

After the Diagnosis: Coping with the “New Normal”



LIVING WITH ALS
RESOURCE GUIDE



After the Diagnosis: Coping with the “New Normal”

Contributors:

Joumana Barody, RN

Anne Eichmeyer, MSW

Table of Contents

| | |
|---|----|
| Introduction | 4 |
| Coping with the Diagnosis | 5 |
| Beginning Your New Journey | 8 |
| How to Cope with ALS Day-to-Day | 9 |
| Finding Meaning | 11 |
| Talking to Loved Ones About the ALS Diagnosis | 13 |
| Support Groups | 20 |
| Intimacy and Sexuality with Your Partner | 22 |
| A Loved One as a Caregiver | 26 |
| Mindfulness | 35 |
| Reflections | 37 |
| Becoming an ALS Advocate | 37 |
| How The ALS Association Can Help | 38 |
| Summary | 38 |
| Resources | 43 |
| Bibliography | 49 |

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



Introduction

ALS is often difficult to diagnose. The onset may initially be so subtle that the symptoms are overlooked. The journey leading to the diagnosis may be long and filled with uncertain medical opinions. This can lead to frustrations and anxieties when symptoms progress without a definitive diagnosis.

Additionally, in the early stages of the disease, the symptoms can be similar to those of a wide variety of other, more treatable diseases or disorders, leading to false hope. In other cases, the definitive diagnosis may come sooner. Regardless, the final diagnosis is inevitably met with an overwhelming sense of confusion and conflicting emotions.

This resource guide is designed to provide a framework for you to consider thoughts, feelings, responses and coping strategies to the diagnosis of ALS—in yourself or in a loved one.

What we will cover in this guide:

- Reacting to the diagnosis and learning to adjust
- Finding meaning in your life
- Talking to loved ones about the ALS diagnosis
- Parenting and ALS
- Support groups
- Intimacy and sexuality
- The family caregiver role and challenges
- Mindfulness
- Reflections
- Becoming an advocate
- How The ALS Association can help

Coping with the Diagnosis

What Now?

Since being diagnosed, you likely remember the exact moment you heard your doctor say, **“I’m sorry, you have ALS.”**

Perhaps you remember how it felt as if someone had kicked you in the stomach, leaving you breathless. It felt as if time stopped. You don’t remember anything else after that. The doctor may have talked to you for hours or minutes; you just don’t remember. You may not even remember anything that happened that day or how you got home. You have burned into your mind, however, the words, **“There is no cure for ALS.”**

Coping with the ALS diagnosis is very individual. Everyone responds differently when life throws them a curve ball. Some may bounce back “by hitting that ball back” and go on to make the best of their lives while others may need more time to adjust to the news and come up with a plan. Some may let it rule the rest of their lives.



There is no right or wrong way to feel when you hear bad news about your diagnosis. It is important to remember that it does not mean you cannot have a life; it means that you just need to work a little harder and make some adjustments.

Receiving the diagnosis of ALS may trigger a wide range of emotions, including fear, anger, loss, sadness and depression. It also has a rippling effect: Everything changes, and this often affects familial roles and relationships.

Persons diagnosed with ALS, and those who care for them, are confronted with a profound and difficult situation. Questions about coping, living fully, interacting with loved ones, and preparing for the inevitable will certainly arise.

There is no doubt the diagnosis of ALS can be devastating to you or your loved ones, but **it does not mean it is the end to all your hopes and dreams.**

When you learn you have ALS, you also learn there is no cure yet and effective treatments are still in development. You may wonder, "Why is ALS so different from other very serious diseases?" For the longest time, people have been told that nothing can be done for ALS, whereas people with other diseases have had options. While outcomes may not always be successful for these other diseases, at least there are treatments. However, much has changed in the care and treatment of ALS, and there have been advancements in understanding the disease and helping to manage it, despite no cure at this time.

Maintain a positive, determined and optimistic attitude.

With the rapid advancement of scientific technology and neurological research, there is more hope than ever before that more and better treatment options will be available. While this is positive news, it is essential to achieve a balance between hope and realistic expectations.

Empower yourself by learning everything you can about ALS and how it will affect you.

While many people may be familiar with ALS prior to their diagnosis, some may not have heard about it at all. Some may be more familiar with the term "Lou Gehrig's Disease," named

after the famous New York Yankees baseball player who had ALS. Following the diagnosis, most people start searching for information from various sources, but it is important to trust your sources:

- **Start by talking to your doctor and medical team**, and ask what physical, mental and emotional changes you should expect as ALS progresses.
- **Go to the local library or bookstore** and search for medical books about ALS.
- **Search the internet for information about ALS, but be careful.** Watch out for any site selling a product or service. If it sounds too good to be true, then it probably is. Look for reliable sites like those of The ALS Association, your local ALS Association care team or Certified Centers, the National Institute of Neurological Disorders and Stroke (NINDS), the National Institutes of Health (NIH), Centers for Disease Control (CDC), National Organization for Rare Disorders (NORD) and university medical center websites. You can also find information about clinical trials by visiting www.clinicaltrials.gov.

These resources can provide information that is accurate, will answer your questions, ease concerns and direct you to other local and national resources. **It's also possible that knowing the facts about ALS may also increase your level of anxiety, which is why it's important to meet with an ALS specialist or ALS multidisciplinary team of healthcare professionals to help you sort through the information.** ALS symptoms and the rate of disease progression vary from person to person. Working with the team will offer you and your family guidance in reaching important decisions and accessing services, support and education appropriate to each stage of the disease.

The hardest part about coping with ALS as symptoms progress is letting go of your way of life, as you have known

it. With all the challenges facing you, be proactive and take control of your own care. **Do not allow yourself to be “locked in.”** There are solutions for every problem you may face, but you have to educate yourself and seek guidance from an ALS specialist and a multidisciplinary clinic team.

Beginning Your New Journey

When you are first diagnosed, it is common to resist the diagnosis. You might search for alternative answers from other providers or resources. You might avoid talking about ALS altogether or you might think about it constantly until you feel overwhelmed. You could also feel very angry, sad, hopeless or depressed that this happened to you or your loved one.

- **“Why me?”**
- **“How did this happen?”**
- **“What could I have done differently?”**
- **“What can I do differently to change this?”**

You may have heard there are steps or stages one goes through to gain acceptance. There are many researchers who have come up with different models of the stages of acceptance, grief and loss. These “stages” describe reactions, all of which are very normal.

There are so many ways we, as humans, strive to gain acceptance over things that happen that are out of our control. You may experience any number of these reactions on your journey toward acceptance.

We hope you can find a way to be kind to yourself in this journey and allow your feelings to come and go, recognizing they are normal and that you are not alone.

How to Cope with ALS Day-to-Day

Even though the diagnosis of ALS can cause you to experience all sorts of conflicting emotions, you will eventually realize you are not likely to die suddenly. At this point, the most prevalent question is:

How Do I Live with ALS: How Do I Cope with Life Now?

