Amyotrophic Lateral Sclerosis (ALS)

Veteran Handbook

VA | U.S. Department of Veterans Affairs

Veterans Crisis Line

24/7, confidential crisis support for Veterans and their loved ones.

If you're a Veteran in crisis or concerned about one, reach caring, trained responders **24 hours a day, 7 days a week.**

You don't have to be enrolled in VA benefits or health care to connect.

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Dial 988 then Press 1

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Text 838255

About this Handbook

This handbook has been prepared by VA Clinicians that work with Veterans with Amyotrophic Lateral Sclerosis (ALS). It is intended to support you along this journey by sharing additional information, education, and resources we have gathered over time in caring for Veterans. This resource is best used in partnership with the care provided by your ALS team. You are not alone - please consult your VA team when you have questions.

It is an honor and a privilege for us to care for every Veteran with ALS.

I CARE
DEPARTMENT OF VETERANS AFFAIRS

We welcome your suggestions on how we can improve this handbook to better serve Veterans; please send feedback to: alscare@va.gov.

For clinical care – contact your local VA.

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Understanding Amyotrophic Lateral Sclerosis (ALS)

In this section, we will provide an overview of some of the changes that are commonly experienced by persons with ALS. You may have some, all, or none of these symptoms. We know that it can be overwhelming at times to think about what changes might happen down the road, but we are here to assist you. Our goal is that you and your loved ones are well-prepared to take on any changes or challenges that may come in the road ahead. Later in this Handbook we will revisit these common symptoms and introduce strategies for managing symptoms of ALS.

How does ALS affect your body?

Amyotrophic lateral sclerosis (ALS) is disease that affects nerve cells (or neurons). While ALS can impact many parts of the brain, it is most known for its effects on the motor system. Motor neurons (nerves) from the brain to the spinal cord send impulses to the muscles that provide voluntary movement. Due to ALS, the upper and lower motor neurons of your nervous system fail (called degeneration). This results in muscle weakness, atrophy (wasting), and muscle spasms throughout your body.

Weakness can affect your arms, legs, trunk, neck, throat, mouth, and breathing muscles. Twitching (fasciculations) are also common signs of motor neuron involvement. Muscle stiffness or spasms ALS can start in one or more body regions, and progress to involve other body regions. Oftentimes, weakness from ALS affects one side of your body more than the other side. As the disease progresses, voluntary movement continues to decline and eventually affects your breathing (respiratory) muscles resulting in the need for machines to help you breathe (respiratory support).

What causes ALS?

Currently, the cause of ALS or ways to prevent it are unknown. It is thought that ALS may result from genetic risk factors in some combined with environmental exposures. ALS is more common in Veterans than in non-Veterans. Studies have shown that Veterans are 1.5 times more likely to develop ALS than people who were never in the service. Because of this, in 2008, the Department of Veterans Affairs designated ALS a presumptively compensable illness for all Veterans with 90 days of continuously active service in the military.

Veterans are 1.5 times more likely to develop ALS than non-Veterans.

How long do people live with ALS?

There is no cure for ALS, it is a terminal disease. The typical life expectancy is 2 to 5 years. About 10% of people with ALS live more than 10 years following onset of symptoms. People with ALS who receive supportive care from a specialty ALS interdisciplinary team have been shown to have improved survival. An interdisciplinary team often consists of doctors, nurses, therapists, social workers, nutritionists, and other health care professionals.

What can you expect to change?

ALS progression is not predictable. Symptom progression can be slow, fast, and even plateau during your life with ALS. The onset of ALS symptoms is generally described as either limb onset or bulbar onset. Most individuals diagnosed with ALS will experience limb onset, meaning initial symptoms are noticed in a limb muscle. Changes in mobility (stand, walk, move) occur at varying rates unique to each person with ALS. About 3 in 10 people will experience bulbar onset ALS, meaning initial symptoms are noticed in speech, swallowing, and breathing. Some individuals may also experience changes in their memory, thinking and mood.

Breathing difficulties

ALS affects the chest wall and diaphragm muscles. When this occurs, it can become more challenging to take a deep breath or to breathe out completely. Breathing difficulties often first show up at nighttime when you lay flat. Later on, you may notice worsening shortness of breath with activities. Feeling short of breath can trigger anxiety and discomfort, however there is support and medicines to help with this.

Swallowing difficulties

Most people with ALS will experience difficulty with chewing and swallowing over the course of their disease due to muscle weakness. While choking (blocking off the airway with food so no air can pass) is very uncommon, aspiration (getting small amounts of food or liquid in the airway) is common and can cause a lot of discomfort and even lung infections. In addition, weakness with chewing and swallowing can interfere with nutrition, making it more difficult to maintain your weight, energy levels, and keep up with medications to stay healthy and comfortable. For those reasons, a feeding tube is offered as a way to support nutrition and medicines. This will be discussed in a later section.

Speech difficulties

Speech can be affected by muscle weakness in the lips and mouth, as well as decreased lung and diaphragm function. Nearly 80% of people with ALS will experience changes with their speech. The first symptoms may be mildly slurred or slowed speech, especially when tired. Speech difficulties can also be due to weakening of the breathing muscles.

80% of people with ALS will experience changes with their speech.

Cognition

It is believed that the process that causes ALS may also be related to changes in memory and behavior. Specifically, ALS has been linked to frontotemporal dementia (FTD). FTD is a form of dementia caused by a loss of function of the frontotemporal part of the brain.

About half of all people with ALS notice some degree of difficulty with memory or thinking/processing. For most people, these changes are mild; only a small percentage of people with ALS will develop more severe thinking changes and be diagnosed with FTD. In all cases, it’s important to have early conversations you’re your loved ones about planning, structure, and support in all the areas of human needs: physical, nutritional, intellectual, emotional, spiritual, and social are critical for quality of life and life with dignity. Your health care team can provide suggestions and resources for both the person with ALS and their caregiver(s) to have comfort, strength, and hope.

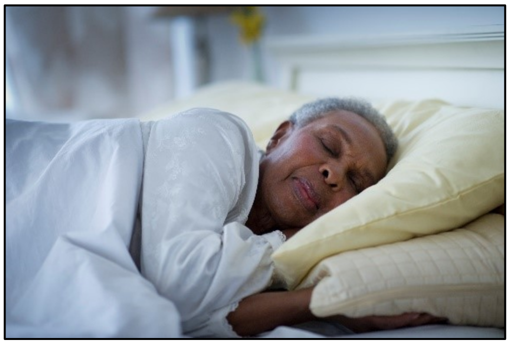
Mood Disturbances

Anxiety and depression are common symptoms, and can affect other body systems, such as breathing. Your ALS team can assist with anxiety management, counseling/therapy, and cognitive strategies and/or address these symptoms with medicines.

Sleep

Sleep can be affected by several factors, for example, physical discomfort, mental discomfort, bladder issues, and breathing difficulties, among others. If you are having difficulty with sleep, please let your ALS team know. They can help troubleshoot the problem or assess whether medicines might be helpful to ensure a good night’s sleep.

Talk with your VA ALS Team if you’re having challenges with sleep.



Fatigue

Your daily energy level is a finite resource, like a bank account. With ALS, all transactions are more costly than they were prior to the disease's onset. Many people experience fatigue with activities that were previously not difficult to complete. Your ALS team can help assess for ways to improve energy levels. These may include addressing poor sleep quality, finding help with tasks that you can delegate to others, energy conservation techniques, or medicines to assist with daytime energy levels.

Drooling

Drooling, called sialorrhea, is a common symptom in ALS, especially in patients with more throat/voice/speech symptoms at the start of the disease. Drooling is another treatable symptom of ALS. Some people use handkerchiefs and oral suction devices to manage this (a portable suction device is available). There are also many types of medicines available for drooling, including oral drops, pills, and patches. When these medicines don't work, injection of botulinum toxin (Botox®) into the saliva glands is an effective treatment that can last several months.

Inappropriate Laughing or Crying

Some people experience laughing or crying more often than they did prior to the start of ALS, even when in a situation where they normally wouldn't laugh or cry. This is known as pseudobulbar palsy. Inform your health care team if you notice this happens to you.

Pain

One of the hallmarks of ALS is "painless weakness," because the disease process itself does not usually cause changes in sensation or pain. However, pain is unfortunately very common in ALS, affecting about 60% of persons with ALS. Pain in the shoulders, neck, or back can often result from or be worsened by the weakness in ALS. There are many available treatments for pain.

Muscle Spasms

Muscle spasms can be uncomfortable. The first-line treatment for spasms is stretching. This can be performed on your own or with help from a caregiver. There are also several medicines that can help calm overactive or spastic muscles.

Bladder and Bowel Changes

While bladder and bowel function changes aren't common as a first symptom of ALS, it's fairly common to see constipation and difficulty emptying the bladder or bladder urgency as the disease progresses. There are many treatments that can help make it easier to manage both of these functions so they don't control your day.

Intimacy and Sexuality

Intimacy and sexuality are complex topics, and ones that can sometimes be hard to bring up in a medical visit. ALS can interfere with these functions due to physical or emotional changes, and it's important to bring up concerns with your ALS care team for referrals to address any concerns you may have.

To learn more:

- The ALS Association has Living with ALS Resource Guides. You can order printed copies or download online versions for free at https://www.als.org/order-portal

It's important to keep your VA ALS Team informed of new or changing symptoms you're experiencing.

How to Connect to VA Care for ALS

ALS can be an overwhelming diagnosis to confront. Seeking trusted sources of information can help Veterans with ALS better understand the disease. It’s important to learn about medical issues you may encounter, strategies for symptom management and daily living, about treatments and current research, and to find support. We strongly encourage you to connect with the nearest VA ALS clinic to allow us to support you.

Initiating VA health care

After your diagnosis, your VA’s ALS Coordinator will assist you to navigate enrollment, expedite access to VA and ALS care, and coordinate your care. In addition, they will:

- Provide emotional support, help with navigating the VA system, and connecting you to valuable resources.
- Help you pursue all entitled benefits through the VA.
- Initiate referral to a Veteran Service Organization.

If you are already enrolled in VA health care, ALS Coordinators can help facilitate expedited scheduling and ensure access to needed VA care and benefits.

The VA ALS Coordinator will help you navigate your life with ALS.

VA Clinic Locations

Veterans living with ALS should become familiar with their care options through the Veterans Health Administration (VHA). Getting connected to an ALS Interdisciplinary Clinic has been shown to improve patient outcomes including life expectancy and quality of life. Every VA Medical Center has an appointed ALS Coordinator. To become familiar with services, Veterans are encouraged to contact their ALS Coordinator.

You can find VA locations near you by visiting: www.va.gov/find-locations/

To locate a VA ALS Clinic near you, please visit:

- **VA ALS System of Care – Veterans Health Administration**
    - Website: www.va.gov/health/als.asp

- **ALS Geospatial Hub (arcgis.com)**
    - Website: https://als-geospatial-hub-nonprofit.hub.arcgis.com/

Partnering with your VA ALS Team

The VA ALS care team is an interdisciplinary team - a group of health care professionals from diverse fields who coordinate their efforts to work toward common health care goals for the Veteran. **The Veteran and their support system are at the center of the team.**

Working with an interdisciplinary team can be an enriching experience and can also present unique challenges, given the number of clinical team members involved. It is important for Veterans with ALS to understand the role and functions of each team member and how communication can best be facilitated between all parties involved. The following questions and answers should help to clarify how to work with the VA ALS care team.

Who is part of your ALS health care team?

