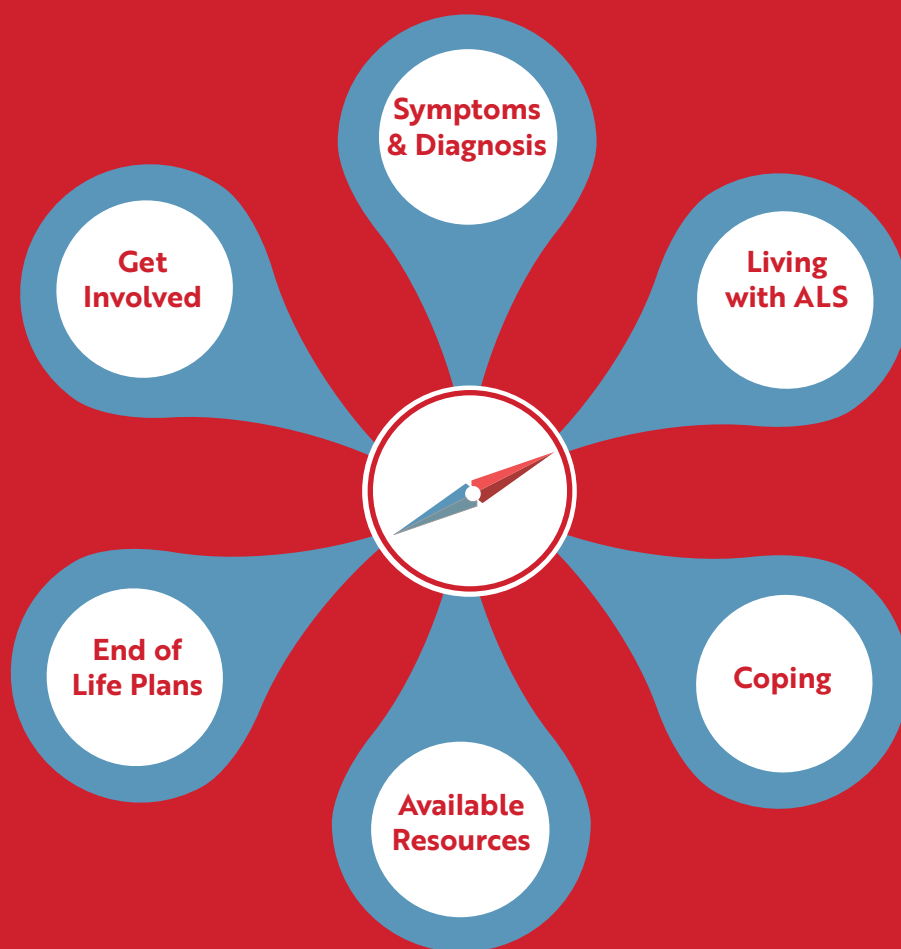




# NAVIGATING ALS

**This is Navigating ALS**, a comprehensive tool intended to raise awareness about ALS by offering information and guidance related to the many aspects of the disease. It is designed to provide an overview of what to consider when ALS has touched your life, personally or professionally. You'll find articles, infographics, useful links and more among the available resources.

Get started by selecting one of the six sections below or view the Index on the next page to find more specific topics.



# Welcome

Each of the six sections in this tool are divided into subcategories to help you more easily find the information you're seeking. You can navigate to any single section or subcategory simply by following the related link below. The icons in the lower left of each page (pictured at right) will return you either to the main page of the section you're reading, or to this index. If you have questions about any of the material presented in Navigating ALS please contact us at [info@alsmn.org](mailto:info@alsmn.org).



Section Main



Index Page

## **\* About Us** ..... 3

## **I Symptoms** ..... 4

<a href="#">Second Opinions</a>	5
<a href="#">Symptom Management</a>	6
<a href="#">Multidisciplinary Clinics</a>	13

## **II Living With ALS** ..... 14

<a href="#">About ALS</a>	15
<a href="#">Daily Living Activities</a>	16
<a href="#">Living Settings</a>	21
<a href="#">Reaching out to Family &amp; Friends for Help - Care Connection</a>	22
<a href="#">Treatment Options</a>	23

## **III Coping With ALS** ..... 24

<a href="#">Help With Coping</a>	25
<a href="#">For The Caregiver</a>	29
<a href="#">Leisure Activities</a>	32

## **IV Resources** ..... 33

<a href="#">Local Resources</a>	33
<a href="#">Insurance &amp; Finances</a>	34
<a href="#">Navigating Taxes</a>	38
<a href="#">Transportation</a>	39

## **V End of Life Plans** ..... 40

<a href="#">Hospice Care</a>	42
<a href="#">Final Plans</a>	42
<a href="#">A Peaceful Death</a>	40
<a href="#">Advance Directives</a>	41
<a href="#">Palliative Care</a>	43

## **VI Get Involved** ..... 44

<a href="#">Research</a>	45
<a href="#">Become an Advocate</a>	46
<a href="#">Fundraising Efforts</a>	47
<a href="#">Volunteer With Us</a>	48

# About Us

---

The ALS Association supports people living with ALS and their loved ones through services and education. Through our compassionate care and support, state and federal advocacy efforts, and contributions to global research, we're committed to building a future without ALS.

Our Care Services team is here to help, regardless of where you're at on your journey with ALS. They can be reached during business hours at **612.672.0484** or toll free at **888.672.0484**. You can also **email questions** to the team at any time. If you're interested in learning more about our service offerings beyond what you'll find in this booklet, please visit us online at [als.org/mn-nd-sd](https://als.org/mn-nd-sd) or follow us on **Facebook**.

---

## ALS Association Services

Below is a list of programs and services that are offered in the Minnesota/North Dakota/South Dakota Area. The affiliated links will take you to either another section of this tool or to our website to learn more. While both provide excellent overviews of each program, we encourage you to talk to your care team (and ours) about which options are best for you.

- **Hrbek-Sing Communication & Assistive Device Program**
- **Jack Norton Family Respite Program**
- **Durable Medical Equipment Loan Pool**
- **Home Safety Program**
- **Support Groups (both online and in-person)**
- **Family Assistance Program**
- **Smart Home Technology Program**
- **Lending Library**

---

## Disclaimer

*THIS DOCUMENT IS PURELY FOR INFORMATIONAL PURPOSES AND SHOULD NOT BE RELIED UPON AS A SOURCE FOR DEFINITIVE ACTION. ALWAYS CONSULT YOUR PHYSICIAN AND/OR CARE TEAM BEFORE MAKING DECISIONS THAT WILL IMPACT YOUR HEALTH AND WELL-BEING. THE INFORMATION PRESENTED IN THIS DOCUMENT HAS BEEN LEGALLY OBTAINED AND APPROPRIATELY SOURCED THROUGHOUT. IN THE CASE OF A DISPUTED SOURCE OR NOTICE OF UPDATED SOURCE INFORMATION, CALL 612.455.6156 OR **EMAIL US**. THIS DOCUMENT CAN NOT BE PUBLISHED OR REPRODUCED WITHOUT THE EXPRESS WRITTEN CONSENT OF THE ALS ASSOCIATION.*

## Symptoms and Diagnosis

Whether you have recently received a diagnosis or are seeking information about the process, this section will answer questions you may have. A good starting point is with our Multidisciplinary Clinics. Located throughout our region, they'll be your number one resource for all things related to an ALS diagnosis.

### Second Opinions

Due to the complex nature and broad range of symptoms associated with an ALS diagnosis, a second opinion is often recommended. View our second opinion FAQs to learn more about whether additional confirmation of this life-changing diagnosis should be considered.

### Symptoms and Symptom Management

The greatest challenge of living with ALS is how to live with it day to day. This section will review many of the challenges you may face. It offers a comprehensive look at the symptoms you might experience and ways in which you can improve the quality of your life.

### Multidisciplinary Clinics

The ALS Association Certified Centers specialize in the management, care and support of people with ALS, providing resources and clinical expertise that make it easier for individuals to cope effectively with ALS and live the highest quality of daily life. Learn more about the benefits of all-in-one services and explore listings of multidisciplinary clinics near you.



## Second Opinion FAQs

An interview with Rup Tandan, M.D., F.R.C.P., Professor and Vice Chairman of Clinical Affairs and Medical Director of The ALS Association Certified Center of Excellence in the Department of Neurological Sciences at the University of Vermont, Burlington.

### Is a second opinion worth the trouble?

Yes. If a patient wants a second opinion, he or she should get it. I actually recommend getting a second opinion because the diagnosis of ALS is so life changing. The only way a person can begin to accept such a diagnosis is to be certain that the diagnosis is correct, and ALS look-alike and ALS-mimic conditions are considered and excluded.

### How often is the first diagnosis of ALS wrong and the problem turns out to be something else?

In up to about 10 to 15% of the cases, patients get what we call a false-positive. That means they are told they have ALS, but, in the end, another disease or condition is discovered to be the real problem.

### Are some patients told they don't have ALS and then it turns out that they do?

Yes, up to 40% of patients are initially told they have another disease, and then it turns out they have ALS. Many conditions can mimic ALS. This type of a diagnostic error is called a false-negative error of diagnosis.

### What typically causes a delay in getting the right diagnosis and what is the impact of getting a delayed diagnosis of ALS?

An international study that surveyed physicians in the United States, Europe and Latin America showed that a delay in diagnosis typically occurs at three key times:

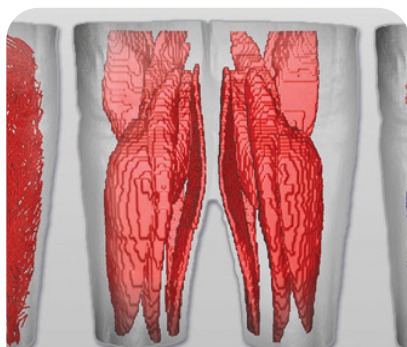
- At the onset of symptoms, some patients take up to six months to see a physician. Some patients do not see a neurologist right away, and it may take from three to six or seven months before they do so.
- Sometimes the neurologist doesn't give a diagnosis of ALS because the patient doesn't fulfill all the established diagnostic criteria of the disease, or the disease is atypical, or patients have not shown the expected progression of symptoms; in such cases, a delay in diagnosis of 3 to 4 months can occur.
- Depending on which of these factors combine to produce a diagnostic delay, it can take nine to twelve months before a diagnosis of ALS is made.



# Symptoms and Symptom Management

ALS shares common symptoms with a wide range of medical conditions, diseases and disorders. If you are experiencing any symptoms or behavior that you feel could be associated with a neurological condition, you should consult with a physician immediately. This section is designed to address the management of symptoms for those living with ALS.

Each of the six categories below provides in-depth detail about a specific set of symptoms, physical changes that you might expect, and ways in which to manage the process. Each person's disease progresses differently, so there is no predetermined order in which symptoms occur.



**Changes in  
Muscles**



**Difficulty  
Swallowing**



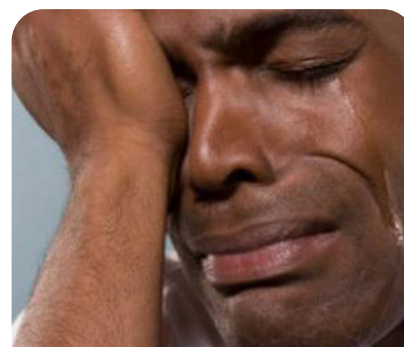
**Difficulty  
Speaking**



**Difficulty  
Breathing**



**Changes in  
Thinking**



**Emotional  
Lability**

**Pain in ALS** A factsheet, written by Ileana Howard, MD, Physical Medicine and Rehabilitation physician, provides an overview of several reasons that the weakness associated with ALS may cause pain, as well some strategies to help treat or manage pain symptoms associated with ALS.

