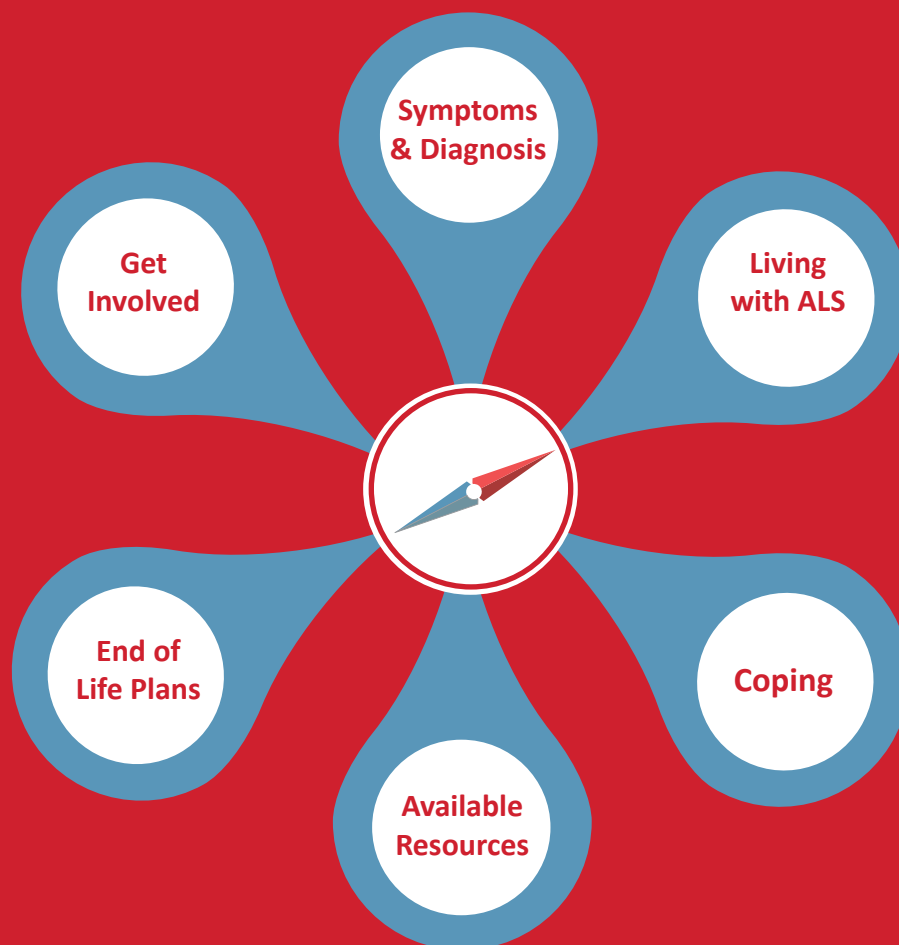




NAVIGATING ALS

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 ALS Navigator, please contact our Chapter at info@alsa-midamerica.org.



.....
Section Main



.....
Index Page

About Our Chapter 3

I	Symptoms	4
	Second Opinions.....	5
	Symptom Management.....	6
	Multidisciplinary Clinics.....	13
	Drug Therapy.....	4

II	Living With ALS	14
	About ALS.....	15
	Daily Living Activities.....	16
	Living Settings.....	21
	Care Connection.....	22
	Treatment Options.....	23

III	Coping With ALS	24
	Help With Coping.....	25
	For The Caregiver.....	29
	Leisure Activities.....	32

IV	Resources	33
	Insurance & Finances.....	34
	Navigating Taxes.....	38
	Transportation.....	39
	Chapter Resources.....	33

V	End of Life Plans	40
	Advance Directives.....	41
	Palliative Care.....	43
	Hospice Care.....	42
	Final Plans.....	42

VI	Get Involved	44
	Research.....	45
	Become an Advocate.....	46
	Fundraising Efforts.....	47
	Volunteer With Us.....	48