An ALS Interdisciplinary Care Team is a group of VA medical facility health care clinicians from different fields. An ALS Interdisciplinary Care Team includes:

- ALS Team Doctor or Medical Provider
- ALS Coordinator
- Social Worker
- Speech-Language Pathologist
- Physical Therapist
- Occupational Therapist
- Respiratory Therapist
- Dietitian

Other team members may include:

- Primary Care Provider
- Home Based Primary Care
- Physiatrist
- Therapeutic Recreation Specialist
- Assistive Technology Specialist
- Kinesiotherapist
- Clinical Pharmacist practitioner
- Psychologist
- Pulmonologist
- Gastroenterologist/ Interventional Radiologist
- Palliative and Hospice Care
- Chaplain
- Veteran Service Officer

What do I do in the ALS Clinic?

What happens in the VA ALS clinic differs from person to person, depending on their specific needs and concerns. You may meet with some or all of the clinicians on the VA ALS Care Team in one clinic visit. Each team member will assess your current needs and provide education and recommendations. You may also have other assessments completed the same day as your clinic visit, such as a Pulmonary Function Test (breathing test), for example. Your time in clinic is for you to be able to ask questions and relay any current concerns you have.

Why should I come to the VA ALS Clinic?

ALS can be a complex diagnosis with many variables. The VA ALS Care team is committed to providing you with excellent patient-centered, coordinated care. It may be helpful for you to have a specific specialty team, such as the VA ALS Care Team, that is familiar with the diagnosis and can support the best quality of life for you.

How often do I come to the ALS Clinic?

Typically, follow up appointments at the ALS Clinic occur every 3 to 6 months. The frequency of visits will depend on the progression of your disease, distance from the clinic, and your ability to travel to the clinic. Your team encourages and welcomes consistent and frequent communication to review current issues and to discuss things we foresee as potential issues in the future. We will work with you as an individual for an optimal treatment plan.

ALS appointments typically occur every 3 months.

Who do I call with questions related to my care?

All team members can be available to answer questions you may have for their specific area of specialty. It may be most efficient and helpful to first contact the VA ALS Coordinator by phone or secure e-mail (through My Health*e*Vet) who can then direct your questions and concerns to specific team members. This way, you have one primary point of contact who can assist with the overall coordination of your care.

How can I contact the ALS Team outside of my ALS Clinic visit?

Each VA location has an appointed ALS Coordinator. Please check with your ALS Coordinator and ALS Team to determine the best point of contact for your location. In addition to in-person assessments and visits, VA offers the support of secure messaging through My Health*e*Vet, Telephone Clinics, and virtual video follow up through Clinical Video Telehealth.

VA is here to support your life with ALS.

ALS Clinic Care Team

We use a team approach in our ALS Clinic. When you come to the ALS Clinic for appointments, you may meet with several members of your care team. Each team member plays a unique role in your care. The next section will tell you about the team members and what they can do to help you.

Who are your team members & how can they help?

- **ALS Physician/Provider** can provide assistance with confirming a diagnosis and discussing genetic testing. They will discuss the disease process and treatment options with you and your family. They provide symptom management to make you comfortable and prevent complications. Assessments are made on an ongoing basis to identify specific needs and concerns, anticipate future needs and to guide timely referrals. They will also discuss end of life issues with you and your family.

- **ALS Coordinator** is the main point of contact for Veterans and caregivers. They will help troubleshoot problems that arise and relay messages to other team members as needed. They will help coordinate your care as your needs change. They facilitate clinical care, schedules, team appointments and maintain regular contact with all Veterans enrolled in ALS Clinic. They may also screen Veterans and caregivers prior to appointments and present screening findings in the multidisciplinary huddle for care planning.

- **Social Worker** uses psychosocial interventions to improve the health and wellbeing of you, your family, and caregivers. They review resources, discuss advance directive planning, and support you and your caregivers. They may advocate for your needs and help you navigate VA and community programs. They provide an overview of VA benefits and services programs that can assist and support you and your family to meet your goals of care. They assist with housing, in home supports, transportation and financial benefits. A Clinical Social Worker is a mental health clinician who can assess individual and family strengths and challenges and provide brief supportive therapy for adjustment and grief.

- **Occupational Therapists (OT)** help you maintain your independence and quality of life. They specialize in self-care management which may include evaluations for durable medical equipment, home modifications and manual and/or power wheelchairs. Based on your goals, they can give you adaptive equipment and assistive technology to help with activities of daily living such as dressing, bathing, eating, and toileting.

- **Speech-Language Pathologist (SLP)** manages communication and swallowing problems such as dysphagia (swallowing difficulty) and dysarthria (change in speech) and thinking skills (cognition). The SLP will make sure you can communicate as effectively as possible and eat and drink safely. They also specialize in assistive technology (AT) and can provide speech-generating devices (SGDs) and other technology such as voice amplifiers to help you meet your communication needs at home and in the community.

- **Physical Therapists (PT)** complete regular evaluations of strength and mobility to establish a baseline and track any trends observed, educating and treating trends/changes as appropriate. They evaluate and issue adaptive equipment to help with mobility and function (ex: cane, walker, transfer boards, lifts). In addition, they provide additional formal PT to assist with maintaining strength and mobility appropriate to current abilities (ex: working on balance, strength, on walking in early stages vs. range of motion and how to transfer with assistance in later stages). Finally, they provide ongoing education for how to maximize quality of life and your mobility and independence.

- **Wheelchair Clinic** will evaluate your seating and mobility needs and may recommend and issue manual or power wheelchairs with seating and other features to meet your needs. VA rehab therapists and the Prosthetics Department can assist you to obtain ramps, vehicle lifts or changes to your vehicle so you can travel safely with your wheelchair.

- **Registered Dietitians** guide Veterans in prevention of malnutrition and optimizing nutrition. They do this by assessing nutritional needs and recommending changes in the diet to assist the Veteran in meeting their nutrition and hydration needs. They will help maintain adequate calories to help prevent weight loss. For patients with ALS, maintaining your body weight and nutrition will help preserve your highest level of function. The dietitian will work with the speech therapist to provide guidance on how you and your caregivers can prepare meals that will be easy and safe to swallow. The dietitian can also provide information and support for tube feeding in a way that supports health care choices and quality of life.

- **Respiratory Therapists (RTs)** help manage your breathing as ALS progresses. They can answer your questions about tools to manage secretions like cough assist, suction, and assisted ventilation.

- **Palliative Care** is an approach to your health care that is appropriate for individuals with serious diseases including ALS. Palliative care focuses on helping to manage symptoms and stress associated with the disease. Palliative care clinicians will assist you in navigating complex and often overwhelming healthcare decisions and assist you and your family to identify and communicate your goals of care. They complete POLST (Physician Orders for Life-Sustaining Treatment) forms (also known as State-Authorized Portable Orders [SAPO] or Medical Orders for Scope of Treatment [MOST], depending upon the state you live in), advanced directives and can help offer guidance related to end of life and refer to hospice services.

- **Chaplain Services** is here to assist in the spiritual care of Veterans and their families while the Veteran is receiving care from a VA facility. Specifically, counseling, prayer, and worship based on the Veterans faith. Chaplains can often assist in the transitions experienced during a disease process.

- **Hospice Care** is a specific benefit and type of care that can be provided in various settings and is usually provided in the home. The purpose is to provide care, comfort and support to the Veteran and their caregivers through the last months of life as well as bereavement care for the family following the death of their loved one. Hospice care helps many people with terminal conditions to have a peaceful and dignified death.
- **Psychologists** work to provide emotional support for Veterans and families navigating an ALS diagnosis. They work with the treatment team to understand goals of care and then promote discussions with Veterans and families to ensure that decisions being made are understood and consistent with their values. They not only assess for mood changes, but also help you to think about ways to improve your quality of life. They can also provide more detailed assessment of cognition (thinking) if there are concerns about memory loss or other changes. Family support is available, as ALS can affect the whole family. You can see a psychologist as part of a routine ALS clinic visit or you can make a separate appointment. They can contact you or your family caregivers by telephone or virtual appointment for support if you find it hard to get to the VA. If you would like to see a psychologist, ask your medical physician or provider, social worker, or ALS Coordinator to refer you.
- **Recreation Therapists** offer resources and information about ways to spend your leisure time. They can help you take part in leisure and recreation activities that are important to you and your family. Whether it is using adaptive equipment or finding other solutions. They can also tell you about community accessibility, travel, adaptive recreation opportunities, and programs for Veterans.

VA's ALS Care Team will support you through your journey with ALS.

Medicines for ALS

There are several medicines that have been approved by the U.S. Food and Drug Administration to treat ALS.

Riluzole (Rilutek®):

- This drug acts to slow the progression of ALS symptoms and prolong survival by inhibiting the release of the neurotransmitter glutamate. Neurotransmitters are molecules that nerve cells use to communicate, and excess levels of glutamate are thought to damage nerve cells in many instances in ALS.

Edaravone (Radicava®):

- Also known as Radicava®, this drug has been shown to slow the loss of physical function.

Tofersen (Qalsody®):

- This treatment is available for adults who have ALS due to a mutation in the superoxide dismutase 1 (SOD1) gene. Tofersen has been shown to reduce neurofilament light chains, a marker of neurodegeneration. Tofersen is administered through recurring spinal injections by a healthcare professional.

Off Label & Alternative Therapies

There are limited treatment options for people with ALS. As a result, some Veterans express interest in exploring alternative, off-label, and complementary therapies that aim to alter disease progression or focus on symptom management. Common alternative therapies may include special diets, nutritional supplements, cannabis, acupuncture, chelation, and energy healing.

These therapies may be pursued as alternatives to or in conjunction with current disease modifying drugs. It is important that Veterans and caregivers discuss these treatment options with their ALS team and consult with reputable sources of information prior to starting off-label treatments and alternative therapies in order to make informed decisions. Education and resources that address efficacy and safety are especially important.

To learn more:

- PatientsLikeMe - ALS
    - Website https://www.patientslikeme.com/join/als

- ALS Untangled
    - Website: https://www.alsuntangled.com/

- Your ALS Guide
    - Website: https://www.youralsguide.com/alternative-treatments-for-als.html

Succinylcholine Allergy

Succinylcholine can cause severe side effects to patients who have muscle weakness. Succinylcholine is given by injection to relax muscles in an emergency or in the operating room (usually when a breathing tube needs to be placed). When this drug is used in people with ALS, it can cause a sudden increase in potassium levels in the blood. High potassium levels can result in abnormal heart rhythms or stop the heart.

You should take the following actions to prevent serious harm:

- Tell any health care providers about the serious risk of using this drug, especially if you are having a procedure or surgery planned.

- Tell any Home Health Care agencies and EMTs that may assist in the home.

Tell all health care providers and first responders about your risk with succinylcholine.

Living with ALS

This section discusses things that you can do to optimize your life and health with ALS.

Taking care of your mouth (oral care)

Oral care is essential in reducing the risk of aspiration pneumonia for Veterans with ALS. Aspiration pneumonia occurs when food, liquid, or saliva enters the airway and reaches the lungs. ALS related muscle weakness, including the muscles involved in swallowing and maintaining good oral hygiene, can increase the risk of aspiration pneumonia. Proper oral care can reduce your risk of aspiration pneumonia.

Additionally, the health of the teeth and gums is an important part of overall health. It is recommended that you brush your teeth twice a day. Your Speech Language Pathologist will provide ongoing assessment, recommendations, and provide adaptive devices when taking care of your mouth may be challenging.

Basic oral care habits like brushing, flossing, and mouth rinses should ensure the best oral care for as long as possible. Veterans should brush teeth after meals and before bedtime to remove food particles and bacterial plaque that could cause gingivitis. It is important to focus on the gum line because it is the portal through which bacteria begin their damage.

Electric toothbrushes provide a great alternative to manual brushing. There are also other assistive devices to facilitate gripping and movement. These are available in stores or can be discussed with an occupational therapist. A portable suction device may be needed as patients with ALS develop swallowing difficulties.

