



**ONTARIO PROVINCIAL
ALS PROGRAM:
ENHANCING CARE &
QUALITY OF LIFE
OF PEOPLE LIVING WITH ALS**

2024 PRE-BUDGET SUBMISSION
THE ALS SOCIETY OF CANADA

Summary of Recommendations

Invest \$6.6 million to implement the recommendations outlined in the Ontario Provincial ALS Program to address the urgent needs of Ontarians living with ALS:

- 1** Incremental investment for the five Regional Multi-Disciplinary ALS Clinics to standardize and enhance existing care models and commitment to funding the total cost of multi-disciplinary care for incremental patient volumes to meet the Canadian Best Practice Recommendations for the Management of ALS.
- 2** Sustainable funding for the ALS Society of Canada's Equipment and Community Services Programs (presently donor-funded) for people living with ALS to maintain autonomy and safely stay in their homes.
- 3** Formation of a Secretariat to provide oversight and coordination of ALS care in the province of Ontario as well as comprehensive data capture, knowledge dissemination, and system planning.
- 4** Development of a regional strategy for northern and rural Ontario to provide equitable and accessible ALS care closer to home.

Urgent Needs of Ontarians Living with ALS

Amyotrophic Lateral Sclerosis (ALS) is a terminal and progressive neurodegenerative disease that can affect anyone. The disease causes progressive paralysis, and eventually, a person living with ALS will lose the ability to walk, talk, eat, move, swallow – and breathe. With no cure, four out of five people with ALS will die within five years of diagnosis. In Ontario, every day a person is diagnosed with ALS and another person dies of ALS.

1,300 Ontarians are living with ALS.

The impacts of the relentless progression of the disease are profound – physically, emotionally, and financially, extending beyond the person with the diagnosis, to the family, caregivers and community.

Due to the complex nature of ALS, people living with the disease have substantial care and equipment needs that evolve and increase over time. Multi-Disciplinary ALS Clinics throughout the province must be appropriately resourced to support the ever-changing, complex care needs of a person living with ALS – ALS neurologist, respirologist, occupational therapist, physiotherapist, speech language pathologist, social worker, dietitians and more. Yet, the five multi-disciplinary ALS clinics in Ontario are beyond capacity, under-resourced and unable to meet the unique levels of care.

Current funding mechanisms for clinical care, community support services and equipment program are inadequate and inappropriate to address the urgent, evolving and complex needs of a person living with ALS which negatively impacts patient and caregiver outcomes, causing inequities across province, and increasing healthcare costs.

The ALS Society of Canada is a not for profit charity that has been addressing the gaps in critical equipment and community-based support services. Ensuring people have timely access to the multitude of different types of equipment they will require over the course of their disease. Community Leads throughout the province provide direct support to people living with ALS, their caregivers and family, ensuring they have information and psycho-social supports, and assistance with navigating resources and the health care system. The support provided by the ALS Society of Canada and the care provided by the five regional multi-disciplinary ALS Clinics in Ontario are critical in to ensuring the best outcomes for people with ALS, their caregivers and families.

The Ontario Provincial ALS Program

Today, Ontario's health care system fails to meet the unique needs of people and families living with ALS, leaving people affected by ALS unable to access the critical care and support they urgently require. Without dedicated and sustainable funding for ALS care and support, people living with ALS face even greater risk, leading to increased strain on our health care resources and further compromised health outcomes.

The Ontario government has an opportunity to demonstrate leadership and create a future where Ontarians diagnosed with ALS can access the care and support they need in a timely and equitable manner. The ALS Society of Canada, in collaboration with the five regional multi-disciplinary ALS Clinics in Ontario, developed the Ontario Provincial ALS Program that addresses the complex, critical needs of the ALS community.

For the 2024 Pre-Budget Submission, we are calling on the Ontario government to implement the recommendations outlined in the Ontario Provincial ALS Program:

- 1** Incremental **\$3.4 million** investment for the five Regional Academic Multi-Disciplinary ALS Clinics to standardize and enhance existing care models and commitment to funding the total cost of interdisciplinary care for incremental patient volumes to meet the established Canadian Best Practice Recommendations for the Management of ALS.
- 2** Sustainable **\$3.2 million** funding for the ALS Society of Canada's Equipment and Community Services Program (presently donor-funded) for people living with ALS to maintain autonomy and stay safely in their homes.
- 3** Formation of a Secretariat to provide oversight and coordination of ALS care in the province of Ontario as well as comprehensive data capture, knowledge dissemination, and system planning.
- 4** Development of a regional strategy for northern and rural Ontario to provide equitable and accessible ALS care closer to home.

We are asking for an investment of **\$6.6 million** to begin implementing the Ontario Provincial ALS Program, which holds the promise of significantly improving the lives of people living with ALS, reducing the strain on our health care system and contributing to the broader economic prosperity of Ontario.