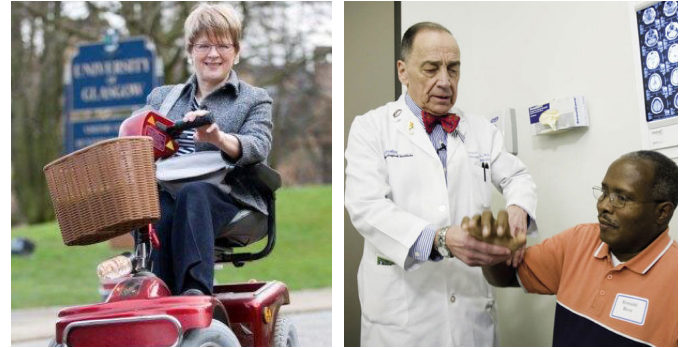
Our Care Services team is prepared to answer any questions you have regarding symptoms of ALS. However, if you haven't yet been diagnosed, it would be best to speak to your primary physician and possibly arrange a visit with a neurologist to evaluate your situation. If you have received a diagnosis and are seeking a second opinion, **refer to the FAQ section** earlier in this booklet.



# Changes in Muscles

As your ability to function changes, you can meet the challenges of maximizing your mobility, independence, safety, and comfort with the help of physical therapy (PT), occupational therapy (OT), or a physiatrist (physical medicine & rehabilitation physician). Staying informed about potential physical changes will allow you to better maintain function for extended periods.

Getting up out of a chair, going downstairs, walking to the corner store, and carrying groceries are some typical daily activities. Most people don't think about how much simple pleasure they get from these changes of scenery or from the independence of being mobile. Living with ALS causes you to pay attention to and come up with ways to maintain your everyday activities. The ALS Association has put together another **manual** in its Living With ALS series to provide detailed information on how to function when your mobility is affected. The information below is meant to supplement the depth of the booklet.



## Range of Motion Basics

Range of motion is the movement of a body part through an unrestricted and pain-free arc of movement. There are 3 forms of range of motion (ROM) programs designed by therapists. It may be an active program in which the individual independently completes the movement, Active-Assisted ROM in which the individual moves a body segment with the assistance of another person, or Passive ROM in which the individual has someone else move the body segment through the arc of movement.

The primary goal is to minimize or prevent development of joint contractures. A joint contracture is the tightening of tissues around a joint that prevents normal movement or flexibility of that body structure. Joint contractures are often painful and can interfere with safe mobility.

**Read more to learn** about additional benefits and guidelines of ROM programs.

## Muscle Weakness Q&A

Edward Kasarskis, M.D., Ph.D. is Director of the multidisciplinary ALS Center at the University of Kentucky Neuroscience Center in Lexington, Kentucky. He took time to answer some basic questions related to **muscle pain**, twitching and **fasciculations**. While a good introduction to the subject matter, you should consult with your care team for additional information.



Dr. Edward Kasarskis

**Follow [this link](#) or refer back to pg. 47 to learn our tips to help minimize fatigue.**

**10 Ways to Minimize Fatigue**

- 1) Learn methods of making every task easier. Use assistive devices when needed. See an occupational therapist for determining what is best for your needs. If you have trouble walking, don't resist getting a wheelchair. A motorized wheelchair will spare you the exertion of manually wheeling around in a standard model.
- 2) Pace yourself. Move slowly and easily. Stop and rest often and take a few breathers before you start again. If you become breathless during a task, it is time to stop. Schedule heavier task during predicted times of higher energy. Plan your activities and gather everything you need before you start. Don't stand when you can sit. Utilize possible shortcuts. Obtain assistance in completing tasks if you need help. Always allow enough energy to enjoy at least one valued experience each day.
- 3) Alternate activities with periods of rest. Schedule regular rest periods each day, perhaps a half hour after morning care and an hour in the early afternoon. Rest before going away.
- 4) Get a handicapped parking sticker. Your local DMV has the form that your physician will need to fill out.
- 5) Try to establish a regular sleeping pattern.
- 6) Avoid prolonged bathing in warm water, as it may worsen muscle fatigue. Be cautious of extreme temperatures.
- 7) Maintain your nutritional requirements each day, and prevent unnecessary weight loss.
- 8) Avoid stressful situations as much as possible. Understanding fatigue will help family members cope better with emotional upsets, realizing they are not personal attacks, but normal responses to fatigue.
- 9) If you feel noticeably weaker or have difficulty breathing after taking a medication, let your doctor know. Perhaps your medication needs to be substituted for another one or the dosage altered. Trouble breathing, however, may be related to breathing fatigue and may warrant an evaluation by your doctor.
- 10) Make your living environment accessible for daily activities, and promote energy conservation. Moving a bed to another location or relocating personal items are some examples.



## Adaptive Devices and Equipment

While ALS can result in muscle weakness that interferes with speaking, walking and/or other activities of daily living (ADL's), adaptive devices and equipment can assist you with: staying as independent as possible, helping you to conserve your energy and allowing you to partake in your daily living activities. Most people with ALS find that using a number of adaptive devices and durable medical equipment assists them in being safe and functional in performing their ADL's, mobility, and communication. Find out exactly how our team can help equip you with devices that will improve your quality of life through our **Durable Medical Equipment Loan Pool** and **Hrbek-Sing Communication and Assistive Device Program**.



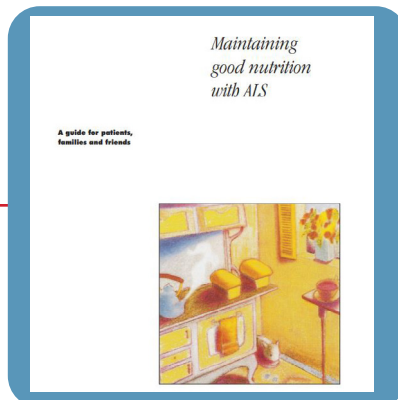


# Difficulty Swallowing

The majority of us take the acts of swallowing and speaking for granted. These abilities are both necessary in everyday life and important in many aspects of our social interactions. As with many aspects of symptom management, the key components are preparation and lifestyle adjustment. It's important to remember that you have options and that the choices are yours to make.

When dealing with the challenges of ALS, be aware of how you can make simple modifications in your diet — food and fluids — to help assure that you meet your body's needs for proper nourishment, and also how you can modify your communication methods in order to maintain effective communication. Both issues are discussed at length in The ALS Association's **Living with ALS Manuals**. On this page, you'll find additional information related to feeding tubes, managing excessive saliva, and nutrition planning.

This guide for individuals living with ALS, families and friends was written to help people with ALS overcome the obstacles of eating well. To find out more about maintaining good nutrition with ALS, [click here](#).



## Managing Excessive Saliva

Individuals with ALS who experience swallowing problems often notice that they seem to salivate more. The fact is, they may not be salivating more, but the saliva is pooling in the mouth because of an inability to swallow it. Excessive saliva can be one of the most frustrating symptoms of ALS to manage. It can also be life threatening, since it frequently causes choking, especially at mealtimes when saliva secretion is increased and chance of aspiration is greatest.

Early in the course of the disease, excess salivation can be controlled by simply being aware of the problem and making a conscious effort to swallow the saliva or wipe it away with tissues. With progression of the disease, however, individuals with ALS may find that excess saliva has become a nuisance and an embarrassment, and needs to be controlled by other means. One helpful measure is to have a suction machine available in the home. Modern technology has provided portable, battery-operated suction machines for those "on the go." Your physician may also prescribe certain medications to control saliva.



## Questions and Answers About Feeding Tubes

The subject of feeding tubes, as with many matters of personal care, is a very personal matter and one that has residual effects on your total health. We've gathered some of the most common questions and concerns that individuals have had, and organized them in the following two documents. As always, consider these pieces a guide, but the best course of action for you can only be determined by you and your care team.



[Feeding Tube  
Common Questions](#)

[Do I Want a  
Feeding Tube?](#)



# Difficulty Speaking

How well you speak is affected by the strength and coordination of your breath, vocal cords, tongue, lips and jaw. ALS can alter the muscle control of these physical aspects of speech, thus presenting various challenges to communicating. With perseverance, ingenuity, technical assistance, and support from others, you can continue to communicate with those around you.

Expressing needs, feelings, ideas, preferences, and opinions allows people to control and modify their environment. Changes in speech can have a definite impact on everyday expressions — from saying “Hello” to asking for a doctor’s appointment.

## What can you do if your speech sounds slurred?

Slurred speech is a symptom of dysarthria, a neurologically-based speech disorder that results in weakness or spasticity of the lips, tongue, jaw movement, soft palate, and respiratory muscles. In order to adjust to these weakened muscles in the mouth, you can make changes in how, where, and when you speak, and what you do to be understood.



## Tips for Overcoming Speech Issues

- 1) Be sure to have the attention of the listener.
- 2) Speak slowly and carefully; repeat your words if necessary.
- 3) Convey your message in as few words as possible, words at the end of a sentence are lost more easily.
- 4) Carefully pronounce all the syllables in words; if you have trouble speaking slowly, tap out each syllable with your finger as you say it, for example, “re-frig-er-a-tor.”
- 5) Emphasize the final sounds of each word, since slurred speech can omit them, for example, boo“k”or ha“t.”
- 6) Take a breath before each phrase or set of words, because breath is the power behind your voice, making your words easier to say and hear.
- 7) Say your most important words more loudly by taking a breath first
- 8) Substitute sounds for those that are difficult. A speech therapist can help.
- 9) Try adding gestures, such as facial expressions and pointing.
- 10) Keep the mouth free of excess saliva. A suction machine or drugs that dry the mouth can also help.
- 11) Avoid tightness of neck muscles by doing relaxation exercises.
- 13) A voice amplifier, a small machine with a microphone to make your voice more powerful, may be helpful

## Communication Devices

Choosing the right communication device can be challenging because there are many factors to consider. A communication assessment/evaluation should be done to determine the most appropriate device for you. Since communication devices come in many different shapes and sizes, receiving a proper evaluation is essential prior to selecting a device. [Click here](#) to read more about how The ALS Association can make more options available to you.



# Difficulty Breathing

ALS varies greatly from person to person and symptoms related to your breathing can start early or much later in the course of the disease. In some people the progressive loss of motor neuron function is very slow, in others faster. The following will help prepare you for potential changes in breathing function and offers guidance regarding respiratory decisions.

The ALS Association has a **comprehensive manual** on the subject of respiratory changes related to ALS, which we recommend you explore as necessary, but the information below will serve as an overview. The motor nerves for the respiratory muscles are often affected later in the disease after weakness occurs in the arms or legs. But sometimes the respiratory muscles are affected very early in ALS, when minimal weakness exists elsewhere. The complications of respiratory muscle weakness can include difficulty breathing and clearing secretions.

There are a number of devices and techniques commonly used by many people with ALS that can support your breathing if your respiratory muscles are affected.



If you have ALS and take proper care of yourself, you can stay healthy longer and avoid many breathing complications. The following are some simple guidelines:

- Try not to become underweight because it will weaken your body, muscles, and immune defense system. Avoid becoming overweight, because it can increase the work of the muscle used for inhaling and exhaling and the likelihood of breathing problems during sleep.
- Try to control constipation which can lead to uncomfortable stomach problems and interfere with breathing; constipation usually responds to added fruit, vegetables, fiber, and liquids in your diet, or to drinking a full glass of warm water in the morning. A stool softener may be used and, occasionally, a mild laxative if needed.
- Breathing and coughing techniques can help maintain healthy lung function. Deep breaths help to fully expand the lungs; take five-to-10 deep breaths, with a short rest in between, several times a day. Effective coughing is needed to clear secretions. Also, assisted cough methods can be very helpful, particularly if you have a cold or chest infection.
- Individuals with ALS are at a greater risk of developing influenza-related complications, including pneumonia. It is recommended that you talk to your physician about an annual flu (influenza) vaccine, as well as whether or not you should receive a pneumonia (pneumococcal) vaccine. **Read more.**
- If you are a cigarette smoker, strongly consider stopping. **Read more.**

It is best to try and plan ahead so that you do not have to make plans during a crisis. **The first step is to get information about assisted breathing options** and discuss it. Respiratory Decisions in ALS is a series of three educational videos that guide people and families through the process of evaluating and making important decisions about respiratory care as the disease progresses.



