

Information and Supportive Resources for Financial Help and Tax Benefits

As you may know, tax preparation can be a complicated matter. It is often recommended to use the services of a qualified accountant, tax planner or specialist to complete your tax return and help you benefit from the credits to which you are entitled as a caregiver.

Educaloi

Your starting point for legal information (<https://www.educaloi.qc.ca/en>)

Éducaloi is a non-profit organization that was created in 2000. Its mission is to inform Quebecers of their rights and responsibilities. It fulfills its mission in these ways:

- It creates reliable, accessible legal information and education resources.
- It makes citizens aware of the legal aspects of everyday situations and how to exercise their rights.
- It is a leader in communicating legal information in plain language.

Stepping into the caregiver role raises lots of questions. Can I take time off work to care for someone? Do I have a role when it comes to health care decisions? Can I act on behalf of the other person?

The law has tools to help caregivers **understand their roles, make decisions and accompany others**. Éducaloi has put together a toolkit of **key legal information** for caregivers, topics include:

- Balancing work and caregiving
- Healthcare decisions
- Navigating the Health and Social Services Network
- Planning ahead for peace of mind
- Legal protections for vulnerable people
- Housing Issues

Follow this link to access the Éducaloi toolkit for caregivers: <https://www.educaloi.qc.ca/en/caregivers-practical-legal-tools>

Chambre des notaires du Québec

We live in a world where laws are increasingly complex and affect every aspect of our daily lives. Being a caregiver for someone with a life-threatening illness, such as ALS, can bring about the need to think about advance care and legal planning for you and your family.

Find out about your rights

1-800-NOTAIRE is a free service which provides the entire population of Québec with access to basic legal information. Since it was first launched in March 2007, the service has answered over 250,000 calls from every part of Québec.

With a team of 11 notaries who have over 20 years of experience, the 1-800-NOTAIRE service answers questions from Quebecers by providing general legal information. As it is not the mission of the Chambre des notaires to issue legal opinions, the answers provided must not be taken as such. To receive a personalized legal opinion, the user must consult a notary who is duly listed on the roll of the Order.

1-800-NOTAIRE offers answers by phone or through our website.

Telephone service

The 1-800-NOTAIRE (668-2473) telephone service allows Quebecers to speak, free of charge, to notaries who have worked in several areas of notarial law. It is accessible from Monday to Friday, from 8:30 a.m. to 5 p.m.

For more information about this legal resource please visit their website at: <http://www.cnq.org/en/notaries-forum.html>.

Federal government benefits and tax credit programs

The Government of Canada offers a number of programs that can assist caregivers.

Employment Insurance compassionate care benefit

Eligible Canadian workers who take time off work to care for a gravely ill family member can receive up to 26 weeks of Employment Insurance benefits and will have their jobs protected. For more details about this program, visit the Government of Canada website: <https://www.canada.ca/en/employment-social-development/programs/ei/ei-list/reports/compassionate-care.html#h2.11>.

Canada Caregiver Credit (CCC)

The CCC is a non-refundable tax credit which combines three previous credits: the caregiver credit, the family caregiver credit, and the credit for infirm dependants aged 18 or older.

An individual is considered to depend on you for support if they rely on you to regularly and consistently provide them with some or all of the basic necessities of life, such as food, shelter and clothing. To obtain up-to-date information regarding who you can claim this credit for, what amount you can claim, what documents you need to support your claim, or information about completing your tax return please visit the Government of Canada's website here and search for Caregiver Credit: <https://www.canada.ca/en.html>.

Family Caregiver Benefit for Adults

The Family Caregiver Benefit for Adults allows eligible caregivers to receive up to 15 weeks of financial assistance to provide care or support to a critically ill or injured adult. Caregivers must be family members or someone who is considered to be like family by the person needing care or support.

For more information about this benefit, please visit the Government of Canada website at: <https://www.canada.ca/en/services/benefits/ei/family-caregiver-adults.html>.

Medical expenses tax credit

You can claim eligible medical expenses that you paid for the family member you're caring for. For more details on this tax credit, visit the Government of Canada website http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330-331/menu-eng.html#hw_clm.

Disability tax credit

The disability tax credit is a non-refundable credit for eligible individuals or their representatives. It reduces income tax payable on your tax return. As a caregiver, you can claim an amount for this credit if the person you're caring for does not need or isn't able to claim all or part of it on their own tax return. For more details on this tax credit, visit the Government of Canada website: <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/318-eng.html>.

Spouse or common-law partner amount

This is a non-refundable tax credit meant to help families living in the same dwelling where one spouse is financially responsible for the other spouse. For more details on this tax credit, visit the Government of Canada website: <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/303/menu-eng.html>.

Home accessibility expenses

If you have renovated your home to make it more accessible and comfortable for the person living with ALS, you may be able to claim expenses for building materials, fixtures, equipment rentals, building plans, and permits. For more details on this tax credit, visit the Government of Canada website: http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns360-390/398/398-eng.html#lgb_ndvdl.

Caregiver benefits through individual employers

Some employers allow employees to take leave without pay for the long-term care of family members. Unpaid leave can vary in length and set their own policies. Check with your employer to see what is might be available for you.

5H DEALING WITH BEREAVEMENT

PLEASE NOTE

The following pages deal with and provide information on a sensitive topic – bereavement and adjusting to life after loss. You may feel you need to put this section aside for now and pick it up later.

Dealing with the loss of a loved one is a tremendously difficult process. When a loved one dies, what you feel is influenced by your relationship with that person, the supports around you, and the circumstances leading up to their death.

You may find yourself experiencing some or all of the emotions described below. They are all part of the normal grieving process and something we all have to go through when someone close to us passes away.

- **Shock:** You might have thought you were prepared, because the person's death was expected. But whatever the circumstances, it is very common to feel an initial sense of shock.
- **Numbness:** The feeling that you are living in a daze is one of the initial reactions to loss and is a way we deal with overpowering emotion.
- **Sadness and grief:** Feelings of overwhelming grief and sadness will follow shortly after the initial shock and feeling of numbness. You may feel like crying a lot of the time. You may have feelings of depression and isolation.
- **Anger:** There may come a time when you feel angry – angry at the person who has passed for leaving, angry at fate or a higher power, or angry at yourself for not doing more. You may feel guilty that you are still alive or that you couldn't do more.
- **Relief:** Sometimes when someone we care about has gone through a devastating illness like ALS, there is a feeling of relief when their struggle is over. You may also feel thankful that the stress of being a caregiver is over. This is normal and you shouldn't feel ashamed or guilty about having these feelings.

There may also be times when you feel tired and weak, have trouble sleeping, or don't feel like eating.

How long will these feelings last?

Everyone reacts and deals with grief in their own way. Grief may last a long time and it may always be a part of how you feel. Grief rarely ends when the traditional period of mourning does. Time, patience, and a supportive network of family and friends are factors that help us deal with grief.

