

NON-MOTOR ASPECTS OF ALS

Amyotrophic lateral sclerosis (ALS) is often characterized by the loss of motor function; however, people living with ALS typically display non-motor symptoms that will impact their quality of life. Non-motor symptoms arise when areas of the central nervous system outside of the motor neurons are affected. Scientists are still working to understand how these areas are involved in ALS. These symptoms can also happen due to unknown causes.

The non-motor aspects of ALS can fall into many categories. Below are some of the more common non-motor symptoms, although people living with ALS may also experience other, less common ones.

Mood, cognitive, and behavioural changes

Up to 50 per cent of people living with ALS may experience cognitive and behavioural changes. ALS often impacts mental health, leading to emotional challenges such as depression and anxiety. These feelings are completely valid and often arise in response to the changes and uncertainties that come with the progression of the disease, including the loss of physical abilities and the ongoing nature of symptoms.

Some people living with ALS can also experience pseudobulbar affect, also known as emotional lability, which is uncontrolled episodes of laughing or crying that don't match their mood or the situation. This can cause significant confusion for people living with ALS, caregivers, and others. There are medications that can help with pseudobulbar affect. People with ALS should speak to their health care provider to determine what medication is right for them.

Research shows that ALS and frontotemporal dementia (FTD) are related diseases. FTD is a group of disorders that damage the temporal and frontal lobes of the brain. These areas of the brain are responsible for personality, memory,

and higher-level cognitive skills such as planning, managing behaviour, and emotional regulation. For some people living with a genetic form of ALS, the FTD connection can be more apparent. People with ALS-FTD may show cognitive and behavioural changes such as impulsiveness, apathy, difficulty with planning and problem-solving, language issues, and repetitive and/or inappropriate actions. Even with a family history of FTD or genetic connection, it is unadvised to associate symptoms with a diagnosis of cognitive impairment without the support of a qualified clinician. There are specialized tests to help detect cognitive changes associated with ALS/FTD. ALS Canada encourages genetic counselling to discuss individual risk. For more information, visit [The Association for Frontotemporal Degeneration's webpage on ALS and FTD](#).



Sleep disturbances

Sleep issues, such as insomnia, daytime fatigue, and restless leg syndrome, are common in people living with ALS. Sleep can be disrupted due to a variety of reasons, including physical symptoms of ALS such as cramps, pain, and spasms, as well as emotional or mental health symptoms, for instance depression and anxiety. Difficulty breathing due to weakened respiratory muscles can also disturb sleep. Speak to your clinician about strategies to improve sleep quality and length.



Pain and discomfort

ALS can cause discomfort and, in some cases, pain. It can occur at any stage of the disease, in any part of the body, and vary among different individuals. People with ALS can experience pain from muscle cramps and spasms, and less commonly, neuropathic pain. Other pain occurs due to weakened muscles, reduced mobility, and long-term use of assisted breathing machines, which may cause sores on the face.

Treatment for pain is tailored to each person and can include stretching, physical therapy, and medications. For many people, moving around and not sitting in the same position for too long can help reduce pain in the lower back, neck, and shoulders.

Careful positioning to avoid strain or stress such as sitting in a reclined position, placing arms and legs on a pillow or footstool or using a neck collar, shoulder sling, special cushions, and chair backs can also help relieve pain.

Pain should be discussed with your physician, physiotherapist, or occupational therapist.



Autonomic dysfunction

Autonomic dysfunction can occur in people living with ALS, and it impacts the autonomic nervous system, which controls involuntary and vital functions such as heart rate, blood pressure, breathing, digestion, urination, and defecation. Autonomic dysfunction in people with ALS can look like urinary urgency and incontinence, constipation, arrhythmia, difficulty regulating body temperature, and sexual dysfunction.

Gastrointestinal symptoms

Some people with ALS may experience constipation, which is infrequent bowel movements compared to their normal frequency and consistency. Factors contributing to constipation in people living with ALS include decreased physical activity due to muscle weakness, changes in diet leading to lower fibre intake, reduced fluid intake due to difficulty swallowing, weakened abdominal muscles and pelvic muscles making bowel movements challenging, and medication side effects. Gastrointestinal symptoms should not be ignored as it can lead to serious complications for people living with ALS. For more information, please visit this [ALS Canada factsheet on constipation](#).

KNOW THAT WE ARE HERE TO HELP

The ALS Society of Canada can assist in connecting people and families living with ALS 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.

Please note that ALS Canada does not provide medical advice or make referrals related to drug therapies or alternative therapies. These questions should be discussed directly with a medical professional – ideally an ALS neurologist, who would be qualified to interpret clinical information for individual situations. Please visit [our list of ALS clinics](#) to help you connect with a clinic in your area.