



THE ALS EXPERIENCE: IT'S DIFFERENT AND HARD

A Book for Teens in Families Living With ALS

ALS
ASSOCIATION

Melinda S. Kavanaugh, PhD, MSW, LCSW

Megan Howard, MA

University of Wisconsin-Milwaukee

WHY DID WE WRITE THIS BOOK?

We wanted to create a space that lets you know that other kids have questions about ALS, caregiving, and how to talk to their family about ALS.

You are *not alone* in living with and, for many of you, providing care for someone with ALS in your family.

Over the years, we have met many, many young people like you, living in families with ALS or other diseases. We wanted to create a space that lets you know that other kids have questions about ALS, caregiving, and how to talk to their family about ALS. You are not alone in living with and, for many of you, providing care for someone with ALS in your family.

We used real people in this book. Their names are changed to protect their confidentiality, but *their stories are true*. You can see what other young people go through, and maybe you can learn from them. In this book, we give you options based on what the folks in the book did, or may have done when talking with friends, family, and other adults. We also include some examples of when they don't talk about ALS. The path you choose is up to you.

Who was the book written for? The book was created primarily for youths ages 13 to 18, but it is available to youths of any age who have a family member with ALS. We have another book for younger children and one for young adults. You may choose which one is right for you.

How can I get a copy? You can get this book online through The ALS Association at www.alsa.org, or through your local ALS Association chapter. We want to make sure as many young people as possible have a copy. You can read it at your own pace. Stop or start when you need to. Keep it in your book bag, or place on your bookshelf. Read it when you need to.

The creation of this resource was not a singular process. We want to particularly thank the extraordinary families who participated in the ALS family study and in the youth education and training programs in Wisconsin and Colorado. Participating in research and telling your story is a gift to this book. We thank you and hope by reading this book, other young people will find support and tools in sharing your experience.

Melinda and Megan

TABLE OF CONTENTS

CHAPTER 1

What is ALS? How do I talk about it? 6

Living in a family with ALS: youth examples 7

Lara, Bradley and Ian: introduction to character experiences 8

Questions we hear about ALS 12

Talking about ALS 18

Youth examples 19

What other youth have to say 24

CHAPTER 2

School and Peers 32

Dealing with ALS while at school 33

Talking with friends 36

CHAPTER 3

Caregiving, or what it is like to help 38

Being a caregiver 39

What other youth have to say 42

Assistive devices and ALS 46

CHAPTER 4

When someone dies: Grief and Loss 50

Talking about Death and Dying 51

Grief 53

Support Groups and Advocacy 58

Follow **Bradley**, **Ian**, and **Lara** experiences to help you *understand* how they approached their family member's ALS. You can also see how other approaches are available to choose from, to show what may have happened if they had taken a different path. That way you can *help* figure out what approach might work **BEST FOR YOU** and your family. But first, let's go over the **BASICS OF ALS** – what it is and what it is not.



CHAPTER

WHAT IS ALS?

HOW DO I TALK ABOUT IT?

Q “Challenging and always there reminding you”

This is how a 15-year-old describes living with ALS in his family. This may sound like your experience with ALS – or not. Living with ALS is *different for each* **PERSON** and **FAMILY**.

LIVING IN A **FAMILY** WITH ALS: YOUTH EXAMPLES

It can be hard to think about ALS and how it impacts your family, or even that others are feeling the same way. To help you think about ALS and how it impacts you and your family, we are going to turn to *three people a lot like you*. We asked them to describe what it is like to live with a family member with ALS and how they talked about ALS.

FIRST, we will give you some background, letting them tell *their story*. Then you will get to see what **CHOICES THEY EACH MAKE** in talking about ALS, caregiving, and death and dying. Each of these options includes possibilities for talking with adults and friends, or not talking at all. You will have the chance to make some choices for these characters as you move through this guide.

Let's start with some background on our guides.

LARA



15 years old



lives with her mom, dad, and little sister.



Lara is 15 years old and lives with her mom, dad, and little sister. Lara's parents moved to the U.S. right after they were married, and Lara and her sister were born in the States. Her extended family is pretty big – about half live here in the U.S., but the rest still live back home. Her mom's older brother lives in the U.S. and is a favorite uncle to everyone. He is really more like the "dad" in the family, since he is the oldest and since Lara's grandfather died long ago. Lara's mom is really, really close to her brother and treats him with the respect she would her own father. They all live about two miles apart and see each other all the time. About 6 months ago, Lara noticed that her uncle would drop things and sounded strange when he talked, like he had something in his throat. She asked her mom, who said it was nothing, but Lara knew something was wrong. Her mom would cry all the time, shut herself in her room, and was always on the phone with family. They would go visit her uncle and everyone was sad. He was getting worse physically, but was still his funny self. Lara and her sister did not know what was going on, and no one was telling them anything. They were both angry and sad and felt like they were being treated like little kids.

Lara and her sister did not know what was going on, and no one was telling them anything.

IAN



16 years old



an only child



**lives with his mom
in a suburban
neighborhood.**

Ian is 16 years old, an only child, and lives with his mom in a suburban neighborhood.

He loves to play basketball and has a lot of friends on his local team. They have lots of family friends. When he was 2 years old, his father was diagnosed with ALS. They always talked about it as a family, so his dad having ALS was just a normal thing. In fact, ALS is just about all Ian knows. The disease progressed fast at first, then it really slowed down. Ian's dad used a power wheelchair and other assistive devices for most of Ian's childhood, but was still able to work for many years. He was a computer engineer and had a room full of technology in their home. He used to show Ian all the wires, conductors, and complicated machines. Ian wanted nothing more than to be like his dad; they were very close.

**Ian's dad
having ALS
was just a
normal thing.**

BRADLEY



14 years old



**loves riding his
bike and reading.**



**He is quiet and
very observant of
all around him.**

Bradley is the middle child. He has an older brother, Andy, whom he loves and is very close with, and a younger sister, Stacey, who drives Bradley crazy.

Stacey only seems to want to talk about her friends and famous people, but rarely anything about her family. Bradley lives in a medium-sized town and knows just about everyone. His parents were married for a long time, but three years ago, they broke up. Bradley was really close to his dad, so the divorce hit him pretty hard. His parents were honest and said they broke up because they just did not get along anymore, but that they would still live near each other and care about each other. Bradley lives with his mom but rides his bike over to his dad's every day.

About a year and a half ago, Bradley's dad started falling—a lot. He had always been a big guy, so seeing him trip and fall was weird and scary for Bradley and his whole family. His dad was diagnosed with ALS about four months after he started falling. Each family member reacted differently to the news. His mom cried a lot, his brother started acting like he was the “man of the family,” and his sister—well she did not talk about it at all. Bradley did not know what to do. He loved his dad and was really worried about what this diagnosis meant for him. He started reading everything he could about ALS, which may not have been the best idea since there is some freaky stuff on the Internet.

Bradley loved his dad & was really worried about what this diagnosis meant for him.

QUESTIONS WE HEAR ABOUT ALS

 **“I know that it starts, like it has steps, and some people it affects their lower bodies, often it’s both. Well, for my mother it’s both parts of the body.”**

The 14-year-old above is correct. ALS can affect people in **DIFFERENT WAYS** and in different areas, which makes it *pretty confusing* to understand. To help us understand what ALS a bit better, here is a brief overview by Drs. Ezgi Tiryaki and Holli Horak, both experts in ALS and authors of the guide, *“What is ALS?”* the first resource guide in the Living with ALS series.

What is ALS?

ALS is sometimes called “motor neuron disease,” or MND. This is a better description of what happens in the body. We are going to get real detailed, so hang on.

First, the nerve cells that communicate (innervate) with muscles are diseased and die. However, this term, MND, is used less often because there are other causes of MND besides ALS (in other words, MND does not refer only to people with ALS). ALS is a type of Motor Neuron Disease (MND).

What are MNDs?

MNDs are diseases that damage the motor nerve cells, which are cells required for movement. Amyotrophic is a medical term meaning loss of nutrition to the muscle. Muscles lose their bulk and get smaller.

The term sclerosis means scarring or hardening. In ALS, this scarring is due to the damage and loss of nerve cells. Lateral means the side and refers to the area of the spinal cord that houses the fibers of the nerve cells that die off in ALS.

