Melinda S. Kavanaugh, PhD, MSW, LCSW | University of Wisconsin-Milwaukee

School, Friends, Work, and ALS:

A Young Adult Guide to Balancing Life With ALS

ALS ASSOCIATION

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.

Why this book?

Being a young adult is a huge transition – going to college, moving away from home, partnering. Add ALS to the mix and it can be overwhelming and lead to stress and confusion about what decisions to make.

This book draws on current research and clinical practice to help address some of the confusions and stress inherent in becoming an adult while living in a family with ALS. Specifically, much of the data and quotes come from a national study of families and ALS conducted by the University of Wisconsin-Milwaukee, with support from The ALS Association. The case examples are interviews with young adults who are currently living with ALS in the family.

We wrote this book because there was nothing else out there for young adults that addresses the topics and challenges discussed in this resource. Young adults often get lost in the discussion about families. Are you still a child? Are you an adult? How do you move away from family and start your own life when ALS is present? What are your responsibilities? We put this book together using actual young adults and their stories to help start the process to provide support and guidance for young adults like yourself.

The book is also a support resource for professionals assisting with families affected by ALS, as well as for family members to get a sense of what it is like to be a young adult in a family impacted by ALS. A key theme throughout this guide is communication—how to do it, maintain it, and include it in everyday life.

What is included in the book? This book is part of a series of guides for children, youths, and young adults in families with ALS. Each book uses clinical expertise, research findings, and one-on-one interviews – so lots of data and knowledge. But it is not comprehensive, or meant to be the final answer to every question concerning families and ALS. Indeed, we anticipate more questions over time – particularly as children, youths, and young adults feel more comfortable and open talking about ALS. We hope families like yours use these guides as a reference for questions encountered in engaging with and supporting children and grandchildren.

This book was not a singular process. The young adults in this book are real and graciously shared their stories, the good and the bad, of living in a family with ALS. All the pictures in the book are of real families living with ALS. For the stories of the young adults, and the pictures of the families – we are grateful. We hope by reading this you and your family find support, suggestions, and comfort in knowing you are not alone in this journey with ALS.

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Helen Bader School of Social Welfare
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Hope For Karie
Together We Fight
Against A

Table of Contents

> "When someone gets diagnosed, the doctor looks to the spouse and gets all the treatment and guidance. It is like they assume that *you as the youth are too young* – must not be involved in the progress and part of it. But, if you leave the youth out they are *excluded.* They need to be told about ALS and how important they are and recognized."

22-YEAR-OLD LIVING WITH A PARENT WHO HAS ALS

1

ALS

The Facts, Case Examples and Talking with Family and Friends

Young Adult Cases

The book is structured around several young adults and their stories.

We follow each young adult through discussions about ALS with their family, friends, caregiving, role of school and work, and finally discussions around death, dying, grief, and loss.

Each section is labeled, so feel free to stop and start as you feel ready to read over each section.

Three different stories.

Three different ways to think about, talk about, and live with ALS.

We will follow each of these young adults throughout the book, showing the variety of ways they deal with ALS.

Manouk, 22

mother with ALS

Manouk was 4 years old when her mother was diagnosed with ALS. As she will tell you, “that is all I ever knew.” Her experience with ALS spans her entire childhood and into adulthood. Her family talks about ALS openly and naturally. It is part of their normal routine. It is not uncommon for the family to frequently discuss whether treatment or therapy needs have changed, based on disease changes and progression. In fact, Manouk often goes with her mom to get a new chair or to the special dentist.

Anissa, 21

grandfather with ALS

Anissa comes from a tight-knit family, where all members live within a few blocks of each other. Her grandfather was diagnosed with ALS when Anissa was 15. Everyone was worried, since no one in their family had ever been diagnosed with a disease like ALS. His ALS progressed pretty slowly at first. They all got into a routine of “checking in” on grandpa, since he didn’t require much additional care. Then, when Anissa was a senior in high school, her grandpa started declining rapidly. Anissa and her family are an example of a large but close group, who do not necessarily talk about ALS.

Not everyone’s ALS story spans such a long period of time. Sometimes the disease presents itself when other family members are in their teens and progresses rapidly.

But what if your family member had ALS, and you wanted nothing to do with it?

James and Brittany, 18 and 19

father with ALS

James and his sister Brittany live with both their parents, and their father has ALS. He has had ALS for some time, but recently his health has declined and, as a result, the additional caregiving has become a stress on the family. Both siblings just want a normal family and feel “imposed on” by the existence of ALS.

This section is a brief primer on what ALS *is* and *is not*. This section is in the resource guide, "*What is ALS*" published by The ALS Association. It is part of a full series of guides on ALS titled, "*Living with ALS*", and is a great resource. If you want more information, contact The ALS Association, or go to www.alsa.org to read or download a copy.

If you feel confident you know about ALS, feel free to skip that section. But you never know- there is some confusing information out there about ALS. So we went straight to the experts to guide us.

What is ALS?

ALS is a motor neuron disease, or MND. This is a better description of what happens in the body.

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 kinds 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 MND’s?

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 to the body?

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.

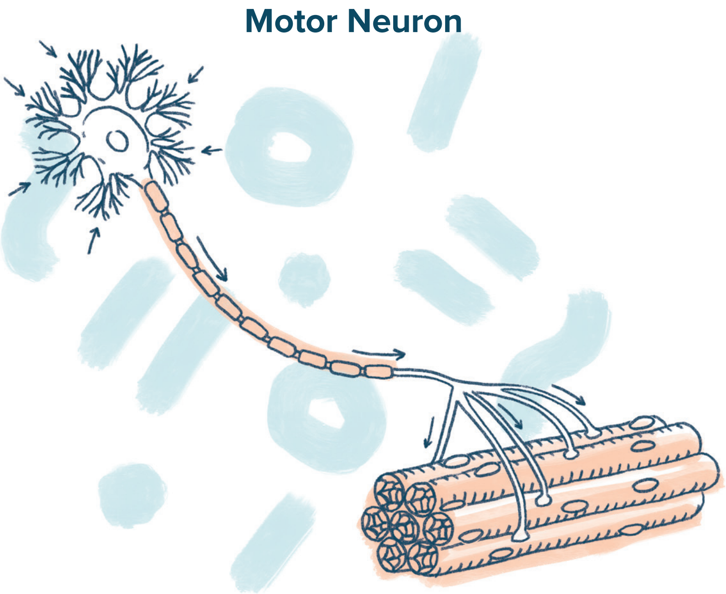
All body movements require nerve cells in the brain and in the spinal cord. These nerve cells are called motor neurons, and they control our muscles. The brain sends signals to the appropriate nerve cells in the spinal cord that control the muscles in the arms, legs, and feet, for example, to perform 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 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 atrophy, or shrink without an axon (see figure below). 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.



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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.

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 (e.g., parents, siblings, grandparents; 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 (medical term: paralysis) of all muscles in the arms and legs, and the muscles of breathing, swallowing, and speaking. Some people have severe weakness of one area, but little in others (e.g., unable to swallow but still able to walk and drive), but other individuals may demonstrate a similar severity of involvement of different areas.

