


LIVING WITH ALS 2  
RESOURCE GUIDE



# After the ALS Diagnosis: Coping with the “New Normal”





# **AFTER THE ALS DIAGNOSIS: COPING WITH THE “NEW NORMAL”**

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***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.

**Living with ALS**  
**After the ALS Diagnosis:**  
**Coping with the “New Normal”**

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## TABLE OF CONTENTS

INTRODUCTION .....	2-4
COPING WITH THE DIAGNOSIS .....	2-5
TRUSTED SOURCES OF INFORMATION .....	2-7
BEGINNING YOUR NEW JOURNEY .....	2-8
HOW TO COPE WITH ALS DAY-TO-DAY .....	2-9
FINDING MEANING .....	2-10
TALKING TO LOVED ONES ABOUT THE ALS DIAGNOSES .....	2-11
RESOURCE AND SUPPORT GROUPS .....	2-14
INTIMACY AND SEXUALITY WITH YOUR PARTNER .....	2-15
FAMILY PLANNING AND ALS .....	2-20
A LOVED ONE AS A CAREGIVER .....	2-21
MINDFULNESS .....	2-26
REFLECTIONS .....	2-27
BECOMING AN ALS ADVOCATE .....	2-28
HOW THE ALS ASSOCIATION CAN HELP .....	2-30
SUMMARY STATEMENT .....	2-30
RESOURCES .....	2-34
BIBLIOGRAPHY .....	2-36

## INTRODUCTION

ALS can be difficult to diagnose. The onset may initially be so subtle that the symptoms are overlooked. The journey leading to the diagnosis may be long in many cases 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 some cases, the definitive diagnosis may be determined more quickly. 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 your thoughts, feelings, responses, and coping strategies.**

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?

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

Perhaps you remember that it felt as if someone had kicked you in the stomach, leaving you breathless. It may have felt as if time stopped. Maybe 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 a very individual process.** Everyone responds differently when life throws him or her a curve ball. Some may bounce back, “by hitting that ball back” and go on making 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 learn your diagnosis.** It is important to remember that it does not mean you cannot have a life; it means that you need to go about your life differently and make 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. People 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 future will certainly arise.

*I was in shock...life changed forever.*

(Contributed by The ALS Association Alabama Chapter)

*It felt like I had been hit with a sledgehammer.*

(Contributed by The ALS Association Golden West Chapter)

*I went through a process. First I didn’t know what ALS was. The first few doctors I saw, including a world famous ALS expert, didn’t take the time to explain it to me. Then I went through about six months of hope, traveling the country, hoping I was going to find a doctor who could cure me. Then there was deep sadness as I accepted that I was going to die from ALS at some point.*

David Adox (Contributed by The ALS Association Greater New York Chapter)

There is no doubt the diagnosis of ALS can be devastating to the individual and his/her loved ones, but **it does not mean it is the end to all hopes and dreams.**

*Now is the time to live. We have ALS, but ALS does not have us.*

Greg, living with ALS, and Kathy Sizemore, his wife and caregiver.  
(Contributed by The ALS Association Central and Southern Ohio Chapter)

*Quite frankly I'm tired of being the sick one waiting and wondering where this monster will stage the next heist. 'Get busy living or get busy dying' -- a favorite quote from Shawshank Redemption. I've been living like I was dying. Now I'm ready to live like I am living. Time to re-engage. The shift will really take place in my head as my friends and family will probably not see a major change in my day-to-day activities.*

Shelly Hoover  
(Contributed by The ALS Association Greater Sacramento Chapter)

*Hello, my name is Natalie. I was diagnosed with ALS in July of 2012. At the time I was pursuing a degree in Nursing as well as tending to my family. I have truly been blessed with six great kids, ages 5-15, and an amazing husband, Neil. My initial reaction was what one might expect: I was extremely scared, but with the grace of God I have been blessed with a gift of peace that has shown me that everything will be okay. I try to faithfully live in the moment, taking one day at a time, thankful for each new day. It is with the help of my community, family, friends, and the ALS Association Rhode Island Chapter that makes this much easier! My family and I are truly grateful!*

Natalie Swift, person living with ALS  
(Contributed by The ALS Association Rhode Island Chapter)

When you learn you have ALS, you also learn there is no cure 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 there have been options for people with other diseases. While outcomes may not always be good for these other diseases, at least there are treatments. However, much has changed in the care and treatment of ALS and there have been important advancements in understanding the disease and helping to manage it, despite having no cure at this time.

