



Families and ALS:

A Guide for Talking with and
Supporting Children and Youths



A note to the reader: The ALS Association has developed the Living with ALS resource guides for informational and educational purposes only. The information contained in these guides is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.

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Children and Youths**

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FAMILIES AND ALS: A Guide for Talking with and Supporting Children and Youths

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TEAM TINKER

TEAM

Talk to
ALS
Association

Someone I
love needs a
cure.

It is often said that children do not come with a manual. Neither does illness.

Why this manual? This manual is the result of many years of clinical social work practice and research with families, children, and youths affected by neurological illness. While much attention is paid to the person with ALS and their adult family member/caregivers, children and youths are often voiceless, despite experiencing much of the same shock, sadness, caregiving, and grief as their adult counterparts. Over the years, families have asked me and other clinicians many of the questions posed in this manual. How do I talk to my children about my illness? How do I help them understand the disease? How do I talk about the care they are providing? Where do I go for support, education, and guidance?

Who should read this manual? The manual was created primarily for families living with ALS, including parents, grandparents, siblings, and other family members. Moreover, it was also created to support the many school-based and health care professionals who work with families affected by ALS. The goal of this manual is to help families start answering many of the above questions, as well as to offer support and suggestions for professionals assisting with families affected by ALS. A key theme throughout this manual is communication—how to do it, maintain it, and include it in everyday life.

What is included in the manual? This manual draws on current research and clinical practice. Specifically, much of the data and all of the quotes come from the national study of families and ALS conducted by the University of Wisconsin-Milwaukee and The ALS Association. While the manual is comprehensive, it is not meant to be the final answer to every question concerning families and ALS. Indeed, we anticipate more questions over time. However, we hope that families use this manual as a reference for questions encountered in engaging with and supporting children and/or grandchildren.

Who are children and youths? This manual addresses how to talk with young children as well as older youths. We use both terms “children” 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.

This manual was not a singular process. It could not have been accomplished without the steadfast support from The ALS Association national office and numerous chapter staff who offered invaluable edits and clinical insights. We want to particularly thank the extraordinary families and youths who

participated in the ALS family study and the families who answered the call to send in their family photos. Participating in research and sharing their photos is a gift to this manual—highlighting the love, compassion, and intense desire of families living with ALS to do all they can to support their children and youths.

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Dr. Kavanaugh is a licensed clinical social worker and assistant 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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CHAPTER 1



TALKING ABOUT ALS WITH CHILDREN AND YOUTHS

“I think just, like, talking to her, I think is probably the best thing. Just kind of like good communication and stuff like that . . . so I think having a conversation with her helps a lot.”

18-year-old living with
a parent who has ALS

INTRODUCTION

When a parent has an illness, one of the hardest things to do is discuss the illness, progression, and emotion with their child. Many parents may feel a sense of fear that 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 the child or youth. One thing that has become clear in our research and clinical work: Children and youths want to know about the illness, and they want to hear about it from the parent. This is also true when the person with an illness is a grandparent or other family member. Avoiding discussion during the illness may only serve to create more confusion, blame, or fear in the child and create communication barriers in the family.



This manual includes data and quotes from families who participated in the national study of families living with ALS and the children and youths assisting in care. Throughout the study and the many interviews with youths who have family members with other neurological disorders, one of the most powerful themes identified has been the desire for the child and youth to be heard and told the truth. They often understand much more than we give them credit for, so starting from a point of openness and honesty is very important. What to do next?

PREPARING FOR THE DISCUSSION

ALS can be very difficult to discuss. Many persons with ALS are coming to terms with their own diagnosis and may fear crying or being overly emotional in front of their children. In addition, not everyone diagnosed with ALS progresses the same way; progression can go very quickly or last a long time. This can be scary for the person with ALS and their family, particularly if they have never openly discussed it. Moreover, given the differing progression, it can be difficult to know what to say or how to say it when the person with ALS does not know what to expect. If we think about ALS as being a disease of the family, not just of a person, it helps to assess how to discuss it with the family. **All family members are affected.** That said, telling your children can be tough, as all family members are different and respond in their own way.

This chapter was created to offer some suggestions to help guide the conversation and options to get it started. The goal is to help persons with ALS and their families feel less fearful and more empowered to talk to children and youths, while allaying fears for all involved.

STARTING THE CONVERSATION

First, have the conversation. That may seem obvious, but many families avoid it. They don't want to burden their child, or they assume the child or youth has been told by someone else, or they think the few "hints" that were dropped by the parent was enough.

The first conversation can be as simple as asking what the child or youth knows. It may scare you to ask, but starting with where the child or youth is in terms of knowledge will be very important. That way, you can gauge what he or she already knows, dispel any myths, and fill in gaps.

Second, it is important to discuss the disease *early in the diagnosis*. Children and youths have access to social media and the Internet, more so than ever before. Unfortunately, this access does not always mean accurate information or information presented in an understandable manner. As the parent, you can be the one to frame or guide what they hear and clarify what they think they know.

TIP: *Starting the conversation. Find a time when you are doing something "normal" and not stressful, like watching TV or relaxing at home. This models the normalcy of the conversation and puts less pressure on it being a "big talk."*

This first conversation does not need to be long or in-depth. In fact, often the best way to handle it is to use the exchange as a way to open the door to future conversations. No pressure, just starting the conversation.

HAVING THE CONVERSATION—FAQS

Below are several frequently asked questions to help start and move forward the conversation with your child or youth about ALS.

Question: *What if my child does not want to talk about ALS?*

Your child or youth may not want to talk and that is OK. What you are doing by starting the conversation is showing them that it is OK to think about it, talk about it, and ask questions. Here are a few suggestions to help guide the initial conversation(s):

- Provide the space and let them come to you.
- Tell them they can come to you at any time when they are ready.
- Make the conversation normal with no pressure. It may take a few starter conversations, but being available and open will help smooth the way to a full conversation.

- *Something to consider:* They may not want to talk about it because you don't talk about it. It is very important to know where you stand before you talk to your child or youth, so that you are modeling open and honest discussion.

Question: *What if they ask a question I am not prepared to answer?*

This can be tough because it may mean you are not OK with what is happening. How children and youths deal with illness is directly related to how you as the parent copes or deals with the illness. When a parent has strong coping skills, those can translate to how well the child or youth copes. Points to consider:

- Think about possible questions, things that make you uncomfortable. How would you like to talk about it? What would make you comfortable?
 - This can be setting, time of day, or other people involved.
- Show your willingness to discuss difficult issues. Start with saying something about ALS that makes you uncomfortable, perhaps how something has changed.
 - For example, *"I am sad that I cannot use my arms any longer."*
- Answer honestly and don't be afraid to say you don't have answers or that *"we will find out as we go along."*
- Also, answer per the child's developmental stage. Suggestions for this are discussed below.

In the national ALS study, many children and youths noted that they did not bring up ALS because they could tell it was difficult for their parent saying, *"I did not want to upset him,"* despite the youth wanting to know more. The person with ALS deserves as much support as possible in dealing with the disease and talking about it with their child or youth.

TIP: *Remind your child that any question is OK to ask. Even if you do not have an immediate answer.*

Question: *Is there anyone who can help start the conversation?*

Yes! The ALS Association chapters across the United States are staffed with care coordinators who can help talk you through options for starting the conversation and address your own fears as well as those of your child. The chapters would also be able to identify professionals in the area who could help (e.g., counselors and mental health therapists). To find your local chapter, visit <http://www.alsa.org/community/>. (**NOTE:** Talking about loss, death, and dying is a concern for many families. This can be extremely difficult so we devote an entire chapter to it later in the manual.)



Question: *How do I adapt to a “new normal” life with my children?*

You were just like any other family, but now you have ALS. Your life is not what it once was, and that can be hard for all involved. Living with ALS requires you to think of ways to develop new routines and new ways of doing things—to **live with ALS, not in spite of it**. In the words of a 17-year-old, *“Everyone has their thing—this is ours.”*

Many families discuss changes to their family routines, including difficulty with equipment accessibility and the fear of being in public when something happens. While these are all valid concerns, one thing we know from interviewing and working with children and youths is that they want to keep as much “normal” activity as possible.