For some people with ALS, the disease progresses very slowly; for others, the progression happens 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 (medical term: bulbar) involvement have a shorter life span due to the problems with loss of function in this area, such as breathing and swallowing. It is also generally true that the spread occurs from one body part to the next. 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 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 talk to the doctor. That way the doctor may be able to treat the symptoms and prepare you for upcoming changes.

The body changes – often drastically. 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 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, and arm and hand weakness, which impacts the ability to feed oneself.

Is there a cure?

Unfortunately, there is no cure for ALS. Yet. 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.

Talking About ALS

Not the easiest thing to do.

Everyone has different communication styles, and families have different expectations for how they share information.

Talking with family

The initial discussion is not an easy conversation. ALS can be very difficult to discuss, and families do not often know where to start. The time of diagnosis can be extremely stressful and scary for everyone involved. Many persons diagnosed with ALS are coming to terms with their own diagnosis and may fear crying or being overly emotional in front of you – and you in front of them. 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.

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 affecting the family as a whole, not just of a person, it helps to assess how to discuss it with the family.

But, not everyone wants to talk about ALS – including you. At some point you have to talk about it, as hard as it is. But in figuring out how to talk, it is very important to stop and take a moment to think about you and your family:

How do you normally talk about things?

Are you an open, sharing family?

Do you keep things "close to the chest"?

Manouk's Story:

Open talkers – the family who shares

Manouk's family has lived with ALS for a long time, so they have a history of figuring out how to talk about it. They went through many ups and downs, particularly when the disease would progress. When she was a teenager, Manouk used to avoid the conversation and go to her room. It felt like ALS was *everything* in the family. Her family would have discussions (not always Manouk's first choice), but these conversations created an atmosphere of openness where members could ask questions and voice their feelings.

Just because Manouk's family talks about ALS does not mean she has had an easy time with it.

Her biggest struggles have to do with caregiving, which is a huge part of her life. We will check back in with Manouk when we discuss caregiving in the next chapter. You can skip there now if you want to dive right into the discussion of being a caregiver with ALS.

Turn to page 40

TAKE AWAY

"Open talking" means you can ask questions, even if they seem scary or uncomfortable. Questions may include:

How does it feel to have ALS?

How do you feel as a young adult living with a parent or family member with ALS?

It's critical in these types of conversations to be honest, but kind. Be respectful of others' feelings while sharing yours. These are not always easy balances.

Not all families are at this place, and certainly not right away. It can take time to get to a place of open conversation. Just like Anissa's family.

Anissa's story:

When your family doesn't (or won't) talk about ALS

Anissa's family is very tight, but that doesn't mean that they talk. When you ask Anissa about this, she talks about her Hispanic culture dictating how family members discuss issues. First, it is a very hierarchical family. The older family members take the lead in the family – which, in Anissa's case was tough, since it was her grandfather diagnosed with ALS.

At first, no one said anything. Absolutely *nothing*. In Anissa's words, *"All I knew was he had ALS and we were not to say anything beyond that. I respected my grandfather, so would never ask, but I really wanted to know and talk about it. Definitely a generational thing"*.

Anissa talked to her parents, who were pretty distraught. They also did not ask the grandfather. All this not talking was creating an extremely isolating experience for Anissa and for each family member. Since they all lived so close and saw each other every day, it was almost too much to handle. Anissa decided to reach out, beyond the family.

Talking to other people

Anissa decided to talk to the school social worker. Because the social worker was also part of the Hispanic community, Anissa felt she would get the whole picture. Anissa says these discussions saved her, as she had someone to share her fears and worries about her grandfather. The social worker listened and let Anissa get emotional, which was extremely therapeutic as she could not express those feelings with her family.

When it came to details about ALS – disease progression, symptomology, etc. – Anissa told the social worker she was doing some online research. The social worker cautioned her not to believe everything she read, as some people post false information online. **This is very important advice.**

As a young adult, you grew up with the Internet and social media. You know how to use it and may even feel more comfortable using an online platform than talking to someone face-to-face. BUT, in the words of Anissa, *"Don't be afraid to reach out. But be careful where you research because that can get really scary really fast. I'm an over researcher and I found that out. The social worker told me not to do that, but I do anyways. It is not the best way, so don't be afraid to reach out to people."* **Be very wary of the Internet.**

If you do Internet research, make sure it is a credible source, such as The ALS Association. Take notes of questions you may have and follow-up with your local chapter. They will be the best and first resource for detailed questions about ALS.

> “Make sure you build your support system early.”

This is advice from Anissa, after seeing the social worker, and it is critical. Whether your family is open, like Manouk’s, or closed, like Anissa’s, **you need and deserve support as soon as possible**. If you are struggling like Anissa to get answers from your family, think of someone you trust and talk to them. Also, reach out to The ALS Association chapter in your area. It may seem like they are just there for the person living with ALS, but actually they are there for the whole family. The earlier you reach out for support, the better.

Also – friends. We will get to them in a later chapter when we talk about school, but you can jump there now if you want. School and friends take on a very different role the older you get, especially young adults like you who may be just starting college. ***Turn to page 49***

James and Brittany’s story:

When you really, really don’t want to talk about ALS

So, let’s talk about James and Brittany. They are like many, many young adults, with or without ALS in their lives. Talking about feelings is just not what they do. Then you add ALS into the mix and it gets super tricky. James actually talks more than Brittany, but not much.

Teens and young adults are often viewed by adults as selfish and self-absorbed. They walk away from conversations and lock themselves in their rooms for hours on end. Sometimes youths see this in themselves. Manouk, when talking about her teen years, described herself as “egocentric” and had more problems because the family did not understand each other. Teenagers see things from their own view and often feel “put upon.”

To be honest, this is a pretty typical trait for teenagers. Developmentally, your teen years are the time when you figure out who you are as a person and where you fit in the world. To outsiders, this can be seen as only caring about yourself, when what is really happening is a sense of confusion and being overwhelmed with the world around you. With the advent of social media, this is perpetuated by older generations who were not raised by constant interaction with others and discussions about what you eat, where you go, and what you think – daily. It can make for a stressful home life and difficulty connecting teens and young adults with parents and grandparents. Even families who have had very close relationships in the past can go through this. Again, it can be very normal. What is important is that you, as the young adult, and your family find a way to communicate. The last thing you want is to build a wall between you and your family with no way to break through. Here are a few questions to think about:

What is going on when you don’t want to talk?

Are you hiding from something that is so painful you don’t know what to think?

Are you avoiding potential next steps and progression – what comes next?

Or are you saying you just don’t care?

Process these questions whether alone or with a family member or friend. You deserve to know where the feelings are coming from and how to deal with them. Here is a story of someone who did not process or reach out for help. We will call her Wendy.