To learn more:

- ALS Association – Oral Care for People Living with ALS
    - Website: https://www.als.org/navigating-als/resources/fyi-oral-care-people-living-als

Managing your Saliva (Secretion Management)

Sialorrhea, also known as drooling or excessive saliva is a common issue for Veterans with ALS. These changes can increase the risk of aspiration pneumonia and limit the use of supportive devices to help you breathe. Sialorrhea can be both a common and bothersome symptom of ALS. Early interventions for sialorrhea may include simple strategies such has using a cloth to wipe the mouth. As this symptom becomes more burdensome, use of devices such as suction machines may be considered. There are several medication interventions that may also be helpful in controlling salvia.

To learn more:

- ALS Association – Managing Excessive Saliva
    - Website: https://www.als.org/navigating-als/resources/fyi-managing-excessive-saliva

Speech and Communication

There are many options for treating your communication. These treatments depend on how your speech changes. Communication with others is a two-way street and your partner can assist you with by learning what gestures, facial expressions, or eye contact you are using to assist with your communication. This is called using a low-tech alternative communication (AAC) system. Examples of other low tech AAC devices include alphabet boards, pictures and charts, and portable writing systems.

If you no longer have the energy to verbally communicate your needs, or if others are having difficulty understanding what you are saying, use of alternative communication (AAC) is important. It is helpful to work with your speech therapist to find which strategies and tools/devices will work the best for you, and to practice using it so that you are comfortable with them when you do need it. Some people with ALS will make recordings of their own voice (called "voice and banking") so they can use the recordings at a later date to communicate their needs.

The type of AAC strategies and tools/devices you use will depend on your speech difficulties and your mobility to access the device. You may be hesitant to use a device instead of trying to speak however, there are many benefits to changing how you communicate, including:

- Conserving your energy
- Improving your quality of life
- Helping to maintain your relationships with others

It is also important that you are able to fully participate in discussions about your health, medical procedures, and care needs. Initially, you may speak clearly but have limited strength in your breathing muscles resulting in low voice volume. You may benefit from a voice amplifier which can be attached to a wheelchair or worn as a headset. A voice amplifier can also be used for you to access voice-activated equipment such as an environmental control unit, a smart phone, tablet, or a computer.

As your voice quality changes, you may transition to AAC devices that generate speech. In other words, you use your existing mobility – hand movement, head movement, or eye movement for example, to input what you want to say, and the device "speaks" for you. AAC devices can include a smart phone, a tablet, a computer or dedicated speech generating device. Your speech therapist will help you decide which device will best meet your needs and assist with changes/programming the device as your needs change.

To learn more:

- The ALS Association – Suggestions and Information about Speech Changes & Augmentative Alternative Communication (AAC)
    - Website: https://www.als.org/navigating-als/resources/fyi-suggestions-and-information-about-speech-changes
- Les Turner ALS Foundation – ALS and Communication
    - Website: https://lesturnerals.org/als-communication-guide/

Changes to the Way You Think (Cognitive Changes)

Initially, the majority of people who have ALS will not have any significant changes in their thinking, memory or emotions related to ALS. At some point during the disease process, however, approximately half of all people with ALS will experience some degree of degeneration (loss of function) in parts of the brain responsible for cognitive function. A smaller percent of these individuals have severe enough degeneration in the frontal and temporal lobes of the brain (the area above your eyes and as far back as your ears) to meet the criteria for frontotemporal lobar degeneration (FTLD) or frontotemporal dementia (FTD).

When ALS and dementia occur at the same time, this is called ALS-FTD. The cause of FTD in ALS is not known, however FTD is more often associated with onset of ALS at an older age, symptoms beginning in the speaking or swallowing muscles (bulbar-onset ALS), and significant bulbar (brainstem) ALS.

The frontal and temporal lobes are responsible for higher thought processes that make up “executive functioning”. This includes organization, solving complex problems, following a series of directions, making important decisions about finances, driving, or employment; making or following complex plans; or demonstrating sound judgment about safety, health and life skills. In addition, depending on which hemisphere (half) of the brain is affected, a person with FTD may have more difficulty with language, judgment and insight, or managing their emotions. Depression, anxiety, poor sleep hygiene, decreased oxygen levels, and medication side effects can all also impair cognitive function; and must be ruled out before an FTD diagnosis is made.

Talk with your VA ALS Care Team if you or your loved one may be experiencing changes in mood or thinking.

Family members will usually report seeing a progressive decline in behavior and/or language, with memory usually remaining intact. The person with FTD may exhibit behavioral changes including:

- Loss of motivation (apathy), initiation, ability to complete tasks.
- Decreased recognition of and response to the feelings and needs of others.
- Being disruptive in public and/or acting inappropriately toward loved ones and caregivers.
- Repetitive or ritualistic activities or habits.
- Excessive and uncontrolled laughing or crying, and emotional lability (pseudobulbar affect).
- Loss of insight about their disease process and their thinking abilities, memory.
- Easily frustrated and quick to anger; aggressive outbursts or potentially risky behaviors.
- Difficulty with language – either finding the right word, spelling a word, or inability to speak (aphasia).

Once the diagnosis of ALS-FTD is confirmed, it is very important to plan for the long-term management of your health while you are fully able to participate in decisions about your health care. Establish a good social support network, and identify a care team that can address health, financial and legal planning.

Other individuals who have had FTD provide the following suggestions:

- Accept the diagnosis and learn about FTD for yourself and others.
- Mourn the losses – express your sadness and grief so you can then refocus on what you can still do.
- Treat the symptoms as disabilities – develop strategies to adapt and manage the symptoms; compensate by doing what you want or need to do differently; develop a routine and structure your day for success adapting activities to utilize remaining strengths and minimize frustration.
- Create a support team who you can trust to help you as your needs change – this may include family, friends and health care professionals.
- Plan for the future right away so you can be fully involved in legal matters such as your powers of attorney, advanced health care directives and will.
- Develop a routine – do things you like and stay connected to friends; practice wellness through healthy diet, exercise, and good sleep habits; find methods that will work to manage your stress.
- Let others support you – there are many things others can do to help – for example transportation to medical appointments, meals and household tasks, financial paperwork, and companionship.
- Get support for the things you cannot change – talk to a professional about changing interpersonal relationships, people who don't understand FTD and coping with the disease if you are alone.

To learn more:

- The ALS Association – Cognitive and Behavioral Changes in ALS: A Guide for People with ALS and their Families
  - Website: https://www.als.org/navigating-als/resources/fyi-cognitive-and-behavioral-changes-als-guide-people-als-and-their
- The Association for Frontotemporal Degeneration
  - Website: https://www.theaftd.org/

Pseudobulbar Affect

Pseudobulbar affect (PBA), also called emotional lability, is a condition affecting some people with ALS, as well as people living with other neurological disorders. It is characterized by uncontrolled displays of laughter or crying which is independent of mood.

About 4 in 10 people with ALS will experience PBA. This is higher than other similar diseases such as Parkinson's disease, Alzheimer's disease, and other forms of dementia. PBA is primarily observed in bulbar onset ALS and is diagnosed with an exam.

While a medication may be prescribed, it is also important to rule out any underlying depression. Interventions typically include patient and family education to assist in understanding the uncontrolled emotions. Coping includes distraction, change in body position, redirection, and relaxation when noted to reduce symptoms.

To learn more:

- ALS News Today
  - Website: https://alsnewstoday.com/pseudobulbar-affect-als/

Coping With ALS

Grief and Coping

Grief is a process people go through when they lose something important to them. ALS may be associated with a variety of losses, including loss of function, loss of employment, changes in aspects of self-identity, and changes in relationship roles.

Grieving looks different for everyone. While grief is an individual process, Elisabeth Kübler-Ross, MD, identified five common reactions to loss. Not everyone experiences all of these ways of grieving. Although everyone's process is unique, identifying ways of responding to loss can give people a way to talk about how the grief they're experiencing.

Common Reactions to Loss/Stages of Grief

- **Denial:** "Not me."

Soon after an ALS diagnosis, you may not be ready to face the changes. Denial can help make the situation a little easier to deal with. Denial isn't always a bad thing. Sometimes it motivates people to work hard in therapies or find creative solutions to keep them involved in activities that are important to them. However, sometimes it can cause problems, such as when ignoring important medical advice or avoiding use of adaptive equipment puts your safety at risk.

- **Rage and anger:** "Why me?"

You may be angry with yourself, someone else, or your situation. Sometimes anger can get misplaced onto other people, like partners or members of your healthcare team.

- **Bargaining:** “Yes me, but. . .”

Bargaining can be thought of as another form of denial. You know things are different now, but you may try to bargain to feel more in control of the situation. For example, you may tell yourself, “I have problems now, but if I work really hard then no matter what the doctors say I’ll be back to my old self.”

- **Depression:** “I’m devastated by the changes,” or “I’m really sad about my situation.”

Depression is a very common reaction to loss. Depression can be expressed in many different ways, including problems with mood, sleep, appetite, energy level, motivation, concentration, memory, and libido. In some cases, depression can lead to suicidal thoughts. If you’re having thoughts of harming yourself, you can call 911, go to the nearest emergency department, or contact the Veterans Crisis Line by dialing 988 then Press 1.

- **Acceptance:** “I don’t have to like it, but I’m going to make the best of it.”

This is a stage where you see changes in your life. Accepting your situation doesn’t mean that you stop trying to improve. It’s an active process that includes looking forward and establishing new goals within the context of your current strengths and limitations.

To learn more:

- CaringInfo
    - Website: https://www.caringinfo.org/planning/grief-and-loss/

Negative Emotion and Disability

Living with a chronic disease can be challenging at times, and it's not uncommon for people to experience negative emotions like depression, anxiety, anger, and frustration. If you find that these negative emotions are leading to unhelpful behaviors, identifying what's causing the emotion can help you figure out what you can do about it. Let's take a look at some common reactions to disability that can come up for people with living with ALS.

- **Fear of Loss and Control.** Many people with ALS experience a sense of a loss of control over their body, their thoughts, their feelings, or their behaviors. When this fear becomes overwhelming, it can lead to anxiety and other strong negative emotions (e.g., helplessness, anger, frustration). Sometimes, when people are worried about a lack of control in their own lives, they make efforts to gain control over other people or other situations.

- **Fear of Dependency.** Those with ALS may fear becoming dependent on others physically, emotionally, and financially. This may be related to worries about a loss of independence and/or worries that you'll be a burden to others. Sometimes, when people fear becoming dependent on others, they ignore or minimize problems, discount medical recommendations (e.g., don't use their assistive devices, don't complete home exercises), and/or withdraw from family and friends.

- **Altered Self Image.** Having ALS may impact how you view yourself. You may no longer be working, you may not be able to do some of the hobbies you used to enjoy, you may need help with things you used to do on your own, and there may be changes in family roles. When people have difficulty responding to changes in how they interact with their world, they may notice problems with decreased self-esteem, anxiety, or depressed mood.

- **Stigma.** ALS may not only impact how you view yourself, but it can also impact how others view you. Being different from the cultural majority (i.e., able-bodied individuals) can present challenges. People may respond to your disability with denial, minimization, avoidance, fear, discrimination, hostility, condescension, disgust, pity, or curiosity. Your own feelings about your ALS can impact your sense of stigma. To cope with stigma, you have to manage both the attitudes of others as well as your own attitudes about your disability.

- **Fear of Social Isolation and Abandonment.** The fear of being alone is not exclusive to those with ALS. However, some people with ALS worry that their family and/or friends will abandon them. In addition, physical symptoms and environmental barriers (accessibility issues, transportation issues, etc.) make individuals with ALS feel more socially isolated. You may also feel like no one really understands what you're going through, which can lead to feeling emotionally isolated.

What to do with strong emotions

Everyone experiences strong emotions now and then. With practice, these emotions can cue use of active coping skills that will help you deal more effectively with your emotions in the moment.