While life clearly changes, what can you do to create a “new normal” for your family?

- If you were a camping family, do short day trips or bring others along to assist.
- If you went to the theatre, arrange aisle seats.
- If you love the beach, rent a sand wheelchair like the family in the photo.

Question: *What if my child wants to talk to someone else?*

Your child or youth may feel more comfortable talking with someone else. This is OK and should not be seen as a reflection of a poor relationship between you and your child. Indeed, many children and youths have close relationships with coaches, teachers, social workers, and others. Here is some advice given by a teen with a parent with ALS:

“You’ve just got to find that one special person that you can talk to that’s a real close friend or a real close relative.”

If you have started the conversation, assess how the child feels about continuing it with you, or someone else.

Let your child know you are not upset or offended that he or she may want to talk to someone else. Allowing your child to talk to another trusted person will help lessen his or her anxiety, fear, and confusion about the disease and may open the door to conversations with you. If your child does prefer to talk with someone else, make sure that person has access to the subject matter experts for details about ALS and support.

WHAT TO TELL YOUR CHILDREN AND YOUTHS ABOUT ALS

After you start the conversation, follow with basic information about ALS. It is important not to overwhelm them with too much detail at the beginning. Your children may only know what they see in their family member with ALS and how it affects that person at a moment in time, so help guide them to understand the disease.

Example: *If the person with ALS can still walk but can no longer talk, let the children know this is what ALS looks like in this situation, but that it may be different in another person. That way, they do not see ALS as a “voice disease.”*

In the national study of families and ALS, many children/youths have some basic information, but they confuse the details. This misinformation can lead to assumptions about gender, age, and how you get it, for example, “*only girls get ALS.*” This conversation is the opportunity to clarify details and help your children know the fundamentals of ALS. Even though you may be living with ALS, that does not necessarily mean you are the expert at details. The ALS Association has materials that will provide you with specifics about the disease, which you can then use to guide the conversation with your children.

One thing to note. Not telling your children anything about ALS can feel as though you are protecting them and keeping them “normal” and away from the pain and stress of what is happening to you or your loved one with ALS. However, the “protecting” can create secrecy and fear in children and convey the message that they don’t need or deserve to know what is happening. This can create conflict because the children see that something is different.

Think about why you want to protect them:

- If it is because you don’t know what to say, talk to someone at The ALS Association or a counselor/therapist specializing in this type of practice.
- If it is because you know your children and they will not handle it well, engage with a trusted family member, friend, or therapist to help guide your conversation.
- But if it is simply because you don’t trust your children or don’t want them to know, that can foster resentment and isolation for many years to come.



Keep the conversation ongoing. It does not have to be a constant conversation all the time, but don't stop talking. Keep your children and youths engaged. Be open and allow them the opportunity to ask anything, knowing they will get a straight answer. Check in with them from time to time, especially at times when ALS progresses and your "new normal" is changing. See how they are doing and if they have any further questions. It is not always up to them to come to you. Keeping the conversation going is one way to make the family experience "normal."


Listen. Perhaps the best thing you can do is be there and listen. Your children may be angry, confused, or sad. Hear them and allow them their feelings. Then keep the conversation going.

DISCUSSIONS BY AGE GROUP

Children and youths cope in a variety of ways with parental and family illness. In addition to knowing how your child responds to stressors and difficult situations, it is also important to understand how children may respond by developmental stage, meaning how their age, cognition, and emotional skills help them deal with ALS. Based on cognitive, social, and developmental theory¹ and clinical practice, the below sections are created as starting points to think about how to talk to children across different ages. While there is no "right" way or an "ideal" child or youth, understanding how to approach the conversation by age group can be extremely useful.

Age Range	Developmental Milestones	Suggestions for Discussion
Infants and Toddlers (Age 0–3)	<ul style="list-style-type: none"> ■ Babies and toddlers need routine, need to feel safety, and can pick up anxiety and fear in the parent. 	<ul style="list-style-type: none"> ■ Keep the normal routine as much as possible. ■ Allow the child to ride on the wheelchair or sit with the person with ALS. Create a “new” normal environment (meal times, feedings, sleep, etc.).
Young Children (Age 3–7)	<ul style="list-style-type: none"> ■ At this age, children are concrete thinkers and do not need complex discussions, but they have curiosity and will most likely ask questions—many, many questions—some of which will be very direct. ■ 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. ■ Children in this age group are also very literal. ■ Children in this age group do not have the ability to understand abstract or hypothetical situations. Children during this age are focused on what they perceive, rather than what is logical. ■ Finally, kids in this age group are not future oriented, thus time does not mean the same thing to them. 	<ul style="list-style-type: none"> ■ Parents may feel this is too young to talk about ALS, but the truth is the child sees and knows that “Daddy looks different from Mommy.” ■ It is important to be clear and honest. 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. ■ Using slang or complicated terms may be confusing. You can use simple straightforward language (Daddy hurts, Daddy can’t walk, etc.). ■ Addressing what the child sees (Daddy in a wheelchair) is important. Let the child know the disease makes it happen, but that it may look different in different people. ■ 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.
Middle Childhood (Age 8–12)	<ul style="list-style-type: none"> ■ Children in this stage are focusing on identity. Who am I? Am I the kid with a parent in a wheelchair? ■ Children in this age group are able to solve problems and can use logic. 	<ul style="list-style-type: none"> ■ When discussing ALS, you can be more complex and provide more detail. ■ Continue to make sure children know that this is not about them and that having a parent with ALS is not a negative thing. ■ While having a parent with ALS isn’t “normal,” it is important to “normalize” the experience in terms of the family and how you talk about it. ■ Talking about ALS can be a bit easier if you provide details and outcomes.

Age Range	Developmental Milestones	Suggestions for Discussion
		<ul style="list-style-type: none"> ■ 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. ■ Let them know it is OK for them to be sad about how things might be changing, while letting them describe their thoughts. Encourage them to discuss and describe as much or as little as they want.
Adolescents/ Youths (Age 13–18)	<ul style="list-style-type: none"> ■ Adolescents often deal by focusing on the emotion, even when they are struggling to control those emotions. ■ This conflict is influenced by hormonal changes and struggle with their own identity and sense of belonging. ■ At this stage, most youths have developed more cognitive skills and the ability to understand the abstract. ■ They can create hypotheticals in their minds, including what life may be like moving forward with ALS. ■ 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. ■ Conflict with adolescents can be very developmentally appropriate given their need to find themselves and belong to peers. ■ Adolescents tend to respond well when they know they are heard and respected and you see their point of view. 	<ul style="list-style-type: none"> ■ Addressing the emotional aspect of what they understand about ALS is important. ■ Check in to see how they are feeling and allow them to express their feelings without judgment. ■ Addressing hypotheticals may result in outward distress and emotions that can wildly fluctuate, which many parents avoid. ■ However, addressing how the youth feels is just as important as how he or she thinks about it. The youth may not be able to explore the emotions. ■ Engaging with a professional at this point can be extremely helpful. The professional can assist the youth in processing the emotional aspect and is an outside party who may access the youth's need for confidentiality. ■ When talking with your adolescent, acknowledge that he or she is becoming his or her own person. ■ Keep the communication connection, but allow the adolescent to be with friends to lessen the very common conflict. ■ Keep the conversation open. Make sure your adolescent knows he or she can come to you at any time with questions. An adolescent may shut down if you ask too often; just let your adolescent know you are there.



In the end, you know your child and youth and how he or she hears and absorbs information. Hopefully the above guide will serve to add to this information and help you and your family talk opening and honestly about ALS, fears, concerns, and joys.

Reference

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

CHAPTER 2



CAREGIVING CHILDREN AND YOUTHS

“It’s challenging. It’s just kind of . . . it’s always there reminding you, kind of just sort of that sort of thing. You kind of have to put your own care aside because you really have to be there to help out.”