*Every day that you wake up is a good day and one more day closer for all the wonderful doctors who are working towards a cure for this devastating disease. NEVER GIVE UP HOPE!*

Debbie Robl (Contributed by The ALS Association Wisconsin Chapter)

Many people with ALS have suggested that it helps to **maintain a positive, determined, and optimistic attitude.**



*Time now means something different to me than to most people. I try to find the happy in each day and choose to live in the moment by focusing on what I have and what I can still do. I think I've become a far better person who is more empathetic and takes the time to listen. Everybody is battling something, so tread lightly, go carefully, be gentle. We're all just walking each other home.*

Paul Weisman (Contributed by The ALS Association Greater New York Chapter)

*Todd was also known for his incredible inner strength and determination, so he immediately made the conscious decision to fight; he was determined he was going to beat the disease, not let it beat him. He was going to LIVE with ALS.*

Excerpt from Ticket To Freedom: The Todd Kumnick Story  
(Contributed by The ALS Association Florida Chapter)

*When people ask how I'm doing, I say "Physically challenged but BLESSED BEYOND BELIEF."*

Litracy Mitchell, person living with ALS  
(Contributed by The ALS Association Kentucky Chapter)

With the fast advancement of scientific technology and neurological research, **there is more hope now than ever before** that more and better treatment options will be available. These facts give hope, but 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.**

*We could never have had the quality of life together and positive perspective that we enjoyed without all the support of information, planning, medical help ideas, equipment, and genuine caring from our local ALS chapter.*

David and Cindy Amerine  
(Contributed by The ALS Association Northern Ohio Chapter)

## TRUSTED SOURCES OF INFORMATION

While many people may have been familiar with ALS prior to their diagnosis, some may not have heard about it at all, or may only be familiar with the term **Lou Gehrig's Disease**, named after the famous New York Yankees baseball player who had ALS. Even if familiar with the term, many people do not understand the complexities of the disease. Following the diagnosis, most people start searching for information from various sources. It is important to find trusted sources of information:

- **Start by talking to your doctor and your medical team** and ask what physical, mental, and/or 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 (National website), your local ALS Association chapter, ALS Association certified treatment 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 Diseases (NORD), Northeast ALS Consortium (NEALS), and university medical center websites. You can also find information about clinical trials by going to [www.clinicaltrials.gov](http://www.clinicaltrials.gov). The website ALS Untangled (<http://alsuntangled.com>) offers a scientific review of alternative treatment options.

These resources can provide information that is accurate, will answer your questions, ease concerns, and direct you to other local and national resources.

**Be aware that knowing the facts about ALS may also increase your level of anxiety, which is why it is important to meet with an ALS specialist or ALS interdisciplinary team of healthcare professionals to help you sort through the information.** The 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 along with accessing services, support, and education appropriate to each stage of the disease.

*The positive, caring, informative staff; they ALL were exceptional. We learned so much. We left feeling hopeful rather than helpless.*

(Contributed by The ALS Association Mid-America Chapter)

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, you must be proactive and take control of your own care. 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 avoid talking about ALS altogether. Conversely, you might think a lot about ALS and feel like it is overwhelming your brain.

You might feel very angry that this happened to you or your loved one. You might also become curious about the diagnosis, questioning and searching for answers.

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

### ■ “What can I do differently to change this?”

And you might feel sad, hopeless, or depressed.

You may have heard there are steps or stages one goes through to gain acceptance. Many researchers have described 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 are out of our control. You may experience any number of these reactions on your journey towards acceptance.

*Now that I have accepted my illness, you can usually see a smile on my face. I've been told it's a good smile, so why not smile. I still have bad days, but I am mostly in good spirits. I try to live a normal life. I enjoy doing things an abled-bodied person enjoys doing. I enjoy going to local sporting events, going to movies and restaurants, and listening to live music. For the most part getting around Cedar Rapids and local cities is no problem accessibility-wise, which is excellent. It allows me to do things a normal person can do.*

Excerpt from Troy Musser Rockwell Speech  
(Contributed by The ALS Association Iowa Chapter)

**We hope you can find a way to be kind to yourself in this journey and allow your feelings to come and go, recognizing that your feelings 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 questions are:

### **How Do I Live with ALS? How Do I Cope with Life Now?**

The most important step of living with ALS 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 fuller and enjoyable life.

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

- **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. Don't let ALS take away your 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, other professionals on your healthcare team, 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 healthcare provider hasn't already done so, request that he or she refer you to the nearest ALS clinic. Your providers 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 Resource/Support Group.** You don't have 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 ALS Association chapters and other local agencies may have support groups.
- **Plan Ahead.** Planning for the future allows you to be in control of decisions about your life and your care. Work with your healthcare team 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. You may also want to consider formalizing advance directives and assigning a power of attorney.

## FINDING MEANING

### Your 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 well-being is the concept of meaning. Our values are what hold meaning for us and ultimately what guide our behaviors, our relationships, and our accomplishments.

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 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 and these may change or become enhanced during the progression of ALS. For some people, as ALS progresses, the ways they participate in activities might change as well. For example, someone who values being in nature and went on hikes every weekend prior to diagnosis, may still find ways to get outside and enjoy nature, even if it is just to observe the beauty surrounding him or her.

## Religion and Spirituality

Religion or spirituality may become an integral part of your ALS journey. Like all 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 for conversations you want to have. It is common for these conversations to include topics or questions of purpose, relationships, higher power, afterlife, etc.

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 without spiritual practices or religion, you can find ways to continue to live your values and find communities that support them.

*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, p. 21)

## TALKING TO LOVED ONES ABOUT THE ALS DIAGNOSES

People respond to news of ALS in their own unique way. Keep in mind that any emotion or reaction is normal. Many people who 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. As a result, some people may even become more distant or limit contact. **There is no right or wrong way to feel about sharing and receiving the news.**

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 to provide you with the type of care and communication you want for yourself.