Sometimes people grieve when they hear of a loved one's terminal diagnosis. This anticipatory grief can be just as devastating as grief after a loss. Sometimes people find themselves grieving some time after – even several years later. This is all normal and over time most of us learn to manage our emotions and adjust to the new reality.

It is also common to feel sadness even after much time has passed, especially at special events such as a child's wedding, the birth of a grandchild, or a birthday. You may wish the deceased person was present for these special moments and feel sad that they are no longer there. This feeling of sadness could last for just a short time, but sometimes it lasts for days.

For some people, the intense period of mourning feels as though it will go on forever. If grief affects your life so much that you are unable to manage your daily activities or other relationships, you should try to seek help through counselling. Your family doctor or your provincial ALS Society may be able to refer you to counselling services.

Coping with grief

Dealing with feelings of grief is one of the hardest things to do as you go through the mourning process. There is no formula for how to manage grief and its associated feelings because everyone grieves in their own way. Some suggestions that have worked for others are provided below:

- **Hold a service as a way to accept the reality of death.** Many people find that holding a memorial or funeral service is helpful because it underlines the finality of death and allows family, friends, and members of the wider community to offer support and say goodbye.
- **Communicate your feelings.** Sharing your feelings openly with friends, support group members, counsellors, or someone who can offer spiritual care can provide comfort and strength.

- **Ask for help.** You may need help dealing with the practical issues that come with death. Do ask for help and delegate tasks to those around you, whether it is grocery shopping or dealing with banks or estate matters.
- **Get enough sleep.** This may be easier said than done. You may, in fact, have trouble sleeping, especially during the early days. You may feel anxious, restless, or fearful. Things that may help you relax include eating regularly and nutritiously, exercise, meditation, yoga, or other relaxation techniques. If sleep still does not come, try taking a relaxing bath, reading a book, or listening to soothing music. Sedatives taken on a doctor's advice may be necessary.
- **Start a small task list.** This is useful if you find it difficult to carry out daily activities. Set a task with a reasonable time limit. When the task is completed, check it off and start a new one. Gradually expand the list until you are able to accomplish several tasks a week.
- **Do something to remember the person who passed.** You could plant a tree, make a donation in their memory, or finish a project you have been meaning to complete.
- **Use a diary or other creative outlet to express thoughts and feelings.** Expressing your feelings through art, music, or writing is often therapeutic and can help release some of the grief you may be experiencing.
- **Lend a helping hand.** Volunteering at a nursing home or school can make you feel as if you are taking care of others much as you did with your loved one. In the early stages of grief, it is advisable not to work directly with others who have ALS.
- **Tap into spiritual or religious beliefs.** If faith is part of your life, seeking spiritual or religious support can often help you cope with grief and loss.
- **Join a bereavement support group.** Contact your local ALS Society for recommendations on bereavement support and counselling services in your area. You can also visit www.MyGrief.ca/ for a list of resources by province.

Helping others around you grieve

People around you may be grieving as well. You may feel a sense of responsibility toward them and may wish to help them grieve, but remember that it is good advice to help yourself before you help others.

Grief and children

Children grieve differently from adults. How children grieve is often based on their age, developmental stage, relationship with the person who died, and previous experience with death. Adults may feel they need to shelter children from the reality of death. The truth is, people of all ages are affected by loss and need a supportive environment so they can mourn.

Children have short attention spans and are easily distracted. They often go back to their daily activity soon after hearing sad news. It may seem as if they don't understand or care. But in fact, children do grieve, and deeply. They often find it difficult to put into words what adults can easily say. Children may seem okay, but could be feeling a range of emotions:

- They could be feeling fearful and worried about what will happen to them.
- They may be wondering if they will die.
- They may feel guilty and think they did something to cause the person to die.
- They may "regress" to less-mature behaviour, such as becoming angry, clingy, or moody.

When helping a child grieving the loss of a loved one, keep the following suggestions in mind:

- **Be honest.** Don't hide what happened. Children are extremely sensitive and will know that everything is not as it was before.
- **Use correct words.** Say words such as death or died instead of "passed away" or "went to sleep." These phrases may come easily to adults and we understand what they mean, but they often confuse children.
- **Allow children to witness other people grieving.** Seeing that others are mourning too will help children recognize that what they themselves are feeling is normal.

- **Provide reassurance and support.** Let children know that they aren't going to die too and will continue to be a part of a family that loves them.

Should children attend a funeral or memorial service?

Taking part in the funeral or memorial service can help children accept the finality of death and allow them to say their goodbyes, and it can reaffirm their important place within the family. Where possible, children and teenagers should be given a choice about whether they wish to attend. They should not be forced either way.

If children are attending, it is helpful to explain to them exactly what will happen before, during, and after the funeral. Provide examples of what people might say or how they may act. Reassure them that it is okay to express their grief.

Some children and teenagers may find it overwhelming and decide they don't want to attend. They may wish to visit the grave or memorial at a later date with a trusted adult.

Even if they don't attend the funeral, young people may wish to be involved in planning the service. They may like to help choose the music that will play at the funeral or write something to be read. They may also wish that something personal be placed inside the coffin if there is one.

A pamphlet is available that may help you help children understand death and death rituals: www.MountRoyalCem.com/images/stories/documents/involving%20children.pdf

Grief and teenagers

Being a teenager isn't easy. Teenagers struggle with issues of identity and independence as they try to bridge the gap between childhood and adulthood. The death of a loved one can be an especially difficult event for young people. Unlike young children, teenagers fully understand death.

Teenagers may show grief by crying or withdrawing. They may feel lonely and exhausted, and could experience disturbances in sleep and eating patterns.

The following are some things to remember when dealing with a teenager who is grieving:

- **Stick with routines.** Most teens want to fit in. When a tragedy such as death occurs it can set someone apart from the rest of their peer group. You can provide support

in this situation by sticking with routines and making sure they have time for regular activities and for meeting friends. Friends are often whom teens turn to for support and encouragement.

- **Curb the desire to direct behaviour.** Let your teenager take the lead and avoid telling them what you think they should do or feel. Give them space and respect their need for solitude if that is what they prefer.
- **Be vigilant.** Sometimes teens may act out or use drugs or alcohol in response to the death of a loved one. The best way to deal with this is to calmly set limits on behaviour and actions.
- **Share common reactions that grieving people may experience.** This may be the teen's first experience with death. Explain that everyone grieves differently and emotions including anger are normal.
- **Inform others.** Let other adults in your teen's life (such as teachers and coaches) know what has happened.
- **Be there.** Listen when they are ready to talk to you.



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BEYOND BEREAVEMENT

After the initial period of bereavement a caregiver may find themselves feeling lost. It is common for caregivers to feel a lack of purpose after the loss of the loved one they have been looking after. After spending so much of your time caring for the needs of your partner, parent, child, or sibling, you may wonder how you will spend your days. Grief is likely still present and with it perhaps feelings of apathy and lack of motivation. In spending so much of your time taking care of someone, you may not have been able to take time out to care for yourself.

