



**ALS Society of Canada's Written Submission for the Standing Committee on Social Policy's
Consideration of Bill 74, The People's Health Care Act, 2019**

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EXECUTIVE SUMMARY

The ALS Society of Canada (ALS Canada) is pleased to participate in the Standing Committee on Social Policy's consideration of Bill 74, The People's Health Care Act, 2019 (henceforth referred to as Bill 74). This submission addresses both the opportunities and concerns faced by people living with ALS amid the implementation of the health care reforms detailed in Bill 74.

Amyotrophic Lateral Sclerosis (also known as ALS, Lou Gehrig's disease, or motor neuron disease) is a disease that gradually paralyzes people because the brain is no longer able to communicate with the muscles of the body that we are typically able to move at will. Over time, as the muscles of the body break down, someone living with ALS will lose the ability to walk, talk, eat, swallow, and eventually breathe. The causes are unknown. With no cure and few treatment options that have a significant impact on the disease, 80 per cent of people with ALS die within two to five years of being diagnosed. Approximately 1,000 Ontarians are living with ALS, and the number of people affected is even greater when you consider the profound emotional, financial, and psychological impact of the disease on family members, employers, and friends.

We are pleased that Bill 74 aims to address some of the challenges in the current healthcare system as identified by ALS Canada's 2019 Ontario pre-budget submission, including:

- Insufficient levels of home and community care support.
- Variations in home and community care services throughout the province.
- A lack of integration within the healthcare system that results in service duplication and inefficiencies.
- Difficulties in transitioning from one part of the health care system to another.

We know Ontario's Government for the People is committed to change that will make a significant difference to Ontarians. We are eager to work with the government on the implementation of Bill 74 to ensure the development of an efficient health care system that makes life better for every Ontario family living with ALS. That is why we developed the following four recommendations with the aim of ensuring home and community care is sustainable and provides the care that people with a complex terminal illness like ALS need.

Summary of Recommendations

The ALS Society of Canada issues the following recommendations to the Standing Committee on Social Policy as it relates to the committee's consideration of Bill 74, The People's Health Care Act, 2019:

- 1) Improve access to essential mobility and communications equipment.**
- 2) Ensure personal support workers and long-term care providers have the resources needed to serve those living with complex health needs.**
- 3) ALS Clinics should be considered as an existing team of providers serving a specialized patient population.**
- 4) Provide equitable entry points for those requiring integrated and long-term care.**

ABOUT THE ALS SOCIETY OF CANADA

Founded in 1977, the ALS Society of Canada (ALS Canada) works with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS. We are a registered charity that receives no government funding – all of our services and research are funded through the generosity of our donors. Through the ALS Canada Research Program, we fund peer-reviewed research grants, foster collaboration and build capacity within Canada’s ALS research community, and participate in new areas of research where we are well-positioned to have an impact. Within Ontario, ALS Canada has a role similar to that of the provincial ALS societies providing services and support to help meet the needs of people living with ALS. Through advocacy federally and provincially within Ontario, ALS Canada gives voice to the collective experience of people living with ALS to help drive program and system changes for the ALS community.

Vision and Mission

Our **vision** is a future without ALS. Our **mission** is our everyday journey as an organization: We work with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

RECOMMENDATION 1: IMPROVE ACCESS TO ESSENTIAL MOBILITY AND COMMUNICATIONS EQUIPMENT

Given that people living with ALS become increasingly paralyzed as the disease progresses, they will require medical equipment to support mobility, comfort, and safety. This could include hospital beds and mattresses, wheelchairs, ceiling lifts, shower commodes, ramps and other equipment as their needs change. While the LHINs have provided some of this equipment for acute short-term use, there is variation in practice across the province and currently no mechanism that enables people with ALS to access mobility equipment for more than 30 days at a time.

With no government-funded mechanisms to provide medical equipment for long-term use, people living with ALS must make these purchases on their own if they are able to afford the high costs. Alternatively, they must rely on the support of ALS Canada, a charitable organization that is funded entirely by donors, to fill the gap through the loan of used equipment which helps keep people out of hospitals and long-term care homes.

Through the donor-funded equipment loan program, ALS Canada supports individuals with their long-term equipment needs as soon as the LHIN removes its short-term equipment. As a result, there is duplication as both the LHIN and ALS Canada end up organizing the delivery, cleaning, and maintenance of needed equipment. Not only is this requirement inefficient, but it is also unnecessarily expensive. Further, it creates a tremendous inconvenience for people who must have multiple providers in their homes for the same services.

Under the establishment of Bill 74, which aims to create a strong public healthcare system, people should not have to rely on a charity to access the equipment that is necessary for them to communicate, move and live safely in their own homes.

As Ontario Health and the Ontario Health Teams are established, their mandate must include providing long-term access to essential medical equipment. By providing equipment in the home for more than 30 days, this will help people stay out of the hospital and long-term care and protect their caregivers from unnecessary physical risk and injury, which result in further implications and costs on the healthcare system.