The most important step of the journey is accepting the diagnosis. However, acceptance of ALS does not mean giving up on all your hopes and dreams. It should be the first step in making the most of your life with ALS. There is much that can be done to help you live a full and enjoyable life.

A common initial response to the diagnosis is to be overwhelmed and concerned. You may feel extraordinarily compromised and hopeless at times. The meaning of the diagnosis is very different to each person. To some, it is unthinkable, unbearable and unacceptable. To others, it offers answers to their quest for some understanding of what has been happening to them. **Coping with ALS and managing the emotional stress resulting from it can be quite emotionally draining for you and your family.** The thought of losing physical functions combined with financial concerns and quality of life issues can compound and create additional stress.

The following tips may help you and your family, cope with ALS. *(Adapted from Neurology Reviews: October 2010)*

- √ **Take Time to Adjust.** Being diagnosed with ALS is nothing less than shocking. Take time to absorb the information and understand what to expect. Allow yourself time to work through emotional reactions such as denial, anger, sadness and grief.

- √ **Be Hopeful.** Your attitude is everything. Try to remain hopeful. Be positive. It isn't helpful to pretend that everything will be fine or that ALS is not a very serious condition. Don't let ALS take away your intellect, personality or spirit. Don't let your illness define who you are. Try to think of ALS as only one part of your life, not your entire identity.

- √ **Think Beyond Physical Changes.** You can look at ALS as a slow death or as an opportunity to enrich your life and make the most of the time you have—time to foster deeper connections with family and friends and broaden your spiritual awareness.

- √ **Seek Early Treatment.** Many symptoms can be reduced with simple treatment. Often these treatments can ease the effects of disease progression. Ignoring manageable problems can make a difficult situation worse.

- √ **Take Charge of Your Care.** Physicians and other professionals on your healthcare team, hospice and family can help with healthcare decisions, but remember that you are in charge throughout your illness. Don't let others dictate your care. If your doctor hasn't already done so, request that they refer you to the nearest ALS clinic. Your doctor will also be able to help you in other ways in the future, such as signing your application for disability and social security benefits.

- √ **Engage Family and Friends.** Life with ALS can trigger overwhelming emotional reactions. Keep lines of communication open so that you are comfortable expressing your feelings. Encourage your family and friends to express their feelings as well.

- √ **Join a Support Group.** Don't think that you need to face this alone. You can get a lot of support and useful information from others who have faced this disease. Your family and friends may also benefit from a support group devoted to

caregivers. The Muscular Dystrophy Association (MDA) and The ALS Association have support groups. A considerable number of support groups and resources are now available online.

- √ **Plan Ahead.** Planning for the future allows you to be in control of decisions about your life and your care. Work with your doctor, hospice and family to formulate plans for life-extending treatments and end-of-life care. **Make a living will and discuss it with your family.** See <http://www.agingwithdignity.org/> for more details on living wills and Five Wishes.

Even though the life expectancy for someone who is diagnosed with ALS is on average between two to five years, maintaining a high quality of life may prolong this life expectancy. This gives hope for a longer life. The best way to approach it is to deal with it one day at a time.

Finding Meaning

Values

As human beings, we all have our own values, beliefs and attitudes that we have developed throughout the course of our lives. One significant area of wellbeing is the concept of meaning. Our values are what hold meaning for us and ultimately guide our behaviors, our relationships and our accomplishments.

What Holds Meaning for You?

Having an understanding of your core values can help guide the care you receive, as well as the way you want to live out your life with ALS. To help you think about your values, there are tools and values inventories online that ask questions and use scales to help you rate your universal human values.

One of these is the **Values Inventory Assessment (VIA) of Character Strengths** and can be found at the Authentic Happiness website (see helpful resources at the end of this resource guide). Some universal human values include Creativity, Concern for Others, Independence, Humility, Spirituality, Love of Learning, Curiosity and Interest in the World and Humor.

You may already have a clear idea of your core values, but these may change or strengthen during the progression of ALS. Some people might also change the ways they access their values as ALS progresses. For example, someone who values being in nature and going on hikes every weekend prior to their diagnosis may still find ways to experience nature, even if it is just to observe the surrounding beauty.

Religion and Spirituality

For some people, religion or spirituality become an integral part of their ALS journey. Like all of your values, spirituality may continue to play a role in the decisions you make and the community, activities and care you seek. It might also serve as the foundation to conversations you want to have. It is common for these conversations to include topics or questions of purpose, relationships, higher power, and afterlife.

Many people continue to attend or seek support from their churches, temples, synagogues, mosques or other places of worship throughout the progression of ALS. It is also common for people to seek out prayer or meditation. Often, religious leaders are willing to make home visits, and many healthcare facilities have chaplains who are also willing to support spiritual health.

Even for people without spiritual practices or religion, many people dealing with ALS find ways to continue to live out their values and find communities that support them.

Talking to Loved Ones About the ALS Diagnosis

Each person responds to news of ALS in their own unique way. Keep in mind any emotion or reaction is normal. Many people you tell will be shocked or will cry. Some may immediately jump to ways they can help. Others may have a lot of questions or feel uncomfortable.

Many will not know how to respond; they may fear they will say the “wrong” thing, or they might have their own fears of mortality.

There is no right or wrong way to feel.

You might find that you don’t want to talk about ALS at all. Or you might find that you want to talk about it with some people, but not with others. If you don’t feel like talking about ALS, don’t force yourself. Perhaps you will be able to open up later after you have lived with the reality of the diagnosis for more time.

However, your family and closest friends will want to know that you have ALS. Tell them when you feel comfortable to do so, and if you simply cannot tell them, find a compassionate person with whom you can share this important task. Honest and open communication will likely help the people in your life provide you with the type of care and communication you want for yourself.

“These changes do not always mean limitation or loss, but rather an adaptation to a new period of life. [People with ALS] move into a period of their life where they stop being ‘human doers’ and begin being ‘human beings.’”

(MacKinlay, 2001)

What Do We Tell the Children?

It is common for parents diagnosed with ALS to inquire about how to talk to children about ALS. It is normal to want to protect

children, worry about how they will be affected by your emotions and feel unsure of their ability to understand what is happening. However, **it is important to tell your children about ALS because without good information, they may sense something has changed, become concerned or anxious or imagine an incorrect situation.**

Children may grieve not only because their parent is ill, but also because of the many small changes that may result from ALS, like changes in daily routine, increased responsibilities or changes in the ability of the parent with ALS to interact as they have in the past. When you tell your child about ALS, try to anticipate or be aware of any initial fears that might need to be addressed, such as relocation or changes to routine. **Tell your children there is information you would like to share about your health, and tell the truth about the disease using simple, age-appropriate language.**

It is ok to express your own emotions to your child; this can give your child the confidence to share their own feelings. **It is also important to invite your child to ask questions.** Provide honest, simple answers. If you don't know the answer, it's ok to say, "I don't know the answer to that." How children and youths deal with illness is directly related to how you as the parent cope or deal with the illness. When a parent has strong coping skills, those can translate to how well the child or youth copes.

