

Talking With Young
People About

ALS

For Schools



ALS

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About Amyotrophic Lateral Sclerosis (ALS)

Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's Disease, or motor neuron disease in some regions of the world, is a progressive fatal neuromuscular disease. It is characterized by the degeneration of nerve cells in the brain and spinal cord that control voluntary muscle movement. These cells are called motor neurons. Degeneration leads to progressive weakness, wasting, and paralysis of all muscles involved in mobility, swallowing, speaking, and breathing. The region of the body where the onset of symptoms may occur can vary from person to person. Onset may begin in nerves associated with muscles of the upper or lower limbs, the throat, or upper chest area.

In some cases cognitive abilities may be affected such as executive function. These executive functions may appear as: subtle changes in personality and behaviour; difficulty in attending to a task or conversation; and/or a decrease in one's level of tolerance or ability to work through problems. Often, these changes are attributed to

factors such as fatigue, grief or sadness, but they can also be due to frontal lobe changes associated with ALS.

ALS does not usually involve the loss of sensory, bowel, bladder, and sexual function. People with ALS are usually very aware of what is happening and must cope with each stage of progression.

The patterns of weakness and rate of progression varies from person to person, however people with ALS are likely to face rapidly increasing levels of disability. Some general facts include:

- Approximately 2,500-3,000 Canadians are living with ALS at any given time (prevalence)
- The number of new cases each year (incidence rate) is 2/100,000
- The number of people who die each year with ALS (mortality rate) is also 2/100,000
- The cause is unknown
- There is no treatment to date that slows progression and prolongs life significantly