About Our Chapter

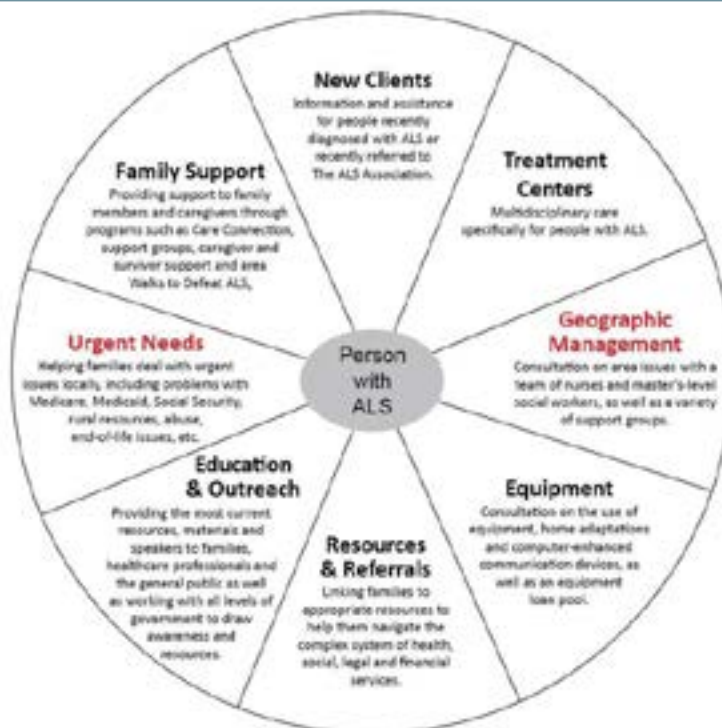
The Mid-America Chapter of The ALS Association supports people living with ALS and their loved ones through services and education. Through our compassionate care and support, state and federal advocacy efforts, and contributions to global research, we're committed to building a future without ALS.

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 **(800) 878-2062**. 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 alsa-midamerica.org, or follow us on **Facebook**.



The Care Services Team

ALS Association Mid-America Chapter Services



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 (800) 878-2062 OR **EMAIL OUR WEBMASTER**. 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 patients 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.

Drug Therapy

At present there are two FDA-approved drugs to treat ALS. Riluzole inhibits glutamate release, prolonging life by approximately three months. Radicava works by reducing the oxidative stress in the body. People with ALS have high levels of oxidative stress. The Mayo Clinic has **additional information** on the drug, commonly known as Rilutek/Riluzole. The ALS Association has **additional information** on Radicava. You can read more about research developments, on our National **Research Webpage**.

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 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.

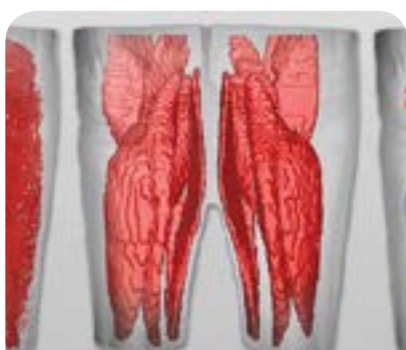
There is an FDA-approved drug, Rilutek,[®] which has been shown to produce a modest increase in survival and slowing of the course of the disease. Research indicates that the drug is most beneficial if started early in the disease.



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



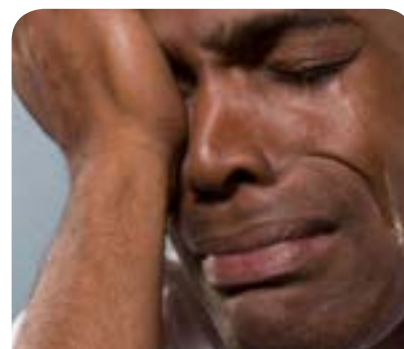
Difficulty
Speaking



Difficulty
Breathing



Changes in
Thinking



Emotional
Lability

Our Chapter's 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 specialist). 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



10 Ways to Minimize Fatigue

Follow **this link** or refer back to pg. 47 to learn our tips to help 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 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 Chapter can help equip you with devices that will improve your quality of life through our **Equipment and Adaptation 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.