It is important to try to find a renewed sense of purpose. Re-creating structure in your life can be challenging, but it is certainly possible. Envisioning what you liked to do before providing care can help create a new structure for your life. These are some questions you may wish to ask yourself:

- How did I spend my time before I became a caregiver for my loved one?
- What were my hobbies?
- Is there anything or anyone I have ignored that I can attend to now?

Remember to give yourself enough time and space to do things at your own pace. There will be ups and downs, positive days and not-so-positive times. We pick ourselves up as best we can, and as we need to.

“ Time does not heal. What you do with your time does. ” – Bereavement support group member

What to do when someone passes away

Coping with the loss of a loved one is one of life's hardest challenges. It may also be overwhelming trying to deal with everything that needs to be settled. This checklist is meant as a guide to help you navigate what may need to be done when someone passes away. Not all of these items will apply in every situation.

Please note that this checklist is for information only and may not be comprehensive. While every effort has been made to ensure accuracy, this information is subject to change. This list is not legal advice and is presented as a general guide. It may not apply to your specific circumstances.

<https://www.quebec.ca/en/family-and-support-for-individuals/death/>

First steps

- Notify the following as soon as possible:**
 - Family and friends
 - Employers (both the deceased's and yours)
 - Religious organization
 - Funeral home
 - Executor/estate administrator
- Locate the will.** The will may contain the deceased's wishes regarding funeral arrangements.
- Register the death and obtain several copies of the death certificate.** To register a death, a family member and funeral home director must complete the Statement of Death. The Statement of Death is a legal record of the death. A death certificate is a document containing the details of a death and can be used to cancel a health card or driver's licence and for insurance purposes.
- Plan the funeral, if this has not already been done.** Tasks may include:
 - Determining whether the deceased will be buried, cremated, or entombed
 - Deciding details of the service itself
 - Preparing the obituary
 - Nominating a charity to receive donations in lieu of flowers
 - Selecting a casket or urn

- Paying for the funeral
- Collect documents. It is useful to collect important documents before starting to complete forms and official paperwork so you have all the relevant information on hand.
 - Birth certificate
 - Deeds and titles to property; stock or investment certificates
 - Automobile registration
 - Insurance policies
 - Marriage certificate
 - Income tax forms

Government

- If death occurred in a province of Canada you do not need to inform Service Canada. The province will notify Service Canada. **If death occurred outside Canada or in one of the territories you will need to notify Service Canada by providing a death certificate** (or statement from the funeral director) as proof of death and the deceased's Social Insurance Number.
- Obtain information regarding the Canada Pension Plan Death Benefit.** Contact: 1-800-227-9914. <https://www.canada.ca/en/services/benefits/publicpensions/cpp/cpp-death-benefit.html>
- People related to the deceased may be eligible for benefits from government programs such as Old Age Security or Employment Insurance. **Check the Benefit Finder on Service Canada to see if any benefits apply to you or other family members.** <http://www.CanadaBenefits.gc.ca>
- Cancel government-issued cards**
 - Contact Passport Canada to cancel a passport: 1-800-567-6868.
 - Contact Citizenship and Immigration Canada to cancel a citizenship card or permanent resident card: 1-888-242-2100.
 - Cancel Secure Certificate of Indian Status (SCIS; status card) by contacting Indigenous Services Canada: 1-800-567-9604.

- Contact the Canada Revenue Agency and cancel benefit payments in the name of deceased: 1-800-959-8281.
- Cancel provincial health card.
- Contact relevant provincial government agencies to cancel provincial benefits and to determine survivors' eligibility for benefits.
- Contact Veterans' Affairs if the deceased was a veteran and receiving veteran's benefits: 1-800-522-2122.

Legal and financial

- Contact a lawyer or notary with questions regarding handling of the estate or will.
- Determine whether it is necessary to probate the will. If so, follow the procedures that apply in your province or territory. (Probate is the procedure by which a will is approved by a court as the valid last will of a deceased person. Probate also confirms the appointment of the person named as executor/administrator in the will through a Certificate of Appointment. This certificate is what grants the legal authority for the executor to perform their duties.)
- If the deceased received pension benefits, contact the pension plan administrator to inform them of the death and to determine whether dependents or other survivors are eligible for continued benefits.
- Inform banks and other financial institutions where the deceased had accounts (including credit cards). Request removal of the deceased's name from joint accounts or transfer sole accounts to the estate. Cancel credit cards.
- Notify insurance companies and obtain information on any benefits.
- Complete an income tax form for the deceased. Once necessary returns have been filed and any tax owed has been paid, obtain an Income Tax Clearance Certificate. For more information, see <https://www.canada.ca/en/revenue-agency/services/forms-publications/publications/t4011.html>

Housekeeping

- Remove name of deceased from mailing lists directly or through the bereavement register at <https://www.canada-bereavement-registry.ca>
- Contact the provincial ALS Society to notify them of the loss of your loved one, to arrange return of any loaned equipment and discontinue services, and discuss new services
- Secure the deceased's home, if empty
- Contact utility companies
- Cancel telephone, internet service, and magazine or newspaper subscriptions
- Arrange for care or adoption of any pets
- Arrange for re-routing of mail

6.0

ALS RESEARCH

6A OVERVIEW

ALS/MND (referred to here as ALS) research is seeing unprecedented progress. The identification of genes linked to ALS and the biological processes affected by mutations in these genes, coupled with technological developments, has allowed researchers to make rapid progress in understanding this complex disease. More advances were made in the last 10 years than in the previous one hundred years. Researchers are optimistic that these discoveries will one day lead to successful treatments for ALS.

Once thought to be a single disease, ALS is now believed to result from numerous causes, all interacting and all sharing biological processes that lead to the destruction of motor neurons. Every newly identified ALS gene provides scientists with a piece of the ALS puzzle and creates new opportunities to study the disease and to help researchers identify how ALS happens. Even though the inherited form of ALS occurs in only about 10% of cases, studying the genetic factors helps us understand the disease as a whole.

By learning about the biology of ALS, we will ultimately understand the disease. Understanding how the disease works will allow us to develop treatment options. Already, new drug and gene therapies are being developed. Because ALS is complex, it could be that a combination of treatments will provide the best chance at altering the course of the disease.



FOR MORE INFORMATION ON ALS RESEARCH

For more information on the Research Program at ALS Canada and/or what ALS researchers do, email research@als.ca or call ALS Canada and ask for the Vice President of Research, or see the Research Section at als.ca/guide-research.

Throughout the year, ALS Canada hosts virtual webinars explaining ALS and ALS research. Look for upcoming dates, topics, and registration links on als.ca/guide-webinars.

For up-to-date information on the latest advancements in ALS research you can go to the ALS Canada blog at als.ca/guide-researchblogs and search for posts tagged "Research."

Alternative treatments and information accuracy

A lot of information about ALS is available, and sometimes you may hear or read conflicting and/or incorrect information either from someone or on the internet. In some cases, misinformed individuals or companies are intentionally trying to take advantage of the dire situation in which ALS families find themselves. Don't believe everything you read on the internet.

