

# CREATING CONSISTENCY

IMPROVING HOME AND COMMUNITY CARE ACROSS ONTARIO



WHILE YOU READ THIS DOCUMENT, TRY REMAINING ENTIRELY STILL. RESIST ANY URGES YOU MAY HAVE TO MOVE, ITCH, FIDGET OR ADJUST YOUR BODY. DON'T SPEAK. DON'T DRINK OR EAT. STAY COMPLETELY SILENT AND STILL.

THIS WILL GIVE YOU JUST A SMALL SENSE OF WHAT A PERSON LIVING WITH AMYOTROPHIC LATERAL SCLEROSIS (ALS) EXPERIENCES EVERY DAY.

"ALS is a death sentence. Waiting and watching your body lose its ability to be controlled is emotionally and physically draining."

**ALS IS A PROGRESSIVE TERMINAL DISEASE** that involves the brain and spinal cord, the body's muscles, and the motor neurons that send signals between the two. The disease causes progressive paralysis, and eventually someone with ALS will lose the ability to walk, talk, eat, move, swallow – and breathe.

**RECEIVING AN ALS DIAGNOSIS IS DEVASTATING**, and the physical, emotional, and financial impact of the disease on a person and their family is immense. Due to ALS's complex nature, people living with the disease have substantial care needs that evolve and increase over time. This care can include supporting the activities of daily living, such as moving, eating, dressing, showering and going to the washroom.



WITHIN THE CURRENT HOME AND COMMUNITY CARE SYSTEM, GOVERNMENT-FUNDED SERVICES PROVIDE SOME SUPPORT TO HELP FAMILIES. YET ALL TOO OFTEN THE HEALTH SYSTEM FAILS TO MEET THE UNIQUE NEEDS OF PEOPLE AND FAMILIES LIVING WITH ALS. MUCH OF THE CARE FALLS ON THE SHOULDERS OF FAMILY AND FRIENDS. THIS CHALLENGE HAS ONLY GROWN WITH THE ONGOING COVID-19 PANDEMIC.

**DONOR-FUNDED ORGANIZATIONS LIKE ALS CANADA MUST STEP IN TO HELP.** We offer equipment loans to any Ontarian living with ALS, help them navigate the health system, and facilitate support groups. While we do not provide direct care, the supports we provide can delay admission to long-term care, reduce unnecessary emergency room visits, and enhance community care. With the stress COVID-19 is placing on hospitals and long-term care, our work is more vital than ever. But acute fundraising challenges arising from the pandemic now put these programs at risk.

THE PANDEMIC IS ALSO INCREASING PRESSURE AND UNCERTAINTY IN THE LIVES OF ONTARIANS LIVING WITH ALS. Day-to-day stressors are on the rise – disease progression, isolation and mental health challenges, financial impacts, and difficulty accessing qualified paid caregivers and necessary medical procedures. Continuity of care has been threatened, existing challenges amplified, and new issues are emerging that impact the entire ALS community.

The number of ALS Canada-facilitated support groups rose approx. 50% since the start of the COVID-19 pandemic. (March 2020).

### NOW IS NOT THE TIME FOR THE 1,000 ONTARIO FAMILIES LIVING WITH ALS TO BE AT THE MERCY OF THE UPS AND DOWNS OF CHARITABLE FUNDRAISING.



No person should have to go without the care and support they need to live safely at home, forced into hospital or long-term care in the midst of a global pandemic and contributing to hallway health care.

**BUT THERE IS HOPE.** Government has an important opportunity to respond to these unprecendented circumstances in a way that will create a future where Ontarians diagnosed with ALS can access all of the treatments and services they need. A future where they have long-term access to equipment that will give them dignity, independence and the support they need to live safely. And a future where high-quality, reliable community care and supports are available to families and caregivers, keeping them out of the hospital and improving their quality of life.

ALS Canada. Based on organizational data, number of ALS Canada-facilitated support groups in Ontario in 2019/2020.