14-year-old living with
a parent who has ALS

INTRODUCTION

Families provide the majority of care for a family member with an illness.¹ This care is frequently provided by adult spouses and adult children. However, there are many family caregivers who are deeply involved, but rarely get attention. These are the many children and youths in the home.

In the United States, approximately 1.4 million children and youths are caregivers and engage in a variety of caregiving activities including keeping their family member company, assuring their safety, and bathing and feeding their ill family member.² Yet, despite the often enormous care they provide, very little attention or support is given to these caregivers or the care they provide, leaving these youths and the patients who rely on them feeling isolated and unsupported.

How do we address or acknowledge the role youths play in caregiving?

This can be a very difficult topic to discuss as some people may feel it is wrong or somehow abusive to rely on a child or youth in the home for personal caregiving. However, it is important to note—*caregiving as a child or youth is not inherently bad*. But, when there is no communication, support, or guidance around caregiving and the needs of the caregiver, it can result in negative outcomes for all involved. Using data from the ALS family study, as well as other research on young caregivers, this chapter was created to provide details about the level of care provided by children and youths, allay fears from parents and youths, and provide suggestions to support youths from their family members and friends.



CHILDREN, YOUTHS, AND CAREGIVING

Children and youths have complex experiences and feelings when they have a parent or family member with ALS. Not only do they live with the illness in the home or within the family, but in many, if not most cases, they are actively involved in providing some measure of direct care for their family member with ALS. In the national study of families living with ALS, over a third of all families in the study have a youth under the age of 18 in the home—with the majority of those youths providing care.

TALKING ABOUT CAREGIVING

While family members providing care to another family member is extremely common, having a child or youth involved in care is rarely discussed, despite how many children are involved in providing care. Therefore, exploring how both the person with ALS and the youth feel is important to the well-being of the family.

Parental concern. Parents with ALS may feel concerned about telling other people that their child helps with care, not wanting to call attention to the care they provide for fear of making it a big deal with the youth. Parents may also feel that relying on a child or youth is somehow abusive or negative. These feelings are understandable, but often exist as barriers to care needs and family communication. If you are relying on a child or youth to provide care for a family member with ALS, that does not mean you are bad parent. It means you need assistance. Things to consider:

- **Talk about it.** The key is to address it, talk about it, and not treat the need for care as a barrier in the home. Moreover, open discussion may reveal that the child or youth would benefit from support and an outlet, be it activities or talking, to deal with what the youth is doing to help you.
- **Don't try to "protect" them.** In the national study of ALS young caregivers, several parents detailed the caregiving tasks provided by a youth in the home, yet did not want the youth to be interviewed, stating, *"I don't want them to think about it."* Much like talking about ALS, it is understandable to want to protect or shield your child. But if the child is involved in caregiving, he or she already knows what is going on—or thinks he knows what is going on. Engaging young caregivers with respect to the care they provide and how they feel about it will serve to support the youth and may even bring families closer. It may also bring to the forefront the need to involve others, including health care professionals, other family members, or adult friends to assist and share in the care. Also, talking about the care you need and the care children and youths provide offers an opportunity to discuss needs and concerns with all involved. Whatever the outcome, the goal is to talk about the situation and seek ways to support the whole family.

CAREGIVING YOUTHS—FAQS

What does it mean to be a caregiver at a young age? How does the parent, grandparent, or other family member talk about it? What can be done to help or support the youth and the person with ALS? Here are a few of some common questions about young caregivers.

Question: *What is a young caregiver?*

While the age range is often debated,³ young caregivers are typically defined as children and youths under the age of 18 who provide some level of care to a family member (parent, grandparent, or sibling) that goes beyond basic or typical household chores.

Question: *What do young caregivers do?*

They are involved in a variety of care tasks including bathing and feeding, keeping someone company, and making sure their family member does not fall or choke. Young caregivers engage in activities that are time-consuming and outside the “typical” or “normal” range of activities for children and youth.³ This care can be daily or weekly, but often entails many hours a day. While these children and youths provide care beyond simple household chores, they also are still involved in these tasks and their typical responsibilities (such as keeping their room clean).

Question: *How does caregiving differ in families with ALS?*

From the national study on families with ALS, we know children and youths in families with ALS are involved in a range of care tasks much like the millions of other young caregivers in the United States. However, given the complexity of symptoms in ALS, young caregivers for people with ALS, in comparison with other young caregivers, are more frequently placed in the position of dealing with assistive devices such as suctioning equipment, breathing machines, feeding tubes, or other adaptive devices. Moreover, given the often shorter and intense trajectory of ALS, they are often involved in more complex care tasks for shorter periods of time, as opposed to those who care for a disease with a longer trajectory, like Huntington’s disease.⁴

Below is a list of some of the caregiving tasks identified by children and youths in families with ALS:

- Setting up, managing, and supporting communication devices
- Talking to the doctor for the family member with ALS
- Assisting with preparing food and feeding the person with ALS
- Tracking and administering medication(s)
- Cleaning and managing respiratory equipment
- Engaging with range of motion exercises with the person with ALS
- Cleaning drool/saliva and helping with oral hygiene
- Transferring and bathing

Question: *How do you talk about caregiving with your children/youths?*

First, think about how you talk as a family. When there is a difficult discussion, what is the “normal” way you discuss things? Are you an open, communicative family, or do you keep discussions and feelings internal? Assessing how you communicate under ordinary circumstances is crucial for understanding how you can communicate about caregiving. Given the need for open, honest communication, adapting how your family communicates will be vital moving forward.

- Let your children or youths know you are appreciative of the care they provide and that you love them regardless of the care they **do** or **do not** provide.
- As with talking about ALS, let your children know they can talk about feelings and experiences of caregiving at any time with you without hurting your feelings.
- Model the conversation by telling them **how you feel**, that maybe it is hard at times to have your children help you, but that sometimes you need it. That way they may feel comfortable also saying that sometimes it is difficult.

TIP: *If you, as the person living with ALS, feel these conversations may be hurtful to you, this is an excellent time to stop and talk with a counselor, mental health provider, or ALS care coordinator. You deserve to be supported during this time.*

Question: *How do youths feel about being caregivers?*

While you are assessing your family communication style and having open communication about caregiving, it is important to think about how your children *feel* about providing care. This is a complicated question, often wrapped up in how they feel overall about their parent/grandparent with ALS and what they know about the disease. It is vital that they have honest, accurate information that is appropriate to their developmental stage. This information will help them process the tasks and understand how they feel about caregiving—what they like doing and what they don’t like doing. As with many other aspects of childhood, young caregivers can feel different ways about being in that role.

Positive Feelings

Children and youths provide care for a variety of reasons, not the least of which is that they want to help. It is an expression of love and care—and something they can do at a time when there is not much that can be done about having ALS. Many youths feel extremely positive about providing care. They are giving back and they want to do it.

TIP: *Young caregivers often feel both positive and negative feelings about caregiving. Assure them it is OK to feel both ways. Encourage them to feel what they feel and to talk about it.*

Negative Feelings

Alternatively, youths struggle with the care they provide. They may feel trapped and have a sense of requirement to provide the care, or they feel they cannot stop. They may feel that they are losing their childhood and are not like other “normal” kids.

Here are some excellent ways to communicate with youths about potential feelings associated with caregiving:

- Let them know how you feel, that they are supported, and that they are not the only young caregivers in the world.
- They need to know their voices are heard in the care process. Many youths report feeling like they don’t have a say in things, even though they are very involved in the care of their parent. While it is not necessary to make young caregivers the decision makers, engaging them and hearing what they have to say will make them feel a part of the process.
- When thinking about how they may feel about caregiving, the best thing to do is to talk about it and let them know whatever they feel is OK—even if that means they struggle with it.

These points are reflected in a quote by a 16-year-old young caregiver, who offered this advice to other youths:

“It’s important to make sure that you don’t make the person you are caring for feel like a burden. Learn to love taking care of the person and create a hard-working attitude; but never feel like you always have to be the strong one. It wears on the body very harshly.”

