ALS SLA CANADA

FACT SHEET

ALS & CONSTIPATION

The bowel and bladder are not typically affected by ALS.[1] However, some people with ALS may experience constipation, which is defined as infrequent bowel movements—usually three times a week or less. Though each person's "regular" is a little different, both frequency and consistency of bowel movements are important.

Regular digestion and elimination are important aspects of the body's overall health. When constipation becomes an ongoing problem, it can decrease a person's appetite and lead to decreased food intake, weight loss, and malnutrition, all of which can be detrimental to health.

If you are experiencing constipation, speak with your healthcare team to come up with a treatment plan.

What are the causes of constipation in people living with ALS?

There are many factors that contribute to constipation in people living with ALS, including:

- Decreased physical activity due to decrease in muscle strength.
- Decreased dietary fibre intake because of changes in food choices, or difficulty chewing and swallowing.
- Decreased fluid intake because of difficulty swallowing liquids.
- Weakness in the abdominal and/or pelvic muscles, slowing the process of emptying of the bowel.
- Side effects from various medications such as those used to control saliva or pain.

What can people living with ALS do to reduce constipation?

Managing constipation needs a broad and individualized approach that targets hydration, diet, mealtimes, bowel routines, and medications. A team-based approach may address the following:

- Improve hydration by increasing intake of nonalcoholic beverages, including water, juice, and milk.
- Increase fibre intake with whole grain products (bread and cereals, pasta, brown rice), vegetables, fruits, legumes (dried peas, beans and lentils), and fibre supplements (bran, psyllium).
- Regular mealtimes and routines.
- A thorough medication review to identify any medications that may be causing constipation.
- It may be necessary to discuss the use of laxatives with your doctor to help manage bowel regularity

ALS & CONSTIPATION SUMMARY

- Constipation can affect people with ALS for a number of reasons, including lowered physical activity, dietary factors, muscle weakness, and medications.
- Regular digestion and elimination are important in your body's overall health and that each person's "regular" is a little different.
- Discuss any concerns about constipation with your healthcare team so that a complete treatment plan can be started!

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Sources

1 Nature Reviews Disease Primers. 2017 Oct 5;3:17071.

ALS SLA CANADA

FACT SHEET

ALS AND GENETICS

While researchers are still working to understand the exact causes of ALS, it is widely understood that ALS develops as a result of multiple different risk factors, some of which are genetic and some of which are environmental. This complex relationship between genetic susceptibility and risk factors related to lifestyle is not yet understood, but significant progress is made every year.

Approximately 10% of individuals with ALS will have a family history of the disease. In these cases, ALS is caused by a change in the genetic code, called a mutation or variant, and is passed from parent to child. This is traditionally termed "familial" ALS and in some cases, there may also be a shared history of frontotemporal dementia (FTD). For the 90% of individuals with ALS without a family history, traditionally termed "sporadic", it is estimated that more than 10% of cases are caused by known ALS genes. Familial ALS and sporadic ALS both have the same general signs and symptoms and are clinically indistinguishable.

FAMILIAL ALS

In familial ALS, an inherited genetic mutation causes ALS. Many different genetic mutations have been linked to ALS, and not all families have the same mutation as the cause of their disease. In approximately one-third of cases of inherited ALS, a mutation has not yet been discovered.

Some genetic mutations are associated with a high likelihood that someone will develop ALS symptoms, while other mutations may not cause ALS in everyone. This is a phenomenon called penetrance. Some mutations are also linked to specific disease symptoms or rates of progression. Further, it is likely that lifestyle and environmental risk factors play some role in how or when ALS develops in people with an inherited mutation. It's important to note that many known genetic mutations in ALS are still not well understood, and only the most common ones have a solid base of knowledge.

SPORADIC ALS

In most cases of sporadic ALS, the cause is unknown; however, it is still probable that an individual's genetics are playing a role in a significant number of cases. Rather than a single gene mutation, there is likely a complex genetic susceptibility that researchers have yet to understand.

