

# At School:

A Guide to Supporting Students Who Have Been Affected by ALS

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### ABOUT THE ALS ASSOCIATION

Established in 1985, The ALS Association is the only national nonprofit organization fighting ALS on every front. The Association leads the way in research, care services, public education, and public policy – giving help and hope to those facing the disease. The Association’s nationwide network of chapters provides comprehensive patient services and support to the ALS community. The mission of The ALS Association is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

For more information about The ALS Association, visit our website at [www.als.org](http://www.als.org).

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# Glossary

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**ALS** – amyotrophic lateral sclerosis

**Caregivers** – often referred to as an “informal caregiver”, a member of a person’s social network, primarily family, who helps them with activities of daily living.

**Caregiving** – tasks undertaken to assist in the health and well-being of a person living with an illness, or care recipient, ranging from making sure someone is safe, to more complex care such as feeding, bathing, and toileting.

**MND** – motor neuron disease

**Mandated reporter** – people who have regular contact with vulnerable people and are therefore legally required to ensure a report is filed when abuse is observed or suspected

**Young caregiver/carer** – typically an unpaid person under the age of 18, who cares for a person who has any type of physical or mental illness, physical and/or mental disability or misuses substances such as alcohol or drugs.

**Children/youths** – This manual addresses how to talk with young children as well as older youths. We use the terms “children,” “kids,” and “youths” to include all young people in the family. However, we do not place an age limit, as children can be as young as 1 or 2, while youths may be over 18, yet still be at home assisting in care.

# Amyotrophic Lateral Sclerosis (ALS): An Overview

As a primer for working with families impacted by ALS, we provide the below section from the **Resource Guide 1: Living with ALS** written by :

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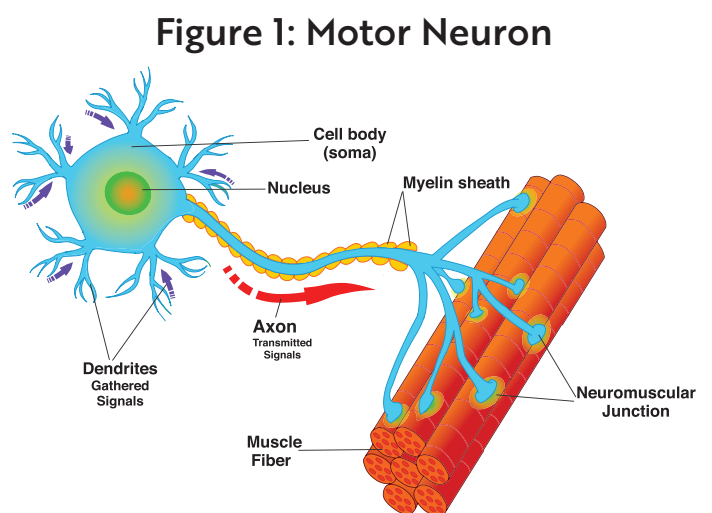
## What Does Amyotrophic Lateral Sclerosis (ALS) Mean?

**A**LS is a type of motor neuron disease (MND). MNDs are diseases that damage the motor nerve cells, which are cells required for movement. Amyotrophic is a medical term meaning loss of nutrition to the muscle. Muscles lose their bulk and get smaller. The term sclerosis means scarring or hardening. In ALS, this scarring is due to the damage and loss of nerve cells. Lateral means the side and refers to the area of the spinal cord that houses the fibers of the nerve cells that die off in ALS. ALS causes weakness and wasting of all voluntary muscles. This means that the muscles we use to move, swallow, and even breathe, become affected by ALS. The disease can start in different places in the body. However, as time progresses, the weakness worsens in the muscles that were affected first and then spreads to other parts of the body. Unfortunately, there is no cure for ALS. There is no known way to stop or reverse this disease. There are, however, treatments that ALS specialists recommend to help people manage their symptoms.

## The Role Motor Neurons Play in How Our Bodies Move

All body movements require nerve cells in the brain and in the spinal cord. These nerve cells are called motor neurons and they control our muscles. The brain sends signals to the appropriate nerve cells in the spinal cord that control the muscles in the arms, legs, and feet, for example, to perform actions such as picking up a glass or moving a foot. These cells send messages to the muscles via a long nerve fiber called an axon (Figure 1).

Without this signal, there is no way for a muscle to know what to do. It is similar to computer keyboards: if they are not plugged in, there is no connection and the computer screen remains blank. The muscle also needs



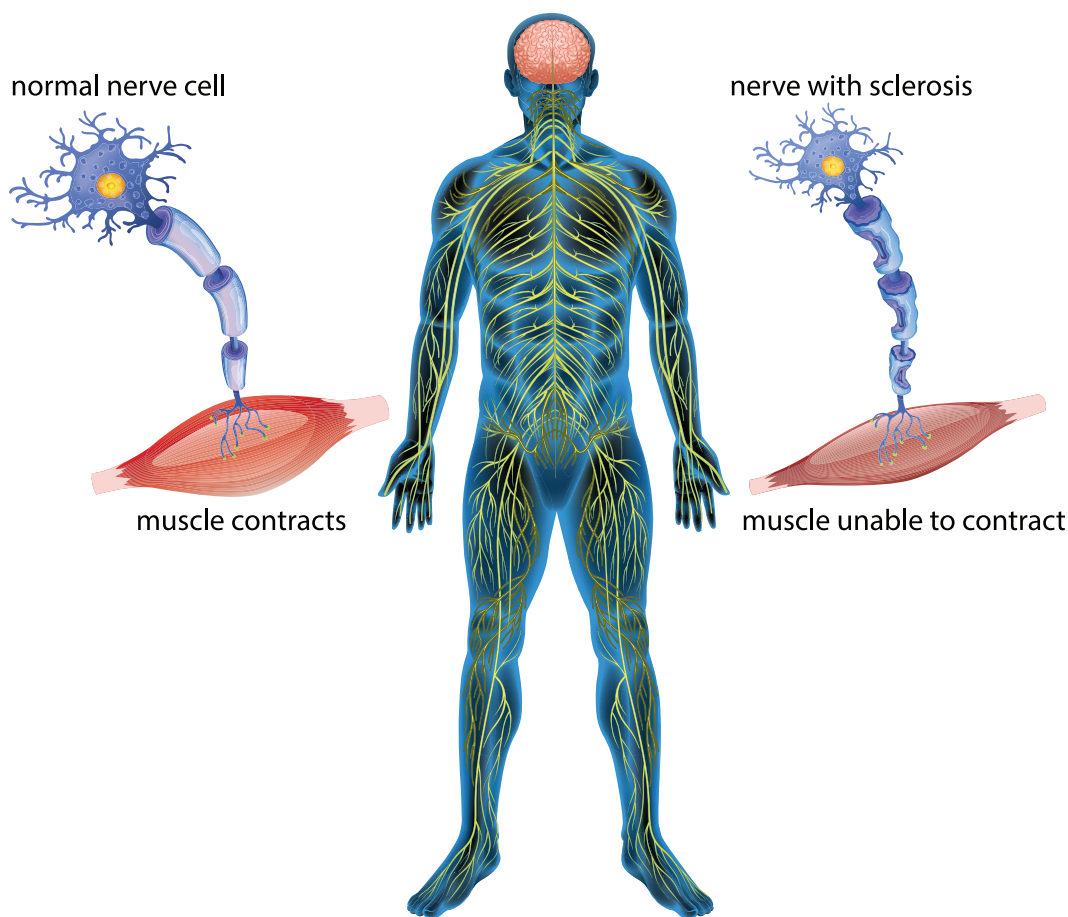
this nerve connection to survive. There is a symbiotic relationship between every muscle in our body and a specific nerve axon – they need each other. If the connection is severed, not only will the muscle not get the signal of what to do, it also will shrink (medical term: atrophy) without an axon (Figure 2). This is why, in ALS or other MNDs, we cannot stimulate the nerve artificially to reverse the effects of the disease: the axon must be intact for the muscle to remain healthy.

## What are ALS and MND?

The term amyotrophic lateral sclerosis is not a very good description of the disease, because we know the problem is **not** nutrition to the muscle, but rather death of the nerve that connects to the muscle. However, clinicians and people in North America still use the term ALS because it is so well known and more specific than MND.

