ALS CANADA

AMYOTROPHIC LATERAL SCLEROSIS (ALS): A GUIDE FOR SCHOOLS

An ALS diagnosis impacts the whole family. For children and youth living with someone who has ALS, it brings significant changes and challenges to their daily lives, including changes to their emotions, responsibilities at home, their living space, and their relationships. Coping with these changes may lead to children being distracted, changes in mood or behaviour, and even missing school, all of which can have an impact on school performance and well-being.

This fact sheet aims to help educators understand what ALS is, what students might experience while navigating an ALS diagnosis of someone close to them, and how school staff and school administrators can support students who have been impacted by ALS, especially in learning and school performance.

WHAT IS AMYOTROPHIC LATERAL SCLEROSIS (ALS)?

ALS, also called Lou Gehrig's disease or motor neuron disease, is a terminal, progressive, neuromuscular disease. In people living with ALS, nerve cells called motor neurons which communicate messages from the brain to the muscles of the body that we use to move, talk, eat, swallow, and breathe, break down and die. This leads to less communication between the brain and muscles, causing the muscles to weaken and eventually stop working.

QUICK FACTS ABOUT ALS

- While it is considered a rare disease, nearly 4,000 Canadians are currently living with ALS with two to three people being diagnosed with ALS every day in Canada.
- 1,000 Canadians die from ALS every year.
- Anyone can develop ALS at any time regardless of gender, socioeconomic status, geography, or race.
- 80 per cent of people with ALS die within two to five years of diagnosis.
- ALS affects people differently, but some common signs and symptoms include muscle twitching or cramping, slurred speech, tripping, shortness of breath, and difficulty swallowing.
- Some individuals experience non-motor symptoms including, but not limited to cognitive and behavioural changes, pain, and sleep disturbances. The type and severity of these changes vary from person to person.

HOW DOES AN ALS DIAGNOSIS IN A FAMILY IMPACT CHILDREN AND YOUTH?

ALS is less common than many other illnesses. It's also different from other illnesses. Unlike many other diseases, ALS is unpredictable. For some people living with ALS, it can progress quickly and leads to rapid changes and for others, it can progress very slowly over many years. This can be emotionally and physically demanding on the person living with ALS and their family members, including children. Children and youth who are close to someone diagnosed with ALS may experience feelings of sadness, anxiety, confusion, or anger. It can feel isolating for children and youth, as they often don't know anyone their age who is also experiencing this or taking on a caregiving role.

PRIMARY SCHOOL STUDENTS

Younger children are often focused on the present, they may or may not understand the terminal nature of ALS and they may appear unaffected. Younger children often see things mainly from their point of view.

The 5 C's are important considerations for adults who are supporting a child with processing their experience. Children may not share that they are wondering about these things, so it is important for adults to provide reassurance and information with the 5 C's in mind. Addressing these questions will help to ease a child's worries.

- Did I **cause** it?
- Can I **catch** it?
- Can I **cure** it?
- Who is going to **care** for me?
- How do I stay **connected** to my person?

Children may want to or be required to help care for the person who is living with ALS by doing simple tasks such as fetching items for the person living with ALS, helping them move around, or cleaning and tidying. In some cases, children may be involved in more significant primary caregiving responsibilities, such as helping with feeding and toileting.

MIDDLE/JUNIOR HIGH SCHOOL STUDENTS

Having a family member with ALS can add to the challenges of being a pre-teen. They are often juggling multiple challenges of their own including physical, cognitive, and social-emotional changes, while striving for increased autonomy and individuality, navigating social and peer pressures, as well as changing relationships. They generally prefer not to stand out from their peers, which can leave them feeling uneasy about sharing what is happening in their personal lives related to the person with ALS. Some students appreciate normalcy and don't want "special treatment" in fear that it will make them stand out to their peers.

Older children are more likely to be involved with caregiving duties that are similar to adult caregivers. This can include physical transfers, personal care tasks such as bathing and toileting, household chores, running errands, and helping with assistive devices. Increased caregiving responsibilities can impact their academic performance and lead to reduced participation in extracurricular activities.