Developing a Care Plan



Respiratory Support Options



Your Decisions for Quality of Life

**Invasive ventilation:** Means having a tracheostomy tube placed (a plastic tube surgically inserted through the neck and into the trachea/windpipe) and being connected to mechanical ventilation (a device to assist you with breathing). It is crucial to understand the option of invasive ventilation and its impact on your life and the life of your family. **Click here** for more information.





# Changes in Thinking

Up to 50% of people with ALS will experience some degree of change in thinking or behavior. Building awareness around cognitive and behavioral changes unique to ALS helps empower a person with ALS, validate the experience of caregivers and family members, and educate providers working with an affected person so that decisions are made in a manner consistent with honoring the individual's longstanding values, preferences, and desires.

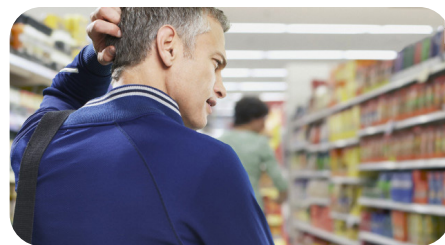
## What can thinking and behavior changes in ALS look like?

- Person seems to have lost "a filter" with regard to making comments or expressing opinions.
- Person begins eating sweets, or only one type of food to the exclusion of a more balanced diet.
- Person loses table manners.
- Decreased attention to hygiene.
- Loss of judgment and potential departure from previous views.
- Lack of concern for others, one's own illness and symptoms, and/or no view of the future.
- Inability to concentrate or to shift focus from one activity to another.
- Fixation on a single idea or activity with a need to repeat the concern or repeat the activity.
- Increased aggression.
- Writes or says words in the wrong order or without respect to grammar.
- Thinks of the word he/she wants to use but cannot get it out in conversation.
- Says sentences that convey little meaning.
- Cannot follow instructions to complete PT/OT/Speech therapy exercises, stretches, or guidelines.
- Difficulty remembering what he/she intends to do.

**[Click here for additional information on cognitive and behavioral changes.](#)**

## Diagnosis of Cognitive and Behavioral Impairment in ALS

In order to evaluate whether the cognitive and behavioral symptoms you see are related to ALS or another process, you may be referred to a neuropsychologist for cognitive evaluation. This helps to determine if there is impairment and what type it could be.



## Recommendations for the care of someone with ALS and cognitive or behavioral impairment:

- Simplify communication with the affected person. Break sentences up into short phrases.
- Ask yes/no questions.
- Slow down when speaking.
- Provide supervision and accompany the person to all appointments
- Set realistic expectations for the person with ALS.
- Educate providers and caregivers working with the affected individual about where to set expectations
- Continue to enjoy activities that bring joy and can be conducted safely.

## Additional Resources

**ALS, Cognitive Impairment & Dementia: A Professional's Guide**  
**FTD/ALS Phone Support Group for Caregivers**



# Emotional Lability

After an ALS diagnosis, a significant portion of individuals living with the disease will notice that their emotions have become more difficult to control, and that they experience involuntary fits of laughter or crying. Understandably, a life-changing diagnosis like ALS will have an impact on your mood and behavior, but what you're likely experiencing is known as pseudobulbar affect, and it is a condition that is treatable in many cases.

## Emotional Lability or Pseudobulbar Affect

Emotional lability or **pseudobulbar affect** (PBA) is a neurologic disorder characterized by uncontrollable episodes of crying and/or laughing. Approximately half of those with an ALS diagnosis will have PBA.

Those who do may find themselves crying uncontrollably at something that is only moderately sad or being unable to stop themselves for several minutes. Or, a person with ALS may laugh uncontrollably when they are actually angry, frustrated or sad.



**PBA can make you feel like you've lost control of your emotions at both ends of the spectrum.**

PBA is a secondary condition to the ALS diagnosis and may also appear in other neurological diseases or brain injury. **Symptoms of PBA can be severe and the onset can be sudden**, the episodes can last for just a few seconds or they can go on for several minutes, and they can occur several times each day without warning.

While PBA is not as disabling as the physical symptoms of ALS, it can have a significant impact on an individual's social functioning and their relationship with others. The episodes can be embarrassing for the person and may lead to social isolation or withdrawal.

Neudexta is the first FDA-approved drug to treat PBA. **Treatment with Neudexta** may significantly decrease laughing & crying episodes. Talk to your doctor about treatment options, and click [here](#) to read a Q&A with Dr. Edward Kasarskis, M.D., Ph.D., Director of the multidisciplinary ALS Center at the University of Kentucky Neuroscience Center in Lexington, Kentucky.





# Multidisciplinary Clinics

The ALS Association's Certified Centers provide multidisciplinary care at a single site, so that people with ALS and their families can see a wide range of experts at each visit. Rather than going from department to department or office to office over several days, people with ALS receive well-organized consultations from a dedicated, centralized collaborative team representing the disciplines essential to their care.

## Benefits of The Approach

People who come to The ALS Association Certified Centers are motivated by their desire to do all they can to deal effectively with ALS, says Eric Sorenson, M.D., Associate Professor of Neurology and former Director of The ALS Association Center and Research Program at the Mayo Clinic, in Rochester, Minnesota.

"Individuals who come to the Centers want to be proactive, addressing questions and problems before they arise and working with leading experts in ALS," Sorenson says. "Having a team that works together – rather than seeing individuals through separate visits in different locations and organizations – helps to ensure that specialists are addressing the big picture."

This teamwork also ensures that each individual gets the care appropriate to his or her case. Every individual with ALS has a unique course and progression, explains Sorenson. "The psychological response to the disease, the speed of the disease's progression, and its impact are different for almost everyone," he says. "The ALS Association Certified Centers are designed to ensure that each person with ALS is connected to a dedicated team able to help the individual cope with the uniqueness of his or her experience, based on the team's broad experience and expertise."



**Find a Center Near You**

## Hallmarks of Center Care

Certified Centers are located throughout the United States. Each reflects the personality and approach of the medical director and staff, and they use a variety of approaches in organizing and running the clinics. But all Certified Centers share these same essential features:

- **A collaborative multidisciplinary team** that works together to provide answers and solutions to individuals and their families. This approach ensures that team members work closely together and consult each other regularly to help ensure the highest level of care possible.
- **Shared decision-making between the individual and the team.** The individual is considered a full and active participant in determining what approaches to care will be followed.
- **The individual's treatment decisions are respected by the team.** Individuals and families are encouraged to ask questions, weigh alternatives, and express their thoughts about options.
- **Members of the multidisciplinary team are present at each visit** and are available to individuals and families at virtually any time to answer their questions and help solve problems.
- Centers focus on **maintaining function and treating symptoms** to help individuals achieve the best possible quality of life.
- **The medical director is involved in ALS research**, which can involve clinical trials.
- **Each Center is regularly evaluated by an ALS Association committee** whose members are all from Certified Centers and are familiar with the national standards of care.



**Learn more about Certified Centers**

# Living With ALS

One of the most common questions of the recently diagnosed and those in their care circles is, *'How do I live with this disease?'* and while there are no easy answers, there are resources available to those in need.

Read about how best to prepare yourself, your home and your personal care network for the road ahead, keeping in mind that you are not alone in this journey.



## About ALS

Explore The ALS Association's **Living With ALS Manuals** and videos for answers to the numerous questions you may have. These cornerstone educational materials were designed to inform and educate people about ALS in a comprehensive and easily understood format. They address many of the common concerns and issues that face people living with ALS. You'll also be able to read up on the latest happenings in our **eNewsletter**.

## Daily Living Activities

While your healthcare provider will be able to answer many of your questions related to the changes brought on by ALS, you'll need to prepare both yourself and your home for the road ahead. This section will provide tips for **self-care** and **home safety measures**, as well as topics like personal **energy management** and **intimacy**.

## Living Settings

Preparing your home and living environment is a key consideration following an ALS diagnosis. As your disease progresses, lifestyle changes and adaptations to your living space become necessary. In addition to evaluating your **home care options**, it is a good idea to familiarize yourself with alternatives such as **assisted living** and **nursing home care**.

## Reaching Out to Family & Friends for Help

It is easy for people with ALS and their families to become overwhelmed by the wide range of needs they have, from everyday errands to making meals, maintaining their home, and so much more. Those who want to lend a helping hand, often do not know how they can contribute in a helpful way. The **Care Connection** program can be a solution.

## Treatment Options

In addition to complementary and alternative medicine options, there are only three FDA-approved drugs available to treat ALS. This section details the current treatment landscape. There are other medications available to manage symptoms caused by the disease. Please speak with your ALS specialist about those.

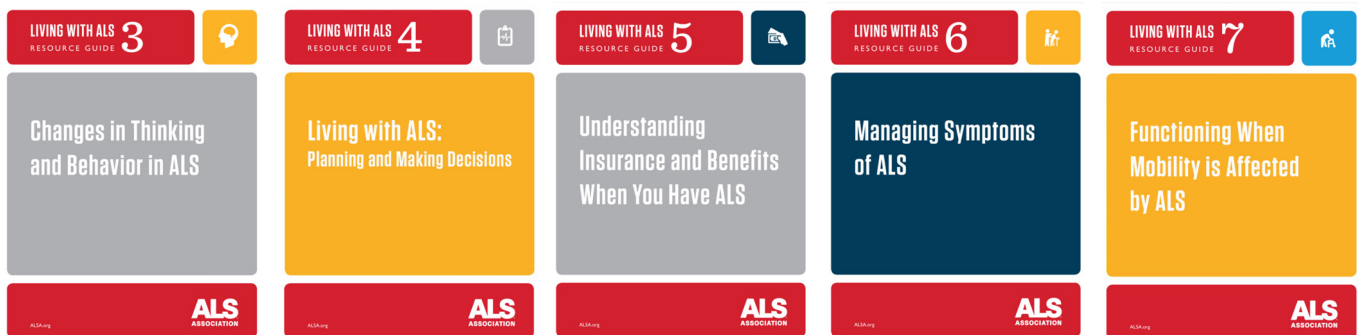
# About ALS

Recent years have brought a wealth of new scientific understanding regarding the physiology of this disease. Although there is not yet a cure or treatment that halts or reverses ALS, scientists have made significant progress and learn more each day. People with ALS may experience a better quality of life by participating in support groups and attending an ALS Association Certified Treatment Center of Excellence or a Recognized Treatment Center. The manuals and guides below are a good starting point for additional information.

## Manuals and Guides

These manuals contain a wealth of information about what to expect following an ALS diagnosis.

Reading all 11 manuals at one time can be overwhelming to both persons with ALS and their families. We highly recommend that you only access the information that pertains to you and your present circumstances.



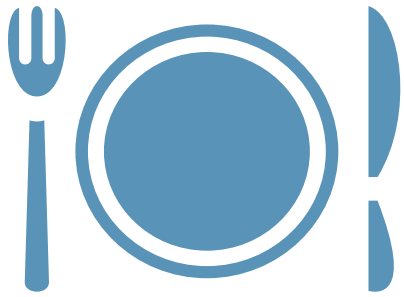
**Click here** to order a printed copy of any of the guides, or contact our National office at [alsinfo@als.org](mailto:alsinfo@als.org).

## Familial ALS

It can be overwhelming to learn that you or a family member has ALS. Receiving the diagnosis of familial ALS (in approximately 10% of all cases of ALS) can raise extra questions and concerns about the future. **This booklet** will help answer these questions and provide information to support you and your family.

## Daily Living Activities

There are a number of lifestyle changes that become necessary when living with ALS, and the best way to cope with those changes is to prepare both yourself and your physical surroundings. Follow the links below to learn about how The Association can assist the transition into your new normal.