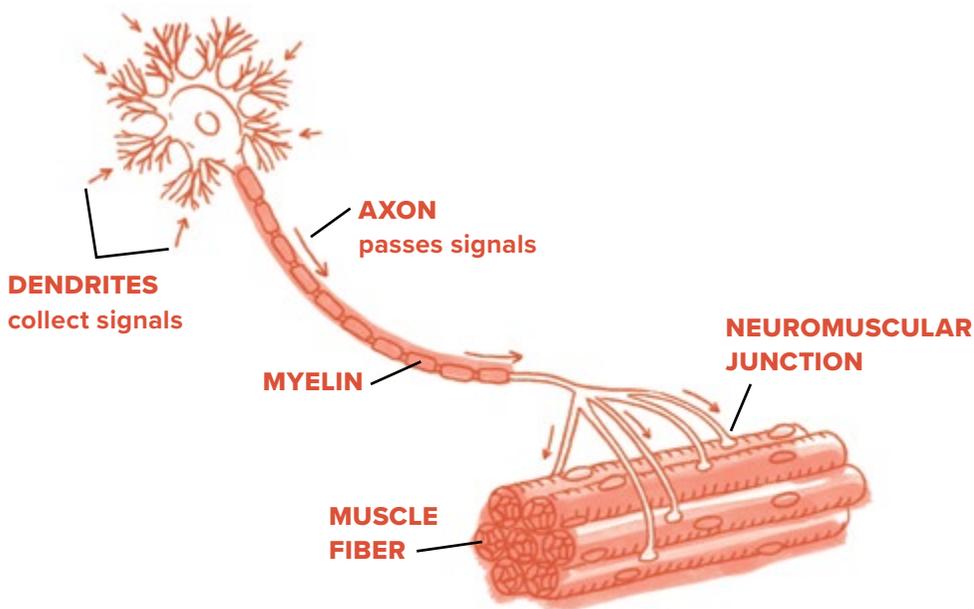
What does ALS do?

ALS causes weakness and wasting of all voluntary muscles. This means that the muscles we use to move, swallow, and even breathe, become affected by ALS.

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

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

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



IS ALS EVERYWHERE IN THE BODY?

The disease can start in different places in the body. However, as time progresses, the weakness worsens in the muscles that were affected first and then spreads to other parts of the body.

What causes ALS?

ALS most often occurs sporadically, meaning without a known cause or warning. There is no known direct cause. That means we can't say if it has to do with what you eat, how you exercise, or the air you breathe. But, there is a lot of research being done to figure out what factors in the environment may influence how someone develops ALS.

If we don't know what causes it – how do we know who will get it?

Sporadic ALS is responsible for approximately 90 percent of all cases of ALS diagnosed. Sporadic means the *disease is not passed down in families*. Researchers are looking for genes that may make one person more likely than another to develop ALS.

There is a small group of people with a genetic form of ALS, referred to as familial ALS or fALS. This makes up approximately 10 percent of people with ALS, and it has a high presence in the family (medical term: penetrance). This means that many family members are affected by it (such as parents, siblings, or grandparents; but not typically a second or third cousin, or remote family member). However, if you have concerns about a family connection, you should speak to your physician or health care provider to discuss the potential of developing fALS and any recommended genetic testing.

HOW DOES ALS GET WORSE?

This is a tough one to answer, since no two people experience ALS exactly the same. Some people have it worse and decline in one area before it spreads, while others have a rapid progression throughout their body. In some people, the disease progresses very slowly.

HOW LONG DOES SOMEONE LIVE WITH ALS?

In general, people with ALS live about three to five years after they experience the first sign of weakness. This is a generalization, which is based on averages. **PEOPLE WITH ALS CAN LIVE ANYWHERE FROM A FEW MONTHS TO DECADES DEPENDING UPON DISEASE CHANGES AND THE TYPES OF MEDICAL CARE AND ASSISTIVE DEVICES THEY CHOOSE.** ALS is different in each person and will run an individual course.

So, what happens in ALS?

A person with ALS may develop severe weakness (the medical term is paralysis) of all muscles in the arms and legs, and the muscles of breathing, swallowing, and speaking.

BUT REMEMBER – EVERY PERSON IS DIFFERENT. Some people have severe weakness of one area, but little in others (for example, they may be unable to swallow but still able to walk and drive), but other individuals may demonstrate a similar severity of involvement of different areas. Some people have the disease and it progresses very slowly, while others have changes that happen more quickly.

It is very difficult for doctors to predict how a person's ALS will progress at the time the diagnosis is made. So, they try to see the person with ALS as much as possible so they can watch and track how the symptoms progress.

Can you tell us anything about what may happen next?

Although no ALS health care provider can know for sure, it is generally true that individuals who experience a more rapid onset will have a more rapid course of the disease, while individuals with a slow onset will likely experience slow progression. In general, people with face and tongue (the medical term is bulbar) involvement have a shorter life span due to the problems with loss of function in this area (breathing, swallowing).

It is also generally true that the spread occurs from one body part to the next. So, for instance, if the disease starts in the legs it would be expected that the arms would be affected next. Symptoms do not begin all at once or suddenly.

How fast can the changes happen?

Many people fear that they will wake up paralyzed, **BUT SYMPTOMS DO NOT CHANGE OVERNIGHT.** Some family members may notice an abrupt change, but that change is likely due to the person living with ALS trying to compensate for the things they can no longer do. They just can't do them anymore, so it looks like they changed really, really fast.

Is there anything we can do to help with the changes?

Well, keep any eye out for changes. No, you don't have to stare at your family member with ALS, but just notice when things change. Then let your mom or dad know and they will tell the doctor. That way the doctor may be able to treat the symptoms and prepare you for upcoming changes.

I KNOW THINGS CHANGE – I DO A LOT TO HELP MY DAD.

Yes, that is true. People with ALS will lose the ability to do a lot of things, including getting out of bed, moving onto a chair, getting dressed, showering, eating, and toileting. This is due to the loss of the motor neurons causing paralysis. Also, people living with ALS lose muscle mass and, as a result, lose body weight. Weight loss is also due in part to increased need for calories, decreased ability to eat adequately because of swallowing difficulties, as well as arm and hand weakness, which impacts the ability to feed oneself.

Is there a cure?

Unfortunately, there is no cure for ALS. There is no known way to stop or reverse this disease. There are, however, treatments that ALS specialists recommend to help people manage their symptoms.

i The above is a tough section full of details, bizarre terms and lots of information. After reading it is a great time to stop and ask more questions of your parents, doctors, or your local ALS Association chapter staff.

ALS can be pretty confusing, so the best thing to do is ask. If you are not sure what to ask or how to talk about ALS, the next section is just for you!

TALKING ABOUT ALS

- ① When did you find out about ALS?
- ② Did someone tell you, or did you just hear about it?
- ③ Did your family talk about what ALS is, or did you have to look it up?

You can find out about ALS in a variety of ways. Some people **LEARN** about a diagnosis right away, and others *much later*. Sometimes younger family members feel **ANGRY** or mad that they didn't know their relative had ALS or that their parents didn't talk to them, like in the case of **Lara**. Other's may feel like they have to look everything up on their own like **Bradley** – which can be scary. Either of these reactions is totally *understandable*. You want to know things and be a part of conversations.

So, **TALKING IS GOOD** – even when it's *hard*. But what does communication actually look like in families? How do kids talk about ALS – and with whom?

Let's check in and see what options you have for talking.

Bradley was 13 years old when his dad was diagnosed with ALS.

Initially, Bradley had a hard time facing the fact that his dad was very sick. Bradley was already going through a number of changes in his life. His parents had divorced a few years prior, and he was having to split his time between his mom's house and his dad's house. His dad's health was declining quickly – he was already having trouble speaking and walking within a few months of being diagnosed with ALS. Bradley was sad after his dad was diagnosed, but he wasn't sure if he was ready to talk about his dad's ALS. He didn't need another reason for people to see him as 'different' since his parents were divorced, and they did not have much money. He had a few close friends and was close to his mom, but he didn't know how to talk to her – did she still love his dad? I mean, she cried a lot, but Bradley wasn't sure. He loved his brother and was close to him, but Andy was acting really weird, like a "new dad".

If you were Bradley, what would you do?

- a) **Talk to your friends.** ➡ Turn to page 26
- b) **Talk to a trusted adult (parent, teacher, coach).** ➡ Turn to page 28
- c) **Don't talk to anyone.** ➡ Turn to page 30





Ian wanted to learn as much about ALS as possible, so he could be informed and talk intelligently about it.