As mentioned, another term for ALS is “motor neuron disease,” or MND. This is a better description of what happens in the body: the nerve cells that communicate (innervate) with muscles are diseased and die. However, this term, MND, is used less often because there are other causes of MND besides ALS (i.e., MND does not refer only to people living with ALS). ALS is a type of MND. Other types of MND include progressive bulbar palsy, primary lateral sclerosis, and progressive muscular atrophy.

**Figure 2: Amyotrophic Lateral Sclerosis**



## When and How Likely Is It for ALS to Occur?

ALS most commonly occurs between the ages of 40-70, but it can occur at much younger and older ages as well. Men are slightly more affected than women. ALS is a rare disease that, on average, affects about 6 in 100,000 people at any given time (prevalence rate). The number of newly diagnosed cases per year is approximately 2 per 100,000 people (incidence rate). The research and data collected annually through the National ALS Registry provides more current information on the actual number of people who have ALS in the United States.

## What Causes ALS?

ALS most often occurs sporadically, meaning without a known cause or warning. There is no known direct cause. Current research shows no correlation to diet, exercise, activities, or jobs. There is a relationship between military service and smoking leading to a higher likelihood of getting ALS, but it is unclear if either military service or smoking actually causes ALS. Research is being done to figure out what factors in the environment may influence the likelihood of developing ALS, but there have not been any valid findings to date. Occasionally, there are rumors of 'ALS triggers,' but none have yet been proven.

## FORMS OF ALS (SPORADIC ALS, FAMILIAL ALS)

Sporadic ALS is responsible for approximately 90% of all cases of ALS diagnosed. Sporadic means that the cause or causes of the disease is unknown. Researchers are looking for genes that may make one person more likely than another to develop ALS. There is a group of people with genetic or inherited form of ALS referred to as familial ALS (fALS). This makes up approximately 10% of people living with ALS. For familial ALS, a person could have one or more family members living with ALS or that died from ALS. This could include parents, siblings, and grandparents; not typically a second or third cousin or other remote family member.

## GENETICS AND ALS AND FTD

Even though we have just identified ALS as "sporadic" in the majority of cases, researchers and clinicians are beginning to see a pattern with other diseases and genes that are associated with ALS. One of these conditions is Frontotemporal Dementia, or FTD.

FTD is a rare form of dementia that causes trouble



with decision-making and sometimes changes in behavior (e.g., saying inappropriate comments or not responding to emotions). There may be a common link to both ALS and FTD. It is believed that up to 50% of people living with ALS may have some mild changes in decision-making and behavior (medical term: frontotemporal dysfunction), but not outright FTD.

## How Does ALS Progress?

Many people want to know how quickly ALS progresses. This is another difficult aspect of this disease as no two individuals present exactly the same. Some people have severe involvement in one area before it spreads, while others experience rapid progression throughout their body. In some people, the disease progresses very slowly. In general, people living with ALS live about three to five years after they experience the first sign of weakness. This is a generalization, which is based on averages. People living with ALS can live anywhere from a few months to decades depending upon disease changes and the types of medical care and assistive devices they choose. ALS is different in each person and will run an individual course.

## Certified Treatment Centers of Excellence Program

The ALS Association has Certified Treatment Centers of Excellence and Recognized Treatment Centers that provide medical care and guidance for people living with ALS and their families. Both certified and recognized centers have all the required medical professionals available to provide the best care possible, including:

- Neurologist (medical doctor who specializes in diseases of the brain, nerves, and muscles and is experienced in treating ALS)
- Nurse or Nurse Practitioner (RN or NP)
- Respiratory Therapist (RT)
- Physical Therapist (PT)
- Occupational Therapist (OT)
- Speech-Language Pathologist (SLP)
- Dietitian (RD)
- Social Worker (SW)
- Mental Health Professional
- ALS Association Chapter Liaison

Many centers offer the services of a pulmonologist (doctor specializing in the respiratory system), gastroenterologist (specializing in the digestive system), palliative care physician (specializing in supportive care and pain management), physiatrist (specializing in physical and rehabilitative medicine), psychologist and other mental health professionals such as psychiatrists (specializing in assessment of thinking and mental health).

If you are not familiar with the ALS clinic in your area, please visit The ALS Association website to find the clinic nearest you: [www.als.org](http://www.als.org)



# Research on Families and Illness

**“ I moved to a new school. We had to go up and tell about the family...and I didn't like talking to everyone about his sickness. But like I told my teacher about it, him. And so then my friends asked about him. I finally told like someone that I really trusted. ”**

**K**ids spend an average of 6 hours per day in school, which is increased by after school programs and events. It follows that adult school staff may be the adults children most often engage with and turn to for support. As the quote above shows, children are not always in the same school and must re-introduce themselves each time they change academic settings or classrooms. Research highlights disparities in education among children of color and economic status<sup>1,2</sup>, among other issues, resulting in programs and initiatives to decrease these gaps<sup>3</sup>. Yet, despite the eventual impact on school performance and attendance, one population that rarely receives the same level of attention is children who live with and provide care for a family member with an illness — in this case, ALS.

## FAMILY ILLNESS AND CHILDREN

Research on the impact of a significant diagnosis within a family finds elevated levels of depression, stress, social and peer isolation, and decreased academic performance in children<sup>4,5,6</sup>. These effects are found across disorders<sup>7</sup>, including mental illness<sup>8,9</sup> and substance abuse<sup>10,11</sup>. Children living with a major disease in the family are not always told about the details. This lack of information highlights potential anxiety, fear, and guilt when they are not told why the parent or family member is ill<sup>12</sup>. Additionally, they often feel as though they are not worthy to know that information.

Living with an ill family member may lead to poor coping skills, including self-isolation and





feelings of guilt and responsibility for the ill person<sup>13</sup>. This underscores the need for children to have correct information about what the disease is, the perception of the person with the illness, and how to access support<sup>14</sup>. The need for support is particularly critical for children in families with diseases such as ALS, with no treatment or cure, and often quick progression.

As a school professional, you have a unique opportunity to engage at multiple points throughout the school day and beyond to provide support for the child.

## HOW FAMILIES TALK ABOUT ALS

Despite the social discourse around illness in families, social isolation around the illness is rarely due to the child. In the national study of families and ALS, almost one-third of families stated they did not want their child to “*know too much*” about ALS<sup>15</sup>. Multiple reasons may account for this perspective.

Many parents and family members may feel a sense of fear they will harm their child or scare them by disclosing such personal information, so they avoid any conversation. **While these fears can be real, they should not stop conversations with children.**

- Often, the person living with ALS is coming to terms with their own diagnosis and may fear crying or being overly emotional in front of their children/grandchildren.
- Adults are often more concerned with “protecting” their kids from what they see as painful and unknown. It feels too much to burden the children and cause them fear or sadness.
  - “Protecting” kids can create secrecy and fear in children and convey the message they don’t need or deserve to know what is happening. This can create conflict because the children see something is different but are left out.
- The unclear progression of ALS and lack of treatments can be scary for the person living with ALS and their family, particularly if they have never discussed it openly.
- Fear of emotions, and lack of understanding of the specific disease process, encourages atrophy in family conversations – even for the most open families.
  - How children deal with illness is directly related to how their parents or family cope or deal with ALS. When a parent or family member has strong coping skills, those can translate to how well the child copes.

One thing that has become clear in the research and clinical work: ***Kids want to know about the illness, and they want to hear about it from the parent or family member living with ALS.*** Avoiding discussion may only serve to create more confusion, blame, or fear in the child, and eventual communication barriers in the family.

While the above may not be true for all families with ALS, it is a good baseline for professionals to frame conversations and develop ways to engage the family and their children. In the next section, we focus in on talking with children about the illness and working with them and their families in living with and dealing with ALS.

# Talking with Kids and Their Family

**“ I feel like they wouldn't understand. ”**

The above quote from a 10-year-old explains their concerns about talking to their teacher about the impact ALS has had on them. The quote implies that, even if the child is familiar with you as a professional, they may still be unsure when or how they can talk to you about ALS. You may know the family well, through teacher meetings or the community, or you may have never met the parents or person living with ALS. Whatever the case, you have the opportunity to develop a relationship with the child and their family as they navigate the changes associated with ALS progression and its potential impact on the child's school performance and attendance. While it is not uncommon for kids to want to tell their teacher, social worker or other school staff about ALS, their family may be more reticent. Alternately, you may have met with parents who want to talk about how ALS may be affecting them, but the child does not want to talk about it – to anyone.