### Self-Care Tips

This section will cover activities that someone will likely do each day; such as, eating, dressing, and personal hygiene. You'll find information about possible ways to make these tasks easier.



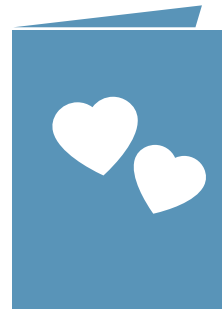
### Home Safety and Accessibility

Personal safety within your home is important for all of us, but as someone living with ALS, or a caregiver, the issue requires extra attention. This section will cover information related to emergency preparedness, home accessibility and medical alert systems.



### Energy Management

Our bodies use energy daily to maintain our internal organs, digest food and participate in physical activities. Fatigue can occur when we don't have sufficient rest, proper nutrition, feel anxious or depressed or we experience pain or physical discomfort. Here you'll find basic tips for minimizing fatigue.



### Intimacy and Sexuality

Intimacy and sexuality are topics that may be difficult to approach following a diagnosis. However, it may be helpful to reflect on how the presence of ALS is affecting your intimate/sexual relationship and to take the opportunity to address this with your partner and your health care provider.





# Self-Care Tips

Many of the tasks related to dressing, eating, and hygiene are automatic. We don't really think much about the process of buttoning a button, holding a utensil or brushing our teeth. However, these activities can become more difficult as persons lose muscle strength and coordination. The following are some helpful tips that may make these tasks easier so that you can spend more time on activities of interest to you. Your occupational therapist will be able to help you determine modifications/adaptations and equipment that meet your unique needs. The ALS Association has local Care Services Managers that are also available to consult with you.



## Eating

*Stabilizing the plate, holding utensils and drinking from a cup are common activities of eating that can become more difficult. An occupational therapist will be able to evaluate your current situation and determine what would be most helpful since everyone is unique.*

1. Cut a piece of grippy shelf liner to use as a place mat to stabilize your plate and cup.
2. Use lighter weight utensils (some individuals have even used small child sized utensils)
3. Wrap the handle with foam to increase the size
4. Use a plate that fits solidly on the table without a slanted bottom to prevent tipping
5. Use a plate that has a slight, raised lip around the edge making it easier to aid fork-use
6. Use a mug that has a larger handle which will allow you to slip your fingers through to hold the mug with your entire hand rather than your thumb and 2 fingers.
7. Light weight plastic glasses are easier to lift than those made from glass.
8. Plastic, ribbed cups may be easier to grip than those with a smooth surface.

## NOTE:

*We also have many devices in our equipment loan pool that can make feeding yourself easier.*

*Examples include: large handled utensils, scoop plates, and long straws.*



## Dressing

1. Attach a loop of fishing line (filament) or a round metal ring to a zipper pull. This allows you to use more fingers to manage the zipper.
2. To make buttoning easier: remove the button; sew the 'hook' piece of Velcro where the button was and the 'loop' piece under the button hole. Then sew the button hole shut and sew the button that was removed on top of the hole.
3. Buy pullover tops that don't require buttoning.
4. Keep a lighter weight sweater or jacket partially zippered and put it on like a pullover shirt.
5. Use elastic waist pants.
6. Purchase clothes two times bigger than your typical size for ease in dressing.
7. Purchase sweat pants without elastic at the ankle or remove the elastic which will make it easier to slide your foot through the leg opening.
8. Consider stretchy fabric when purchasing clothes.
9. Buy front closing bras or fasten back closing bra in front and then turn it around.
10. Sew two loops on the inside of pants large enough to place your hands into when dressing

## NOTE:

*There are many retail options for adaptive clothing. The following are representative of options available:*

**1) Easy Access Clothing**

**2) Silverts**

**3) Dignity by Design**



## Hygiene

1. Take 2 wash cloths and sew them together on 3 sides to form a pocket. Your hand (and soap, too) can slide into the pocket so you don't have to grip as much to hang on.
2. Build up handles of your hair brush, comb, and tooth brush to make them easier to hold/use
3. Lift the toothpaste tube between your palms and squeeze together to put toothpaste directly on your tongue or side teeth.
4. Leave the toothpaste cap off between uses – saves screwing the top on and off.
5. Set the toothpaste on the counter. Use the palms of your hands to squeeze the paste on.
6. Flip top lids can be opened and closed against the edge of a sink or counter.
7. Some people like electric toothbrushes for the large handle and decrease in muscle fatigue.
8. Sit near the sink and prop your elbows to help reach your hair while combing.
9. Have an easy care hair style.
10. Comb your hair in the shower. Sometimes the tangles work out better when the hair is very wet.
11. Nail a nail clipper on to a block of wood. You can then use the side of your hand or forearm to push down and clip the nail.
12. A pair of kitchen tongs can hold toilet paper to give a few extra inches of reach
13. Wet wipes can make cleaning easier after toileting.

## NOTE:

*Many times it is the little things that become difficult and frustrating. Consider the suggestions in this section and choose those that work for you.*

*Consult with your occupational therapist or a care services manager for assistance.*

# Home Safety and Accessibility

Staying safe and maintaining access to all areas of your home are concerns for everyone, but living with ALS means having to carefully evaluate your living situation and make adjustments over time. There are a number of options to help you make the best decisions for your future. Remember, The ALS Association's Care Services Team is available for consult should you have questions.

## Emergency Preparedness

Emergencies and disasters can strike quickly and without warning, forcing people to leave or be confined in their home. For the thousands of Americans with ALS, emergencies such as fires, floods and acts of nature present a real challenge. It is important that people with ALS and their family members make plans to protect themselves in the event of a disaster. This needs to be addressed not only at home, but also when away from home, such as at work or on vacation.

### Step 1

Make the conscious decision to be prepared. It takes work, but it is worth it! The more you do, the more confident you will be that you can protect yourself when the time comes.

### Step 2

**Make a plan.**

### Step 3

Be informed. There is a website that can help you stay prepared for a variety of emergency situations: [ready.gov/fema.gov](https://ready.gov/fema.gov)

**Click here** to view a helpful webinar on the topic of Home Safety and Environmental Modification Considerations.



**Medical Alert Systems** can literally save your life should you fall or have a medical emergency requiring a swift response. The ALS Association does not endorse any products listed in this document. However, one option available nationwide is **Philips Lifeline**.



# Energy Management

Although the course of ALS is unpredictable, fatigue is inevitable, often resulting from muscle weakness and spasticity. Fatigue can range from mild lethargy to extreme exhaustion. People often complain of tiredness, dwindling strength, and lack of energy. Despite the adverse effects of fatigue, symptoms can be minimized through effective management. By recognizing the signs of fatigue, knowing which factors worsen symptoms, and learning how to conserve energy, persons with ALS can greatly improve their quality of living.



Noticeable signs of fatigue include: Slower body movement, slower speech responses, short answers, lower voice volume, dull tone of voice, shortness of breath, increased sighing, anorexia, irritability, anxiety, crying episodes, decreased smiling, lack of enjoyment of previously enjoyed experiences, decreased caring about things that were previously important, deterioration in appearance and grooming, increased forgetfulness, increased preference for being alone, and disinterest in decision making daily plans.

## 10 Ways to Minimize Fatigue

1. Learn methods of making every task easier. Use assistive devices when needed. See an occupational therapist for determining what is best for your needs. If you have trouble walking, don't resist getting a wheelchair. A motorized wheelchair will spare you the exertion of manually wheeling around in a standard model.
2. Pace yourself. Move slowly and easily. Stop and rest often and take a few breathes before you start again. If you become breathless during a task, it is time to stop. Schedule heavier task during predicted times of higher energy. Plan your activities and gather everything you need before you start. Don't stand when you can sit. Utilize possible shortcuts. Obtain assistance in completing tasks if you need help. Always allow enough energy to enjoy at least one valued experience each day.
3. Alternate activities with periods of rest. Schedule regular rest periods each day, perhaps a half hour after morning care and an hour in the early afternoon. Rest before going away.
4. Get a disability parking sticker. Your local Department of Motor Vehicles has the form that your physician will need to fill out.
5. Try to establish a regular sleeping pattern.
6. Avoid prolonged bathing in warm water, as it may worsen muscle fatigue. Be cautious of extreme temperatures.
7. Maintain your nutritional requirements each day, and prevent unnecessary weight loss.
8. Avoid stressful situations as much as possible. Understanding fatigue will help family members cope better with emotional upsets, realizing they are not personal attacks, but normal responses to fatigue.
9. If you feel noticeably weaker or have difficulty breathing after taking a medication, let your doctor know. Perhaps your medication needs to be substituted for another one or the dosage altered. Trouble breathing, however, may be related to breathing fatigue and may warrant an evaluation by your doctor.
10. Make your living environment accessible for daily activities, and promote energy conservation. Moving a bed to another location or relocating personal items are some examples.



# Intimacy and Sexuality

Intimacy and sexuality are topics that may be difficult to acknowledge following a diagnosis. However, it may be helpful to reflect on how the presence of ALS is affecting your intimate/sexual relationship and to take the opportunity to address this with your partner and your healthcare provider.

Intimacy with another relies on a foundation of trust which allows each person to expose his or her innermost feelings and thoughts without fear of rejection. This openness to vulnerability often develops as a relationship grows over time. Loss of independence, changes in one's body, or communication challenges experienced by individuals with ALS may result in a greater sense of vulnerability and fear of intimacy.

There is a section in **this booklet** that provides tips on how to maintain intimacy while living with ALS.

It is important to communicate with your partner how you will maintain a continued intimate relationship in spite of ALS-related changes. Consider whether or not additional help is needed for caregiving, child care, or other household tasks that need to be accomplished. Try to schedule time for you and your spouse/partner to simply enjoy each other's company. Perhaps our **respite program** for the caregiver would be helpful. We also have a **volunteer program** and information about programs that are available to assist in organizing others to help with various tasks.

While our culture seems to emphasize the sexual act of intercourse, there are many other ways to express one's sexuality and continue to have a fulfilling intimate relationship. Change in any area of life is challenging, and with ALS it becomes even more so. You may need more information about this area as you and your partner adjust to ALS. Because ALS progresses differently in each person, the ongoing challenge is to continue to communicate and adapt as needed to have a satisfying intimate, sexual relationship based on mutual communication.





# Living Settings

While staying in your home is ideal and a realistic possibility for some people living with ALS, there are alternative living situations that may result in greater comfort or allow for easier symptom management. Your circumstances are unique to you, so take some time to review the information gathered below from a number of reliable partners in the care service field.

## Home Care

For most, living at home for as long as possible is the best case scenario. In addition to the obvious emotional benefits and convenience, the financial impact of home care is typically less severe than the alternatives. In any case, there is still plenty to consider if you're staying in your home.

- [When to hire in-home help](#)
- [Paying for home health care](#)
- [Medicare and home health care](#)
- [Independently hiring help](#)
- [Choosing a home health agency](#)
- [Home health care glossary](#)

## Assisted Living

Assisted living facilities offer a housing alternative for adults who may need help with dressing, eating, and toileting, but do not require the intensive medical and nursing care provided in nursing homes.

- [What is it? How to choose? What's the cost?](#)
- [Assisted Living Locator](#)

## Nursing Homes

Nursing homes offer a high level of service, attention and medical assistance for individuals in need. Once the decision to move is made, it comes down to finding the right facility.

- [Guide to choosing a nursing home](#)
- [Nursing home checklist](#)
- [Compare nursing homes](#)



## Care Connection

Care Connection is a simple online tool that helps organize the community of people who want to help. It coordinates their efforts to more efficiently support families living with ALS.