As the parent, it may be very hard to hear this, but this is why communication and seeking out support for both you and your child is so important. You may be in a position where you need the youth to help due to a variety of reasons. You both deserve to talk about it, to be honest and open, and to figure out ways to get help and support for both of you.

Question: *How does caregiving impact children and youths?*

Young caregivers experience a variety of outcomes as a result of being a caregiver, from positive feelings to isolation. Some display a change in mood, including depression and anxiety.⁷ They may withdraw and even have difficulty sleeping. This can be due to fear of the unknown, worrying about the well-being of their family member with ALS, or exhaustion from caregiving while keeping up with school. It is important to assess how your child is doing and talk with him or her about his or her feelings and emotions.

In addition to feeling anxious or depressed, many young caregivers struggle with school. They are often late from oversleeping, don’t always finish their homework, and struggle to stay awake and concentrate in class.² While not all young caregivers have the same experiences, it is vital to pay attention to how they are doing, feeling, and performing in school and other activities. In a later section we will discuss school, but overall the key is to openly communicate, listen, and look for ways to support them.

SUPPORTING YOUNG 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.”

The above quote from a 15-year-old highlights the need for supporting young caregivers as individuals and acknowledging the care they provide. Whether it is an adult or a child, caregivers are often overlooked by other family members, physicians, and the community. However, given the extensive care provided by family members, ensuring that the needs of the caregiver are addressed is crucial for both the patient and the caregiver. In a study of youths who care for parents with Huntington’s disease, young caregivers stated they wanted to be acknowledged and supported in what they do.⁴ They are not asking to have all the attention, but to know they have support and someone to go to about caregiving and their feelings. This is no different for young caregivers of people living with ALS.

Here are a variety of ways youth can be supported—by friends, family, and other adults.



Friends and Peers

Caregiving youths are often in a confusing position with friends. They want to belong and feel accepted, which is developmentally where they should be—particularly older youths who are developing their identity and individuation away from the family. However, we know that young caregivers can feel isolated because, out of all their friends, they are often the only ones who provide care to a family member.^{2,3,5} In the national ALS family study, almost 50% of the youths interviewed stated it is hard to talk to friends about caregiving, yet they want to talk to someone who is going through the same thing. The value and importance of peers and peer support is crucial and one of the most important findings about young caregivers is the need to have friends who “get it.”⁵ Friends can provide support, but can also “normalize” the life of the youth.

Here are a few things you can do to encourage more engagement with your child's friends and peers:

- Encourage your child to be with friends and to attend school functions and activities in order to maintain their childhood and develop peer networks.
- In addition to their current friends, it is important to look for opportunities to engage with youths in similar situations of caregiving and having a family member with ALS. Examples:
 - Support groups through organizations dealing with ALS
 - Youth respite camps



The ALS Association chapters are ever expanding youth programs, many of which provide support groups, family programs, and respite or camp programs that allow youths time to build community with other youths dealing with similar situations. The goal of the youth programming is to lessen the potential for long-term resentment or poor psychological well-being due to unsupported or unacknowledged caregiving. Talking about feelings and sharing with others in similar situations in respite or camp settings can allay fears and show that the youth is not alone. More discussion of chapter resources can be found later in the manual.

Other Family and Adult Friends

Often other family members or adult friends know youths are engaged in caregiving, but are not sure what to do to help or support the family. While the first step should always be talking with the person with ALS and adult parent/family members, there are many ways family and friends can support youths in the home.

- **Acknowledge** the youths and let them know you hear them and are there for them. Young caregivers are often isolated and vulnerable. They rarely have peers who are also caregivers, so acknowledging them and asking how they are doing and what they need can make a huge impact on their lives.
- Don't be afraid to **ask about the care** they provide and **ask how they feel** about it. But know that they will often be more concerned about the well-being of the person with ALS than their own feelings. Make sure you are open and let them know they can share in whatever way they need.

For the person with ALS and their family, it is just as important for them to reach out to their friends and family to support and provide respite for the young caregiver.

- Engage with other family members and friends to provide respite or time away for the youth. Much like adult caregivers, youth benefit from time to do their own activities (school, friends, community), which is crucial to their own self-care. Engage other adults and friends to offer support or care respite for the patients with ALS, allowing for the self-care time for the youth.
- Organize a "care connection" program, which can serve to relieve some of the caregiver stress for all family caregivers. Creating a care connection team is a way to free up time for the well parent to spend time with the caregiving youth, while a volunteer care connection participant provides companionship to the person living with ALS. For information on how to set up a care connection go to <http://www.alsa.org/als-care/caregivers/care-connection.html>.
- If you are a friend or family member, offer caregiving assistance, as many youths do not want to feel as though they are complaining or being a burden on you to help their parent. The youth may have a positive association with caregiving, and you do not want to diminish that by taking over without asking and ensuring that he or she is OK.
- Ask the youth what you can do to help with actual care or just supporting him or her. The young caregiver may feel uncomfortable asking for help, so offering is important. In the ALS study, young caregivers want assistance, particularly with hands-on care. Having another adult engage with the care will go a long way to easing the mind of the youth and lessening the potential stress and burden.

CAREGIVER TRAINING AND EDUCATION

“Help me know what to do and how to do it.”

As shown in the above quote from an 11-year-old caregiver, being a caregiver requires training and guidance, particularly when the care involves complex symptoms and numerous assistive devices. Therefore, training the caregiver is a crucial aspect of both patient and caregiver well-being. However, as in many aspects of life as a young caregiver, they are often left out of caregiver training and education.

Young caregivers don't always know what to do. They are frequently in a position to provide care for which they were not trained and often just “wing it.” Moreover, the complicated assistive devices associated with ALS can be confusing and scary. Young caregivers may worry they are actually causing harm to the family member. This is an excellent opportunity to engage with the local ALS Association chapter or clinic around training and guidance for the youth.

Many times, a nurse, physical therapist, occupational therapist, speech therapist, or health care professional will come to the home to provide guidance on best care practices, but the child or youth is overlooked as the caregiver. This is a missed opportunity to engage and train the youth. Even if the youth only has minimal involvement in some caregiving areas, such as using a feeding tube, or only rarely toilets the parent, they still need to know the proper way to transfer to the bathroom and how to thoroughly clean and care for a feeding tube.

Children and youths may be reticent to engage with training. To smooth the process, let them know that it is important that they know what to do, and that even you, as the person living with ALS, did not know what to do at first. This may lessen the potential stress and anxiety. Points to consider:

- Keep communication open and honest.
- Allow your child or youth to ask questions about the care the person living with ALS needs and wants.
- Start conversations around what helps, how things feel, and what is the best way to do things. This way you are bringing it up and showing the child, rather than having them ask.

Examples of Ways to Engage Youths in Training and Education

- Talk with durable medical equipment (DME) providers. If you have a piece of assistive technology or DME, ask to have the provider show the youth how to use the machine when the parent is not using it. This will allow the youth to ask questions and explore, without fear of hurting the parent or ruining the machine with them in it.
- When you visit the clinic for a follow-up appointment, ask your child if he or she would like to go with you to talk to any of the therapists (physical therapists, occupational therapists, or speech therapists) about how best to do some of the tasks. They are often available during clinic hours and may be an excellent resource for training and guidance.



- If your child does not want to attend clinic and may be more comfortable at home, ask if any of the therapists can do a home visit (or work with a home health agency) to show the youth appropriate care practices.

LONG-TERM IMPACT OF CAREGIVING

This is one area that receives very little attention, so it is difficult to provide specifics. Some research has shown that current young caregivers have higher depression and anxiety than noncaregiving youth.⁷ However, 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.^{8,9} However, others have stated they feel a stronger sense of self and feel good about the care they provided.^{10,11} 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 young caregivers may internalize negativity about the care they provided, particularly if they were never allowed to discuss it.

