

2020 PRE-BUDGET
SUBMISSION FROM THE
ALS SOCIETY OF CANADA



MODEST CHANGES; BIG IMPACTS

IMPROVING ALS CARE IN ONTARIO



Picture yourself sitting on your couch when, suddenly, you feel an itch on your forehead, **but you can't scratch it.**



Imagine trying to get out of bed to use the washroom in the middle of the night, **but you can't move.**



Think about wanting to tell someone you love them – **but you can't speak.**

This is the reality faced **every day** by Ontarians living with Amyotrophic Lateral Sclerosis (ALS).

ALS is a terminal disease that involves the brain and spinal cord, the muscles of the body, and the motor neurons that send signals between the two. Because ALS causes the motor neurons to die, over time the brain stops communicating with the muscles, causing them to become gradually weaker and resulting in progressive paralysis, including losing the ability to walk, talk, eat, move, swallow and eventually breathe.

With no cure for ALS, and few treatment options available, four out of five people with ALS will die within five years of diagnosis.

ALS does not discriminate — anyone can develop the disease regardless of gender, socioeconomic status, geography, or race. Any given year, approximately 1,000 Ontarians are living with ALS, but the number of people affected is even more significant when you consider the profound emotional, financial and psychological impact of the disease on family members, caregivers, and friends.

At ALS Canada, we have the privilege and responsibility of connecting every day with people and families who are living with ALS and supporting them in their journey. We want a future where Ontarians diagnosed with ALS have access to treatments and services that are fully covered by Ontario's health system. A future where they have long-term equipment to give them dignity, independence and a home where they can live safely. And a future where community care and supports are available to families and caregivers, keeping them out of the hospital and improving their quality of life.



THE REALITY OF ALS¹

ALS changes everything.

ALS is “slowly being imprisoned in a non-functioning body.”

Living with ALS is like “running full speed on a treadmill but still moving backwards.”

The disease “took over my life.”

WORKING TOGETHER TO IMPROVE CARE FOR PEOPLE WITH ALS

Over the past year, significant steps have been taken to strengthen Ontario's health system. These changes include programs to focus the system on patients, end hallway health care, cut red tape, and give Ontarians the care they need when they need it. We are eager to work with government to make sure this ambitious agenda improves the lives of every Ontario family living with ALS.

We have developed three recommendations that will help achieve this goal. Not only will our recommendations improve the lives of people living with ALS, but they will also help the government in its comprehensive four-pillared plan to end hallway health care. They are smart, low-cost solutions that aim to eliminate some of the gaps in current care models and are essential to creating a sustainable, effective, and modern health system capable of creating a better patient experience, and the health system that all Ontarians want to see.



For a terminal disease that affects a relatively small community, modest changes and investments by government can have a huge impact on families living with ALS by bringing them needed care, equipment and promising treatments.

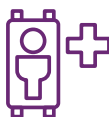
WITH THESE CHANGES, **GOVERNMENT CAN HAVE A BIG IMPACT** ON PEOPLE & FAMILIES AFFECTED BY ALS:

1



Cut red tape preventing Ontarians from getting fair, timely, and affordable access to newly-approved drugs.

2



Modernize Ontario's medical equipment program to reduce hallway health care and increase patient safety and independence.

3



Make sure people have the support they need to live at home and in the community.

RECOMMENDATION 1

CUT RED TAPE PREVENTING ONTARIANS FROM GETTING FAIR, TIMELY, AND AFFORDABLE ACCESS TO NEWLY-APPROVED DRUGS.

ONTARIO'S LENGTHY DRUG REIMBURSEMENT WAIT TIMES

Fair, timely and affordable access to proven ALS therapies should not be a luxury – it should be a given. While Ontario's Public Drug Program (OPDP) provides relief to families by reimbursing the cost of a limited number of drugs, there continue to be gaps and barriers in the province's reimbursement system, particularly for people living with a disease like ALS that has a relatively small population.

Under the current pathway, people can wait two to three years or more for a drug to become available through public drug plans once approved by Health Canada. Some drugs for rare diseases have taken significantly longer. We are encouraged by the efforts underway to review the OPDP, but the ALS community cannot wait.

Most people with ALS will die within five years of diagnosis. Time for them and their loved ones is measured not by months or years, but by loss – loss of function and loss of life. In the years it takes for a drug to go through the entire drug access pathway, including the OPDP reimbursement decisions, more than a thousand lives in Ontario will be lost to this devastating disease.