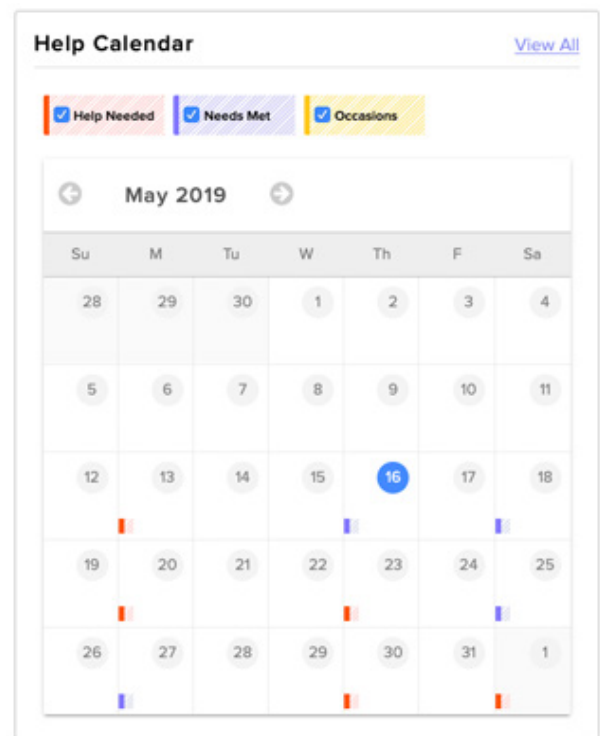


The impact of an ALS diagnosis is profound. It's not uncommon for daily tasks, such as meals, laundry, and children's activities, to be less of a priority when providing care for a loved one with the disease. Caregivers may feel defeated by the growing list of tasks they are no longer able to manage.

It's often hard to know when and how to ask friends and neighbors for help. And for those who want to offer a helping hand, it's difficult to know just what is needed and how to make a difference.

Now, when someone asks what they can do to help, the answer is "give me your name and email address so I can provide access to our ALS Care Connection page." Care Connection is a private online calendar at [alsa.lotsahelpinghands.com](https://alsa.lotsahelpinghands.com). It can be used to support to the entire family – by organizing volunteers to take care of some of those tasks families describe as "falling through the cracks."

To learn more about this tool and its features, [visit our website](#) or [review our step-by-step guide to getting started](#).



# Treatment Options

At present there are three FDA-approved drugs to treat ALS: Riluzole, Tiglutik (liquid form of riluzole) and Radicava. Radicava was approved in 2017 for treatment in ALS. **Visit this website** to learn more about Radicava. The Mayo Clinic has **additional information** on the drug commonly known as Rilutek or Riluzole. **Click here** for the most up-to-date information on clinical trials, and to learn more about the newest research developments. Explore the section below to learn more about complementary and alternative medicine.

Complementary and Alternative Medicine (CAM) refers to therapies that extend outside of the normal practices of conventional medicine used by either a medical doctor (MD) or a doctor of osteopathy (DO). Complementary medicine is used in conjunction with conventional medicine whereas alternative medicine is used in place of conventional medicine. For treatment options related to specific symptoms please see [this section](#).

While some scientific evidence exists regarding some CAM therapies, for most there are key questions that are yet to be answered through well-designed scientific studies. These are questions such as whether the therapies are safe and whether they work for the diseases or medical conditions for which they are used. If you are considering CAM, it is critical to discuss with your medical doctor to determine safety and for assistance using appropriately in combination with other therapies.

## When considering CAM, what questions should patients ask their CAM health care providers?

*What benefits can I expect from this therapy?*

*What are the risks associated with this therapy?*

*How will this therapy interact with my conventional treatment(s)?*

*What are the potential side effects?*

*Is this therapy part of a clinical trial? If so, who is sponsoring the trial?*

*Will the therapy be covered by health insurance?*

## Be Sure to Consider Cost

Costs vary widely: it is important to check with the institution as well as with your insurance company to verify the costs that may be incurred. Ask any cost-related questions you have beforehand.

It is important to tell all your health care providers about any complementary and alternative practices you use or are considering. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care. You can find additional information about CAM, including reports of research on specific therapies, from the **National Center for Complementary and Alternative Medicine**, a division of the NIH (National Institutes of Health). or from the **Mayo Clinic website**.

## Complementary & Alternative Therapy Options

Acupuncture	Nutritional Counseling/Herbal & Botanical
Ayurvedic	
Chiropractic	Traditional Chinese Medicine
Homeopathic Medicine	
Massage	Yoga



## Coping With ALS - Adults & Children

Acceptance of an ALS diagnosis does not come easily. Learning to live with the disease and explaining the circumstances to those around you can be challenging. The information in this section is meant to help you gain perspective and connect with a supportive community of others who understand what you're going through.



### Help with Coping

There's so much emotion and grief in the months after a diagnosis that it can be easy to find yourself in a negative space. This **extensive manual**, as well as information on **support groups**, dealing with **depression**, **Anticipatory Grief**, and **talking to your kids** about ALS are good places to start.

### For the Caregiver

As a caregiver, often the last thing on your mind is your own health and well-being. Learning when to take a break and how to care for yourself are important steps in the process. The ALS Association offers programs for **respite** and **family assistance** that you might find helpful.

### Leisure Activities

One of the best ways to cope with change and manage stress levels is to find activities you can share and enjoy on a regular basis. Spending time each day in a fun, relatively carefree environment can have a positive impact on your overall physical and mental health.



## Help With Coping

Learning to manage the many emotions you'll feel when confronting ALS is just as important as recognizing and validating those feelings in the first place. The pieces below should help you find the kind of support and perspective that can lead to greater understanding of your situation.

LIVING WITH ALS  
RESOURCE GUIDE 2

After the ALS Diagnosis:  
Coping with the "New Normal"

After the ALS Diagnosis:  
Coping with the "New Normal"




Talking to  
Kids About ALS



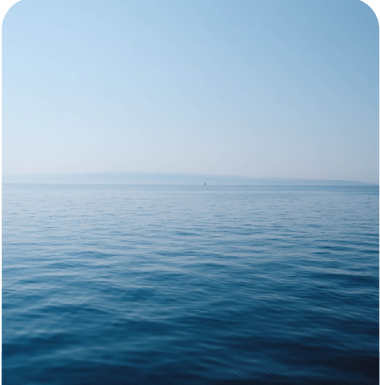
Support Groups



Depression  
and ALS



Hope vs.  
Optimism



Anticipatory  
Grief

The Living With ALS guides and manuals contain a wealth of information about what to expect following an ALS diagnosis. There are six total in the series, [click here](#) to explore them all.



# Support Groups

When facing ALS, both as someone living with the disease or as a caregiver for a loved one, it's not uncommon to feel alone or isolated. It's important to recognize that you are not on your own on this journey, and The ALS Association's various support groups are in place to provide an educational and supportive environment for you to share your experiences.

## List of Current Support Groups



# Talking to Kids About ALS

Because it can be extremely difficult to approach a subject like ALS with children, we have compiled a list of resources that parents can use as a guide to initiating the conversation and following through as their young ones adjust to receiving news of this magnitude.



## Available Resources

*You know better than anyone how your kids are going to respond to adversity. The information below is meant to help you find the right time and way to have this discussion. Pick and choose the pieces that will work best for you and your family.*

### Discussing ALS with Children

### Resources for Young People

### Helping Children Cope with ALS

### The ALS Experience: It's Different and Hard

### School, Friends, Work, and ALS: A Young Adult Guide to Balancing Life with ALS

### When Someone Special has ALS

### For Educators to Support Students



# Depression and ALS

Depression is common among people with ALS and their families. Estimates vary, but most experts estimate that more than a third of people with serious chronic illness experience symptoms of depression. It's easy to understand. There's so much to process, great adjustments in the way life is lived, frustrations and questions, and the necessity to rely more and more on others. Sometimes all of this is complicated by financial challenges and all the other issues with which everyone must grapple in everyday life. The feelings are a very normal reaction to the stress of having ALS. Any loss of ability or function is experienced as a loss, and it all tends to add up.

**The symptoms of depression are also often commonly seen with ALS itself, so it's easy to be confused about whether the problem is largely ALS or is something more.**

## Typically, people who are depressed experience:

- Fatigue or a decrease in energy
- Apathy (caring less about things in general)
- Difficulty concentrating
- Loss of interest in daily activities
- Sleep problems: restlessness, wakefulness, or sleeping more than usual

## What action should be taken by those living with ALS who are also depressed?

It's important to talk with your physician about your feelings. Sometimes issues directly related to ALS may be the cause, and solving those problems may improve your emotional state. Your care provider may be able to suggest modifications in your treatment or may refer you to physical, occupational or respiratory therapists who can make tangible improvements in your daily life. Your physician will also be able to help explore with you whether your depression should be treated more directly. Antidepressants are frequently effective, especially when combined with "talk therapy" or counseling. Often the process of working through your thoughts and feelings with someone outside your network of family and friends can be helpful.

## There are also some strategies that may help:

- Express your feelings, talk about your sense of frustration, grief, and loss.
- Set new, achievable goals. Plan for activities you can and will enjoy.
- Focus on your abilities, and use assistive devices to improve your quality of life and ability to do things by yourself.
- Engage with friends and family; try not to isolate yourself.
- Take care of yourself. It may take a lot of time and effort, but look your best. You're likely to feel more social and more self-confident and upbeat if you do.
- Seek spiritual support. Prayer and meditation can be extremely helpful.

**Remember that depression can be contagious.** If family members are also depressed, they, too, should talk with their physicians and get help finding appropriate and necessary ways to deal with it. People with ALS who have overcome depression say that the trick is to find a way to avoid focusing on the loss and to concentrate on the present, and the things you can and do enjoy. That may take time. But by talking with your physician and getting the help you may need, you may find yourself in the sunshine sooner.

## Books to Purchase

**Unstuck: Your Guide to the Seven-Stage Journey Out of Depression by James S. Gordon M.D.**

**Self-Coaching: The Powerful Program to Beat Anxiety and Depression, 2nd Edition**

**Depression: A Stubborn Darkness--Light for the Path**

**Talking to Depression: Simple Ways To Connect When Someone In Your Life Is Depressed**





# Hope vs. Optimism

The following passage was authored by Jan Stanton, a chaplain, author and speaker on the topics of grief and loss, aging, caregiving and spiritual health.

*Recently I came across some old class notes with the heading: Hope vs. Optimism. This caught my attention: Are hope and optimism the same? Or do they differ?*

*My notes tell me that optimism means “everything will work out okay.” To me, this means that an illness will be cured, a broken relationship reconciled, the jobless employed. In other words, the external circumstances of life will be fixed, somehow. Hope, however, is different. Hope goes deeper. Though not everything will evolve as I want, hope teaches me that I can trust that a dimly burning wick flickers amidst my challenges. Life is changing, loss is real, but a light—somewhere—still glimmers. Note these familiar light-filled metaphors for hope: the light at the end of the tunnel, a beam of hope, a ray of hope, a break in the clouds.*

*Moving from optimism to hope is not easy. There have been times in my life when I clung desperately to optimism, waiting for “everything to work out okay.” It was as though I held my breath, trying to control an outcome by doing so! But when things didn’t work out as I had wanted, I had to make a choice. I could continue to hang on (usually with fear) or I could let go, trust the process, and embrace the life that was waiting for me. I could choose to move from optimism to hope. Holding on to hope is one of the most difficult challenges of all grief and loss experiences. Whether we’re coping with the loss of a loved one or struggling with a progressive illness, we wait—and hope!—for hope to appear. But when hope seems relentlessly absent, what then? I find it helpful to remember that hope does not appear without my help. I’ve discovered that hope requires my active engagement. I must build my own hope, and I do so by creating some meaning from my experience of loss and grief. Here are some thoughts:*

**Connect with yourself.** We cannot heal what we do not allow ourselves to feel—a strange paradox indeed. And when we feel our feelings, we need to express them. Express them to a friend, a support group. Write them in a journal.