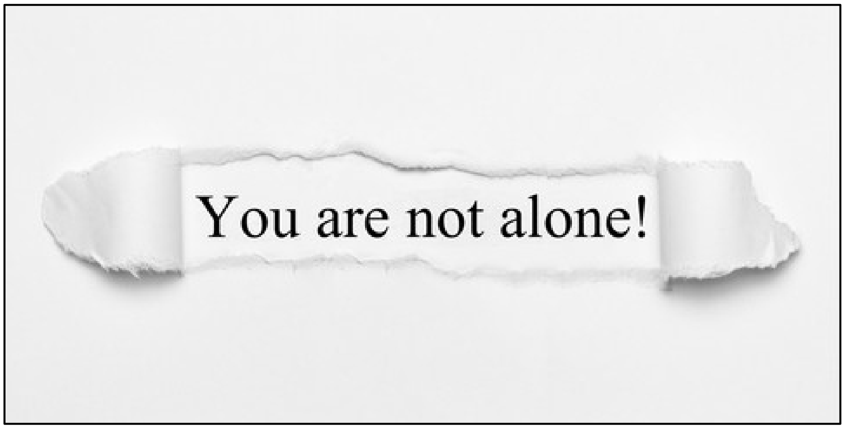
What to do when you are feeling depressed

Humans experience a range of different emotions. Everyone feels down from time to time, but feelings are usually short-lived and pass within hours or days. When you notice problems with low mood or a lack of interest in activities that last for two weeks or more, it might be a sign that you're experiencing a depressive episode. The following symptoms may be associated with depression:

Symptoms of depression

1. Lack of interest in activities or finding little pleasure in life
2. Feeling down, depressed, or hopeless
3. Sleeping too much or too little
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself
7. Trouble concentrating on things
8. Moving or speaking so slowly that other people have noticed
9. Being extra fidgety or restless
10. Thoughts that you would be better off dead or thoughts of hurting yourself

Some of the symptoms typically associated with depression can look similar to physical symptoms related to ALS. Meeting with a mental health professional can help better assess the nature of your difficulties and assist with treatment planning.



Anxiety

Anxiety is another common reaction to stress. It can actually be helpful in some situations, such as times you need to respond quickly to a threat. However, sometimes anxiety can become excessive and extend into many parts of your life. Even if you realize the anxiety is excessive, you may have difficulty controlling it and it may negatively affect your daily life. For people with a Generalized Anxiety Disorder, problems with worry last more than 6 months and may include several of the following symptoms:

Symptoms of Anxiety

1. Restlessness or feeling keyed up or on edge

2. Being easily fatigued

3. Difficulty concentrating

4. Irritability

5. Muscle tension

6. Sleep problems

Some people experience symptoms of anxiety and depression specifically related to their ALS diagnosis. If the problems with depression and/or anxiety don’t meet full criteria for a depressive disorder or an anxiety disorder but are still interfering with your daily life, it may be an adjustment disorder.

Mental Health Treatment

Psychotherapy

Psychotherapy involves talking with a mental health professional, such as a psychiatrist, psychologist, social worker, or counselor to improve your quality of life. Treatment approaches may vary depending on the presenting problem as well as biological, psychological, and social factors that are unique to the individual. Psychotherapeutic interventions may be offered in individual or group settings.

Social Support Groups

Coping with an ALS diagnosis can be a challenging for individuals with ALS and their family members. Studies indicate that one of the primary coping strategies for living with ALS is seeking social support. Support groups can help Veterans feel less isolated, less fearful, and more empowered by connecting them with individuals who share similar experiences. In addition, support groups may provide information and education regarding community resources and strategies for managing ALS symptoms. Groups may be led by people with ALS or trained professionals.

Some of the benefits of ALS support groups include:

- Learning to cope with an ALS diagnosis.
- Exchanging medical information and resources for the treatment and management of ALS
- Building a sense of community
- Sharing experiences and learning from others
- Developing coping strategies
- Discovering ways to support and advocate for the ALS community.
- Learning more about strategies for preserving independence and maximizing quality of life
- Gaining additional emotional support, practical guidance, and resources

To learn more:

- I AM ALS
    - Website: https://www.iamals.org/action/join-a-support-group/
- The ALS Association
    - Website: https://www.als.org/support/support-groups
- ALS Ride for Life
    - Website: https://alsrideforlife.org/
- Les Turner ALS Foundation
    - Website: https://lesturnerals.org/support-services/free-als-support-groups-online/
- ALS Network Connection Groups
    - Website: https://alsnetwork.org/navigating-als/connection-groups/

Support groups can help you feel less isolated, less fearful, and more connected. There may be virtual and in-person options.

Changes in Your Breathing

Managing shortness of breath and adequate respiration (breathing) is critical to your life with ALS. The start of breathing problems or weakness in the muscles of respiration may begin early in the disease or much later. As ALS progresses, breathing muscles become weak, and it may be difficult to cough or sneeze and clear mucous out of your lungs or airway. Most deaths are due to respiratory failure (not being able to breathe).

Breathing symptoms can include:

- Shortness of breath, with and without activity
- Shortness of breath when lying flat
- Fatigue during the day despite a full night sleep

Respiratory problems can include:

- A poor cough reflex can lead to pooling of secretions in the lungs and the back of the throat. This can lead to upper airway obstruction or infections like pneumonia.
- Ineffective coughing can lead to fatigue, shortness of breath, and exhaustion.
- Frequent yawning or sighing during the day.
- Waking up in the morning with a headache or fuzzy-headed feeling (morning confusion)
- Awakening frequently during the night (insomnia)
- Difficulty lying flat; needing to use more than 2 pillows to sleep at night.

Some people with ALS have weakness of the breathing muscles but do not have symptoms. This is why it is important for ALS clinics to regularly check breathing status.

To learn more:

- The ALS Association
    - Websites:
    - https://www.als.org/navigating-als/resources/fyi-breathing-difficulties
    - https://www.als.org/navigating-als/living-with-als/therapies-care/addressing-respiratory-changes/managing-breathing-issues
    - https://www.als.org/navigating-als/living-with-als/therapies-care/addressing-respiratory-changes
- Les Turner ALS Foundation
    - Websites:
    - https://lesturnerals.org/respiratory/about-this-decision-tool/
    - https://lesturnerals.org/als-breathing-guide/

Your VA ALS Care Team will work with you to measure your lung function and determine treatment options.

Pulmonary Function Testing

Pulmonary Function Tests, or PFTs, provide us a quick assessment of your lung and chest wall function. ALS can affect several components of your breathing:

- Ability to manage saliva or keep secretions out of your airway
- Weaken muscles of the chest wall and diaphragm that need to expand to allow your lungs to fill with oxygen

The American Academy of Neurology has outlined standards of care for persons with ALS, and we use this to guide our practices. The current recommendation is for lung function tests to be performed every three months, particularly in the early phase of ALS after diagnosis. This close monitoring allows your team to get a sense of the rate of changes in your body. Rate of change is different for each individual. PFTs help us prepare you with the tools you need to stay as healthy as possible.

Respiratory Equipment

- **Noninvasive ventilation**. Provides breathing support and air exchange through the use of a face mask, nasal mask, or sip and puff interface. Noninvasive ventilation also sometimes called BiPap or Bilevel Positive Air Pressure or Average Volume Assured Pressure Support (AVAPS) help to address the weakness of the breathing muscles which is a common problem faced by individuals living with ALS.

- **Nebulizer.** It is a machine used to change liquid medication into vapor that you can inhale. It works by pumping pressurized air through the liquid to form a fine mist, which can then be breathed in through a mask or mouthpiece.

- **Cough Assist.** Many patients have difficulty producing a strong cough to clear secretions. Clearing secretions is important both for comfort and to avoid lung infections. A cough assist device is used to help produce an effective cough. When you breath in, the machine gives you air to help expand your lungs.

When you blow out, the machine creates a sucking force that pulls the air out of your lungs. This rapid change in pressure during the different phases of breathing helps make your cough stronger and more effective.

- **Suction machine.** Suction machines are required for some patients who have difficulty clearing their secretions. These machines provide enough pressure to clear the air way adequately without causing trauma and should be easy enough for anyone to handle.

- **Invasive ventilation/Tracheostomy.** With more advanced breathing weakness some Veterans choose to have a permanent airway placed. This involves the surgical placement of a plastic tube into the trachea called Tracheostomy. A tracheostomy is connected to a ventilator.

Person with Tracheostomy.

Nutrition and Weight Loss

Weight loss is common in persons with ALS, even very early on in the course of this disease. Weight loss can result from several causes:

- **Loss of appetite**. There are several reasons people may have decreased appetite such as difficulty chewing/swallowing, depression, nausea, pain. Many of these factors can be treated with medicines or other interventions. Please let your medical team know if any of these are affecting your appetite.

- **Loss of muscle bulk due to ALS.** As muscle is heavier than other body tissues, the loss of muscle in persons with ALS will affect a person's body weight significantly. There isn't a good reason to try and overcompensate with calories to replace all of the lost body weight - particularly if you are replacing muscle tissue with fat. Being leaner does have some advantages - it makes caregiving a bit easier and can make mobility easier despite muscle weakness.

- **Increased metabolic demands of ALS.** It is estimated that persons with ALS may need up to 10% more calories per day than persons without ALS.

- **Difficulty preparing food or feeding yourself due to ALS.**

Maintaining proper nutrition and hydration can help to sustain weight to prolong and maintain quality of life. Proper nutrition is critical in efforts to maintain muscle strength and can protect against weight loss which can lead to faster muscle wasting. It is important to consume a variety of foods and an appropriate number of calories to meet daily energy needs, in addition to maintaining hydration.

Strategies to compensate for weight loss

1. It is important to treat any conditions (such as pain or nausea) that are interfering with the appetite. Please let your ALS physician or provider know if you are experiencing any of these symptoms.
2. Medicines (both traditional and complementary/alternative medicine remedies) are available that can stimulate the appetite.
3. When the appetite is limited, it’s more important to focus on good quality nutrition (healthy foods with a balance of proteins, vitamins/minerals, fruits and veggies) - quality is important, as well as quantity.
4. Supplemental shakes can help boost overall calorie intake. These can be helpful to sneak in between meals and add to the daily calorie intake. Unfortunately, these are not available from the VA pharmacy - so you need to privately purchase these.

Swallowing Difficulties

Dysphagia refers to difficulty swallowing and is both a common and significant issue for Veterans with ALS. Dysphagia in ALS can result in a range of challenges including difficulty initiating a swallow, weakness during swallowing, and impaired control of the mouth and tongue muscles needed for chewing and manipulating foot. One of the primary concerns with dysphagia in ALS is the risk of aspiration, which occurs when food, liquid, or saliva enters the airway instead of the esophagus. Aspiration can lead to pneumonia, a potentially serious complication.

Common symptoms of dysphagia include:

- Coughing or choking during or immediately after eating and drinking
- A change in the sound of your voice to a 'wet' or 'gurgly' sound during mealtimes
- Trouble breathing when eating.
- Trouble 'starting' a swallow, and/or feeling the throat muscles fatigue during mealtime.
- Weight loss is also a symptom of a swallowing problem in persons with ALS, as you may be losing weight because eating and drinking is too effortful or too tiring.

These are all symptoms that could mean your swallowing muscles could be losing their function.

You'll work with a Speech-Language Pathologist to screen for swallowing problems.