### **IMPACT OF AN ALS DIAGNOSIS**

**The disease carries a tremendous burden** - emotionally, mentally, physically and financially.

**Every situation is different** with unique considerations.

**Families often face a \$150,000 to \$250,000 financial burden** over the course of the disease, 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.

### WHO IS AFFECTED?

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 impact of the disease on family members, caregivers, and friends.

**With no cure**, 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.

### **OPPORTUNITIES AHEAD**

Government has taken significant steps to protect Ontarians from COVID-19 and stabilize the economy. Now, with new vaccines available, it's time to start thinking ahead about how to capitalize on what we as a society have learned. We must improve our health system for generations to come. Together we can build on initiatives in long-term care and hospitals so that all Ontarians, including those living with ALS in home care settings, receive the care they need. We can create a more integrated, more patient-centred, and more compassionate health system.

We have developed four recommendations for the Government of Ontario that would reduce the burden on the health system and improve the standard of care provided to people and families living with ALS, as well as Ontarians with other life-limiting diseases and conditions.



- SUPPORT THE NON-PROFIT SECTOR SO VULNERABLE ONTARIANS DON'T LOSE ACCESS TO VITAL CARE IN THE MIDST OF A PANDEMIC.
- MODERNIZE ONTARIO'S
  EQUIPMENT PROGRAMS
  TO REDUCE RED TAPE,
  INCREASE EFFICIENCY AND
  MITIGATE THE SPREAD OF
  COVID-19.
- ENSURE ALL ONTARIANS
  HAVE ACCESS TO
  NECESSARY HOME AND
  COMMUNITY CARE
  SUPPORTS, REGARDLESS
  OF WHERE THEY LIVE.
- 4 ELIMINATE BARRIERS
  PREVENTING ONTARIANS
  LIVING WITH ALS FROM
  HAVING TIMELY, FAIR AND
  AFFORDABLE ACCESS TO
  THE DRUGS THEY NEED.

# SUPPORT THE NON-PROFIT SECTOR SO VULNERABLE ONTARIANS DON'T LOSE ACCESS TO VITAL CARE IN THE MIDST OF A PANDEMIC.

Like other health charities across the province, ALS Canada fills gaps in our health system by providing essential supports and services to some of Ontario's most vulnerable people. However, the COVID-19 pandemic has hit health charities hard – resulting in a significant reduction in fundraising revenues paired with an overwhelming increase in demand for services. This is putting vital supports at risk.

As a 100% donor-funded charity, ALS Canada has been affected considerably. In 2020 our revenues decreased by approximately 30 per cent because we could not host in-person fundraising events and onsite activities with our corporate partners which are instrumental to our ability to raise funds. It will take years for the health charity sector to recover.

Recent relief programs are a step in the right direction, but red tape gets in the way of charities that serve a vulnerable population throughout Ontario. For example, March 2020's \$200 million in social services relief funding was administered municipally; organizations that operate at a provincial level like ours were ineligible. We have done our best to leverage aid community by community, but these project-specific micro-grants require excessive administration for the funding given and do not reflect our province-wide service delivery model.



The support services we provide to Ontarians are critical to helping improve care and quality of life for the hundreds of families living this devastating illness. We fear that without increased financial assistance from government, many of them could be face the dire and tragic situation where they cannot access the support they need.

They will have no choice but to turn to hospitals or long-term care homes, putting more strain on our system at a time when capacity must be reserved for those with the most critical need.

That's why we're in alignment with the Ontario Non-profit Network (ONN) and other provincial health charities in urging the government to further support the Province's charitable and non-profit sector by taking the following actions.

### **HERE'S WHAT GOVERNMENT CAN DO:**

### **CREATE A STABILIZATION**

**FUND** for the non-profit sector so that charitable organizations, like the ALS Society of Canada, can continue to provide the critical support services that help people living with ALS and their caregivers across the province.

# **PORTION** of the Charitable Donation Tax Credit through to the end of 2021 and make the credit refundable so that charitable contributions are treated the same as a contribution to a political party in Ontario.