Detour discussion - Wendy

Several years ago, I worked with a family affected by another neurological disorder, Huntington's disease (HD). Wendy was a caregiver, sister, daughter, and student. Having lived with HD for many years, she was "done." She wanted to *"put her mom in a nursing home and walk away."*

Now, that may seem harsh, but let's break it down:

1. ***She has lived with HD for many years*** – much like James and Brittany living with their dad with ALS, yet she did not feel heard or supported, particularly in all the tasks she did as a caregiver (much more on this in a bit).
2. ***Wendy did not reach out to school staff or social workers*** – and they, in turn, did not reach out to her. She felt like her friends did not "get it," and her father was so absorbed by her mom's illness that she felt no one paid attention to her. So, her logical conclusion was to put her mom away – as the old saying goes, "out of sight, out of mind."

Of the things we have talked about –

1. ***Early support*** – These are diseases affecting the whole family – not just the person with the diagnosis. All members need to be included, educated, and supported as early as possible. Knowing she was not alone and had someone outside the family to talk to might have helped her process and deal with HD. Having school staff and friends of the family reach out to her would have been extremely helpful. We know how hard it is to ask for help, so adults have to step up to the plate.

NOTE: We discuss how to help adults talk about ALS in the adult family guide, Families and ALS: A Guide for Talking with and Supporting Children and Youths. If your family has not read it, you can get a copy on The ALS Association's website, ***www.alsa.org***.

what might have helped her?

2. ***Talking*** – Her family was not really open at the beginning. Her parents wanted to "protect" her and keep her "as a kid." What this did was isolate her and her sister to the point where she began to resent her mom just for having the disease. Her family needed to have shared with her from the beginning – making sure what they shared was appropriate for each age and stage of development. That way, she would have known what was happening and had the chance to talk (or not talk) all along the way.

3. ***Maintain the family*** –It's important to make sure the family maintains the family. This means everything should not solely be about the person living with ALS. It can be tough, but when I talk to adults, I strongly encourage them to do things they used to do – camp, movies, etc. Adapt, but maintain.

So, how does Wendy apply to James and Brittany? From their mom's point of view, they shut down and checked out. They are angry and only focus on themselves. They don't want to do things with their dad, and mom feels they are losing out.

Here is what they have to say: James says he tries, but it is hard to talk with their mom, who always has the answers and does not seem to listen to them. He was really close with his dad. To think about him not being here, or not being the same "dad" makes James want to shut down. He prefers being with his friends, who know little about ALS. He says it is not that he doesn't care, but that *"it is too much."* When asked, Brittany says much the same, except that she does not want to get stuck with the care because she is a girl. She and her mom never really got along, and now it is worse because she feels like she can't do anything right. When asked, Brittany says she *"hates ALS."* She adds: *"I mean, our family wasn't perfect before, but with ALS, it is bad."*

Case Family Follow-ups

Anissa went back to her family with her online research and having practiced several potential conversations with the social worker.

Her family was surprisingly responsive, but not her grandfather. He was upset that everyone was “talking about him.” While it initially upset her grandfather, it was extremely helpful in getting the rest of her family to talk about ALS, since they were all thinking similar things but did not want to come across as disrespectful. Nothing changed overnight. In fact, it took quite a few conversations to get the family on the same page. Eventually her grandfather would talk about his ALS and came to see Anissa as the point person for ALS in the family. These conversations became critical as time went on, particularly when it came to caregiving.

James and Brittany struggle.

The family is very involved with the local ALS Association chapter, and the parents talk to others all the time about ALS, but they still feel frustrated with their kids. James has tried to reach out to his dad more. He even told his dad he would miss him. To James, this was a big breakthrough. Brittany seems to get worse, even talking less to James about it. They used to share time together, talking to each other about it. Now she doesn’t even talk to James. Their mom reached out to a care coordinator and they are planning a “family meeting” soon.

> “If something does not work out or
> you have trouble, say it.
> It does not need to be perfect.
> Talk it over.
> Don’t try to be perfect – you are not a
> professional, you are their child.
> Accept how things are right now.
> If it takes longer, it is OK.”

MANOUK

2

CAREGIVING

The Good, the Bad and the Regrets

Young Adult Caregiver

What does it mean to provide care for a family member when you are "launching" yourself – when you are graduating high school, going to college, and maybe even starting a family of your own?

First, know that you are not alone.

This may seem simple, but over the years I have talked to many, many youths and young adults who genuinely feel that no one else does what they do. This is because there is so little support for young caregivers.

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 support the young caregiver and the person living with ALS?

What do teen and young adult caregivers do?

Teen and young adult caregivers 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 youth and young adults.[1] This care can be daily or weekly, but it often entails many hours a day. While young caregivers provide care beyond simple household chores, they are also still involved in these tasks and their typical responsibilities (such as keeping their room clean). Older teens and young adults often take on more intensive care, as well as driving their family member places and managing doctor appointments.

Here is a brief list of some of the caregiving tasks – do any sound familiar?

- 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
- Cleaning and managing respiratory equipment
- Engaging with range-of-motion exercises with the person with ALS
- Cleaning drool/saliva and helping with oral hygiene
- Toileting and bathing

This picture is of a young woman helping her father with his feeding tube. Unlike many other disorders, the use of a feeding tube is not uncommon in ALS, and neither is having a teen or young adult assist with feeding and cleaning of the tube.

Despite the often enormous care you, and others like you provide, very little attention or support is given, often leaving the whole family struggling with how to deal with the care they need – and with little understanding of how to talk about caregiving.

How do we talk about caregiving?

This can be a **very difficult** topic to discuss. If you think families have a hard time talking about ALS in general, talking about caregiving is often more difficult. *Why?*

- Parents may feel their role as parent is being usurped because you are "taking care" of them.
- Because our society does not recognize children or young adults as caregivers, parents with ALS may feel concerned about telling other people that their child helps with care. Parents may feel that relying on a child or young adult is somehow abusive or negative. These feelings are understandable, but they often exist as barriers to care needs and family communication.
- You may feel frustrated because you are caregiving when you are the one who needs your parents to care for you.
- You may feel like you are the "adult" in the home, when all you want to do is be the kid. Like you grew up too fast – and certainly faster than most of your friends.

So, what can you and your family do?

- **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 you and your family would benefit from support and an outlet, be it activities or talking, to deal with what you are doing to help.
- **Think about how you normally 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? This goes hand-in-hand with the discussion of ALS earlier. 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.

The difficulty in talking about caregiving is compounded by others - professionals, school personnel, medical staff - who may feel it is wrong or somehow abusive to rely on a child or young adult in the home for personal caregiving. However, it is important to note—*caregiving as a teen or young adult 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. Some of these outcomes we will discuss just a bit further on.

How Does it Feel to be a Caregiver

It is important to think about how you feel about providing care.

This is a complicated question, often wrapped up in how you feel overall about your parent, grandparent, or loved one with ALS.

It is not uncommon to become a caregiver at a young age to a family member whom you have had a difficult relationship with. Maybe your mom has never really "gotten" you. Or your grandparent has been mean to you your whole life. Suddenly, you are in a place to provide care to someone, and you may struggle with how you feel about them.