Many barriers exist in families dealing with illness. One of the most important is the fear of telling others, and exposing their family “issue,” particularly to school personnel whom they fear may not understand what they are going through.

## Supporting the conversation with the kids and families

As the school social worker or counselor, you may have been referred to the child and their family by other school staff who had concerns. Or, you may be the teacher who noticed something was “off” about your student and wanted to meet with the family. In either case, or any others as school staff, you have an opportunity to be a support for kids in their journey with ALS.

The following suggestions are intended to add to existing tools/assessments when meeting with families living with ALS. These suggestions may be used to help families communicate about ALS and get support as a group.

- Ask the person living with ALS to think about possible questions or things that make them uncomfortable.
  - Have them or someone on their behalf write these down and think about how they would answer them before talking with the child. This will prepare them for possible tough questions.

- Find alternate ways to talk through those questions and what would make them more comfortable in answering those questions.
  - These alternatives include engaging a therapist, the local chapter of The ALS Association or a trusted family friend. Additionally, alternatives may include journaling, painting or other expressive arts. Sometimes fewer words are better.
- Encourage people with ALS to show their willingness to discuss difficult issues. This may be telling their kids something about ALS that makes them uncomfortable, or perhaps how something has changed, like: *"I am sad that I cannot use my arms any longer."*
  - These are also good suggestions to have the person living with ALS think about ahead of time. This discussion very much helps to normalize what the entire family is going through.
- Look for opportunities to discuss sensitive topics – including finances and health – when appropriate. Families living with any illness may be dealing with a host of issues, not the least of which are accessing appropriate care, food, transportation and housing. These are all issues faced by families living with ALS.
  - Assess the need for social services, food banks, accessible housing, and financial assistance (heating, electricity, etc.).
  - Make referrals to local nonprofits who assist families in dealing with crisis and health issues.
- Always encourage the family to access as many resources as possible through the local chapter of The ALS Association or other qualified individuals or organizations: [www.als.org](http://www.als.org)





# The “New Normal”

“In the beginning, I felt so sorry for myself. I felt sorry for him, and then I realized, and he helped me realize that it’s just a part of life and that he’s better than he was before and he’s learned so much and he’s become such a better person. And I’ve become such a better person because of it, and it’s really helped me to understand like my future and my life.”

Living with ALS requires families to think of ways to develop new routines—to live *with* ALS, not *in spite of* ALS. As the above quote from a 13-year-old highlights, lives are dramatically changed by ALS, including how kids see themselves and their family member with ALS. These changes can be negative or positive. **Life is not what it once was, and that can be hard for all involved.**

The concept of developing a *new normal* is not singular to the ALS population. It has been applied across many disease states, particularly with those who have life limiting illnesses. The new normal helps to re-orient families **away from the immediacy of the diagnosis** and the inevitability of death and **toward a daily accommodation** and integration to everyday life and routine — many of which need to be adapted to the *new normal*.

Many families discuss changes to their family routines, including difficulty accessing appropriate equipment, adapting their living environment, and the fear of being in public when something happens



as a result of ALS. While these are valid concerns, one thing we know from interviewing and working with children is that they want to keep as much “normal” family and overall life activity as possible.

When students discuss ALS, or mention struggles they are having, or when you meet with the family during parent/teacher meetings or social work sessions, these are excellent times to bring up or help guide families to think about their own “new normal.”

**NOTE:** As with all conversation about ALS, you are not expected to be the “expert.” We offer the below as suggestions. It is always appropriate to make a referral to the ALS chapter in your area for more ALS specific support.

## Suggestions for how to help families talk about and adapt to their “new normal” life with ALS

- Encourage children to talk about something new or different that ALS brought into the family and how that makes them feel.
- How has ALS made their family communicate differently? Has it made the child see life in a new way – good or bad?
- Often younger children gain benefits from drawing their feelings, so having some art available when you talk with them can be helpful.

As with many issues, illness or otherwise, there may be denial, indifference, or even anger to the discussion. Depending on when the person was diagnosed, some families may not be ready to see anything beyond the initial diagnosis. This is normal, as some families need time to process and adjust to the diagnosis. While doing so, you can provide information about the local ALS Association chapter, support groups, family counselors or other qualified individuals or organizations in your area.

In the end, you may not get all families engaged, and others may need more than the school resources or professionals can accommodate. The key is to make sure when you interact with the family, they know they can talk with their child, they have the support to do so, and the school is willing to make referrals to the appropriate services.

# Discussions by Age Group

Based on cognitive, social, developmental theory<sup>16</sup> and clinical practice, the below sections are created as starting points to think about how to talk to children across different ages. It also may help in thinking about how to engage these children in your classroom or school activity. While there is no “right” way, understanding how to approach the conversation by age group can be extremely useful for you, other school staff and for the families you serve.

This section is available for download on The ALS Association’s website at [www.als.org/navigating-als/resources/Youth-Education](http://www.als.org/navigating-als/resources/Youth-Education).

Age Range	Developmental Milestones	Suggestions for Discussion
<b>Infants and toddlers (Age 0–3)</b>	Babies and toddlers need routine, need to feel safety, and can pick up anxiety and fear in the parent.	Keep the normal routine as much as possible.  Create a “new” normal environment (meals times, feedings, sleep, etc.).
<b>Young Children (Age 4–7)</b>	<p>At this age, children are concrete thinkers and do not need complex discussions, but they have curiosity and will most likely ask questions, some of which will be very direct.</p> <p>Children in this age group can be very egocentric (everything is about them) and are “magical thinkers,” meaning they believe that something happens because they made it happen or because they thought it. They may feel they, their behavior, or lack thereof, caused ALS.</p> <p>Children in this age group do not have the ability to understand abstract or hypothetical situations.</p> <p>Finally, kids in this age group are not future oriented, thus time does not mean the same thing to them.</p>	<p>Parents may feel this is too young to talk about ALS, but children see and know that “daddy looks different from mommy.” It is important to be clear and honest.</p> <p>The child may feel he or she is at fault, was not obedient enough, did not listen, etc. This is a crucial place to reassure and support the child that he or she is not responsible for ALS.</p> <p>Using slang or complicated terms may be confusing. Use simple straightforward language (Daddy hurts, Daddy can’t walk, etc.). Addressing what the child sees (i.e., Daddy in a wheelchair) is important. Let the child know the disease makes it happen, but that it may look different in different people.</p> <p>When you say “6 months,” young children have no idea what that means, so talk in the now and do not use abstract time dimensions.</p>



Age Range	Developmental Milestones	Suggestions for Discussion
<b>Middle Childhood (Age 8–12)</b>	<p>Children in this stage are focusing on identity. Who am I? Am I the kid with a parent in a wheelchair?</p> <p>Children in this age group are able to solve problems and can use logic.</p>	<p>Continue to make sure children know that they are not responsible for their parent or family member having ALS.</p> <p>While having a family member with ALS isn't "normal," it is important to "normalize" the experience in terms of the family and how you talk about it.</p> <p>You can help children see and make connections between their emotions and their thoughts. How do they feel about being told about ALS? Guide them to interpret their emotions in a healthy way.</p> <p>Let them know it is OK for them to be sad about how things might be changing, while letting them describe their thoughts.</p>
<b>Adolescents (Age 13–18)</b>	<p>Adolescents often deal by focusing on the emotion, even when they are struggling to control those emotions.</p> <p>This conflict is influenced by hormonal changes and struggle with their own identity and sense of belonging.</p> <p>At this stage, most teens have developed more cognitive skills and the ability to understand the abstract.</p> <p>They can create hypotheticals in their minds, including what life may be like moving forward with ALS.</p> <p>Adolescents are developing their own selves, so they may seem to be uninterested or uninvolved in the conversation. While it certainly can be due to the emotional aspect, they are also processing who they are in the context of what you are telling them.</p>	<p>Addressing the emotional aspect of what they understand about ALS is important.</p> <p>Check in to see how they are feeling and allow them to express their feelings without judgment.</p> <p>Addressing hypotheticals may result in outward distress and emotions that can wildly fluctuate, which many parents avoid. However, addressing how they feel is just as important as how they think about it. The adolescent may not be able to explore the emotions.</p> <p>Engaging with a professional at this point can be extremely helpful. A professional can assist in helping a teenager process the emotions they are going through. As an outside party, this may create a feeling of confidentiality.</p>

Age Range	Developmental Milestones	Suggestions for Discussion
<b>Adolescents (Age 13–18)</b>	<p>Conflict with adolescents can be very developmentally appropriate given their need to find themselves and belong to peers.</p> <p>Adolescents tend to respond well when they know they are heard and respected and you see their point of view.</p>	<p>When talking with your adolescent, acknowledge that they are becoming their own person. Keep the communication connection, but allow the adolescent to be with friends to lessen the very common conflict.</p> <p>Keep the conversation open. Make sure your teenager knows they can come to you at any time with questions. An adolescent may shut down if you ask too often; just let them know you are there.</p>

## References

1. Hutchison, E. (2013). *Essentials of the human behavior*. Thousand Oaks, CA: Sage.



# Children and Teens As Caregivers

“...sometimes I just feel kind of like always helping other people, and no one's there to help me, I guess. That would be the best thing — is just kind of have someone go, hey, good job, whatever. You know, sometimes.”