### 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, to worry about how they will be affected by your emotions, and to feel unsure about their ability to understand what's happening. **It is important to tell your children about ALS because they may sense something has changed, become concerned or anxious, and without good information, imagine a wrong explanation.**

Children may grieve not only because their parent is ill, but also because of the many small changes that may result from ALS, such as changes in their 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. Tell the truth about the disease using simple, age-appropriate language.**

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

It's 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 the school guidance counselors and teachers about ALS. You might also **ask your local ALS chapter for resources in your area that exist to support children through a parent's serious illness.**

**Table 1 gives a simple outline of coping 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 (Providence Hospice of Seattle's Safe Crossings Program for Grieving Kids and Teens, 2011).

## Parenting and ALS

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

- **Dedicate time** to spend with your children and give them your undivided attention. **Enjoy simple activities** that you enjoy together and are easy for you to handle.
- **Try to maintain 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 to make them feel involved.** Accepting outside help, however, with household chores allows you more 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.
- **Provide information in a way that is comfortable and manageable for you.** Do not hesitate to ask for assistance from professionals. You do not have to do this on your own.

**Table 1:** Coping Behaviors and Ways to Support Children at Different Stages of Development

Age	Characteristic	Ways to Support
Infants and Toddlers 0-2 Years	<ul style="list-style-type: none"> <li>• Have no understanding of time or finality of death.</li> <li>• Are sensitive to separation and might be distressed by changes in regular routine.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide care in consistent and predictable ways.</li> <li>• Maintain a routine (e.g., feeding, diapering, bathing, and sleeping).</li> <li>• Use the same equipment (e.g., bottles, cups, stuffed animals, toys, and blankets).</li> </ul>
Preschool 3-5 Years	<ul style="list-style-type: none"> <li>• Because language is not yet mastered, feelings are often seen in behavior.</li> <li>• Grief responses are intense but brief.</li> <li>• Are highly aware of parents' reactions.</li> <li>• Often regress in behavior and skills.</li> <li>• Do not yet have an understanding of irreversibility of death.</li> <li>• Have difficulty separating fantasy from reality, or believing that they can affect events by wishing or thinking something.</li> <li>• See the world as it relates to them (egocentrism).</li> </ul>	<ul style="list-style-type: none"> <li>• Provide comfort and reassurance that they will be cared for. If there will be changes in who will provide care, share specific names and any other details.</li> <li>• Continue to meet basic needs, such as healthy meals and snacks, consistent bedtimes, and other activities related to maintaining a regular schedule.</li> <li>• Regularly engage with preschoolers and provide honest information.</li> <li>• Use concrete and observable examples.</li> </ul>
School-age Children 6-12 Years	<ul style="list-style-type: none"> <li>• Are often immersed in acquiring physical, academic, and social skills.</li> <li>• May act as though nothing has happened, grieving in spurts.</li> <li>• Are often concerned about how and why their loved one became sick, and ask repetitive questions about this.</li> <li>• Exhibit regression in behavior and skills.</li> <li>• Wish to "fit in"; are more socially aware and concerned with how others are responding.</li> <li>• May desire privacy and not want information shared, i.e., with friends and teachers.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide clear, honest information regarding ALS.</li> <li>• Provide consistent answers to questions.</li> <li>• Encourage and validate the healthy expression of feelings.</li> <li>• Engage in physical activities as an outlet for grief expression.</li> <li>• Be available, but also allow alone time.</li> <li>• Inform appropriate school personnel but acknowledge that some children might not want to be approached about what is going on in their home.</li> <li>• Make sure children know who to contact within the school system should they need to talk.</li> </ul>
Adolescents 13-18 Years	<ul style="list-style-type: none"> <li>• Have a more complex understanding of death and loss.</li> <li>• Experience an emotional struggle between independence and dependence.</li> <li>• Are more likely to talk with someone outside the family.</li> <li>• May demonstrate grief through physical or behavioral expressions.</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage and validate the healthy expression of feelings.</li> <li>• Listen, listen, listen with openness.</li> <li>• Recognize and affirm their need for time alone and with peers.</li> </ul>

## RESOURCE AND SUPPORT GROUPS

**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.

**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 for people affected by ALS may be available in your area. **Check with your local ALS Association chapter 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 diagnosed with ALS. Some groups may combine both people with ALS and their loved ones.

For many people, support groups are an option, but you might not be ready to attend a support group. Sometimes it can be intimidating or scary early on, because you may see others at later stages of the disease. 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, or you may 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 you are not alone in dealing with the challenges that come with ALS.**

*It is with the great care of the staff at the Stonybrook ALS Association clinic, and with the annual updates on medical and advanced technology that are discussed at monthly ALS Support Groups that I have come to terms with, “I have ALS, ALS doesn’t have me.”*

Andre Williams (Contributed by The ALS Association Greater New York Chapter)

## **INTIMACY AND SEXUALITY WITH YOUR PARTNER**

Sexual health and sexuality are an important part of everyone’s well-being. 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. Your healthcare provider may be able to direct you to resources on creative, yet practical solutions for positioning. The need to express sexual desire is not eliminated, even if the practice is. Some people find comfort and satisfaction in other forms of intimacy.

ALS can also weaken an individual's **respiratory function**, making breathing more difficult, and therefore making sexual activity a strain. Noninvasive 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.