HIGH SCHOOL STUDENTS

Teenagers continue to deal with physical, cognitive, and social-emotional changes while developing their self-identity. They may worry and feel anxious about their future, the health of their family member, and family dynamics. They may be grieving the loss of who their family member was before the disease or the relationship they had with them as well as anticipatory grief while watching the decline of the family member with ALS.

Teenagers may face increasing expectations to take on caregiving tasks similar to adult caregivers. This can include assisting with mobility, preparing and feeding meals, medication management, helping with bathing and toileting, caring for other siblings, and managing finances. Increased responsibilities at home can be exhausting and interfere with their ability to focus and concentrate on academic expectations. This can lead to reduced participation in extracurricular activities or social events. High school students may also change their post-secondary plans or goals to support their family.

HOW CAN THE SCHOOL HELP?

When a family member has an ALS diagnosis, a student's school and home environments as well as relationships with friends and family are impacted. Emotional impacts can include changes in mood, behaviour, mental health, and sleep. This makes it harder for them to focus on school expectations including performance and attendance. Ideally, when school administrators and staff actively foster a secure and supportive environment, schools can become a safe space—offering them a sense of normalcy and emotional safety. There are many ways that school administration and staff can help support students who are navigating an ALS diagnosis in the family. It is important that the school staff work with the student and their family to develop a support plan that meets the student's needs.

Open dialogue:

- Ensure that you are informed about ALS by seeking information from reputable sources such as ALS Canada.
- Identify a staff member who the student has recognized as a safe connection who can be the key contact.
- Offer regular check-ins that respect boundaries and confidentiality with both the student and their family. This provides an opportunity to stay updated on the student's needs, how they are managing at school, and changes that are happening at home (e.g., home modifications, different routines, medical equipment, increased caregiving duties, etc.).
- With consent, share information and the support plan with all staff who work with the student, so the student isn't required to explain their situation multiple times.
- Be vigilant and prepared to advocate for the student who is taking on more significant caregiving responsibilities.

Accommodations:

- Maintain structure and routine at school along with flexibility.
- Flexibility can look like extending deadlines on homework and projects, alternative assignments, modifying school hours, and remote learning.
- Offer academic support and accommodations to allow the student time to catch up on learning that they might miss to ensure they don't fall behind their peers.
- Identify a quiet, safe space within the school for the student to work or take a break if they choose.

Counselling:

- Consider a referral to the school counsellor or social worker for individual or family support.
- Provide information on external programs, or qualified professionals to help students develop coping strategies to deal with stress, strong emotions, caregiving responsibilities, and grief.

Connect with other organizations:

Organizations that specialize in services or support to children who are close to someone with a life-altering disease can provide resources and professionals who may be able to help support both students and school staff. These can include hospice organizations, children's grief organization, and ALS Canada. Please see below for a list of organizations and resources.

Each student and family will be different in terms of their engagement, needs, and accommodation. It's important to explore their needs and provide information about the supports and resources that are available to them, empowering them to make informed decisions that are best for their child and family.

Resources

- ALS Canada Children and Youth Resource Hub: https://als.ca/get-support/childrens-hub/
- AWC Grief Support: https://awcgrief.com/
- Canadian Hospice Palliative Care Association (CHPCA): https://www.chpca.ca/education/resources/
- Children and Youth Grief Network: https://www.childrenandyouthgriefnetwork.com
- KidsGrief.ca: https://kidsgrief.ca/
- Kids Help Phone (call 1-800-668-6868 or text 686868): https://kidshelpphone.ca
- Young Caregivers Association: https://youngcaregivers.ca/

KNOW THAT WE ARE HERE TO HELP

The ALS Society of Canada can assist in connecting people and families living with ALS in Ontario to support services, equipment, and ALS clinics. We also invest in the most promising Canadian ALS research, advocate federally and provincially for the needs of people affected by ALS, and provide information to empower Canadians affected by the disease. Learn more at www.als.ca where you can also find more resources in the "What is ALS?" section.

If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region.

Please note that ALS Canada does not provide medical advice or make referrals related to drug therapies or alternative therapies. These questions should be discussed directly with a medical professional – ideally an ALS neurologist, who would be qualified to interpret clinical information for individual situations. Please visit our list of ALS clinics to help you connect with a clinic in your area.