**Connect with others.** One of the most difficult—if not the most difficult aspect of grief—is feeling alone with it. Sharing our grief greatly reduces its pain. Try organizing a lunch or dinner group with people who have had similar losses. Find someone you trust, perhaps someone who has also experienced a similar loss to yours. Let them sit with you, hold your hand, listen to you. Connect with your spiritual resources. What brings you peace and calm? What helps you relax? What helps you transcend the “difficult dailiness” of coping with grief? Do you like to spend time in nature, listen to music, meditate, pray, attend events with your spiritual community? And how do you like to be creative? Creativity is healing, and things like making a scrapbook or sewing a quilt can also be a way to honor your losses.

**Practice gratitude.** Expressing gratitude does not mean negating the hardships of life. Deceiving ourselves about what has deeply impacted our lives does not promote health. We promote health when we are honest, when we hold our brokenness and wholeness in loving tension, grateful for whatever goodness emerges. It is not so much a matter of being grateful as it is practicing gratitude, a discipline that is a blessing itself.

*Hope comes to us in various and individual ways. Know yourself and choose how you will summon hope into your life. And remember: sometimes a small glimmer of hope is all we need. We can always build on that small glimmer, allowing hope to grow and flourish. And on those bad days, in those moments when all seems hopeless, consider the words by Brother David Steindl-Rast: “The hope that is left after all your hopes are gone—that is pure hope, rooted in the heart.”*

*May your journey be filled with healing, peace—and hope.*





## For the Caregiver

There are a number of lifestyle changes that become necessary when living with ALS, and the best way to cope with those changes is to prepare both yourself and your physical surroundings. Follow the links below to learn about how The Association can assist the transition into your new normal.



### Respite Care

Being a family caregiver, while a fulfilling role, can consume a great deal of physical, mental, and emotional energy. Consequently, respite is very important because it gives family caregivers of persons with ALS an opportunity to create a plan of care for themselves; something a caregiver often overlooks.

### Family Assistance Program

We understand that living with ALS makes daily tasks more challenging. In order to make life a little easier, we created the Family Assistance Program. Through this program, we match trained volunteers with families affected by ALS to assist with tasks or simply be a friendly visitor.

### Care Connection

It is easy for people with ALS and their families to become overwhelmed by the wide range of needs they have, from everyday errands to making meals, maintaining their home, and so much more. Those who want to lend a helping hand often do not know how they can contribute in a meaningful way. The **Care Connection** program can be a solution.

# Respite Care

Being a family caregiver, while a fulfilling role, can consume a great deal of physical, mental, and emotional energy. Consequently, respite is very important because it gives family caregivers of persons with ALS an opportunity to create a plan of care for themselves; something a caregiver often overlooks. Through The ALS Association's Jack Norton Family Respite Program, as well as additional community resources, you have a number of options for respite care in your community.

## The Jack Norton Family Respite Care Program

Respite simply means an interval of rest or relief. Respite gives you, the family caregiver, an opportunity to take a much-needed break from the daily care that you provide for your loved one. A period of respite may be a few hours or a few days at a time, depending on what is decided between you and the care recipient. There are a number of ways you can spend your "time off" during your respite. Here are just a few examples:

- **Go to the movies**
- **Read a book or take a nap**
- **Treat yourself to lunch at a restaurant with a friend**
- **Take a walk**
- **Get your hair cut**
- **Attend a caregiver support group**



The Jack Norton Family Respite Program is a free program (the ALS Association pays the bill) available to a live-in family caregiver of a person with ALS residing in our service area. You can apply to the program using [this form](#). If you have questions about the Jack Norton Family Respite program, please contact: [respitemn@als.org](mailto:respitemn@als.org), or call the office at 888/612-672-0484.

## VA Respite Options

Respite care can be helpful to **veterans** of all ages and their caregivers. Veterans can receive respite care in an inpatient, outpatient or home setting. The program is for veterans who need skilled services, case management and help with activities of daily living. Examples include help with bathing, dressing, fixing meals or taking medicines. Respite care can be used in combination with other home and community-based services.



## Adult Day Care

Adult day care **centers** are designed to provide care and companionship for adults who need assistance or supervision during the day. Programs offer relief to family members and caregivers, allowing them to go to work, handle personal business, or just relax while knowing their relative is well cared for and safe.



# Family Assistance Program

We understand that living with ALS makes daily tasks more challenging. In order to make life a little easier we created the Family Assistance Program. Through this program we match trained volunteers with families affected by ALS to assist with tasks or simply be a friendly visitor.

## How We Can Help

There are a wide variety of ways in which a Family Assistance volunteer can assist you. The following list provides some examples of the possibilities.

- Cleaning
- Decluttering and Organizing
- Laundry
- Preparing Meals
- Mowing
- Gardening
- Seasonal Yard Work
- Pet Care
- Errands
- Grocery Shopping
- Basic Technology Set-up or Training
- Online Care Calendar Set-up or Management
- Hobbies
- Companionship

## Is there anything a volunteer can't do?

We will send you a list of the program guidelines before connecting you with a volunteer. If you are considering the program, please know volunteers cannot provide personal or medical care. Also, if the person living with ALS cannot be home alone then a caregiver must be present while a volunteer is in the home.

## How can I request assistance?

You can request assistance directly through our [program website](#).

## How do you fulfill a request?

Depending on the amount of help being requested, we will seek one or more volunteers. We check our pool of trained volunteers to see if someone is an appropriate match. These volunteers are then contacted and told about the family and the request. If we cannot find an already trained volunteer, we advertise the request on volunteer recruitment websites and in [our newsletter](#). Once a volunteer is found, we contact the family and share information about the volunteer. At that time, the family can accept or decline the volunteer's offer of help. Identifying information is only revealed when the family and the volunteer have both agreed to the match.

## Who volunteers?

Most of the volunteers joined the program because of a loved one with ALS. Some volunteers even used the program themselves and, knowing how helpful it was, want to help another family. There is a small group of volunteers without a connection to ALS. Regardless of what brought the volunteer to the program, everyone who volunteers is interested in making a direct difference in people's lives.

## How are volunteers screened, trained, and supervised?

The screening process includes an application, an interview, reference checks, and a background check. Before being connected with a family, volunteers go through a thorough training about ALS, The ALS Association, and the family assistance program. Volunteers are contacted two weeks after being connected with a family and then on a monthly basis.

## Leisure Activities

One of the best ways to cope with change and manage stress levels is to find activities you can share and enjoy on a regular basis. Spending time each day in a fun, relatively carefree environment can have a positive impact on your overall physical and mental health.

Participation in leisure activities typically contributes to the quality of one's life. It's important to continue to be involved in the activities you enjoy. However, given the ALS diagnosis this may mean that you need to identify what you enjoy. Questions you may ask yourself are:

1. What activities do I enjoy?
2. What feeds my spirit?
3. Am I still able to participate in these activities? Do I need help?
4. Do I still want to participate in them?
5. Are there other similar activities that I might try?

There are many, many kinds of leisure activities. You may enjoy quiet or active leisure, indoor or outdoor recreation: reading, table games, computer games, soaking in a tub, fishing, camping, skiing, gardening, or traveling. There are too many to list.

You may be able to continue participating in your chosen leisure activities without any change in how you participate. However, you may find that using an assistive device or modifying the environment will make it easier to enjoy something you love. The ALS Association staff is available to assist you with identifying devices that are available or community resources that offer recreational options for people with disabilities. People with ALS continue their avocation as artists, yoga practitioners, hunters, fishers, card players, gardeners, musicians, and more.

The following websites are examples of some of the available resources that you may be unfamiliar with at this time. They are meant to broaden your awareness of the possibilities that are available.

**Armchair Travel**

**Wilderness Inquiry**

### Talking Book

Talking Book is a program for people with physical disabilities that make holding a book or reading print difficult. We encourage those who love to read not to stop. Technology is available to keep you entertained and enjoying a good read! The application process is online; the form does need to be printed and the disability needs to be authorized by a medical professional. Please follow the appropriate link below for more information:

**Minnesota**

**North Dakota**

**South Dakota**





## Available Resources

It's important to remember that whether you've been diagnosed with ALS or are caring for someone with the disease, you don't have to face it alone. The ALS Association makes it our mission to ensure that you have all of the tools and support at your disposal when necessary. Read on to discover what's available in your community.



## Insurance and Financial Information

The complexity of the health insurance world can be daunting for anyone, particularly if you're coping with an ALS diagnosis. We've gathered relevant information about the latest Medicare support, insurance and financial aid that may be available to you.

## Navigating Your Tax Burden

Beyond what you'll want to know about insurance and disability support, there are tax considerations that come into play for those living with ALS. It's vital that you understand what sort of deductions are available to you and your family based on IRS regulations.

## Transportation

As your disease progresses, getting around will likely require alternative transportation. Your personal vehicle, public transport, parking possibilities and your own ability to drive are all things to consider in advance.

## Other Resources

Contact our **Care Services** department for information on additional resources available to people with ALS and their families, including local programs and services, State Help Lines, and grants for scholarships, travel, and other types of financial assistance.

## Insurance and Financial Information

Receiving an ALS diagnosis impacts all facets of your life. As you prepare to address each stage of your disease progression, your financial wellbeing needs to be considered carefully. There are a number of resources available to you and your loved ones that will help you find financial stability.



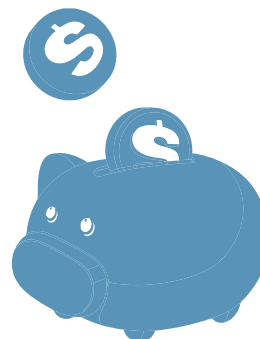
### Are You A Veteran?

ALS is a disease entitled to presumptive service connection. This means that if a service member is diagnosed with ALS, his or her condition will be presumed to have occurred during or been aggravated by military service and as such, may be entitled to service connection and full benefits.



### Medicare and SSDI

Social Security Disability Insurance (SSDI) provides monthly cash benefits and Medicare entitlement to disabled individuals who have paid sufficient FICA and Medicare taxes on their earnings to meet certain insured status requirements.



### Insurance Counseling

To make your journey with ALS a little easier, we highly recommend discussing your health insurance options with an insurance counselor. By thinking through and planning for what your coverage needs may be, you will be able to make choices that will provide you with the most appropriate coverage when you need it.

### Apply for Aid in MN, ND, or SD

Depending on which state you're in and the particulars of your situation, state aid may be an option for you. We can help get you started down the right path, but for more complete information, visit the sites above associated with each state.



# Service Connection for Veterans

Due to the ongoing efforts of The ALS Association, key members of Congress, advocates and the Department of Veterans Affairs, ALS has been listed as a disease entitled to presumptive service connection. Read on to find out what this could mean for you, as a veteran.

## The benefits listed below apply to service-connected individuals only.

**VA compensation** – Disability compensation is a monetary benefit paid to veterans who are disabled by an injury or disease that was incurred or aggravated during active military service. These disabilities, including ALS, are considered to be service connected. Disability compensation varies with the degree of disability and the number of veteran's dependents and is paid monthly. Veterans with certain severe disabilities may be eligible for additional special monthly compensation. The benefits are not subject to federal or state income tax. Tables listing current compensation levels are **available [here](#)**.

**Special Monthly Compensation (SMC) for Serious Disabilities** – VA can pay additional compensation to a veteran who, as a result of military service, incurred the loss or loss of use of specific organs or extremities.

**Death and Indemnity Compensation (DIC)** – A monthly payment to survivors, if eligible.

### Insurance benefits for your dependents

**Specially Adapted Housing grant (SAH)** – Certain veterans and service members with service-connected disabilities may be entitled to a Specially Adapted Housing (SAH) grant from VA to help build a new specially adapted house or buy a house and modify it to meet their disability-related requirements. Eligible veterans or service members may now receive up to three grants, with the total dollar amount of the grants not to exceed the maximum allowable (\$65,000 at the time of this writing).