Vitamin D

- Majority of adults are vitamin D deficient
- Benefits to supplementation
 - Helps calcium build strong bones
 - Regulates immune system
 - Regulates neuromuscular system
 - Important in life cycle of our body's cells
- Found in fish, eggs, fortified milk and cod liver oil

Talk to your health care provider about vitamin D supplementation

Nutrition Webinar ft. Adele Pattinson, RD, LD

This webinar features Registered Dietician, Adele Pattinson, of the Mayo Clinic in Rochester, MN. Adele has more than two decades of experience advising people living with ALS on their nutritional needs and eating habits, and the session covers a broad range of related topics. A dietician or nutritionist will be part of a care team at the ALS Certified Center near you.

Managing Excessive Saliva

Patients 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, patients 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.
- 12) Avoid muscle-relaxants such as diazepam (Valium) if breath is short, because they may depress breathing.
- 13) A voice amplifier, a small machine with a microphone to make your voice more powerful, may be helpful

*For additional techniques for improving verbal communication and a list of 3 and 4-syllable phrases see our **Suggestions and Information on Dysarthria and Augmentative Communication** document.*

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.
- Obtain a complete baseline health examination from your primary care physician, which should include an office review of your health and any symptoms you are experiencing. Remember to make good use of the time by preparing notes ahead. If you can, bring along a family member or friend to listen to what the doctor says. In addition to your history and physical examination, this visit also may include blood and urine tests and a chest x-ray.

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



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.

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.

Additional Information on Cognitive and Behavioral Changes



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 for professionals: ALS, Cognitive Impairment & Dementia:
A Professional's Guide**



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

Patients 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 Director of The ALS Association Center and Research Program at the Mayo Clinic, in Rochester, Minnesota.

"Patients 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 patients through separate visits in different locations and organizations – helps to ensure that specialists are addressing the big picture."

This teamwork also ensures that each patient 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 patient 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 patients 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 patient and the team.** The patient is considered a full and active participant in determining what approaches to care will be followed.
- **The patient's treatment decisions are respected by the team.** Patients 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 patients and families at virtually any time to answer their questions and help solve problems.
- Centers focus on **maintaining function and treating symptoms** to help patients 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.



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 Chapter happenings in our [Local Connections Newsletter](#).

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**.

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 helpful way. The **Care Connection** program can be a solution.

Treatment Options

In addition to complementary and alternative medicine options, there is a single drug therapy available to those living with ALS. This section details the current treatment landscape.

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 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.



Register with our Chapter to receive the latest news updates. You can also find us on Facebook and Twitter.

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.



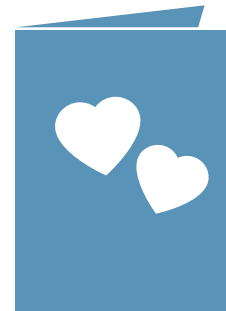
Home Safety and Accessibility

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. Your occupational therapist will be able to help you determine modifications/adaptations and equipment that meet your unique needs. The Care Services Coordinators of The ALS Association Mid-America Chapter also are 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 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 toothbrush to make them easier to hold.
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. Electric toothbrushes offer a 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 coordinator 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. The Mid-America Chapter has a [Home Adaptation Team](#) who is available to assist you in considering any changes.

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](#)

Click here to view a helpful WebEx-based webinar on the topic of Home Accessibility Solutions presented in collaboration with *Beyond Barriers*.



Medical Alert Systems can literally save your life should you fall or have a medical emergency requiring a swift response. The ALS Association, Mid-America Chapter does not endorse any products listed in this document.



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 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.



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.