"I just did not like her."

One young woman, Beth, really struggled with helping her mom who was diagnosed when she was very little. Beth never really knew her "real mom" – the one without the disease – and she did not have the mother-child bond to draw from when times got tough. She cried, feeling terrible about how she resented the care she was providing for someone she hardly knew and really did not like.

Beth needed support and to be told it is OK to have these feelings. It truly is. The important takeaway is process through the feelings. Do not hold on to them, and do not let them define the entirety of your relationship with this person. Find that trusted person, and share your feelings.

Caregiving for anyone is tough, and the caregiver needs and deserves support. If you can't get to a point where you can deal with the negative feelings, it is best for both that you not be involved in care. **This is critical.** Talk to family and friends, get the support you need, and find a way to get care from someone else.

Caregiving is also affected by what you know about the disease. The more you know about ALS, the more solid you will feel about being a caregiver.

- Seek resources from The ALS Association. I know it may feel weird to call and ask, so look up their website and get the details you need.
- ALS progresses differently in each person, so also try to attend doctor appointments with the person living with ALS you provide care for. Ask the doctor questions about progression and needs.
- Talk to the allied health professionals (Physical Therapist, Occupational Therapist, Speech-Language Pathologist, to name a few) about ways to assist in care and best practices.
- Get support from the social worker and care support staff. That is what they are there for!

As we mentioned earlier, you are going to feel many different ways about being a caregiver, and all of them are legitimate.

Positive feelings:

Caregiving can be an expression of love and care—and something you can do at a time when there is not much that can be done about having ALS. Many teens and young adults feel extremely positive about providing care. They are giving back, and they want to do it.

Anissa talks about how being her grandfather's caregiver gives her a sense of pride for the whole family, that she is giving to him and vicariously to the family. For families like hers that are very tight-knit and close, caregiving can be an extremely powerful expression of love.

Negative feelings:

Alternatively, many struggle with the care they provide. They may feel trapped and have a sense of duty 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.

Think back to the young woman whose mom had HD, Wendy. She was not at all happy about being a caregiver. Some of it had to do with how long she had provided care, but it was made worse by the lack of support and attention she received being a caregiver. Contrast that with Manouk, who has been a caregiver for over 15 years. She has certainly struggled, but one thing that helped was her parents' insistence on having time for herself and talking about ALS. Here is one suggestion which helped her a lot:

> "When we travel, we decide what the trip is about and *who it is for*. If it is a trip for my mom, like an ALS meeting or something, I go with mom as a carer – my mom's needs are foremost priority. But when we go on holiday as a family, my opinion is equal and I get to do things that I want to do. We talk about what each person needs, and try to do things that we both enjoy – something to share."

The caregiving is **balanced** by time to be a family and time to be a youth. This is just one example, and does not take away the anger, frustration, and difficulty of ALS and being a caregiver, but it does offer an alternative for finding balance.

So, you feel good about caregiving and you feel bad about it. It is hard, and your family is stressing you out. This is a good time to think about **who you are** in all this.

Who Are You in All This?

Often families get lost in the living with ALS and can lose sight of who each person is in the family.

Are you the daughter? Son? Niece? Caregiver? Breadwinner?

As a young adult these roles get more confusing as you move out of the house, go to school, or develop relationships outside your immediate family.

Manouk's story

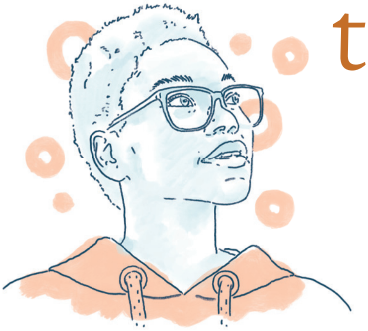
Manouk describes the confusion with role changes by saying first and foremost, her mom is her mom – not a patient. But that does not mean Manouk is always a perfect daughter. In fact, it is important to take a moment to acknowledge who you are and the roles you play – as a family member and as a caregiver. Manouk says, *"I am not always a nice daughter because she has ALS – I am not going to act different around her. My brother puts her opinion before his, but I can't. You have to maintain the relationship you started with. We are still mother/daughter. But it can be difficult when I have to say, 'Finish your food. If you don't finish your plate, you don't get dessert.' We treat it like a joke, not too serious. But we both know she has to take care of herself and I help her do that."*

Manouk, who has been her mother's caregiver for almost as long as she can remember, reminds us all that caregiving is tough and requires discussion and patience. And she shows the complexity of role reversal – telling her mom she has to eat or she won't get dessert. Her mom knows she needs to take care of herself, but sometimes she just wants to be social and does not recognize that going outside without a coat is not smart for the winter. Caregiving can be a lot of reminding – to eat, to wear a coat, to put socks on, etc. For many young adults, they can't imagine saying these things to their parent. But if you are a caregiver – you likely have said it.

TAKE AWAY

As Manouk says, **keep it light**! If you can, make a joke. Remember, your parent or grandparent likely does not enjoy being told to eat by their daughter or granddaughter, so keep that in mind. The role reversal is tough for you both, so talk about and acknowledge it so you can move forward.

She feels pressure to do the “right thing”



Anissa’s story

Anissa describes herself as a granddaughter and caregiver. She feels pressure to do the “*right thing*” with her grandfather, and realizes she does not think about herself in this equation. She goes out with friends but worries while she is out. Often she will turn down an invitation if she is the only one to care for her grandfather. She is conflicted. She wants to go out, but she feels like she needs to stay home with her grandfather. She is losing sight of herself and her own needs.

Not adding yourself to the picture is pretty common for all caregivers – young and old, child and adult. It is the process of being a caregiver. BUT, as a young adult, you need to find who you are, what you are doing, and what you want to do. This may mean you have to talk to someone about it – parents, teachers, guidance counselors, etc. If you don’t address this, time will go on and allow anger and potentially bitterness to set in.

!

WARNING

Don’t get caught in the cycle of hating what you do to the point where the day will come when your loved one is gone and you missed it by being angry. I have seen it happen way too many times, and it is heartbreaking for everyone – especially for the caregiver who now beats themselves up for missing those years with their loved one. **Talk about it early, often, and honestly.**

Complex Impacts of Caregiving

Caregiving is not a singular experience. In fact, it impacts all aspects of life for the caregiver – particularly as you start college, begin your career, date, or move out of your childhood home.

So, let’s break it down.

Caregiving and family interaction

As we discussed above, roles get reversed in caregiving situations. For example, is your mom still your mom even though you feed her?

Anissa says living with her grandfather really changed that relationship. She always looked up to him, and still does, but now he seems more human. “*It sounds crazy*,” says Anissa, but it is real. Since her grandmother is frail herself, Anissa has begun asking an uncle to come and assist with personal care for her grandfather. She wants to be his caregiver, but the personal care – specifically bathing – is just too uncomfortable for **both** of them. She does not want to start seeing him as a child in need for care.