**The partner without ALS may also experience feelings and psychological symptoms that may 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 potential 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.

**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, however, can easily lead to avoiding sex and other intimate contact.

**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.

**The good news is that there are a number of considerations that could help with intimacy and make sex more enjoyable with ALS.** The first step to sexual health is acknowledging and understanding the sexual difficulties and talking about these challenges with your partner. The inability to discuss sex and intimacy with your partner can easily lead to an avoidance of sex and other intimate contact.

## **Intimacy: Find What Works Best for You**

Depending on the stage of the disease, creativity in the bedroom can help. A knowledgeable, sex-positive physical therapist or occupational therapist might also offer some good ideas about what could work best for each individual.

- **Be open with your partner.** One of the most important aspects of sex with ALS is communicating what you can and can't do, which can help both partners continue to feel loved, trusted, and wanted.
- **Be flexible.** Fatigue and tiredness are frequent concerns for people with ALS. This requires you to be more flexible about when you make love. Some people feel less tired in the morning while others find that the evening is the time of day when they are least tired.
- **Be creative.** Try different sexual positions to accommodate your body's changing abilities. Some positions are more comfortable than others. This is very much a matter of personal preference, so it would be helpful to experiment in order to find the most comfortable position for you. Some people find that sitting or lying in an upright or semi-upright position enables them to breathe more freely. This might mean that positions on a sofa or in a comfortable chair are more supportive. If you have restricted movement, it might be necessary for your partner to take a more active role to enable you to be comfortable. Whatever you try, a willingness to laugh together while you experiment can help to maintain intimacy.

- Experiment with positions that minimize weight-bearing or tiring movements. It is helpful to experiment with less demanding sexual positions.
  - If you are in a wheelchair, consider a model with removable arms to help facilitate greater closeness.
  - Use a waterbed to relieve pressure on joints and to minimize weight-bearing positions.
  - For a person with bulbar ALS who has difficulty controlling saliva, adopting a sexual position on his/her side or a more upright position supported by pillows can reduce awkwardness or embarrassment.
- **Find alternate methods of communication.** Sex is often a time when people can express themselves without having to talk, so in one respect it might not be such a problem if you have lost your ability to speak. However, you might want to develop a sign language or a personal code that has a special meaning for you as a couple and can also be used at other times of the day.

*“The intimacy in sex is never only physical. In a sexual relationship we may discover who we are in ways otherwise unavailable to us, and at the same time we allow our partner to see and know that individual. As we unveil our bodies, we also disclose our persons.”*

Dr. Thomas Moore, “Soul Mates,” *Psychology Today* (Mar/Apr 1994) pp. 28, 29.

- **Consider alternate ways to be intimate.** In addition to, or in place of, trying new positions, other intimate activities (holding hands, hugging, kissing, massage, cuddling, caressing) can help partners feel connected.
- **Be adventurous and explore new ways to experience sex and sensuality.** Many people find it helpful to rediscover the sensual areas of their body by gently exploring the whole body and identifying the areas that are pleasurable by altering the pressure and rhythm of touch. It is important to learn about the whole body and not just areas that are commonly associated with sexual pleasure. The purpose is to learn about each other’s preferences, likes, and dislikes. This process is called body mapping and can be done either alone or with a partner. If done together, it provides an opportunity to learn (or re-learn) what each other finds stimulating and pleasurable. Some people may prefer to use touch or kiss, lick, or nibble each other’s bodies to discover what each other enjoys. The process can help improve communication and understanding between couples.
- **Incorporate relaxing elements into sex.** Add massage and soothing caresses into your sexual activity to calm your muscles and give them a chance to relax. You could also take a warm shower/bath before (or during) sex. Additionally, bathing in warm water prior to the sexual activity may reduce spasticity and relax muscles and joints.
- **Talk to a healthcare professional.** The sexual health concerns of persons with disabilities need to be taken into account and addressed. Compared

to other rehabilitative specialties, little research on sexual rehabilitation is available. Many healthcare professionals don't initiate the conversation and mention sexuality to people because they are either uncomfortable with the subject, worried about being intrusive, or because they believe that people would ask if they had any concerns.

The American Occupational Therapy Association (AOTA, 2008) has categorized sexual expression—defined as “engaging in desired sexual and intimate activities”—as an Activity of Daily Living (ADL). This places it in the same realm as dressing, eating, and toileting in terms of activities to focus on during rehabilitation (Friedman, 1997). It is very appropriate for you to talk to your healthcare professional about any concerns you have regarding sexuality. Choose someone you feel comfortable talking to about this subject. If they are unable to answer your questions or discuss these matters with you, they could refer you to someone who is able to help.

## Sexual Health Professionals

There are a number of different appropriate clinicians involved with individuals with ALS who can discuss sexuality with them (MacHattie, E., Naphtali, K., Disabilities Health Research Network 2009).

**Sexual Medicine Physicians or Psychiatrists (MD):** Are specialized doctors who can assist with maximizing sexual physiology by reducing the medical issues that often interfere with sexual interest and activities, for example, medications, pain, bladder and bowel continence, and spasm. These physicians can refer clients to other healthcare professionals as needed.