Children often need to know that their needs will continue to be met. It will help if you can give specific details about how these needs will be met and by whom. **Try to keep your children's routine as normal as possible and acknowledge any changes that might occur.**

It is possible your child will benefit from an explanation that ALS is not something that someone caused, nor is it something that anyone can catch. If your child is in school, it can also be helpful to notify their guidance counselors and teachers about ALS. You might also **ask your local ALS care team for resources in your area that exist to support children through a parent's serious illness.**

Your children may not want to talk about it or ask questions and that is OK. Provide them space and let them come to you when they are ready. Make the conversation normal with no pressure. It may take a few starter conversations, but letting them know you are always available and open will help smooth the way to a full conversation.

Below is a simple outline of behaviors to anticipate at the different stages of your child’s development, considering the challenges your children experience with a parent living with ALS. We have also included suggestions intended to assist you as you support your children. Note that many of the characteristics described are often interchangeable between age groups, depending on each child’s unique development. (Families and ALS: A Guide for Talking with and Supporting Children and Youths. Melinda S. Kavanaugh, PhD, MSW, LCSW University of Wisconsin-Milwaukee).

| Age Range | Developmental Milestones | Suggestions for Discussion |
|--|---|---|
| <p>Infants and Toddlers (Age 0–3)</p> | <ul style="list-style-type: none"> Babies and toddlers need routine, need to feel safe, and can pick up anxiety and fear in the parent. | <ul style="list-style-type: none"> Keep the normal routine as much as possible. Allow the child to ride on the wheelchair or sit with the person with ALS. Create a “new” normal environment (meal times, feedings, sleep, etc.). |
| <p>Young Children (Age 3–7)</p> | <ul style="list-style-type: none"> At this age, children are concrete thinkers and do not need complex discussions, but they have curiosity and will most likely ask questions—many, many questions—some of which will be very direct. | <ul style="list-style-type: none"> Parents may feel this is too young to talk about ALS, but the truth is the child sees and knows that “Daddy looks different from Mommy.” |

| Age Range | Developmental Milestones | Suggestions for Discussion |
|---|--|---|
| <p>Young Children (Age 3–7)</p> | <ul style="list-style-type: none"> Children in this age group can be very egocentric (everything is about them) and are “magical thinkers,” meaning they believe that something happens because they made it happen or because they thought it. They may feel they, their behavior, or lack thereof, caused ALS. Children in this age group are also very literal. Children in this age group do not have the ability to understand abstract or hypothetical situations. They are focused on what they perceive, rather than what is logical. Finally, kids in this age group are not future oriented, thus time does not mean the same thing to them. | <ul style="list-style-type: none"> It is important to be clear and honest. The child may feel they are at fault, were not obedient enough, did not listen, etc. This is a crucial place to reassure and support the child that they are not responsible for ALS. Using slang or complicated terms may be confusing. You can use simple, straightforward language (Daddy hurts, Daddy can’t walk, etc.). Addressing what the child sees (Daddy in a wheelchair) is important. Let the child know the disease makes it happen, but that it may look different in different people. When you say “six months,” young children have no idea what that means, so talk in the now and do not use abstract time dimensions. |
| <p>Middle Childhood (Age 8–12)</p> | <ul style="list-style-type: none"> Children in this stage are focusing on identity. Who am I? Am I the kid with a parent in a wheelchair? Children in this age group are able to solve problems and can use logic. | <ul style="list-style-type: none"> When discussing ALS, you can be more complex and provide more detail. Continue to make sure children know that this is not about them and that having a parent with ALS is not a negative thing. |

| Age Range | Developmental Milestones | Suggestions for Discussion |
|---|--|--|
| <p>Middle Childhood (Age 8–12)</p> | | <ul style="list-style-type: none"> • While having a parent with ALS isn't "normal," it is important to "normalize" the experience in terms of the family and how you talk about it. • Talking about ALS can be a bit easier if you provide details and outcomes. • You can help children see and make connections between their emotions and their thoughts. How do they feel about being told about ALS? Guide them to interpret their emotions in a healthy way. • Let them know it is OK for them to be sad about how things might be changing, while letting them describe their thoughts. Encourage them to discuss and describe as much or as little as they want. |
| <p>Adolescents or Youths (Age 13–18)</p> | <ul style="list-style-type: none"> • Adolescents often cope by focusing on the emotion, even when they are struggling to control those emotions. • This conflict is influenced by hormonal changes and struggle with their own identity and sense of belonging. • At this stage, most youths have developed more cognitive skills and the ability to understand the abstract. | <ul style="list-style-type: none"> • Addressing the emotional aspect of what they understand about ALS is important. • Check in to see how they are feeling and allow them to express their feelings without judgment. • Addressing hypotheticals may result in outward distress and emotions that can wildly fluctuate, which many parents avoid. |

| Age Range | Developmental Milestones | Suggestions for Discussion |
|---|--|---|
| <p>Adolescents or Youths (Age 13–18)</p> | <ul style="list-style-type: none"> • They can create hypotheticals in their minds, including what life may be like moving forward with ALS. • Adolescents are developing their own selves, so they may seem to be uninterested or uninvolved in the conversation. While it certainly can be due to the emotional aspect, they are also processing who they are in the context of what you are telling them. • Conflict with adolescents can be very developmentally appropriate given their need to find themselves and belong to peer groups. • Adolescents tend to respond well when they know they are heard and respected and you see their point of view. | <ul style="list-style-type: none"> • However, addressing how the youth feels is just as important as how they think about it. The youth may not be able to explore the emotions. • Engaging with a professional at this point can be extremely helpful. The professional can assist the youth in processing the emotional aspect and is an outside party who may access the youth’s need for confidentiality. • When talking with your adolescent, acknowledge that they are becoming their own person. • Keep the communication connection, but allow the adolescent to be with friends to lessen the very common conflict. • Keep the conversation open. Make sure your adolescent knows they can come to you at any time with questions. An adolescent may shut down if you ask too often; just let your adolescent know you are there. |

Parenting and ALS

Watching a parent go through the changes caused by ALS can be frightening to children of all ages. Maintaining normal daily family routines is important for them to feel safe and secure.

A good resource for talking with children is 'Families and ALS: A Guide for Talking with and Supporting Youths', available from The ALS Association.

Practical Advice

- ✓ **Dedicate time** to spend with your children and give them your undivided attention.
- ✓ **Plan simple activities** that you enjoy together and are easy for you to handle.
- ✓ **Try to keep their lives as normal as possible** and show them that life goes on. If you are no longer able to keep up with their activities, seek help from family members, friends and neighbors.
- ✓ **Allow your children to be involved in planning family activities.** This helps them feel useful and better understand lifestyle changes that must be made.
- ✓ **Encourage children to help whenever they offer so they feel involved.** However, accepting outside help with household chores allows you time with the children.
- ✓ **Keep an open and honest relationship with your children.** Avoid secrets that may make them uncomfortable. Encourage them to share their feelings and express their emotions.

