Tips for Supporting Students Who Have a Family Member Living with ALS
The ALS Association Oregon and SW Washington Chapter is the central source for care services and education for people with ALS, their families, caregivers, health care professionals, educators and support professionals in all of Oregon and six counties of SW Washington.

Thank you for your interest in responding to the needs of students who have a family member living with ALS. This information is insightful, accurate, and we believe useful for teachers, school counselors, administrators or other school staff who educate, care for and support children. We hope you find value and support in this booklet – *Tips for Supporting Students Who Have a Family Member Living with ALS.*

Our support of families is strengthened by our community based partnerships with organizations that provide compassionate care and support to children, teens and families experiencing the complexities of loss and grief. Their work helps our Chapter fully meet the needs of families and their children living with ALS.

We are grateful to The Dougy Center for Grieving Children and Families and their Pathways Program for children, teens, and families facing advanced serious illness. *For more information about The Dougy Center, please visit www.dougy.org.*
These tips can be helpful as you support a student during this very challenging time:

1. **LISTEN.**

   One of the most helpful and healing things to do for a child or teenager is to listen to their story without judging, interpreting, evaluating or offering advice. Well-intentioned adults often seek to comfort a child with a critically ill family member by offering phrases like, “It’ll be okay,” or “I know how you feel.” To a child or teenager, this sounds absurd. How could anyone possibly know what it feels like to have a parent or sibling who is critically ill or dying? Children quickly learn that most people are uncomfortable talking about dying, so they often choose to keep their feelings to themselves. Being able to listen, even briefly, to anything they’re willing to share is an incredible gift. It sends the message that you are a safe and supportive person.

2. **ACKNOWLEDGE.**

   Say something to the child or teen that acknowledges you know about their family member’s serious illness and care. For example, “I was sad to hear about your dad’s illness and I want you to know I would like to help in any way I can.” Be authentic in what you share. Although “I’m sorry” is a common response, many teens tell us they don’t like people to say “I’m sorry” because it implies that you’re responsible in some way. Better to say “I’m thinking of you” or “You’ve been on my mind.”

3. **REMEMBER.**

   Don’t be afraid to talk to or about the family member with the illness. The ill person may be able to participate and attend some of the student’s school activities, at least for a time. Engage with them when possible. As the health of the family member declines, check in with the student. Convey to the student the changes you see occurring. For example, “I know your mom isn’t able to bring you to school now. How are you doing?” Or, “Is there something I can do to support you?”
4. **UNDERSTAND.**

Know that you can’t take away the feelings of pain, fear, loneliness, or being different that children and teens experience when a family member has been diagnosed with a terminal illness. It’s natural to want to ease a child’s pain and to provide comfort and support in a time of hurting. Sometimes, in our efforts to help, we try to fix things that are un-fixable. Understand that your role is not to get rid of those feelings, but to create a safe environment where they can be shared. Children and teens don’t require that we understand exactly what they are going through, and, in fact, may genuinely appreciate adults who acknowledge that they don’t fully understand but are there to listen and support.

5. **PROVIDE CONSISTENCY.**

The structure, routine and consistency of the school environment can provide a child or teen dealing with a family member’s illness with a sense of stability. Living within a family that is trying to cope with a ALS can feel chaotic and unpredictable. Daily routines can help alleviate the disorder and anxiety that an advanced serious illness brings into the family. At the same time, allow for some flexibility for students who may be having a bad day or a difficult time.

6. **HELP.**

Help the student make a plan for completing schoolwork. As important as structure is for a student, there will be times when flexibility is needed. In addition to care-taking responsibilities at home, stress and anxiety can manifest in students as well as difficulties with concentration, memory, low energy and fatigue. All of these responses may impact school performance and the ability to complete homework. Communicate often with the child and parent(s) if needed to discuss assignments, and make a plan with specific and flexible goals for schoolwork completion.

7. **SAFETY.**

Provide a safe place for students to go when feeling overwhelmed, stressed or anxious. Have the student designate a counselor, teacher or other support staff person who is willing to be available, to listen to and talk with the student.
8. PROVIDE RESOURCES.

Get the student help if needed. Most students have a mix of some easy days and other days that are challenging and difficult to get through. They experience sadness, anxiety, confusion, guilt and anger, but they are able to attend to school, enjoy friends and participate in activities. However a child or teen who is profoundly affected may experience drastic changes which can include: prolonged depression or anxiety, risk-taking behaviors or suicidal thoughts. If you observe changes such as these, it is important to consult a qualified mental health professional for additional support.

Grief Responses of Students

Each child or teen will grieve the changes and losses that accompany coping with a family member’s advanced serious illness in their own unique way. The following are some of the responses that a student may exhibit. Acknowledge any concerns to the student and offer your support, and if their behavior is of concern, refer to a qualified mental health therapist.

Everyone grieves differently, so students’ reactions to a life-limiting illness will be impacted by a variety of factors, including:

- Age and developmental level of the student
- The relationship, if any, with the ill family member
- Previous experiences with serious illness, death and other types of loss
- Support systems available to them
- Modeling of grief responses from those around them

Academic Responses

- Difficulty focusing or concentrating
- Failing or declining grades
- Incomplete work, or poor quality of work
- Increased absences or reluctance to go to school
- Forgetfulness, memory loss
- Over achievement, trying to be perfect
• Language errors and word finding problems
• Inattentiveness/Daydreaming
• Difficulty watching movies or reading books related to illness, dying or death

Behavioral Responses

• Noisy outbursts, disruptive, ‘hyperactive-like’ behaviors
• Aggressive behaviors, frequent fighting
• Non-compliance to requests
• Increase in risk-taking or unsafe behaviors (drug/alcohol use, sexual acting out, physically risky behavior, stealing)
• Isolation or withdrawal
• Regressive behaviors
• Increased need for attention

Emotional Responses

• Insecurity, issues of abandonment, safety concerns
• Concern about being treated differently from others
• Fear, guilt, anger, rage, regret, sadness, confusion
• “I don’t care” attitude or appears unaffected by the family member’s serious illness
• Change in values, questioning what is important
• Depression, hopelessness, intense sadness
• High need for attention
• Overly sensitive, frequently tearful, irritable
• Preoccupation with the illness, can’t stop thinking about it
• Recurring thoughts of death or suicide

Social Responses

• Withdrawal from friends
• Withdrawal from activities or sports
• Changes in relationships with teachers and peers
• Changes in family roles
• Wanting to be physically close to safe adults
Physical Responses

- Stomachaches, headaches, heartaches
- Frequent accidents or injuries
- Increased requests to visit the nurse
- Nightmares, dreams or sleep difficulties
- Loss of appetite or increased eating
- Low energy, weakness
- Nausea, or upset stomach
- Increased illnesses, low resistance to colds and flu
- Rapid heartbeat

Spiritual Responses

- Anger at God/higher power/other spirituality
- Questions about the meaning of life
- Feelings of abandonment and emptiness
- Doubting or questioning previous beliefs
- Seeing the future as meaninglessness
OUR MISSION

The ALS Association leads the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig’s Disease and their families to live fuller lives by providing them with compassionate care and support.

For more information about ALS and additional resources available please visit us www.alsa-or.org or email careservices@alsa-or.org.