Feeding Tubes

If swallowing muscles have weakened to the point that it has become too difficult, or too tiring, to swallow all of your food and liquids, a feeding tube (or gastronomy tube, aka g-tube) can be placed. The placement procedure is called a Percutaneous Gastronomy Placement (aka “PEG”) or Radiographically Inserted Gastrostomy (RIG) tube. Hopefully this is something you have had time to think about, and this may even need to be placed prior to you needing to use it. If respiratory (breathing) strength falls below a certain level having a feeding tube placed is much riskier. While the decision is up to you, if you do decide to have a feeding tube put in place (in case you need it), it is better to do it sooner than later. Please talk with your ALS physician or provider about this.

A common misconception is that once a person with ALS starts using a feeding tube, they will no longer eat any food or drink any liquid. This is not the case. As you become aware of what foods or liquids are still swallowed without difficulty, you will likely begin to avoid foods that are troublesome, eat foods that are easier to swallow, and may then use your feeding tube to ‘make up’ for the nutrition you have not swallowed by mouth.

Another great strategy is, if swallowing water is too difficult to do without choking, you can use your feeding tube for your daily water intake, therefore preventing your risk of dehydration. Additionally, if you find that swallowing is easier in the earlier part of the day, but that you are too tired to eat in the evening, you may swallow your breakfast and lunch, then use your feeding tube for your evening nutrition. There are lots of creative ways that you can use your feeding tube to help support your nutrition and hydration, prevent fatigue, reduce aspiration, but still take in some foods and fluids that you enjoy.

If you are interested in having a feeding tube placed, your ALS care team might recommend having it placed sooner rather than later. The reason for this is that the procedure is relatively low risk, but the risk increases as ALS affects your breathing ability. There are several “windows of opportunity” during which the feeding tube can be placed, and expert opinion agrees that having a lung capacity at or above 50% of the predicted value is the safest window during which the feeding tube can be placed.

To learn more:

- The ALS Association
  - Websites:
  - https://www.als.org/navigating-als/resources/maintaining-good-nutrition-als
  - https://www.als.org/navigating-als/resources/fyi-information-about-feeding-tubes
  - https://www.als.org/navigating-als/living-with-als/therapies-care/nutrition-feeding-tubes
  - https://www.als.org/blog/feeding-tubes-what-you-need-know-help-decision-making
- Les Turner ALS Foundation
  - Websites:
  - https://lesturnerals.org/nutrition/about-this-decision-tool/
  - https://lesturnerals.org/als-nutrition-guide/
- Your ALS Guide
  - Website: https://www.youralsguide.com/feeding-tubes.html
- Veterans Health Library – Tube Feeding Videos
  - Website: https://www.veteranshealthlibrary.va.gov/Resources/VideoLibrary/?e=0#gallery

How to Care for Your Skin After Feeding Tube Placement

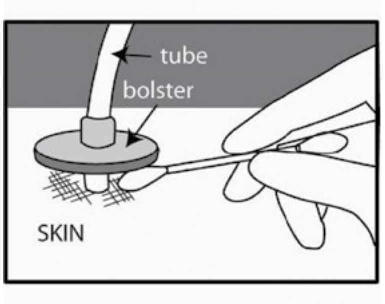
It takes a few weeks for the wound around the feeding tube to heal up, and about three months for the tract from skin to stomach to heal up completely. During this time, it's important to keep the skin clean and protected from moisture so it heals properly. Here is what we recommend:

- If you have stitches in place after the feeding tube placement, make sure you have a plan for where and when the stitches should be removed. This usually happens between 2 and 4 weeks after the procedure.
- Caring for your skin is important! Your health and comfort depend on taking good care of the skin around your feeding tube. The use of a gauze dressing after the first week is optional if there is no drainage around your tube site. Discuss with your medical team when it is appropriate to shower or take a bath.

Always keep the skin around the tube clean and dry.

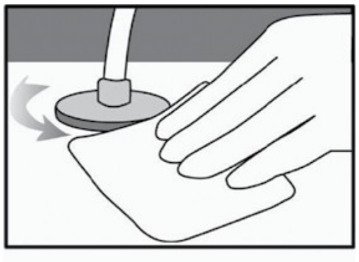
See cleaning instructions:

To clean under the bolster (see illustration):



1. Wash your hands with soap and water.
2. Dip a cotton-tipped swab dipped in warm water.
3. Very carefully, slide the swab under the bolster and around the feeding tube. (Loosen the bolster if it is too tight.)
4. Be careful not to pull on the tube.
5. Gently pat the skin dry with a soft cloth or gauze.

To clean the skin around the tube or bolster:



1. Gently wipe the tube and the skin around it 1-2 times per day.
2. Use a soft, clean cloth or gauze with warm water or with a small amount of a gentle soap mixed with water.
3. Begin cleaning next to the tube, then work out in wide circles to push germs away from the feeding tube site.
4. Rinse the site with another clean cloth and warm water and allow the area to dry.
5. Do not use alcohol to clean your skin.

With each feeding, check the skin for redness, tenderness, pain, swelling, or a bad smell. Also, check for leakage of formula or drainage around the tube. If this happens, clean the skin with gauze or a clean washcloth, and call your ALS Team.

Lastly, you might notice some beefy red tissue grow around the tube insertion site. This tissue can cause a little bleeding onto the dressing. This is known as “hypergranulation tissue” and is a sign that your body is just healing. This can often be treated in the clinic. Please notify your ALS Team if you notice this change so that follow up care can be arranged.

Skincare and Pressure Ulcers

Skincare

As ALS progresses to its later stages, Veterans' skin and hygiene care, including daily bed, bath, and oral care, may be provided by others.

In addition to daily skin care inspection and monitoring, it is important to assess areas susceptible to breakdown. An activity as simple as sitting up in a chair or wheelchair is exercise in itself and should be encouraged; it helps the body and mind and facilitates tasks such as changing linen or airing the mattress. There are devices to assist patients with transferring between a bed and a chair.

A bedridden person should be turned from side to side every few hours during the day and throughout the night for comfort and to alleviate pressure on certain parts of the body. Special mattresses, soft booties, elbow pads, and supports can be used to provide comfort, but are not substitutes for frequent turning or changing of positions.

Contractures are when muscles or tendons in your body become tight and stiff, making it hard for you to move that part of your body as much as you normally would. It can happen if you don't move or stretch your muscles enough over time. Contractures immobilize joints and are a common problem. Prevention includes promotion of activity and exercise, establishing and keeping routines and activities, including programs for muscle strengthening. A doctor, nurse, or physical therapist can demonstrate how to exercise the person's extremities and how to position the person in bed or in a wheelchair so as to prevent contractures.

Adequate nutrition, fluid intake, and adequate hydration should always be promoted and maintained.

A person with ALS can also have altered bowel and bladder functions. They can become incontinent, constipated or impacted. Collection and disposal of urine (incorporating external catheters, male cups, etc.) and feces should be provided as needed. In addition, a bowel program can be developed to prevent these complications. Suppositories and stool softeners can be helpful.

Pressure Ulcers

Persons with ALS are at high risk of developing pressure ulcers/injuries. These are the result of pressure to an area of the body from sitting or lying in a bed or chair. Any surface that presses against the skin and underlying tissues decreases circulation to the area. The pressure collapses capillaries, interrupting the tissue’s supply of oxygen and nutrients and causing tissue breakdown.

There are different signs that a pressure ulcer is developing, starting with redness that won’t blanch and progressing eventually to deep tissue destruction. The areas most prone to developing pressure ulcers are bony prominences of the vertebrae in the lower spine, tailbone and hipbones.

Pressure ulcers are easier to prevent than to treat. Position changes are key to prevention. Positioning appropriately helps prevent continuous pressure on any body part. A Veteran who is immobilized should be turned or moved regularly and properly supported by pillows or foam to provide maximum comfort and prevent sores and deformities.

If a person has upper body strength, encourage wheelchair pushups; some wheelchairs are designed to release pressure, or they may be able to tilt to redistribute pressure. Cushions made of foam or gel, or those filled with water or air can relieve pressure.

Hospital beds that can be elevated at the head should be raised no more than 30 degrees to prevent friction injury, which occurs when the skin rubs on surfaces, such as a bedsheet.

Other devices like mattress overlays and alternating pressure pads protect against pressure sores. When a Veteran is sitting, proper limb positioning helps prevent joint stiffness and contractures.

Other strategies that can help decrease the risk of pressure ulcers include quitting smoking and staying active.

Create a plan with your VA ALS Team to prevent pressure ulcers.

Bowel and Bladder Care

Why is this important?

Although bladder and bowel function are less affected by ALS than other bodily functions, bladder and bowel problems are very common in persons with ALS. Changes in bowel and bladder function can severely affect an individual's comfort or ability to engage in enjoyable activities, and sometimes can challenge a person's independence. This doesn't have to be the case, as there are many strategies to address bladder and bowel problems.

Please don't feel embarrassed to bring up problems related to bowel and bladder management with your care team. These are common problems, and usually your care team can provide suggestions to improve your bladder and bowel management.

What effects bowel and bladder function?

- Decreased mobility (not walking) that can slow the bowels and constipation.
- Taking medicines (particularly pain medicines) that can cause constipation.
- Changes in eating habits (less fluid intake, less food altogether).
- More difficulty getting to the bathroom in a timely manner.
- Trouble getting on and off the toilet.
- Difficulty standing to urinate (men).
- Difficulty using abdominal muscles to strain for bowels (everyone) or strain against an enlarged prostate (men).
- Trouble communicating to caregivers when you need to use the restroom.
- Some types of ALS are associated with bladder urgency/ overactive bladder

Bladder Care

Emptying the bladder on a regular schedule, such as every two hours when awake, can help avoid "emergencies." Not drinking lots of fluids after 5 p.m. can help reduce nighttime trips to the bathroom.

Let your medical team know if you're noticing increasing problems with urinary frequency, getting up at night to urinate, or bladder accidents.

Bladder care for men

Sometimes, medicines can help when your prostate appears to be preventing your bladder from completely emptying.

A portable urinal can be provided and may come in handy as an alternative to making a trip to the bathroom. Many people use this at nighttime or when they are out of the house. In addition, a condom catheter can be worn on the outside of the penis and removed when not needed. For some, this can be a relief at night or when taking road trips to avoid multiple trips to the bathroom.

Bladder care for women

There are a number of options that can help with bladder management for women as well. It’s important for you to feel comfortable and to get relief in a quick and convenient manner. Talk to your health care team about creating a plan that works for your lifestyle and health.

Pros and cons of indwelling catheters

If your mobility is severely limited and getting to and from the bathroom starts to impede your quality of life, an indwelling foley catheter might be a reasonable option. Traditionally, these are placed in the urethra, however, some people with ALS who have severe mobility limitation may have a small surgical opening in the lower abdomen created to keep the bladder drained- this is called a suprapubic tube.

Benefits and Drawbacks of an Indwelling (Internal) Catheter in the Bladder	
Benefits:	Drawbacks:
• No more trips to the bathroom • No sense of urgency • No bladder accidents • Small “leg bags” can be worn under the pants in daytime for discretion. • Catheter is changed only once a month, and this can be done by home care.	• Risk of infection, which would be treated with antibiotics. • Having a tube coming out of your body might affect body image. • Usually requires assistance from caregiver to manage.

Bowel Care: How to avoid bowel trouble.

Many find that in ALS, their bowel habits change slowly or suddenly. Symptoms can include:

- Constipation
- Diarrhea
- Stool incontinence or leaking
- Loss of feeling that you need to have a bowel movement.
- Increase bloating and flatulence

These symptoms are also known as neurogenic bowel, which is a condition resulting from the nerves that control gastric movement, or the movement of stool within the intestines and colon, dying or becoming damaged.

We also rely on being able to coordinate abdominal muscle movement to “bear down” to produce a bowel movement. In ALS, motor nerves that can help us tense these muscles to bear down may have also died or are damaged, and as a result our abdominal muscle movements can become more difficult to coordinate.