Watching a parent go through the changes caused by ALS can be frightening to children of all ages. Maintaining normal daily family routines is important for them to feel safe and secure.

- √ **Keep the conversation ongoing.** It doesn't have to be a constant conversation, but don't stop talking. Keep your children engaged. Be open and allow them the opportunity to ask anything, knowing they will get a straight answer. Check in with them from time to time, especially at times when ALS progresses and your "new normal" is changing. See how they are doing and if they have any further questions. It is not always up to them to come to you. Keeping the conversation going is one way to make the family experience "normal."
- √ **Listen.** Perhaps the best thing you can do is be there and listen. Your children may be angry, confused or sad. Hear them and allow them to express their feelings, then keep the conversation going.

Comments heard about attending a support group:

"These groups are a safe place to vent!"

"At my ALS Support Group, it was a relief to be with people who understood."

Support Groups

Support groups can be helpful for practical and emotional support.

Each group may be unique in how it is formatted, but often the groups are facilitated by someone with ALS experience who can guide the conversations in ways that help provide ideas and solutions to effectively cope with ALS and its accompanying challenges.

There might also be time in your support group meeting to share your

experience with others. Some people find it helpful both to learn from the experience and knowledge of others, as well as share their own knowledge. Others might find it is a good place to vent, because the people in the room also have experience with ALS.

Support groups for people affected by ALS may be available in your area. **Check with your local ALS Association care services**

team to gain information about the support groups that are available to you and your loved ones. Some support groups are specific to loved ones of a person with ALS, while others are specific to the people living with ALS. Some groups may combine both people with ALS and their loved ones.

In recent years, in part due to the COVID-19 pandemic, online and virtual support groups have become more prevalent. Online support groups provide an alternative avenue of support for people living with ALS by linking them with their peers. They have the potential to improve the access and delivery of support to a wide range of people, including some who are no longer able to travel. They also reduce the sense of isolation caused by geographic or physical/medical constraints and increase feelings of validation.

There are two types of online support groups:

Asynchronous online support groups. These groups do not have scheduled meeting times. Instead, members can share posts on message boards.

Synchronous online support groups. These groups meet at a certain time, at specified intervals, typically via an online video call platform, such as Zoom. Most commonly, they take place monthly or bi-weekly and last for around one to two hours.

For many people, support groups are an option, but you might not be ready to attend one. Maybe you'll feel more comfortable with the idea at a later time. You might also try a support group and decide it is not for you. And you might already know this about yourself and that's ok! Different people find different ways to cope with ALS.

Ultimately, our hope is that you know that you are not alone in dealing with the challenges that come with ALS.

Intimacy and Sexuality with Your Partner

Sexual health and sexuality are an important part of everyone's wellbeing. Any illness or disability can have a huge impact on how we feel about ourselves, but an ALS diagnosis brings with it a host of physical and emotional responses that can be exhausting and, for many, can reduce arousal and lead to a diminished interest in sex.

Although ALS does not directly affect fertility or sexual function, sexuality is an issue for many people with ALS and their partners.

Understanding how ALS affects sexuality is the first step to alleviating problems with sex and intimacy imposed by the disease.

ALS is a disease that affects the parts of the nervous system that control voluntary muscle movement. Involuntary muscles, those that control the heart, GI tract, bowel and bladder function and sexual functions are not directly affected in ALS. **Although ALS does not affect sexual functioning per se, reduced function of the mouth, hands and legs can have an adverse impact on sexual expression for the person affected and their partner.** Additionally, weakness in the arms and legs and/or spasticity, can make many sexual positions difficult and exhausting. The need to express sexual feelings is not eliminated, even if the practice is. Some people find comfort and satisfaction in other forms of gratification.

ALS can also weaken an individual's **respiratory function**, making breathing more difficult and therefore making sexual activity a strain. Non-invasive positive pressure ventilation (NIPPV) can help, but the equipment needed may require more creativity.

Other ALS symptoms, as well as some ALS medications, can have an indirect impact on one's sex life. Fatigue, lack of sleep, muscle spasms or muscle tightness and decreased ability to

communicate can all affect physical comfort as well as sexual desire. ALS can also affect self-image as a sexual being. Having ALS can make you much more aware of your own body, noticing the changes that have taken place and anticipating further changes. Individuals who experience depression, anxiety, loss of self-esteem, diminished sexual confidence or negative feelings about bodily changes brought on by ALS may experience diminished sexual function and a decline in intimacy.

Addressing Sexual Problems

Many sexual problems you may be experiencing may be secondary to the disease or to some of the treatments you may be receiving. These can be managed with the help of your healthcare team. Here are some examples:

- **Pain** can be controlled with medications.
- **Spasticity** can be reduced with medication, cold packs and stretching or massage.
- **Fatigue** can be alleviated through energy management. Planning and scheduling sexual activity may help.
- Alternative sexual positioning can help with both spasticity and **weakness**. Using pillows for support or trying different positions can relieve discomfort.
- **Medication side effects** may be minimized by taking them at a different time of day or by changing the timing of sexual activity. Your doctor may consider switching to other medications with fewer sexual side effects. You may want to consult with your doctor.

Talk to your doctor, health or rehabilitation professional about your problem so they can help you find solutions. Some people may feel uncomfortable bringing up sexual issues openly, but it is important to keep in mind that sexuality and sexual health are a normal part of human functioning, and these problems can be addressed just like any other medical problem.

Talk to your partner and coordinate sexual activities during the time of day when you are likely to be the least fatigued.

When having sex, arrange things in advance and position yourself so that you can move freely but safely and avoid pain. This may mean having sex in a new way or unfamiliar position. Discuss this with your partner.

Remove any outside distraction. Make room for romance and let intimacy thrive.

“There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.”

**– Former first lady
Rosalyn Carter**

Even though ALS can restrict the activities of daily living, maintaining a sexual relationship can be a source of comfort, pleasure and intimacy. It is also an affirmation of one’s true self when other roles have been stripped away. A satisfying sex life, for the person with ALS and their partner, is one way to feel “normal” when so many other areas in their lives have changed.

Many people associate the term having a sexual relationship with intimacy. However, a good intimate relationship rests on a much broader foundation of trust, open and honest communication, goals, mutual respect and concern. It can include physical or emotional closeness, or even a mix of the two in which partners connect with one another.

Physical intimacy leads to emotional intimacy that positively impacts people’s physical and emotional well-being.

Making love does not necessarily mean having intercourse. Having intercourse is not the only way to experience sexual pleasure. Most people experience great physical and mental arousal from foreplay. People with ALS and their partners may want to redefine sexuality for themselves. This may mean putting more emphasis on other forms of intimacy and touching that provide warmth, like cuddling, kissing, caressing and massaging.

