



FROM INVESTMENT TO IMPACT: ONTARIO PROVINCIAL ALS PROGRAM

**2026 PRE-BUDGET CONSULTATION SUBMISSION
FROM THE ALS SOCIETY OF CANADA**

January 2026



SUMMARY OF RECOMMENDATIONS

ALS Society of Canada (ALS Canada) recommends that the Government of Ontario renew the \$1.8M funding for ALS Canada's Equipment Program as a core component of the Ontario Provincial ALS Program.

Continued investment will protect demonstrated system gains, ensure equitable access to care, support and equipment for people living with ALS, and sustain a model that has proven to deliver meaningful impact for Ontarian families affected by ALS and the health system.

DRIVING PROGRESS THROUGH THE ONTARIO PROVINCIAL ALS PROGRAM

When the Ontario government invested in the Ontario Provincial ALS Program, it sparked a ripple effect of hope and meaningful change for the ALS community. For years, the ALS community advocated for standardized, equitable access to care, community services, and essential equipment in Ontario. **In 2024, the Ontario government answered that call with a pivotal investment in the Ontario Provincial ALS Program. This \$13 million investment addresses the urgent and complex needs of people living with ALS by ensuring timely access to multi-disciplinary care, community-based support, and equipment.**

For people living with ALS and their families, this investment translated into a restored sense of hope, dignity and comfort in the face of a terminal disease.

“My wife has been living with ALS for 3 years now. With the invaluable assistance from ALS Canada, friends and family, she can live at home and maintain her quality of life. Thank you, Ontario Government, for your valuable support through this investment.”

Caregiver to a person living with ALS, Toronto, ON

The Ontario Provincial ALS Program enabled Ontario to move beyond fragmented, inequitable access and toward a system that responds to and improves the health outcomes for 1,450 Ontarians living with ALS and their families in 2025, while reducing strains on the healthcare system, minimizing unnecessary hospitalizations and emergency visits.

ALS is a devastating disease that impacts not only the patient but also to their family and friends. I thank the Ontario government for their compassion and hope this program will always be there for those who suffer so much.”

Bereaved caregiver to a person living with ALS,
Sault Ste. Marie, ON



IMPACT OF THE ONTARIO PROVINCIAL ALS PROGRAM

Strengthened Multi-Disciplinary ALS Clinics Aligned with Canadian Best Practices

Ontario's investment through the Ontario Provincial ALS Program has strengthened care delivered through the province's five regional multidisciplinary ALS clinics, Sunnybrook Health Sciences Centre, London Health Sciences Centre, McMaster University Medical Centre, Providence Care Hospital, and The Ottawa Hospital, aligning them with the Canadian Best Practice Recommendations for the Management of ALS.

Access to multi-disciplinary ALS clinics is essential for people living with ALS, as allied health professionals - including dietitians, social workers, respiratory therapists, and occupational therapists - play a vital role in optimizing care and supporting people living with ALS through this rapidly progressive terminal disease – ultimately improving health outcomes and prolonging survival.

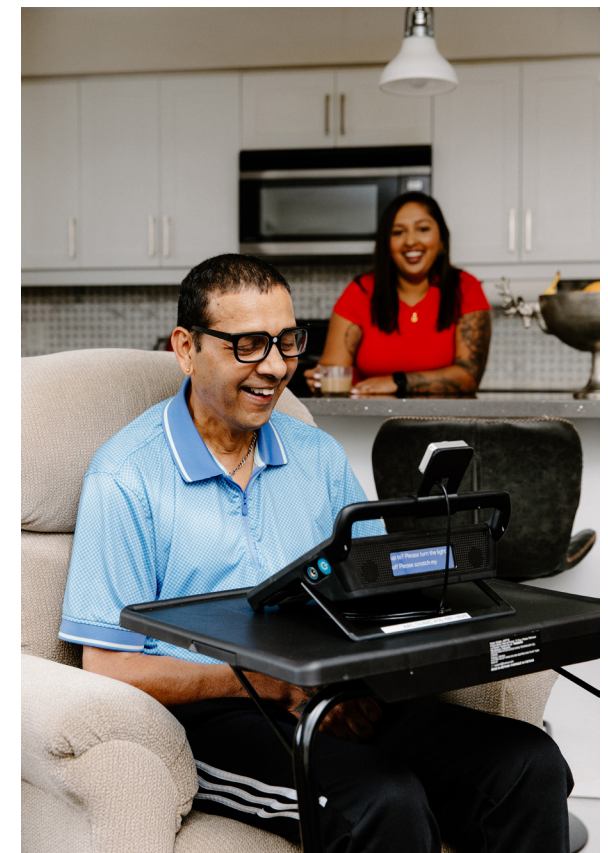
Prior to this investment, clinics often lacked the dedicated funding required to deliver fully integrated multi-disciplinary care. This resulted in variability across regions, delayed access to key allied health professionals, and avoidable strain on health systems.