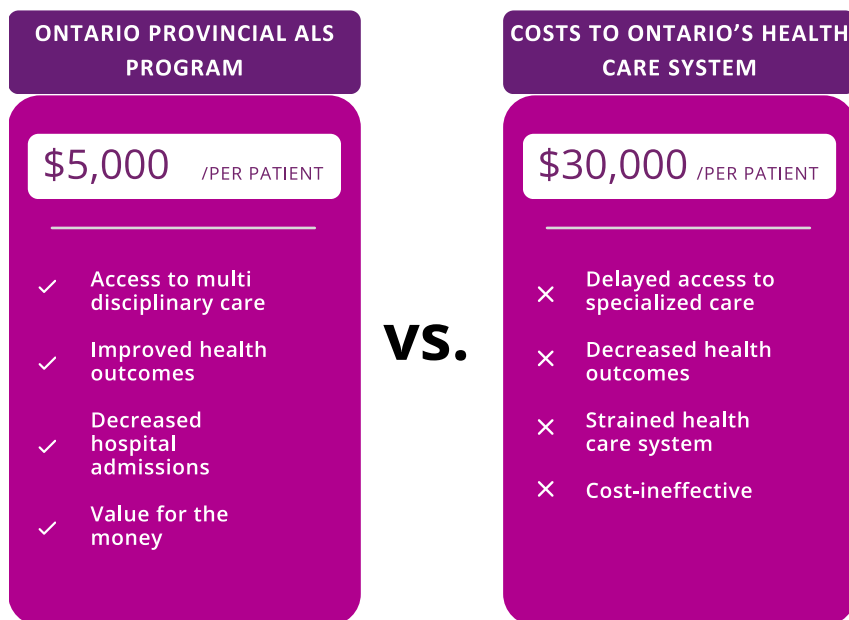
RECOMMENDATION 1:

INVESTMENT FOR THE FIVE REGIONAL MULTI-DISCIPLINARY ALS CLINICS TO STANDARDIZE AND ENHANCE EXISTING CARE MODELS & MEET THE CANADIAN BEST PRACTICE RECOMMENDATIONS FOR THE MANAGEMENT OF ALS

In Ontario, people living with ALS receive care under one of the five regional multi-disciplinary ALS clinics (Sunnybrook Health Sciences Centre, London Health Sciences Centre, McMaster University Medical Centre, Providence Care Hospital and The Ottawa Hospital). However, ALS clinics often fail to meet Canadian Best Practice Recommendations for Management of ALS as they do not have adequate funding for the required multi-disciplinary care.

The lack of a coordinated approach results in the inequitable distribution of services and delays in ALS care, resulting in unnecessary Emergency Department (ED) visits and costly hospital/Intensive Care Unit (ICU) admissions. For people living with ALS, having access to multi-disciplinary ALS clinics is critical as healthcare providers, such as dietitians, social workers, respiratory therapists, and occupational therapists, play a key role in optimizing their care, supporting individuals and families as they navigate this rapidly progressive terminal disease, resulting in improved health outcomes, prolonged survival, decreased burden on hospital systems and expedited access to adaptive equipment.

Investment vs. Cost



For less than a single hospital stay, the Ontario government, can ensure each person living with ALS receives optimal care, thereby improving their quality of life and reducing the strain on and costs to the health care system.

The incremental investments in the five ALS Clinics through the Ontario Provincial ALS Program will not only standardize and enhance existing care models but also commit to funding the total cost of multi-disciplinary care to meet the expected standards outlined in the Canadian Best Practice Recommendations for the Management of ALS, providing a person-centered care approach that ensures quality care that is effective, efficient and provides value for money; the cornerstone to health care in Ontario via the Ministry of Health and Ontario Health.

RECOMMENDATION 2:

SUSTAINABLE FUNDING FOR ALS SOCIETY OF CANADA'S COMMUNITY SUPPORT PROGRAM (PRESENTLY DONOR-FUNDED) FOR PEOPLE LIVING WITH ALS TO MAINTAIN AUTONOMY AND STAY IN THEIR HOMES

The ALS Society of Canada augments our health care system. Throughout Ontario, ALS Canada Community Leads provide care navigation, psychosocial supports, and services to respond to the unique needs of people living with ALS, their families and caregivers in a timely manner, which helps delay admission to long-term care, reduce unnecessary ED visits, support in clinic and community care.

In addition, the ALS Society of Canada's Equipment Program provides necessary mobility and medical equipment at no cost to the individual for the length of time a person living with ALS needs it. ALS Canada is required to step in to fill this critical gap due to the red tape, excessive restrictions and an Assistive Devices Program (ADP) funded by the province that does not meet the unique and complex needs of ALS, putting the health and well-being of individuals, caregivers and families of people living with ALS at risk. We improve the lives and health outcomes of almost 8,000 Ontarians each year through these supports.

While these critical services are supported by provincial governments in other provinces, such as Nova Scotia and Quebec, this is not the case in Ontario. The reliance on donor dollars to provide access to essential support and equipment at each stage of a person's journey living with ALS is unsustainable.

No one living with ALS should have to go without the care and support they require to live safely at home and in their community and instead be forced into hospital or long-term care, contributing to ED, ICU visits and more expensive long-term care solutions.

By working in collaboration with the ALS Society of Canada to fund equipment and community support programs for people living with ALS, the Ontario government can play a significant role in improving their quality of life and helping people living with ALS maintain their independence, dignity, and safety for themselves and their caregivers.