**Occupational Therapists (OT):** Help clients to manage and perform daily activities. OTs can address issues around sexuality by teaching skills such as how to organize a daily routine to allow time and energy for sexual activities, manage personal hygiene before and during sexual activities, compensate for reduction or loss of typical body functioning in order to sexually satisfy self and/or partner, and alter or eliminate environmental barriers to improve the quality of sexual activity (e.g., poor lighting, inadequate bed system, etc.). OTs can also adapt sexual devices to meet the abilities of clients (e.g., adding switches, making ‘hands-free’ options, etc.).

**Physiotherapists (PT):** Address clients’ physical function. They can educate and assist clients with skills such as transferring from wheelchair to bed, repositioning in bed, maintaining balance, managing spasm, and maximizing comfort in sexual positioning alone or with partners.

**Nurses (RN):** Can assist with the execution of many of the suggestions given by the OT, PT, or MD and are critical in assisting with the overall medical management of a disability. **Sexual Health Clinicians (SHC)** are nurses specialized in the area of sexual health. They are experts in educating clients and their partners on the complex changes to sexual function as a result of chronic illness or disability, and are qualified to make specific suggestions to enhance sexual functioning and/or fertility.

**Social Workers (SW):** Can play a large role in educating and counseling partners and families around sexual and fertility issues. Social workers can also assist with funding options for the purchase of equipment.

**Psychologists:** Explore in depth with clients the many different emotional components of sexuality such as self-esteem, assertiveness, and positive self-talk, as well as collaborate with partners and family around sexual and fertility issues. Psychologists can also address trauma around sexuality.

**Recreation Therapists:** Work with clients to explore meaningful recreation and leisure choices. Using client interests ranging from creative arts and drama to physical recreation and sport, recreation therapists connect people with community-based resources that help build confidence and increase opportunities for social interaction. Friendship development through involvement in recreational activities of mutual interest is often key to deepening existing relationships or meeting potential partners.

**Peer Counselors:** Persons with disabilities themselves are critical sources of information and support. They are the experts on what their bodies experience. They also have experience accessing different resources in the community and can share suggestions on what has or hasn't worked for themselves or other clients.

While not much has changed in terms of sexual-health training for healthcare professionals, recent studies, books, and articles in the area of sexual rehabilitation recognize that "sexuality and disability" is an important area to be addressed. However, there are still limited resources that offer specific, practical suggestions for clients and clinicians.

## FAMILY PLANNING AND ALS

When individuals are diagnosed with ALS later in life, the question of having children after the diagnosis is not an issue for many. But for those who are faced with this diagnosis at a relatively young age, they may have to deal with the difficult decision of whether or not to have children despite the diagnosis.

While some couples choose not to even consider this option, others feel that having children is the best decision they have to make. This is a very personal decision. For some couples, having a child when one person has an illness that's likely to drastically shorten life isn't appealing and can be overwhelming. For others who want to consider children, there are many factors to consider. All aspects of the decision have to be carefully weighed, including the type of ALS, the willingness and ability of the family caregiver to handle the added responsibilities, financial considerations, and the best interests of the child, among others. Additionally, for women with ALS, pregnancy may worsen the symptoms of the disease, and the weakened respiratory and abdominal muscles can pose some special risks during childbirth. Please talk to your healthcare provider about the best birth control options for you if you decide not to have children and want to prevent unwanted pregnancies.

Alternatively, some couples may consider taking advantage of the advances in the reproductive field and the many options that can help preserve their fertility and allow them to have a family in the future. There are several options to preserve fertility for both women and men. The choice of which option is best for you depends on age, overall health, and your willingness to use donor eggs or sperm. The most commonly used preservation options with successful published results are embryo freezing, egg freezing, and sperm banking. These interventions can be costly and may not be an option for everyone.

Regardless of the method, the decision to have children in the face of the ALS diagnosis should be given serious consideration. It is highly recommended that couples discuss all the ramifications of their decision before going ahead.

## A LOVED ONE AS A CAREGIVER

*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

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.

*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

## 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.

For 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.

*The most difficult is to figure out how to stay a wife, as I become more of a caregiver. The loved ones' group helps me identify this need and explore ways to keep my marriage at the forefront when possible.*

Kim (Contributed by The ALS Association Golden West Chapter)

## 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 about handling 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.**

**Check for environmental/home safety.** Most of the 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, however, can help you plan ahead and make changes to accommodate future needs.

**Research 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.

**Get 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.

These lists and other necessary 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. To coordinate care, try using a shared calendar with family members and friends who may assist with caregiving and provide respite.

**Complete advance care planning.** This is the process that allows you to make decisions about the care your loved one would want to receive if he/she were unable to communicate. In most of the cases with ALS, caregiving happens gradually. Most of the time, people with ALS make their own care decisions, but there may be instances when a caregiver needs to act on his/her behalf. Knowing and understanding your loved one's values and wishes and having an open communication will be important as you become more responsible for making decisions for them. This is why advance care planning is important.

- **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. Details about living wills and powers of attorney are covered in The ALS Association's resource guide, *Living with ALS: Planning and Making Decisions*.