There is also a growing appreciation for the number of cases of sporadic ALS that can be traced to single, known genetic mutations, even if a person does not have an obvious family history of ALS. This may be the result of a mutation occurring spontaneously for the first time, or due to an inherited ALS-associated mutation in an individual where family history information is lacking or unknown. In both cases, the mutation could be passed on to future offspring.

SHOULD I TAKE A GENETIC TEST?

As someone living with ALS, or a relative of someone affected by ALS, you may feel conflicted about whether to take a genetic test.

Speak to your neurologist, or other ALS expert clinician, to help you decide if genetic testing is right for you. Your neurologist may be able to connect you with a genetic counsellor, who will take a detailed medical and family history and discuss the impact of genetic testing. The decision of whether to be tested is always yours.

It is important to note that there are many mutations in known ALS genes that don't yet have sufficient research and information to fully understand their impact on someone. Some physicians may hesitate to order genetic testing out of discomfort with not being able to provide comprehensive support in understanding a complicated result. However, given that ALS-associated mutations have been identified in seemingly sporadic cases of ALS, and that therapies targeting these mutations are entering, or are ongoing in, clinical trials, many experts are pushing for everyone to be offered genetic testing, accompanied by genetic counselling. The availability of genetic testing and counselling varies from region to region, so it is important to note that genetic testing practices in ALS are rapidly evolving, but not sufficient yet to meet the needs of everyone.

Genetic testing is not recommended for people under 18, because they cannot give their full consent.

If you are a blood relative of someone affected by ALS, in whom a causative mutation has been identified, you may also be eligible for genetic testing. Genetic testing in an individual at risk of developing a disease, but who is not currently exhibiting any symptoms, is called predictive testing. Predictive testing requires extensive genetic counselling. Further research is needed in this area.

Reasons people may want to be tested	Reasons people may not want to be tested
• Assist in family planning decisions • Be proactive about their health (e.g. getting a diagnosis earlier) • Give themselves time to adjust to the idea that they may develop ALS • Reduce anxiety if they find they do not have the mutation • Proactive identification of genetic status for future therapeutic trials, and contribution to research, to further understanding of ALS	• It can be difficult to live with the knowledge of a possible impending illness • It can cause tension with other family members, who may not wish to know the test results • Genetic status may inadvertently reveal the status of another family member (e.g. if someone wants to get tested, but the parent does not) • Avoiding guilt about passing on the illness to children, or testing negative when others test positive

FUTURE DIRECTIONS

Genetic research is an important component of ALS research. Researchers frequently use genetically modified animals as models for ALS. They can use these to understand the disease, and to test new potential treatments for ALS.

While the number of gene mutations associated with causing ALS is ever expanding, there is also growth in our understanding of how genetics play a role in increased risk, types of symptoms a patient gets, or how their disease progresses, without directly being the cause of their ALS. A better understanding of the role genetics plays in ALS provides critical information to understanding the ALS disease spectrum as a whole.

There are currently numerous therapies in development for the genetic forms of ALS. While some are only just entering clinical trials, some are much further along, with preliminary data available. With a very specific target identified, these kinds of therapies are offering significant hope for the near future.

LEARN MORE

Visit ALS Canada's YouTube channel to view a webinar about genetics and ALS.
https://www.youtube.com/watch?v=LegL2d_d4z4

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Thank you to Kristiana Salmon, National Programs Manager for Genetic ALS at the Montreal Neurological Institute, for her contributions to this fact sheet.

ALS SLA CANADA

FACT SHEET

ALS, MS, AND MD: HOW DO THEY DIFFER?

Amyotrophic lateral sclerosis, multiple sclerosis, and muscular dystrophy can sometimes be confused as the characteristics and symptoms of these diseases can overlap. People living with ALS, MS, and MD often require the same kinds of wheelchairs and assistive devices. However, ALS, MS, and MD are separate and distinct diseases.