Following the earlier chapter on talking to youths about ALS, talking with children and youths about the care they provide and ways they are involved with their family member is just as important. Normalizing and supporting them will go a long way to minimizing any long-term difficulties.

TIP: *Youths may feel blame or guilt if they do not provide the “best” care possible or if the disease progresses to a point they are no longer able to help. Let your child know regardless of what happens, he or she is not to blame.*

LOSS OF CHILDHOOD

“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 or youths, like the 15-year-old quoted above, many describe feeling that they grew up too quickly because of the level of responsibility. They missed out on “normal” youth milestones because they were either needed at home or felt they should stay around to help. They could not attend school functions, sports, or after-school activities. They 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” youths their age.

It is crucial to encourage your youth to engage with peers, school activities, and attend school to create a sense of “normalcy.” Young caregivers often feel that they cannot go be with friends; that they need to be at home instead. They need reassurance that they should go out at times and be with peers. Find someone to fill in during times when the youth has sports, after-school activities, or is simply hanging out with friends.

TIP: *Make sure your child or youth knows it is OK to spend time with friends, even if he or she is involved in providing care.*

Often, caregivers, both adults and youths, worry that someone else won’t do things “right” or provide the best care. For youths, it is particularly important to make it clear that their job is also to be a child or youth, and that you want them to do things for themselves.

Not all young caregivers will have negative associations with caregiving. Indeed, as stated earlier, many feel positively about the care they provide. Many may choose to go into a helping profession because of the care they provided and the positive associations they felt as a result. Therefore, including the positive aspects is important.

CONCLUSION

In closing this section, we want to reiterate that being a young caregiver is not inherently bad or negative, nor is the person with ALS a bad parent or grandparent for needing the care provided by a child or youth. Indeed, being a caregiver can be an extraordinary opportunity to share and build relationships in the home. What is crucial is that the youth be recognized, supported, and encouraged to have outlets beyond care. This includes engaging with other family and friends to ensure the youth does not hold the sole caregiving responsibility and that he or she can discuss the experience with other youths like themselves. In the words of a 12-year old:

“If I had to tell somebody that was my age if they had a family member with ALS, I would tell them that you just have to be patient because sometimes their speech isn’t that good. And you kind of got to wait for them to get the whole point across. And if they got it, and you were used to having a parent who could do regular stuff, it’s just going to be a time of adapting. And that you can’t just, it won’t just be like overnight. You have to get used to the new things. And you kind of just got to accept that that happened. And there’s nothing you can do about it.”

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CHAPTER 3



SCHOOL, YOUTHS, AND ALS

“We moved to a new school. When I came we all had to say about my family. We had to go up and tell about the family . . . I was really nervous, because I was new. 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.”

12-year-old living with
a parent who has ALS

INTRODUCTION

Going back to school or starting a new school is exciting, scary, and often a difficult transition for children and youths. They are meeting new peers for the first time or getting reacquainted with their peers and teachers after summer. Children and youths use this time to size each other up, make friend groups, and form bonds with peers. While all children and youths go through these transitions, it can be more difficult for youths who have a parent or family member with ALS:

- The transition may be particularly difficult if the parent has progressed or was newly diagnosed over the summer, representing a change in their “normal” status.
- Moreover, we know that nearly a third of all ALS families have youths in the family who assist in care and who may have engaged in numerous caregiving tasks over the summer. Scaling back on the caregiving in order to go back to school can be a stress release, but also may be anxiety-producing with the youth wondering who will provide the care now that he or she is back in school. This can make the transition back to school more stressful.



Thus, helping a child or grandchild get through the initial transition of school can be difficult and emotional for all involved. Using the words of children and youths, this chapter provides suggestions and options for helping to ease the transition for your child or family member.

CHECK IN WITH YOUR CHILD BEFORE THE START OF SCHOOL

Before the transition to school, talk to your child or youth about how they feel. Are they nervous? Concerned? Neither? What may help alleviate any fears or concerns? Your child may be nervous due to going to school or starting a new school. However, ALS may compound that fear.

TIP: *Have the discussion with your child before he or she starts school so that you can address any fears or anxieties. As discussed earlier, the majority of youths want to talk to their parent about ALS and ways it affects them. Talking about school is an important part of these conversations.*

TALKING TO THE SCHOOL

“... at my old school, they always asked how my dad was doing. And like my teachers sometimes still ask me if my dad feels good. And like my principal does too.”

The above quote is from a 10-year-old who described starting a new school and the role school personnel played in how she felt about having a dad with ALS. The school can be an invaluable tool in helping the transition and eventual support for the youth.

Before you talk to the school, check in with your child and think about the following questions:

- Would your child feel comfortable if you talk to his or her teacher?
- Would your child prefer a group meeting, or would he or she like to talk to the teacher/counselor alone?
- Has your child talked to teachers, social workers, coaches, or any personnel in the past? Does your child feel a connection with that person?
 - If so, use that person as a connection for the child. It is important to make sure your child participates in the choice. The child needs to know what is happening so he or she can be prepared and not caught off guard if asked a question or engaged by school personnel.

Practice the Discussion

It may be helpful to practice the discussion with the school ahead of time. Let your child or youth know what you are going to say and have your child help craft the conversation. Ask how much information your child would like to have told and to whom. Engaging the child in talking to the school will help him or her feel a sense of control at a time when he or she has very little control. This will also help the child feel as though he or she can talk to you about it as well. These conversations can be a powerful way to connect to your child by being the one to talk to him or her, being open to having your child come to you, and keeping the lines of communication open.

Make an Appointment with School Personnel

After you have spoken with your child, set an appointment to talk to the school social worker or counselor. They can be a very useful first contact and connection for how best to support your child/youth as he or she gets back to school.

TIP: Give your child the option to be in the meeting with school personnel. This will make the child feel involved and that his or her opinion matters.

Engage Teachers

Teachers are often tasked with enormous details with all the children and youths in their classes. They may not know why someone is off or acting out of character, so providing some information to the teacher can be very useful. This will help them to keep an eye out for changes in your child's behavior, sleeping in class, or problems with homework or school work. Making sure the teacher is engaged is crucial. If a youth is absent, late, or distracted, it may be a variety of things, including the youth being involved in care. Teachers can talk to the caregiving youth in a safe space, when no one else is around. Moreover, if the teacher knows about ALS, they can make referrals to the school social worker or counselor if necessary. Again, your child should know that you are talking with the school and should be involved to an extent that you and your child feel comfortable.

SCHOOL AND PEERS

"I've been asked to talk to other students at my school about it so that they can have an understanding. I was glad I did it. It helped me feel better."

The above quote from a 13-year-old highlights a fantastic way to have your youth take ownership of ALS in his or her life, while engaging peers and school personnel. Some children or youths may want to do a presentation to their class to share their stories and experiences. By telling their story first, it can break down barriers and misconceptions about the parent with ALS and lessen the possibility of bullying. This allows the child/youth to tell his or her side of the story and put the information out there before someone can use it against the child. As always, check in with your child to make sure he or she is comfortable doing this before offering it as an option to the class. The ALS Association can be a valuable tool in providing information, details, and charts about ALS for the youth to use. You may also want to consider having your youth interview the doctor or other health care professional about ALS, treatment, and dealing with ALS.

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

As evidenced by the quote from a 15-year-old, having 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, is crucial. Supportive youths can help with the transition back to school or starting school and provide a sense of “normalcy” in the school setting.

TIP: *Check in with your child. Does he or she have a good friend? Someone to talk to? This may be the person your child shares with about ALS.*

If your child does not have a close friend at school, check with the local ALS Association chapter. Programs for youth are increasing in number throughout The ALS Association, as well as throughout the United States. Look to your local chapter for youth programs, resources, and support, many of which are detailed in Chapter 5 of this manual.


Your child may find a youth also living in a family with ALS in their area who can make him or her feel less “different” and more “normal,” easing the transition back to school with other kids. Also, Facebook and/or online support groups can be very helpful for older youths to reach out and ask questions of other youths like them who may be feeling overwhelmed about going back to school, leaving the parent or family member with ALS at home, and feeling like no one will understand.