That way, when his friends asked him what was going on with his dad, he could give them a full answer. When talking with people who didn't know his dad, they would sometimes ask what he did. Ian always told them, his dad was sick and he was sick with ALS. Talking with someone who had no idea what ALS was meant Ian had to do a lot of explaining, mostly because they have likely never seen someone with ALS and they do not know what ALS does to the body. Ian came up with a line to tell people – “ALS attacks and kills all muscles in the body.” But these days, his dad's ALS has gotten worse. Ian gets up late at night to help turn his dad, or help his mom take him to the bathroom, so Ian isn't getting enough sleep.

What would you do if you were Ian?

a) Talk to your friends. ➡ Turn to page 26

b) Talk to a trusted adult (parent, teacher, coach). ➡ Turn to page 28

c) Don't talk to anyone. ➡ Turn to page 31

Even though Lara knew something was wrong, she did not know what.

Lara's family is part of a tightly-knit community, but the adults were the only ones to talk about things like illness in the family. Lara and her sister were never included in the conversation. Lara had good friends at school but didn't know how to talk about her uncle's illness – she didn't know quite what to say. She felt isolated and alone... she just wanted to know what was going on with her uncle and how she could help.

If you were Lara, what would you do?

- a) **Talk to your friends.** ↪ Turn to page 26
- b) **Talk to a trusted adult (parent, teacher, coach).** ↪ Turn to page 29
- c) **Don't talk to anyone.** ↪ Turn to page 30



Many families out there do a great job of talking about ALS. They are open and share thoughts and information with family members, including youth in the home. They process information and share feelings, which is helpful for all involved.

BUT, some families have a *hard time* talking about illness and ALS. Let's cover some of the *reasons* why families do not talk about ALS. Do any of these sound like **YOUR FAMILY**?

Your family feels like they are *protecting* you by not talking about it

Your parents' and family's main role is to make sure you are provided for and safe. They may view talking to you about ALS as making you sad and hurt. Parents often say that they don't want their kids to "worry" about ALS, but what happens is they end up not talking to you about ALS at all.

They are also concerned about what you may find out on your own through the Internet. We know you have access to the Internet. In fact, you grew up with the Internet and access to all kinds of information. You can look up just about anything very easily. However, that information is not always correct. Parents talk about this a lot – they want to protect you from what is out there on the Internet.

What can you do? Let them know you are OK, and that you want to talk about it – as hard as it may be for them to have the conversation. Open and honest is a good way to start.

Adults may be *scared* themselves and unsure of how they feel about it

Being diagnosed with ALS is tough for everyone in the family, most of all the person being diagnosed. Many people feel shocked, upset, scared, and worried when they get diagnosed with ALS. It can really upset the whole family dynamic, like we read about with Lara's family. It's important to remember that people need time to understand and process the impact of the diagnosis.

They need to know where they stand with their own feelings before they can talk to anyone about it. For some people, this process may take longer than others. Knowing that your family member may still be figuring out how they feel about their diagnosis – and that you can figure things out together – may make you feel better.

Adults just *don't know what to say*

We have talked to many parents and many say that talking about ALS is just tough – for everyone. *Just because they are the adult, does not mean they always know what to say.*

WHAT CAN YOU DO? It is OK to let your parents and family members know you want to hear what they have to say. It may help to ask a question to show your interest and let the conversation flow from there. We tell parents not to make a “big deal” over the first time they talk to you about ALS – it's just the beginning of the conversation. So, either one of you can just start talking. Sometimes this takes several times, as you figure out how to get more comfortable with it. As hard as it is (and maybe as much as you want to just stay in your room), *keep trying.*

Now that we have a bit more information about where your parents are coming from, let's see what questions other teens have.

We interviewed over 60 kids who have a family member with ALS. They had a lot of questions and comments. Here are a just few. Have you wondered about any of these?

WHAT OTHERS HAVE TO SAY

“I don't know what to say to my dad”

Sometimes, your parent may want to talk to you, but you don't want to talk to them. We all know being a teenager is tough. Even without being impacted by ALS, this is a time of figuring out who you are, who your friends are, and where you fit in your family. These are big questions and can make you feel like “checking out” and being far away from your family member living with ALS. This is very normal – it is tough to know what to say, or what to ask.

What can you do? While it is OK to not want to talk about it, you need to talk sometime. Make sure you talk and ask questions at some point. As hard as the questions can be, they may even bring you closer.

“I feel like we are not the same family”

You were just like any other family, but now you have a family member with ALS. Things are not the same, and that can be hard for everyone. Living with ALS requires your family to develop new routines and new ways of doing things — to create a “new normal” and live with ALS, not in spite of it. In the words of a 17-year-old, “Everyone has their thing—this is ours.”

What can you do? Here are some examples of ways that other families have adapted their routines and adjusted to living with ALS:

IF YOU WERE A CAMPING FAMILY, DO SHORT DAY TRIPS OR BRING OTHERS ALONG TO ASSIST.

IF YOU LOVE THE BEACH, RENT A SAND WHEELCHAIR.

IF YOU WENT TO THE THEATRE, ARRANGE AISLE SEATS.

What ways can you think to adapt your family to a **“NEW NORMAL?”**

“Is it OK to talk to someone else?”

Absolutely! In fact, it can be very helpful to talk to a coach, a teacher, or a mentor. Sometimes this is an ideal solution because these adults are removed from the immediate situation, but they are still available to lend a listening ear to let you talk things out. We will hear from Ian later about how he talked to his coach, which was really helpful.

“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 about ALS with your family. This can be extremely difficult, so we devote an entire chapter to it later in the guide.

Option A: Talk to your friends

BRADLEY

Bradley decided to talk to his best friend, Craig, about his dad's ALS diagnosis when they were riding their bikes through town. Bradley thought it would be a hard thing to talk about, but it helped that they were just riding their bikes like always – it wasn't like a scheduled, sit-down conversation, which would have made Bradley feel weird. Craig asked a couple of questions about what ALS was, and Bradley was able to share some of the information he had learned while at one of his dad's medical appointments. Craig offered to help Bradley with homework or taking extra notes if Bradley ever had to miss classes to help out at home. Bradley felt better after sharing his news and having someone else know what he was going through.

[↩ Go back to pg 22](#)

IAN

Ian decided to talk to a few of his close friends about his dad's declining health. They all knew his dad had ALS, and Ian was really open about it. But he had not talked about how bad things had gotten. Ian helps his family a lot during the week, and his mom has a respite worker come in on the weekends to help out and give them a break. Ian went to basketball practice and told them that things were rough with his dad's new meds and being up late to help his mom. His friends offered to help Ian with his homework and checked in the next week to see if things were better. It was helpful for Ian to have his friends listen and be supportive.

[↩ Go back to pg 22](#)

LARA

Lara has some really great friends, some of whom she has known her whole life. She and her friends are all part of the same, tight-knit community and know each other's families well. They go to the same community center and religious services. Her friends had heard that her uncle was having some health problems, but they didn't know it was ALS. Because of their shared community, they all understood that it can be hard to talk about things within your family – mostly because their families are the same way. They listened to Lara and were supportive, which made Lara feel less alone.

[↩ Go back to pg 22](#)



- ② What can you take away from each of these real-world examples?
- ② Did anyone say or do something that makes sense to you? How can talking to friends about ALS help you in school?



Option B: Talk to a trusted adult



BRADLEY

Even though Bradley had good teachers at school, he just did not feel comfortable talking about his dad’s ALS since his brother and sister attended the same school. He felt like he would be betraying his family since he knew his siblings had not talked to anyone. Through The ALS Association chapter in his state, Bradley heard about a “youth event” that was part of a larger adult ALS meeting. Bradley had no intention of going to the youth event, but his dad wanted to go to the adult meeting and needed help with transportation. Bradley and his brother, Andy, took their dad to the meeting, and Bradley decided to try the youth event while Andy stayed with their dad. Bradley met some other kids – which was great – but he still felt like he could not open up and talk to anyone. During lunch, one of the social workers sat next to him and just started talking. She was easy to talk to and seemed to know a lot about ALS and kids. Bradley told her all about his family, his sister who won’t talk about it at all, his brother who acts like he is the dad, and his mom who is just sad. The social worker made a very large impact on Bradley and how he thought about living with a parent with ALS. She talked about not giving up on his dad, no matter how bad his ALS got and to understand that some people have a really hard time talking – but that does not mean they don’t care. This helped Bradley understand his sister a bit better.