Caregiving literature focuses on adults: how being a caregiver affects work, health, and family. Social programs, state, national and nonprofits all target the adult caregiver — providing support and education, while raising awareness and advocacy for adult caregivers. Yet, as evidenced from the above quote from a young girl who cares for her mom with ALS, missing from these programs and policies are the approximately 1.4 million children between the ages of 8-18 in the U.S. who provide care to an ill family member — “*young caregivers*.”<sup>17</sup>

Providing care as a child can be a positive or negative experience — oftentimes it is both. This has implications for the interaction with the person receiving care, as well as peers and school performance and attendance. In the next section we address the impact on the adult/child relationship, how care impacts a child's well-being, young caregivers and ALS, and ways schools can support youth caregivers.

## Caregiving and Adult-Child Interaction

Normative social expectations assume the parent is the caregiver, modeling behaviors for the child as they develop. However, with the intrusion of a significant diagnosis on the parent/child interaction, the normative trajectory is interrupted, causing a change in the relationship and expectations. Adding caregiving duties to the child may further change the parent/child interaction, in both positive and negative ways. With the change in the interaction from parent as caregiver, to child as caregiver, the normative parent/child interaction is disrupted even further. This can bring on feelings of positive self-worth in the child — knowing they are helping someone they love and participating in their care. At the same time, it can potentially create negative outcomes including poor school performance, emotional dysregulation, acting out, or withdrawal.

## HOW CAREGIVING AFFECTS CHILDREN

**Mental and physical health.** Data shows being a young caregiver impacts mental health, with an increase in depression and anxiety<sup>18</sup>. Research in the UK shows that children who



provide care rate their overall health only as fair, compared to non-caregiving children<sup>19</sup>. While anecdotal evidence has shown caregiving happens in the evening and overnight, current research is addressing how caregiving impacts sleep, increases stress and inflammatory processes in young caregivers.

**Peers.** Caregiving children are often in a confusing position with friends. They want to belong and feel accepted, which is developmentally where they should be — particularly older kids who are developing their identity and individuation away from the family. However, we know that youth caregivers can feel isolated because, out of all their friends, they are often the only ones who provide care to a family member.<sup>20, 21</sup> Through our conversations and interviews with children, we also know that kids as young as **six years old** are providing care for their family member. Youth caregivers want to have peers who “get it”<sup>21</sup>, and want their friends to see their family is just like any other family — just dealing with an illness.

**Long term impacts.** This is one area that receives very little attention, so it is difficult to provide specifics. While research shows some current young caregivers have higher rates of depression and anxiety than non-caregiving children<sup>18</sup>, it is unclear whether this has a long-term effect. While some adults who provided care as children may not have high levels of depression, they may still be at risk into adulthood.<sup>22, 23</sup> However, others have stated they feel a stronger sense of self and feel good about the care they provided.<sup>24, 25</sup> One thing is clear — when a caregiver has no outlet to discuss a potentially difficult or stressful situation, such as providing care to a family member at a young age, they may internalize negative feelings about themselves and the person with the illness, with no reflection on whether that is an appropriate or common feeling. Therefore, they may become more isolated over time. Thus, long-term youth caregivers may internalize negativity about the care they provided, particularly if they were never allowed to discuss it.



## WHAT ABOUT THE PERSON LIVING WITH ALS?

The need for care provided by a child is particularly difficult on the adult, most acutely when it is a parent. In the study of families impacted by ALS, parents described feeling **proud** of their child as a caregiver, while simultaneously feeling **disappointed** in themselves and guilty for the responsibilities put on their child. These complicated feelings deserve to be addressed. If you have a student in your school who helps take care of a person living with ALS, it is likely they may be grappling with some of the above feelings.

Much like the overall conversation about ALS, having a child involved in care is rarely discussed in families. People with ALS may feel concerned about telling professionals, including school personnel,

**“ If parents are relying on a child to provide care for a family member living with ALS, that does not mean they are bad parents — it means they need assistance. ”**

that their child helps with care. They may not want to call attention to the care they provide for fear of making it a big deal with the child, or even social services, in order to avoid any misconceptions or stigmas around youth caregiving. These feelings are understandable, but the fear of telling can exist as a barrier to care needs and family communication.

We suggest the family be referred to the local chapter of The ALS Association, or a therapist in your area for more support. In sections below, we discuss this issue in more depth including roles of mandated reporters.

### Young Caregivers and ALS

Since 2015, The ALS Association has funded several research and evidence-based projects addressing children living with, and providing care for, a person living with ALS. These projects seek to understand youth experiences and inform the development of support and educational programming. Data from these projects shows:

- Almost 50% of youth caregivers were younger than 12 years old.
- The majority were female, but many young males do participate in care.
- Children provide care for varying periods of time, ranging from 1 month to 8 years.
- Many children provide care on a daily basis, often for many hours per day.
- Overwhelmingly, these young caregivers provide care alongside another adult in the home or family.
- All children felt they had *some* responsibility for care, while 44% felt they had *a lot* of responsibility for care.

# Loss of Childhood

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“I would call myself a caregiver because I do more than a normal kid would do for their parent/dad. I help a lot. It is like a job sometimes.”

For those who were caregivers as children, like the 15-year-old quoted above, many describe feeling that they grew up too quickly because of the level of responsibility. These kids:

- Missed out on “normal” childhood milestones because they were either needed at home or felt they should stay around to help.
- Could not attend school functions, sports, or after-school activities.
- Know more about hospital beds than pop culture and have a hard time connecting to peers who are not caregivers.

The lack of peer interaction and engagement can create a divide between them and other “normal” children their age. ***This may be particularly pronounced in school settings.***

Alternately, many children make the decision to not participate in sports or after-school projects so they can spend more time with their family member living with ALS. This is particularly salient given the often extremely quick progression and lack of clarity as to how ALS will progress.

Whatever the reason, when children are providing care, they are not doing other activities that their peers are doing. They need support and to know they are heard and understood by the adults around them. As with the conversation about ALS in general, the need may arise to talk with your students or their family members about caregiving. From previous studies, some of the issues noted by teachers underscoring the need to engage the student/family include:

- Reports of bullying by other students
  - Peers can be cruel, especially when a child/youth is not “like the others,” which can include having a parent with a disability/illness
- Changes in student personality
  - Normally outgoing, now withdrawn, previously happy, now quick to anger
- Student falling asleep in class
- Student dropping out of extracurricular activities



Often, these issues get “swept under the rug” in a climate of schools that are stretched thin and classrooms that are packed. Alternatively, these issues might be seen as the student being “difficult,” or it might be assumed that the issues at home are something other than family illness and caregiving. Often these issues are manifested in the family where the care provided by the child is not overtly addressed, leaving families isolated from each other.



Knowing many families may resist this conversation, it may take a few starts, or may need to include the school social worker or other trusted adult. We offer a few suggestions for school staff to facilitate the conversation with families in order to support them and their child.