James and Brittany do not do much caregiving for their dad, mostly because their mom does so much. They do help out with food and taking their dad places, but they actively avoid any personal care James tries to go out as much as possible with his friends, and Brittany feels it will get dumped on her. They both worry that being involved in too much care will make it feel like they are the parents to their dad – which freaks them both out.

Caregiving and dating, marriage, and having your own family

You are dating, marrying, and possibly starting your own family, so you want to live the life of a young adult. But you are responsible for your family member. What do you do? How do you talk to a potential partner about ALS and being a caregiver?

Open and honest from the start is the easy answer. Just tell them – they will be fine.

But you worry, what if they are not fine about it? How do you tell them? Will they leave, not want to help?

It's totally normal to think these questions, but get to the bottom of them. Do you want someone who would not help you? Do you want someone who would make you choose between them and your parent? Hopefully not.

Manouk says she admittedly has not always dated the "best guys." But in her current boyfriend, she found someone who is kind and open to her mother with ALS. It has made Manouk see things differently as well, stating that you cannot "do this battle alone." She says:

> “
>
> You have to share yourself. You have to make decisions together with any BF or spouse. It can be hard because this is not what other people have to do. You cannot make the decision by yourself. *It is not only about you.* This is different than when you were younger and everything was about you. Involve more people to make a more informed decision.
>
> ”

Because **Manouk** talks to her partner and shares her concerns, they understand the need to help her mom while Manouk slowly develops her own life.

What about guilt that you will need to live with your parents? *"I want to live with him, but I feel guilt when I want to live with him. My mom wants me to be independent, but I want to help her."* What do you do?

Manouk made a big move recently. During the week, she lives with her parents and attends college in their town. On the weekends, she lives with her boyfriend, who has a house in another town. This works for everyone, but sometimes it is tough. She forgets things at the different houses, and she even describes it as living with divorced parents – dividing her time.

While this arrangement may not be like other young adults her age, it works for Manouk. It allows for the development of independence, while still engaging in caregiving.

What works for one family may not work for another.

Anissa's family is stricter, and living with a boyfriend before marriage is not allowed. She has a boyfriend, but she did not tell him about her grandfather for a long time, mostly because her family was so freaked out and refusing to talk. Once she decided to open up, it helped. He lives nearby and has become very close with the family. In fact, Anissa says her mom *"likes him almost as much as me."* Anissa has maintained the mindset that if her boyfriend was ever weird about her grandfather, or did not "get" her family, the relationship would be over.

Neither **James nor Brittany** are dating. However, Brittany had a boyfriend for a while. She did not talk to him about ALS, because she did not think he would be OK with it. She resents that this is *"one more thing"* to have to think about or "add to" dating at this point in her life. She heads to college in the fall, and thinks then will be a better time to date since she will be going to school in Minnesota – away from home. Brittany's response is not uncommon. Much like Manouk's discussion of always dating the wrong guys, Brittany is unsure what the right guy may be for her now, given that she has not fully come to terms with ALS in her family. Not only do you need to find the right person for you (whatever that means to you), but also to find that at the right time. It is important to think about you, and what you want out of dating and the right time to date – whether you have ALS in your family or not.

It is important to think about you,

Coping with being a caregiver

Talking about caregiving and ALS, sharing with your partner – all are critical to how you deal with ALS in your life, or any disorder for that matter. What complicates matters is that you are also trying to be a young adult, wanting to spread your wings but feeling held down by adult responsibilities, which many of your friends don't have. This conundrum has no real easy answers. It can be hard to cope with your responsibilities and may mean you don't always make the best choices.

Manouk felt pretty overwhelmed with caregiving. When she was in high school, she went drinking on the weekends because she "*got to be the child I wanted to be, but struggled being a teenager and caregiver.*" During the week, she had to be the adult and provide care, and go to school. But drinking and partying on the weekend was affecting her work during the week. In high school, the social worker talked to her about stopping her drinking. But what really struck Manouk was that the social worker never asked *why* Manouk was drinking. "*She should have asked.*"

When Manouk was in high school, she never reached out to anyone. She could have, but she was nervous to ask for help. If someone had asked her what was going on or what she needed, she says she "*might not have given a very honest answer anyway.*" It can be hard to ask for help when you are a teenager. Now in college, Maounk finds other ways like going to markets, dinner with friends, and has met new friends with whom she shares her life with ALS.

Anissa only partied a few times. It is not really her thing, but when she did – it helped. She says she needs to find more activities to cope and just get out of the house and away from her family. It is really tough and the more she stays home, the more she realizes she is not dealing with the rest of her life.

and what you want.

How do you cope?

Think about this early in the process and develop a plan to deal with or cope with caregiving.

Some people take up running, some write, while others knit, dance, or even do poetry slams (personal fave).

Find a thing that you can do, then **make it a priority**. This will mean finding ways to ensure your family member is taken care of, meaning more people must be involved. If you find that you cannot get time away, get more family, friends, community, or a religious institution involved to help. It can be extremely surprising how many people are willing to come over for an afternoon, or take your family member out for the day. But it requires asking and reaching out. Don’t hesitate to do it.

Caregiving and school

Often, young adults expect to go to college – maybe even one in a different state. This is seen by many as a rite of passage: to go off to school, spread your wings, and become who you will be. But for young adults who provide care to a family member, moving away may not be an option, and it may be tough to reconcile.

Anissa's story

Anissa was headed to college in the fall, across the country from her family. Both she and her cousin were very close to their grandfather with ALS. They were the oldest child cousins, and the only "young adults" in the family. In her senior year of high school, she went to her grandfather's house every day after school and took care of him while all the other adults worked full-time. Both she and her cousin took turns providing care. Her grandfather was adamant that she go to college, but Anissa knew there was no one else to care for him unless one of the other adults quit their job, which did not seem like a real possibility. So, Anissa decided to go to a local college and move in with her grandparents to save money and be a more engaged caregiver. Anissa says this is not the "best" option, but it is the one that she wanted to make for her family. She still shares the care with her cousin; however, her cousin married early and is now pregnant, so Anissa foresees an increase in her caregiving responsibilities after the baby's birth.

Anissa's story highlights a part of caregiving that is rarely discussed – how older adults and young adults adjust their lives to provide care when other adults are unavailable. Young adults like Anissa, and maybe like yourself, are at a place where you are exploring who you are, going off to school, and starting your life. Caregiving can disrupt that.

Manouk's story

Manouk went to a school near home, not just because of caregiving, but because it was a good school. She really wanted to enroll in a study abroad program but couldn't because she needed to be near her mom. Manouk didn't look at any other possibilities because it made her sad to think about what she was unable to do. She does not see this as a huge issue, but she knows how many of her friends don't have to consider the things she has to take into consideration.