As the only national charitable organization that invests in ALS research across the country, ALS Canada supports peer-reviewed research. Regarded as the international benchmark of excellence in research funding, peer review uses a panel of independent experts to evaluate and rank proposed research projects based on their scientific merit and, in our case, on their potential to advance ALS research. That means ALS Canada only supports research that experts agree is useful.

Additional resources for reliable ALS research are peer-reviewed journals. Articles and research findings published in peer-reviewed journals will have gone through a strict expert review process before being published. PubMed (<https://www.ncbi.nlm.nih.gov/pubmed>) is a free database that can be used to search for the latest in ALS research from respected medical journals. Use the keywords "amyotrophic lateral sclerosis" to search for relevant publications. Keep in mind that the articles you may find in this database are written for medical experts.



RESOURCE FOR INFORMATION ON ALTERNATIVE THERAPIES

Fortunately, help is available for patients trying to understand whether claims made about alternative or "off-label" therapies are legitimate (off-label means that particular use of an otherwise approved drug has not been authorized by Health Canada).

Dr. Richard Bedlack, Director of the Duke University ALS Clinic in the US, is also the founder of ALSUntangled, an initiative that promotes patient safety and information. On Twitter (<http://twitter.com/ALSUntangled>), ALS patients can ask questions and receive answers about off-label or alternative ALS therapies. You do not need a Twitter account to view previous questions and answers. Visit the website to look at completed reviews of alternative ALS treatments and their level of evidence: <http://www.alsuntangled.com/>

6B CLINICAL TRIALS

Clinical trials are research studies that use human volunteers to test new therapies. After scientists test experimental treatments in the laboratory, those with promising results move to clinical trial to determine whether the therapy is safe and effective for use in humans. A new therapy must successfully pass through a series of phases before ultimately being approved by Health Canada and being made available to the Canadian public. This process can often take years because strict protocols and processes are in place to ensure that new treatments are ready to be prescribed for people with as little risk as possible.

In general, ALS clinical trials are therapeutic or observational.

- Therapeutic clinical trials test new drugs, therapies or devices that aim to either slow the progression of the disease or help to manage symptoms.
- Observational trials aim to learn more about the disease and are essential to understanding, diagnosing, and ultimately treating ALS.

In many cases people who participate in clinical trials will not benefit from the therapy, but their generous involvement will help to find a successful therapy for those diagnosed in the future. One day, a clinical trial will likely test a treatment that slows the progression of ALS and those involved may directly benefit from taking part.

The goal of a clinical trial is to answer questions like these:

- What is the best way to give the treatment?
- Is the drug safe?
- Is the drug tolerated and at what dosage? Is the drug effective? (that is, is the drug actually changing the expected course of the disease in patients receiving the drug, compared to others who are not receiving it, and how much difference is there?)



FOR MORE INFORMATION ON CLINICAL TRIALS

Ask your neurologist for up-to-date information on what clinical studies are currently being conducted to see if you are eligible to participate.

- ALS Canada keeps an up-to-date list of trials being conducted in Canada on its website: als.ca/guide-clinical-trials.
- Health Canada also provides a searchable database of clinical trials: <https://health-products.canada.ca/ctdb-bdec/index-eng.jsp> A database of all legitimate, recognized ALS clinical trials registered globally can be found at <https://ClinicalTrials.gov>.
- Visit the European Union Clinical Trials Register at <https://www.ClinicalTrialsRegister.eu/>
- Visit the World Health Organization International Clinical Trials Registry at <http://apps.who.int/trialsearch/> for additional information.

6C RESEARCH PARTNERS

IMPORTANT

If you are interested in providing data to assist ALS research, please talk to your doctor to discuss your eligibility and opportunity to contribute, at one of the 14 clinics across Canada: Vancouver, Calgary, Edmonton, Saskatoon, Winnipeg, London, Hamilton, Toronto, Ottawa, Montreal (2 clinics –MNI & CHUM), Quebec City, Sherbrooke, Fredericton, and Halifax. Patients living elsewhere, and those not currently seeing a neuromuscular specialist, can register by contacting the CNDR National Office at the University of Calgary at 1-877-401-4494.

Canadian ALS Research Network

The Canadian ALS Research Network (CALNS) is a network of doctors involved in ALS clinical care and research at academic healthcare centres across Canada. The mission of CALNS is to connect ALS treatment centres across Canada and to improve both patient and clinic participation in research. The benefits of having a Canadian clinical research network include the following:

- A united national voice to attract clinical trials to Canada
- Agility and flexibility resulting from having a small number of committed teams and leaders
- The ability to work together on diverse types of research, including clinical trials and other clinical research
- Opportunities to get involved in research projects across the country
- Mentoring opportunities for new researchers

6D GENETICS AND RESEARCH

A massive global initiative referred to as Project MinE is underway in more than 15 countries. The goal of Project MinE is to map the full DNA profiles of 15,000 people with ALS and 7,500 control subjects (people with similar demographic characteristics who do not have ALS) to establish a global data resource data that will enable scientists worldwide to understand the genetic signature that leads someone to develop ALS. By accumulating such a large amount of data, which no single country could achieve alone, it is expected that Project MinE will identify new genetic causes of the disease that will improve our ability to slow down or stop ALS. ALS Canada is leading Canada's fundraising efforts for Project MinE.



FOR MORE INFORMATION ON PROJECT MINE

To find out more about Canada's participation and how you can contribute, contact the Vice President of Research at ALS Canada (research@als.ca) or call ALS Canada. You can also ask your neurologist for more information about these studies or visit <https://www.ProjectMinE.com/>.

7.0

RESOURCES

The materials and websites referred to in this section are provided for information purposes only. The ALS Society of Canada does not assume responsibility or liability for materials available at linked sites. Reference to materials or websites is not an endorsement or recommendation by the ALS Society of Canada nor a guarantee of the reliability of the information contained within these materials or websites.

ALS Management Guides

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families

By Hiroshi Mitsumoto, MD

This bestselling book covers several aspects of the management of ALS, from clinical features of the disease, to diagnosis, to an overview of symptom management. Sections deal with medical and rehabilitative management, living with ALS, managing advanced disease, end-of-life issues, and resources that can provide support and assistance.

Demos Health, 2009

ISBN: 1932603727

Patient and Family Resource Guide to ALS

Les Turner ALS Foundation

Assembled by the staff of the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine and members of the Support Services Team, this frequently updated guide is available online for viewing, downloading, and printing.

<http://lesturnerals.org/2018-resource-guide-for-people-living-with-als/>

To request a print copy please contact info@lesturnerals.org or Les Turner ALS Foundation, 5550 W. Touhy Ave., Skokie, IL, 60077, United States. Tel: 847 679 3311.

Living with ALS Resource Guides

ALS Association

These 11 guides developed by the ALS Association in Washington, DC, inform and educate people about ALS in a comprehensive easy format. Updated in 2017, they address many of the common concerns and issues that face people living with ALS. Available online at <http://www.alsa.org/als-care/resources/publications-videos/resource-guides/>.