As government reforms the OPDP, it is critical to address the urgent need for access to emerging therapies and the realities of living with a terminal illness. A comprehensive plan must be put in place to streamline the process for newly-approved ALS therapies moving through the OPDP.



ALS can cost a family upwards of \$150,000 to \$250,000, including the cost of treatment, care, and equipment needs, as well as the income families lose when people living with ALS and family caregivers stop working.¹

1 Gladman et al. Economic burden of amyotrophic lateral sclerosis: a Canadian study of out-of-pocket expenses. Amyotroph Lateral Scler Frontotemporal Degener. (2014) 15: 426-32.

HERE'S WHAT THE GOVERNMENT CAN DO

1



Expedite and prioritize the Ontario Public Drug Program's reimbursement decision for Radicava (edaravone), which is only the second ALS treatment to receive Health Canada approval and the first in nearly 20 years.

2



Work in collaboration with the federal government to eliminate barriers preventing all Ontarians from getting timely access to the ALS drugs they need at no cost to them.

3



Demonstrate leadership by partnering with patient organizations, front-line providers and other health stakeholders to understand the issues and opportunities to reform the drug reimbursement process in Ontario.

CASE STUDY

OUR COMMUNITY'S EXPERIENCE WITH RADICAVA (EDARAVONE)

“ALS is a death sentence. Waiting and watching your body lose its ability to be controlled is emotionally and physically draining. People need hope in their lives and Radicava could be that seed of hope. Hope all is needed to live a more fulfilled life.”

– A PERSON LIVING WITH ALS ON THE HOPE RADICAVA BRINGS

In October 2018, Health Canada approved Radicava (edaravone) for use in Canada. Radicava is only the second ALS treatment to receive Health Canada approval and the first in nearly 20 years. Yet, over a year after its approval by Health Canada through a Priority Review and positive funding recommendations (with conditions) from CADTH and INESSS, Radicava is still not available through public reimbursement to people living with ALS in Ontario.

People affected by ALS have expressed that Radicava access would bring a tremendous amount of hope. They have said it would mean “everything,” “more time,” and “the world.” These kinds of sentiments are shared not only by people living with ALS, but also by caregivers, family members, and friends.

Deemed a safe and effective treatment for ALS by Health Canada, Radicava has been shown to slow the progression of this degenerative, debilitating and ultimately fatal disease in a segment of people living with ALS. Yet, with no defined timeframe or transparency in the public reimbursement process, Ontarians living with ALS have no sense of how long they might have to wait to have affordable access to the drug.

Now that the manufacturer of Radicava has entered into active negotiations with the pan-Canadian Pharmaceutical Alliance (pCPA), Ontario has the opportunity to take a leadership role within these negotiations by urging the signing of a Letter of Intent to reimburse this therapy.

People who may benefit from edaravone must have timely, equitable and affordable access to this important therapeutic option. For those individuals and families who continue to measure time by the unimaginable loss of living with ALS, we urge public and private drug plans alike to enable access to Radicava without further delay.

“[Radicava would mean] more family and community time, Christmas, birthdays, camping, helping others with ALS... more hugs and ‘I love yous’... more time to treasure.”

– CAREGIVER ON WHAT RADICAVA WOULD MEAN FOR THEM & THEIR LOVED ONES

TIMELINE OF RADICAVA'S JOURNEY

MAY 2017	FDA APPROVES RADICAVA (EDARAVONE)
MAR 2018	MANUFACTURER APPLIED TO HEALTH CANADA
APR 2018	A PRIORITY REVIEW OF RADICAVA BY HEALTH CANADA BEGINS
MAY/JUNE 2018	CADTH & INESSS CALL FOR PATIENT INPUT
OCT 2018	HEALTH CANADA APPROVES RADICAVA FOR TREATMENT FOR ALS
JAN 2019	INESS POSITIVE FUNDING RECOMMENDATION (WITH CONDITIONS)
MAR 2019	CADTH POSITIVE FUNDING RECOMMENDATION (WITH CONDITIONS)
OCT 2019	PCPA CONFIRMS THE MANUFACTURER HAS BEEN INVITED TO PARTICIPATE IN NEGOTIATIONS, BUT NO CONFIRMATION THEY HAVE BEGUN
OCT 2019	RADICAVA COMMERCIALY AVAILABLE IN CANADA
OCT 2019	SOME PRIVATE INSURERS AGREE TO COVER THERAPY
??	DRUG PRICE IS SET BY PMPRB
??	PCPA NEGOTIATIONS CONCLUDE AND ONTARIO AND OTHER PROVINCES/ TERRITORIES SIGN A LETTER OF INTENT
??	PUBLIC REIMBURSEMENT IN ONTARIO

RECOMMENDATION 2

MODERNIZE ONTARIO'S MEDICAL EQUIPMENT PROGRAM TO REDUCE HALLWAY HEALTH CARE AND INCREASE PATIENT SAFETY AND INDEPENDENCE.