[↩ Go back to pg 22](#)



IAN

Most people in Ian’s life know his dad has ALS. But when things started getting worse, it was really hard for Ian. He wanted to be a “normal” kid, but it was getting harder and harder to get to basketball practice, even though his mom worked really hard to make sure Ian had as “normal” a life as possible. After Ian was late for practice, he decided to tell his coach, Mr. Henderson, what was going on at home. Sharing how he felt with Mr. Henderson was really helpful. Mr. Henderson even gave some suggestions about how Ian could talk about his feelings and not just ALS. Ever since the day he talked to Mr. Henderson, Ian felt better after sharing his story, knowing that his coach supports him.

[↩ Go back to pg 22](#)



LARA

Lara did not know who to talk to about her uncle's illness, or even what to say. She was still not entirely sure what was going on. She heard ALS mentioned and looked some things up on the Internet. It was pretty scary, especially knowing that her uncle would eventually die. She really wanted to talk to an adult and get some answers. One day, Lara came home from school and decided she had to talk to her mom. She went to her mom and said she knew her uncle had ALS and that she was scared. She told her mom how hard it was to see her cry all the time. Lara and her sister were doing everything they could to help her mom, but now Lara needed to know what was going on. Lara's mom was shocked, but actually grateful Lara brought it up because she did not think she could ever start that conversation. They talked – but not a lot. It would take several conversations for them to get more comfortable and open about ALS, but they eventually did. Even though it was hard to hear some of the information about her uncle, Lara felt better knowing what was going on.

[↩ Go back to pg 22](#)

Option C: Don't talk to anyone

Some of you may be saying – yeah, well *I don't want to talk to anyone. I am fine.* I don't need to talk about everything, all the time. It feels way more **COMFORTABLE** to stay in your room, avoid home, or take on extra shifts at work.

LOTS of people feel this way. Maybe they are just *too overwhelmed*, or *too sad* to talk. Maybe they are **ANGRY** that this happened to their family. Or maybe they are just angry that they have to deal with it. There are many reasons why someone does not talk about it.

Let's check in and see what it looks like when you don't talk about it with anyone.



BRADLEY

Bradley decided not to talk to anyone about his dad's ALS. Bradley withdrew from his friends at school – he felt different and weird and didn't know how to talk to other kids about what was going on at home. His dad's best friend, Mr. Schmidt, tried to reach out, but Bradley just did not know what to say. Bradley had to miss some school, as well to attend his dad's doctor appointments and struggled to keep his grades up. He wanted to talk to his mom but didn't know what to say to her either. His sister did not talk to anyone, and his brother was acting so bizarre, Bradley did not know what to think.

[↪ Go back to pg 22](#)

LARA

It was easy for Lara not to talk to anyone, because no one in her family was saying anything. Lara figured out that her uncle had ALS, but she did not have anyone to talk to. She shut out friends and family and got really sad. Her mom cried all the time, so Lara spent her energy taking care of her mom but never talking about what was really going on. Both Lara and her sister knew but kept everything bottled up.

[↪ Go back to pg 22](#)





IAN

Ian struggled to talk about his dad's declining health at home. He didn't want to be singled out in his classes, so he stopped talking to his teachers about his dad's diagnosis and kept his feelings bottled up. Even though everyone knew about his dad's ALS, because he had it for so long, things were getting worse and Ian just did not want to talk about it. His coach, Mr. Henderson asked what was going on, but Ian said nothing and went back to practice. Ian did not talk to his mom either – or his dad. He just wanted it to stop getting worse and worse. Ian started getting angry and feeling resentful about all the ways ALS was affecting him and his life.

[↩ Go back to pg 22](#)

i Not talking – while initially comfortable – can end up being a bad idea. When we don't talk to anyone, we can't let go of feelings – good or bad. We need to let off steam, ask questions, and get support. We have met many kids who did not talk to anyone. Some just did not know how to bring it up. They ended up feeling really stressed out, sad, and isolated from everyone. You deserve to talk it out with someone and to get the support you need.

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SCHOOL & PEERS

Is school a “getaway” for you – a place where you can just be a normal kid – without thinking about ALS?

Is school **STRESSFUL**? Do you *worry* about your *family member* while at school?

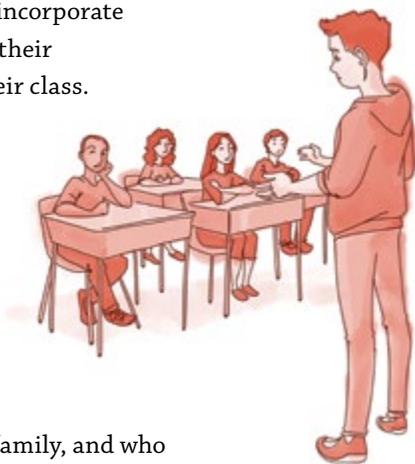
DEALING WITH ALS WHILE **AT SCHOOL**

Students told us what it is like to **LIVE** with ALS in the family, and try to live a “**NORMAL**” life at school. Some feel *isolated* from other kids who do not have a family member with ALS, while others feel loads of *support* and help at school.

Talking about ALS in school can be complicated

To find a balance, many students find a way to incorporate ALS into their school – primarily by talking to their classmates or presenting a report on ALS to their class.

When a 13-year-old who has a father with ALS was asked to present on ALS in his school, he was really nervous at first. He had not talked very openly in the past and did not know how his fellow students would take the conversation. But, after he talked it out with his teacher, he decided to open up to his class because he realized his fellow students really did not understand ALS and its impact on the family, and who would be better to tell them than him? In the end he was glad he did it. It actually made him feel better.



When we ask students about school and ALS, kids who had talked to friends and fellow students said talking was very helpful. Here is why:

- **YOU CAN TAKE OWNERSHIP OF ALS IN YOUR LIFE**, while talking with peers and school staff. By telling your story, you can help your peers better understand ALS and how it can impact families.
- **YOU HAVE THE POWER SHARE** as much information – or as little – as you feel comfortable.
- **BY GETTING OUT AHEAD** of any questions they may have or gossip about your mom, or dad, or grandfather – you get to start the conversation.

If you are thinking about doing a talk or a presentation – where do you go for information?

Ask *The ALS Association!* The ALS Association can be a valuable tool in providing information, details, and charts about ALS for you to use. You may also want to think about talking to your family member’s doctor or other health care professional about ALS, treatment, and dealing with ALS.

 What would it look like if you gave a presentation about ALS? Have you already done it? How can you help other students who might want to give a presentation about ALS?

Presentations also bring awareness

Some of the students who gave a presentation found out that their peers were really curious and actually wanted to do something about ALS! In fact, giving a talk in school has led to:

- **WALKS FOR ALS** – some of these have been conducted with the whole school getting involved.
- **BAKE SALES** – kids get to show off their cooking skills and raise money and awareness.
- **SPORTING EVENTS** – I have seen basketball tournaments, Frisbee, triathlons, and flag football – you name it! If it is sport, it can be done to help raise awareness and support for ALS!

Giving a presentation, creating a fundraiser, and raising awareness can be a lot of fun and a great way to engage the school, your peers, and your whole community. As a side benefit – it can also bring together families!

But.....

What if I don’t want to talk to teachers or others at the school?

It’s OK if you aren’t comfortable talking to teachers or school staff right away. In fact, many teens say they would never just go and talk to a teacher – it feels so weird to do that. If this sounds like you –write down a list of reasons or thoughts about why you aren’t ready to talk about it. Go back to the list after a few days or weeks and see if things have changed.

Some students have mentioned these reasons for not wanting to talk to people at school:



“...I feel like they wouldn’t understand”



“I don’t like talking about it at school and stuff because it just... I try not to...it’s hard”



Other students mention feeling separated from their peers and not wanting to be singled out. School is a place where you are a kid, a friend, a student – not a caregiver or someone who is an ‘other.’ It is tough to try and always explain to people what your home life is like.

The truth is, many, many students have home lives that are not necessarily “normal” for a variety of reasons. Talk about this with your family or a trusted friend. Maybe include the teacher to see what they think about it. It may be helpful.

Actually, if you think about it – what is normal? Everybody has something. You aren’t required to visit the school social worker or talk to your teachers about your family member with ALS, but it can be helpful to have the school know what is going on, so they can offer you support. School personnel are required to keep these conversations confidential, so you don’t need to worry about other students finding out about what you discuss in private. And sometimes it’s helpful to talk to another adult who isn’t related to you or involved in the situation.

