

Imagine waking up thirsty but being unable to get out of your bed to go get a glass of water. There is a walker next to your bed, but your arms and legs have become so weak that you can't hold yourself up anymore. Your family has requested a wheelchair from the province's regional health authority, but it might still be a couple days before the right one is delivered to your home and even then, you can only keep it for a short time. None of your loved ones are strong enough to pick you up without hurting themselves and your personal support worker's shift doesn't start for another couple of hours – though they haven't been showing up consistently. So, you must lay there, thirsty, unable to move.

As bleak as this sounds, these are the realities currently facing about 1,000 Ontarians and their families who are unlucky enough to be living with ALS, a terminal disease that can affect anyone. Gradually the body becomes paralyzed 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 brain's connection with the muscles of the body breaks 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. And the impact on families – emotionally, financially, and psychologically – is tremendous.

ALS has a cost to families
of \$150,000 to \$250,000*

We want to see a future where Ontario families affected by ALS do not face an overwhelming financial burden as a result of the disease; where sustainable support is available to families and caregivers; and where Ontarians diagnosed with ALS have access to treatments and services that are fully covered by Ontario's health care system, keeping them out of the hospital.

We know Ontario's Government for the People is committed to change that will make a big difference to Ontarians: Ending Hallway Medicine; building a higher-quality, more

efficient home and community care system; restoring trust and accountability with government; and finding efficiencies and better value for money. We are eager to work with the new government to make sure this ambitious agenda makes life better for every Ontario family living with ALS. That's why we developed the following five recommendations to improve quality of life in the face of a terminal diagnosis for Ontario families living with ALS, at little to no cost to Ontario taxpayers:

- 1. Remove barriers to participation in the Direct Funding Program:** Ontarians living with ALS stand to benefit greatly from the Direct Funding Program – yet there are significant barriers to accessing it. Simple solutions would better serve those the program intends to help.
- 2. Provide fair access to non-invasive respiratory support:** Extend the Ventilator Equipment Pool to enable people living with ALS to use BiPAP devices regardless of where they live.
- 3. Improve access to essential mobility and communications equipment:** Making essential mobility and communications equipment available for longer periods of time and in all communities across the province would reduce duplication and help to keep people living with ALS out of the hospital.
- 4. Improve timely access to therapies:** Implement a real plan that streamlines the process for newly-approved treatments moving through the Ontario Public Drug Program.
- 5. Sustainable long-term access to home and community care:** Ensure home and community care is sustainable and provides the care that people with a complex terminal illness like ALS need.



*Gladman, M. et al. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2014 Sep;15(5-6):426-32.

1 | REMOVE BARRIERS TO PARTICIPATION IN THE DIRECT FUNDING PROGRAM

Ontarians living with ALS stand to benefit greatly from the Direct Funding Program – yet there are significant barriers to accessing it. Simple solutions would better serve those the program intends to help.

Ontario's Direct Funding Program was designed to enable adults with a physical disability to self-manage their own attendant services. Acting as employer, program participants manage their own team of service providers with an approved budget customized to meet their needs. When successful, Direct Funding can provide many Ontario families with an innovative alternative to traditional home and community care services.

Direct Funding can be a great option for people living with ALS: the program helps them to maintain independence while ensuring they have the help they need with the daily routines that most of us take for granted – like brushing our teeth, lifting our arms to wash our hair, or dressing ourselves. The program can relieve some of the financial burdens of an already high-cost disease – and because most program participants have more than one care professional, they have options in the event that an attendant is unable to fulfill a scheduled shift.

Yet while Direct Funding could be an effective solution for people living with ALS, the design of the program has inherent barriers to participation. A person living with ALS will gradually lose mobility, become fatigued quickly, require support from a family caregiver to leave their home, have medical equipment needs, and lose the ability to speak – all of which can create significant challenges in qualifying for or participating in Direct Funding. For example:

- Wait times between initial application date and interview date: After applying for Direct Funding, the next step is an interview. The gap between these two steps can take upwards of one year and while progress has been made to shorten this timeframe, the physical abilities of someone living with ALS can change even faster. In a matter of months, one's mobility can change from being able to walk independently to requiring caregiver assistance and equipment to even leave the home. As a result, many people living with ALS will have progressed beyond being able to continue to live in the community before having even completed the steps involved in qualifying for the program.

- Interview requirements: When program applicants are invited for an interview, they are currently required to attend in person, without anyone else present. Yet many people living with ALS are unable to leave their home or require significant caregiver support to do so, even though they have the mental capacity and communications ability to manage a team of attendants. For example, they may have extremely limited mobility or require assistance with medical devices such as feeding tubes, portable saliva suction pumps or respiratory devices. Making simple adjustments to the interview process would enable Direct Funding to be more aligned with the needs of those it purports to help.