Additionally, many find that as ALS progresses, they are not able to be as active as they once were. We know activity greatly helps us to have regular bowel movements by promoting movement of stool through the intestines and colon.

If you are experiencing symptoms of neurogenic bowel, please discuss with your ALS Physician or provider. There are a variety of ways to manage neurogenic bowel which can include, but are not limited to:

- Medication (stool softeners or laxatives)
- Diet changes and adequate hydration
- Applying absorbent briefs or underwear for incontinence
- Implementation of a bowel program

Keeping a consistent schedule of bathroom habits can also be helpful for preventing constipation and can help you maintain control of your bowel function.

Work with your care team to establish a bowel routine that works for you.

Constipation

Constipation can have many causes. These include:

- Eating a low fiber diet
- Eating too much dairy products
- Not drinking enough liquids
- Not enough exercise or physical activity (which is challenging with ALS)
- Changes in lifestyle or daily routine, including pregnancy, aging, work, and travel
- Frequent use or misuse of laxatives
- Ignoring the urge to have a bowel movement or delaying it until later
- Taking medicines, such as certain prescription pain medicines, iron supplements, antacids, certain antidepressants, and calcium supplements

These lifestyle changes can help prevent constipation:

- **Diet.** Eat a high-fiber diet full of fresh fruit and vegetables, high fiber cereals, whole grains, nuts, and legumes. Reduce the amount of dairy foods, meats, and processed foods you eat.
- **Fluids.** It's important to get enough fluids in your diet each day. Drink plenty of water when you eat more fiber. If you are on a diet that limits your fluids, talk with your physician or provider. .
- **Be as active as possible.** Movement helps to prevent constipation.
- **Set a good routine.** Go to the bathroom when you feel you need to. Don't ignore the urge to have a bowel movement. Set aside time after meals to go to the bathroom.

You can also talk to your health care team about medicines that can help to regulate your bowels.

Gastroparesis

Gastroparesis means that your stomach empties very slowly. This happens when the nerves controlling stomach emptying are damaged or do not work properly. This can cause bloating, stomach discomfort or pain, feeling full after eating only a small amount of food, nausea, or vomiting. These symptoms may lead to poor appetite. If you experience these symptoms, talk to your ALS physician or provider and dietician. Your team will help develop a plan that ensures you are getting enough calories and nutrition while improving your symptoms. Medications can help with both constipation, poor appetite, and help with the movement of contents through your digestive system.

Pain Management

Pain in ALS

The ALS disease process does not typically cause pain itself. However, symptoms associated with ALS, such as muscle weakness and decreased mobility, can contribute to increased musculoskeletal pain, including:

1. Back, neck, shoulder or other joint pain related to positioning, arthritis, muscle weakness.
2. Pain in the buttocks or tailbone from extended sitting or lying.
3. Muscle cramps or spasms

What can be done about pain in ALS?

Fortunately, there are many pain management options for persons with ALS. Some examples of ways to alleviate pain include:

1. Cushioning or adjusting positioning to alleviate pressure or uncomfortable positions.
2. Stretching, with or without a caregiver's help
3. Heat/ice, vibration (for spasms)
4. Non-narcotic pain medicines like acetaminophen (Tylenol®), ibuprofen (Motrin®), tramadol, gabapentin, duloxetine
5. Narcotic pain medicines like codeine, hydroxycodone, oxycodone (see more information in the table below)
6. Muscle relaxants - like cyclobenzaprine, baclofen, tizanidine
7. Injections - for example: cortisone injections for painful shoulders/joints

Narcotic Pain Medicines: Advantages and Disadvantages	
Advantages	Disadvantages
• Can provide excellent pain relief. • Very useful for alleviating discomfort at the end of life	• Can be habit-forming/addictive • The body can also become tolerant to the medication over time, making the pain relief less effective. • Can cause constipation- this can be prevented/treated with medicines. • Can cause drowsiness. • Can slow breathing - it is helpful to use respiratory support, like a bi-level (Bipap) device when using narcotics

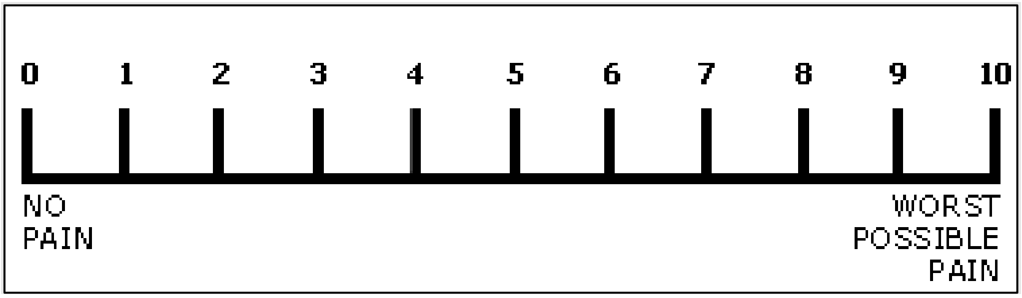
How can I talk to my ALS team about pain control?

There are many things that are out of our control with ALS, but pain management isn't one of them. Here are some suggestions to make sure you and your ALS team are working together to manage your pain symptoms:

1. If you're having trouble with pain management, let your ALS team know; your comfort is important to us. Consider bringing in a list of items you want addressed during your visit. This will help you remember important questions and concerns and can help you make the most of your visit.

2. If you don't feel like your team has successfully addressed your concerns, ask to be referred to a specialist for your kind of pain symptoms. For example, you may benefit from meeting with a musculoskeletal or spine specialist (for limb or spine pain) or rheumatologist (arthritis/joint pain).

3. It can be helpful to "rate your pain" on a 10-point scale so your team has a better sense of what the pain feels like to you. It also helps you and your team know how well the pain management treatments are working. This 10-point scale is the one that most people are familiar with:



Pain Scale

Pain and Mental Health

Many people think of pain as a purely physical sensation. However, pain has biological, psychological and emotional factors. Comprehensive pain management often involves addressing each of these components. In addition to the medical treatments detailed above, psychological treatments are also an important part of pain management. Understanding and addressing thoughts, emotions, and behaviors associated with your physical discomfort can help you respond more effectively to your pain and can actually reduce the intensity of your pain.

Mental health practitioners can help you cope with thoughts, feelings and behaviors that accompany chronic pain. When working with a mental health practitioner, you can expect to discuss your physical and emotional health. You will likely be asked about the type and intensity of your pain, when and where it occurs, and what factors may affect it. You may also be asked to discuss any worries or stresses, including those related to your pain.

Working on pain management with a mental health practitioner often involves teaching relaxation techniques, changing old beliefs about pain, building new coping skills and addressing any anxiety or depression that may accompany your pain. Here are a few general tips for coping with chronic pain:

- **Stay as active as (safely) possible.** Pain, or the fear of pain, can lead people to stop doing the things they enjoy. It's also important to know your limits. Considering talking with your doctor and your therapists to determine what types of activities you might enjoy.
- **Know your limits.** Continue to be active in a way that acknowledges your physical limitations. Make a plan about how to manage your pain, and don't push yourself to do more than you can handle.
- **Make social connections.** Call a family member, schedule time to visit with a friend, check out a support group. People with more social support are more resilient and experience less depression and anxiety.
- **Use distraction.** Find ways to distract your mind from the pain (watch a movie, get outside, engage in a hobby, talk to a friend). Pleasant experiences can help you cope with pain.
- **Check out your ALS team resources**. Many people learn to manage their pain and think of it in a different way. If pain is impacting your quality of life, talk to your team to see what the team can do to help (complementary/alternative medicine, psychological treatment, medicines, etc.).
- **Follow prescriptions**. If medicines are part of your treatment plan, take them as prescribed. In addition to helping, you develop ways to cope with and manage your pain, mental health practitioners can help you develop a routine to stay on track with your treatment.

Fatigue and Energy Conservation

Fatigue from your ALS may limit your ability to do things you want to do in your life. Energy conservation means changing your daily routine to reduce the amount of effort needed to complete tasks and adding more rest during the day. Keep in mind that not every technique will work for you, and energy is like money - you only have so much, so plan how you are going to spend it.

There are several basic rules for energy conservation:

1. **Arrange your "work" area:**

- Store everyday supplies and things you use near where you complete the activity to reduce unnecessary steps and/or movement.
- Set up your kitchen in a work triangle with dishes and cooking utensils close to the stove and refrigerator.
- Place frequently used items at heights that are easy to reach from a seated position such as a wheelchair,
- Use a wheelchair tray, side pouch, cup holder etc. to transport items.

2. **Make a plan:**

- Schedule the activities that are most important to you for when you have the most energy.
- Spread necessary jobs such as laundry, vacuuming, grocery shopping out over the course of the week – the stress of fitting too many jobs and events in one day can result in an increase of your symptoms – pain, fatigue, difficulty breathing.
- Work during the cooler part of the day. Keep the thermostat temperature turned down, or wear cooling garments during work activities.
- Adjust the frequency of your activities to build in rest breaks. Consider changing your self-care routine to allow your body to rest. For example, shower in the evening before going to bed; or reduce the number of showers and sponge bathe on alternate days.

3. Change your position:

- Working in different positions requires different amounts of energy – it takes more work to stand up than it does to complete the task when sitting. It takes more work to obtain objects that are further away from waist level than storing things within easy reach. Bending over to put on socks and shoes may reduce your ability to breathe, and you are more likely to hold your breath when working in a difficult position or placing more demand on your muscles.

4. Adapt your method:

- Gather all the supplies you need for a task or project before starting, so everything is in one place.
- Cook in larger quantities and refrigerate or freeze extra portions for later.
- Build seated rest breaks into activities as often as possible.
- Let dishes soak before washing, and then air dry. Put heavier items on top shelf of dishwasher.
- Order your groceries on-line or by phone and have them delivered.
- Eliminate or reduce tasks that are not that important to you.
- Delegate tasks to friends or family members who offer help.
- Consider hiring professionals, such as a cleaning or lawn care service, to cut down your workload.

5. Use adaptive equipment:

- There are hundreds of pieces of equipment that have been designed to assist with decreased strength and dexterity. Adaptive equipment may only be useful to you for a limited time, but their use is well worth the energy you will save for other more enjoyable activities. If the equipment is not available from the VA, local medical equipment companies, drug stores, and local ALS organizations usually have equipment for rent, sale or loan. The Internet is also a good source by using one of the search engines and typing in the piece of equipment you are looking for. It is recommended that you consult with a medical professional such as an occupational or physical therapist to determine which equipment is most appropriate for you.

6. Let others help:

- Many family members and friends may be challenged by not being able to change how the disease is affecting you. Involving others in your daily routine and allowing them to help you is usually a "win-win" situation – you are able to reserve some energy for something enjoyable, and they will feel they are able to help contribute to better quality of life for you. Help comes in many ways – a phone call, a shopping trip, working in the garden, bringing your mail, reading to you – spend some time to create your own list and share it with others.
- When these strategies aren't sufficient to manage your ALS-related fatigue, talk to your ALS physician or provider about what other options, like medications, might help with your fatigue symptoms.

To learn more:

- The ALS Association
    - Websites: https://www.als.org/navigating-als/resources/fyi-minimizing-fatigue

Activities of Daily Living

Activities of daily living (ADL) are the routine tasks that we complete every day such as self-care, or home management. Under normal circumstances, these "chores" are a small part of our day, and we complete them without effort or thought. With ALS, as your body changes you will likely notice that taking care of yourself requires more effort and energy. You may need some assistance to complete self-care activities.

An occupational therapist can help you look at your daily routine and offer recommendations about modifying it to make it easier for you. There are usually three ways to change most activities. You can change how you do the task – called energy conservation – by sitting, taking rest breaks, or changing the sequence or number of steps in the task. You can use adaptive equipment to compensate for weak muscles or limited mobility. Or you can allow someone to help with the most difficult aspects of the task – for example, getting clothes out of the closet before dressing, or helping you to balance when standing to pull your pants over your hips. Your occupational therapist will meet with you to evaluate your function, get information about your home and routine, and make recommendations about ADL.