Print copies may be ordered online through <http://portal.alsa.org/> or by contacting the ALS Association, 1275 K St. NW, Ste. 250, Washington, DC, 20005, United States. Tel: 202-407-8580.

The “How To” Health Guide

Health Charities Coalition of Canada

This guide was developed to assist patients, caregivers, friends, and families in understanding and navigating the Canadian healthcare system, and to inform people about the actions you can take to help you receive the best possible healthcare. Updated occasionally.

In English: http://www.HealthCharities.ca/media/30187/HCCC_HowToHealthGuide_2016_EN-Final.pdf

In French: http://www.HealthCharities.ca/media/30165/HCCC_HowToHealthGuide_2016_FR-Final.pdf

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2764727/>

Cookbooks

The Dysphagia Cookbook: Great Tasting and Nutritious Recipes for People with Swallowing Difficulties

By Elaine Achilles, EdD

Cumberland House Publishing, 2004

ISBN: 1581823487

Meals for Easy Swallowing

Muscular Dystrophy Association, ALS Division

This online resource includes a collection of recipes, swallowing tips, helpful hints for increasing calorie intake, and sample menus developed by ALS patients and their families. 2005.

https://www.mda.org/sites/default/files/publications/Meals_Easy_Swallowing_P-508.pdf

The I-Can't-Chew Cookbook: Delicious Soft Diet Recipes for People with Chewing, Swallowing, and Dry Mouth Disorders

By J. Randy Wilson

Turner Publishing, 2004

ISBN 9781630267155

Easy-to-Swallow, Easy-to-Chew Cookbook: Over 150 Tasty and Nutritious Recipes for People Who Have Difficulty Swallowing

By Donna L. Weihofen, RD; Joanne Robbins, PhD; and Paula A. Sullivan, MS

John Wiley & Sons Canada, 2002

ISBN: 0471200743

Caregiver Guides

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers

By Maria M. Meyer with Paul Derr, RN

An excellent guide to caregiving in the home. A chronological structure is used to define preparation for caregiving and the day-to-day expectations. A list of numerous resources augments the content.

CareTrust Publications, 2nd edition, 2002

ISBN: 0966476735

ALS Caregivers Guide & Journal

By Sandra Donalds

The information in this book is first-hand knowledge of the caregiver's responsibilities, struggles, challenges, love, and gratitude for someone taking over as a caregiver.

CreateSpace, 2013

ISBN: 1483947793

The Four Things that Matter Most: A Book about Living

By Ira Byock, MD

Four simple phrases – “please forgive me,” “I forgive you,” “thank you,” and “I love you” – carry enormous power and could possibly be the most powerful words in our language. This book teaches us how to practise these words day to day. Dr. Byock demonstrates the value of stating the obvious and provides practical insights into the benefits of letting go of old grudges and toxic emotions. Powerful real-life stories help us

to forgive, appreciate, love, and celebrate one another and live life more fully.

Atria Books/Simon and Schuster, 2004, reissued 2014

ISBN: 1476748535

Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill

By Cappy Capossela and Sheila Warnock

This book grew from the experience of 12 people coming together and caring for their terminally ill friend for three and a half years. The authors documented the systems developed during that period for others to follow. Share the Care offers a sensible and loving solution, a unique group approach that can turn a circle of ordinary people into a powerful caregiving team.

Touchstone, 1995, 2nd edition 2004

ISBN: 0743262689 (2004 edition)

www.ShareTheCare.org

The Helper's Journey: Working with People Facing Grief, Loss, and Life-Threatening Illness

By Dale G Larson, PhD

Written for professionals and volunteers on the front lines of caregiving, this book focuses on skills and strategies to meet the challenges of caring for people facing grief, loss, and life-threatening illness. Most examples are drawn from Dr. Larson's work in hospice, psychotherapy, and oncology.

Research Press, 1993

ISBN: 0878223444

What If It's Not Alzheimer's? A Caregiver's Guide to Dementia

Edited by Lisa Radin and Gary Radin

Although the public most often associates dementia with Alzheimer's disease, the medical profession now distinguishes various types of other dementias. This book is the first comprehensive guide dealing with frontotemporal degeneration

(FTD), one of the largest groups of non-Alzheimer's dementias. The contributors are either specialists in their fields or have exceptional hands-on experience with FTD.

Prometheus Books/Penguin Random House, 3rd edition, 2007
ISBN: 9781616149680

The Courage to Laugh: Humor, Hope, and Healing in the Face of Death and Dying

By Allen Klein

This book is a poignant and inspirational reminder of the life-affirming nature of the human spirit even under difficult circumstances. The author is an award-winning speaker and workshop leader for patients and their caretakers who calls himself a "jollytologist." Just because a situation is serious doesn't mean it has to be solemn.

Penguin Publishing Group, 1998
ISBN: 0874779294

In the Shadows: Living and Coping with a Loved One's Chronic Illness

By Dr. David Luterman

Dr. Luterman is a professor of communication disorders who has given workshops on the impact of disabling disease on the patient's family. The book details his family's struggle with his wife's multiple sclerosis.

Jade Press, 1995
ISBN: 0964486202

The Caregiver's Survival Handbook: Caring for Your Aging Parents Without Losing Yourself

By Alexis Abramson, PhD

In this supportive guide, Dr. Abramson addresses the most pressing concerns, such as balancing demand on one's time and resources, dealing with feelings of guilt, and avoiding conflict with an aging loved one.

Perigee Trade, 2004
ISBN: 0399536426

A Caregiver's Guide: A Handbook about End-of-Life Care

By Karen Macmillan, Jacquie Peden, Jane Hopkinson, Dennie Hycha

This book provides information for family caregivers to draw upon when preparing and caring for a loved one who has a progressive illness, especially at home. It was developed to complement resources and information provided to caregivers by healthcare professionals, including hospice palliative care teams.

Canadian Hospice Palliative Care Association/Order of Saint Lazarus, revised 2014

Individual hard copies can be ordered directly from the Order of Saint Lazarus from the Chancery's Office: chancery@stlazarus.ca

A Guide for Caregivers

This handbook was created for caregivers of people facing the end of life to give you the tools you may need to help yourself. Available in French and English.

Canadian Hospice Palliative Care Association

To order print copies, visit <http://market-marche.chpca.net/Living-Lessons-A-Guide-for-Caregivers>

End-of-Life Books and Guides

Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying

By Maggie Callanan and Patricia Kelley

Written by two hospice nurses, this book is packed with case stories about how patients near the end of life convey messages and how communication at this time takes on special meaning. The practical advice on how to respond to the requests of the dying and help them live fully to the very end is of value to anyone in a caregiving role.

Simon & Schuster, 2012
ISBN: 1451667256

The Guide to Recalling and Telling Your Life Story

This workbook is designed to help a person tell his or her life story. The book suggests topics and provides questions to help share and record memories and experiences.