“Direct Funding is an important vehicle for families living with ALS to get the care and support they so desperately need. But what people don't realize is how physically and mentally taxing it can be to manage a team of service providers with no help, especially when you are facing the realities of a disease like ALS. Simply allowing a caregiver to go to the Direct Funding interview or help with attendee scheduling could really help more people access this life-changing program.”

Laurie Laxer, Regional Manager
ALS Society of Canada

- Lack of flexibility in managing attendants: Direct Funding participants must independently manage their team of service providers – a task that can result in extreme fatigue if the participant cannot communicate verbally. Because personal caregivers cannot be liaisons between the program participant and the attendants, many people living with ALS choose not to move forward with Direct Funding and do not get the quality of care they need.

Improving the Direct Funding Program to allow more flexibility will reduce barriers to this important resource that helps Ontarians to get the care they need while reducing the time spent in hospital.

Here's what government can do:

Recommendation: Allow personal caregivers to participate in the Direct Funding interview process or conduct the interviews at the applicant's home.

Recommendation: Allow personal caregivers to serve as designated representatives for the program participant.

Recommendation: Prioritize the review of Direct Funding applications from people living with ALS so that their interview takes place within three months of submitting their application.

2 | PROVIDE FAIR ACCESS TO NON-INVASIVE RESPIRATORY SUPPORT

Extend the Ventilator Equipment Pool to enable people living with ALS to use BiPAP devices regardless of where they live.

People living with ALS often need non-invasive respiratory support, such as Bilevel Positive Airway Pressure (BiPAP), when breathing on their own becomes more challenging. This device improves quality of life by helping the person breathe more comfortably without having to constantly cough and gasp for air. This equipment is funded through the Ministry of Health and Long-Term Care's (MOHLTC) Ventilator Equipment Pool under the Assistive Devices Program for in-home use only. Yet as someone's ALS progresses and care needs increase, living at home may not be a feasible option – meaning that someone who relies on BiPAP to breathe is not able to consider moving to a long-term care home or residential hospice.

In March 2018, ADP extended funding support to residents of long-term care homes who require Positive Airway Pressure systems – but this extension was not mirrored for BiPAP devices. Since then, we have been working with the MOHLTC's Long-Care Homes Division, as well as VEP and ADP, to reflect this same update in funding support for BiPAP devices. A working group has been developed to look at the issue, but people living with ALS don't have time to wait. The time has come to extend the VEP to allow BiPAP devices into long-term care homes or residential hospices so that Ontarians living with ALS don't have to choose between being able to breathe comfortably or moving to a facility that can provide the required level of care.

The experiences of the ALS community demonstrate how a lack of access to equipment can lead to unnecessary hospital stays and Ontarians not getting the quality care they need. For example:

- An Ontarian living with ALS required hospitalization while in their long-term care home. While in hospital it was



determined that the person would benefit from a BiPAP device. Because of this need, the person could not return to their long-term care home because its staff was not willing to obtain the necessary rental equipment or to be trained on BiPAP use, despite offers from ALS Canada and their Local Health Integration Network (LHIN) to support the training. Since the person could not return to the long-term care home, they had to stay in the hospital resulting in unnecessary and higher costs to the healthcare system. In the end, the person died in hospital instead of in the long-term care home where they felt comfortable and safe.

- An Ontarian living with ALS had been accepted into a long-term care home. During their time there, their disease progressed, and they eventually required a BiPAP device to breathe comfortably. While they were able to stay in their long-term care home, they had to wait six months for the BiPAP equipment to be rented and for the staff to receive training. During this time the person experienced an unnecessary decline in quality of life as they struggled to breathe.

Here's what government can do:

Recommendation: Extend the VEP program so that people living with ALS can use BiPAP devices in long-term care homes and residential hospices, with the necessary training and support from staff.

3 | IMPROVE ACCESS TO ESSENTIAL MOBILITY AND COMMUNICATIONS EQUIPMENT

Making essential mobility and communications equipment available for longer periods of time and in all communities across the province would reduce duplication and help to keep people living with ALS out of the hospital.

Personal and professional caregivers play a significant role in helping people living with ALS to manage and accomplish daily tasks. But for people with ALS to live safely at home and stay out of the hospital, it is vital that they are supported with the right equipment. This could mean hospital beds and mattresses, wheelchairs, ceiling lifts, shower commodes, ramps and more as the disease progresses and their needs change. While LHINs provide some of this equipment for acute short-term use, there is variation in practice across the province and currently no mechanism within government that enables people with ALS to access mobility or communications equipment for more than 30 days at a time.