- Encourage parents and family members to let their kids know they appreciate the care they provide, and they are loved - regardless of the care they do or do not provide.
  - Some children fear their care is not “good enough” but have not told their family member. Having the adult tell the child will help to lower their fears and open conversation.
- Let families know children should be encouraged to talk about feelings and experiences of caregiving at any time - without fear of hurting anyone’s feelings.
  - This is a good place to encourage families to meet with the social worker or therapist to craft ways to communicate about care and share in a safe environment.
  - Children should also be encouraged to talk about how they feel about caregiving – positive or negative, in a safe space, such as the social work office, school nurse office or other private location.
- Coach families in modeling the conversation by helping the person living with ALS identify how they feel. By understanding how the person living with ALS feels, children may also feel comfortable saying how they feel.
  - Many therapists and social workers have games around “I feel” statements. Encourage the use of these. Families may think they are sharing, but until they say how they feel about something, it is not clear to others.
- Let children know they are supported, and they are not alone as a young caregiver.
  - Connect them with the local chapter of The ALS Association or other qualified individuals or organizations, who may have many other families looking for child connections.
  - Consider working with the school social worker or nurse to connect children in the school who are caregivers. There may not be others caregiving for ALS, but there are most certainly others who are caring for Alzheimer’s disease, cancer, diabetes or any other illness. For these children, caregiving is caregiving and they deserve the peer support from as many peers as possible.

# Young Caregivers and School

**“ Well, I just kind of distanced myself from everybody. I didn’t really want to be around anybody, which I don’t like being at school anyway because I just can’t get into it. I can’t concentrate. ”**

One of the most profound ways caregiving impacts children is school performance and attendance<sup>26</sup>, as evidenced above by a quote from a boy who has a father living with ALS. Research highlights youth caregivers missing school, falling asleep in class, and worrying too much to concentrate<sup>17</sup> – all due to caregiving duties. Yet when asked, most youth caregivers say they do not tell their teachers or other school staff. Often it is because they do not know what to say, or they feel they are betraying the family by talking about personal issues. Regardless of the reason, caregiving children continue to self-isolate, potentially impacting their school performance and attendance.

During school, children worry about the well-being of their family member living with ALS and who is providing care while the child is in school, or experience sleep deprivation or exhaustion from caregiving while trying to keep up with school assignments and activities, often impacting their classroom experience.

## In The Classroom

Some children may want to do a presentation to their class to share their stories and experiences. Telling their story first can break down barriers and misconceptions about the parent or family member living with ALS and lessen the possibility of bullying. This allows the child to tell their side of the story and put the information out there before someone can use it against the child.

**“ A lot of my friends, since I completely trust them, they all know what’s happening and everything, and they ask me about it. ”**

Caregiving children, perhaps more so than other peers, need friends who “get it” and who can show compassion and support, even if they do not have a parent or loved one living with ALS. Supportive peers can help with the transition back to school or starting school and provide a sense of “normalcy” in the school setting. Indeed, being in school is one of the few places young caregivers are “normal,” and thus do not want to tell anyone about being caregivers.

They can see school as a respite from their home life. Therefore, when talking with the child, pay close attention to how they describe their time in school, what they need, and how you can best support them.

## Suggestions for Teachers

- Talk to the youth caregiver in a safe space, when no one else is around.
- Make a referral to the school social worker or counselor.
- Connect the student with other peers who may have a family member with an illness. Even if this is not ALS, young caregivers want to know other young caregivers and feel like they “belong.”
- Keep an eye out for changes in the student’s behavior. Are they sleeping in class? Having problems with homework or schoolwork? These could be symptoms of a variety of things, including being involved in caregiving.
- Come up with a plan for schoolwork — perhaps allow late homework or extensions on projects.

### In The Classroom

Beyond you as the teacher, what can your classroom do for the student who experiences ALS, or any other disease in the family?

- Have a fun event, fundraiser or awareness day that the child with ALS in the family gets to plan.
- Create a “let’s talk about ALS” day. Make the conversation normal and simply part of the that day’s lesson.
- Invite the person living with ALS to class to share their experiences and possibly demonstrate how technology helps them in their daily life.

Whatever you choose to do, make sure it is **with the child’s consent** and with their engagement in planning the event. The ownership they will feel can go a long way to helping them manage their feeling about ALS and how they interact with their friends and teachers.

## Suggestions for Social Workers and Counselors

There are many roles for school staff outside the classroom, including school social workers and counselors. These individuals can play a large role in connecting families to social services, programs and supports outside the school setting.

- Encourage families to engage with other family members and friends to provide respite or time away for the child.
  - Much like adult caregivers, children benefit from time to do their own activities (school, friends, community), which is crucial to their own self-care. Help the family identify other

adults and friends to offer support or care respite for people with ALS, allowing for the self-care time for the child.

- Ask about other friends or family members who may be able to offer caregiving assistance.
  - Many children do not want to feel as though they are complaining or being a burden to others, but when offered they may accept the extra assistance.
  - Additionally, they may be reluctant to give up their responsibilities as a caregiver — even for a day — out of a sense of love and a sincere desire to help and to feel like they are contributing to their loved one’s well-being.
- Ask the child what other people can do to help with actual care or ways to support them.
  - Kids may feel uncomfortable asking for help, so offering is important. In the ALS study, young caregivers want assistance particularly with hands-on care<sup>27</sup>. Having another adult engage with the care will go a long way towards lessening the potential stress and burden of care.
- Share information about a program called “Care Connection.”
  - The ALS Association Care Connection is a simple online tool that helps organize the community of people who want to help, coordinating their efforts to more efficiently support families living with ALS. It is a private online calendar that can be used to support the entire family — by organizing volunteers to take care of some of those tasks families describe as “falling through the cracks.” Setting up the Care Connection webpage and calendar may be a way for a child to help that feels more comfortable for them. For information on how to set up a care connection go to <https://www.als.org/navigating-als/for-caregivers/als-association-care-connection>.



# Professional Stance

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**M**any children have close relationships with school staff, including coaches, teachers, social workers, and others. These adults may be the only ones a kid connects with and feels safe to discuss their experience with ALS and care tasks. *You may be that person for one of your students.* As you interact with them, it is critical to understand your own stance as a professional, how you feel about illness, children and care. Here are a few tips when talking with kids:

- **Assess how you feel about talking about ALS.**
  - It is important to assess your own comfort in having conversations about ALS and the challenges it brings. Your role and professional experiences will help you determine if you, or another professional, should facilitate the conversation. If you feel another professional should be brought in to assist, be open and honest, and facilitate the connection to that other professional.
- **Make sure you have the correct details.**
  - Many kids have some basic information, but they confuse the details. This conversation is the opportunity to clarify details and help children know the fundamentals of ALS. If you don't feel comfortable, or don't have correct information, The ALS Association has materials to guide the conversation with children.

## Caregiving and Abuse/Neglect

On occasion, people can misinterpret the fact that a child is acting as a caregiver as abusive or neglectful. However, it is important to be clear: being a young caregiver is not inherently abusive or neglectful. Here are a few things to think about when considering any potential referral:

- Removal of the child who is providing care is often unnecessary and may be more detrimental, leaving families splintered at the very time they need each other the most.
- Providing care for a loved one can give children a sense of pride and self-worth and allows them to contribute to their well-being – removing them from the care role may impact their own sense of well-being.
- Families would require more care and possibly be broken up if the child was removed as caregiver.

That said, in all cases with children it is critical to be aware of any potential abuse or neglect in these families. As a quick reminder, **social workers, teachers, principals, and other school personnel are all mandated reporters.**



The circumstances under which a mandated reporter is required to notify authorities varies from state to state. Typically, a report must be made when the reporter, in his or her official capacity, suspects or has reason to believe that a child has been abused or neglected. Another frequently used standard is the requirement to report in situations in which the reporter has knowledge of, or observes a child being subjected to, conditions that would reasonably result in harm to the child. Mandated reporters are required to report the facts and circumstances that led them to suspect that a child has been abused or neglected.



They do not have the burden of providing proof that abuse or neglect has occurred. Permissive reporters follow the same standards when electing to make a report. For more information about being a mandated reporter, go to: <https://www.childwelfare.gov/pubPDFs/manda.pdf>.



# Death and Dying

**“ Unless she brings it [discussion of death] up, like, I’m not gonna bring it up...’cause I don’t wanna make her any sadder than she already is. ”**

Talking about death and dying is not easy, as shown by the above quote from a 16-year-old whose parent has ALS. “Normal” life development assumes that we lose our parents when they are older, when we are adults. However, this is not the case for many children who have an ill family member — like a parent with ALS. Dealing with death and dying is complicated and brings about fear and a mixture of emotions, including a lack of clarity about how, when and why to talk about death. Many families feel ill-prepared to talk to their kids about disease progression and impending death.

Research on death and dying with children and youth tells us:

- Talking with children and letting them express their feelings and grief helps them feel less anxious about death.<sup>28,29</sup>
- Talking helps children process the loss of a parent.<sup>30</sup>
- Children benefit from clear information in order to feel comfortable in expressing their feelings<sup>31,32,33</sup> and parents are the ideal ones to start and have the conversation.