James and Brittany's story

James decided to go closer to home for school, but not because of his dad's ALS. He got a really good soccer scholarship. He says this might be good for the family after all. Even though he does not do much to care for his dad, James does think about it and says him going to school closer to home *"is a good thing."* Conversely, Brittany chose a school three states away. She said it was a school she really loved and felt was a good fit for her. But, it is also far away so she can be herself and not *"stuck at home."*

These different trajectories are but a few of the ways young adults choose where to go to school. Of course for families like yours, with ALS and the need for caregiving, it is a bit trickier. Talk about what you want and where you want to go. Chances are high that your family will want you to make the best decision and want you to go out on your own. But talk this over. Make sure whatever decision you make is one you can live with – even if it is not the "best" or the one you always wanted. There is no easy way to say it, but often it is about compromise and sometimes, sacrifice. You and your family have to be at peace with the decision –otherwise, like the bitterness that can set in about being a caregiver, you can also become bitter if you feel your dreams were not met or were stifled. Some may see Brittany's decision to go far from home as "running away" or "avoiding," but in the end, she may be making the best decision. She may, over time, become closer to her family by being far away. However, if she were required to stay closer to home, she may become more angry or resent that decision. In the end, there is no one way to balance school, family, and ALS – or any other disorder.

If you are at the place where you are deciding what to do – here are a few options to consider:

- **Can you take a gap year?** This is very common with many young adults these days, and colleges are often very happy to assist in making this happen.
- **Think about a school near home,** and maybe at a point in the future you could transfer somewhere else. This may have a bonus in that it can be easier for some schools to transfer in, rather than get admitted right away.
- **Look into online courses.** These are growing in popularity and may be a great option for you.
- **Overall, don't forget to be a young adult.** Go out, meet friends, take up a sport. Do things that make you feel like you and that you can integrate into your life.

Caregiving and Friends

This is often the most emotional topic for people of all ages. Finding friends who "get it" and having peers who share your experiences is so important.

Trying to explain why you cannot do an activity or why you are late can be exhausting, and many young adults just don't understand caregiving.

Manouk said that if she does not help her mom, either things won't get done or her dad has to do more. With his full time job, that can be pretty overwhelming. This means she may be late with her friends or even miss an outing. Manouk says, *"My friends just could not get that. I have to carry my load. They don't understand that I have things to do and can't stop. They don't truly get it."* This is a very important point, because what people see are just a few hours out of your day, which often does not represent all the other hours, including at night, spent caregiving.

The idea that friends don't "get it" is a theme across caregivers in all disorders – primarily because our society does not acknowledge or address the role that youth play as caregivers.

Anissa felt she had some support from close friends because in the Hispanic culture, caregiving is more accepted and is somewhat of a norm, even for kids. But as time went on and she met people from outside her immediate group, it became harder to always explain when she could not do things due to caregiving.

The national ALS family study uncovered some good advice about talking to friends.

- **Talk honestly to your friends.** They may be weird about it, but it is a part of your life, so they have to take it as it is.
- **Find other young adults like yourself.** Go through the disease organization – The ALS Association national office and your local ALS Association chapter – and see what programs they have.
- **Start a support group.** Now, this was usually said with a note that the group should not be a big circle where you stare at each other and talk, but rather to go to dinner, or share in an activity, and do something enjoyable.
- **Create or join an advocacy or fundraiser group.** Over the years, many children, teens, and young adults have created their own fundraisers or advocacy programs, including walks, basketball tournaments, bowling, or weekend retreats. You can be as creative as you like – and the benefit is not just funding for a cure, but meeting new friends.

Alternatively, it can be a real release to **have friends who have nothing to do with ALS**. These can be your "dinner and a movie" friends, or "going to the nightclub" friends. The people you do stuff with that remind you that you are a young adult and like to be around other young adults – who know nothing about ALS. It is OK to have different friends.

How many of you were trained, or told how to do the caregiving tasks?

Not many.

This is one more area that has little attention. You are tasked with some incredibly complicated care, but there is little training out there for children, teens, and young adults.

When I interview young people, the majority say that most often their other parent or adult in the home tells them what to do, or the person living with ALS tells them what to do. This is complicated because when you have a disease, you have to step outside yourself to see it from the other point of view. You have to "see" as a caregiver how to do things. This is not always doable for many people. Also, relying on the person living with ALS assumes they understand and have come to terms with the disease progression and how caregiving tasks may change – *or they are comfortable with you providing care*. This can be difficult when young caregivers are bathing or toileting a family member. Both parties might feel extremely uncomfortable, so rather than taking the time to make sure it is done correctly, people rush through it just to get it over with.

When asked, **Manouk** says that working through the disease progression was a tough transition, and she didn't always know what to do. *"I used to have trouble with her progression. It is hard to help her accept to have to learn new things."* Her mom dealing wit her own disease progression hindered Manouk from knowing what and how to help with the new symptoms and care demands. Now, Manouk must cut all her mother's food and feed her, as her mom has lost almost all use of her hands. Every now and then, Manouk thinks – *is this the right size? Should I cut it down more?*

In addition to new symptoms and progression, there are assistive devices. **There. Are. So. Many.** And each one needs detailed instructions. It may feel like every week there is a new device for your family member. These are totally overwhelming, particularly when no one tells you how to use them. **Anissa** describes the respiratory equipment as *"crazy scary"* – mostly because she knows it means things are getting worse, but also because she will now need to make sure it works correctly with the right settings and gets cleaned well. That is a lot of pressure. She was taught how to use each machine by the company person who delivered it, but after that – nothing. Plus, her grandfather seems to get weaker by the day, so she is also having to figure out how best to lift and transfer him using only her own strength. She says,

> "There has to be a better way, but I can't use my grandmother to help. She is smaller than me."

So what to do? **Ask for help. Period.** Ask a nurse, doctor, physical therapist, occupational therapist, or social worker. These are the folks to guide you and make sure you are doing things correctly. Even if you have been caregiving for a long time, like Manouk, things change. The task may take on new difficulty, like Anissa lifting her grandfather. The ALS Association is there to help with these questions. They can do a home visit and help assess caregiving needs. It is not a bad thing to ask for help – you all deserve it.

Long term care, insurance, and home health

> “There are no classes on this.”

You may have to interact with one or all of these. It can be extremely confusing and overwhelming, particularly if you are the primary caregiver. Alan was his mother’s primary caregiver, so at the age of 21 he was responsible. He says he spent hours on the phone trying to figure out insurance, often missing a class or a college event. It needed to get done, but it was completely frustrating. You may be the one to make the calls, but you also may be the one to make the decisions. Kristina was her father’s only child, and her mom was not in the picture. Therefore, she was her dad’s power of attorney. She was in college, doing her best to care for him and be in school. However, as things progressed, she was at a loss for what to do. She says she needed someone to provide her information about financial aspects, long-term care, and who pays for what. She says, *“There are no classes on this,”* and because many young adult caregivers are overlooked, they are not included in broad caregiver outreach. If you are in this position, here are some suggestions:

1. **Call your local area on aging.** They work with older adults, but also with people living with disabilities. They may have some excellent resources.
2. **The ALS Association often has respite available** in addition to care coordinators who can help you navigate the long-term care and insurance process.
3. **The National Alliance for Caregiving** can be a great resource to help people navigate caregiving, long-term care, etc.