**Look for community resources.** Look for local resources available in your area. Contact the local chapter of The ALS Association in your area or other organizations that may offer services to assist you. These may include meal delivery providers, 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's important to note that while a caregiver does not have the disease, many of the same emotional stages the person with ALS goes through will be experienced.

**As caregivers, we have to remind ourselves of the importance of our own desires, goals.** Maintaining a balanced outlook on life and taking care of yourself, which some fear being selfish, is necessary for both your sanity and well-being. Caregivers are often too busy caring for others that they tend to neglect their own emotional, physical, and spiritual health. The demands on a caregiver's body, mind, and emotions can easily seem overwhelming, leading to stress, fatigue, hopelessness, and ultimately to burnout.

**There are many factors that cause caregiver's stress, which eventually leads to burnout.** Besides the household disruption, financial pressure and the added workload, the following are common factors:

- **Role confusion or change in the family dynamic:** It is often difficult for a person to separate the caregiver role from that of a spouse, lover, child, friend, etc.
- **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, especially if the loved one with ALS is showing behavioral changes.

- **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:

- Anxiety
- Depression
- Irritability or overreacting to minor nuisances
- Difficulty sleeping
- New or worsening health problems
- Feeling tired and run down
- Trouble concentrating
- Feeling increasingly resentful
- Drinking, smoking, or eating more than usual
- Neglecting responsibilities
- Cutting back on leisure activities

### Common signs and symptoms of caregiver burnout:

- 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
- Feeling helpless and hopeless
- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Changes in appetite, weight, or both
- Changes in sleep patterns
- 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's 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:

- Educate yourself about ALS to better understand the disease, current treatments, and what to expect.
- 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 **activities and relationships** that bring you joy.
- 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 his/her ability to provide care. It hurts both the caregiver and the care recipient. **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 receives care.**

As much as it is said, and it still cannot be said too often, the best way to be an effective caregiver is to take care of yourself and seek respite.

*ALS is very demanding on caregivers and loved ones. Remember that you are just human and no one is perfect. Forgive yourself for the mistakes and just try to do the best you can. Taking breaks to do self-care will help you support your loved one for the ever changing demands of ALS.*

Jacqueline (Jackie) Tripi Pfadt, daughter of person with ALS  
(Contributed by The ALS Association Northern Ohio Chapter)

## 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 being cared for by another caring individual.

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, residential facility, or hospice care center.

*Consider using volunteers to allow for time away. Burn out is very much real. I felt it at times. There are also grants available to assist in paying for resources that can make quality of life so much easier/better for all involved. You MUST take the time to be you. Life does continue. Dream big and bold!*

Husband and full-time caregiver of woman with ALS who recently passed away.  
(Contributed by The ALS Association Golden West Chapter)

## 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.

Worrying creates additional stress, however, and releases stress hormones and chemicals that may only make us feel worse. Take some 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 on all the worries and stress today or tomorrow might bring.**

Originally rooted in Buddhism, secular mindfulness practice has become widespread in our culture. At its foundation, mindfulness meditation is about setting the intention of being present and non-judgmental of one's emotions, thoughts, and sensations in the present moment.

Some people find mindfulness meditation is a tool they can use easily, while others might feel like 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 *Mindful Self Compassion* in the Resources section at the end of this guide).

Here is one example of a meditation. It can be adapted to any position, including lying in a bed or sitting in a wheelchair.

### Exercise: Meditation

1. With both feet on the floor and a relaxed body, allow 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 breathe in.
5. Gently breathe out.
6. You might allow yourself in this moment to feel safe, to feel loved, to feel whole, and to feel at peace.

## 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 setting and achieving goals need to stop. As you continue to set goals and think ahead to how you want to live your life, you might also find it helpful to spend time reflecting on the things you have 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. Here is an exercise for you to try:

### Exercise: Reflective Questions to Ask 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 of 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?
- What are the positive things in your current life? What are you most grateful for?
- What are the things that went well today? What about you caused those good things to happen?

**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 think about the negative things that happen in life. If we allow ourselves to also let in the positive, however, we are actually able to rewire our brains towards optimism (Seligman, 2011).

## BECOMING AN ALS ADVOCATE

One of the missions of The ALS Association is **nationwide advocacy**. An ALS Association Advocate is a fighter in the battle to defeat ALS; 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; and someone who is willing to effect real change in the way our government responds to the needs of the ALS community.

*We were impressed with the organizational effort put forth by the national ALS Association. We met with five representatives and their aids to ask for continued support with initiatives like Department of Defense funding, the Steve Gleason Act, the National ALS Registry, and abandoned therapy support. As a person with ALS, it's an honor to be associated with such a fine organization. I know that the ALS Association is my partner in battling this disease. Only with such a concerted effort to get the word out about ALS will progress to be made against this disease.*

(Contributed by The ALS Association Greater Chicago Chapter)

You can open doors through your outreach to your legislators and make your voice heard. As an ALS Association Advocate, you can help change the laws and policies that affect thousands of persons with ALS and their families.

You may also ask to be nominated for the ALS Clinical Research Learning Institute (CRLI), sponsored by the ALS Association's TREAT ALS initiative. It is an

annual two-day program dedicated to educating attendees on clinical research and therapy development and empowering this group to be advocates for ALS clinical research. Becoming an ALS Research Ambassador provides individuals with ALS and their families a new way to join the fight to find a cure for ALS.