**Automobile grant** – Financial assistance is available to purchase a new or used automobile (or other conveyance) to accommodate a disability for a veteran or service member with certain disabilities that resulted from an injury or disease incurred or aggravated during activity military service. The veteran or service member may only receive the automobile grant once in his/her lifetime. The grant is paid directly to the seller of the automobile for the total price (up to \$11,000) of the automobile.

**Adaptive equipment** – The purchase of adaptive equipment and for repair, replacement, or reinstallation required because of disability or for the safe operation of a vehicle purchased with VA assistance.

**Clothing allowance** – Any veteran who is service-connected for a disability for which he or she uses prosthetic or orthopedic appliances may receive an annual clothing allowance.

**Aide and attendance allowance** – A veteran who is determined by VA to be in need of the regular aid and attendance of another person, or a veteran who is permanently housebound, may be entitled to additional disability compensation or pension payments. A veteran evaluated at 30 percent or more disabled is entitled to receive an additional payment for a spouse who is in need of the aid and attendance of another person.



# Medicare and SSDI

Disability insurance and financial aid can provide significant relief during a time when there are often more questions than answers. This information will provide an overview, but we recommend exploring all of the resources listed below to ensure that you're fully informed before making decisions regarding your financial future.

## Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI) provides monthly cash benefits and Medicare entitlement to those blind or disabled individuals who have paid sufficient FICA and Medicare taxes on their earnings to meet certain insured status requirements. Spouses and children of SSDI recipients may also be eligible for cash benefits.

According to the Social Security Act, the definition of disability is the "inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. [Click here](#) for more information.

## Medicaid

Medicaid provides health insurance for low-income and needy parties. It covers children, the aged, and blind and/or disabled individuals. Medicaid is jointly funded by the Federal and State governments.

Certain states may have different Medicaid programs available for those who do not have as great of a financial need, such as programs designed for catastrophic or high monthly out-of-pocket costs. A person who has any financial hardship should contact their state's Medicaid program for information.

## Medicare Waiver

Due to the tireless lobbying efforts of The ALS Association, other groups, and individuals with ALS and their families, Congress passed landmark legislation in July 2001 benefiting the ALS Community. The usual 24-month waiting period for Medicare was eliminated for SSDI recipients disabled by ALS. Medicare entitlement now begins the first month the recipient receives cash benefits (approximately 5 months after an individual is deemed disabled).

## Medicare Benefits

Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services (CMS.) Medicare is available to the following groups of individuals:

- Persons age 65 and older and their spouses
- Persons eligible for SSDI (and some disabled civil service workers not eligible for SSDI due to not having paid FICA taxes). Incidentally, individuals with end-stage renal disease may also be eligible for Medicare



## Additional Resources

**Social Security Administration:** 1-800-772-1213; [www.ssa.gov](http://www.ssa.gov)  
**Medicare Information Line:** 1-800-MEDICARE (1-800-633-4227); [www.medicare.gov](http://www.medicare.gov)  
**Medicare Rights Center:** 1-800-333-4114; [www.medicarerights.org](http://www.medicarerights.org)  
**Center for Medicare Advocacy:** [www.medicareadvocacy.org](http://www.medicareadvocacy.org)

Please feel free to contact The ALS Association's Care Services Department with questions at 888/612-672-0484. You may also email us at [info@als.org](mailto:info@als.org).





# Insurance Counseling

Each state in our region offers free insurance counseling for individuals and families in need of such services. There is no harm in asking questions as the implications of your decisions will impact which coverages are available to you. Our Care Services team is available to help guide your initial steps in the process.

## Getting Help With Insurance

As a person with ALS, a key piece of your health care planning is selecting the best health insurance for you! The advocacy efforts of The ALS Association came to fruition in 2001 with the passing of legislation that waived the 24-month waiting period for Medicare coverage for persons with ALS. This means that those who qualify for Social Security Disability Insurance (SSDI) now qualify sooner for Medicare Insurance. This eligibility for Medicare brings with it a set of additional decisions to make ... should I also purchase Medicare Part B? Should I purchase a Medicare Supplement? Will a Medicare Advantage Plan save—or cost—me money in the long run?

In order to get the best guidance possible, it is essential for persons with ALS to be very clear with the insurance counselor about their condition, prognosis, and anticipated needs. Please consider and discuss the answers to the following questions:

**What medications do I currently take/plan to take in the coming year?**

**How might my ALS progression over the next year impact my need for:**

- *Durable medical equipment, such as a power wheelchair or hospital bed*
- *A device that helps an individual when they have lost their ability to verbally communicate*
- *Appointments at an ALS clinic or with other physicians*



## Where to Start

For information about what your needs may be as your disease progresses, we encourage you to consult with your ALS physician and/or a Care Services Coordinator at The ALS Association at 888/612-672-0484, or [infomn@als.org](mailto:infomn@als.org). Changes can be made to your Medicare plan annually, so review your options every year to be sure you have the best plan to meet your needs.

Insurance counselors are available, free of charge, in Minnesota, North Dakota, South Dakota and Wisconsin.

- **MN residents:** Senior Linkage Line at **1-800-333-2433**
- **ND residents:** Senior Health Insurance Counseling (SHIC) Line at **1-888-575-6611**
- **SD residents:** Senior Health Information & Insurance Education (SHIINE) Line at **1-877-331-4834**



# Navigating our Tax Burden

ALS often causes great financial strain that can add to the stress and worry of tax season. With another tax cycle always on the horizon, we turned to a local expert, Terri Moreland, of Lucas, Moreland & Associates, to provide some tips.

## ALS and Tax Breaks

Unfortunately the IRS does not necessarily consider a severe disability or illness to be a reasonable cause for not filing a tax return," Moreland explains. "If, however, the individual's income is severely affected by an illness, they can apply to be considered uncollectable, which is a temporary reprieve from tax collection action by the IRS.

**Moreland also reminded us that the IRS only taxes income producers, so remember, if you do not earn taxable income, you most likely don't need to file.**

## Know Your Deductions

Nearly all medical treatments and procedures are deductible, but expenses must exceed 10 percent of the taxpayer's adjusted gross income for those less than 65 years old (7.5 percent if over 65). Transportation expenses (including mileage), glasses, nontraditional medical care, and mental health expenses are all considered deductible.

*A medical bill is considered paid when the doctor or practice providing the service has received their payment," Moreland continued. "So, if you paid any medical bill charging your card in December of 2014, but didn't pay the credit card bill until January of 2015, the credit still goes to your 2014 taxes. However, if you received an invoice for treatment provided in 2014 and didn't pay the doctor until 2015 that would go toward your 2015 taxes.*

## What Isn't Covered?

Over-the-counter medicines, vitamins, health foods, cosmetic surgeries, and gym memberships are not considered deductible expenses. The general rule of thumb is that if it's not covered by your insurance, it's not deductible by IRS standards.

## Tax Obligations Regarding Private Nurses and Caregivers

How a caregiver is handled tax-wise primarily depends on the nature of the "business relationship." A caregiver is an independent contractor if they are able to decide when and where the work is performed, provide their own equipment, and/or have the flexibility to outsource work to another caregiver. In this case, the family is required to file a 1099 if total compensation exceeds \$600 over the course of a calendar year. If you set the specific terms of employment, the private nurse or caregiver is then considered a "household employee." According to the IRS, this means you are responsible for payroll taxes and must also issue a W-2. If the caregiver is hired through an independent agency, person with ALS or the family is not required to issue any forms.

## Other Things to Keep in Mind

- Speak with your tax preparer about accelerated benefits rider – ABR for Terminal Illness – which is highly subject to individual details.
- Tax laws vary from state to state, and anyone with ALS should consult a local tax expert to see if any exemptions apply to them.
- Reimbursed medical expenses, i.e. veteran benefits, cannot be deducted.
- Save proof of payment of medical expenses for three years (typical IRS audit period) after filing.
- Survivors must file a tax return on the behalf of the deceased for income earned in the year a person passes away. If an estate is left behind, refer to your state's policy on estate and inheritance taxes

**Have additional questions about ALS and how it impacts your taxes?**

**The IRS provides answers to common questions and offers live-chat support where taxpayers can submit questions.**



# Transportation

Transportation becomes a greater challenge with the progression of muscle weakness. At some point most people with ALS will need to use a wheelchair (manual and/or power). You will need to address how you plan to transport not only yourself, but also any equipment necessary in your daily life.



**Driving Evaluation**  
**MN, ND, SD, WI**



**Transportation Considerations/FAQ**



**Van Rental and Purchase Resources**

**Disability Parking Info**  
**MN, ND, SD, WI**

## Questions About Transportation?

The ALS Association's Care Services Team is here to answer any questions you have about private or public transportation. Call us at 888/612.672.0484 or email [info@mn.als.org](mailto:info@mn.als.org). The links above will familiarize you with options in your region, but we recognize that everyone has different needs and it can be helpful to talk through and thoughtfully devise a plan for transportation now and in the future.





# End of Life Plans

## Overview

By being proactive and deciding what end-of-life care best suits your needs, you can help those close to you make the right choices when the time comes. This not only honors your values, but also allows those closest to you the comfort and confidence to help with decisions when the time comes.



## Advance Directives

Advance directives are documents that allow you to spell out your decisions about end-of-life care ahead of time. They give you a way to share your wishes with family, friends, and health care professionals and to avoid confusion later on. The information in this section will help you start the planning process. Additionally, **Prepare for Your Care** is a separate tool that can assist you with making medical decisions for yourself or others, talking with your doctors, and ultimately, receiving the medical care that is right for you.

## Palliative Care

Palliative care is a multidisciplinary approach to specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, physical stress, and mental stress of a serious illness—whatever the diagnosis.

## Final Plans

Here you will find a comprehensive guidebook that will answer many of your questions about end-of-life preparations. Should you have additional questions on the topic, do not hesitate to reach out to our **Care Services team**.

## Hospice Care

Hospice care provides medical services, emotional support, and spiritual resources for people confronting a life-limiting illness or injury, such as ALS. Hospice care also helps family members manage the practical details and emotional challenges of caring for a loved one.

## A Peaceful Death

By Dr. Sam Maiser, Neurologist, Palliative Care Physician, & Medical Director of the ALS Center of Excellence at Hennepin Healthcare

Until we find a cure, many people with ALS wonder how they will die. “What will it look like? Will I suffer? What will my family and friends have to do for me? I hope that my last days will be comfortable. I hope that I don’t suffer.” These questions and concerns are common and normal for people with ALS, and so is the hope for a peaceful death.



# Advance Directives

Every one of us has an opportunity to let others know ahead of time what our health care preferences are in case we find ourselves in a situation where we are unable to communicate them. Receiving a life-changing diagnosis such as ALS makes this type of communication even more important. An advance directive is a legal document used to instruct others about your health care wishes. It acts as a guide for your loved ones and health care providers to make health care and treatment-related decisions on your behalf, should you become unable to convey them due to illness or incapacity.

## An advance directive allows you to:

- Name one or more people as your health care agent or proxy (decision-maker). It is the planning conversations that you have with your health care decision-maker(s) and providers that are crucial, as they help those around you to truly understand your wishes.
- Put into writing what type of care and treatments you would or would not want, depending on the situation and possible outcome.

## How an advance directive is beneficial:

- It empowers you, the person with ALS. The process of completing an advance directive gives you an opportunity to think through and plan for the different aspects of your disease, to express yourself to those around you, and hopefully to provide you with peace of mind that you will be able to influence your care even in the event that you are unable to communicate it.
- It empowers your loved ones. By completing an advance directive and talking with your loved ones about your preferences, you give them the gift of knowledge. In doing so, it will minimize any possible feelings of guilt and uncertainty they might have if they ever need to speak on your behalf.