Amyotrophic Lateral Sclerosis (ALS)

Our brain is connected to our muscles through millions of specialized nerve cells, called motor neurons, which serve as our bodies' internal wiring and enable us to move our bodies as we choose. Motor neurons work in pairs: an upper motor neuron in the brain extends to the brainstem at the back of the neck or the spinal cord, and a lower motor neuron extends from the brainstem or spinal cord to the muscle. The brain sends a signal along these motor neurons telling a muscle to contract. This signal is an electrical impulse created by chemicals in our neurons.

In ALS, motor neurons gradually break down and die. This means that the brain can no longer communicate with the muscles of the body. As a result, the muscles become weak and eventually someone living with ALS will be unable to move them. Over time, someone living with ALS will lose the ability to walk, talk, eat, swallow and eventually breathe.

At any point in time, there are approximately 3,000 Canadians living with ALS. Two to three Canadians die of ALS each day, and approximately 1,000 Canadians are diagnosed with the disease each year. Most cases (approximately 90 per cent) of ALS do not have a family history (termed "sporadic"), meaning that the disease is not genetically inherited from a parent. However, some cases without family history can still have a known genetic cause.

The underlying biology of ALS still isn't fully understood though significant advances have been made. There is currently no cure, but there are treatments to help manage the symptoms of the disease and potentially slow its progression to some extent.

Multiple Sclerosis (MS)

Multiple sclerosis is a chronic autoimmune disease of the central nervous system, meaning it affects the brain, spinal cord, and optic nerves. MS varies considerably from person to person, and in the severity and course of the disease. At the time of diagnosis, a neurologist is unable to predict how an individual may be affected long-term.

MS attacks myelin, the protective covering of the nerves, causing inflammation and often damaging the myelin. When this happens, the usual flow of nerve impulses along nerve fibres is disrupted. MS can cause symptoms such as fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder and bowel problems, cognitive impairment, and mood changes.

Canada has one of the highest rates of MS in the world, with an estimated 90,000 Canadians living with the disease. Most people are diagnosed between the ages of 20 and 49 and the unpredictable effects of the disease will last for the rest of their lives.

People with MS can expect to live 95 per cent of their normal life expectancy. There are a variety of treatment options for people living with MS that can manage the disease, from medications to wellness strategies such as physical activity and eating a balanced diet. The exact cause of MS is unknown, it is believed to be a combination of genetic and environmental factors.

Muscular Dystrophy (MD)

Muscular dystrophy (MD) is the name for a group of neuromuscular diseases where the primary effect is on the muscles. MDs are inherited or caused by genetic variations (mutations) responsible for healthy muscle structure and function. Each type of MD is characterized by a mutation in a different gene. The types of muscles affected, severity, age of onset and specific symptoms varies depending on the type of MD. Generally, persons living with MDs experience some level of muscle weakness.

This may affect their arms and legs, and in some MDs, the muscles needed for eating, speaking, breathing, heart, and eye function may be affected as well. Some MDs have a multisystem effect and might affect other parts of the body such as the endocrine system, cognitive function, and gastrointestinal system. Muscular dystrophies are diseases of the peripheral nervous system, not the central nervous system.

The majority of MD types show symptoms at birth or in childhood, and are progressive in nature, and other muscular dystrophies such as oculopharyngeal muscular dystrophy have a later onset, typically as in mid- late adulthood.

While there are no curative treatments for muscular dystrophies yet, there are supportive therapies and life-changing treatments available for a sub-set of MDs that are prolonging life expectancy, helping with management of symptoms and contributing to improved quality of life. Current research is underway to further identify causes and developing treatments aimed at halting disease progression.

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https://www.als.ca/about-als/what-is-als/

https://mssociety.ca/about-ms

https://muscle.ca/discover-md/what-is-muscular-dystrophy/

ALS SLA CANADA

FACT SHEET

CARING FOR YOURSELF: INFORMATION FOR CAREGIVERS

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

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

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

What are the signs of caregiver stress?