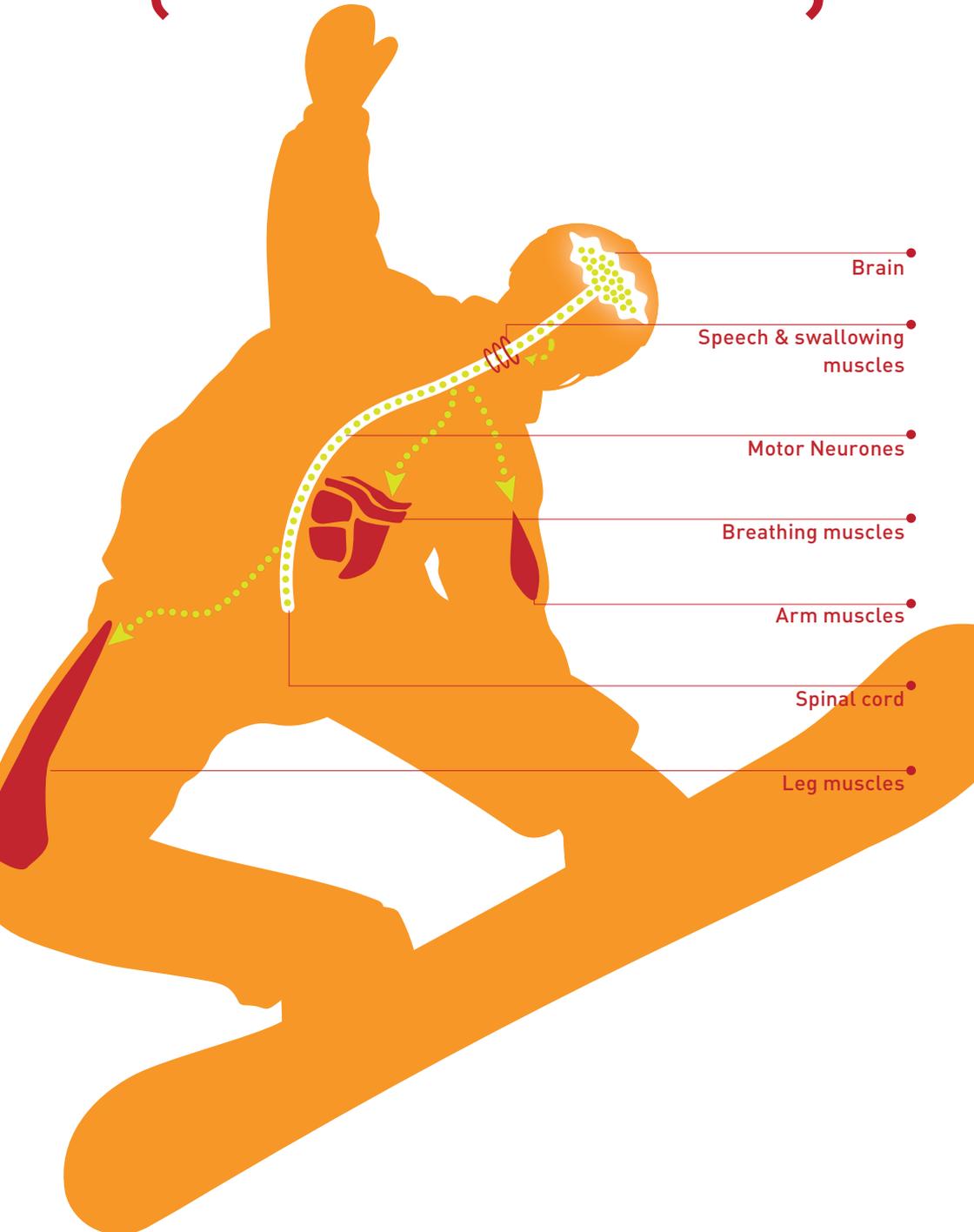


- ALS typically strikes most people between the ages of 40 and 70, but people as young as teenagers and those in their 90's have been diagnosed with ALS
- Eighty percent of those diagnosed live for two to five years after diagnosis; 20% live past five years, and only 10% live 10 years or longer
- In 90% of cases it strikes people with no family history of ALS
- A person with ALS is best supported by a coordinated health care team that can assist with symptom management and adaptive technology to remain as independent and comfortable as possible for as long as possible

ALS affects the whole family. It is particularly challenging when a person diagnosed with ALS is also caring for school-aged and teenage children. This booklet is aimed at familiarizing educators with ALS, providing a better understanding of what a student whose parent has ALS must cope with, and suggesting how school personnel can be supportive, not only while the disease progresses, but also during bereavement.

Additional sources of information that may be helpful are listed at the back of this booklet.

Motor Neurons in our Brains & Spinal Cord carry messages to muscles in different parts of our body



How ALS can affect young people

Schools have experience providing support for students who are facing loss and grief. However, few staff are likely to have worked with a young person who has a parent with ALS. ALS is less common than most life-threatening illnesses but it is also one of the toughest conditions any family has to confront.

ALS is different from many other life-threatening illnesses because of its speed of progression and change—parents and children face a rapid series of impacts with each increasing level of disability. The pressure on the parent who is the primary caregiver and the children to support the parent with ALS emotionally and physically can be very intense and exhausting.

Many children and teenagers have to make the hard journey of ALS with their parent, sometimes in company with another parent, sometimes on their own.

“During the ALS journey students can become isolated at school, exhausted by having to manage their anxiety and growing sense of loss, as well as the demands of growing up, managing school work, and trying to meet the expectations for their teachers and friends. Many young people also take on considerable responsibilities for the care of their parent. They often display magnificent qualities of resilience and courage as they and the rest of their family strive to live as normal a life as can be possible in such circumstances.”
(Dr. Paul Brock, Director of Learning and Development Research, NSW Department of Education, 2007. Dr. Brock has ALS.)

All children living with a parent's terminal illness are living with grief. They will grieve in individual ways, sometimes experiencing unexpected waves of sadness, anger, and resentment as well as moments of normal happiness and fun. Students may be destabilized by these feelings. They may not be able to control how or when they will occur.

The world for a young person living with a parent's ALS can seem out of control. Their home may no longer feel like a safe and familiar place—different health professionals will be coming and going and they may feel “out of sorts.” They may want to punish a parent with ALS for “messing up their life,” so when asked to help, they might react dismissively with a “Why should I?” They may feel guilty about their behaviour later, which can compound their feelings.