Through the Ontario Provincial ALS Program, the province replaced fragmented ALS care with the full scope of multi-disciplinary care required to meet the Canadian Best Practice Recommendations for the Management of ALS and improve the care experiences of people living with ALS while supporting more efficient use of health system resources.

“The Provincial ALS Program will truly change lives. Clinics will be better equipped to diagnose and treat people living with ALS, while also providing essential equipment and connectivity for individuals across Ontario. Just as my brother lost his life to ALS, so too will many others - and they will need your continued support.”

Bereaved family member of a person living with ALS, Belleville, ON

The ALS clinics in Ontario are now better equipped to provide coordinated, person-centred care that reflects the complex and rapidly evolving needs of people living with ALS. This has improved care planning, supported families throughout the disease trajectory, and enabled proactive interventions rather than reactive interventions following a crisis.



Improved Province-Wide Access to Community-Based ALS Support

ALS Canada Community Leads are frontline professionals who provide community-based support for people living with ALS and their families throughout their diagnosis. Working across Ontario, Community Leads provide care navigation, psychosocial supports and services tailored to the unique and rapidly evolving needs of people living with ALS, ensuring no one faces ALS alone.

“Thanks to the support of ALS Canada, I’m not coping with ALS alone. When I was diagnosed three years ago, an ALS Canada Community Lead reached out to me right away. She spoke to my heart. She listened and saw me as a person, not just as ALS. Having someone guide me and give me strength I didn’t know I had was incredible. Since then, ALS Canada has been by my side – providing equipment and helping me navigate the health care system as my disease progresses”

Person living with ALS, Brampton, ON

This support plays a critical role in augmenting Ontario’s health care system. By helping people living with ALS and caregivers anticipate needs, access appropriate services, and manage care in the community, Community Leads contribute to delayed hospital admissions and more coordinated use of health system resources. Families are better supported to remain in their homes and communities, reducing stress, isolation, and crisis-driven care.



CASE STUDY



Jane is a 40-year-old mother of two young children, living in Hamilton. She was diagnosed with ALS in 2025. Her family carries a genetic variant of the disease that has resulted in the loss of three relatives, each within nine months of diagnosis.

Five days after her diagnosis, the ALS Canada Community Lead for Hamilton conducted the initial home visit and found that Jane was experiencing severe respiratory and mobility challenges due to rapid disease progression.

Recognizing the urgency, the ALS Canada Community Lead coordinated an accelerated response across our organization. Within two days, the client received five essential pieces of equipment, immediate access to respiratory supports, and in-home care services through Ontario Health atHome. Delivering this level of support required swift, coordinated action from several team members across ALS Canada who worked together to stabilize her situation and provide comfort during an overwhelmingly difficult time.

Before ALS Canada's involvement, the family had been feeling unsupported and deeply overwhelmed by the pace of her decline. When the ALS Canada Community Lead followed up the next day, Jane's husband expressed profound gratitude, sharing through tears how much it meant to have timely help that could offer his wife meaningful quality of life in the months ahead.

Through the Ontario Provincial ALS Program, the government's investment has enabled ALS Canada to continue and strengthen the delivery of these community-based supports across the province. With sustainable funding in place, Community Leads are bridging the gap between clinical care and daily living, ensuring continuity across the care journey, particularly during periods of rapid progression or change. This community-based model complements clinic-based care and equipment access, strengthening the overall provincial ALS care system.

- **1,450 Ontarians** living with ALS were supported in 2025 through ALS Canada's Community Services Program.
- Average of **4.3 days** to receive support from Community Leads from upon diagnosis in 2025.
- **55 education sessions** delivered by ALS Canada Community Leads were attended by **1,650 healthcare professionals** involved in the care of people living with ALS.
- **3,000 caregivers** were supported with care navigation, support groups and information by their Community Leads.
- **62 support groups** hosted for people living with ALS and caregivers in 2025.

Sustained Timely Access to Equipment to Support the Safety and Independence of Ontarians Affected by ALS

Timely access to equipment is essential for people living with ALS, as needs related to mobility, communication, and respiratory support can change rapidly and unpredictably. A person diagnosed with ALS typically requires an average of 7 to 11 pieces of equipment to maintain their mobility, comfort, and safety.

ALS Canada's Equipment Program provides essential mobility and medical equipment to Ontarians living with ALS for as long as they need it. By offering flexibility, a comprehensive inventory, and no-cost provisions, the Equipment Program effectively addresses gaps left by the Ministry of Health's Assistive Devices Program.

“The equipment from ALS Canada allows people living with ALS to remain in their homes, with their families, for as long as possible. The impact on quality of life cannot be understated”

Person living with ALS, Thunder Bay, ON

Prior to the implementation of the Ontario Provincial ALS Program, ALS Canada provided equipment to people living with ALS across the province through the generosity of donors. While this donor-supported model enabled critical assistance for many families, it became increasingly unsustainable. Demand for equipment grew as the number of people living with ALS increased, costs rose, and charitable donations became less predictable. Without a stable funding base, ALS Canada faced mounting pressure that risked service reductions across the province, potentially leaving families vulnerable to delays in accessing essential equipment.