Given that people living with ALS become increasingly paralyzed as the disease progresses, it is very likely they will require mobility or communications equipment for longer than one month. Yet to access long-term equipment, they must rely on the support of ALS Canada, a charitable organization that is funded entirely by donors to fill the gap. In a province like Ontario with a strong public healthcare system, people should not have to rely on charity to access the equipment that is necessary for them to communicate, move and live safely in their own homes.



Duplication of Services

With no government-funded mechanisms to provide long-term equipment use, local community and ALS clinic-based occupational therapists work around the system by submitting an equipment request to the LHIN and ALS Canada at the same time. Since the ALS Canada equipment loan pool is entirely reliant on donor funding, there can be a waiting period for equipment and duplicating the equipment request helps to ensure that ALS Canada can support individuals with their equipment needs as soon as the short-term equipment provided by the LHIN is removed. This means that both the LHIN and ALS Canada end up organizing the delivery, cleaning and maintenance of needed equipment. Not only is this duplication in service 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.

Here's what government can do:

Recommendation: Recognize communications and mobility equipment as an essential health care service so that it can be provided for the long term to help people live safely in their homes and out of the hospital and to protect their caregivers from unnecessary physical risk and injury.



4 | IMPROVE TIMELY ACCESS TO THERAPIES

Implement a real plan that streamlines the process for newly-approved treatments moving through the Ontario Public Drug Program.

Health Canada's recent approval of edaravone is an important and hopeful milestone for the ALS community and provides people living with ALS the option of a second treatment for the first time in nearly twenty years. However, Health Canada's approval of the drug was only the first step. On November 23, 2018 the Ontario Public Drug Program posted its deadline to receive patient evidence submissions for edaravone. Yet there is no defined timeframe for a decision and no transparency in the process, meaning Ontarians living with ALS have no sense of how long they might have to wait before knowing if they will have affordable access to the drug with reimbursement from the Ontario Public Drug Program.

"The advancements in research over the past few years have brought a lot of hope to the ALS community that new and effective treatments will soon become available. But if changes are not made now to streamline the approval system, this hope will be gone because we won't have the physical or financial means to access a therapy that could save our lives. That is why it is so important that the Ontario government put a strategy in place today to improve the barriers to drug access for people living with ALS."

Margot Algie, person living with ALS
and facilitator of peer support group

We appreciate that Ontario is taking a leadership position on improving the process as a member of the Expensive Drugs for Rare Diseases Working Group, and understand that Health Canada and the Canadian Agency for Drugs and Technology in Health have taken steps to streamline reimbursement recommendations, but there is more work to be done – especially given the fact that the majority of people living with ALS die within two to five years of diagnosis. Our concern as we look to the future is that the agencies and decision-makers proposing changes are not taking into consideration emerging therapies and the realities



of living with a terminal illness. We don't want to see a single person lose their life while waiting to see if a newly-approved treatment will be covered by the provincial formulary.

Hope for the Future

With the recent approval of edaravone and the number of ALS therapies in the development pipeline, now is the time to make sure the challenges of past are not repeated as other therapies come forward.

The ALS community is one that measures time by loss – loss of their own function and loss of community members. Approximately 500 Canadians died of ALS during the expedited review that Health Canada undertook for edaravone. How many more will die while we wait to learn whether the drug will be covered by the Ontario Public Drug Program?

Here's what government can do:

Recommendation: Work together with other provinces, territories and the federal government, in consultation with stakeholders, to streamline and condense the entire drug access process, from approval to public reimbursement.

Recommendation: Work with the same partners to develop a strategy to improve transparency in Canada's regulatory and reimbursement framework and ensure a consistent funding approach across each province.

5 | SUSTAINABLE LONG-TERM ACCESS TO HOME AND COMMUNITY CARE

Ensure home and community care is sustainable and provides the care that people with a complex terminal illness like ALS need.

An effective home and community care system must prioritize the needs of those it serves and build a foundation for all agencies and care providers to work together to ensure the highest quality, safest and most efficient service is provided. In Ontario, the current system is challenging to navigate with different agencies working in silos and significant variation in service levels across LHINs. For example, the level of government-funded support can differ from region to region, even for people with the exact same disease and care needs. In addition, because of how complex the system is, few people manage to receive the maximum levels of home and community care services they qualify for.

For those Ontarians who are able to secure home and community care funding, human resources challenges mean there often aren't enough qualified personal support workers (PSWs) to provide the required levels of support. This can result in PSWs needing to miss shifts or individuals unfamiliar with the person coming to the home, putting both the family and patient at risk.