**Becoming an ALS Advocate or an ALS Research Ambassador may give you a purpose, a reason to fight for your rights and those of others.** Talk to someone at your local ALS Association chapter to find out more.

*The public policy advocating event in D.C. this past May was the most emotionally grueling experience in my life. I would much rather have been back in combat in Iraq than experiencing the D.C. advocating event. That being said, as a person living with ALS, I completely understand the importance of advocating and would gladly attend again as much as I am able.*

Justin Dodson, Veteran and person living with ALS  
(Contributed by The ALS Association Greater Chicago Chapter)

*Our goal for Advocacy Days was to meet our members of Congress, tell them our story, and ask for their support for bills assisting ALS patients. It was a very enlightening and exhausting few days. I was very honored and privileged to be a part of the cause for awareness and to make a difference for people fighting ALS.*

Excerpt from Troy Musser Rockwell Speech  
(Contributed by The ALS Association Iowa Chapter)



## HOW THE ALS ASSOCIATION CAN HELP

We encourage you to reach out to your local ALS Association chapter to learn more about what they can offer you and your loved ones. Local chapters can provide information and resources that could benefit you and your loved ones.

The local chapters may also provide **resources/support groups, durable medical equipment, caregiver support, respite programs, transportation assistance, or assistance with technology**. Often chapters have employees who will consult with you on the phone, via video, email, or text, or even come to your home. The staff at The ALS Association is knowledgeable about local resources, centers, providers, vendors, and others who are dedicated to supporting people dealing with ALS.

Each chapter 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 ALS 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 STATEMENT

*No doubt ALS has been my greatest challenge. No need to list the losses and fears. Yet, there's an immeasurable upside. I've met the most courageous, generous, and loving people that I never would have met without ALS. When you or a loved one is faced with an untreatable, debilitating disease, you have permission to let go of your inhibiting filters and simply love. It's demonstrated by people with ALS as they courageously face each day with grace and encourage others to do the same. It's demonstrated by caregivers and family members who sacrifice everything to give their loved ones what they need. It's demonstrated by service providers, healthcare professionals, and scientists who are whole-heartedly devoted to finding an effective treatment or cure.*

Shelly Hoover (Contributed by The ALS Association Greater Sacramento Chapter)

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, that 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, what you are about, or what is important to you. It has no respect for what you have accomplished or what you are working towards.

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 renewal of hope and finding new meaning in your life in the present.**

We grow in understanding, spirit, and wisdom as we live, and hope enhances our capacity. 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: More 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 (oftentimes 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.”*

*“Our ALS Association chapter provided us with a ton of equipment. The support and information they provided us throughout the journey were 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 to do other than caregiving helped me to 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.” – A.T.*



## RESOURCES

### ALS-Specific Websites

#### ALS Forums and Chat

Open support community for people affected by ALS/MND.

[www.alsforums.com](http://www.alsforums.com)

#### Care Connection

A network of community volunteers who provide the person with ALS, the family, and caregivers with help for day-to-day responsibilities.

<http://www.alsa.org/als-care/caregivers/care-connection.html>

#### Information for Teens / Young Adults

ALS Society of Canada's als411 resources for teens/young adults (also available for order in print).

<http://www.als411.ca/eng/teens/resources.html>

#### ALS Activity Book for Kids

<http://webst.alsa.org/site/DocServer/ChildrensActivityBook.pdf?docID=72224>

#### Sex and Relationships

Motor Neurone Disease Association (MNDA) information sheets, one for people living with MND (ALS) and one for partners.

<http://www.mndassociation.org/about-mnd/living-with-mnd/relationships-and-family>

ALS Society of Canada's information sheet, *Sex, Intimacy and Chronic Illness*.

<https://www.als.ca/sites/default/files/files/Sexuality,%2520Intimacy%2520And%2520Chronic%2520Illness.pdf>

### Other Helpful Online Resources (not ALS-Specific)

#### Arch Respite

A website that can help you find respite.

<http://archrespite.org/>

#### Authentic Happiness

Created by researchers at the University of Pennsylvania, it contains questionnaires, including a Values Inventory Assessment (VIA), which help you identify your values and character strengths. Knowing what is important to you is helpful in making any decisions about how you want to live your life.

[www.authentic happiness.com](http://www.authentic happiness.com)

#### The Caregiver Space

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

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

#### Caring Connections

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

<http://www.caringinfo.org>

#### Caring Bridge

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

[www.caringbridge.org](http://www.caringbridge.org)

#### Christopher and Dana Reeve Paralysis Resource Foundation

Created in 2002, it provides a comprehensive, national source of information for people living with paralysis and their caregivers. The PRC is a one-stop center that offers information quickly and compassionately.

[www.paralysis.org](http://www.paralysis.org)

#### Family Caregiver Alliance

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.

<https://www.caregiver.org>

#### Help Guide

This website focuses on common mental and emotional health issues and information that supports their healing.

[www.helpguide.org](http://www.helpguide.org)

#### Lotsa Helping Hands

An online tool that organizes a community to help a caregiver.

<http://www.lotsahelpinghands.com>

#### Mindful Self-Compassion

Started by clinical psychologist Christopher Germer, this site has information about the practice of mindful self-compassion, as well as free guided meditation downloads.