“I never really wanted to help, but I knew it was an obligation. I wanted to just be a kid and do fun things. I felt spending time helping with my dad's care took time away from my childhood and I was quite upset about that. Now I look back and wish I had done more. It's funny how things change.”

On the other hand, some young people devote all their time and energy to helping at home to the exclusion of their own friends and interests. They still need close friends and their support.

“A lot of the time I stayed home from school to help, or I turned my friends down. I also gave up dance lessons because it got too expensive and I was too tired—it became a task not an enjoyment anymore.”

How the school can help

Parents living with ALS appreciate regular information about how their children are managing at school. They also need to be



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alerted to any worrying changes in their children's behaviour that may require help. For example, anxious children may start being bullied, or an angry child may start bullying others.

Teachers may notice negative changes in behaviour or academic performance. It is important that anti-social attitudes or activity are managed with compassion and tact, so that the young person continues to see school and its routines as a helpful and friendly balance to the many changes in life at home. Parents in turn could be asked to inform the school of changes at home likely to affect their child's performance or behaviour.

As ALS progresses, there may become the need for home modifications, new methods of communication, the introduction of medical equipment at home, and changes to normal routines like meal time when a parent's ability to eat by mouth becomes too difficult. The addition of home care personnel in the home is also likely to occur. All of these changes can be unsettling for a child.

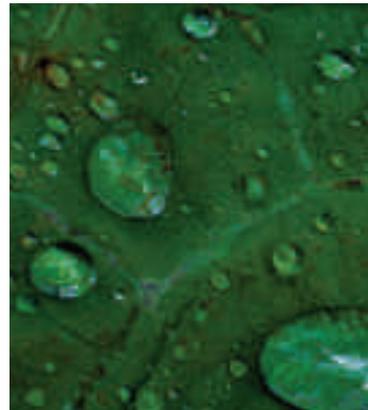
“The problem was that the people who came to help kept changing so you'd try to get used to someone and then they'd be gone and someone new would come in. There were lots of people coming in. I remember walking home from the school bus and seeing five different cars in front of our house and thinking, 'who's there now?' not even recognizing the cars. I was polite and nice, but I kind of thought, 'I wish you weren't here.'”

The Principal could invite the family to discuss any particular needs that could be addressed by the school. The issue of student confidentiality should be discussed with the student and parents and an agreement reached about the boundaries of confidentiality. It may be important to invite the parent without ALS to meet alone if there are sensitive issues they need to discuss such as changes in personality or behaviour in the parent with ALS. While cognitive changes do not occur in all persons with ALS, when they do it can be confusing and frustrating for a child.

It can be helpful to identify a staff member with whom the student is particularly comfortable, as a special friend or mentor. The child is more likely to turn to them when feeling distressed.

Trust in individual teachers is likely to develop through the child's own interests in sport, art, English etc. Being given a task they can complete successfully can be a terrific boost to a young person's sense of competence and confidence. Praise from teachers the student respects can be very helpful in improving lowered self-esteem.

Some teachers have found that students like compiling a "My Mom/Dad Book" for their parents. The child whose parent has ALS can use the exercise to strengthen the bond with their mother or father, without feeling singled out as a "special" student. A number of schools have found that puppet shows or plays around the theme of disability are valuable in creating a





better understanding of a parent’s illness. For older students, it can be helpful if they can leave class to “chill out” in the library or another safe place in the school if things become overwhelming.

“I knew that I was free to leave whenever I needed to and did not have to report to or ask anyone and that was enough. I never did leave but it was good to know that I could if I needed to.”

Wherever possible, disability access should be provided so that a parent with ALS can continue attending school activities as their condition changes.

What school staff can do

“My principal knew most of the students’ names and had been my brother’s principal two years before. When I first started grade eleven she called me to her office and we had a general chat about things and about Dad ... She was very laid back and let me talk and let me know that she was always there to talk. I always knew she was there if I needed her help, and I felt very comfortable talking to her.”