Couples may want to remind themselves that “making out” can be as pleasurable.

Caregiving and Sexuality

The partner without ALS may also experience feelings and psychological symptoms that affect intimacy and sexual desire, including grief, fear, stress and depression, but their feelings are sometimes overlooked. When the partner is the main caregiver (which is the case with the majority of couples), exhaustion and resentment over care duties may build up, affecting sexual feelings and intimacy. Switching between the roles of lover and caregiver may also be difficult and it is often hard for partners to talk about these issues with the person who has ALS.

It is important for the partner to maintain some regular personal time away from caregiving duties because that helps prevent the feelings of resentment. It may be helpful for the couple to be creative and dedicate a separate time for sex and romance that is free from any caregiving duties.

An important part of a happy and healthy sexual relationship is communication. The first step to addressing sexual problems is acknowledging and understanding them, and then talking about them with your partner. Openness between partners can create the right environment to develop particular ways of giving and receiving sexual pleasure. The inability to discuss sex and intimacy with one’s

partner is often the biggest problem. Avoiding talking about these issues can easily lead to avoiding sex and other intimate contact.

A Loved One as a Caregiver

As you cope with changes brought on by ALS, you face the reality of having others assist you in your activities of daily living. Because people desire to maintain independence, an illness such as ALS is often difficult to accept and may cause feelings of defeat or despair. Changes in independence may result in profound changes to your sense of self-worth and integrity, leading to anger, sadness and grief for what one no longer has.

Coming to terms with the need for caregivers is generally something most people are very slow to accept. It is initially difficult to receive intimate care from spouses, children or parents. Even the initiation of personal care by a professional caregiver requires time, patience and understanding. However, the problems associated with caregiving are not limited to the person with ALS; the caregiver, whether a relative, friend or a professional, needs acknowledgment and support in the process of starting and maintaining the care-providing relationship.



Accepting Role Changes and Challenges

There can be great rewards to being a caregiver. Making a difference in someone's life, improved relationships with the care recipient as well as with other caregivers and personal and spiritual growth are some of the benefits caregivers might experience.

In couples facing the diagnosis of ALS, many find themselves in the all-too-common position of being a caregiver to their spouse. **Caring for a spouse can be very rewarding, but this shift in the relationship can be difficult, too.** Even the strongest relationships can be pushed to the brink when one spouse is caring for the other. Still, some couples find ways not only to cope with the challenges, but also to use the experience to strengthen their bonds.

Supporting a Loved One with ALS

Caring for a loved one is not always easy, nor is it something most of us are prepared to do. Learning about the illness and all aspects of caregiving relevant to the disease may help you provide the care your loved one needs. **The following tips may help you prepare for better caregiving.**

In most cases with ALS, caregiving happens gradually. In the initial stages, your loved one may be able to make their own decisions about care. Knowing and understanding your loved one's values and wishes and having an open communication will be important as you become responsible for making decisions for them.

Advance care planning is the process that allows you to make decisions about the care your loved one would want to receive if they happen to become unable to communicate.

- Advance directives are tools that enable people to write down their preferences on a legal form and appoint someone to speak for them if they are no longer able.
- A living will, healthcare power of attorney, financial power of attorney and a plan for funeral arrangements can help ensure peace of mind for your loved one and for you, the caregiver.

Environmental/home safety. Most ALS caregiving takes place in the individual's own home. Typically, most homes are not designed for caregiving. Being knowledgeable about the disease and the specific needs associated with every stage of the progression can help you plan ahead and make changes to accommodate future needs.

Equipment needs. Learn about the assistive and adaptive equipment that may be needed at every stage of the disease. Knowing what can appropriately be used at every step of the disease progression can ease your anxiety and improve your loved one's safety and quality of life.

Getting organized. Getting and staying organized can help you care for your loved one and maximize the amount of quality time you can spend together.

- √ Make a list of all the names of your loved one's clinical team, their respective specialty and contact information.
- √ Make a list of your loved one's medications (dose and frequency, specific instructions).
- √ Make a list for other emergency contacts in case you cannot be reached.
- √ Make a shared calendar with family members and friends who may assist with caregiving and providing respite.

These lists and other needed information can be put into a clearly marked notebook and kept where others can easily find them. Your notebook should contain enough information so that someone filling in for you will know exactly what is needed and what to do.

Community resources. Look for local resources available in your area. Contact The ALS Association or other organizations in your

area that may offer services to assist you. These may include Meals on Wheels, caregiver-training classes, transportation assistance, friendly visitors and respite care so that you can have a break.

Being an effective caregiver requires acknowledging the role and embracing both the joys and pains of caring for a loved one.

While generally very rewarding, caring for a loved one also involves many stressors. It is important to note that while the spouse of a person with ALS is not dying, they will go through many of the same emotional stages as the person who is.

As caregivers, we have to remind ourselves of the importance of our own desires, goals and overall wellbeing.

Maintaining a fresh outlook on life and occasionally being selfish is necessary for both your sanity and wellbeing.

Caregivers are often too busy caring for others that they neglect their own emotional, physical and spiritual health. The demands on a caregiver's body, mind and emotions can easily become overwhelming, leading to stress, fatigue, hopelessness and ultimately to burnout.

There are many factors that cause caregiver's stress, which eventually leads to burnout.

“Although there were many challenges to caring for my father when he was diagnosed, I wouldn't give up that time with him for anything. We were able to communicate on a level that was never possible previously. We became closer than I could have imagined. It was the best time I ever had with him, strange as that might sound. All the past was left behind and we focused on what was important—the love of family.”

— Anonymous

Besides the household disruption, financial pressure and the added workload, the following are common factors:

- **Role confusion or change in family dynamic.** It is often difficult for a person to separate their role as a caregiver from that of a spouse, lover, child, friend or other relationship.
- **Unrealistic expectations.** Many caregivers expect their involvement to have a positive effect on the health and happiness of their loved one. This may not always be realistic.
- **Lack of control.** Many caregivers become frustrated by a lack of money, resources and skills to effectively plan, manage and organize their loved one's care.
- **Unreasonable demands.** Some caregivers place unreasonable burdens upon themselves, in part because they see providing care as their exclusive responsibility.

Caregiver stress can be particularly disheartening when there's no hope that the family member being cared for will get better. Without adequate help and support, the stress of caregiving leaves the person vulnerable to a wide range of physical and emotional problems. Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively.

Signs and Symptoms of Caregiver Stress and Burnout

Learning to recognize the signs of caregiver stress and burnout is the first step to dealing with the problem.

Common signs and symptoms of caregiver stress include anxiety, depression, irritability, difficulty sleeping, overreacting to minor nuisances, new or worsening health problems, feeling tired and run down, trouble concentrating, feeling increasingly resentful, drinking, smoking, overeating, neglecting responsibilities and cutting back on leisure activities.