[www.mindfulselfcompassion.org](http://www.mindfulselfcompassion.org)

#### Mindful—Taking Time for What Matters

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

[www.mindful.org](http://www.mindful.org)

#### The National Alliance for Caregiving

[www.caregiving.org](http://www.caregiving.org)

### The National Family Caregiver's Association

<http://caregiveraction.org/>

### PleasureAble—Sexual Device Manual for Persons with Disabilities (Authors: Kate Naphtali and Edith MacHattie, Disabilities Health Research Network, 2009).

[http://www.dhrn.ca/files/sexualhealthmanual\\_lowres\\_2010\\_0208.pdf](http://www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf)

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

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

<http://safecrossingsfoundation.org>

### Rare Caregivers

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

[www.rarecaregivers.org](http://www.rarecaregivers.org)

### Sex and Disabilities Information—Disability Sexuality (Author: James Kirby, 2012)

<http://www.disabled-world.com/disability/sexuality/disabilities-sex.php>

### UpToDate

The premier evidence-based clinical decision support resource, trusted worldwide by healthcare practitioners to help them make the right decisions at the point of care.

<http://www.uptodate.com/home>

## Books

### ***Caregiving: The Spiritual Journey of Love, Loss and Renewal***

By: Beth Witrogen McLeod

ISBN: 0471254088

Publisher: Wiley and Sons Publishing, 1999

### ***How to Help Children Through a Parent's Serious Illness***

By: Kathleen McCue

ISBN 0-312-11350-1

Publisher: St. Martin's Press, New York, 1994

### ***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, 2004

### ***Straight Talk About Death for Teenagers***

By: Earl A. Grollman

ISBN 0-8070-2500-3

Publisher: Beacon Press, Boston, 1993

### ***Last Touch—Preparing for a Parent's Death***

By: Marilyn R. Becker

ISBN 1-879237-34-2

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

### ***Talking about Death: A Dialogue between Parent and Child***

By: Earl A. Grollman

ISBN 0-807023-63-9

Publisher: Beacon Press, Boston, 1991

### ***The Caregiver's Survival Handbook***

How to Care for Your Aging Parent Without Losing Yourself

By: Alexis Abramson

ISBN: 0399529985

Publisher: Penguin, 2004

### ***We Are Not Alone; Learning to Live With Chronic Illness***

By: Sefra Robrin Pitzele

ISBN 918351-01-4

Publisher: Thompson and Co, Minneapolis, MN, 1985

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The following is a list of topics covered in the *Living with ALS* resource guides:

### ***Resource Guide 1***

#### **What is ALS? An Introductory Resource Guide for Living with ALS**

This resource guide provides an overview of ALS, what it is, and how it affects your body. It provides information on what kind of resources are available to help you deal with ALS more effectively.

### ***Resource Guide 2***

#### **After the ALS Diagnosis: Coping with the “New Normal”**

This resource guide addresses the psychological, emotional, and social issues that you must face when your life is affected by ALS. It provides information on how to cope with the many lifestyle changes and adjustments that occur when you live with ALS.

### ***Resource Guide 3***

#### **Changes in Thinking and Behavior in ALS**

This resource guide addresses how thinking and behavior may be affected by ALS and how these changes can impact disease course, symptom management, and decision making.

### ***Resource Guide 4***

#### **Living with ALS: Planning and Making Decisions**

This resource guide reviews areas where careful planning and decision making will be required and will provide you with resources to help you and your family plan for the future.

### ***Resource Guide 5***

#### **Understanding Insurance and Benefits When You Have ALS**

This resource guide provides strategies and helpful hints to better navigate health insurance and benefits. While understanding insurance and benefits may feel overwhelming, the guidelines outlined here should help simplify the process for you.

### ***Resource Guide 6***

#### **Managing Symptoms of ALS**

This resource guide discusses a variety of symptoms that may affect you when you have ALS. As the disease progresses, various functions may become affected and it is helpful to understand potential changes so that you know what to expect and how to manage these new changes and symptoms.



## ***Resource Guide 7***

### **Functioning When Mobility is Affected by ALS**

This resource guide covers the range of mobility issues that occur with ALS. It discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

## ***Resource Guide 8***

### **Adjusting to Swallowing Changes and Nutritional Management in ALS**

This resource guide will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

## ***Resource Guide 9***

### **Changes in Speech and Communication Solutions**

This resource guide covers how speech can be affected by ALS and explores a variety of techniques, technologies, and devices available for improving communication. By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control of your own.

## ***Resource Guide 10***

### **Adapting to Changes in Breathing When You Have ALS**

This resource guide explains how breathing is affected by ALS. Specifically, it will teach you the basics of how the lungs function, the changes that will occur, and how to prepare for the decisions that will need to be made when the lungs need maximal assistance.

## ***Resource Guide 11***

### **Approaching End of Life in ALS**

This resource guide examines thoughts and feelings about dying and end of life. Approaching end of life is difficult and support is critical to help sort out feelings, expectations, and plans. By talking to friends, family, professionals, and planning and communicating your wishes, you can help prepare for the best possible end-of-life phase.



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### **About The ALS Association**

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

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