Finally, encouraging youths to share their chapter’s Walk or other advocacy activity with their class provides an opportunity to encourage classmates to attend a family-fun activity and to volunteer. Peers can help with the kids games table, at the registration table, or some other volunteer opportunity. This may help the child living in an ALS family to feel more connected to peers and provide the peers with a means to connect personally with their peer’s family member with ALS.

What If My Child Does Not Want to Talk to Teachers or Others at the School?

If your child is wary of having the school know, explore that. It is OK to ask them why. What are your child’s fears? Find out and then address them.

- The child may feel it will make him or her more separate from peers.
 - Let your child know that you want to tell the school so that someone can help and support him or her, not to have the child singled out and “othered” by teacher, peers, or school personnel.
- School may be the only place the child feels like himself, or “normal”—where the child doesn’t have to think about ALS.
 - School can be a safe haven, a place where the child is a kid, not a caregiver, and not a kid who has a parent with ALS.
 - Check in with your child before you talk to the school. This does not mean the school should be in the dark, but that they need to know where the child is and what the child needs at the time.

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- Let your youth know he or she is not required to visit the social worker or talk to the teacher, but that having the school know what is going on will be helpful and may give the youth a different adult to talk with and from whom to get support.
 - Assure your youth of the confidentiality of the adults in the school, which may help to alleviate fears.

However you and your youth decide to address school, we hope that this section provides support for both you and your child. The amount of time spent at school underscores the need to have the conversation early and often, making sure your child/youth receives the maximum amount of support.

CHAPTER 4



DEATH, DYING, LOSS, AND GRIEF

“I don’t know how to describe it. Kinda made me really upset because, yeah everybody’s gonna die, but like my mom is gonna die, like, more than likely way before the average person. And, like, I don’t know. Like, dealing every day, like, knowing that each day she’s, like, getting worse and worse . . . it just . . . I don’t know. It makes me . . . upset.”

17-year-old living with
a parent who has ALS

INTRODUCTION

Death, dying, loss, and grief are topics that carry taboos, confusion, mystery, fear, worry, or pain, to the point where most of us don't know how to talk about how it affects us, including children and youth. "Normal" life development assumes that we lose our parents when they are older, when we are adults. However, that is not the case with many children and youth who have an ill family member—specifically a parent with ALS. Losing a loved one is very difficult at any age, but losing a parent is one of the most difficult experiences for any child to go through. However, many families feel ill-prepared to talk to their child or youth about disease progression and impending death. This can be because the parent is unsure how they feel, afraid of their feelings, or simply want to protect their child from having to think about loss, the dying process, and death. Moreover, many parents have no idea how to bring up the conversation or how to understand their child's grief.



Here is what the research says about talking about death and dying with children and youth:

- Talking with your children and letting them express their feelings and grief helps them feel less anxious about death.^{1,2}
- Talking helps children process the loss of a parent.³
- Children benefit from clear information in order to feel comfortable in expressing their feelings^{4,5,6} and parents are the ideal ones to start and have the conversation.

Children and youths draw their cues about talking or not talking about death from the parent. In a study of youth and Huntington's disease (HD), the majority of youth participants had not talked about death with their parent living with HD, but would have liked to do so.⁷ They recognized the parent may not be willing or able to discuss their impending death, stating:

"I think it makes [the parent] uncomfortable, which makes me uncomfortable."

Recognizing the difficulty of these types of conversations, this chapter draws on clinical practice and published resources to provide information on how to talk about death and dying, how children and youths may deal with death and grief, and how to guide conversations with youths.

LOSS, DEATH, AND DYING

Broadly, we as a society shy away from or avoid conversations about loss and death. However, in families living with ALS, that conversation will come sooner than many others and thus cannot be ignored. But, that does not mean it makes the conversation any easier, particularly for the person living with ALS. Coming to terms with one's own mortality is emotional, complicated, and can be overwhelming. Many times people do not want to "go there" or think about what their dying and death may entail or look like, particularly what and who they are leaving behind. However, children or youths may not feel the same. They may want to know and may want to ask, but are not sure how. They may be confused or scared and need to talk about it. Many children want to know more than simply that their parent may die. They may want details, but don't know how to bring it up.

"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."

This quote from a 16-year-old captures the need for information, acknowledging the difficulty of the conversation but wanting the parent to take the lead. Despite the difficulty, it is crucial to open the conversation and keep it open, allowing the youth to feel comfortable to ask about death and dying. The following are some specific questions children and youth may ask or want to know.

- What will the death look like?
- How will it be handled?
- Will their parent remain in the home?
- Can the child be present during the death?
- What will happen to the child 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?

While your child may not ask all these questions, be prepared to answer them. Be honest—even if that means you are not sure, or if it is upsetting. Tell them that. Let them know you will get the answer. Let them know this may be difficult for you as well, but that as a family you will address it.

Obviously, it depends on age and maturity, but there are a lot of particulars that are important to answer beyond just the “what is death” and “parent will die” discussions. Obtaining these answers may quell anxiety, misinformation, and confusion in the child/youth. Children and youths are keenly aware of the change and the eventual loss, but need to be able to have details and process what that may look like.

Hospice and End-of-Life Decisions

As described above, many children and youths have no idea what their parent may want at the end of life. While many factors go into this, it is important to let the youth know why decisions are being made. You can decide the depth of these answers.

- If you decide to forgo treatment, let your child know why, again, depending on the child’s age and developmental level.
- If you or your loved one chooses to have hospice or home care, let the child and youth know. Talk with him or her clearly about what that entails and who will be in the home. This can be a distressing time and people coming in and out can add to the confusion if the child or youth is not prepared.
- Despite the desire to shield or protect your child, preparing him or her for what is happening and what may happen is vital.

How Do I Talk to My Kids Who Are at Different Ages?

This is a very important question. As we know from talking about ALS in general, children and youths 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 table is taken directly from the wonderful handbook created by Beth Barrett, MSW, and The ALS Association St. Louis Regional Chapter.

TALKING ABOUT DEATH AND DYING ACROSS AGE GROUPS

Developmental Stage	Possible Reactions	Suggestions for Engagement
Infants and Toddlers (Age 0–3) 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"> ■ Fussiness, irritability ■ Clinginess ■ Tears, vomiting, regression in behavior such as toileting, sleeping, or eating 	<ul style="list-style-type: none"> ■ Maintain a regular routine. ■ Provide nurturance and physical security, such as holding and cuddling with child. ■ Provide reassurance and patience. ■ Allow child to play, as this is an outlet for children’s grief.
Preschoolers (Age 3–5) 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.	<ul style="list-style-type: none"> ■ Numerous, repetitive questions; curiosity about death ■ May appear unconcerned or show little reaction ■ Regression in behavior such as nightmares, toileting, possible violent play ■ Fear of separation 	<ul style="list-style-type: none"> ■ Allow questions and talk with child. ■ Answer questions honestly and in simple words and terms. ■ Use real terms, such as death or dead, not “sleeping” or “gone away.” ■ Provide structure and a normal schedule. ■ Offer patience, explanations, and assurance. ■ Resist punishment for acting out. ■ Encourage physical activity and play to express feelings and expend energy. ■ You may have to clarify that death is not contagious.
Young Children (Age 6–9) 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.	<ul style="list-style-type: none"> ■ May want details and explanations about death ■ Crying; active mourning ■ Will be concerned about others’ feelings ■ Grief expression may come and go ■ May appear anxious or emotional; may “act out” 	<ul style="list-style-type: none"> ■ Provide reassurance. ■ Respond to their needs and questions honestly and compassionately. ■ Allow for creative play through art, stories, etc. ■ Encourage physical play as an outlet for grief and energy expression.