Long-term Impact of Being a Caregiver

This is another area that receives very little attention (seeing a theme here?), so it is difficult to provide specifics about what actually is the long-term impact.

Some research has shown that current young caregivers have higher depression and anxiety than non-caregiving youth.[2] 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.[3,4] However, others have stated that they feel a stronger sense of self and feel good about the care they provided.[5,6] 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.

Loss of your childhood

Many, if not most, of the young people I have worked with over the years describe feeling that they grew up too quickly because of their 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. When you feel this way, it can come out in a variety of ways:

1. **Some decide to go onto helping careers, like social work or medicine.** In fact, one young woman who had a father with Huntington's disease (HD) said not only did she decide to go to a school closer to home to help care for him, she switched her entire area of study from history to medicine. She was so involved in his care, and knew everything there was to know about HD, that she wanted to help other families like her own. Caregiving changed her life. It has changed many people's lives – that feeling of giving back to others. It can feel pretty good.
2. **Others never want to see a doctor, social worker, or power chair again in their lives.** Totally understandable. They want to keep moving on, not forgetting, but just moving on.
3. **But what if you feel like ALS and caregiving has ruined your life? It happens.** The truth is, you need to talk to someone about this because you cannot change that ALS happened in your family, but you can change how you move forward from it.

Some people, many years later, feel guilt that they were not more involved, or that they were "too angry" or didn't appreciate their family member at the time. Frankly, this is the last thing we want to see happen. These thoughts and feelings can really mess with you – often for a long time. There is no sense in beating yourself up about it, but you need to address it. Acknowledge how you feel, and if you are comfortable, talk to someone about it. One young man who had a father with ALS was so angry at the care he had to provide and the loss of his childhood that he shut down during his dad's illness. He got into fights in school and started doing drugs. He missed the last year of his father's life. At the time, he was just doing what he could to get by, but years later he has regrets. He says that if he could do it all over again he would "*just not be so angry*." Easier said than done. Hindsight is 20/20 – we always see things so clearly on the other side. Missing out because of anger and pain only hurts you.

QUESTIONS TO ASK

How are you dealing with caregiving?

Are you talking to people about it?

Do you get support?

As hard as it is, reach out. It seems like no one is there, but honestly, people are there. The ALS Association, school staff, friends, family, therapists. It may sound cheesy—**but you truly deserve to get the support you need during this time.**

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> “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 WITH ALS

3

LOSS

Death, Dying, Grief and Loss

Talking About Death and Dying

Death, dying, loss, and grief are topics that carry taboos, confusion, mystery, fear, worry, or pain.

Most of us don't know how to talk about it –

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including young adults.

"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, teens, and young adults who have an ill family member—specifically a parent with ALS. Losing a loved one is difficult at any age, but losing a parent is one of the most difficult experiences for any child to go through, especially for teens and young adults who are just starting their own lives and want their parent around to see them grow into adulthood.

Many families are ill-prepared to talk about disease progression and impending death with their children. This may 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 the conversation.

We draw our cues about talking (or not talking) about death from our parents. In a study of youths 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, and how you may deal with death and grief.

ALS makes the conversation happen earlier than expected

In families living with ALS, the conversation around death and dying 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 dying and death may entail or look like – what and who they are leaving behind. However, youth and young adults may not feel the same. You may want to know and want to ask, but are not sure how. Alternately, you may not bring it up because you don't want to hurt or offend your parent or family member.

Anissa has avoided conversations about her grandfather's death because it may offend him. He holds a place of honor in the family and she does not want to impact that. Additionally, many young adults want to know more than simply that their parent may die. They may want details, but don't know how to bring it up. Someone in our national study said, "*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 captures the need for information, while acknowledging the difficulty of the conversation. Despite the difficulty, it is crucial to open the conversation and keep it open.

The following are some specific questions teens and young adults may want to know. Do you think about any of these? How could you ask them in a way that would be helpful? This is a great place to engage a social worker, teacher, or staff at your local ALS Association chapter.

What will the death look like?

How will it be handled?

Will their parent remain in the home?

Can I be present during the death?

What will happen after death?

What will the services or funeral look like?

What supports are in place?

Where will we live after the parent dies?

As a young adult, you 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. Many teens and young adults are planners – you need to have some idea of what is going to happen. Having the conversation will help you feel like you are involved. So, think about these and other questions and how you can use them to open or maintain communication in your family.

Hospice and end-of-life decisions

As described above, many teens and young adults have no idea what their parent may want at the end of life – meaning, treatment and care that may be life-prolonging or life-limiting. While many factors go into this, it is important to ask – and it has to be done. If you are providing care, you get to know these decisions. Furthermore, talking about it as a family continues the trend of open discussion and allows emotions and concerns to be addressed as we talked about earlier with Manouk.

When Steven was 16, his father died with ALS. He knew it was coming as his dad had ALS for many years. But when the hospital bed came, and the hospice people showed up – that was it. Regardless of how "prepared" he felt, it was not enough for when it happened. He talked at length with his mom to make sure he knew what would happen next and who was coming and going. This was a critical conversation for them both and actually made them grow stronger as his father was actively dying.

Questions to consider:

- **If your parent decides to forgo treatment, ask them why.** This should not be an indictment of their choice, but will help you understand their thinking and what might come next.
- **Talk about hospice or home care as a family.** Make sure you understand 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.
- **All family members deserve to be prepared for what is happening and what may happen.**

Advance directives

An advance directive is a written statement of a person's wishes regarding medical treatment, and can include whether they want a feeding tube, to be put on a ventilator, or even receive CPR if their heart stops. The advance directive incudes:

- **Living will,** made to ensure those wishes are carried out should the person be unable to communicate them to a doctor. This is the place where all the specific wishes are listed.
- **Health care power of attorney (HCPOA),** a document that states who is the decision maker, should the person living with ALS no longer be able to make their own decisions. This can be anyone and does not need to a be a spouse.

Who can be a witness? These documents need to be completed by the person living with ALS, and signed by two witnesses (nonrelated, not your medical provider, and NOT the person designated as the HCPOA). Witnesses are often the social workers or chaplains at the hospital. The documents are in place to ensure you know what your family member wants (or DOES NOT want), and who is the decision maker.

Where do we keep the documents? Keep a copy in the house, at the doctor's office, and on file at the fire department. These are not documents to file away or put in a safety deposit box. Talk about end-of-life decisions more than once. The document can be changed to reflect how our choices change.

How do we talk about this, or get help?

There is help for these conversations. In addition to your local ALS Association chapter, the hospital or nursing home social worker will guide you and your family. Also, because documents vary by state, go to https://www.agingwithdignity.org/. They publish a uniform document called "Five Wishes".

Grief and Loss

Grief is *real* and comes in a variety of ways.

You may think that grief only happens after someone dies, but it is actually a process that can begin well before the loss of the loved one, and includes all the losses associated with illness – big and small.