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

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

What is compassion fatigue?

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

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

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

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

WHAT YOU CAN DO

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

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

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

SUMMARY

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

RESOURCES

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

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FEEDING TUBES

A feeding tube, also known as a "g-tube", is a device that can be used to support the nutritional needs of a person living with ALS. The feeding tube is placed through the skin directly into the stomach, bypassing the mouth. When chewing and swallowing become difficult, a feeding tube can help supplement nutrition, calories, and hydration.

Feeding tubes are recommended on an individual basis, usually when a person is experiencing significant difficulties with swallowing, decreased respiratory function with increased risk of aspiration, and/or if they have lost more than 10% of their initial body weight.[1]

If you choose to have a feeding tube, it is your decision when and how it will be used. If you choose not to have a feeding tube, your ALS clinical care team will support your decision.

When is the best time to get a feeding tube?

The safest time to insert a feeding tube is before breathing function significantly deteriorates. Early insertion can also allow for a more gradual transition from oral to tube feeding, which may be less stressful.

When people with ALS begin to experience significant chewing and swallowing problems, the feeding tube can be a welcome solution.[1]

If your breathing function is considered too poor, you may not be able to tolerate the procedure.

What are the benefits and drawbacks of a feeding tube?

The following are some benefits and drawbacks to consider when deciding if a feeding tube is a good option for you.

BENEFITS

- Reduces risk of choking due to chewing and swallowing problems
- Improves nutrition and weight maintenance
- Can be used to administer medication
- Reduces the stress and exhaustion associated with eating food by mouth
- Allows the person to enjoy food for pleasure, without pressure to eat a certain amount
- Can help to reduce weight loss
- Can prevent dehydration
- May prolong survival if placed early
- Can reduce the risk of aspiration pneumonia, an infection caused by breathing food, liquids or other content into the lungs

DRAWBACKS

- Risk of complications such as infection at the insertion site
- Must maintain the tube and ensure it is clean (flushing)
- You may require assistance to manage the equipment
- Feeding formula and equipment costs may not be fully covered (ask your healthcare provider for guidance)

WHAT IS THE FEEDING TUBE PROCEDURE LIKE?

Feeding tube insertion is typically performed by a gastroenterologist or an interventional radiologist as an outpatient or inpatient procedure requiring a local anesthetic and mild sedation. If your breathing capacity is reduced, the procedure may require a short hospital admission.

If you have a BiPAP machine and/or a Cough Assist Device, it is advisable to bring them with you to the hospital for this procedure.

Please visit the website below for a detailed demonstration of life with a feeding tube: http://sunnybrook.ca/content/?page=nutrition-healthy-eating-videos-tips.

CAN I KEEP EATING WHILE I HAVE A FEEDING TUBE INSERTED?

Many people with ALS can continue to eat normally for some time while they have a feeding tube. Some people use the feeding tube to supplement daily intake while others use it only for fluids and medication. Even if not being used immediately for nutrition, the feeding tube will need to be flushed daily with water to keep it clean.

A dietitian will work with you to determine the type and amount of formula you will need to maintain an appropriate weight and adequate level of nutrition.

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[1] Pols J, Limburg S. "A Matter of Taste? Quality of Life in Day-to-Day Living with ALS and a Feeding Tube." Cult Med Psychiatry. 2016 Sep;40(3):361-82. doi: 10.1007/s11013-015-9479-y. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4945678/

Thank you to Nicole Shuckett, Registered Dietician, and Anne-Marie Ledoux-Burns, Registered Dietician, for their contributions to this fact sheet.

ALS SLA CANADA

FACT SHEET

FIRST STEPS AFTER AN ALS DIAGNOSIS

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

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

Learn about the disease.

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

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

Recognize your own emotions.

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

Recognize that ALS is a progressive disease.

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

Access supports and services.

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

PLAN AHEAD.

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

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

SEEK CAREGIVING HELP.