Developmental Stage	Possible Reactions	Suggestions for Engagement
Middle Childhood (Age 10–12) 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.	<ul style="list-style-type: none"> ■ Distractedness, denial, guilt, anger ■ School work may suffer; grades may fall ■ May fear leaving home or parents; separation anxiety ■ May put on a “brave face” and not show emotions ■ May withdraw or act out 	<ul style="list-style-type: none"> ■ Give permission for expression of feelings. ■ Encourage child to ask questions and give honest answers. ■ Avoid punishment, but offer encouragement, reassurance, compassion. ■ Allow child to NOT be brave by giving them time to express emotions and worries. ■ Ask if and how the child might like to be involved in the memorial services. ■ Remember to give hugs.
Adolescents (Age 13–19) 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.	<ul style="list-style-type: none"> ■ Crying, traditional mourning ■ Denial or risk taking ■ Taking on the adult role; being the “man” or “lady” of the house ■ Depression; suicidal thoughts ■ Willingness to talk with peers or nonfamily members about the death ■ Change in behavior at school; grades falling 	<ul style="list-style-type: none"> ■ Encourage conversation and expression of grief; be honest. ■ Allow child to have time to mourn; do <i>not</i> expect them to take over the adult role. ■ Seek out professional help, if needed, such as a school counselor, professional therapist, or clergy. ■ Utilize teen support group services. ■ Provide love and support.

GRIEF AND LOSS

Grief is real and comes in a variety of ways. While many assume grief only happens after someone dies, it is a process that can begin well before the loss of the loved one. Grief can include all the losses associated with illness. For the child or youth in a family with ALS, the loss of childhood has been noted, but perhaps more important is the loss of the relationship between parent and child. The sense of “normalcy” is disrupted when the parent is diagnosed, but also when the disease progresses and things change. Each time new symptoms, or a progression of a current symptom occurs, that is a loss for the person with ALS and for their child. As each loss mounts, the relationship changes, leaving the child confused, sad, and grieving. There can also be a sense of anticipation or expectation of the loss and the eventual grieving process.

The experience of anticipatory grief can be very different from patient to caregiver or family member, but all represent loss. You can help your child through this by acknowledging that even before the loved one dies, he or she is

experiencing loss. The losses include loss of the parent's voice, hearing the dad's funny jokes, playing with the parent, or going for long walks.

“[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.”

While her mother is still living, this 18-year-old is grieving the loss of her mother's voice, and in effect the loss of what she knew as her “normal.” Her mother will eventually pass away, but the most important loss right now is the loss of the voice and the relationship attached to the voice. These early and incremental losses are often overlooked, yet are a very real part of the process. Therefore, it is important to acknowledge incremental losses and anticipatory grief with your child. Here are some suggestions for talking about loss with your child/youth:

- Check in with your child and ask how he or she feels about the changes and/or progressions. What might he or she be grieving the loss of? What does the child miss about the parent or loved one with ALS?
 - Often these are best expressed through art or play—allowing for the expression without words.
- Let your child know you are also sad and grieving the loss of how things were, what they are now, and what they may look like after the person with ALS passes away.
- This conversation can be extremely emotional and difficult. Therefore, it is an excellent time to engage with a social worker, priest, clergy, or other mental health therapist. They can guide the process and provide numerous supports for working through the anticipation of death and loss.

TIP: *It is important to acknowledge that your child will grieve in his or her own way. What your child needs most is support, the space to grieve, and an open door to talk about it.*

The National Alliance for Grieving Children (www.ChildrenGrieve.org) is a wonderful resource for support and guidance on how children and youths deal with grief. Below is a list of seven points taken from the Alliance of important things to know about children and grief:⁸

Grief is a normal reaction for children regarding the death of someone significant.

When children experience the death of a person who has played a significant role in their life, it is normal for children to struggle, whether the relationship with that person was caring and loving, or contentious and difficult. The absence of a person takes time to fully accept and even then, children may continue to miss the person in their own special way. In truth, children never “get over” a person's death, but they can learn to live with the reality. 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.
- Be patient with your child as he or she adjusts to these changes.

Children need to know the truth. Most parents and caregivers would agree that they would prefer that their children not have to deal with the difficult truths that might accompany a death. So, quite often we avoid words like "dead" or "die" or we shade over the truth about *how* a person died in a desire to protect children. Unfortunately, in doing so, we often create other problems.


- Although it may be challenging to share the truth about how someone died, honest answers build trust, help provide understanding, and allow children to feel comfortable approaching us with questions because they know they can trust us to tell them the truth.
- Children know more than we think they do and by not telling the truth, we risk leaving children to process complicated information on their own, rather than with the loving adults in their lives.



Each child's grief is as unique to him or her as was the child's relationship with the deceased. Because of this, the way children experience and express their grief will vary for each person.

- Some children 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 whatever way children 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 of memories. It is important not to assume what children might be feeling about a person's death. Reactions vary from sadness, anger, fear, guilt, and even relief.



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

Grieving children often feel alone and misunderstood. Many well-meaning adults avoid talking about the deceased person for fear that doing so will exacerbate the grief children are experiencing. In doing so, children might feel as though talking about, or even expressing their grief, is not acceptable. Also, many children feel like they are the only person who has experienced the death of someone in their life, even though there might be other friends experiencing similar circumstances.

- It is important to provide opportunities to acknowledge the grief everyone is feeling.
- It is also helpful when children are able to gather with peers grieving similar situations.

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.

Children will experience grief at different times throughout their lives. Many times, intense feelings of grief will last longer and come more often than we think they should. In time, as children have opportunities to express their grief, tell their stories, share their memories, and process what this death means to them, they might find the intense feelings come less often. But, grief is a lifelong journey and children often experience their grief on different levels and at different times throughout their lives. When a child gets their driver's license, scores a touchdown, goes to prom, or graduates from high school, he or she might revisit grief in a very intense way. This extends into adulthood as well, when he or she has children or gets married. *Grief has no time limit.*

- Allowing 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.

Grieving children often experience personal growth as a result of their loss.

Personal growth is often a by-product of going through grief. 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.

Grieving children feel less alone when they are with other children who have experienced the death of a significant person and when they have loving, consistent adults in their lives.

- Greater than any education, information, or advice we can give to children who are grieving, is to allow children who are grieving to connect with other children going through a similar experience.
- When children have the opportunity to interact with one another, they feel less alone.

- 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.
- Research has shown that one of the top indicators of how well children will do after the death of a significant person in their life is directly related to the type of relationship they have with the surviving adult(s) in their lives and how well these adults are able to cope with their own grief.

COMPLICATED GRIEF

Grief 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 every day life and impairs you. Adults and youths can experience this type of grief. It is important to pay attention to how your child or youth grieves or experiences complications associated with grief. Children and youths who experience complicated grief may exhibit some of the following:

- Loss of interest in daily activities and events, even those they used to love
- Inability to sleep, loss of appetite, fear of being alone
- Regression, or acting younger than they are
- Excessively imitating the person with ALS who died
- Talking about wanting to die to be with the person who has passed away
- Avoiding peers and friends, even close ones
- Extreme change in school performance or avoiding school

Make sure you check in with other family friends and adults who interact with your child (school, coaches, etc.). They may see these signs before you do and may be an excellent resource for catching them early.

If your child is experiencing any of these, don't hesitate to address it and get help. In addition to The ALS Association, your child's school, your religious home, a child therapist, among others can provide support to you and your child or youth, to help him or her move past the complicated aspects of grief while acknowledging the child may still grieve. This may also provide an opportunity for you and your child to delve deeper into conversation and be each other's support after the loss of the loved one.

SUPPORT GROUPS AND ADVOCACY

After the person with ALS has died, support groups may be helpful to your child/youth. Support groups at this stage are focused on what happens next, how to develop another "new normal" and overall dealing with the loss and changes. At this point, support groups should be less focused on the details of the disease and more targeted to support. If you think a group would be good for your child or youth, check in with your local ALS chapter. They may have a group, or may be interested in starting one.

Often, children and youths are wary of a group, or don't want to tell their stories to strangers. From previous clinical experience, support groups for children and youths tend to work best when they are combined with "normal" activities—bowling, art, etc. These normal settings lessen the pressure to "perform" or speak up and provide an opportunity to simply be with other similar youths.