Children draw their cues about talking or not talking about death from parents or other older family members. However, in families living with ALS, that conversation will come sooner than many others and, sadly, cannot be ignored. Adults rarely wish to talk about death and dying, including what this entails or



looks like, with their children. Yet, research shows kids don't always feel the same. Data from a study of children in families with Huntington's disease found kids actively wanted to talk about death and dying with their family, yet did not pursue it for fear of hurting the family members' feelings<sup>34</sup>.

While families will decide when and how they want to discuss this with their children, as professionals it can help to have an idea of what your student may be thinking. While older kids tend to hold in more of their thoughts and feelings, younger children tend to be more open, even blurting out heavy conversations at times wholly unexpected — including in class. Whether they say it out loud or not, kids are thinking about their family members' death and dying, with many wondering the following:

- What will the death look like?
- How will it be handled?
- Will their parent/family member remain in the home?
- Can they be present during the death?
- What will happen to them when the death occurs?
- What will the services or funeral look like?
- What supports are in place?
- Where will we live after the parent dies?

These questions may be posed to you as a school professional, or you may hear them come up in class.

While it is not necessary to have all answers, it is important to have an idea of what students may ask, or may be thinking. **You are not expected to answer these questions**, as it is more than likely you are not prepared to have an answer — particularly in the middle of class.

Our goal is to bring awareness to some of the things kids may be thinking, so when — or if — it comes up you are prepared to either discuss or make a referral to the school social worker, local chaplain, counselor or The ALS Association.

## End of Life Decision Making and Children

As described above, many kids have no idea what their parent or family member is feeling, thinking or may want to have happen at the end of their life. While many factors go into this, it is important to let the child know why decisions are being made. *It is up to the parent/family member to decide the depth of these answers*, but again, these are things to think about as a professional working with families at the end of life. Confusion around death and dying may not be obvious. They may spontaneously cry, or spontaneously be angry. They may self-isolate. They may ask questions about their own death.

Decisions around end-of-life care are highly personal and look different from one family to the

next. These decisions are not always effectively explained to children. You may notice changes in behavior as a result of how these decisions are being made and communicated.

- If the person living with ALS decides to forgo treatment, it is important to share why.
  - This is dependent on the age and developmental level, which we discuss below.
  - If the children are old enough, it is often helpful to let them have more information which will alleviate potential guilt for not “doing enough” to help their family member.
- If the person living with ALS chooses to have hospice or home care, it is important to let kids know.
  - Having new people in the home, a hospital bed in the living room, and more machines can be very stressful and confusing for kids. You may see this stress in class, or emotional outbreaks at times when it is not expected.
  - Families need as many supports as possible during this time, and that support should include talking with the kids.

## Create a Support Plan for the Kids

End of life is a consuming, emotional, upsetting, angry time for all involved — not the least of which the children who may be feeling everything. These feelings may be most acutely felt in the classroom.

If your student is acting out, emotional, or otherwise changed from how they “used to be”:

- **Create a plan** with the school staff, as to what to do if they have an emotional time.
  - Make sure they are safe. *NOTE:* Older kids may have access to a car, so ensure they do not leave without notice.
  - Have someone with them at all times until they are able to calm down or go home.
  - **Young children** — work with the family ahead of time to have a “comfort item” for them. This can be a blanket, toy or picture that can help calm them down.
  - Have a referral plan in place for a family therapist, counselor, or clergy who can assist the child and/or family.
- **Pull them aside and offer a time out.**
  - This can be in the classroom, nurse’s office, or with the school social worker, coach, or another teacher. Know ahead of time whom the student may have the strongest relationship with.
  - Give them space to feel all they are feeling.
- **Contact the parent to let them know what is happening.**
  - This can be difficult for the parent as well. Remember that the “well parent” may be at work or providing care for the person living with ALS. They may not be able to come get their child and could feel tremendous guilt for leaving them at school.
  - Let them know their child is safe and supported.

- Have a back-up plan to bring their child home early if possible.
- **Maintain contact with the family**
  - Once the child leaves the school, you may not see them for some time if the person with ALS is at the end of life. Make sure you have a plan for who will contact your student or their family to provide support and make sure the transition back to school is safe and supportive.
  - Only one person should be the contact at this time. End of life is overwhelming, and the family needs to know who the school contact will be and how/when to connect with the family.

## Know Thyself

As a professional, it is just as critical for you to be aware of your own beliefs and biases about death and dying. Before any conversation with children, or instituting an end-of-life plan for a child, it is important to ask yourself the following:

- How do I feel about death? Am I afraid of it?
  - If so, be aware that this may affect how you provide support for the student.
- Have I been with someone when they died? How did that make me feel?
  - If it was a difficult death, be careful to not transfer those feelings to your student. Every death is different, as is the experience of the family.
  - You can let them know you have also experienced death. They may even ask what it was like, which is normal. Be honest, but careful not to color it with too much narrative of your own feelings.
- Do I feel comfortable talking about death and dying?
  - This is critical. If not, take the time to process why or why not.

Think about these questions and answer honestly. If you have concerns or feel like you need to talk to someone, please take the opportunity to do so before any discussion with a student. Both you and your students deserve it.

# Developmental Stages, Death and Dying

## Talking About Death and Dying Across Age Groups

As we know from talking about ALS in general, children process and understand things differently depending on their age and developmental stage. Moreover, how they respond to changes and death also varies by age. To help guide conversations specifically around loss, death, and dying and how you can engage with them, the following section is from a handbook created by *Beth Barrett, MSW*, and The ALS Association St. Louis Regional Chapter. Please feel free to share this with any families you may know who are going through the death, dying or end of life process.



As with the developmental table in an earlier chapter, this section is available for download on The ALS Association’s website at [www.als.org/navigating-als/resources/Youth-Education](http://www.als.org/navigating-als/resources/Youth-Education)

Developmental Stage	Possible Reactions	Suggestions for Engagement
<b>Infants and Toddlers (0-3)</b> Children this age have limited verbal expression and will demonstrate their emotions and discomfort through actions. This age group has no concept of death. They will not understand that a loved one has died but will sense and react to the emotions of parents and other family members.	<ul style="list-style-type: none"><li>• Fussiness, irritability.</li><li>• Clinginess.</li><li>• Tears, vomiting.</li><li>• Regression in behavior such as toileting, sleeping, or eating.</li></ul>	<ul style="list-style-type: none"><li>• Maintain a regular routine.</li><li>• Provide nurturance and physical security, such as holding and cuddling with child.</li><li>• Provide reassurance and patience.</li><li>• Allow child to play, as this is an outlet for children’s grief.</li></ul>



Developmental Stage	Possible Reactions	Suggestions for Engagement
<p><b>Preschoolers (Age 3–5)</b></p> <p>The preschooler is gaining verbal skills and has a strong sense of curiosity. Expect many questions from this age group. Preschoolers may utilize “magical thinking,” such as worrying that something they did or said caused someone’s death or believing that death is reversible. Preschoolers live in the present tense; they will not understand the finality of death. They may also begin to personify death as a person or thing, such as a skeleton or angel of death.</p>	<ul style="list-style-type: none"> <li>• Numerous, repetitive questions; curiosity about death.</li> <li>• May appear unconcerned or show little reaction.</li> <li>• Regression in behavior such as nightmares, toileting, possible violent play.</li> <li>• Fear of separation.</li> </ul>	<ul style="list-style-type: none"> <li>• Allow questions and talk with child.</li> <li>• Answer questions honestly and in simple words and terms.</li> <li>• Use real terms, such as death or dead, not “sleeping” or “gone away.”</li> <li>• Provide structure and a normal schedule.</li> <li>• Offer patience, explanations, and assurance.</li> <li>• Resist punishment for acting out.</li> <li>• Encourage physical activity and play to express feelings and expend energy.</li> <li>• You may have to clarify that death is not contagious.</li> </ul>
<p><b>Young Children (Age 6–9)</b></p> <p>This age group has developed more cognitive skills and may have a clearer understanding of death. They will begin to understand that they, too, will die someday. (This concept solidifies for older children in this age group.) They have more logical thinking and begin to move away from the magical thinking of earlier years. They may fear death and will begin to be able to mourn. Be aware that while this age group may understand the realities of death, they have not developed sufficient emotional or social skills to deal with their grief. They may need extra attention and support.</p>	<ul style="list-style-type: none"> <li>• May want details and explanations about death.</li> <li>• Crying; active mourning</li> <li>• Will be concerned about others’ feelings.</li> <li>• Grief expression may come and go.</li> <li>• May appear anxious or emotional; may “act out.”</li> </ul>	<ul style="list-style-type: none"> <li>• Provide reassurance.</li> <li>• Respond to their needs and questions honestly and compassionately.</li> <li>• Allow for creative play through art, stories, etc.</li> <li>• Encourage physical play as an outlet for grief and energy expression.</li> </ul>