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

SELF-CARE FOR FAMILY AND CAREGIVERS.

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

WORK WITH YOUR HEALTH CARE TEAM.

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

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PALLIATIVE CARE AND END-OF-LIFE PLANNING IN ALS

ALS is a progressive and fatal neurodegenerative disease that does not yet have a cure. When caring for you, your healthcare team will strive to maximize quality of life from the time you are diagnosed until end-of-life.

People with ALS are faced with many choices that will influence the course of their illness. You will be able to make decisions about symptom management throughout your illness. Early discussion and advance care planning can help ensure your wishes are respected. Communication can often be maintained, using a variety of methods and devices.

People with ALS have the right to a peaceful, dignified death, and to know and understand advance care planning and end-of-life options. Your healthcare team can be expected to support and respect your decisions about your life, body, and death based on your preferences, values and beliefs.

Your healthcare team, along with modern medicine can offer excellent symptom management during the end-of-life stage of ALS. Most people with ALS experience a peaceful death.

What is palliative care?

Palliative care is an approach to care aimed at optimizing quality of life for people facing life-threatening illness such as ALS. It treats physical symptoms in order to reduce discomfort and distress and provides support for the psychosocial and spiritual needs of patients and their families. Palliative care is provided by a team of doctors, nurses and other healthcare providers who work with you, your family and your other doctors to provide specialized support. Many people think that palliative care is only offered in the end stages of life and worry that it signals that end of life is near. However, a palliative care approach can be introduced and applied early in the disease trajectory and delivered alongside active management of your ALS.

What is end-of-life care?

End-of-life care addresses the needs of anyone in the final stage of life, providing support to help them live as comfortably as possible and to die with dignity. End-of-life care includes palliative care and can be provided at home or in a hospice, hospital or long-term care home.

How do people die of ALS?

Some people with ALS worry about death from choking. It is important to know that this kind of death is very rare among people with ALS. People with ALS typically die of respiratory failure. It may be helpful to know that healthcare providers are able to offer symptom management in order to minimize discomfort and distress.

At end-of-life, healthcare teams typically use medications to manage pain and dyspnea (difficulty breathing). These medications very effectively reduce the sensation of shortness of breath and choking. They do not speed up death. One study found that between 88 and 98% of people with ALS die peacefully.

ADVANCE CARE PLANNING

Advance care planning (ACP) is a process that enables individuals to make plans about their future healthcare. Advance care plans provide direction to healthcare professionals when a person is not able to make or communicate their own healthcare choices. This may include writing down your wishes or simply speaking to your family, friends, or loved ones about your healthcare decisions. This does not need to be a legal document.

The important part of ACP is that you think about how you want your healthcare to unfold and that you communicate this openly with the individuals involved in your care and your support.

It is often recommended that people with ALS begin these conversations early. If you wait until later in your disease progression you may have more trouble communicating your wishes and a sudden health event may prevent you from having adequate time to make decisions.

You might worry that this discussion will be upsetting for you or your loved ones. But planning and discussing your wishes in advance means that your family and healthcare team know what you would want them to say about your care and be able to carry out your wishes. Participating in ACP will help you feel a sense of control and can ultimately contribute to an end-of-life experience that respects your wishes.

An excellent resource on advance care planning is the My Speak Up plan, **AdvanceCarePlanning.ca**

WHO CAN MAKE DECISIONS ABOUT YOUR CARE?

There are two ways people are selected to represent you when you are unable to represent yourself:

1. Your substitute decision maker, or SDM, is the person who is entitled by law to make health decisions on your behalf should you be incapable (and only when you are incapable and not before). In Ontario there is a formal SDM hierarchy that determines who will make decisions on your behalf if you have not specifically identified someone by completing a document naming them your Power of Attorney (POA).
2. You can select the person whom you would want to speak on your behalf should you be incapable, your Power of Attorney (POA) for Personal Care, through a legal representative, or by using a form which is available online. Whenever possible be open and clear with everyone about whom you have chosen as your POA, be sure to discuss your wishes and values with your POA and ensure that the individual is prepared to carry out your wishes.