Bullying. Bullies exist, and they target people for a variety of reasons: 1) they feel inferior about themselves; 2) they come from a tough home life, so they take it out on others; 3) they have been abused, so they abuse others; 4) they have a health issue themselves and don’t want to appear weak. Sometimes, kids who have a parent with an illness can be bullied. Some of your classmates and peers can be super supportive, but others can just be mean. Getting the story of ALS out there before someone has a chance to make fun of you, or your family, might be beneficial in helping everyone process ALS.



If you are being bullied, for any reason, talk to someone about it (teacher, parent, family, etc.). You deserve to not be bullied and have as many people as possible support you.

TALKING TO FRIENDS

 **“It would be nice just to have a friend who gets it, I mean about ALS. Someone who I don’t have to always explain everything”**

This 16-year-old is right on. We all need someone who understands us and gets what we are going through – including living with ALS in the family.

Friends are *super important* in your life. Some people have many friends, and others have a few close friends. Regardless of how many friends you have, they play a really important role in your life, helping you see the world in different ways, as well as understand how you fit in the world.

How do you talk to your friends?

Andrea, a 15-year-old, tells us how she can tell her friends everything. She “completely trusts them.” They know what’s happening, and how ALS has impacted her life.

Finding friends is so important – particularly at this time in your life. You don’t need a lot of friends; some people only need one. The important thing is to find someone to talk to who is your age. Many teens talk about how important it is to talk to someone their own age who makes them feel just a bit more “normal”.

This is definitely easier said than done. It’s not easy to put yourself out there to meet new people. Attending an event with your local ALS Association chapter is a good place to get to know other people who “get it.” Check in with your local chapter, or ask your parents.

 **How do you talk to friends? What are some options to figuring out how to talk to friends?**



BRADLEY

Bradley decided to talk to his best friend, Craig, about his dad's ALS diagnosis when they were riding their bikes through town. Bradley thought it would be a hard thing to talk about, but it helped that they were just riding their bikes like always – it wasn't like a scheduled, sit-down conversation, which would have made Bradley feel weird. Craig asked a couple of questions about what ALS was, and Bradley was able to share some of the information he had learned while at one of his dad's medical appointments. Craig offered to help Bradley with homework or taking extra notes if Bradley ever had to miss classes to help out at home. Bradley felt better after sharing his news and having someone else know what he was going through.



IAN

Ian decided to talk to a few of his close friends about his dad's declining health. They all knew his dad had ALS, and Ian was really open about it. But he had not talked about how bad things had gotten. Ian helps his family a lot during the week, and his mom has a respite worker come in on the weekends to help out and give them a break. Ian went to basketball practice and told them that things were rough with his dad's new meds and being up late to help his mom. His friends offered to help Ian with his homework and checked in the next week to see if things were better. It was helpful for Ian to have his friends listen and be supportive.



LARA

Lara has some really great friends, some of whom she has known her whole life. She and her friends are all part of the same, tight-knit community and know each other's families well. They go to the same community center and religious services. Her friends had heard that her uncle was having some health problems, but they didn't know it was ALS. Because of their shared community, they all understood that it can be hard to talk about things within your family – mostly because their families are the same way. They listened to Lara and were supportive, which made Lara feel less alone.

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CAREGIVING, OR WHAT IT'S LIKE TO HELP OUT A FAMILY MEMBER WITH ALS

BEING A CAREGIVER

“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.”

This 14-year-old helps take care of his dad with ALS. He has been doing a lot of things to help his dad, including helping him get dressed or move around from chair to bed. Sometimes he helps his dad bathe. Some people think of these kinds of activities as “caregiving” – but many kids, like yourself, think: Wait, I’m a caregiver? What does THAT mean?

Let’s see what **Ian** had to say about being a caregiver:

IAN

Ian was always a caregiver. Some of his earliest memories were picking things up for his dad, pushing his wheelchair and bringing him something to drink. It was just normal to Ian, the way their family was. He always knew about ALS. But over time, the caregiving became harder and took its toll. When Ian’s dad could not roll over, or get up from bed or a chair, Ian had to help his mom lift and move his dad – even in the night. Other times, Ian would have to get up and help his dad go to the bathroom, which was the worst. Ian would program his dad’s communication device and prepare special liquids for his dad. There were other people who helped – truthfully, his mom did the most and they had a part-time caregiver to help – but getting up in the night kept getting harder and harder. Ian started falling asleep in class, although he tried hard not to. He even ended up being late to practice. Although his friends knew about ALS, being a caregiver sometimes made Ian feel weird. It felt like he grew up too fast. Almost like he missed his childhood. He was not like other kids and had a hard time talking about helping his dad go to the bathroom with other kids, kids who did not have to help their dads go to the bathroom.



Adults, like researchers and health care providers, often refer to kids who provide care or assistance to someone as “young caregivers” or “young carers.” But that doesn’t mean you have to call yourself a “young caregiver.” In fact, you don’t have to call yourself anything – you can **JUST BE YOU!**

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

DID YOU KNOW?

In the National Family ALS study, almost 1/3 of families had a youth in the home who did things to help care for a family member.

Being a caregiver does not simply mean that you clean the house or your room (which of course you are doing, right????). Being a caregiver means that you are doing something to help or take care of another person, which may be a parent, or grandparent, or another family member. Here is a list of the things kids told us they do to care for a family member with ALS:

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



Some kids are caregivers, but not all the time, like **Bradley**.

BRADLEY

Bradley did not live with his dad, so did not feel like he was a real “caregiver.” He would go to his dad’s house every day after school and help him get around and fix dinner, but that was not really being a caregiver. He was just being a son to his dad. His sister didn’t do anything and barely even mentioned their dad. His brother drove his dad places and helped out with his dad’s finances. Bradley saw his brother as the caregiver, but not himself. One night, Bradley got a call from his dad at 1 in the morning. The windows were open, and it had gotten really cold in the room. Could Bradley ride his bike over and shut the windows? Bradley hopped on his bike and took care of the windows. It was hard to wake up, but knowing that he could take care of his dad – and that his dad had reached out to him – made Bradley feel so good about himself.



Still others, like **Lara**, are not currently doing anything to provide care, even though they want to help.

LARA

Lara does very little to help her uncle. Every time they go to his house, he seems to get worse. She wants to help and has, at times, helped him get around. But there are so many people hovering around him, that she does not do much. It’s OK, but she wants to feel like she is being a part of it and being a good niece. Everyone says not to worry, and that she is too young, but Lara doesn’t think so. She wants to help.

Bradley and **Lara** show us how caregiving is experienced in different ways. Just like ALS is different in all people, *being a caregiver is different as well.*



What other kids have to say about caregiving

Over the next section we are going to address caregiving and the different experiences by using the words of the people who participated in a study on youths and ALS.

They are all caregivers.

They told us what it is like to provide care and asked some really important questions about caregiving.

Here are a few of their questions and comments. Some might be saying exactly what you are thinking!



“It is really hard to talk to other kids, they just don’t get it”

Just like talking about ALS in general, it can be difficult to talk about something like bathing or feeding your parent with other kids. Caregiving is one of those topics that people don’t share – even adults!

WHAT CAN YOU DO? Even though it may seem embarrassing to do this, talk to your parents about youth programming through The ALS Association. If there is one place where other kids will “get it” – it is there. You are not alone in being a caregiver. While most of your friends at school may not get it – the kids who participate in youth programming and services from The ALS Association will.

“Sometimes I just want to be heard”

We are human, and we like to be told that what we do is good, or helpful. This includes being a caregiver. Kids tell us all the time how people ask about their mom or dad, their grandparent or loved one, but rarely about them. It is nice to be asked, and you should not feel bad about wanting to be acknowledged. One teenager said, “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.” This is a very normal feeling.



But how do you talk about being a caregiver?

1. **BE HONEST** – It’s OK to say how you feel about caregiving. Chances are your family member is a bit uncomfortable as well.
2. **WITHOUT ANGER** – This is important. You may be really upset, sad, or angry about it, but when you use anger it shuts everyone down. Think about how you feel, maybe write it down, then talk about it with a trusted adult or friend. They may be able to help you find a way to discuss caregiving without getting upset
3. **HUMOR** – Sometimes you just have to laugh – even when it seems like what you are laughing at is not that funny. Laughter can make a situation easier and can make people less worried or upset.

“What is it like for my family member to need care from me?”

This is a great question, and one that is really important to ask. Some parents say they feel SO PROUD that their child helps take care of them. They see you grow and mature – and take on responsibility, which makes them happy.