RECOMMENDATION 2: ENSURE PERSONAL SUPPORT WORKERS PROVIDING HOME CARE AND LONG-TERM CARE HAVE THE RESOURCES NEEDED TO SERVE THOSE LIVING WITH COMPLEX HEALTH NEEDS

ALS progression can differ for each person living with the disease, although generally physical abilities can significantly decline while the breadth of care they require significantly increases. Unfortunately, the current health care system is not geared to provide the right type of care for people living with complex and varying care needs and human resources challenges mean there often aren't enough qualified personal support workers (PSWs) to provide the required levels of support. Subsequently, this can result in PSWs missing shifts or individuals unfamiliar with the person and their disease coming to the home, putting the patient at risk. In addition, when people living with ALS care needs increase they may require hospitalization instead of a long-term care facility because the staff is not provided the right type of resources, training or support to provide the care they need.

For example, an Ontarian living with ALS was hospitalized while living in a long-term care home. While in the hospital it was determined that the person would benefit from a BiPAP device (non-invasive respiratory support) to breathe comfortably. Because of this need, the person could not return to their long-term care home. Since the person could not return to the long-term care home, they had to stay in hospital resulting in unnecessary and higher costs to the healthcare system. In the end, the person died in the hospital instead of in the long-term care home where they felt comfortable and safe.

It is Ontario families who suffer the consequences of these inconsistencies and complications and the health care system has higher costs. As the Ontario Health Teams prepare to deliver care to patients, their mandate must include training for health service providers, to ensure the right expertise and supports are in place to manage care for those living with complex health needs. They must also look to implement a health human resources strategy that includes proper training, wages and benefits would attract personal support workers to the home and community care sector. For Ontario families living with ALS, this could mean the difference between their loved ones being able to live safely at home or in a long-term care facility and needing to live in a complex care or ICU unit at the hospital.

RECOMMENDATION 3: ALS CLINICS SHOULD BE CONSIDERED AS AN EXISTING TEAM OF PROVIDERS SERVING A SPECIALIZED PATIENT POPULATION.

ALS Clinics are vital to the health journey of a person living with ALS. They are multidisciplinary centres aimed at delivering expert care to people and families living with ALS. There are six ALS Clinics located in Ontario, each responsible for serving not only the local area but also people living with ALS in nearby regions.

The Clinics provide education, monitoring, and timely interventions while promoting regular communication with individuals' family doctors and community healthcare providers. Also, the clinics

and their teams of professionals are among the community of researchers in Canada who are working to discover effective treatments for ALS.

As Ontario Health Teams are established and look to work with existing teams of providers serving specialized patient populations, they must consider the role of ALS Clinics in supporting people living with ALS across Ontario. Despite being a local entity, Ontario Health Teams should have the flexibility to efficiently work with ALS Clinics on comprehensive multidisciplinary specialized care, regardless of whether the clinic falls under their direct jurisdiction.

RECOMMENDATION 4: PROVIDE EQUITABLE ENTRY POINTS FOR THOSE REQUIRING INTEGRATED AND LONG-TERM CARE

In the current system, one of the most direct routes to accessing long-term care is for a hospital to refer the patient to a long-term care home, a process that can often be expedited in order to minimize unnecessary hospitalization. However, Ontarians with complex care needs, such as people living with ALS, are often not admitted to hospital but continue to access outpatient care and home care services.

For people living with ALS, the process of being admitted to long-term care can be more challenging and have much longer timelines. Unintentionally, an incentive has been put in place where people admitted to hospital are more likely to receive long-term care in a timely manner, putting people living with ALS in their homes at a disadvantage. To circumvent the system, people living with ALS may present to the hospital through the emergency room, so they can more quickly get transferred to a long-term care home. In the end, they are adding to the number of Ontarians receiving hallway medicine because they can't access the care they actually need.

Under Bill 74, should Ontario Health Teams be centrally located in hospitals, we do not want to see a system that prioritizes care for inpatients, thereby inadvertently putting in place a barrier to access for people with long-term, complex care needs. Multiple entry points must be established for access to long-term care to ensure equitable access to these services if they need them.

CONCLUSION

For a terminal disease like ALS that affects a relatively small community, the Ontario government has an opportunity to take a leadership role in making sure all Ontarians living with ALS can access the care and equipment they need when they need it.

Bill 74 has the potential to have positive impacts on people living with ALS. However, certain considerations must be addressed within its implementation to ensure the needs of Ontarians living with ALS are met, such as equipment and the role of ALS clinics within Ontario Health Teams.

These solutions will require small changes but can result in big impacts on an engaged community. They also help remove the duplication of services, pressures as a result of hallway medicine, and further increase efficiencies within the health care system.