In addition to support groups, children and youths are often helped by finding something meaningful and important they can do to help the family member or the disease advocacy in general. Some youths join groups, while others become active in advocacy, education, and disease awareness. Whatever they choose, allowing children or youths to express themselves and gain support is a crucial aspect of moving through grief and celebrating the person with ALS.

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CHAPTER 5



PROFESSIONAL RESOURCES

INTRODUCTION

This chapter provides guidance for health and mental health professionals and The ALS Association staff to use information presented in earlier chapters. The below sections discuss ways to engage children and youths in clinic and home visits, as well as ways for The ALS Association chapters to develop educational and supportive tools for youth. Any of the below suggestions and programs can be tailored to chapter setting or clinical practice.

PATIENT CLINIC VISITS

Many health professionals engage with families, including physicians, physical therapists, occupational therapists, nurses, speech language professionals, respiratory technicians, registered dietitians, social workers, psychologists, and others. These professionals are often tasked with answering questions and providing family and youth support. However, clinic staff frequently report that families do not bring their children to the clinic, limiting opportunities to interact with children and youths. Parents may feel it is too scary or overwhelming for the youth to bring them to clinic. As a way to overcome these concerns, health care professionals may consider talking with the parents ahead of time about the possibility of bringing their child or youth, in order to support the youth and answer questions during clinic visits. While the focus of clinic visits is on the patient, having the family in clinic is an excellent opportunity to engage, acknowledge, and support the youth when meeting with the patient. When seeing families:

- Ask the parent and child if they have any questions or concerns.
 - Depending on the age of the youth, he or she may be extremely helpful in creating care plans and supports.
 - Allowing the youth to feel engaged and heard will go a long way to helping him or her process and deal with life in an ALS family.
 - Engaging the youth provides encouragement for the family to develop positive communication skills.

Caregiving Youth

Clinic visits also provide an opportunity to ask if the child assists in care. When asking about potential caregiving, make sure parents understand that this question is not meant to be invasive or punitive in any way. As a health care professional, you simply want to make sure you provide support and care for all family members. Addressing caregiving may open a new avenue to engage with the family and assess their needs. Questions to consider: What type of care does the child provide, how often, and for how long?

- This line of questioning can be used as an assessment tool to further understand care needs and respite needs for all caregivers in the family.
- Ensure the child or youth that he or she is not weird, odd, or nonnormal for their caregiving activities.

- Allow the family the opportunity to discuss how they all feel, but don't push it with the child or youth. Some feel a sense of responsibility with the parent, and they might disappoint the parent if they say anything negative about caregiving.
- There may be an opportunity to talk with the child/youth away from the parent. Check in with the parent to see if the parent is open to you talking with the child in a separate room. If the parent agrees, this may provide a good setting for the child/youth to discuss how he or she feels without upsetting their parent.

Finally, one specialist is often not a member of the ALS care team, yet can be extremely useful—child life specialists. Typically, these professionals are centered in children's hospitals. They most often work with families around childhood illness, death, and dying. However, many child life specialists focus on helping children deal with, and transition around, parental illness. They can be an invaluable resource for many ALS clinics when children and youths attend clinic visits with the person with ALS. Most hospitals will have lists of child life specialists. ALS chapters have begun to engage them and get them involved in clinic visits and chapter functions, an invaluable tool in supporting children and youths in ALS families.

HOME VISITS

Many health professionals such as social workers, nurses, physical therapists, and occupational therapists engage in home visits. These visits provide crucial opportunities to engage with the family in the home and conduct assessments and training opportunities for children and youth caregivers. While conducting home visits, take the time to address any possible caregiving undertaken by children or youths in the home.

- Ask if the child or youth provides care. If so, what training might be helpful?
- The family may not readily provide this information, so make sure to discuss it in broad, normalized terms. Be very clear that many families rely on other members, including children and youths.
- One way to provide training is to involve the durable medical equipment (DME) provider to show the equipment to the kids. Let them sit in the chair and understand how the devices work. Have the children ask questions so they feel comfortable and engaged with it and don't worry that they will do something wrong to harm their parent.
- Even if no youths are engaging in caregiving, make sure to talk with, and acknowledge, the youths in the home.
- Provide information on the local ALS Association chapter, youth programming, and ways to communicate as a family.

CHAPTER RESOURCES AND PROGRAMS



Many ALS Association chapters across the United States have engaged and supported youth for years. These chapters provide care, programming, and guidance for families as they live through the ALS diagnosis and disease process. The below information is a reflection of the amazing programs and supports 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 supports 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 for youth
3. Creating peer engagement programs
4. Educating youth about ALS and caregiving

Backpack Programs

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

Newsletters (Print and Online)

- Chapters have created newsletters, Facebook pages, and an online presence specifically for youths. These can be written by youths or for youths. Some include poems and personal experiences. They provide excellent opportunities for youths to engage with other “like” youths, lessening isolation and developing positive peer interactions.

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 for youth when they are developed around activity, as opposed to a “traditional” talk support group.

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. Service programming includes participating in walks, which allows for school credit and provides an 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 youths in ALS families.
- Some chapters have ALS Club partnership with schools where they volunteer in the homes of patients, making connections and offering support.

ALS Workbooks

- These guides are developmentally appropriate and include many features endorsed by child psychologists.
- These workbooks can also be developed online, as has been done with other disease-based organizations. Youths can participate in games, puzzles, and activities that teach them about ALS and help them develop coping skills.

Grief Programming

- There are many grief tools and materials available online and in print. Chapters make use of numerous self-help books on anticipatory grief, grief development stage charts, and supports for professionals on how to address grief with youths.
- In order to condense the many options out there for grief, a couple of these tools are included in the previous chapter on grief. This will allow a one-stop shop for supports and tools to address grief in children and youths.

Community Counseling Partners

- In order to provide mental health support for youths, many chapters have partnered with licensed clinical social workers and psychologists who are skilled in working with youths 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.



Youth Respite Camps

- In a study of a camp for youths who have a parent with Huntington's disease (HD), in addition to information about HD and support from HD professionals, youths stated the most important take away was they no longer feel alone, and they now have peers to reach out to who understand what their lives are like.¹ Camps are an excellent way to address the support and the needs of youths by including like peers. Several ALSA chapters are engaged in developing multiple-day camps. These camps include education, support, games, and free time for youths to connect and build community. Things to consider when developing camps:
 - Having professionals engaged with the camp, including social workers, nurses, counselors, and physicians who are experienced in ALS. Youths may experience emotional responses and would benefit from professional support.
 - Including developmentally appropriate educational components. This has been shown to lead to higher rates of self-esteem and resilience in youths affected by Huntington's disease.
 - *Who attends the camp?* Some camps are youths only, while others are family-based. Some youths 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 youths and feel like a "normal youth." In creating a camp, make sure it is clear who should and should not attend.

The above is a listing of current projects, yet there are likely many more projects and supports for youths and families with ALS in chapters and communities across the United States. We encourage chapters to use any and all of these ideas, and build their own. The goal is to share as many programs as possible, in order to provide wide-ranging and developmentally appropriate services and supports for children and youths.

NON-ALS RESOURCES

The goal of this manual is to create a tool for families and healthcare providers as they support and engage youths. However, it is by far not the only resource available to help and support families. The below list of sites 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 engaging with youths.

Children, Teens, and Grief

National Association for Grieving Children (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). 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). 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). 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.

School Associations

The American School Counselor Association (ASCA) (www.schoolcounselor.org). This association supports school counselors' efforts to help students focus on academic, career, and social/emotional development so they achieve success in school and are prepared to lead fulfilling lives as responsible members of society.

School Social Work Association of America (www.sswaa.org). The School Social Work Association of America empowers school social workers and promotes the profession of school social work to enhance the social and emotional growth and academic outcomes of all students.

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About The ALS Association

The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

For more information about
The ALS Association, visit our
website at www.alsa.org.