In the end, it is Ontario families who suffer the consequences of these inconsistencies and complications. And for Ontario families living with ALS, sufficient home and community care could mean the difference between their loved ones being able to live safely at home and needing to live in a complex care or ICU unit at the hospital. For example:

- An Ontarian living with ALS frequently experienced gaps in care when their PSW would not show up for evening appointments. The situation was made even more challenging when a new PSW arrived who was unfamiliar with the person's care needs. As a result, this person's elderly mother was often put in the position of needing to



physically pick up her adult child living with ALS in order to transfer them into bed, thus putting both herself and the person living with ALS at risk of injury. Furthermore, despite a specific request for female personal support workers given the intimate nature of care required, male workers continued to be assigned to provide the care. In the end, the person living with ALS chose to go to hospice for their last days instead of living at home with family because relying on home and community care to provide consistent and quality care was no longer a viable option.

Innovative solutions are needed to build a home and community care system that keeps all Ontarians, including those living with ALS safely at home and out of the hospital.

Here's what government can do:

Recommendation: Implement a health human resources strategy that includes proper training, wages and benefits to attract personal support workers to the home and community care sector.

Recommendation: Reconsider the current contract model to create integrated neighbourhood care teams for people.

Recommendation: Work with LHINS to establish consistency in access and levels of care across the province.



6 | 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 bringing needed care and equipment and moving promising ALS treatments swiftly through the system so that all Ontarians can access supports they need when they need them. This will make a significant difference to the 1,000 Ontario families living with ALS, and these low- or no-cost solutions will help build a better quality, more efficient health system and assist in ending hallway medicine. We urge the government to consider our five recommended strategies to help Ontarians receive the care they need:

1. Remove barriers to participation in the Direct Funding Program: Ontarians living with ALS stand to benefit greatly from the Direct Funding Program – yet there are significant barriers to accessing it. Simple solutions would better serve those the program intends to help.

2. Provide fair access to non-invasive respiratory support: Extend the Ventilator Equipment Pool to enable people living with ALS to use BiPAP devices regardless of where they live.

3. Improve access to essential mobility and communications equipment: Making essential mobility and communications equipment available for longer periods of time and in all communities across the province would help to keep people living with ALS out of the hospital and reduce duplication.

4. Improve timely access to therapies: Implement a real plan that streamlines the process for newly-approved treatments moving through the Ontario Public Drug Program.

5. Sustainable long-term access to home and community care: Ensure home and community care is sustainable and provides the care people with a complex terminal illness like ALS need.



ALS SOCIETY OF CANADA RECOMMENDATIONS	GOVERNMENT PRIORITIES			
	End hallway medicine	Build higher-quality, more efficient home and community care system	Restore trust and accountability	Find efficiencies and better value for money
Remove barriers to participation in the Direct Funding Program	✓	✓		✓
Provide fair access to non-invasive respiratory support	✓	✓		✓
Improve access to essential mobility and communications equipment	✓	✓		✓
Improve timely access to therapies			✓	✓
Sustainable long-term access to home and community care		✓	✓	✓

7 | ALS IN ONTARIO¹



925

People living with ALS
registered with ALS Canada



482

People living with ALS using the
ALS Canada equipment program



1,984

Equipment requests fulfilled



100+

Total support group meetings for
caregivers and people living with ALS

8 | THE ALS SOCIETY OF CANADA

The ALS Society of Canada has the privilege and responsibility of connecting every day with people who are living with ALS and supporting them in their journey. They are our clients, our colleagues, and our friends. We see firsthand the tremendous impact of the disease – physically, psychologically, and financially.

Working in partnership with ALS Societies across the country, we aim to maximize our impact to make the greatest difference for people living with ALS while responding to the variation that exists between provincial healthcare systems where we each play a role in filling gaps. Within Ontario, ALS Canada is responsible for providing services and support to help meet the needs of people living with ALS in this province.

In Ontario, ALS Canada's team of Regional Managers assists people and families living with ALS in navigating their

journey. Regional Managers offer home and virtual visits to discuss individual and family needs, provide information and education, and assist with connecting Ontarians to other healthcare providers and community supports. They also facilitate support groups for people living with ALS as well as caregivers. Additionally, through the ALS Canada Equipment Program, ALS Canada helps Ontarians diagnosed with ALS to cope with the daily challenges of decreasing mobility and communication ability and to help with retaining independence. The Program provides access to basic and essential assistive equipment through a pool of loaned equipment; funding assistance for some leased and rented equipment and flexible funding for small bathroom equipment.

ALS Canada receives no government funding at any level and is supported entirely by the generosity of donors.



¹ Based on ALS Society of Canada client files and registration details.