Developmental Stage	Possible Reactions	Suggestions for Engagement
<p><b>Middle Childhood (Age 10–12)</b></p> <p>This age group has developed the understanding that death is final. At this age, death becomes personal. These children may focus on the consequences of the death, such as concerns about having to move, changing plans, or not being able to participate in activities due to the death. They may have curiosity about the biological details of death. This group may not talk as much about death or they may try to be “brave” for other family members.</p>	<ul style="list-style-type: none"> <li>• Distractedness, denial, guilt, anger.</li> <li>• School work may suffer; grades may fall.</li> <li>• May fear leaving home or parents; separation anxiety.</li> <li>• May put on a “brave face” and not show emotions.</li> <li>• May withdraw or act out .</li> </ul>	<ul style="list-style-type: none"> <li>• Give permission for expression of feelings.</li> <li>• Encourage child to ask questions and give honest answers.</li> <li>• Avoid punishment, but offer encouragement, reassurance, compassion.</li> <li>• Allow child to NOT be brave by giving them time to express emotions and worries.</li> <li>• Ask if and how the child might like to be involved in the memorial services.</li> <li>• Remember to give hugs.</li> </ul>
<p><b>Adolescents (Age 13–19)</b></p> <p>Teenagers think abstractly and have full understanding of death. They realize the finality of death and understand that everyone will die. While they have feelings of their own immortality, they also realize how fragile life can be. Their thinking is comparable to an adult’s in many ways, but this age group may not have the social support from peers who understand their grief. They may also be experiencing grief for the first time and these intense feelings can be surprising or frightening.</p>	<ul style="list-style-type: none"> <li>• Crying, traditional mourning.</li> <li>• Denial or risk taking.</li> <li>• Taking on the adult role; being the “man” or “lady” of the house.</li> <li>• Depression; suicidal thoughts</li> <li>• Willingness to talk with peers or non-family members about the death.</li> <li>• Change in behavior at school; grades falling.</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage conversation and expression of grief; be honest.</li> <li>• Allow child to have time to mourn; do not expect them to take over the adult role.</li> <li>• Seek out professional help, if needed, such as a school counselor, professional therapist, or clergy.</li> <li>• Utilize teen support group services.</li> <li>• Provide love and support.</li> </ul>

# Grief and Loss: Anticipatory and Complicated

“ [the machine] makes communication a lot harder . . . I think it’s just that it isn’t her voice. Because that’s all you really want to hear. And all you hear is that . . . machine. My dad’s old phone has my mom’s voice message on it. And we call so we can listen to it. ”

With a diagnosis of ALS, changes are happening, some slower and some faster. These changes include cumulative losses, including the loss of voice as shown above in the quote from an 18-year-old. These losses to families are many.

- Loss of childhood due to providing care
- Loss of the relationship between parent and child
- Loss of “normalcy” in the everyday routine when the parent is diagnosed, when the disease progresses, and things change
- Loss of the family as they once knew it
- Loss of the innocence that people do not die

As each loss mounts, the relationship changes, leaving the child confused, sad, and grieving.

In families with ALS, there are **three key transition points** where you will likely notice changes in your student:

- At diagnosis
- When the disease progresses, or new symptoms lead to loss of function
- End of life

The losses include loss of the parent’s voice, hearing your dad’s funny jokes, getting that big bear hug from your grandpa, playing dominoes with grandma, or going for long walks as a family. These early and incremental losses, or *anticipatory grief*, are often overlooked, yet are a very real part of the process. This is particularly true for younger children who may not fully understand ALS.

## In The Classroom

As these losses mount, you can talk them through with your student and work with them to make a special journal of memories, picture book or anything that captures what they loved about the person.

As it becomes clear the family is dealing with grief, we recommend the integration of The ALS Association chapter staff, chaplain, or social worker who have training in dealing with grief in families. One particularly helpful resource is the National Alliance for Grieving Children ([childrengrieve.org](http://childrengrieve.org)). They have online materials and can connect families with grief support in your area.

Below is a list of points from the Alliance of important things to know about children and grief<sup>8</sup>, and suggestions for ways to support the child/youth through grief.

- 1. Grief is a normal reaction for children regarding the death of someone significant.** Grief is not a problem we are trying to fix for a child; it is an experience they are living with.
  - Mood changes or feelings of grief, even several years out from the event, are a common part of adapting to life without someone and to the changes that come with that person's death.
  - It is important to support the grief, offering opportunities to meet with the social worker, counselor, or a trusted staff person.



### **In The Classroom**

- If it comes up, talk about it. This can even be a class discussion about feelings. While not spending the entire time on grief, bringing it into the classroom helps normalize that child's experience and allows their peers to support them.
- 2. Each child's grief is as unique to him or her as was their relationship with the deceased.** Because of this, the way they experience and express their grief will vary for each person.
    - Some kids have a need to talk about the person who died and their feelings about it.
    - Others might not talk about the person at all.
    - Others might express their grief through art, play, music, or writing.



### **In The Classroom**

- Allow students to share in class about the parent or family member they lost. Make these conversations normal and part of everyday learning.

In whatever way kids might experience and respond to their grief, these expressions are how they are adapting to life without the physical presence of that person and adjusting to one consisting of memories. It is important not to assume what they might be feeling about a person's death. Reactions vary from sadness, anger, fear, guilt, and even relief.

- It is important to listen to them, meet them on their terms, and come to understand their unique grief reactions.



### **In The Classroom**

- Think about how your classroom or school office can be a "safe space" for a student to discuss feelings or just to come and sit with you. You can be the person they go to for comfort during grief.



- 3. Grieving kids often feel alone and misunderstood.** Many well-meaning adults avoid talking about the deceased person for fear that doing so will exacerbate the grief kids are experiencing. In doing so, they might feel as though talking about, or even expressing their grief, is not acceptable.
- Make sure you talk about the loss, who that person was to the child, and the things that gave them meaning.
  - Provide opportunities to acknowledge that everyone feels grief. Normalizing the experience is very helpful to anyone in grief.



### **In The Classroom**

- During classwork around family, make sure your student knows even though they lost a family member, they can still add them to the project or exercise. Have a discussion with the full class about how our family is always family, even when they die.

When children feel understood by family and friends and when they have the opportunity to express their grief in their own unique way, they feel less alone and, in turn, fare better than they would otherwise.

- Allowing grieving children to share openly about feelings can help to normalize this experience and help them find ways to deal with these powerful feelings that will come and go...and come back again throughout their lives.

- 4. Personal growth is often a by-product of going through grief,** whether child or adult. It is important to note that personal growth does not diminish the sense of loss or grief a person feels, nor does it imply that someone's death was a positive experience. Yet, many children have reported that they are more compassionate toward others, value relationships with friends and family on a new level, or experience a greater sense of appreciation for life after the death of someone.

- Greater than any education, information, or advice we can give to children who are grieving, is to allow them to connect with other peers going through a similar experience.
- When they have the opportunity to interact with one another, they feel less alone. This is a great opportunity to connect with the local ALS chapter in your area to ask if they have youth programming.
- Many children want to participate in advocacy for ALS — lemonade stands, fundraisers, walks, whatever makes them feel like they are involved and not left behind.
- It is important for children to have adults in their lives who provide a safe environment that is consistent, teaches resilience, and encourages accountability, while allowing children the freedom to express their grief. As a school professional, you may be that adult in their life.

# Complicated Grief

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**G**rief is normal and can last for some time. Grief comes and goes, diminishes over time, and for many people does not create a long-term negative impact. However, sometimes grief becomes more than that – it affects everyday life and impairs a person. Adults, children and adolescents can experience this type of grief. It is important to support families and encourage them to observe and understand how their children grieve or experience complications associated with grief.