EQUIPMENT AS AN ESSENTIAL HEALTH CARE SERVICE

As a person's ALS progresses, they slowly lose the ability to move and speak. Mobility and communications equipment and devices, can drastically improve the quality of life for people living with ALS. Equipment is critical to helping people maintain independence, dignity, and ability – all while helping them live safely within their homes and out of hospital.

However, there is currently no government-funded mechanism that enables people with ALS to access mobility equipment for more than 30 days consecutively. While some LHINs provide some equipment, it is for acute short-term use only and there is considerable variation in practice across the province.

To access equipment for the length of time they need it, which is often longer than 30 days, Ontarians living with ALS must rely on the support of ALS Canada, a charitable organization that is funded entirely by donors, to fill the gap. We do this by providing much-needed equipment free of charge to people with ALS and financial assistance for people in need to help with the client portion of the government programs for power wheelchairs and communication devices. In a province like Ontario, with a strong public health care system, people should not have to rely on charity to access the equipment that is necessary for them to move and live safely in their own homes. Giving people living with ALS the equipment they need for longer periods, and making the process of getting this equipment easier, will keep people in their homes and out of hospitals, which in turn will reduce hallway health care and cut wait times.

DUPLICATION OF SERVICES

To make sure people living with ALS have the equipment they need for the length of time they need it, 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 strain on people already living with a challenging disease when they must have multiple providers in their homes for the same services.



In 2018, the ALS Canada Equipment Program provided 2,600 pieces of equipment, at a cost of \$1.3 million, to Ontarians living with ALS at no cost to the family.



FAIR ACCESS TO NON-INVASIVE RESPIRATORY SUPPORT

A BiLevel Positive Airway Pressure (BiPAP) machine is a device that can help a person living with ALS breathe more comfortably, significantly improving their quality of life. This equipment is funded through the Ministry of Health's Ventilator Equipment Pool (VEP) under the Assistive Devices Program (ADP), which currently specifies that equipment and training are provided in the home but excluded in long-term care facilities. But, for people living with ALS, living at home is not always feasible and they cannot transfer the BiPAP to long-term care or residential hospices. This puts them in an impossible position of having to choose between breathing comfortably and remaining at home with inadequate care or losing their BiPAP device and their quality of life so they can get the level of care they need in a long-term care home or residential hospice.

A working group of representatives from the government divisions of long-term care and ADP, along with ALS Canada and various health care providers and associations has been developed to look at the issue. However, momentum has slowed over the past year and people living with ALS cannot wait. BiPAP devices must be allowed to be transferred into long-term care homes or residential hospices.

CASE STUDY

QUALITY OF CARE VS. QUALITY OF LIFE

An Ontarian living with ALS was hospitalized while living in a long-term care home. While in the hospital, doctors decided that the person would benefit from a BiPAP device to help them breathe more comfortably. Because the person was now using the BiPAP device they could not return to their long-term care home, unless they gave up use of the equipment. This put

them in the position of needing to choose between their quality of life or their quality of care. With nowhere else to go, they had to stay in hospital resulting in unnecessary and higher costs to the health care system. In the end, the person died from ALS in the hospital instead of in the long-term care home where they felt most comfortable and safe.

HAVING A STRONG, RESPONSIVE ASSISTIVE DEVICES PROGRAM

People living with ALS also face barriers to access when trying to get new and innovative equipment. For example, the sophistication of power wheelchairs has been increasing over the past few years, creating opportunities for people to live with more independence. But these sophisticated power wheelchairs are more expensive, creating an increased cost to people and families, which is not covered by ADP. Instead, what is available through ADP can be partially outdated and not responsive to the changing demands of a disease that causes progressive paralysis. Additionally, what is considered 'basic' equipment is evolving and not always incorporated into the lists of approved equipment quickly enough.

Even when someone living with ALS does receive equipment through ADP, it can take months for it to be delivered. If they need that equipment repaired, they can be without it for weeks more, robbing them of precious time and independence. If they rely on a power wheelchair to get outdoors and participate in daily activities, delays in repairs can lead to weeks of being unable to leave the house. Also, when you consider that people living with ALS often rely on communications devices to speak, a loss of their device – for even a day – means less autonomy, dignity and connection to the world. Without the ability to communicate, they are completely “locked in” and they cannot tell people what they need.