Reciprocal communication forms the foundation for intimacy with another person. Communication with others occurs through our senses, our eye and body movements, our tears and our smiles. Through communication we share our needs, dreams, thoughts, and desires with others. Verbal expression requires pronunciation of words as well as changes in vocal tone and volume. All of these aspects of communication may become more difficult because of the progression of ALS. Consider asking your speech therapist and/or occupational therapist for ideas about how you can capitalize on the communication abilities you have and alternatives available to you. Intimacy provides the basis for a satisfying sexual relationship. 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. On the converse because of these changes individuals and/or their partners may be more open, more kind and supportive of the other's vulnerability which may lead to a deeper level of intimacy.

Individuals often have unasked questions about the physical expression of their sexuality while managing their ALS progression. This is a topic that may be discussed with your physician even if you do feel somewhat embarrassed or hesitant about doing so. If your physician doesn't have answers for you ask to speak with another team member with expertise in this area. There is very little specific research about how the presence of ALS influences the many aspects of sexual expression: physiological, emotional, psychosocial and physical. Most of the research has been done with people with spinal cord injuries or other medical conditions; such as, heart disease, arthritis, or respiratory difficulties. However, some of this research seems to apply to persons with ALS. Many medications have side effects that influence one's bodily functions. Always ask about any side effects a new medication may have. Medications can affect a man's ability to have an erection or ejaculation. In both men and women some medications can influence desire, arousal and orgasm. Knowing the side effects of your medication may answer some questions you have about changes you are experiencing in your sexual function.

Typical bodily barriers to sexual expression experienced by persons with ALS include spasticity, weakness, fatigue, and respiratory insufficiency. If spasticity interferes with your sexual experience talk with your physician about the pros and cons of antispasmodic medications or other options for decreasing the influence of spasticity. Weakness, fatigue and respiratory insufficiency may require changes in timing of sexual intercourse and/or body positioning during intercourse. Sexual activity right after a nap or in the morning may be more rewarding because you are less fatigued. Conversely, sexual activity after a meal (and full stomach) may decrease respiratory capabilities creating discomfort and a dissatisfying sexual experience.

A perceived or very real change to the role of 'patient and caregiver' between spouses and partners may create a relationship that feels more medical and therapeutic than typical in a loving relationship. It's important to address this possibility with each other.

Ask yourselves how you will maintain a continued intimate relationship in spite of these 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 the Chapter's **respite program** for the caregiver would be helpful. The Chapter also has 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.

The following internet resources address this topic and may be helpful to you:

goaskalice.com - an open forum to ask any question graphically and anonymously.

aasect.org – The American Association of Sex Educators, Counselors, and Therapists – offers lists of counselor as well as available books to the public.



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

The Care Connection program is simple. It is a group of people from your network – friends, neighbors, co-workers, members of community organizations like your church, or other service groups – that provide help for the person with ALS. It can give the family caregiver a much-needed break from their many responsibilities. And it can enhance the lives of group members by giving them a meaningful way to contribute.

The program provides a plan for organizing help from within your network. Care Connection uses a website – lotsahelpinghands.com – that allows Care Connection group members to sign in and see the community calendar where tasks have been posted by the Care Connection coordinator. It is easy to see what people have already signed to do and what jobs need more help. Ideally, the Care Connection Coordinator should be a close friend or family member, but not a primary caregiver of the person with ALS. Some groups have two coordinators and are able to divide the duties. Find what works best for you and the family you are helping.

1. Choose a Care Coordinator
There are many points to consider when choosing a Care Coordinator or agreeing to become the Coordinator. Make sure the right person takes the lead.

2. Build the Connection Team
Meet with the Family to list what they need help with, and identify people who may be willing participants. Arrange a meeting for prospective participants. You can use this [outline](#) of what to cover in the meeting.

3. Scheduling
You can use the electronic schedule found on lotsahelpinghands.com, or go old school and use a [paper calendar](#). The Coordinator will need to keep track of who is doing what, and when, and relay that to the Family.

4. Communicate
Stay in touch with Family needs and changes, and communicate any issues that may have arisen to Participants. Regular emails or phone calls will help keep the Care Connection operating smoothly.