As your ALS progresses, you may find it too tiring to complete all of your daily self-care tasks by yourself. Putting together a notebook that contains your care plan and routines will be helpful to your family, friends and caregivers. You should use the notebook to communicate important information such as your medication schedule, special routines or equipment for self-care (i.e., splints, turning schedule), dietary needs, upcoming appointments, and home exercise programs. Including a daily log with your care plan can be used to note vital signs, questions for health care professionals, notes for other caregivers, and jobs to be completed.

Advance Care Planning

Advance Directives

An Advance Directive is a legal form that helps your doctors and loved ones understand your wishes about medical and mental health care and make decisions about your care, if you are not able to make decisions for yourself.

An Advance Directive is the best way to ensure that your future medical care reflects your wishes.

The VA Advance Directive includes sections that allow you to identify the person who would make decisions for you (also called a Health Care Agent) and to specify your treatment preferences.

Those sections are:

- **Durable Power of Attorney for Health Care** – the part that says who will make decisions for you.
- **Living Will** – the part that details your wishes about treatments.

VA Advance Directive Website:
https://www.va.gov/geriatrics/docs/VA_Form_10_0137_Advance_Directive.pdf

The VA honors all types of legal Advance Directives, including forms from another state, Department of Defense or VA. The VA form contains more detail than most other forms and allows you the option to attach additional documents. If you do not use an Advance Directive form to choose a health care agent and you become incapacitated, then your VA health care physician or provider will choose a spokesperson to make decisions for you in this order: legal guardian, spouse, adult child, parent, sibling, grandparent, grandchild, or close friend. If the physician or provider cannot find anyone from this list, VA staff or a court will make decisions for you.

Planning and Making Health Care Decisions

Planning and making decisions about your health care is a collaboration between you, your care partners, and your health care team. Managing your health may be particularly difficult if you have multiple chronic conditions. Identify what matters most first, then share this with your team to focus your care.

The MyHealthPriorities (https://myhealthpriorities.org/) website will help you plan and make decisions by walking through these five steps:

1. Identify What Matters Most to You
2. Set Your Health Goal
3. Review Your Health Symptoms and Problems
4. Review Your Health Care Tasks and Medications
5. Choose The One Thing to Focus On

You can work on this on your own or have a family member or friend help.

This **two-page handout** has information on advance care planning and Advance Directives and includes a questionnaire to help you and your caregivers decide what matters most to you.

Website:
https://www.va.gov/GERIATRICS/docs/Advance_Care_Planning_handout_2024.pdf

To learn more:

- VA Geriatrics and Extended Care
  - Website: https://www.va.gov/geriatrics/pages/advance_care_planning_topics.asp
- The ALS Association
  - Website: https://www.als.org/navigating-als/end-of-life-plans/advance-directives
- I AM ALS
  - Website: https://www.iamals.org/get-help/advanced-care-planning-for-als/

State-Authorized Portable Orders

Individual states have Physician orders for life-sustaining treatment (POLST) or medical orders for life-sustaining treatment (MOLST). These are forms which provide guidance about your medical care so that health care professionals can act on immediately in an emergency. These orders are often documented on a brightly colored form that you keep on your refrigerator. They are filled out by your physician or provider based on talking with you about your preferences. They serve as a medical order in addition to your advance directive.

Life -Sustaining Treatment Orders

Life-sustaining treatment orders are for veterans with serious illness. They are legal medical orders which document of patients' preferences for treatments intended to prolong life and the related goals-of-care conversations. These orders are placed by a VA medical physician or provider during a clinic visit or when the veteran is admitted to a VA hospital to assure that the veteran's wishes are followed.

Life-Sustaining Treatment orders include Do Not Resuscitate /Do Not Attempt Resuscitation as well as orders to limit or not place limits on one or more Life Sustaining Treatment which include artificial nutrition, artificial hydration, mechanical ventilation, dialysis and transfers to the hospital.

To learn more:

- National POLST
    - Website: https://polst.org/
    - POLST Form: https://polst.org/form-patients/

Home Modifications

People who have a physical disability are more likely to receive better care, maintain function longer, and have better quality of life if they are able to receive treatment and remain in their own home. In order to remain at home, most people with ALS in time will need some type of home modification to accommodate the use of a wheelchair. Initial changes usually include providing you with adaptive equipment to make daily activities easier. Unlike home modifications, adaptive equipment (i.e., walkers, bath bench, and transfer pole) are able to be moved in the home and are not permanently attached to the walls or other structures in the home. Home modifications may involve:

- adjusting the location of items (e.g., moving furniture)
- installing special equipment (e.g., grab bars and handrails)
- making changes or additions to the structure (e.g., widening doorways, adding a first-floor bathroom or a ramp).

It's important to set your home environment up for success.

Planning for use of a wheelchair in your home before it happens can reduce stress and ease the transition while maintaining your independence. It is helpful to review each room in your home to determine whether you need to use the room, how you will use the room, and what changes need to be made for this. Depending on where you live, a VA occupational therapist may come to your home to complete an evaluation including taking measurements, drawing a floor plan, and making suggestions for alternate arrangements (i.e., removing furniture, moving living areas to one floor). If you live outside your VA occupational therapy area for home visits, the VA can authorize a fee-based occupational therapist to complete the same evaluation. If an in-home visit is not possible, providing your occupational therapist with photographs of your home and sketching a floor plan with some standard measurements is useful to discuss this transition.

To learn more:

Refer to benefit section for information on eligibility for VA home modification grants

- The ALS Association
    - Websites:
    - https://www.als.org/navigating-als/living-with-als/adapting-your-environment
    - https://www.als.org/navigating-als/resources/fyi-home-adaptations
    - https://www.als.org/blog/living-als-making-sure-your-home-environment-safe-and-livable
    - https://www.als.org/sites/default/files/2020-07/HomeModificationswithALSinMind_2020.pdf
- Les Turner ALS Foundation
    - Website: https://lesturnerals.org/als-home-modifications-guide/
- Your ALS Guide
    - Website: https://www.youralsguide.com/home-modifications.html

Mobility and Independence

Remaining mobile is important for both physical and mental health and most people associate mobility directly with independence. Many people express concerns about feeling self-conscious using a mobility aid or think that using the device will make them more handicapped. It is important to remember that as you get weaker, these devices will help you maintain your independence albeit in a different way and help reduce your risk of injury from a fall.

Meeting with your physical therapist will be important to determine what equipment and means of mobility will be best for you, and how to maintain your safety. You may initially continue to walk using a leg brace and cane, progressing to a walker and eventually a wheelchair. During these transitions, your occupational therapist will help you plan for home modifications when using different mobility devices, and additional equipment for you to complete daily self-care activities.

Mobility in Your Home

Mobility in your home involves a series of different activities – transfers or moving from one surface to another, mobility or moving from one place to another, and supportive positioning when you have reached where you want to go. The goal is to use the most appropriate equipment to make your mobility as easy as possible, and safe for both you and your caregiver.

Walking

Weakness in the ankles can make it difficult to hold your toes up when walking (called foot drop) and can require more effort to clear your foot off the ground and increase your risk of tripping and/or falling. Use of a lightweight ankle support called an ankle-foot-orthosis (AFO) will help your balance and make your walking more efficient. As well as using your AFO and wearing sturdy lightweight shoes rather than slippers, you should make sure that area rugs are removed, and walkways or hallways in your home are clear of clutter. There should be enough room for you to walk using a mobility aid or when someone is assisting you.

If you are using an ankle brace and cane or crutch, and still feel unsteady on your feet or tire easily, it may be time to consider using a walker or manual wheelchair.

A walker or wheelchair can help you manage your energy and stay safe.

Manual Wheelchair

Manual wheelchairs including standard wheelchairs and transport wheelchairs can provide lightweight options for wheeled mobility. The caregiver’s ability to push a manual wheelchair and lift the manual wheelchair into a vehicle are important considerations when deciding if a manual wheelchair is a good option. When manual wheelchairs are used for extended periods of seating, an additional cushion should be considered. Manual wheelchairs may be considered for Veterans with ALS while power mobility options are being explored and are likely only to be recommended for use early in the progression of ALS due to the Veterans safety and comfort. Some Veterans may find that manual wheelchair use is necessary within their home if space does not allow for use of power mobility.

Power Mobility

Power mobility devices include 3 and 4-wheel scooters, standard electric wheelchairs, and custom electric wheelchairs with power seating systems. These are provided by the VA based on your medical and functional needs. At some point during the disease progression, you will likely need and use a power mobility device. The type of device selected will depend on your functional abilities and the rate of your ALS progression. The process of evaluation, ordering the device, and issuing the device to you can take anywhere from one to four months, so it is important to start this process before you require the device for safe mobility. As your needs change, your occupational therapist will re-evaluate you and may recommend a different power mobility device to keep you independent and safe in your mobility and ADL.

Power mobility can even enhance your recreation.

Scooters

A power scooter can be useful when you are having difficulty walking longer distances in the community. Scooters require you to be able to transfer in and out of the seat, sit upright for the duration of scooter use, and have some arm strength and dexterity to use the tiller to steer and drive. Many scooters can be disassembled and loaded into your vehicle for travel, however it is important to consider who will be managing the scooter, the physical requirements for loading and unloading the scooter parts, and your ability to transfer in or out of the vehicle. For these reasons, your occupational therapist may recommend that you consider use of a power wheelchair rather than a scooter depending on how fast your strength and function change.

An electric wheelchair or scooter can help you maintain independence.

Power Wheelchairs

There are many different types of wheelchairs, and your occupational therapist will help you decide which model will work the best for you in your home environment. Power wheelchairs are usually ordered that can be adapted as your function and needs change. For example, at some point the seating system size may be adjusted; or individual parts may be changed for other parts that will provide greater support for your arms and/or legs and protect your skin if you lose weight. If you lose the ability to drive the power wheelchair with your hand, alternative controls are available to reduce the amount of movement and grasp needed to operate the wheelchair. If you can no longer use your hand to operate the wheelchair, and still have reliable movement in another part of your body such as your foot or your head, specialized alternate drive controls can be installed on the wheelchair to enable you to continue with independent wheelchair operation. Current power wheelchair electronics will also allow you to operate the wheelchair's seating system, and control external devices such as an environmental control unit or computer mouse.

Your VA ALS Team will help you to decide which wheelchair would work the best for you by evaluating your abilities and reviewing your home environment. Selection of a power wheelchair includes deciding which type of wheelchair base (whether the drive wheels (with motors) are at the front, middle or back of the wheelchair) would be most beneficial. This will determine how the wheelchair maneuvers in your home and how it operates outside at higher speeds.

The next decision is what type of seating system will go on the base. The seat can range from a van seat to a power seating system and will be built with your custom measurements to provide you with the best support and skin protection possible. The wheelchair can be ordered with four primary power seating functions:

- **Tilt:** the entire seat rotates backwards at a pivot point without changing the position of your hips. This function is useful for relieving pressure from sitting for long periods, elevating your feet and legs to prevent edema, and providing you with better line of sight and ground clearance when driving outdoors.
- **Recline:** the back of the seat reclines, and leg rests or foot platform raise to flatten out your position in the wheelchair. This can be helpful for joint range of motion, positioning for comfort, and helping with self-care tasks such as tube feeding or bladder catheterization.