**COMMIT TO MATCHING DONATIONS** from all Ontarians to provincial charities or national charities with provincial mandates.

# ENSURE ALL ONTARIANS HAVE ACCESS TO NECESSARY HOME AND COMMUNITY CARE SUPPORTS, REGARDLESS OF WHERE THEY LIVE.

# A COMPREHENSIVE, FLEXIBLE AND EFFECTIVE PERSONAL SUPPORT WORKER FRAMEWORK IN ONTARIO.

Personal Support Workers (PSWs) provide essential care for people and families living with ALS. They play a critical role in delivering high-quality care to the ALS community. They do this despite working in inadequate conditions that include low wages, long hours and burnout, and lack of training. Due to these health system inadequacies our team of Regional Managers, who connect every day with Ontarians living with ALS to help them navigate their ALS journey, often hear of circumstances where people fail to receive the support they need to live safely and with dignity in their homes. Our community does not receive enough PSW hours per day, experiences critical PSW shifts that go unfilled or cancelled (often at the last minute), or are provided PSWs who don't know how to manage their complex care needs.

This leaves people living with ALS on their own for long periods without the help they need for activities we take for granted, like moving, eating, and going to the washroom. They must turn to personal caregivers such as family or friends (if available) to provide enormous amounts of care, which can be strenuous, dangerous and puts the health of the caregivers at risk.

Government has taken some action to address these concerns. We applaud recent government announcements increasing the level of home care for people transitioning out of hospital and raising PSW wages and the number of hours of care/day in long-term care homes. But there needs to be a robust and reliable supply of PSWs in home and community care to help people living with ALS.

As Ontario continues its ambitious transformation of our health system, the province needs a comprehensive and integrated health human resources strategy that includes a strong focus on recruitment, retention and training of PSWs in the home and community sector.



### **CASE STUDY**

A 67-year-old woman lived alone in her home after her husband died of brain cancer. She was diagnosed with ALS one month after he passed away and the disease has progressed quickly. Through her LHIN she originally received one hour of PSW support, two mornings a week. This did not meet her needs. As a result of her disease's progression, she could not care for herself without support and needed to use medical and mobility equipment. After several falls, the LHIN reallocated her PSW care to one hour in the morning and one in the evening, however, this still meant that for 22 hours a day she was

not being supported. In any other circumstance she would have moved to a long-term care facility but due to the COVID-19 pandemic, only crisis beds were available. The LHIN continued to look for PSW support, but due to PSW shortages she was unable to receive the right amount of support hours to live safely at home. This meant the only remaining option available for her was to be admitted to hospital, increasing the strain on an already burdened health system.

### **PALLIATIVE CARE SUPPORTS**

Until more effective therapies are available, palliative care will continue to be part of a person's ALS journey. Palliative supports provide improved care and better prepare people and families for end-of-life. And earlier palliative care consultations can help people with ALS access services and supports that improve quality of life. Palliative care services empower families to make care decisions that reflect their wishes. Every person living with ALS should have the same basic supports whether they live in rural Ontario or downtown Toronto.

Yet access to these supports and services can be inconsistent. The point within disease progression where a person qualifies for palliative care varies from region to region. As well, once a person living with ALS is considered palliative, the types of services they can access differ depending on where they live. One region may have access to respiratory therapists or additional nurse practitioner hours while another has none.

According to a 2019 paper published in the journal Neurology that explored the use of palliative care services in Ontario, fewer than half of the people living with ALS had access to palliative care services<sup>2</sup>. Whether services were not offered to people living with ALS, or they did not know or understand their palliative care options, this further demonstrates the inconsistencies.

We applaud Members of Provincial Parliament for adopting the *Compassionate Care Act*, 2020 in December 2020, which is a step in the right direction for supporting Ontarians living with ALS. We believe people living with ALS must have equitable access to palliative care services and supports regardless of where they live and hope that the adoption of the *Compassionate Care Act*, 2020 results in a framework that takes a patient-centric approach and provides greater consistency in supports and services regardless of geography.