This video offers an overview of the Care Connection program as well as testimonials from individuals and families involved.

Treatment Options

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



Drug Therapy

At present there are two FDA-approved drugs to treat ALS. Riluzole inhibits glutamate release, prolonging life by approximately three months. Radicava works by reducing the oxidative stress in the body. People with ALS have high levels of oxidative stress. The Mayo Clinic has [additional information](#) on the drug, commonly known as Rilutek/Riluzole. The ALS Association has [additional information](#) on Radicava.

Coping With ALS

Acceptance of an ALS diagnosis does not come easily. Learning to live with the disease, and explaining the circumstances to those around 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** and **talking to your kids** about ALS are good places to start.

For the Caregiver

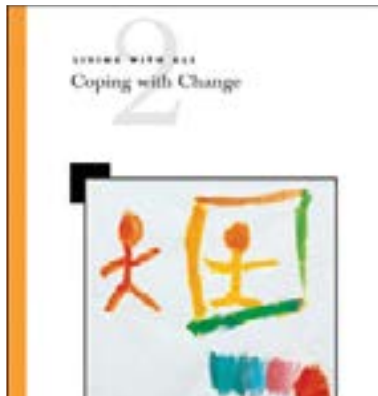
As a caregiver, often the last thing on your mind is your own health and well-being. Learning when to take a break and how to care for yourself are important steps in the process. The ALS Association offers programs for **respite** that you might find helpful.

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.



**Coping With Change:
A Living With ALS Manual**

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.



**Talking to
Kids About ALS**



Support Groups



**Depression
and ALS**



**Hope vs.
Optimism**

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

Support Group
Calendar



For further information about any of these groups please contact Family Support Team leader, Shannon Todd, MSW stodd@alsa-midamerica.org or call the Chapter office at (800) 878-2062. Due to unpredictable weather, location changes, facilitator illness, holidays, and/or other possibilities, we ask that you RSVP for each group. If the group is cancelled for any reason, we will make every attempt to notify you.

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.

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

Resources for Young People

Helping Children Cope with ALS

When your Parent has ALS: A Booklet for Teens

When Someone Special has ALS

For Educators to Support Students

Activity Book for Children



Depression and ALS

Depression is common among people with ALS and their families. Estimates vary, but most experts agree 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.

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.
- Don't be a loner. See friends and family.
- Maintain your decision-making role. That alone reduces frustration and the sense of helplessness.
- 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.
- Try not to isolate yourself. Involve your caregiver and family members in the effort to deal with depression together.

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.

Additional Resources

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. For more of Jan's work, visit her website at www.jan-stanton.com

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.



Quality of Life Grants

For families living with ALS, the emotional, physical and financial challenges can be overwhelming. As the disease progresses and the person with ALS loses more and more of their abilities and independence, family members often have increased responsibility of day to day caregiving tasks. Coupled with ongoing household chores, yard work and car maintenance the workload can start to become unmanageable.

The ALS Association Mid-America Chapter's care services department has developed a new Quality of Life Grant program to assist ALS families with the challenges they face every day. The Quality of Life grant will reimburse ALS families for their needs in respite, communication, home modification, access to medical care and for special circumstances. Our goal is help maintain the highest quality of life despite ALS.

An annual grant of \$400 can be awarded to families battling ALS. An [application](#) is required.

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 helpful 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.

The 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 Mid-America Chapter offers a financial assistance program to assist ALS primary caregivers with short term respite. You can apply to the program using this [form](#). If you have questions about the Mid-America Chapter Quality of Life Program, please contact Sally Dwyer at sdwyer@alsa-midamerica.org or call Care Services at (800) 878-2062.

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.



Mid-America Chapter Portal Program

The portal is a secure online website tool that is designed to improve quality of care, improve communication and provide quick symptom management. The goal is to engage you and your caregiver and improve outcomes by enhancing communication, empowering clients and providing support care.