But some family members feel badly. They don’t want to make you feel stressed or worried, but sometimes they just need help. You may consider talking to someone like a teacher or social worker at school. Let them know you want to talk to your family but don’t know how.

THE BOTTOM LINE IS: TALK ABOUT IT! We know it can be tough. Everyone involved is worried about others’ feelings, but we also know that talking can help you feel more at ease with the situation. And it will probably help your parents feel better too. Here is what a 16-year-old had to say:



“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.”

“I guess I feel good and bad about it – not just one way”

Some people, no matter how old they are, feel good about being a caregiver. They want to help because it shows that they love and care for their family member. Providing care in any form is something that they can do at a time when there is not much else that can be done about their loved one having ALS. They feel they are giving back and they want to do it.

But..... It's important to realize that people also struggle with the care they provide. They may feel stuck and have a sense of duty to provide care, or they feel they cannot stop. They may feel that they are losing their childhood and are not like other “normal” kids.

Some kids are just angry. They are angry that they have to help, that their childhood has passed, that their parents are not always there for them as they have been in the past. It is tough to talk about these feelings, because people don't want to admit it, or they just want to look past them. But they are real – and you may feel this way.

What can you do? Think about how you feel and maybe why you feel that way. This is not always easy, so this is a great time to talk to someone about your feelings. It is NOT a time to shut down and avoid your feelings and people. These are the kinds of feelings that can create real problems later on. After your parent or loved one dies, you may feel regret that you were not there or did not talk to them. We don't want that to happen. You deserve to talk through your feelings and to come up with a plan to deal with them.

Here are some ways other young caregivers have coped with feelings:

1. **WRITE IN A JOURNAL** – all the feelings: good, bad, and ugly. Then put the journal down. Know that the feelings are there, but that you don't have to hold on to them.
2. **TALK TO SOMEONE YOU TRUST TO TELL THE STRONG STUFF.** Sometimes just being heard helps. Then go be with your family member – eat dinner, go for a walk or a ride, talk, watch a movie. Whatever it is, just be there with them

 What other plans can you come up with?



“I feel like I lost my childhood”

- ② What happens when you have to provide care for a loved one for a long period of time?
- ② How does this affect you as you grow older?

Many young caregivers describe feeling that they grew up too quickly because of their caregiving **RESPONSIBILITIES**.

Have you missed school functions, sports, or after school activities because you are needed at home? Sometimes you may feel like you know more about hospital beds than pop culture, which can make it *hard to connect* with friends or classmates who haven't had experience with caregiving.

Everyone needs *balance*. It's important for you to have an opportunity to hang out with friends, go to school, and participate in sports and school activities. It's OK to take a break from caregiving. Sometimes you need time to *take care of yourself*. Remember that your job is also to be a kid, not just a caregiver. One young caregiver gave us excellent advice:



“Don't, like, let frustration get in the way because like every moment counts with them. So, you just got to take a second, calm down and just remember that it's important. So, you've just got to keep things going forward.”

ASSISTIVE DEVICES AND ALS

“What is different about caregiving in families with ALS?”

We know children 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 often use assistive devices such as suctioning equipment, breathing machines, feeding tubes, or other adaptive devices.



“I feel embarrassed sometimes that my dad is in a wheelchair. Does that make me bad?”

Absolutely not. It is hard to make the transition to having your dad or mom look different or progress through ALS. In the youth interviews we conducted, many, many people said they feel “weird” being a caregiver and having a parent attached to various assistive devices. It can be tough because it does feel weird. Your family is different from other kids’ families, and this can feel really hard and scary. We like to feel similar to others around us, and it can be difficult to feel like you are somehow different or “worse” than other kids. It’s not unusual to feel that the devices your parent or family member with ALS uses are just too bizarre. People stare, maybe people say things about the device. It may be hard to deal with that.

But, one way to think about it is..... *how cool is it that these devices can help??*

What is cool about a power wheelchair?



What is cool about communication devices?

Those are really cool and can be used to create unique sayings or phrases using a computer-generated voice, or even your family member’s voice! During training and skill development programs, kids loved being able to program words or voices. They got to see all the amazing things the machine does. We showed these devices at a youth day event. Cara said her mom refused to use it, but Cara really wanted to know what the device did. So, she got to play around with it. This was exactly what Cara needed. She went home and told her mom to get one. She even said that she would help her mom program it. The next day, her mom called her local ALS Association chapter office and made an appointment to get a device.



We can’t take away ALS or the fact that you do things to help care for your family member. But, it is important to remember that your family member with ALS is *still the same person*. Whether they use a power wheelchair or communicate through a computer. Nothing about you or your family is “wrong”, “weird”, or “bad.” You are you, and your family is just different.

“Sometimes I don’t know what I am doing. I give my mom her meds, but I am not sure how”

- ② Do you do things to help out, but are not sure if you are doing them correctly?
- ② Has anyone ever talked to you about what to do?
- ② How do you get help?

Did you know 60% of kids who provide care for a family member living with ALS have never been told how to do it? Many said they just “wing it.” That can be scary. If you’re doing something to care for someone, but not sure what you are doing – **ASK FOR HELP!** It is OK to say, “I am not sure what to do” and get an adult to help you.

But what if you want to know how to do something better – or learn more? Your local ALS Association chapter is a good place to start! They can connect you with a Physical Therapist (PT), Occupational Therapist (OT), or other therapist to guide you and train you in what to do.

i Your parents and family members are figuring this out alongside you. They are trying to balance their emotions around caregiving with the needs of the family member as well as your needs and feelings. They may still be figuring out how to talk to you about caregiving. It’s important to remember that even if your parents have not approached you, you can approach them to start the conversation.

So, what about **Ian**, **Bradley**, and **Lara**? How did they get support with caregiving?

Getting Support Being a caregiver

BRADLEY

Bradley learned a lot by attending the youth day with his local ALS Association chapter. Being with the other kids, learning about caregiving and how best to help his dad – that made him feel like the other kids “got it.” He didn’t have to struggle to explain why he would get up in the night to close his dad’s windows. While at the session, Bradley was able to ask other kids how they did things to help their parents, and he learned how best to help his dad move from chair to chair. (He found out he was doing it all wrong!)

IAN

Many people never even asked about Ian being a caregiver. They all assumed his mom did everything, even though Ian had been providing care for his dad for as long as he could remember. People would come to the house and talk to his mom about caregiving, assistive devices, and what his dad needed – but they never asked Ian. When people would find out he helped with the care, they usually didn’t say anything. It was like they didn’t know what to say. He was frustrated. Even when he answered their questions, they still didn’t see him as his dad’s caregiver! Ian finally talked to his mom about how he was feeling. She was very understanding and said that some people just assume that kids never provide care for an ill parent.

Ian worked with his local ALS Association chapter to help develop support programs for kids like him. He made sure that discussions included caregiving, and how to talk to and support young caregivers.

LARA

Lara sees that caregiving is a normal thing for all family members, even though her family is still resistant to let her provide a lot of care for her uncle. Everyone pitches in – from oldest to youngest – and no one acts like it is something weird or strange. Her family is still very sad and doesn’t talk about the disease a lot, but everyone does something to help. Lara recently started assisting her uncle with his foot exercises. She enjoys working with him and thinks she may be a physical therapist one day. Even though it is hard, she talks to her family about all the things she is learning and how best to exercise her uncle’s feet and legs.

i **Being a caregiver is tough – and can be really lonely when no one recognizes what you do, which was the case with Ian. Making sure you talk about caregiving and seek the support and education you need – like Bradley and Lara did – is important. Families are not perfect, especially when they have an illness like ALS. But they are just the way they need to be!**



CHAPTER

WHEN SOMEONE DIES: GRIEF AND LOSS

TALKING ABOUT DEATH AND DYING

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

This is a *tough* topic. We don’t know many people who like to talk about this subject. Most people run far from it. But what we know is how *important* it is to talk about loss and express **YOUR FEELINGS**, because this can be a really difficult time.

You and your family deserve to talk about how things are **CHANGING**, what the loss of your family member will look like, and what do you do after they are gone. Pushing these feeling down can only make things worse – sometimes many years later. So, having *honest* open conversation now is *so important*.

What do you ask? What do you want to know? Everyone has questions, including young caregivers like you.

- ① What will the death look like?
- ① How will it be handled?
- ① Will my parent remain in the home?
- ① Can I be present during the death?
- ① What will happen to me when the death occurs?
- ① What will the services or funeral look like?
- ① What supports are in place?
- ① Where will we live after the parent dies?