Ensuring people have access to the newest and most innovative equipment and communications technology and that equipment lending and repairs are done quickly and with as little disruption to independence as possible will help people affected with ALS live more safely and at home for longer.

“The technology is great until it shuts down inexplicably...far too often, it needs to be serviced externally, taking three to five days during which I am unable to work or express myself. These episodes are infuriating and exhausting for us. I am even more helpless than usual, and Darlene has to be hypervigilant because I am unable to express my needs...My technology and access to the internet are vital to life within the horrendous physical restrictions of ALS.”

- EXCERPT FROM DR. JEFF SUTHERLAND'S BOOK STILL LIFE

HERE'S WHAT THE GOVERNMENT CAN DO

1



As Ontario Health and Ontario Health Teams (OHTs) are established, they must be mandated to provide access to essential medical equipment for the length of time people need it. A standard approach across OHTs that permits long-term or indefinite use of equipment by people living with ALS will remove duplication and ensure consistent access to vital devices.

2



Extend the Ventilator Equipment Pool and associated staff education supports to enable people living with ALS to use BiPAP devices at all long-term care and residential hospices in Ontario.

3



Update the Assistive Devices Program to offer the newest and most innovative equipment and communications technologies in its listings and cut red tape to speed up equipment lending and repair processes.

RECOMMENDATION 3

MAKE SURE PEOPLE HAVE THE SUPPORT THEY NEED TO LIVE AT HOME AND IN THE COMMUNITY.

A FLEXIBLE AND EFFECTIVE PERSONAL SUPPORT WORKER FRAMEWORK IN ONTARIO

PSW recruitment and retention challenges are well documented and recognized as an urgent issue in the province's health care system. Low wages, long hours, burnout, reliance on part-time employment contracts and lack of career advancement opportunities for PSWs have resulted in a growing shortage of this vital health human resource in the province. This negatively and directly impacts people across Ontario and within the ALS community.

Due to the complex and progressive nature of ALS, people living with the disease have substantial home and community care needs, which are often not being fulfilled by our home care system. This negatively affects the quality and level of care every day. People living with ALS often fail to receive enough PSW visits per day, have critical PSW shifts go unfilled or cancelled (often at the last minute), or PSWs who are unfamiliar with and unable to manage their complex care needs. In the end, people living with ALS can be left at home alone for long periods without supports that help them to do basic things like moving, eating and going to the washroom, or put in a compromised and dangerous situation by untrained staff.



CASE STUDY

WHEN PSW HOURS ARE NOT ENOUGH

A woman in Ontario living with ALS had rapidly progressed and lost the ability to move and speak within six months of diagnosis. Her caregiver was her husband – who was in bad health with serious heart issues. As a family they relied heavily on home care but consistently had issues with PSW support and continuity of care. Despite making it clear to all service providers that the husband was continually in the position of needing to provide care he was not physically capable of, they were not allocated enough PSW hours to provide proper care. And the small number of shifts they did have were often cancelled last minute. As a result, the woman living with ALS was often stranded for hours without anyone to help

her do the basic things she needed to do. Some days she had to hold her bladder for upwards of 4 hours until a PSW would arrive to take her to the bathroom.

One day the woman living with ALS was waiting for her PSW to show up, but no one arrived. After hours of waiting, her husband had no other choice but to try to move his partner to the washroom. In a devastating turn of events, her husband had a massive heart attack and died while moving her, dropping and severely injuring the woman living with ALS. She had to lay there, unable to move with her deceased husband beside her until the next PSW shift started three hours later.



On top of this, caregivers and family members are often the ones left to pick up the substantial levels of care that can be strenuous and dangerous, putting their health at risk.

Ontario needs a comprehensive and integrated health human resources strategy that includes a strong focus on recruitment and retention of PSWs so that people get the care they need when and where they need it. In particular, ensuring a robust and reliable supply of PSWs in home and community care will help people and families living with ALS live more safely and independently at home and for longer.

IMPROVING HOME AND COMMUNITY CARE WITH HEALTH SYSTEM PARTNERS

Organizations like ALS Canada play a vital role in providing services and care to people who need it. They help by filling gaps in our health care system, particularly for people living with chronic, rare and complex illnesses. Their patient supports can help delay admission to long-term care, reduce unnecessary emergency room visits, and enhance community care that is closer to home.