<sup>2</sup>Dying of amyotrophic lateral sclerosis: Health care use and cost in the last year of life. Jocelyn Zwicker, Danial Qureshi, et al. Neurology. December 3, 2019. 93, (23), e2083-e2093. Available at: <a href="https://bit.ly/2WIbNGw">https://bit.ly/2WIbNGw</a>

### **CASE STUDY**

### THE RIGHT TYPE OF CARE FOR PEOPLE LIVING WITH ALS

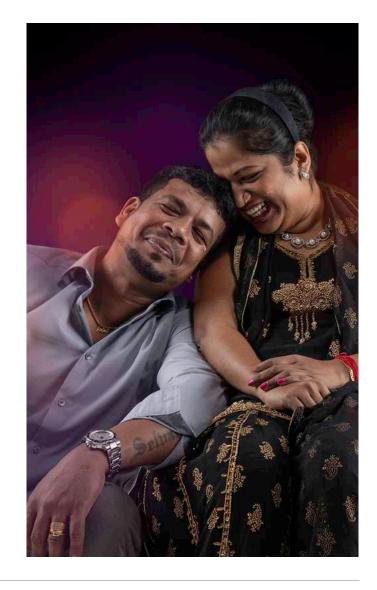
The Central LHIN is an example of the right type of care for people living with ALS and their patient-centric approach should be used as a model across Ontario. The Central LHIN model enables people living with ALS to receive the support they need when they need it. PSW support is more consistent than in other areas and the regional occupational therapist (OT) is familiar with the disease and how it progresses. The LHIN care

coordinator is available throughout a person's entire journey with ALS to provide support and guidance. Importantly, the palliative care team is brought in early and works together with the medical team, local hospital and any other care providers. This type of multidisciplinary and integrated approach to care ensures that people living with ALS can continue to live safely in their own community.

# HERE'S WHAT GOVERNMENT CAN DO:

**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.

TAKE A PATIENT-CENTRIC INTEGRATED HOSPICE PALLIATIVE CARE APPROACH in home and community settings and develop the provincial framework that will provide every Ontarian living with ALS equal access to consistent palliative care and support regardless of where they live.



# MODERNIZE ONTARIO'S EQUIPMENT PROGRAMS TO REDUCE RED TAPE, INCREASE EFFICIENCY AND MITIGATE THE SPREAD OF COVID-19.

AS A PERSON'S ALS PROGRESSES, SO DOES THEIR RELIANCE ON MOBILITY AND COMMUNICATIONS EQUIPMENT AND OTHER ASSISTIVE DEVICES. Over the course of their disease they could transition from needing the support of a walker, to needing a highly customized, powered wheelchair that can support a person living with a more advanced state of the disease. Access to the right equipment and assistive devices can significantly improve quality of life and help people maintain independence, dignity, and safety.

# In 70% of people diagnosed with ALS, symptoms begin with a loss of mobility in their limbs.<sup>3</sup>

However, Ontario's medical equipment programs are not designed to address the progressive nature of a disease like ALS. In reality, the programs put people living with an ALS diagnosis in Ontario at a disadvantage in the province's health system. Due to unnecessary red tape and restrictions, people and families living with ALS must navigate a cumbersome and excessively bureaucratic system that fails to allow them access to government-funded medical and other home health equipment for the length of time they need it. They are left with equipment for short-term use only or with devices that are outdated or not right for them, which can put both themselves and their caregivers or family at significant risk.

In the end, people affected by ALS and their caregivers must turn to the support of ALS Canada, a donor funded charity to fill the gaps. In a province like Ontario, with a strong public health system, people should not have to rely on charity for the essential equipment they need.

In Ontario, people living with ALS must navigate three different programs to access the equipment they need for the length of time they need it:

### HOME AND COMMUNITY CARE (LHIN) EQUIPMENT TRIAL/RENTAL PROGRAM:

Provides acute short-term access to equipment, typically for a 30-day trial period.