Do any of these questions sound familiar? You may not have wondered about all of them. But I bet you wondered about at least one. These are very important questions because they help you and your family process the next steps and how things will change.

Let’s get back to **Bradley**, **Ian**, and **Lara** to see what they are thinking:

BRADLEY

Bradley was really freaked out because his dad's ALS was progressing so fast. It had been less than two years since the initial diagnosis, and his dad couldn't do anything for himself except open his eyes. The doctor had said that the disease can progress quickly, but Bradley wasn't ready for so many changes. His dad's breathing was bad, and they had to use suction quite a bit to keep his airway clear. Bradley had so many questions – even his sister was opening up and wondering what was going to happen. They have a part-time caregiver now, but it does not seem like his dad will be around much longer. **IF YOU WERE BRADLEY, WHAT WOULD YOU DO?**

a) Talk to your friends. ➡ Turn to page 60

b) Talk to a trusted adult (parent, teacher, coach). ➡ Turn to page 61

c) Don't talk to anyone. ➡ Turn to page 63

IAN

People assumed Ian had accepted his dad's disease and the fact that he was slowly dying. His dad had ALS for so long, it was just a part of their lives. But it was very hard for Ian, because he knew about ALS, but not much about what it meant to actually lose his dad. Ian's dad had progressed so slowly that it was almost like they forgot he would die of the disease. But then his dad got really bad and needed full-time care. Suddenly it was right in front of them. Hospice was brought in, a huge bed was put in the living room, and all these new people came and went. It was super overwhelming.

IF YOU WERE IAN, WHAT WOULD YOU DO?

a) Talk to your friends. ➡ Turn to page 60

b) Talk to a trusted adult (parent, teacher, coach). ➡ Turn to page 62

c) Don't talk to anyone. ➡ Turn to page 63

LARA

Even though her family never talked about ALS, they always talked about death and dying – which may seem odd. It was like they jumped right past the diagnosis, care, and treatment and went right to the fact that he was dying. Lara thought this was cultural, since her culture was pretty focused on death and dying, but it still seemed strange and made her feel like it was an incomplete story. She needed to talk it out.

IF YOU WERE LARA, WHAT WOULD YOU DO?

a) Talk to your friends. ➡ Turn to page 60

b) Talk to a trusted adult (parent, teacher, coach). ➡ Turn to page 62

c) Don't talk to anyone. ➡ Turn to page 63

GRIEF

Many people your age have not yet had to deal with the death of a close loved one. You may feel that your friends will not understand what you're going through, or this may be the first time that you've experienced intense grief – and that can be scary.

Grief takes on different forms. You might cry and become very sad or depressed. Or you might take on an adult role – becoming the 'man' of the house, as was the case with Bradley's brother, Andy. You might go into denial and even lash out, or engage in risky behavior. These are normal emotions and responses – but it is *important to acknowledge your grief and work through it with the help of others*. The National Alliance for Grieving Children (WWW.CHILDRENGRIEVE.ORG) is a wonderful source for support and guidance on how kids deal with grief. Below is a discussion from the Alliance of important things to know about grief:¹

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:

- The loss of childhood
- The loss of the relationship between the family member and child
- The sense of “normalcy” is disrupted when someone is diagnosed, but also when the disease progresses and things change.
- Each time a new symptom, or a progression of a current symptom occurs, that is a loss for the person with ALS and for you. As each loss mounts, the relationship changes and may leave you confused, sad, and grieving.
- There can also be a sense of anticipation or expectation of the loss and the eventual grieving process.



“Things are so different, I feel like I lost them, but they are still here.”

This feeling is called anticipatory grief. It is difficult to describe, but basically even before your family member dies, you are experiencing loss. The losses include loss of the parent’s voice, hearing your dad’s funny jokes, playing with your grandfather, or going for long walks with your stepmom. **THESE LOSSES, WHILE SOMETIMES OVERLOOKED, ARE A VERY REAL PART OF THE PROCESS AND NEED TO BE ACKNOWLEDGED.**

“[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.”

She is grieving the loss of her mother’s voice while her mother is still living. In effect, she is mourning the loss of what she knew as her “normal.” Her mother will eventually die, but the most important loss right now is the loss of the voice and the relationship attached to the voice. It is important to acknowledge incremental losses and anticipatory grief.

- ❓ How do you feel about the changes and/or progressions in your family member’s ALS?
- ❓ What are you grieving the loss of?
- ❓ What do you miss about your parent or loved one with ALS?

These conversations can be emotional and difficult. It’s important to know that your family member with ALS is also sad and grieving – and it can be helpful to share your feelings with one another. You may find it helpful to talk with a social worker, clergy, or mental health therapist to guide you through the process and find supports for working through the anticipation of death and loss.

When someone dies, you will be sad, angry, relieved, numb – any number of feelings.

These are all grief. Here are a few things to know about grief.

GRIEF IS NORMAL

- The sadness of losing a family member does not just go away. It takes time, and during this time you will miss them in your own way. You do not ever “get over” a person’s death, but you can learn to live with the reality.
- Grief is not a problem we are trying to fix. It’s an experience you live with. A 16-year-old talks about how her mom died when she was 10 years old, but that even now — six years later — she misses her and cries sometimes. This is totally normal. Just like your family adapted to having ALS – the “new normal” — you are now adapting to the loss of that family member. Another “new normal.” Take the time to work through it and always, always talk to someone about it.

YOUR GRIEF IS YOURS AND MAY BE VERY DIFFERENT FROM SOMEONE ELSE’S

- Just like your relationship with the person with ALS was different than anyone else’s, so is the way you feel after they die.
- Some children have a need to talk about the person who died and their feelings. This is perfectly fine. You can always talk about them – forever.
- Others might not talk about the person at all.
- Others might express their grief through art, play, music, or writing.

❓ How do you express grief? Do any of these sound like something you would do?

GRIEVING CAN MAKE YOU FEEL ALONE AND MISUNDERSTOOD

- Sometimes adults avoid talking about the person who died for fear that doing so will make you feel worse. But, if they do this, it may make you feel as though talking about, or even expressing your grief, is not acceptable.
- 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.

You feel grief at different times throughout your life

- Many times, intense feelings of grief will *last longer* and come *more often* than we think they should.
- **GRIEF IS A LIFELONG EXPERIENCE.** You will experience grief on different levels and at different times throughout your lives.

When you get your driver's license, score a touchdown, go to prom, or graduate from high school, you might think about that person you lost in very intense way. This extends into adulthood as well. My father died 14 years ago. Every time something major happens, I think of him and am so sad he is not here to see me. I can smile and know he would be proud, but that doesn't stop my grief. *Grief has no time limit.*

- Sharing your feelings openly can help to normalize this experience and help you find ways to deal with these powerful feelings that will come and go — and come back again throughout your life.

Grief sometimes is positive and can help you grow

- You may not feel it now, but it can happen. Going through really, really tough times can make us grow as people. It does not take away from the sadness, grief, and loss, and it does not mean the loss was a good thing. But, going through this may make you feel more compassionate toward others and even value the importance of good friends in a way you did not before.

GRIEF IS NORMAL AND CAN LAST FOR SOME TIME. Grief comes and goes, but it changes and lessens over time. But, sometimes grief becomes more than that, and it affects everyday life and impairs you. Everyone – no matter how old they are — can experience this type of grief, called *complicated grief*. Complicated grief may include the following:

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

If you are experiencing any of these, don't hesitate to address it and *get help*. In addition to The ALS Association, your school, your religious home, a therapist, and many others in your community can provide support to you and help you move past the complicated aspects of grief while acknowledging that you may still grieve. **YOU DESERVE** to talk it out and get support. *You can get through this time.*

Support Groups & Advocacy

After the person with ALS has died, support groups may be *helpful* to you. Support groups at this stage should address 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 on supporting you and your family. If you think a group would be good for you, check in with your *local ALS Association chapter*. They may have a group or may be interested in starting one.

References

1. 8. National Association for Grieving Children. Retrieved 12/2/2016 <https://childrengrieve.org>

YOU MADE IT!

Wow! That's it. We packed a lot into this book. We wanted to make sure we addressed everything, but I am sure we left some things out. If we did, check in with your parents or your local ALS Association chapter to get your questions answered. It may not always feel like it, but *people care*, including adults and friends.

Reach out and talk.

OR JUST HANG OUT.

Get the **SUPPORT** you *deserve*.