At ALS Canada, we act as system navigators, information providers, emotional support and equipment lenders for people and families affected by ALS. Today about 40% of caregivers find themselves responsible for organizing the different members of a loved one's health care team and nearly two-thirds of people caring for someone in the same household are solely responsible for managing and organizing all caregiving tasks². Our team of ALS Canada Regional Managers across the province helps families living with ALS navigate the complicated health system to receive the care they need. But despite our best efforts, families and caregivers still struggle to manage the varying and complex care needs of a person living with ALS.

OPPORTUNITY WITH OHTS

With the Ontario Government's rollout of OHTs, there is a significant opportunity to redesign the delivery of home and community care. It can be done in a much more effective way that reduces the burden on families and caregivers, the health system, and patient organizations like ALS Canada, all while improving people's quality of life.

2 Second Annual Spotlight on Ontario's Caregivers. The Change Foundation and The Ontario Caregiver Organization. November 2019. <https://www.changefoundation.ca/spotlight-on-caregivers-report/>

To further integrate the patient experience and strengthen local services that patient organizations provide, the government must engage Ontario's numerous patient organizations in consultation as OHTs are developed and rolled out. Doing so will give government the chance to leverage patient organizations' front-line insights and supports to better incorporate their vital services in integrated care teams.

SPECIALIZED SERVICES AND CARE IN OHTS

We are encouraged by the potential for OHTs to provide better-integrated care at home and in the community, including for people and families affected by ALS. That said, to be successful, the government needs to ensure that OHTs partner with existing teams of health providers already serving specialized patient populations, including Ontario's ALS Clinics.

There are currently six ALS Clinics in Ontario responsible for providing front-line care to people living with the disease. People from both the local area and nearby regions will attend the clinic to connect with a neurologist and comprehensive multidisciplinary team to receive the complex care they need. Under the new design, OHTs should be able to work with any ALS Clinic that is providing service to people within their defined catchment area, even if the Clinic is geographically located outside their region.

Ensuring that OHTs allow Ontarians diagnosed with ALS, or in the diagnosis process, to access the specialized multidisciplinary health care offered by ALS Clinics is critical to truly-integrated, patient-centred care.

ALS Clinics are multidisciplinary centres aimed at delivering expert care to people and families living with ALS. They provide education, monitoring and timely interventions, all while promoting regular communication with an individual's family doctor and community health care providers. The Clinics are among the community of researchers in Canada working to discover effective treatments for ALS.

HERE'S WHAT THE GOVERNMENT CAN DO

1



Establish a comprehensive province-wide health human resources strategy that includes a plan to hire, train, and retain PSWs who can better address the complex needs of people living with ALS.

2



Expand consultations and engagement with Ontario patient organizations, including ALS Canada, as OHTs are developed and rolled out so that our health care system can become further integrated with the services, care, information, and education that organizations like ours provide.

3



Make sure ALS Clinics are designated specialized support services to all OHTs, so that Ontarians living with ALS can access integrated treatment and multidisciplinary support, regardless of where they live in the Province.



CONCLUSION

We are encouraged by the steps the government has taken to build a better-integrated, more patient-centred health system. Still, all too often, people and families affected by ALS fall through the cracks due to their unique and complex care needs. They need quicker and fairer access to approved therapies like Radicava that give them hope, a more comprehensive range of reliable equipment that returns their independence, and more consistent home and community care that enables them to live longer in their own homes.

The ALS community is eager to work with government as you consider our recommendations.

Together we can make modest changes with big impact to bring care and hope to Ontario families affected by ALS.

ALIGNMENT WITH THE GOVERNMENT OF ONTARIO'S 4-PILLAR PLAN TO END HALLWAY HEALTH CARE.

ALS SOCIETY OF CANADA RECOMMENDATIONS:	PILLARS OF THE GOVERNMENT'S PLAN TO END HALLWAY HEALTH CARE			
	PREVENTION & HEALTH PROMOTION	PROVIDING THE RIGHT CARE IN THE RIGHT PLACE	INTEGRATION & IMPROVED PATIENT FLOW	BUILDING CAPACITY
Cut red tape preventing Ontarians from getting fair, timely, and affordable access to newly-approved drugs	✓	✓		
Modernize Ontario's medical equipment and supply program to reduce hallway health care and increase patient safety and independence	✓	✓	✓	
Make sure people have the support they need to live at home and in the community	✓	✓	✓	✓



THE ALS SOCIETY OF CANADA

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.

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 health care 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 health care 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 or flexible funding for some leased, rented equipment or purchased equipment.



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