Common signs and symptoms of caregiver burnout include low energy, feeling constantly exhausted even after periods of rest, neglecting one's own needs, having trouble relaxing even when help is available, feeling increasingly impatient and irritable with the person being cared for and feeling helpless and hopeless. Withdrawal from friends, family and other loved ones is also a common sign, as is loss of interest in activities previously enjoyed, changes in appetite and weight, changes in sleep patterns and emotional and physical exhaustion.

Once burnout occurs, caregiving is no longer a healthy option for either the caregiver or the person being cared for. It is important to watch for the warning signs of caregiver burnout and take action right away when you recognize the problem.

Coping with Caregiver Stress and Burnout

Strategies to avoid or cope with burnout are important. To counteract burnout, the following specific strategies are recommended:

- √ Participate in a **support network**. Consult with professionals to explore burnout issues.
- √ If possible, **rotate responsibilities** with family members.
- √ Attend a **support group** to receive feedback and coping strategies.
- √ **Exercise** daily and maintain a **healthy diet**.
- √ Establish "**quiet time**" for meditation.
- √ Get a weekly **massage**, if you can.
- √ Stay involved in **hobbies**.
- √ Ask for help. Look for **respite** care or enlist friends and family to help out with errands and/or care.
- √ Give yourself a break. **Set aside a short time every day for yourself**. Find ways to pamper yourself, make yourself laugh, get out of the house, visit with friends and share your feelings.

- √ **Practice acceptance.** Focus on the things you can control, find the silver lining and share your feelings.
- √ Most importantly, **take care of your own health.**

When caregiver stress and burnout puts one's own health at risk, it affects their ability to provide care. It hurts both caregiver and the person being cared for. The key point is that caregivers need care, too. Managing the stress levels in the caregiver's life is just as important as making sure the family member gets their care.

It can't be overstated: The best way to be an effective caregiver is to take care of you and seek respite.

Respite Care

Just remember, **everyone needs a break.**

Respite care is the term used to refer to the act of leaving an ill or disabled loved one in the temporary care of another party while insuring the continuation of care in a safe environment. Respite care is an important resource for caregivers who can become easily stressed and suffer from caregiver burnout. It is meant to supplement

the care provided by the individual's family caregiver. Respite care can be for an hour, a day, a weekend or a week.

Using respite affords the family caregiver some time away so they can "recharge," which is beneficial to the health of the caregiver. It provides a chance to spend time with other friends and family, or to just relax, time to take care of errands such as shopping, exercising, getting a haircut or going to the doctor. Respite is a great source of support, comfort and peace of mind knowing that your loved one is in being cared for by another caring individual.

Respite care is the term used to refer to the act of leaving an ill or disabled loved one in the temporary care of another party while insuring the continuation of care in a safe environment.

Respite care can be provided at home—by other family members, friends, or paid caregiving services—or in a care facility setting, such as adult day care or residential facility.

Coping with Exercise

Yoga includes physical exercise, but it is also a lifestyle practice for which exercise is just one component. Training your mind, body and breathing, as well as connecting with your spirituality, are the main goals of the yoga lifestyle.

Yoga can be beneficial for individuals with disabilities through both the physical postures and breath work.

Yoga is so much more than a physical or sporting activity. In addition to exercises that improve your flexibility and muscle toning, there's also a whole other side to this activity. In fact, even if your body is not suited to certain physical activities due to a physical disability, you can still enjoy the benefits of yoga.

Yoga is known to help in multiple areas like **stress reduction, physical fitness, flexibility and core strength**, and it is a particularly good

supplement to other exercises, too. There is a lot of research that suggests yoga also combats pain and other health issues. Exercise in general helps your **mental health** and your **mood** and can contribute greatly to improved sleep patterns.

Instead of trying to force your body into one-size-fits-all poses, however, you should consider **Adaptive Yoga** which fits the movements to what you are able to do. It uses props like blankets, straps and chairs to make it easier on people. Adaptive Yoga can be performed while



seated in a chair or wheelchair. It's designed for people with reduced mobility or with difficulties with balance.

Reconnecting with your body helps you reconnect with your mind—something hugely important in yoga whether you're physically disabled or not.

Exercise: Meditation

This is one example of a meditation, but it can be adapted to any position, including lying in a bed or sitting in a wheelchair:

- 1. With both feet on the floor and a relaxed body, allowing the air to flow gently and slowly in and out, notice the air and what it feels like coming into your body and then out.**
- 2. Thoughts might arise, sounds might also arise around you, and that's ok. It's normal. Just calmly turn your mind back to your body and your breath, focusing on the feelings and sensations in your body.**
- 3. You might close your eyes and feel your body relax. Notice what your feet feel like on the floor. Allow your forehead to soften.**
- 4. Gently breathing in.**
- 5. Gently breathing out.**
- 6. You might allow yourself in this moment to feel safe, to feel loved, to feel whole and to feel at peace.**

Mindfulness

Mindfulness is about moment-to-moment awareness or noticing what is going on, both internally in your mind and body, as well as externally in the space around you. As humans, it is very common for us to ruminate on experiences from the past or worry about the future. With ALS in your life, it is especially easy to have a worrying mind.

However, worrying creates additional stress and releases subsequent hormones and chemicals that may only make us feel worse. Take breaks from the worries that accompany ALS and allow yourself the comfort that existing in the present moment can give. There are many studies that support incorporating mindfulness into your daily routine as a way to boost overall health, wellness and life satisfaction.

Even taking five minutes each morning or evening to sit and relax, to notice the sensations in your body and allow your breath to flow gently and slowly in and out can help your mind focus on now, instead of all the worries and stress today or tomorrow might bring.

There are many different types of mindfulness meditations, secular and not. But at its foundation, mindfulness meditation is about setting the intention of being present and non-judgmental of one's emotions, thoughts and sensations in that moment.

For all of us, life is full of milestones and accomplishments. And we should celebrate them! ALS has entered your life, but it doesn't mean your goals need to stop.

Some people find mindfulness meditation is a tool they can use easily, while others might feel it is too hard to quiet the mind.

A quiet mind is not a necessity to begin a meditation practice. With practice, the mind and body will naturally relax.

Think of mindfulness as a muscle that with time, practice and compassion, you can strengthen.

Some people meditate naturally as a part of their day, while others find it more helpful, especially at first, to listen to guided meditations. You might be able to find a meditation group or center locally, or you can listen to guided meditations. There are even meditation downloads and podcasts online (see resource for Mindful Self Compassion in the Resources section at the end of this resource guide).