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. While Manouk’s mother has a very long trajectory, things still change and progress. They are doing well, adjusting and living their “normal” lives, then a new symptom, or a progression of a current symptom occurs. These progressions require advanced care, but they also represent the slow loss of her mom. It is getting harder and harder to understand her. Soon, her mom will not be able to talk at all. As each loss mounts, the relationship changes and sadness and loss set in.

Anticipatory grief

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. Even before your loved one dies, you are 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. Sisters who have a mother with ALS talked about the loss their mom's voice. She was not dying, but they grieved what the lost voice meant.

> “
> [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.
> ”

Even though their mother is still living, they are grieving the loss of their mother's voice, and in effect the loss of what she knew as her “normal”, the things she said, the inflection when she is angry, and the feeling that mom is gone – even though she is still there. Their mother will eventually die, 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.

How do you feel about the changes and 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?

Some people say, yeah, I can think these things – but would never say them to my parent with ALS. *Why not?* It may actually bring you closer to talk about the things you love about them – what makes them the person they are. It's also important to know that your family member with ALS is also sad and grieving; after all, they are losing quite a bit, AND coming to terms with their own mortality. So, 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.

The National Alliance for Grieving Children (www.childrengrieve.org) is a wonderful source for support and guidance on how children and young adults deal with grief. Below is a list of seven points from the Alliance of important things to know about grief:[8]

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

It is normal to struggle, whether the relationship with that person was caring and loving, or contentious and difficult. We mentioned earlier the young woman whose mom had Huntington's disease, but had it so long she never knew her mom. When her mom died, she was surprised at how overwhelmed and sad she felt. Even though the relationship was not close – she was still her mother. The absence of a person takes time to fully accept. You never ″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 is an experience you live with. After his father died, Ian struggled with knowing his dad was no longer at home, and would never be again. He won′t be sitting in his office, he won′t be watching the news, he simply will never be here ever again. That is the hardest part.

Some key points about grief:

- 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 yourself** as you adjust to these changes.

2. It is important to know the truth.

We often avoid words like ″dead″ or ″die” or we shade over the truth about *how* a person died in a desire to protect our loved ones, including children, teens, and young adults. 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 and help provide understanding.

3. Your grief is your grief – no one else's – just like your relationship with the person who died.

Because of this, the way you experience and express your grief will vary from how others express grief. This is not a time to judge how someone is dealing with death. When my own father died, I was surprised how all my siblings dealt with it differently. Some talked non-stop about him and death in general, while one sibling never said a word – attended the funeral but did not talk about it.

How do you think you would express your grief? Have you lost a loved one? While you never really know until it happens, it is good to think about what you do to express yourself – art, music, writing, etc. These forms of expression can really help as you adapt to life without the physical presence of that person.

4. Grief can make you feel alone and misunderstood.

After Steven's dad died, people just stopped talking about him, as if he never existed. This made him mad, but it also made him feel like he was the only person in the world who grieved his father. Adults avoid talking about the deceased person for fear that doing so will exacerbate your grief. In doing so, this can create an atmosphere in which expression of grief seems not acceptable. Which is completely untrue. Also, like Ian, you may feel like you are the only person who has experienced the death of someone in your life, even though other friends might be experiencing similar circumstances.

- It is important to provide opportunities to acknowledge the grief everyone is feeling.
- It is also helpful to gather with peers grieving similar situations – but only if you are up to it. These groups can be extremely helpful, but can also be overwhelming. Check with your local ALS Association chapter for grief groups. You never know – it may be exactly what you need.

5. Grief comes and goes and is lifelong.

I tell people the loss of my father 14 years ago can feel as fresh as if it happened yesterday. That does not mean that I break down every day, but I feel it – the sadness and the grief. He died – my feelings did not. It is very important to own that grief will come and go. Over time, as you tell stories, share memories, and process what death means to you, the intense feelings may come less often. But, grief is a lifelong journey.

Steven's dad died before he got his driver's license. Getting in the car and going through the paces made him think of his dad, who would have loved to see Steven go through the process. Steven says "*I almost started crying with the license guy in the car.*" We can laugh about that, but it happens to us all. When you went to prom without your mom taking a million pictures, graduated from high school, or got the letter saying you were accepted to the school of your choice. You just may revisit grief in a very intense way. **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.

6. Grief can be an opportunity for personal growth.

This is a not altogether surprising byproduct of going through grief. To be clear – 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. But, many people feel the loss made them 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. It is really important to keep this in mind. Grief and loss are really tough, and have no easy answers. But the possibility of learning a deeper you, and a greater appreciation for loved ones is a pretty good outcome.

it is good to think about what you do to express yourself – art, music, writing, etc.

> “I could not kick it. I could not sleep for months afterward, and all thought about was my father.”

Complicated Grief

This young woman is struggling with something called 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. But, sometimes grief becomes more than that—it affects every day life and impairs you. Adults and youth can experience this type of grief, and 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.
- 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 or work performance or avoiding school.

If you are experiencing any of these, **don’t hesitate to address it and get help**. This is important. In addition to The ALS Association, your school, your religious home, or a therapist, among others, can provide support to you and help you move past the complicated aspects of grief while acknowledging that you still grieve. You deserve to get support and to develop strategies to move beyond the most complicated part of grief to a place where you live with it, but it does not live you.

Support Groups

After the person with ALS has died, support groups may be helpful to you. 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 you, check in with your local ALS Association chapter. They may have a group, or may be interested in starting one.

Where are Our Young Adults Now?

This book addressed just about everything – from friends and school, to caregiving and death, and the young adults we profiled are still balancing it all.

Manouk

Manouk is trying out her new living arrangement and is even considering a study abroad in the spring. She is not sure how it will go, or if it will go, but the fact that she is even considering it is a big step. Her mom is hanging in and remains one of Manuok's biggest supporters.

Anissa

Anissa is finding the balance less easy. It was a big decision to stay in town and go to college there, and she struggles with regret – what would have been if she went to California? Her grandfather has progressed and now uses a power chair to get around. Anissa is thankful – less stress on her back. She has reached out to her family for more help, and has been pleasantly surprised by how many offered.

James and Brittany

James and Brittany and their parents met with a social worker to talk things out. At first, this was a bad idea, as the only person who talked was mom. The entire atmosphere was really tense. But, after two sessions, James and Brittany opened up a little about their fears and just wanting to avoid ALS. They talked about their anger at ALS, which was a big breakthrough with the family. Both James and Brittany are in college now, and happily so. Brittany does not come home often, but she calls and FaceTimes with her dad. For her, the best thing was to get away and do her own thing. She actually does think this made her closer. James comes home a lot and has started helping out his mom – even the personal stuff he always avoided. He still does not talk much about it, but feels better being around.

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We all hope this book is helpful. So many young adults, like yourself, are out there in very similar situations.

We hope you take what you need from this book and have amazing lives.

We are rooting for 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 *The ALS Experience: It's Different and Hard*.

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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