Complicated grief is particularly salient to the school environment, given the length of time spent in schools. Understanding complicated grief is critical for school staff, as they have the most contact with the kids on a daily basis.

As school staff, it is important to recognize not just immediately after the death, but over time:

- **Loss of interest in daily activities and events, even those they used to love**
  - Beyond just daily waning interest – this is loss of interest in something the child excelled at or was deeply dedicated to.
- **Inability to sleep, loss of appetite, fear of being alone**
  - This may manifest as being too groggy in class, not eating at lunch and expressions of anxiety when not being with other children.



- ***Regression, or acting younger than they are***

- This is typically seen in younger children. This can be acting out, refusing to take on new tasks, and wanting to be held or treated as a young child.

- ***Excessively imitating the person living with ALS who died***

- It is entirely normal for children to want to discuss their lost loved one. However, if the child is taking on the personality of the family member, imitating them, or talking like them regularly – this might be complicated grief.

- ***Talking about wanting to die to be with the person who has passed away***

- As with any ideation of death or suicide, this must be taken very seriously. While the child may not actually want to take their own life, they are grieving in a way that is unhealthy and may lead to taking action.

- ***Avoiding peers and friends, even close ones***

- This is a great opportunity for teachers to create more opportunity for peer engagement in classrooms. Group projects, team etc. Also, if the student is self-isolating, it may be a good opportunity to engage them in an ALS fundraiser, walk or advocacy program. These are available at The ALS Association [www.als.org](http://www.als.org)

- ***Extreme change in school performance or avoiding school***

- Particularly for teachers who know the student's academic performance best. The changes can manifest as not doing the work or not completing it, which may look like the student "does not care." This cannot be farther from the truth – they are grieving. Responses to the student may include offering one-on-one assistance, extra time, or bringing in the family to work with them.



If you notice any of the above issues, we strongly encourage you to talk with the school social worker or counselor and engage the family. As you spend more time with the student during the day, the family may not see many of these issues. Complicated grief is difficult but made worse when it is not addressed.

# Resources from The ALS Association

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**A**LS Association chapters across the United States have engaged and supported children for years. These services provide care, programming, and guidance for families through the ALS diagnosis and disease process. The below information is a reflection of the helpful programs and services developed across the United States. This list is current as to the writing of the manual. However, more programs may be developed.

All of these programs and services address several important points raised in this manual and are key aspects of The ALS Association youth programming moving forward:

1. Supporting and guiding communication in families
2. Developing school-based support
3. Creating peer engagement programs
4. Educating kids about ALS and caregiving

As you look through this list, think of ways your school may be involved in programming or advocacy for families living with ALS.

## Books

- Three books created by Dr. Kavanaugh and The ALS Association address ALS, caregiving, school, and death and dying – all from the youth perspective. The books are written by age group and use data and stories from real kids.

**How you can participate:**

- Have copies of the books available in the school library and/or classrooms. Books are available at [www.als.org](http://www.als.org)

## Backpack programs

- Backpacks can be filled with a variety of materials best suited for younger children. Included materials: ALS resources, games, materials, and treats. The goal of backpack programs is to educate and support children in families with ALS.

**How you can participate:**

- Work with your local ALS chapter to have a few backpacks at your school counseling or nursing office.

## Newsletters (print and online)

- Chapters have created newsletters, Facebook pages, and an online presence specifically for kids. These can be written by children or for children. Some include poems and personal



experiences. They provide excellent opportunities to engage with peers, lessening isolation and developing positive peer interactions.

***How you can participate:***

- Have copies of the newsletters out and available in school. Offer to engage your students to write something for the newsletters.

## Support groups

- Support groups provide the opportunity for people to come together and recognize they are not alone in the ALS journey. Support groups can be held monthly or several times a year. Some chapters focus on a theme each time and may include a specific event.
- Some chapters have developed support groups that are family inclusive, providing an opportunity to build crucial communication skills while participating in a fun activity together.
- Support groups often work best when they are developed around activity, as opposed to a “traditional” talk support group.

***How you can participate:***

- Have a listing of support groups for your area available in your school or social work office. Encourage students and families to get involved.

## School-based programming

- Chapters have partnered with local schools and school leaders to create opportunities for community service programming for students who have a parent with ALS. This service programming includes participating in walks, which allows for school credit and opportunity to educate schools and peers.
- Students can present at a school and conduct advocacy programming, providing avenues for educating other students and peers. These presentations address the feelings of isolation and lack of support needed by kids impacted by ALS in their families.
- Some chapters have an ALS Club partnership with schools where they volunteer in the homes of people with ALS, making connections and offering support.

***How you can participate:***

- Partner with your local ALS chapter to integrate programming in your school. Can you get a walk or an awareness campaign going?

## Community counseling partners

- In order to provide mental health support, many chapters have partnered with licensed clinical social workers and psychologists who are skilled in working with children and disease and have education on ALS specifically. These counselors can conduct in-home or clinic-based counseling for kids. These counselors should be vetted by each chapter to

ensure they are knowledgeable and skilled in ALS.

**How you can participate:**

- If you work in a school, connect with the school psychologist or social worker to partner with the local chapter to provide support services for children and their families.

## Respite camps

Camps are an excellent way to address the support needs of youths by including like peers. The ALS Association supports several multiple-day camps. These camps include education, support, games, and free time for kids to connect and build community.

### Things to consider when developing camps:

- Have professionals engaged with the camp, including social workers, nurses, counselors, and physicians who are experienced in ALS. Kids may experience emotional responses and would benefit from professional support.
- Include developmentally appropriate educational components. This has been shown to lead to higher rates of self-esteem and resilience in children living in families with other diseases.
- **Who attends the camp?** Some camps are youth only, while others are family-based. Some children prefer not to have their parents attend, particularly those who are caregivers. This may create a conflict, as they will feel the need to provide care instead of being there to connect with peers and feel like a “normal kid.” In creating a camp, make sure it is clear who should and should not attend.



# Other Resources

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The goal of this guide is to create a tool for school personnel as they support and engage kids. However, it is by far not the only resource available to help and support families.

The below list of websites have long-standing reputations for providing solid education and support for families. They are not an endorsement, rather one more potential tool to add to your toolkit.

## Children, Teens and Grief

- **National Association for Grieving Children** ([www.childrengrieve.org](http://www.childrengrieve.org)). The National Alliance for Grieving Children promotes awareness of the needs of children and teens grieving a death and provides education and resources for anyone who wants to support them.
- **The Dougy Center** ([www.dougy.org](http://www.dougy.org)). The Dougy Center provides a safe place for children, teens, young adults, and families who are grieving a death to share their experiences. They do this through peer support groups, education, and training.

## Caregiving

- **National Alliance for Caregiving** (<http://www.caregiving.org/>). National Alliance for Caregiving is a nonprofit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy.
- **American Association of Caregiving Youth** ([www.aacy.org](http://www.aacy.org)). This association develops school based programs for youth caregivers and their school supports.

## End-of-Life/Palliative Care

- **National Hospice and Palliative Care Organization** ([www.nhpco.org](http://www.nhpco.org)). This organization provides care supports and education which influences health programs and public policies relative to end-of-life care and the needs of the terminally ill and their families.

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# About This Guide

**This guide is the result of many years of clinical social work practice and research** with families and kids affected by neurological illness. While much attention is paid to the person living with ALS and their adult family member/caregivers, children are often voiceless, despite experiencing much of the same shock, sadness, caregiving, and grief as adults. Over the years, I have met with school personnel asking for guidance, manuals, and education on how to talk about and support children and adolescents living with and caring for a person living with ALS. These professionals recognized the limited information and the need to receive guidance in order to lessen the potential social isolation felt by kids in families with ALS — particularly in terms of how these issues affect school performance and attendance. This guide was created through the support of The ALS Association, to address the needs of school staff and personnel working with children impacted by ALS.

**This guide is the part of a series of guides and books for families living with ALS.** These resources can be found on The ALS Association website: [www.als.org](http://www.als.org).

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**About Dr. Melinda S. Kavanaugh:** Dr. Kavanaugh is a licensed clinical social worker and Associate professor of social work. She has over 15 years' experience in practice and research with families and youths living with neurological disorders. She has published and presented widely on the role children and youths play as caregivers, and is one of the few U.S. based experts in her field. In addition to her primary research and program development with The ALS Association, Dr. Kavanaugh conducts research with both U.S. and international organizations and community groups to develop evidence-based supportive and educational programs for young caregivers.

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