## What to Consider When Completing an Advance Directive:

There are numerous treatment options to consider when completing an advance directive. The advance directive form generally lists examples of these situations in order to give you a chance to think about how you feel about each one. However, it will also be useful to consider the following specific treatments commonly associated with ALS: **Feeding gastrostomy tube placement when nutritional needs cannot be met | Invasive mechanical ventilation with tracheostomy due to respiratory/breathing failure**

## Where to Find an Advance Directive form:

Contact your **ALS physician or clinic**

Contact your **State Area Agency on Aging**



## Who to give copies to and where to save:

Copies of your advance directive should be given to your health care agent/proxy, your doctor(s), and to your hospital in the event that you become hospitalized. It is also a good idea to inform key family members and friends about where the document is located. It is helpful to keep track of who has a copy so that you know who needs to be informed of any updates you might eventually make to it.

## Can I change my mind?

You can make changes to your health care directive at any time. It is a good idea to review it from time to time to make sure it still represents your preferences. Be sure to keep your health care agent/proxy informed of your updates, and replace any old documents with the new one.

## Do I need an attorney?

While an advance directive is a legal document, it does not require the assistance of an attorney to complete it. Depending on the State in which you reside, you will need only one or two witnesses, or a notary.

**If you need assistance or have questions, contact The ALS Association's Care Services Department at an ALS Association office near you, or contact The ALS Association's National Office.**

# Palliative Care

Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.



**The following features characterize palliative care philosophy and delivery:**

**Care is provided and services are coordinated by an interdisciplinary team.**

**Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs.**

**Services are available concurrently with or independent of curative or life-prolonging care; Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.**



## Final Plans

### Seven Ponds Planning Guide and Checklist

The guidebook above was authored by the care team at SevenPonds.com and is intended to be a step-by-step guide for your loved ones after your death. It includes considerations for estate planning, burial services, the grieving process, and remembrance events.

### Solid Organ and Tissue Donation

Individuals who have a diagnosis of ALS often ask if they will be able to donate their organs at the end of their lives. These individuals often want to donate so that they can provide hope to others for a chance to live longer, healthier, and more productive lives. It could also even save lives. Unfortunately, there are very few ways for people with ALS to donate. Read [this article](#) to learn more about the current state of tissue and organ donation in our service area.

# Hospice Care

Considered to be the model for quality, compassionate care for people facing a terminal illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the individual's needs and wishes. Support is provided to the individual's loved ones as well. At the center of hospice care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

*The following information is sourced from The National Hospice and Palliative Care Organization's **website**. If you have any questions on hospice care, feel free to **contact** the Care Services Department at The ALS Association.*

**Choosing a Quality Hospice**  
**Hospice Frequently Asked Questions**



## How does hospice care work?

Hospice focuses on caring, not curing, and in most cases care is provided in the individual's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to those of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

**The hospice team develops a care plan that meets each person's individual needs for pain management and symptom control.**

**The team usually consists of:**

- The individual's personal physician
- Hospice physician (or medical director)
- Nurses
- Home health aides
- Social workers
- Clergy or other counselors
- Trained volunteers
- Speech, physical, and occupational therapists, if needed

**What services are provided? Among its major responsibilities, the interdisciplinary hospice team:**

- Manages the individual's pain and symptoms
- Assists the individual with the emotional, psychosocial, and spiritual aspects of dying
- Provides needed drugs, medical supplies, and equipment
- Coaches the family on how to care for the individual
- Delivers special services like speech and physical therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or when the caregiver needs respite time
- Provides bereavement care and counseling to surviving family and friends

## Get Involved

### Overview

One of the most common questions people have following an ALS diagnosis is, “What can I do?” The truth is, there are a number of ways that you, your family and support network can make a difference in the fight against ALS. This section will get you started on the Research, Fundraising and Advocacy fronts.



### Research

The National ALS Registry is a program to collect, manage, and analyze data about individuals with ALS. It is important to include as many participants as possible to get the most accurate information. By participating in trials in your region, you’ll be contributing to work that will help doctors and scientists develop effective treatments for the disease.

### Become an Advocate

Sign up to be an ALS Advocate and join a network that receives important updates and action alerts on the latest ALS advocacy issues. You’ll have access to the current legislative agenda and be given opportunities to take action throughout the year.

### Fundraising Efforts

Each year, The ALS Association holds many fundraising events, including The Walk to Defeat ALS®, the SuperHero 5K Dash, a golf tournament, and the Light the Journey Gala. Take a look at our [events schedule](#) for dates and more information about what’s happening in your community. Are you interested in planning your own event? Check out our [Community Fundraiser Guide](#) for information on getting started.

### Volunteer With Us

Beyond what’s listed above, there are plenty of other ways that you can get involved with The ALS Association. Volunteering is a rewarding and valuable endeavor and our staff will help find the right fit for you or your group. You can also participate in awareness-building campaigns or make a direct donation to support those living with ALS in our region.



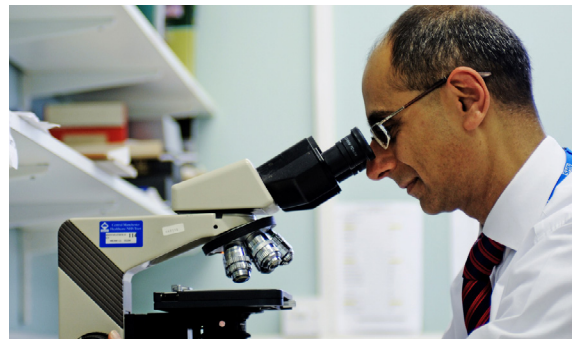
# Research

The ALS Association is the world's largest private funder of research into finding effective treatments and a cure for Lou Gehrig's Disease. Our global research effort has helped increase the number of scientists working on ALS, advanced new discoveries, and has shed light on the complex genetic and environmental factors involved in ALS. If you or someone you care for is living with ALS, there are several ways to make a difference in research.

## The National ALS Registry

**The National ALS Registry** is a congressionally mandated registry for persons in the U.S. with ALS. It is the only population-based registry in the U.S. that collects information to help scientists learn more about who gets ALS and its causes. No one knows for sure what causes ALS and currently there is no cure. If you have an ALS diagnosis, consider joining the Registry and completing the brief risk-factor surveys because your answers could help us take one more step toward a world without ALS.

[Join the Registry](#)



## Ongoing Clinical Trials

Explore the **real-time listing** of available research trials for anyone living with ALS. Define your search criteria to find out which studies are currently recruiting, happening near you, and for which you meet the requirements. Many studies accept healthy participants as well, so there are opportunities for just about anyone to get involved.

## Leading the Charge

The ALS Association remains committed to staying on the cutting edge of global research efforts in the fight against ALS. We work with our partners all over the world, funding studies, sharing findings and comparing results in an effort to more rapidly progress research into effective treatments for the disease. **Visit our site** to read up on the latest advancements in research.



## Tissue Donation

Tissue donation of the brain and spinal cord is an incredibly meaningful and generous contribution to science. Tissue donation does not directly benefit the donor, but it has the potential to make an extraordinary impact on future generations of people living with or at risk for developing ALS.

[Learn More](#)



# Become an Advocate

We know that in order to sustain momentum in ALS research and to guarantee rights and access for people impacted by the disease, our voices must be heard by legislators. Enacting positive policy change and allocating substantial federal dollars to research are the broader goals for The Association's advocacy efforts. Read on to find out how you can contribute.

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 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.



## Advocacy Action Center

You can make a big difference in just five minutes. That's all it will take to learn about the issues and send a letter to Congress or make a phone call to your legislator. The decisions of our government have an enormous impact on people with ALS, their caregivers and families, so please **visit the Action Center** and learn about when and where to get involved.



## ALS Advocacy Conference

Each year, The ALS Association gathers staff, advocates and families across the country to discuss strategy for the upcoming session and meet with representatives. More than one hundred individuals living with ALS have attended the National ALS Advocacy Conference for each of the past several years, and legislators speak to the impact it has on them, personally, to meet people living with the disease and hear their stories. Follow the link on the right to read more about the Advocacy Conference experience.



**Advocacy  
Conference  
Details**



**Become an  
Advocate**





# Fundraising Events

The ALS Association relies heavily on the generosity and support of its donors to ensure our ability to offer programs and services free of charge. One of the easiest and most influential ways to get involved is through one of our many fundraising events.

## Walk to Defeat ALS

The Walk to Defeat ALS is the #1 way to unite and fundraise for those living with ALS. Each year, fundraising through the Walk drives bold and urgent innovation as we march together toward a cure for ALS. [Find a walk near you.](#)



## The SuperHero Dash

The ALS SuperHero 5K Dash is a family-friendly event that attracts avid runners, casual walkers, children of all ages, supporters of The ALS Association, and SuperHeroes of all sorts. Register today and help us #DashOutALS! [Find out more.](#)



## The Larry Sing Memorial ALS Golf Classic

The Larry Sing Memorial ALS Golf Classic carries forward Larry's vision of providing communication devices to people living with ALS and their families. Held on two separate courses in the Fargo/Moorhead area, teams of four can look forward to a day of fun and fellowship on the links. [Click here for more info.](#)



## The ALS Light the Journey Gala

The Light the Journey Gala is an evening filled with fine dining, entertainment, amazing auction items, and most importantly, the opportunity to support ALS research. Secure your seats now! [Learn more.](#)



Please check out our full [events schedule](#) for dates and more information about what's happening in your community.



# Volunteer With Us

As a nonprofit organization, The ALS Association depends on the help of volunteers to help accomplish our mission. These talented individuals and groups assist us in many different ways, from volunteering at events to working with families confronting ALS. Read on to discover if volunteering with The ALS Association is a good fit for you.



Volunteers are essential to The ALS Association. Our programs and services for people living with ALS and their families would not be possible without volunteers. We have a number of volunteer positions available throughout Minnesota, North Dakota, and South Dakota. Whether you are looking to volunteer one day a year at a special event or weekly for a family affected by ALS, we have something for you. Ongoing opportunities include:

## Special Events

Special events raise awareness about ALS. The money raised helps fund ALS research and the free programs and services The ALS Association offers to people living with ALS and their families. You can help with special events by volunteering at an event or by joining a planning committee that meets throughout the year.

## Office Assistance

Office volunteers assist The ALS Association's staff in our St. Paul office. We have both ongoing and on-call positions available. Ongoing volunteers assist the Care Services, Development, and Administrative teams on a regular basis. On-call volunteers help prepare for special events, complete administrative tasks, and work on time-limited projects.

## Family Assistance Program

Living with ALS makes daily tasks more challenging. **The Family Assistance Program** matches trained volunteers with families affected by ALS. Volunteers can help with anything a person living with ALS or their family might need assistance with, outside of direct care. By volunteering for a family affected by ALS, you will help to decrease stress and increase the quality of life for the person living with ALS, making life a little easier for the whole family.

**To learn more about these opportunities and to begin the process please visit our [web page](#).**





# Credits

**Content for the Navigating ALS tool was developed by Jennifer Myhre, MSSW, LICSW at The ALS Association.**

**Contributing members include:**

*Marianne Keuhn*

*Lisa Kronk, RN*

*Linda Lorentzen, OTR/L*

*Cheryl Meyers, MA, OTR/L*

*Kristin Wallock, MS, OTR/L*

*Anne Supplee, MDiv.*

**Additional partners and contributors:**

*Beyond Barriers*

*Edward Kasarskis, M.D., Ph.D.*

*The National Hospice and Palliative Care Organization*

*Terri Moreland, of Lucas, Moreland & Associates*

*Adele Pattinson, Mayo Clinic*

*SevenPonds.com*

*Jan Stanton, janstanton.com*

*Rup Tandan, M.D., F.R.C.P.*

**Design**

*Mike Stephenson, The ALS Association*

*Kaitlin Shore, The ALS Association*

*Amy Lee, The ALS Association*



**1919 University Ave W Suite 175  
St. Paul, MN 55104  
[alsmn.org](http://alsmn.org)**

THIS DOCUMENT STILL BEING TESTED  
BETA v1.7