Hospice Foundation of America, 2001

<https://hospicefoundation.org/>

ISBN: 1893349004

Handbook for Mortals: Guidance for People Facing Serious Illness

By Joanne Lynn, MD; Joan Harrold, MD; and Janice Lynch Schuster, MFA

This is a sensible, comprehensive guide to end-of-life care intended for a general audience. Written by a team of experts and providing equal measures of practical information and wise counsel, it is also valuable to medical professionals in palliative care.

Oxford University Press, 2011

ISBN: 0199744564

A Guide to End of Life Care for Seniors

Edited by Rory Fisher, Margaret M. Ross, and Michael J. MacLean

This guide, a collaborative effort between the Universities of Toronto and Ottawa, supports a consensus of best practices for end-of-life care for seniors.

University of Toronto/University of Ottawa, 2000

Available online through the Government of Canada at <http://publications.gc.ca>

Bereavement Books and Guides

The Courage to Grieve: Creative Living, Recovery and Growth Through Grief

By Judy Tatelbaum

This book deals with difficult emotions and offers advice on how to help yourself and others get through loss and grief.

William Morrow Paperbacks, 1990

ISBN: 0060911859

Don't Take My Grief Away From Me

By Doug Manning

This warm conversational book takes the reader through all the emotions and experiences that accompany the loss of a loved one.

In Sight Books, 2003

ISBN: 1892785749

A Grief Observed

By C.S. Lewis

An account of rediscovered faith following the death of a spouse.

Faber & Faber, 1961

ISBN: 057129068X

Grief Expressed When a Mate Dies

By Marta Felber

This is a straightforward survival guide for anyone who has lost a spouse. Each chapter focuses on various difficult issues surrounding the loss of a spouse with space provided for the reader to jot down and work through personal experiences.

LifeWords, 2008

ISBN: 0979921406

The Grief Recovery Handbook: The Action Program for Moving Beyond Death, Divorce, and Other Losses

By John W. James and Russell Friedman

Incomplete recovery from grief can have a lifelong negative effect on the capacity for happiness. Drawing from their own and others' histories, the authors illustrate how it is possible to recover from grief and regain energy and spontaneity.

William Morrow Paperbacks, 1998; 20th anniversary edition 2017

ISBN: 0061686077

The Grieving Time: A Year's Account of Recovery from Loss

By Anne M. Brooks

A personal account of the first year after a spouse's death, the book honestly and candidly describes the range of emotions the author felt and the experiences that helped her regain hope.

Herodias, 1985

ISBN: 1928746047

Healing Your Grieving Heart: 100 Practical Ideas

Healing Your Grieving Heart for Kids: 100 Practical Ideas

Healing Your Grieving Heart for Teens: 100 Practical Ideas

Healing a Spouse's Grieving Heart: 100 Practical Ideas After Your Husband or Wife Dies

Healing the Adult Child's Grieving Heart: 100 Practical Ideas After Your Parent Dies

Healing the Adult Sibling's Grieving Heart: 100 Practical Ideas After Your Brother or Sister Dies

By Alan D. Wolfeld, PhD

This series of books on grieving and healing provide sound tips, suggestions, and ideas to help survivors express their grief and seek support so they can start the healing process and begin living their lives again.

Companion Press/Center for Loss and Life Transition, 2001–08

How to Go on Living When Someone You Love Dies

By Therese A. Rando, PhD

A guide through the painful but necessary grieving process.

Bantam, 1988

ISBN: 0553352695

Our Greatest Gift: A Meditation on Dying and Caring

By Henri Nouwen

In this book, Nouwen, who was an internationally renowned spiritual author, shares his views of dying and death as part of the spiritual journey, not merely its end, and on coming to terms with dying.

HarperOne, 2009

ISBN: 0061800260

Personal ALS Stories

A Passion for Life

By Paul Brock

This autobiographical account is the story of Dr. Paul Brock, who in 1996 was diagnosed with motor neuron disease and given three to five years to live. Defying the odds, Dr. Brock continued to pursue his passion as an educator in Australia until his death in 2016. An inspirational speaker, Dr. Brock also authored several books.

ABC Books for Australian Broadcasting Corporation, 2004

ISBN: 0733314473

Cries of the Silent: My Journey with ALS

By Evelyn Bell

This book explores the mind and soul of a remarkable woman with ALS.

ALS Society of Alberta, 1999

ISBN: 0968538304

His Brother's Keeper: One Family's Journey to the Edge of Medicine

By Jonathan Weiner

Stephen Heywood was diagnosed with ALS at age 29. His brother Jamie, founder of the ALS Therapy Development Foundation, was an engineer who almost overnight transformed himself into a genetic engineer in an effort to save his brother and discover a cure. In this dramatic account of their story, Pulitzer Prize-winning author Jonathan Weiner provides a sensitive portrayal of a family and a discussion of the frontiers of biomedicine, including gene therapy, stem-cell therapy, and other cutting edge treatments.

Harper Perennial, 2004

ISBN: 0060010088

Luckiest Man: The Life and Death of Lou Gehrig

By Jonathan Eig

This is the life story of the baseball legend who gave his name to ALS, drawing from sources including personal letters.

Simon & Schuster, 2006

ISBN: 0743268938

My Luke and I

By Eleanor and Joe Durso Gehrig

Lou Gehrig's widow describes their lives during his baseball career and the years following his diagnosis with ALS.

New American Library, 1977

ISBN: 0451078187

Falcon's Cry: A Desert Storm Memoir

By Michael Donnelly and Denise Donnelly

A moving account of the Michael Donnelly's experience as an air force pilot in the 1980s and the Persian Gulf War and his life after being diagnosed with ALS just a few years later, at age 35.

Praeger, 1998

ISBN: 0275964620

In Dreams: A Life Journey in Prose and Poetry

By Elizabeth Grandbois

Elizabeth Grandbois shares her inspirational journey and battle with ALS. Diagnosed in 1997, she has been a long-time advocate for ALS, raising awareness and funds for people living with this condition.

Manor House Publishing, 2002

ISBN: 0973195606

Tuesdays with Morrie

By Mitch Albom

This remarkable book details the life lessons shared by Morrie

Schwartz, professor at Brandeis University who was diagnosed with ALS and passed away in 1995. The author was a former student and rediscovered Morrie in the last months of the older man's life. The book is a chronicle of their time together, through which Mitch shares with the world Morrie's lasting gift.

(Also available as an audiobook)

Broadway Books, 1997

ISBN: 076790592X

Journeys with ALS: Personal Tales of Courage and Coping with Lou Gehrig's Disease

Compiled by David Feigenbaum

Real-life examples of 33 people living with ALS.

D L R C Press, 1998

ISBN: 1880731606

Making Sense of the Senseless: The McFeat Family ALS Journey

By Ruth McFeat

This is the story of the McFeat family's 20-month journey with ALS. Ruth's husband, Forrest, had ALS and was cared for at home till his death.