MEDICAL ASSISTANCE IN DYING (MAiD)

In 2016, the Supreme Court of Canada ruled to make MAiD legal in Canada. This means that people with ALS have access to MAiD, should they wish to pursue it. People must be evaluated by two healthcare professionals to ensure eligibility.

Canadians living with ALS can find province-specific information about MAiD laws and regulations at

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

If MAiD is something you want more information about, ask your healthcare team to refer you to a specialist.

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Thank you to Adrienne Barker, Nurse Practitioner – Primary Health Care, Director of Care at Hospice of Waterloo Region, for her contributions to this fact sheet.

ALS SLA CANADA

FACT SHEET

TRAVELLING WITH ALS

While travel can present unique challenges for people with ALS, a comfortable travel experience is possible with planning and patience.

This fact sheet offers tips for planning a trip while living with ALS, whether it is a local day trip or a longer excursion including air travel. These tips may be helpful for things like running errands or visiting a specialist in another city, too.

Managing your energy

It can help immensely to carefully plan your days and manage your energy when travelling.

- Space out tiring activities. If your day involves more than one activity, it could help to plan for a break in between. Or consider alternating between busy days and days that are dedicated to relaxation.
- Consider using a more supportive mobility device for the day. For example, if you usually use a walker, you may choose to use a wheelchair or mobility scooter instead. An Occupational Therapist will be able to recommend the right equipment to suit your needs. Appropriate devices can help you save your energy for the activities you are planning.
- Communicate your needs in advance to the people you'll be travelling with. If you are travelling with others, make sure they understand what you will need in order to enjoy the day.

Local Travel

Local travel may include day trips, sight-seeing, running errands or medical appointments. It can help to plan all stops in advance, including restaurants, and to contact your destinations before travelling to ensure their approach to accessibility will meet your needs and that no further arrangements are required. Some tourist attractions may have power scooters or transport wheelchairs available to borrow or rent.

Packing the right things can also make a day trip more enjoyable. Here are some items you may want to consider bringing with you when you leave your home:

Respiratory equipment and supplies:

- BiPAP with backup battery
- Cough assist and suction machines
- Toothettes

Mobility

- Accessible parking pass
- Backup battery for wheelchair
- Hoyer lift swing
- Other mobility devices as recommended by your Occupational Therapist

Nutrition/Feeding Supplies

- Food, snacks, and/or thickener packets
- Feeding tube equipment and formula
- Straws
- Adapted utensils or grips
- Bottles of water

Other considerations

- Fully-charged communication device (as well as backup low-tech communication device e.g. alphabet board or book)
- Extra clothing/blankets if outdoors
- Urinal and/or incontinence underwear, if unsure of availability of accessible washrooms
- Neck brace or travel pillow
- Tissues, washcloths and/or wipes
- Medications

ACCESSIBILITY TIPS

It is a good idea to ensure your destination is accessible ahead of time. This will help prevent arriving at your destination only to find it is not as accessible as advertised: just because a building has an accessible entrance does not mean you will be able to access the bathroom or other important areas. Ensuring accessibility often requires getting the answers ahead of time. You will likely need to be persistent, and to ask many questions. Phoning ahead, or asking someone to do so for you, can save you a lot of hassle.

When you first call, explain to the person you're speaking with that you have specific accessibility needs and ask them if they or a colleague can provide detailed information to help you plan.

Accessibility language and standards can vary widely across different regions of the world. For example, the terms barrier-free and accessible can have different meanings. Rather than using these terms, it can help to ask directly about the specific accommodations you require.

HELPFUL RESOURCES

AccessNow is a mapping application that ranks buildings for accessibility features and enables people to leave reviews. Visit **www.accessnow.com** or download the app.

AIR TRAVEL

Most people with ALS can fly safely and smoothly with the right planning.