### MINISTRY OF HEALTH ASSISTIVE DEVICES PROGRAM (ADP):

Provides financial support to enable Ontarians to purchase mobility and communications aids. People are limited to one mobility device every five years.

### ALS CANADA EQUIPMENT LOAN PROGRAM:

Provides access to mobility and medical equipment for the length of time a person living with ALS needs it, free of charge.

\*See appendix A for more details

3Amyotrophic lateral sclerosis. van Es MA, Hardiman O, Chio A, et al. Lancet. November 4-10, 2017. 390, (10107), 2084–98. Available at: https://bit.ly/3s6uqmx

### **EQUIPMENT AS AN ESSENTIAL HEALTH CARE SERVICE**

As the pandemic progressed, we worked with a LHIN to develop a pilot project that enables Ontarians living with ALS to continue to use a piece of LHIN-loaned equipment beyond the typical 30-day time limit. Piloted in one LHIN as a test, the project aimed to address a wasteful, confusing and inefficient provincewide system where both the LHINs and ALS Canada organize the delivery, cleaning and maintenance of needed equipment – in some cases the exact same item – resulting in tremendous strain on families and expensive duplication. It also sought to limit the number of providers in the homes of vulnerable Ontarians to reduce the spread of COVID-19.

While a step in the right direction, this project was specific to one LHIN and highlights shortcomings in taking a LHIN-by-LHIN approach to solving the equipment lending limit. Namely, that extensions still were not long enough, the equipment request process was still complex and the project failed to create a meaningful difference and value for people living with ALS. Moreover, it demonstrated that only a standard policy mandated by the Ministry of Health will meet the needs of the ALS community. A standard approach would simplify the process for people and families affected by ALS, ensure consistent access to vital equipment, and reduce duplication. It will also help people live in their homes longer and out of hospitals, reducing hallway health care.

### HAVING A STRONG, RESPONSIVE ASSISTIVE DEVICES PROGRAM

The Ministry of Health's Assistive Devices Program (ADP) limits a person to access one mobility device, such as a walker or wheelchair, every five years. The policy also requires that those accessing the program have a life expectancy of one year from the time of assessment. When the progressive nature of ALS is taken into consideration – and that most people will die within five years of diagnosis – it is clear this program does not address this vulnerable population's needs.

ADP must be more responsive to the needs of people living with ALS and other progressive illnesses. Reforming current policy will ensure all Ontarians living with ALS can get the equipment they need, when they need it, for as long as they need it.

### **CASE STUDY**

After about a year of living with ALS, an Ontario woman started to lose functions that could be well supported through medical equipment in her home. 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**

Items were provided by the LHIN's medical equipment vendor and then removed

### **MONTH TWO**



Items were provided by ALS Canada's Equipment Loan Program

### TWO YEARS AFTER DIAGNOSIS



Received a used power wheelchair from ALS Canada while she waited for a specialized chair from 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 first provided by the LHIN in the short term and then replaced by ALS Canada for the long term, requiring both the LHIN and ALS Canada equipment vendor to come into her home to deliver the item.

### **HERE'S WHAT GOVERNMENT CAN DO:**

MANDATE LHINS AND OHTS TO PROVIDE ACCESS TO ESSENTIAL MEDICAL EQUIPMENT FOR THE LENGTH OF TIME PEOPLE NEED IT. A

standard approach will remove duplication, ensure consistent access to vital devices and keep people out of hospital. MODIFY ADP'S
LIMIT OF ONE
PIECE OF MOBILITY
EQUIPMENT EVERY
FIVE YEARS for

progressive illnesses such as ALS, so people can access equipment they need when they need it. MODIFY ADP'S
REQUIRED LIFE
EXPECTANCY OF
ONE YEAR from the

time of assessment to access a power wheelchair to allow people living with progressive illnesses to optimize their quality of life.



# ELIMINATE BARRIERS PREVENTING ONTARIANS LIVING WITH ALS FROM HAVING TIMELY, FAIR AND AFFORDABLE ACCES TO THE DRUGS THEY NEED.