How The Portal Works

The Patient Portal allows our Care Services Team to identify needs quickly and provide interventions such as equipment or emotional needs, answers to questions, information about ALS and other types of communication.

The main function of the portal at this time is to complete a 12 point questionnaire called an ALS Functional Rating Scale or ALS-FRS, which is the standard tool used in our clinics to assess function in ALS. It basically just asks questions about any changes in your condition.



What does the Functional Rating Scale measure?



- Speech
- Salivation
- Swallowing
- Handwriting
- Cutting Food
- Dressing & Hygiene
- Turning in Bed
- Walking
- Climbing Stairs
- Dyspnea
- Orthopnea
- Respiratory Insufficiency

How long will it take me to complete the survey?

The first visit to the Portal will take a bit longer as we collect information about you and your disease process. After the first visit, with each subsequent visit you can proceed directly to the symptom area that concerns you.

What if I can't find the answers on the portal I need?

In addition to online information, the Portal has an option for you to contact one of our Care Service Team members directly. You can leave a question and request information to be delivered either via an email or a phone call.



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 Chapter 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, etc.

The following web sites 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.

Online Access to Entertainment and Education: Swift, Simple and Fun

Armchair Travel

Wilderness Inquiry



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.

Chapter Resources

If you're utilizing this document, you know that The ALS Association is here to help. Learn more about the full slate of programs and services we can offer to you and your family. **Take advantage of what our Chapter provides** to people living with ALS each day.

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 well being 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.



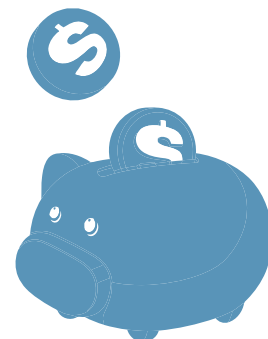
Are You A Veteran?

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 [KS](#), [MO](#) or [NE](#)

Depending on which state you're in and the particulars of your situation, state aid may be an option for you. Our Chapter 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.
- **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.

Medicaid

Medicaid provides health insurance for low-income and needy parties. It covers children, the aged, 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 are not as financially needy, 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. For contact information for a specific state, you can go to www.aphsa.org/Links/links-state.asp.

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

Medicare Information Line: 1-800-MEDICARE (1-800-633-4227); www.medicare.gov

Medicare Rights Center: 1-800-333-4114; www.medicarerights.org

Center for Medicare Advocacy: 1-800-846-7444; www.patientadvocacy.org

Please feel free to contact The ALS Association's Care Services Department with questions at (800) 878-2062. You may also email us at info@alsa-midamerica.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 Mid-America Chapter at (800) 878-2062, or info@alsa-midamerica.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 Kansas, Missouri and Nebraska.

- **KS residents:** Senior Health Insurance Insurance Counseling for Kansas (SHICK) **1-800-860-5260**
- **MO residents:** Community Leaders Assisting the Insured of Missouri (CLAIM) **1-800-390-3330**
- **NE residents:** Nebraska Senior Health Insurance Information Program (SHIIP) **1-800-234-7119**



Navigating Your 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

[KS, MO, NE](#)



Transportation
Considerations/FAQ



Van Rental and
Purchase Resources



Disability Parking Info

[KS, MO, NE](#)



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.

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.

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.

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](#).

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. 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 & 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:

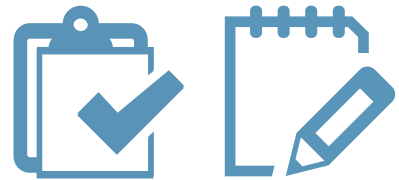
There are numerous treatment options to consider when completing an advance directive. The advance directive form generally lists examples of these situations in order to give you a chance to think about how you feel about each one. However, it will also be useful to consider the following specific treatments 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

Download from the Caring Connections Website



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 Chapter 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

The guidebook below was authored by the care team at SevenPonds.com and is intended to be a step-by-step guide for preparing for, and dealing with, loss. It includes considerations for estate planning, burial services, the grieving process and remembrance events.