Here are several things you can do to help prepare for air travel. Many of these tips apply to long trips of any form, whether by plane, train, or car.

- **Speak with your doctor about your trip before you book.** Your doctor will need to evaluate whether it is safe for you to fly, and what special needs you might have. They can offer valuable advice and they may also be able to provide a letter to clear you for extra luggage, a support person, BiPAP use on board the plane, or medications and nutrition supplements you need to travel with.
- **Contact the airline.** Ask the airline about the accommodations that can be made at the airport and while in flight. Give as many details as possible about what you can and cannot do. It can help to assume people do not know anything about ALS, and to communicate your specific needs instead.

- **Plan around your mobility device.** If you are flying with a mobility device, ask about checking it. If you will have a power scooter or wheelchair with you, ask the airline if it can be accommodated in the cargo hold, and be prepared to tell them what type of batteries the chair has. This is important for security. It can also be helpful to have the make and model of your wheelchair written down in case the airline needs assistance identifying it, or if you need to call for repairs. You may wish to wrap the joystick in bubble wrap to protect it (the airline will be able to push the chair in manual mode). It's also a good idea to confirm that you will have access at the gate to your mobility device when you land.
- **Consider toileting needs ahead of time.** What strategies will give you peace of mind? Some options on board the plane include being transferred to the washroom using an aisle chair, using an external catheter, and using incontinence underwear.
- **Plan out accessible transit at your destination.** Some wheelchairs and scooters can easily be folded and placed in a standard car. Others require accessible transportation. Some accessible transit options include an accessible taxi, renting an accessible van, accessible rideshare such as Uber / Lyft, or public accessible transportation options. It is important to have a plan ahead of time, as accessible transit is not something that can be assumed.
- **Bring important phone numbers.** Always travel with the phone numbers for your wheelchair repair department, important healthcare contacts, and the numbers for your assistive devices service providers. It can also help to see if you can find a local repair option at your destination before leaving, just in case.
- **Charge up.** Ensure all of your equipment (e.g. BiPAP, wheelchair, external BiPAP battery, suction and cough assist machines, communication device) is fully charged before leaving your home.
- **Bring items to enhance comfort.** A gel pad or air cushion can help relieve pressure during long flights or car rides.
- **Look into travel insurance.** People with ALS may have difficulty in acquiring adequate travel insurance coverage, as ALS is typically considered a pre-existing and unstable condition. You may want to inquire about coverage with several different insurance companies and brokers. You may also require a letter from your doctor to support your application.

HOTEL ACCOMMODATION

Knowing what you need before contacting a hotel can help make the process easier. It can help to think through all of the accessibility needs you encounter during a regular day; for example, entering and leaving your home, toileting, bathing, eating, and other activities. Consulting with an occupational therapist can help you to determine what will be needed to make your stay safe and comfortable.

Here are some things to consider when evaluating potential accommodations. Do you need a walk-in or roll-in shower?

- Do you need grab bars or higher seat heights in the bathroom for transfers?
- Do you need a bed rail?
- Does the room/bathroom need to be able to fit your wheelchair, or other mobility device and/or bathroom aids?
- Do you need to be on the ground floor, or is there an elevator that will fit your wheelchair?
- Is the front entrance accessible?
- Are the amenities (e.g. breakfast room, swimming pool, etc.) accessible?

If you are staying for a long period of time, see if the hotel will allow you to rent specialized equipment (e.g. hospital bed, lift chair) from a local mobility store. Some cheaper accessible equipment (e.g. raised toilet seat) may be worth purchasing for a longer stay.

You can also ask your local ALS Society about loaning equipment. They may be able to connect you with someone locally where you are travelling, so you do not have to bring the equipment with you.

KNOW THAT WE ARE HERE TO HELP

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

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

More information about travelling with ALS is included in the ALS Guide at **www.als.ca/alsguide**.

Thank you to occupational therapist Brianna Marshall for her contributions to this fact sheet.