The ALS community cannot wait. Time for them and their loved ones is measured not by months or years, but by loss – loss of function and loss of life. With more ALS therapies in the development pipeline than ever before, any one of which could be proven safe and effective, improving access to ALS therapies is critical. 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.

Under the current pathway, it can take several years for new therapies to be made available for Ontarians. As was seen with the ALS drug Radicava (edaravone), it took almost two years after Health Canada approval for Ontario to make a reimbursement decision. In the time it took for the drug to go through the entire drug access pathway, including the OPDP reimbursement decision, thousands of Ontarians lost their lives to this devastating disease.

No one should lose their life while waiting to see if a newly approved treatment will be covered by the provincial formulary. A comprehensive plan must be put in place immediately to streamline the process so future therapies can move swiftly through the OPDP and into the hands of the Ontarians who need them.



### **HERE'S WHAT GOVERNMENT CAN DO:**

COLLABORATE WITH THE FEDERAL GOVERNMENT AND OTHER PROVINCES TO DEVELOP AND IMPLEMENT THE FORTHCOMING RARE DISEASE STRATEGY and eliminate

barriers preventing all Ontarians from having timely access to the ALS drugs they need at no cost to them.

DEMONSTRATE LEADERSHIP
BY PARTNERING WITH PATIENT
ORGANIZATIONS, FRONT-LINE
PROVIDERS, AND OTHER HEALTH
STAKEHOLDERS to reform Ontario's drug
reimbursement process

### CONCLUSION

Each person's journey living with ALS is different and requires unique care, supports, and services. Some will progress rapidly, while a small number may live well beyond the average five-year life expectancy. Some will experience the loss of function in their arms or legs, while others first experience loss of function in their voice, mouth, or throat. To address each person's varying care needs, Ontario must offer a consistent suite of care that includes home and community care, PSW support, hospice and palliative care, essential equipment loans, and access to new ALS therapies – regardless of where people live.

We urge government to implement the recommendations in this submission. They represent concrete steps that government can take to improve access to critical supports, enhance the quality and standard of care, and eliminate many of the challenges and red tape barriers faced by Ontarians living with ALS.

We have a unique opportunity to address the gaps this pandemic has revealed and build a future where all people living with ALS can access the care and support they need, where and when they need it.

### 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 connections 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.

### **OVERVIEW OF EQUIPMENT PROGRAMS**

ORGANIZATION/PROGRAM	DESCRIPTION	ELIGIBILITY/CRITERIA	COST TO PATIENT/ CLIENT
Home and community care (LHIN) Equipment Trial/Rental Program	<ul> <li>2-4-week trial provided by LHIN (varied)</li> <li>Some LHINs will provide equipment for longer for persons deemed palliative</li> </ul>	Person must have a valid     Ontario health card	No cost for trial period; however, items may be rented or purchased thereafter
Ontario Ministry of Health     Assistive Devices Program     (ADP)	People living with ALS frequently access the ADP mobility aids and communication aids programs	<ul> <li>Person must require the device for more than 6 months and be an Ontario resident with a valid Ontario health card</li> <li>Client must have life expectancy of 1 year from assessment</li> <li>Client is eligible for 1 mobility devices every 5 years, with some exceptions; however, ADP does not consider progressive illnesses like ALS</li> </ul>	75% coverage unless client is on OSDP or Ontario Works, then 100%.
<ul> <li>ALS Canada Equipment Loan Program</li> <li>ALS Canada Funding Assistance Program</li> </ul>	<ul> <li>Equipment loan program of primarily used items which person with ALS keeps for as long as they require it</li> <li>People may have as many items as they need from the loan program</li> <li>ALS Canada supports some people by assisting with up to 100% of the client portion of ADP funding</li> </ul>	Person must be registered with ALS Canada, and does not require a health card	<ul> <li>ALS Canada provides         all equipment free of         charge as a result of         the generosity of its         donors</li> <li>Funding assistance         program is based on         income and there is         a sliding scale that         determines the level of         funding support</li> </ul>