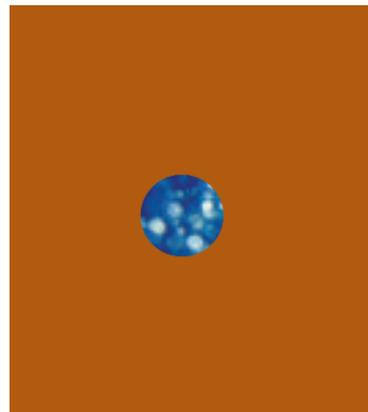
- **Negotiate how much school and home work is manageable, for an agreed period. Review the targets if the student starts falling behind.**



- With the student's agreement, the home room teacher could arrange for a "buddy" to help with school and homework, particularly when they may need to miss school.
- Encourage the young person to get involved in activities like art, sport, music, and journal or diary writing. These can help them to express their feelings in a safe and contained way.

"I found it really helpful to keep a diary and write down all the things I wanted to tell Dad the next day. I did this at night when I went to bed as this is when I used to get really upset ... So I wrote down what I wanted to say so I could process it and relay it when I wasn't so emotional."

- Make allowances for "bad" days by being flexible and relaxed if the student is late with assignments, or has outbursts of anger or misery.
- Normal school rules and boundaries should remain important. They help to provide security as the young person learns that some things in life remain constant, even if their world seems to be falling apart. They also prevent the student from being seen as "different," or singled out as a "favourite."
- Offer them a choice of tasks wherever possible. A grieving young person's level of frustration and irritability can boil over if they feel they are being pushed into a corner.



Students and ALS

The following notes may be helpful for staff with less experience working with students who are living with a parent's life-threatening illness.

“In grade 12 English I had to write a personal essay so I wrote a piece about watching my dad die. I felt that if I didn't write it I wasn't being true to myself or my dad and I actually really wanted my English teacher to know where I had drawn my strength from. I didn't know whether or not she had known my dad had died six months before.”

Primary school students

Psychologists and counsellors working with families living with ALS advise that younger children tend to be very practical and concrete in the way they process their world.

- Very young students may not understand the permanence of a parent's illness or death.
- They may appear not to grieve at all. This can be difficult for adults to understand.
- They may not always be able to separate cause and effect, and may fear that they have caused their parent's illness. (“If I'd been good, Daddy wouldn't have got sick.”)
- They tend to be obsessive about germs, so despite repeated reassurances, they may be afraid that they will catch ALS themselves.
- They may have mixed feelings of love for their parents and resentment that their world has changed. They may believe that their parents have “cheated” them — nice things that their peers at school have, and they want, may not be possible.

- A child may try to punish parents, particularly the parent with ALS, by rejecting or belittling them when that parent can no longer do “normal” things. Their mother or father may not be able to hug them anymore, help with homework, play games or take them out.
- Primary school students may have difficulty paying attention, focusing on schoolwork, remembering things, or completing tasks.
- They may start to bully other children or “act out” their unhappiness and anxiety.

Younger teenagers

School staff often find young teenagers are probably the most volatile age group. A young person living with a parent with ALS also has to manage their own hormone upheavals, development of self-image, peer group expectations, and measuring themselves against popular models of the “cool” teenager.

They are just beginning to get more of their sense of self from their friends and their own achievements than from parents or teachers. They tend to be mortified if viewed as “different,” and particularly, as less “successful” than their friends. Some students may not want anyone outside the family to know about their parent’s circumstances.

Students in this age range stress they do not want to be singled out in public at school or in front of friends. They are more comfortable when staff express empathy obliquely and casually – “Wish Happy Birthday to Dad from me”; “Say hi from me to your Mom.” One young woman recalled:

“I think the thing that was most helpful to me is that school was a normal experience... generally it was more important to me that school was exactly the same as it was for everybody else.”



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It is important for adolescents living with ALS to understand that boundaries and rules also apply to them as much as to other students. Too much leniency can make them unpopular – being treated “normally” can help the student keep their friends.

Sometimes it can be hard to distinguish between normal adolescent rebelliousness and disturbed behaviour. It is very helpful if all staff are sensitive to the young person’s needs and alert to any disturbing changes in their behaviour in or outside the classroom. A useful question to ask is: “Is this new pattern of behaviour an exaggerated form of their previous behaviour resulting from grief, or is it completely out of character?”