Exercise: Reflective Questions to Consider Asking Yourself

- **Who are the people that have meant the most to you? How did they impact your life? Maybe now is the time to tell them.**
- **What are your favorite memories growing up? Do you have photos and stories to tell? You might try writing them down, recording yourself telling them or maybe having someone help you with this.**
- **What are your greatest accomplishments? Was it your schooling, your career, your family, your life experiences?**
- **If you could pass on wisdom to others, what would you share? What would you want others to know?**
- **You might also find benefits in reflecting on the positive things in your current life.**
- **What are the things that went well today? What about me caused those good things to happen?**

Reflections

For all of us, life is full of milestones and accomplishments. And we should celebrate them! ALS has entered your life, but it doesn't mean your goals need to stop. As you continue to set goals and think ahead to how you want to live out your life, you might also find it helpful to spend time reflecting on the things you have already accomplished.

We all impact our surroundings; it might be helpful to take some time to reflect on how you have impacted yours. You might want to do this alone, or you might find it helpful to do this with your loved ones.

The more we are able to reflect on the good things that happen around us, the more we begin to notice those good things on a daily basis. Our brains are powerful and it can be really easy to jump to the negative things that happen in life. However, if we allow ourselves to also let in the positive, we are actually able to rewire our brains toward optimism (Seligman, 2011).

Becoming an ALS Advocate

One of the missions of The ALS Association is **nationwide advocacy**. An ALS Association advocate is a foot soldier in the battle to defeat ALS. An ALS Association advocate is someone who is passionate about getting involved with the government at all levels to draw awareness and resources to the people affected by this disease. An ALS Association advocate is someone who is willing to step outside of their comfort zone to effect real change in the way our government responds to the needs of the ALS community.

Even if you aren't a friend, relative, supporter or business associate of a legislator, you can open doors through your outreach. As an ALS Association advocate, you can help change the laws and policies that affect thousands of persons with ALS and their families.

Becoming an ALS advocate may give you a purpose—a reason to fight for your rights and those of others.

How The ALS Association Can Help

We encourage you to reach out to your local ALS Association care services team to learn more about what they can offer you and your loved ones. This team can provide information and resources that could benefit you and your loved ones.

Support groups, free durable medical equipment, caregiver support, respite programs, transportation assistance or assistance with technology are also available locally. Your local care services staff will consult with you on the phone, via video, email or text, or even come to your home. The staff at the Association is knowledgeable about local resources, centers, providers, vendors and others who are dedicated to supporting people dealing with ALS.

The ALS Association creates a community of people who have dealt with or are currently dealing with ALS, and it is your choice as to how involved or active you want to be in this community. Our hope is that the Association can offer you and your loved ones support, kindness and information, as well as remind you that you are not alone in your ALS journey.

Summary

Many of us live our lives with hopeful expectations. We hope to be physically healthy and independent, to achieve a degree of happiness and success and know our families are vital, supportive and loving. We hope to have many good years without painful or disabling illness for ourselves and our loved ones, and when death comes, it is peaceful.

ALS has a profound impact on these hopes. It interrupts plans and puts the future on hold. ALS is not considerate of where you are in your life, who you are, or what is important to you. It has no respect for what you have accomplished or what you are working toward.

It is almost impossible to predict how one person will react to the news of ALS diagnosis at any particular time. Each one of us has different coping strategies and skills. The reactions and behaviors we adopt to deal with difficult situations will have a critical impact on our ability to accept and maintain a fuller life.

While it is very important to be realistic about the situation, maintaining some level of optimism will work wonders to improve your mental condition and general mood, as it will for everybody else around you.

Discussions with many people living with ALS have revealed one common theme: **The sustaining factor in living with this disease is the continual harvesting of hope and finding new meanings in your life in the present.**

Hope must remain the guiding force throughout your life and your ALS experience. We grow in understanding, spirit and wisdom as we live, and hope enhances our journey. ALS tests our understanding, especially as physical changes occur and life becomes more difficult. **It is important to deal with this disease one day at a time and try to find new ways to experience meaning in your life.** Hope comforts and strengthens; it is what allows you and your loved ones to endure.

Make a commitment to yourself to live every day to its fullest!

In their own words: Insights from People Living with ALS

"ALS affects each person differently. There is no road map as to what's going to happen next. You don't know what each day will bring and the uncertainty can drive you crazy. Everyone we meet seems to know someone who had ALS, or knows somebody who knew somebody that had ALS, and they would share stories with us. I decided early on to avoid self-diagnosis on the Internet and to take stories of others with ALS with a grain of salt (often times they meant MS or Parkinson's).

For my own sanity, I stuck to materials provided by The ALS Association, and I read them in sequence. I didn't rush through it because I didn't want to start imagining symptoms. I wanted to be educated but not too soon. Within weeks of the diagnosis, a friend sent me the book, *Tuesdays with Morrie*, by Mitch Albom. It chronicled the progression of ALS in the author's former college professor through to his death. Though it was an excellent book and intended to be inspirational, the realities of the disease finally started dawning on me.

My wife and I talk about the disease and the future all the time. We try to anticipate each potential obstacle and plan ways to adapt. In short, we plan for the worst while hoping for the best. There are good days and less good days. I don't think the bad days have started yet. Each day, I choose how I feel about living with ALS, and I choose to look for positives. We are careful to have optimistic people around us as it is very easy to go to the dark side. We needed to create distance between friends and family that could only focus on negatives, or need constant comforting from us. It's amazing to see how our circle of contacts changed after my diagnosis—people we thought would be there for us in a crisis fell to the background; others with whom we had a more casual relationship ended up being integral to our lives. It was surprising and saddening at the same time."

“There were so many things to think about after receiving my diagnosis that it was easy to become overwhelmed, frozen in place. We came to the realization that our priorities had changed overnight and that we were not the same people we had been before the diagnosis. We knew we needed to plan so that the next few months weren’t wasted. My wife and I sat down and sketched out things to do over the short and medium term—it really helped us feel like we had some control over things.

One of the first steps we took was to get linked into the ALS community. Through these contacts, I enrolled in a clinical research drug trial and spent the first few months traveling to a facility in a neighboring state. The trial was informative, helping us get down the ALS learning curve more quickly. As a side benefit, we treated the trips like mini-vacations and made the most of our time there.

As my speech degraded, we sampled various speech apps on the iPad and worked on our non-verbal communication (think Charades). For mobility, we moved to a one-level apartment with no stairs and worked on wheelchair solutions. We also planned some vacations and time with friends and family. Looking forward to these trips and time with loved ones really helped keep our spirits up.

I am an independent person. With ALS, you become completely dependent on the care from others. It’s important that I do as much as I can for myself for as long as I can. But I also figured out that there is a time to accept help, and maybe more importantly, ask for help. For example, an important social activity for us is dining out in restaurants, both alone and with friends. I had a couple of embarrassing situations where I could not cut my food, either making a mess or giving up quietly without eating. I was mortified if someone asked if they could help me cut my food at the table. One day, my wife suggested that we order each other’s entree. She would discretely cut up the food, and we’d then trade plates under the guise of trying each other’s selections. As time went by, I asked servers to have certain dishes cut up in the kitchen. Small things but it helped preserve a social activity that would have been easy to abandon.”