CASE STUDY

Laura lives in a retirement home and has been living with ALS for six years. Her progression has remained relatively stable, allowing her to maintain a level of independence that is essential for her to continue residing in a facility that provides only minimal care. This independence is made possible through key mobility equipment, including her power wheelchair (PWC) provided through the ALS Canada Equipment Loan Program.

Recently, Laura contacted ALS Canada in distress when her PWC malfunctioned. Because this device is, in her words, her “lifeline”, the issue left her effectively immobile within her residence. She shared that feeling stuck in that moment was more frightening and overwhelming than receiving her ALS diagnosis. In her panic, she could not remember who to call first.

Our ALS Canada Equipment Coordinator responded immediately, speaking with Laura and arranging for our equipment vendor to visit her residence the same day. The quick response restored her safety and prevented what could have been an unnecessary hospital admission.

Following the repair, Laura sent an email expressing her overwhelming gratitude to the team, emphasizing how much it meant to have support that was not only efficient but deeply understanding of the realities she faces living with ALS.

The Ontario government responded to this significant risk at a critical moment by investing in the Ontario Provincial ALS Program, enabling ALS Canada’s Equipment Program to continue providing consistent, province-wide access to essential equipment aligned with clinical need rather than charitable capacity. This shift from reliance on donor dollars to a system-level commitment ensured that people living with ALS could receive the equipment they need, when they need it and remain safely in their homes and communities for longer, preserving autonomy, dignity, and safety for both individuals and their caregivers.

Through its partnership with ALS Canada, the Government of Ontario has demonstrated how targeted investment can improve the quality of life for people living with ALS while delivering value to the health system. Sustaining these programs through renewal will ensure that people living with ALS continue to receive the care and support they need to maintain their safety and independence.

- **4,000 pieces of equipment** provided province-wide in 2025 by ALS Canada’s Equipment Program through the investment in the Ontario Provincial ALS Program.
 - We offer a broad range of equipment including, small bathroom equipment, walkers, power wheelchairs, scooters, hospital beds, mattresses, lift systems, ramps and easy lift chairs - representing a subset of the **42 different equipment types** available through the program.
- **704 people** living with ALS received equipment support through ALS Canada’s Equipment Program in 2025.
- The ALS Canada Equipment Program achieved an average turnaround time of **10–14 days** from request to delivery and setup, compared to the Assistive Devices Program (ADP), which typically requires **6–8 weeks**.



The Case for Renewal: Sustaining Value in Ontario's ALS Care System

The Ontario Provincial ALS Program operates as an integrated model built on three interdependent components: strengthened multi-disciplinary ALS clinics, timely access to essential equipment and community-based supports. Together, these elements ensure coordinated, person-centred care for people living with ALS.

Renewal of ALS Canada's Equipment Program is essential to sustaining this model and protecting the value of Ontario's investment in the Provincial ALS Program.

Without the renewed funding of the Equipment Program, the effectiveness of the entire Provincial ALS Program would be compromised. Families affected by ALS would once again face delays and inequities, and the system would revert to crisis-driven responses that the Ontario government has worked deliberately to move away from.

Renewing the Equipment Program represents a value-for-money investment that preserves system efficiencies, prevents avoidable health system costs, and sustains an integrated model of care that is already delivering results.

Conclusion

Government of Ontario's investment in the Ontario Provincial ALS Program has made a meaningful difference in the lives of Ontarians affected by ALS and will continue to do so in the years to come.

Renewing the funding for ALS Canada's Equipment Program affirms Ontario's commitment to evidence-based, compassionate health policy and ensures that the progress achieved is sustained. ALS Canada urges the Government of Ontario to continue its leadership by renewing funding for ALS Canada's Equipment Program as a core component of the Ontario Provincial ALS Program.





ABOUT

ALS AND THE ALS SOCIETY OF CANADA

Amyotrophic lateral sclerosis (ALS) is an unrelenting and currently terminal disease. It progressively 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. Nearly 4,000 Canadians live with ALS and approximately 1,000 Canadians are diagnosed each year. Four out of five people living with ALS will die within two to five years of their diagnosis.

The ALS Society of Canada is working to change what it means to live with ALS. Grounded in and informed by the Canadian ALS community, we respond to the urgent unmet need for life-changing treatments by investing in high-quality research that will fuel scientific discovery and by engaging industry, supporting increased clinical capacity, and advocating for equitable, affordable, and timely access to proven therapies.

Responding to the tremendous need for current and credible ALS knowledge, awareness, and education, we empower Canadians affected by ALS to navigate the current realities of ALS, be informed consumers of ALS information, and advocate effectively for change. In Ontario, we provide direct community services to help people navigate ALS.

Founded in 1977, ALS Canada is a registered charity whose work is powered by generous donors who share our vision of a world free of ALS.

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