Older students

Young adults may adopt a very grown-up attitude to their parent’s condition and its effect on their lives. They may seem philosophical about the situation, very “cool,” appearing not to relate what’s happening at home to their own feelings or needs.

They have to grow up more quickly than expected – they are increasingly losing the security of being able to lean on their parent with ALS. They may also need to support their other parent emotionally and practically, while managing school assignments and getting ready for exams. They may even be the primary caregiver themselves.

At home they are likely to be taking on extra responsibilities and may be feeling quite stressed a lot of the time. A boy whose father

has ALS may think he needs to assume the “man of the house” role. A girl whose mother has ALS may feel she has to look after her father and any other children.

“When I came home from school I would help my mom eat and then get her ready for and into bed. She had a call button to let me know if she needed anything while I was in the living room doing my homework until I am each day.”

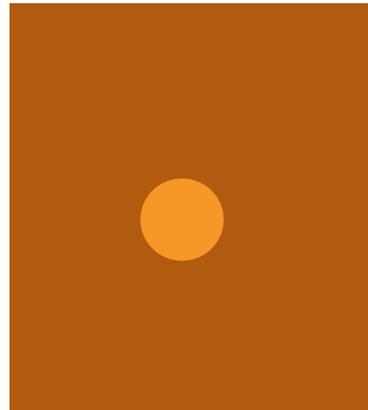
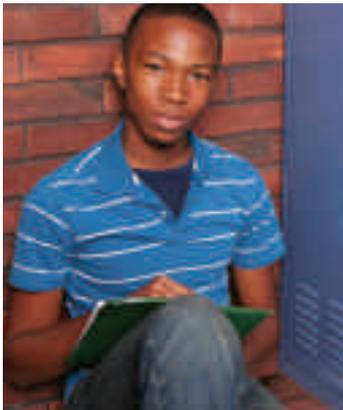
Counselling

Students whose behaviour has changed in concerning ways may benefit from counselling, either at school or privately. However young people do not agree on the value of counseling when they are dealing with a parent’s ALS. One student’s suggestion:

“I think maybe the student could have an interview with a counsellor and agree upon some things that their teachers may need to know; the counsellor can then report this to the teachers. It is different for every young person so teachers need to understand the complex dynamics, but only what the young person agrees upon.”

The possibility for choice in this area is very important for older students. If a student experiences a prolonged period of negativity, it would be wise for their preferred contact teacher to talk with them before getting in touch with the family.

A young person’s hatred of life should always be treated seriously – they may need professional help outside the school.



Bereaved students

When the student's mother or father dies they will grieve in a way that is unique to them. As you know, grieving takes time. The intensity and duration of their overt grief will also be completely individual.

Don't try to "buck up" a grieving student – young people, like adults, never really "get over" the pain of losing someone they love. It just changes shape and is stimulated, felt and expressed differently as they learn how to build life around the painful emptiness.

While the student may prefer to talk to the school counsellor, social worker, or chaplain, it can be helpful if other staff are aware of the child's loss and acknowledge it gently. "I'm sorry that you and your family are having such a tough time" may be enough support, unless the student requests more.

Many students find it easier to talk to a counsellor outside the school system. Visits to the school counsellor may be too obvious and can make the bereaved young person feel "weak" for needing help.

"I had some feelings inside I couldn't get out with my family. That's why I went to a therapist. I didn't have resentment towards my dad, but the burden his ALS put on our lives, I resented that. I had to talk to a therapist to get that off my chest."

It's important to respect a young person's pain even if you are not comfortable about how they express it. Compassionate support helps a child to manage grief. Listening, without expressing an opinion, is a useful way of helping a bereaved young person.

"Teachers who allow their students time and support for healing provide a real gift to them." (The Dougy Center for Grieving Children and Families, USA)

RESOURCES ON ALS, LOSS & GRIEF FOR SCHOOLS

Contact your Provincial ALS Society (see listing below) to inquire about a staff in-service as an effective way to inform staff about ALS. A local palliative care or hospice organization would be an excellent option for further training on issues related to bereavement.