"Asking for and accepting help was difficult, but so important. I made a list of ways people could help: practical things like grocery shopping, mowing the lawn, cooking, etc. Then when people asked, I could give them a task."

"Find a reason to laugh."

"Because we are not religious, we were hesitant to use the Chaplain services offered to us, but our Chaplain really connected to my husband and was able to have conversations with him that we wouldn't have had."

"The ALS Association provided us with a ton of equipment. The support and information they provided us throughout the journey was incredibly helpful."

"When I was caring for my husband, I also was working on my online businesses, which allowed me to be flexible. Having something other than care-giving helped me keep my sanity."

"I have ALS, but ALS does not have me! No white flags for me! I am going to fight until the last breath. I just take it one day at a time. There is no reason to worry about what may or may not happen in the future, I just enjoy the moment. I feel blessed that I have a loving family that supports me unconditionally. I owe it to them to fight."

Resources

ALS-Specific Internet Links

ALS Family of Faith: One Man’s Spiritual Journey Living With ALS

<https://bit.ly/ALSFamilyofFaith>

ALS Forums and Chat

Open support community for people affected by ALS/MND.

www.alsforums.com

Care Connection

A network of volunteers from the community that provide help for the person with ALS and their family, and often give the caregiver a break from day-to-day responsibilities.

<https://www.als.org/navigating-als/for-caregivers/als-association-care-connection>

Caring Connections

www.caringinfo.org

Families and ALS: A Guide for Talking with and Supporting Children and Youths

<https://bit.ly/FamiliesAndALS>

Information for Youth, Teens and Young Adults

The ALS Association’s resources for youth

<https://www.als.org/navigating-als/resources/Youth-Education>

Other Helpful Links Not ALS-Specific

Arch Respite

<http://archrespite.org/>

This website can help you find respite

Authentic Happiness

www.authentichappiness.com

This website, which was created by researchers at the University of Pennsylvania, has questionnaires available, including a Values Inventory Assessment (VIA) that help you identify your values and character strengths. Knowing what is important to us is helpful in making any decisions about how we want to live out our lives.

The Caregiver Space

<http://www.thecaregiverspace.org/>

This website allows you to connect with other caregivers and get resources.

The National Alliance for Caregiving

www.caregiving.org

Caring Connections

<http://www.caringinfo.org>

Created by the National Hospice and Palliative Care Organization to provide free, easy-to-understand resources on a variety of issues, including free resources and information to help people make informed decisions about end-of-life care and services before a crisis.

Caring Bridge

www.caringbridge.org

This website allows you to create a site to update loved ones that you chose) on what is going on in your life with ALS.

Family Caregiver Alliance

<https://www.caregiver.org>

FCA is an organization that addresses the needs of families and friends providing long-term care for loved ones at home through education, services, research and advocacy.

Lotsa Helping Hands

<http://www.lotsahelpinghands.com>

This website is an online tool that allows a community to organize themselves to help a caregiver

Mindful Self-Compassion

www.mindfulselfcompassion.org

This website, started by clinical psychologist Christopher Germer, has a lot of information about the practice of mindful self-compassion, as well as free guided meditation downloads.

Mindful—Taking Time for What Matters

www.mindful.org

A website that celebrates being mindful in all aspects of daily living.

The National Family Caregiver's Association

www.nfcacares.org

**Providence Hospice of Seattle's Safe Crossings
Program for Grieving Kids and Teens**

<http://safecrossingsfoundation.org>

This program provides services to specific areas in Washington State, but the site provides access to many other resources and tools you can download or order.

Rare Caregivers

www.rarecaregivers.org

A site with resources for family caregivers of loved ones with rare diseases.

Books

Caregiving: The Spiritual Journey of Love, Loss and Renewal

By: Beth Witrogen McLeod

ISBN: 0471254088

Publisher: Wiley and Sons Publishing

How to Help Children Through a Parent's Serious Illness

By: McCue, Kathleen.

ISBN 0-312-11350-1

Publisher: St. Martin's Press, New York.

Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill

By: Cappy Capossela and Sheila Warnock

ISBN: 0-684-822367

Publisher: Simon and Schuster

Straight Talk About Death for Teenagers

By: Grollman, Earl A.

ISBN 0-8070-2500-3

Beacon Press, Boston, 1993.

Last Touch—Preparing for a Parent's Death

By: Becker, Marilyn R.

ISBN 1-879237-34-2

Publisher: New Harbinger Publications, Inc., CA, 1992.

***Talking about Death: A Dialogue between
Parent and Child*** [Kindle Edition]

***The Caregiver's Survival Handbook: How to Care for
Your Aging Parent Without Losing Yourself***

By: Alexis Abramson

ISBN: 0399529985

We Are Not Alone; Learning to Live With Chronic Illness.

By: Pitzele, Sefra Robrin.

ISBN 918351-01-4.

Publisher: Thompson and Co, Minneapolis, MN.

Bibliography

Chiò AI, Calvo A, Di Vito N, Vercellino M, Ghiglione P, Terreni A, Mutani R, Mora G (2003). Amyotrophic lateral sclerosis associated with pregnancy: report of four new cases and review of the literature. ***Amyotroph Lateral Scler Other Motor Neuron Disord.*** 4(1):45-8.

Couldrick, L. (2005). Sexual expression and occupational therapy. ***British Journal of Occupational Therapy,*** 68(7), 315-18.

Davis S., Taylor B. (2006). From PLISSIT to Ex-PLISSIT. In: ***S Davis, ed. Rehabilitation: the use of theories and models in practice.*** Edinburgh:

Kaufman M, Silverberg C, Odette F. (2003). ***The Ultimate Guide to Sex and Disability.*** San Francisco, CA: Cleis Press Inc.

MacKinlay, E. (2001). ***The Spiritual Dimension of Aging.*** London, UK: Jessica Kingsley Publishers.

Marsden R, Botell R. (2010). Discussing sexuality with patients in a motor neurone disease clinic. ***Nursing Standard,*** 25(15-17), 39-45.

Seligman, Martin E. P. (2011). ***Flourish: A Visionary New Understanding of Happiness and Well-being.*** New York: Free, 2011. Print. Wasner M, Bold U, Vollmer T, Borasio GD (2004). Sexuality in patients with amyotrophic lateral sclerosis and their partners. ***Journal of Neurology.***

Sexual Function in People with Disability and Chronic Illness: A Health Professional's Guide Marca L. Sipski and Craig J. Alexander (Aspen Publishers Inc.: 1997)

Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People Who Care About Them) Ken Kroll and Erica Levy Klein (Bethesda, MD: Woodbine House, 1995)



The ALS Association
1300 Wilson Boulevard
Suite 600
Arlington, VA 22209
www.ALS.org

About The ALS Association

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of care and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association is working to make ALS a livable disease while urgently searching for new treatments and a cure.