SevenPonds Planning Guide and Checklist



Hospice Care

Considered to be the model for quality, compassionate care for people facing a life-limiting 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 patient's needs and wishes. Support is provided to the patient'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, 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** a Care Services Specialist at The ALS Association Mid-America Chapter.*

Choosing a Quality Hospice

History of Hospice



Hospice Video Series

Hospice Frequently Asked Questions

How does hospice care work?

Hospice focuses on caring, not curing and in most cases care is provided in the patient'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 patients 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 patient's individual needs for pain management and symptom control. The team usually consists of:

- The patient'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 patient's pain and symptoms;
- Assists the patient with the emotional and psychosocial and spiritual aspects of dying;
- Provides needed drugs, medical supplies, and equipment;
- Coaches the family on how to care for the patient;
- 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 the caregiver needs respite time; and
- 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 Mid-America Chapter holds many fundraising events, including The Walk to Defeat ALS®, A Night of Hope Gala and The Joe McGuff ALS Golf Classic. 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 [One Dollar Difference](#) page 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 our Chapter. 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 among the world's largest funders 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 government's **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 Chapter site often** to read up on the latest advancements in research.



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.



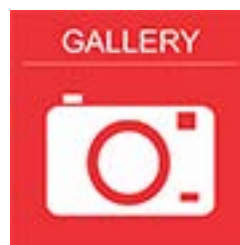
Advocacy Action Center

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 Day

Each year, The ALS Association gathers staff, advocates and families in Washington, D.C., to discuss strategy for the upcoming session and meet with representatives in their offices on the Hill. More than one hundred individuals living with ALS have attended Advocacy Day 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 links on the right to see photos and read more about the **Advocacy Day experience**.



Become an Advocate



Fundraising Efforts

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 with our Chapter is through one of our many fundraising events. There is likely a Walk to Defeat ALS event somewhere near you, but we also a formal gala event and the annual Joe McGuff ALS Golf Classic featuring George Brett and Tom Watson! Chances are you'll find something that your friends and family will want to be a part of.

Walk to Defeat ALS

Since its inception in 2000, the Walk to Defeat ALS has raised over \$215,000,000 nationwide in support of the vision of The ALS Association: **create a world without ALS**. The Walk is a fantastic way to bring the community together and rally around those living with the disease, while raising funds to provide services and fund research into effective treatments. **Find a walk near you.**



The ALS Night of Hope Gala

This themed event, which takes place each spring in downtown Kansas City, helps raise funds to support the programs and services offered to people with ALS and their families, in addition to funding critical research. Gala attendees enjoy tastings from Kansas City Originals, a hosted bar, program, exciting live and silent auctions, and entertainment! **Learn more.**



The Joe McGuff ALS Golf Classic

The Joe McGuff ALS Golf Classic is Kansas City's premiere golf outing! Play a round of golf at beautiful LionsGate while mingling with hometown heroes including Tom Watson and George Brett. Guests enjoy lunch, beverages, a celebrity photo opportunity, an exciting silent auction, dinner, and an inspiring awards program. This tournament is not to be missed! **Find out more about this unique event.**



Are you interested in planning your own event? See our [One Dollar Difference page](#) for more information.



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 our Chapter 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 downtown Minneapolis 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.

To learn more about these opportunities and to begin the process, please fill out our [volunteer application](#) or [contact us](#) directly.



Credits

Content for the Navigating ALS tool was developed by the Care Services team at The ALS Association's Minnesota, North Dakota, South Dakota Chapter. Contributing members include:

Marianne Keuhn

Lisa Kronk, RN

Linda Lorentzen, OTR/L

Jennifer Myhre, MSSW, LICSW

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 Minnesota, North Dakota, South Dakota Chapter

Kaitlin Shore, The ALS Association Minnesota, North Dakota, South Dakota Chapter



The ALS Association, Mid-America Chapter
6950 Squibb Rd., Ste. 210 | Mission, KS 66202
alsa-miamerica.org