R.L. McFeat, 1999

ISBN: 0968539408

I Remember Running: The Year I Got Everything I Ever Wanted—and ALS

By Darcy Wakefield

A young English professor recalls when she was diagnosed with ALS and how she met its challenges by focusing on living a meaningful, rich life. Diagnosed in 2003, Wakefield passed away in 2005.

Da Capo Press, 2006

ISBN: 1569242798

Learning to Fall: The Blessings of an Imperfect Life

By Philip Simmons

Diagnosed with ALS at 35, Simmons chronicles his search for peace and his deepening relationship with the mysteries of everyday life in this warm, uplifting book.

Bantam, 2003

ISBN: 055338158X

Books about and for Children

Understanding ALS

Grandpa, What Is ALS?

Written by Bonny Gold-Babins, illustrated by Matt Abergel

This is a story of the love shared by a grandfather, who develops ALS, and his grandchild, who learns to accept and understand the disease. Their special bond remains unchanged. This book is best suited to the pre- or early reader, but will touch those of any age.

ALS Society of Alberta, 2000

<http://www.alsab.ca/resources>

Tel: 403-228-3857 Toll Free: 1-888-309-1111

Someone You Know Has ALS: A Simple Way to Help Children Understand and Cope with ALS

Written and illustrated by Lois Clark

This book, dedicated to the author's late father, provides information about the disease and how to manage feelings connected with living with someone with ALS. This publication is appropriate for educating the 6–12-year-olds about ALS.

Available through the ALS Clinic at McMaster (905-521-2100 ext. 76870) or email gabri@mcmaster.ca.

411 Books

A series of five booklets designed to help children and teens affected by ALS in their family. Click the links below to download them, or contact the ALS Society of Canada for a print copy.

Helping Children Cope with ALS – A Parental Information Guide

<https://als.ca/wp-content/uploads/2017/02/Helping-Children-Cope-For-Parents-English.pdf>

When Someone Special Has ALS – A Booklet for Children

<https://als.ca/wp-content/uploads/2017/02/When-Someone-Special-Has-ALS-Children-English.pdf>

When Your Parent Has ALS – A Booklet for Teens

<https://als.ca/wp-content/uploads/2017/02/When-Your-Parent-Has-ALS-A-Booklet-for-Teens-English.pdf>

Talking with Young People about ALS – For Schools

<https://als.ca/wp-content/uploads/2017/02/Talking-with-Young-People-English.pdf>

Stories about dying

The Invisible String

By Patrice Karst, illustrated by Geoff Stevenson

Ages 3 and up

This reassuring story deals with the prospect of someone dying. The book explains that even though we can't always be with someone, we are still connected to them by love.

DeVorss & Company, 2000

ISBN: 0875167349

Lifetimes: The Beautiful Way to Explain Death to Children

By Bryan Mellonie, illustrated by Robert Ingpen

Ages 3 and up

Every creature has a beginning and an end. Using large, vivid illustrations this book talks about how all living things have their own special lifetimes.

Bantam, 1983

ISBN: 0553344021

Gentle Willow: A Story for Children About Dying

By Joyce C. Mills, illustrated by Cary Pillo

Ages 4–8

Amanda the squirrel is upset that she is going to lose her friend Gentle Willow, but the tree wizards give advice that eventually helps her accept death. The tree wizards tell Amanda that the medicine she can give Gentle Willow is love.

Magination Press, 2003

ISBN: 1591470722

I'll Always Love You

By Hans Wilhelm

Ages 4–8

This is the gentle, moving story of Elfie, a dachshund, and her special boy as they progress happily through life together. One morning Elfie does not wake up. The family grieves and buries her.

Dragonfly Books, 1985

ISBN: 0517572656

Nana Upstairs and Nana Downstairs

By Tomie dePaola

Ages 4–8

Tommy is four years old and loves to visit his grandmother Nana Downstairs and his great-grandmother Nana Upstairs. One day Tommy's mother tells him Nana Upstairs won't be there anymore, and Tommy must say goodbye to someone he loves.

Puffin Books, 2000

ISBN: 0698118367

The Next Place

By Warren Hanson

Ages 4 and up

This book explains death and immortality in simple terms with the help of beautiful illustrations.

Waldman House Press, 1997

ISBN: 0931674328

The Fall of Freddie the Leaf: A Story of Life for All Ages

By Leo Buscaglia

Ages 8–12

A classic, this inspiring allegory about life and death is about a leaf named Freddie and his companions and how they change with the seasons, eventually falling to the ground with winter's snow.

Slack, 1982

ISBN: 0943432898

Tear Soup: A Recipe for Healing After Loss

By Pat Schwiebert and Chuck DeKlyen, illustrated by Taylor Bills

For families

A simple, easy story, this book about dealing with loss is useful for families and people of all ages – children and adults alike.

Grief Watch, 1999

ISBN: 0961519762

ALS and bereavement activity books and guides

ALS Activity Book: Helping Children Understand the Puzzle of ALS

This is a 20-page book with games, activities, and learning pages designed to educate children about ALS. Available from the ALS Association St. Louis Regional Chapter as a download at <http://www.alsa-stl.org>. For print inquiries, phone 314-432-7257 or 1-888-873-8539.

Saying Goodbye

By Jim and Joan Boulden

Ages 5–9

This book with colour-in cartoons, drawings, and activities helps children understand the finality of death while offering the assurance of the continuity of love. The book has been widely used by hospices, schools, hospitals, and mortuaries as well as by parents and therapists.

Boulden Publishing, 1992

ISBN: 1878076124

Our ALS Family Playbook: Activities to Help Our Children Cope

Order from the Rising Sun Center for Loss and Renewal at <http://www.RisingSunCenter.com>.

The Grieving Child: A Parent's Guide

By Helen Fitzgerald

A practical, compassionate guide to explaining death to children and helping them cope.

Touchstone, 1992

ISBN: 0671767623

Talking about Death: A Dialogue Between Parent and Child

By Earl A. Grollman

This guide for children and adults to read together includes questions and answers and a list of resources.

Beacon Press, 1991

ISBN: 0807023612

Straight Talk about Death for Teenagers: How to Cope with Losing Someone You Love

By Earl A. Grollman

Teens often need more help than anyone else dealing with grief. This book emphasizes understanding feelings and working through grief.

Beacon Press, 1993

ISBN: 0807025011

Videos/DVDs

Respiratory Decisions in ALS

Produced by the Les Turner ALS Foundation and available for viewing on YouTube, this series of three educational videos guides people through the process of evaluating and making important decisions about respiratory care as the disease progresses.