CASE STUDY

After a year of living with ALS, an Ontario woman started to lose critical health functions, but this could be managed at home through access to needed medical equipment. She was assessed by an Occupational Therapist (OT) through the LHIN who prescribed a bath seat, hospital bed and mattress, and walker.

As her ALS continued to progress, she needed to transition from a walker to a power wheelchair and eventually required a Hoyer lift to help her move from her bed to the power wheelchair where she would remain for the rest of the day. Due to the red-tape and restrictions of existing provincial medical equipment programs, fulfilling her equipment needs required three different organizations, three different vendor partners and at least six visits to her home to drop-off and collect the equipment.

MONTH ONE

Needed items were provided by the LHIN's medical equipment vendor – but were then removed.

MONTH TWO

The ALS Society of Canada Equipment Loan Program was forced to step in and provide the items.

TWO YEARS AFTER DIAGNOSIS

The woman was able to secure a used power wheelchair from the ALS Canada while she continued Assistive Devices Program (ADP). The ADP vendor made numerous trips to her home with her OT to take measurements and trial a customized power wheelchair. The Hoyer lift was finally provided by the LHIN - but then removed after one month.

Again, the ALS Society of Canada Equipment Loan Program was forced to step in.

RECOMMENDATION 3:

FORMATION OF A SECRETARIAT TO PROVIDE OVERSIGHT AND COORDINATION OF ALS CARE IN ONTARIO AS WELL AS COMPREHENSIVE DATA CAPTURE, KNOWLEDGE DISSEMINATION & SYSTEM PLANNING

Establishing a Secretariat as part of the Ontario Provincial ALS Program is a critical mechanism for oversight and coordination, playing a pivotal role in ensuring the program's effectiveness and long-term success. A Secretariat provides a centralized body that coordinates and streamlines various aspects of ALS care. This coordination is crucial for ensuring that clinical care, community support and equipment programs work in tandem, providing an integrated experience for people living with ALS and ensuring quality care is maintained.

Facilitation of a comprehensive data capture by the Secretariat, gathering key information such as patient demographics and service utilizations, will allow the Ontario Government and other stakeholders to make evidence-based decisions on the strategic allocation of resources and optimize the funding to ensure that the program meets the evolving needs of the ALS community.

The Secretariat will serve as a hub for disseminating knowledge and best practices across the ALS care ecosystem, ensuring that people living with ALS have access to equitable care and provide oversight and coordination of ALS care in the province of Ontario, which is essential fostering coordination, data-driven decision-making and knowledge dissemination and providing measurements of effectiveness, efficiency & value for money.

RECOMMENDATION 4:

DEVELOPMENT OF A REGIONAL STRATEGY FOR NORTHERN ONTARIO TO PROVIDE EQUITABLE AND ACCESSIBLE ALS CARE CLOSER TO HOME

Many Ontarians living in Northern and rural regions face unique challenges in health care access due to vast distances and limited health care infrastructure. This is the case for people living with ALS in Northern Ontario as well, as they must endure long journeys to attend appointments at one of the five ALS clinics located in Toronto, London, Hamilton, Kingston and Ottawa. Due to the rapidly progressive nature of ALS, timely interventions are crucial for optimizing health outcomes. A regional strategy ensures that people living with ALS receive timely care, aligning with the Best Practice Recommendations, regardless of their geographic location.

As part of the Ontario Provincial ALS Program, the Secretariat will work with the five multi-disciplinary ALS clinics in identifying capacity and capabilities in addressing accessible ALS care needs in Northern Ontario, in addition to exploring the feasibility of a sixth ALS site, satellite office, and other opportunities that permit equitable access to people living with ALS in Northern Ontario, without the burden of extensive travel.

Developing a regional strategy is a crucial step toward achieving equitable access to care, addressing the unique challenges faced by these communities and bridging the gap to ensure that people living with ALS in these areas have equitable and accessible care closer to their homes.

Summary of Recommendations

The Ontario Provincial ALS Program, not only addresses the immediate health care needs of Ontarians living with ALS but also represents the Ontario government's commitment to comprehensive and evidence-based care for a community desperately in need. The urgency is underscored by the rapid progression of this disease and the profound physical, financial and emotional suffering experienced by people living with ALS and their loved ones.

Considering this, the Ontario Provincial ALS Program emerges as a strategic, cost-effective and forward thinking solution, poised to position Ontario as a leader in the care and support provided to people living with ALS.

The incremental investment in multi-disciplinary ALS Clinics, sustainable funding for ALS Society of Canada's critical support programs, the formation of a Secretariat for oversight and coordination and the development of a regional strategy collectively signifies a policy approach that goes beyond the immediate challenges, laying the foundation for a more resilient and responsive health care system.

By implementing the Ontario Provincial ALS Program in Budget 2024, the Ontario government has the opportunity to rewrite the narrative for 1,300 Ontarians living with ALS and their families, providing them with a continuum of care and a lifeline of hope and dignity.

Together with the Ontario government, we can help ease the burden of ALS and provide the appropriate levels of care and support for people living with ALS and their families.