Option A: Talk to your friends



BRADLEY

Bradley decided to talk to his best friend, Craig, about his dad dying. He knows it is close, and he needs to tell someone. At first Craig was real quiet, which made Bradley feel stupid. Then Craig told Bradley he didn't know what to say. He wanted to be a friend but had never lost anyone, so he was scared to say the wrong thing. This actually helped Bradley because it showed he was not the only kid who did not know much about death and dying. Then Craig started asking a lot of questions – many of which Bradley couldn't answer. But hearing Craig ask them was also comforting. It helped Bradley think through some of his own questions and figure out how to ask his mom about these things.

[↪ Go back to pg 53](#)



IAN

Even though Ian had good friends, he decided to talk to his older, 19-year-old cousin, Steve. Steve lost his dad to a car accident several years ago, so he knew what it felt like to lose a parent. Ian asked if Steve would tell him what it was like when his dad died and what they did next, since Ian felt so completely overwhelmed. Steve was really helpful, letting Ian know it will be different for him, but that what he is feeling now is pretty common. Even though Steve's dad had an accident, he did not die for almost 6 months. Steve felt the loss of his dad even before he died, which is exactly what Ian is feeling. Ian feels bad even being in the same room with his dad because he is not his dad, or not like he has always been. All Ian can think about is what he is losing, which makes him feel guilty. Steve assures Ian that is OK – and that he felt the same way.

[↪ Go back to pg 53](#)



LARA

Since her family is so open about death, Lara talks to her cousins a lot. But what Lara really wants is to talk to friends about other things – not to ignore that her uncle will die, but to make her feel more like a kid. She has told her friends but let them know that while she is OK talking about it, she does not want them to treat her differently. She wants to be a normal kid and get away from it every now and then.

[↪ Go back to pg 53](#)

Option B: **Talk to a trusted adult**



BRADLEY

Bradley talked to his mom, which was scary for him. His mom has been sad and crying, but also not very available to talk to Bradley about his dad. Bradley was nervous but just asked what will happen next. He was surprised to know his mom had been thinking about it a lot and wanted to talk to Bradley and his siblings, but she did not know how. Bradley felt major relief. They talked about how scary it was and how much was unknown. His mom let him know she and his dad had talked, and she knew what his dad wanted. He did not want to stay on life support machines, and his mom wanted to make sure he was comfortable. Bradley understood this because he thought he would want to do the same thing. His mom told him all the conversations she had with his dad and encouraged Bradley to talk to his dad as well, even though he could not communicate back. She helped Bradley understand how important it was to feel sad, to know what a loss it will be when his dad dies, but to be with him as much as possible.

[↩ Go back to pg 53](#)



IAN

Ian asked his mom: what will happen next? Since his dad had such a long trajectory, it was hard to answer. She felt it was getting close but could not say for sure. She encouraged him to keep talking about it and said she would do her best to answer as many questions as possible.

Even though they had lived with it for so long that they thought they knew everything, they actually never talked about death and dying. Ian told his mom he felt like his dad was gone, even though he was still there. His mom felt the same way. They were grieving before he died. Ian asked what they would do when he died, since they were always so focused on his dad. His mom said she actually did not know but that she was thankful they could figure it out together, and he was thankful that he'd reached out to start it.



[↩ Go back to pg 53](#)

LARA

Talking about death and dying was oddly normal in her family – except when it came to talking to her mom. She still cried all the time and could barely talk about her uncle. Lara desperately wanted to talk to her mom. What would she do when her uncle died? Would her mom ever get over it? Would Lara have to step up and be the mom to her sister? Lara was starting to freak out, so she went to her school counselor. The counselor had heard about Lara's uncle but had never talked to Lara about it – instead letting Lara come to her. Lara told her all about how her family barely talked about ALS but was so weird about death. About how her mom cried all the time and Lara's fear that her mom would never recover. The counselor was super helpful – mostly because she just let Lara talk, which felt good. Also, because she was not in Lara's family or community, so Lara could say what she wanted without it getting back to her mom. The counselor helped her create some discussion scenarios with her mom and lots of "what ifs." This was super helpful. Lara decided to go home and start talking to her mom....

[↩ Go back to pg 53](#)

Option C: Don't talk to anyone

Not talking may be easier, but in the long run, it causes the most problems. Let's see what happens when our youth don't talk about ALS



BRADLEY

Everyone in Bradley's family was pretty freaked out. He wanted to talk but did not know how. He decided to just go on as usual, ignoring what may happen. He was not sleeping and even started to ignore his best friend, Craig. Bradley knew what death meant – the finality of it – but was starting to confuse the details. He was reading a lot online, but without anyone to talk it through he was not sure what to believe.

[↩ Go back to pg 53](#)



IAN

Ian knew that his dad was dying — and he just went with it. He did everything he was supposed to do and did not ask any questions. He felt like he needed to “grow up” and be the man of the house, even though he felt unsure as to what would happen next. His basketball coach kept checking in, but Ian said he was “fine.” Even though the coach was pretty sure Ian was not fine. His concentration was off, and he had to sit out a game because he missed so many practices. His dad was dying, and Ian felt so alone.

[↩ Go back to pg 53](#)



LARA

Despite the fact that her family was open to talking death and dying, Lara did not want to talk about it. It made her sad to think that her uncle would not be with them one day, and there was nothing she could do to prevent that. Her mom preferred not to talk to Lara about it, and she didn't like discussing the topic with her friends. She just wanted to be a normal kid. Lara tried to hide her feelings and not think about what would happen when her uncle died. But she was struggling in school and having bad dreams at night.

[↩ Go back to pg 53](#)

About the Authors

Dr. Kavanaugh is a licensed clinical social worker (LCSW) and associate professor of social work. She has over 15 years' experience in practice and research with families and youth living with neurological disorders. She has published and presented widely in the role children and youth 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 U.S. and international organizations to develop evidence based supportive and educational programs for young caregivers and their families. Dr. Kavanaugh holds an MSW from Washington University in St. Louis, and a PhD in social welfare from the University of Wisconsin-Madison.

Megan Howard, MA is a research program coordinator at the University of Wisconsin-Milwaukee (UWM). Megan is trained in psychology and child development, and has spent years working on research projects involving children and families. She is currently working with Dr. Kavanaugh on the development of training programs for youth caregivers.

Illustrated by **Phil Gosier**.

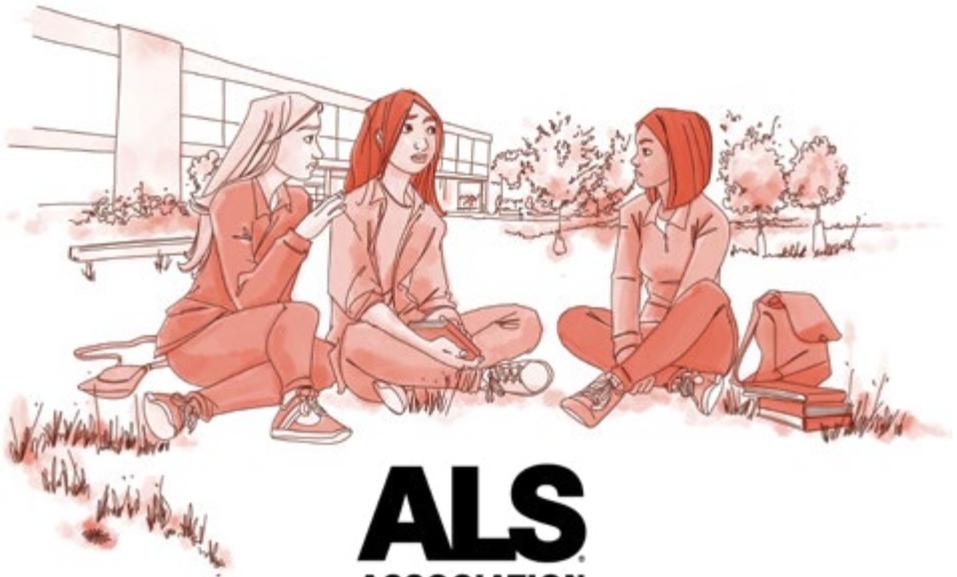
Thank You

We're so thankful for the young people who shared their stories and gave their time to help create this book. Other books in the informational series for kids and young adults include *Real Kids Talk About ALS: Feeling Normal, Sad, and Different* and *School, Friends, Work, and ALS: A Young Adult Guide to Balancing Life with ALS*.

The ALS Association is the only national nonprofit organization fighting ALS on every front. The Association's mission is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

For more information, visit www.alsa.org.





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