ON-LINE ALS RESOURCES

www.als.ca (ALS Society of Canada)

www.alsa.org (The ALS Association, United States)

www.als-mds.org (Muscular Dystrophy ALS Division—United States)

www.mndaust.asn.au (Motor Neurone Disease Association of Australia)

www.mnda.org (Motor Neuron Disease Association, United Kingdom)

To find a listing of bereavement resources and services in your local area, refer to your board of education's referral resource list, or link to www.als.ca/_media/docs/Bereavement-Services-for-kids.pdf

To understand ALS from a child's or teen's perspective, visit www.als411.ca, to access sites developed by the ALS Society of Canada for children and teens.

READING FOR EDUCATORS AND POTENTIAL RESOURCES FOR YOUR LIBRARY

When Someone Special has ALS— A Booklet for Children, a resource published by the ALS Society of Canada and part of the als411 series. It can be downloaded from www.als411.ca, or ordered through your Provincial ALS Society.

When Your Parent Has ALS— A Booklet for Teens, a resource published by the ALS Society of Canada and part of the als411 series. It can be downloaded from www.als411.ca, or ordered through your Provincial ALS Society.

A Child's View of Grief— A guide for parents, teachers and counsellors, Alan Wolfelt, Center for Loss and Transition, USA, revised 2004

Grief in School Communities— effective support strategies, Louise Rowling, Open University Press, UK, 2003



Helping the Grieving Student - A guide for teachers, The Dougy Center for Grieving Children and Families, Portland, OR, USA, 2003

How it Feels When a Parent Dies, Jill Krementz, Knopf, 1988

How to Help Children through a Parent's Serious Illness, Kathleen McCrue, St. Martin's Press, New York, 1997

I thought I was the only one: Coping with grief and loss in schools - a resource for teachers, Hazel Edwards - Collins Dove, Australia, 1992

Mindmatters - A Whole School Approach to Loss and Grief, Dr Louise Rowling, Australia, 2000, www.curriculum.edu.au/mindmatters

Never the Same: Coming to Terms with the Death of Parent, Donna Schuurman, St. Martin's Press, 2003

Our Dad Died, Amy, Allie, and David Dennison, Free Spirit Publishing, 2003

Overcoming Loss—Activities and Stories to Help Transform Children's Grief and Loss, Julia Sorenson, Jessica Kinsley Publishers, 2008

Sad Isn't So Bad, A Good-Grief Guidebook for Kids Dealing with Loss, Michaelene Mundy and R.W. Alley, Abbey Press, 1998

The Colors of Grief—Understanding a Child's Journey through Loss from Birth to Adulthood, Janis A. diCiaccio

Yeah Right! Adolescents in the Classroom, Rob Long, David Fulton Publishers, UK, 2003

Young Carers - At Risk Program: At risk of missing out on school, Carers Australia, 2006, www.youngcarers.net.au

35 Ways to Help a Grieving Child (Guidebook Series), The Dougy Center for Grieving Children and Families, Portland, OR, USA, 1999

Provincial ALS Societies

ALS Society of Alberta (and NWT)

1-888-309-1111

www.alsab.ca

ALS Society of British Columbia (and Yukon)

1-800-708-3228

www.alsbc.ca

ALS Society of Manitoba

1-866-718-1642

www.alsmb.ca

ALS Society of New Brunswick

1-866-722-7700

www.alsnb.ca

ALS Society of Newfoundland and Labrador

1-888-364-9499

www.envision.ca/webs/alsnl

ALS Society of Nova Scotia

1-866-625-7257

www.alsns.ca

ALS Society of Ontario (and Nunavut)

1-866-611-8545

www.alsont.ca

ALS Society of Prince

Edward Island

1-866-625-7257

als_society_pei@hotmail.com

ALS Society of Quebec

1-877-725-7725

www.sla-quebec.ca

ALS Society of Saskatchewan

1-306-949-4100

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