<http://lesturnerals.org/support-services/informative-links/>

Ventilation: The Decision Making Process

This 20-minute video is designed for ALS patients, their family members, and health professionals. It includes interviews with three ventilator-dependent ALS patients, family members, and the medical staff from the Les Turner/Lois Insolia ALS Center at Northwestern University Medical School. <http://lesturnerals.org/support-services/informative-links/> (under Respiratory Resources)

ALS Association's "Living with ALS" videos

The ALS Association in Washington, DC, has a series of videos available online or on DVD. <http://www.alsa.org/als-care/resources/publications-videos/videos/>

You Are Not Alone: A Guide for People Newly Diagnosed with ALS

Living with ALS: Adapting to Breathing Changes and Use of Noninvasive Ventilation

Living with ALS: Clinical Care Management Roundtable Discussion

Living with ALS: Communication Solutions and Symptom Management

Living with ALS: Adjusting to Swallowing Difficulties and Maintaining Good Nutrition

Living with ALS: Mobility, Activities of Daily Living, Home Adaptations

Hospice Foundation of America's "Living with Grief" series

This series is meant for professionals dealing with grief and bereavement, such as counsellors, nurses, nursing home administrators, social workers, funeral directors, and family therapists. Available in DVD or online at <https://HospiceFoundation.org/Shop-HFA>

Bearing Witness: Robert Coley-Donohue

By Dan Curtis

This poignant film follows Robert Coley-Donohue over the last three years of his life living with ALS. His experience is arduous, but also filled with hope and healing. "I don't go out of my way to moan and groan. And I think it's helped me to retain this lighter outlook than to be in the depths of despair." – Robert Coley-Donohue. Available for download through the National Film Board of Canada at https://www.nfb.ca/film/bearing_witness_robert_coley_donohue/

Tel: 1-800-267-7710

ABC NEWS Presents Morrie Schwartz: Lessons on Living

Tuesdays with Morrie is a highly popular chronicle of the time former student and sportswriter Mitch Albom spent with Morrie Schwartz, a sociology professor with ALS. Albom was inspired to reconnect with Schwartz and to write the book after watching him in conversation with journalist Ted Koppel on his Nightline television show. This episode is available for purchase as a DVD through Amazon Canada and other sellers.

Online Resources

For Adults

Provincial Partner Sites in Canada

ALS Society of Alberta: www.alsab.ca

ALS Society of British Columbia: www.alsbc.ca

ALS Society of Manitoba: www.alsmb.ca

ALS Society of Newfoundland and Labrador: www.alsnl.ca

ALS Society of New Brunswick and Nova Scotia: www.alsnbns.ca

ALS Society of Canada (covering Ontario): www.als.ca

ALS Society of Prince Edward Island: www.alspei.ca

ALS Society of Quebec: www.als-quebec.ca

ALS Society of Saskatchewan: www.alssask.ca

International Organizations

International Alliance of ALS/MND Associations:
www.alsmndalliance.org

United States

The ALS Association: www.alsa.org

Les Turner ALS Foundation: <http://lesturnerals.org/>

United Kingdom

MND Association of England, Wales and Northern Ireland:
<https://www.mndassociation.org/research/mnd-register-for-england-wales-and-northern-ireland/>

MND Association of Scotland: www.mndscotland.org.uk

Caregiving websites

Canadian Hospice and Palliative Care Association: www.chpca.net

The Caregiver Network: www.TheCaregiverNetwork.ca

Caregiving Matters: www.CaregivingMatters.ca

Virtual Hospice: www.VirtualHospice.ca

Family Caregivers Voice: www.FamilyCaregiversVoice.ca

Victorian Order of Nurses: www.von.ca

ALS Research

ALS Association/ Northeast ALS Consortium webinars: http://web.alsa.org/site/PageNavigator/ALSA_research_news_webinars

Taylor, J.P., Brown Jr., R.H., and Cleveland, D.W. "Decoding ALS: From Genes to Mechanism," *Nature*, Nov. 10, 2016, Vol. 539, no. 7628.

ALS Therapy Development Institute webinars: www.als.net/als-webinars/

MND Association Research Newsletter: www.mndassociation.org/research/mnd-research-and-you/mnd-research-newsletter/

ALS Canada Research Program: www.als.ca/research/

World Federation of Neurology Research Group on Motor Neuron Disease: www.wfnals.org

For children and youth

Building Resilience Resources: <https://choose2beresilient.com/resources/>

Useful Apps

Speech aids

- Talkitt is an innovative solution that enables people who have motor, speech, and language disorders to easily communicate using their own voice. Talkitt recognizes the user's vocal patterns and "speaks" their words in an understandable language, allowing them to communicate clearly and easily. Talkitt can run on most smartphones, tablets, and computers.
- HelpTalk is for people who have difficulty communicating orally or through writing. HelpTalk allows users to create sets of actions that represent their communication needs, with the actions most suited for each disability and user. When the user taps each of the options the device speaks the selected command.
- GazeSpeak this app, developed in 2017 by Microsoft, uses artificial intelligence to convert eye movements into

speech, so a conversation partner can understand what is being said in real time using a smartphone.

Text-to-Speech apps

- AlphaCore (for Windows) is a text-to-speech app that helps to speed and facilitate communication for people with a wide variety of access needs, such as those associated with ALS/MND. This app is downloadable on desktops and tablets only.
- Speak it! (for iPad) is an easy to use text to speech app designed for iPads, iPhones and iPod Touch
- TTS Text to Speech (for Android)- text to speech app for Android devices
- Predictable (for iPad). If you have created a personal synthesized voice with software such as ModelTalker or VocaliD, this app allows you to import and use your synthesized voice.

Accessibility apps

- Wheel Mate, an app based on feedback from other wheelchair users, helps users locate wheelchair-friendly washrooms and parking spaces on an interactive map.
- AccessNow is based on user feedback and provides accessibility information for places in Canada and across the world.



You are not alone. We are here to support you.



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alsbc.ca
1228 – 13351 Commerce Parkway, Richmond, BC V6V 2X7
Toll free: 1-800-708-3228
T: 604-278-2257
Email: info@alsbc.ca

02 ALS Society of Alberta
alsab.ca
874 10 Street NE, Calgary, AB T2E 8W1
Toll Free: 1-888-309-111
T: 403-228-3857
Email: info@alsab.ca

03 ALS Society of Saskatchewan
alssask.ca
2430 8th Avenue, Unit C, Regina, SK S4R 5E3
T: 306-949-4100
Email: director@alssask.ca

04 ALS Society of Manitoba
alsmb.ca
2A, 1717 Dublin Ave, Winnipeg, MB R3H 0H2
T: 204-831-1510
Email: hope@alsmb.ca

05 ALS Society of Canada
als.ca
393 University Avenue, Suite 1701, Toronto, ON M5G 1E6
Toll free: 1-800-267-4257
T: 416-497-2267
Email: info@als.ca

06 ALS Society of Quebec / Société de la SLA du Québec
als-quebec.ca
5415 Paré Street, Suite 200, Mont-Royal, QC H4P 1P7
Toll free in QC: 1-877-725-7725
T: 514-725-2653
Email: info@sla-quebec.ca

07 ALS Society of Newfoundland and Labrador
alsnl.ca
3 Herald Avenue, Suite 3, Corner Brook, NL A2H 4B8
Toll Free: 709-634-9499
Email: cheryl@alsnl.ca

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