ALS SLA CANADA

FACT SHEET

CANNABIS AND ALS

What is cannabis?

Cannabis is a plant that contains compounds called cannabinoids. The two major cannabinoids that cause the drug-like effects of cannabis are: tetrahydrocannabinol (THC) and cannabidiol (CBD).

Cannabis products may contain mainly CBD or THC or have a mixture of both. THC is what creates the feeling of euphoria, or what some people will call feeling "high". CBD does not cause euphoria but may produce some of the effects of THC like feeling relaxed. The type of product you choose to use will depend on the effect you want or symptoms you are trying to manage.

Is cannabis safe for people with ALS?

Some people with ALS use cannabis to help treat their symptoms. Others may use it simply to relax and enjoy the euphoria (sense of bliss). Cannabis use is generally safe for people with ALS. Before you use cannabis, check with your healthcare professional or pharmacist. This is to ensure that any medicines you take will not react with the cannabis in an adverse or harmful way. If you already use cannabis, make sure your doctor is aware of your use.

How do you use cannabis?

Cannabis can be found in many forms and can be used in different ways. Below are a few of the ways cannabis can be used.

VAPING: Some people with ALS may have trouble breathing. People with breathing problems may find smoking cannabis irritates their lungs. For some people, vaping may be easier. Vaping involves using a device that heats cannabis to the point where it turns into a smokeless gas that is inhaled. This tends to irritate the lungs less than smoke.

EDIBLES: Edible (meaning you can eat or put in a feeding tube) cannabis products are another option for those who are not able to, or who do not wish to vape or smoke cannabis. These products include edible foods, such as cannabis cookies, drinks, or brownies, as well as cannabis liquids, oils, and capsules. Oils may be helpful for people who cannot easily chew and swallow foods.

When using edibles, remember that it may take a longer time to feel effects, but the effects may last for a lot longer. When vaping or smoking cannabis, the effects tend to occur quite quickly, but do not last as long. For all cannabis products, follow the rule of "start low and go slow".

TOPICALS: Cannabis topicals are applied and absorbed into the skin. Topicals can be in the form of lotions, gels, or creams.

WHAT ARE THE EFFECTS OF CANNABIS?

- Euphoria (feeling of bliss)
- Feeling relaxed
- Pain relief
- Relief for muscle spasms or high muscle tone
- Increased appetite
- Changes to the way you experience sensations (for example, brighter colours)
- Better sleep
- Reduced mood shifts and enhanced mood

THE SIDE-EFFECTS MAY INCLUDE:

- Anxiety
- Confusion
- Impaired ability to focus or remember things
- Sweating
- Heart racing
- Vomiting
- Paranoia (intense fear of being threatened without any actual threat)

MEDICAL AND RECREATIONAL CANNABIS USE

Recreational cannabis is cannabis used for enjoyment rather than medical reasons.

People do not need approval to access cannabis sold in the recreation market in Canada. In most provinces, recreational cannabis is sold in licensed, government approved stores.

Medical cannabis use is when a person uses cannabis under the guidance of a doctor or nurse practitioner. Cannabis clinic staff may also be able to provide you with guidance. One of the most common medical uses of cannabis is to treat pain. A doctor or nurse practitioner can approve the use of medical cannabis. A person living with ALS can then use the approval like a prescription to buy medical cannabis from licensed producers.

For the Health Canada approved list click on the following: Licensed cultivators, processors and sellers of cannabis under the Cannabis Act - Canada.ca. Some insurance companies will cover the cost of medical cannabis. Certain expenses can also be included when submitting taxes when it is medical cannabis.

While cannabis may help treat some of the symptoms of ALS, it is not a cure. Cannabis cannot stop the disease from progressing.

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

Additional Resources

https://www.canada.ca/en/health-canada/services/drugs-medication/cannabis/health-effects/effects.html

https://www.als.ca/about-als/resources/living-with-als/

Thank you to Dr Colleen O’Connell for her contributions to this fact sheet.