- **Seat Elevation:** with the seat position upright, the seating system raises vertically from 6-10″ depending on the wheelchair. This function can be useful for reaching objects stored on higher shelves, adjusting your height for sitting at a table, or making a transfer easier by helping you stand up.
- **Power foot positioning:** A small actuator (motor) can be installed on the chair to position your legs separately from the rest of the seating system. Separate power elevating leg rests or a center power foot platform can help straighten and bend your legs for circulation, comfort, and range of motion.

In addition, other custom parts may be ordered to provide the best positioning and support to help you with daily activities, mobility, and comfort. These can include parts such as a wide headrest, a backrest with increased side support, padded armrests with elbow supports, or channeled leg supports. It is important to give your occupational therapist regular feedback about the power wheelchair, and whether your mobility and/or needs are changing so the power wheelchair can be modified. A discussion about transporting your power scooter or wheelchair can be found in the Driver Rehabilitation section.

To learn more:

- The ALS Association
    - Website: https://www.als.org/navigating-als/resources/considering-power-wheelchair

Transfers

Transfers are usually named for the surfaces you are moving to/from – (i.e., bed, toilet, shower, chair, and wheelchair), the type of equipment you are using (i.e., sliding board); and the amount of assistance you need (i.e., minimum, moderate, dependent). Initially, you may only need minimal assistance to transfer such as lifting help for you to move from sitting to standing, or hands-on assistance to help guide your transfer and keep your balance. A gait belt will assure that your caregiver has a firm grip and can help with lifting without stressing your shoulders or back. A pivot disc or sliding board will eliminate the need for you to take steps and turn your body if this is difficult.

If you are no longer able to physically assist with a transfer, a mechanical lift will be used to move you from one surface to the other. Typically, a mechanical lift will cradle you in a u-shaped sling which can then be removed once you are seated. These type of lifts and slings can also be used in the bathroom to place you on the toilet or lower you into a bathtub. Since the bathroom is usually a smaller room in the house, a more custom lift such as an overhead lift, or ceiling lift may be required for a standard tub/shower area.

Prosthetics and DME/ Adaptive Equipment

The use of adaptive equipment (AE) will likely be a large part of your treatment for ALS. Although the decision is yours, there are many studies that suggest that using adaptive equipment can improve your quality of life and will also help to extend your life span. Adaptive equipment, often also called assistive technology (AT) devices, are used for a variety of reasons. AE are intended to help you complete activities of daily living with greater ease and safety. Devices are also used to optimize your health by providing better support, mobility, and comfort or to protect your skin. Another type of adaptive equipment is durable medical equipment (DME) which includes larger devices such as a hospital bed, electric wheelchair, walker, or tub transfer bench.

Researching adaptive equipment, you will find that there are numerous devices of varying complexity and narrowing them down to find those that will work best for you can be very overwhelming. The members of the ALS team can help you identify where you are having more difficulty with ADL and provide you with suggestions for different devices.   Since there is no way to know how quickly your body is going to change, it is important for you to keep your ALS team up to date with your health information. It will be to your benefit to have the ALS team investigate and order adaptive equipment before you need it, to reduce the frustration of being without the equipment when that time comes.

To learn more:

- Your ALS Guide
    - Website: https://www.youralsguide.com/als-equipment-guide.html

The medical equipment provided by the VA may be purchased or rented on your behalf. If you find that the equipment is no longer needed, please check with your ALS Team to determine if the equipment should be returned to the VA. Some equipment will be unable to be returned to the VA. If you are interested in donating your medical equipment, please check with your ALS Coordinator for help with identifying local options.

Electronic Aids/Environmental Control Units

Electronic Aids to Daily Living (EADL), also known as Environmental Control Units (ECUs), are devices that you can use if you have limited movement to control a single or multiple electronic devices. Any device in your home that has electrical power can be set up for you to control by voice command or with minimal physical movement including lights, televisions, stereos, doors, curtains, hospital beds, heating and air systems, fans, telephones, computers, and alarms.

There are three steps to selecting EADL's:

1) identify the devices you want to continue to operate

2) select how you will operate the EADL – an evaluation by your occupational therapist will help identify easy and consistent movements to operate switches

3) choose the best EADL to match your needs.

With today's technology, EADL's can be run through your computer, smart phone, electric wheelchair or may operate independently of these. Your occupational therapist can help you make a list of devices in your home, prioritize which are most important for you to continue to operate, and provide options for how you control the equipment. It is important to keep in mind that your safety and health in the home will be most important issue to address before you consider devices for leisure interests and entertainment. Your needs and abilities for accessing specific devices will also change with your ALS progression so it is important to keep the ALS team up to date on changes in your health as they occur.

Assistive Technology

Without thinking about it, you probably use many devices every day that help you complete tasks more efficiently or with greater ease - items such as electric can openers, computers, TV remote controls, or cell phones are all examples of common assistive technology (AT). AT can be low tech such as a communication board constructed of cardboard with photos/letters attached, or high tech like software for computers or smart phone apps. For individuals with ALS, assistive technology devices can make the difference between relying on others and being able to independently complete daily life tasks that have become difficult or impossible to do. Assistive technology includes but is not limited to:

- Augmentative communication devices such as a letter boards, communication boards, speech storing and generating devices, eye-gaze activation devices.
- Computer accessibility hardware and software including hands-free computer use, voice-activated computer programs, and equipment to compensate for low vision.
- Electric mobility devices such as scooters, power wheelchairs, and other add-on equipment to enable individuals with ALS and/or their caregivers to optimize their positioning for comfort and function.
- Adapted driving systems for vehicles, and vehicle lifts for access to vehicles when you are using a manual or power wheelchair.
- Low vision equipment, reading aids, and home modifications.

- Home automation and environmental control units for hands-free home management, safe access/egress of your home, and independent operation of electric devices such as TV, radio, lights, and fans.
- Adapted recreational equipment including computer access, audio-visual equipment, and adapted sports equipment.

Individuals with ALS have a loss of motor control and benefit from assistive technology at different phases of the disease process to allow an individual to participate in daily life and function with greater independence and improve the quality of life. Both assistive and adaptive equipment help improve people's mobility, communication, and sensory abilities. Assistive Technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve functional capabilities of an individual with a disability. Some equipment is relatively low tech, such as crutches, canes, and basic wheelchairs. Other equipment is very sophisticated, specialized, and technologically advanced.

- low-tech: communication boards made of cardboard or fuzzy felt.
- high-tech: special-purpose computers.
- hardware: prosthetics, mounting systems, and positioning devices.
- computer hardware: special switches, keyboards, and pointing devices.
- computer software: screen readers and communication programs.
- specialized learning materials and curriculum aids.
- AT can be much more—electronic devices, wheelchairs, walkers, braces, educational software, power lifts, pencil holders, eye-gaze and head trackers, and much more.

The VA Assistive Technology (AT) program aims to effectively support Veterans and Service members with cognitive, sensory, and physical disabilities to enhance their independence, comfort, and general quality of life using assistive technology. An interdisciplinary team of specialists work together with the patient and his or her caregiver to assess, identify, and recommend appropriate assistive devices. These include any item, piece of equipment, software, or product system, whether acquired commercially, modified, or customized, that is used to maintain, increase, or improve functional capabilities of individuals with disabilities.

VA divides different types of technologies into 7 general categories:

- Cognitive Aids
- Communication Aids (Augmentative and Alternative Communication Devices)
- Computer Access
- Environmental Controls
- Mobility (Wheeled Mobility)
- Recreation (Adaptive Sports)
- Driving

To learn more:

- The ALS Association
    - Websites:
    - https://www.als.org/navigating-als/living-with-als/therapies-care/assistive-technology
    - https://www.als.org/blog/smart-home-technology-and-als
- Your ALS Guide
    - Website: https://www.youralsguide.com/als-smart-home.html

Creative Arts and Quality of Life

Amyotrophic lateral sclerosis (ALS) has vast implications on the individual and their support system past the physical symptoms throughout the trajectory of the neurodegenerative disease. ALS often results in a loss of motor/movement control, cognitive impairments, decreased capacity for expression, and increased psychological distress and challenges (i.e.: depression, anxiety, pain, end of life, and quality of life and interactions). ALS often influences interpersonal relationships as autonomy decreases and the need for support/caregiving increases. Given the global impact of ALS, particularly the increase of both biological and psychological stressors, the necessity of treatment that facilitates ability to express oneself (verbally, non-verbally, physically, etc.) grows. Expression can aid in maintenance of sense of intrapersonal awareness, enhance awareness for regulation, mitigate emotional distress, and support productive interpersonal relationships.

Creative Arts Therapies (Art Therapy, Dance/Movement Therapy, Drama Therapy, and Music Therapy) use the arts modalities and creative processes to promote various goals specific to individual treatment. Goals are often focused on the integration of wellness, self-efficacy and identity, navigating grief, improving quality of life, increasing access to self-expression, enhancing intrapersonal and interpersonal connection, building resilience, enhancing integration of biophysical experience (I.e.: breath, motor skills, coordination) and more through clinical interventions. Creative Arts Therapies can aid in mitigating effects of ALS' disease progression and ameliorating the impact of the illness.

Resources:

- VA Adaptive Sports and Arts Programs
    - Website: https://department.va.gov/veteran-sports/
- ALS Association Creative Pursuits classes and events
    - Website: www.als.org

Resources for Support

Home Health Care

Home care is a form of health care provided in the home by a licensed health care professional. Persons with ALS who need additional support to stay in the home often utilize these services. Home care can also have significant value to the primary caregiver and/or spouse, who may need added support to assist with personal care activities and to avoid burnout. There are various types of home care and benefits that may be available to Veterans with ALS, which are detailed below.

Veterans may require Home Care Services as their disease progresses and more assistance is needed. These services allow Veterans to stay safely in their homes. Assisted Living facilities, personal residences, and Medical Foster Homes may all be considered a Veteran's home. This flexibility supports Veterans in their choice to stay at home versus making multiple trips to the hospital and even supports their ability to avoid nursing home or long-term acute care hospital placement for as long as possible or altogether depending on their choices and needs. Home Based Primary Care can also decrease the number of outpatient visits for primary care which, in turn, decreases the amount of travel required, travel which can be very taxing on the Veteran and their caregiver.

VHA provides these services using either VHA staff or community agencies that are contracted through Purchased Long-Term Services and Supports (PLTSS). The services under the Home and Community Based Services umbrella include:

- Adult Day Health Care: Therapeutic day program
- Homemaker and Home Health Aide: Provides home and community-based services to Veterans needing assistance with activities of daily living.
- Purchased Skilled Home Care: A professional home care service that VA medical centers purchase from private-sector agencies.

- Veteran-Directed Home and Community Based Services: Provide Veterans of all ages the chance to manage a budget and decide which services will best meet their personal care needs.
- Home Based Primary Care: Provides cost-effective, comprehensive, and interdisciplinary primary care services in the homes of Veterans and includes palliative care, rehabilitation, disease management, caregiver support, and coordination of care.
- Palliative and Hospice Care: Provides comfort-oriented and supportive services for Veterans with advanced life-limiting diseases.
- Respite Care: Provides Veterans with short-term services to give the Veteran's caregiver a period of relief from the demands of providing daily care.

Additionally, Veterans also have the option to move into a Medical Foster Home if they find themselves unable to live at home safely but do not want to live in a nursing home or long-term acute care hospital. Medical Foster Home admission also includes the Home-Based Primary Care program to provide all primary care needs.

To learn more:

- The ALS Association
    - Websites:
    - https://www.als.org/navigating-als/resources/basic-home-care-als-patients
    - https://www.als.org/navigating-als/resources/fyi-different-types-home-care-workers
    - https://www.als.org/navigating-als/resources/fyi-hiring-home-help-independently

Home Health Aide Care

A Homemaker and Home Health Aide is a trained person who can come to a Veteran's home and help the Veteran and caregiver with personal care services. The services of a Homemaker and Home Health Aide can help Veterans remain living in their own home and can serve Veterans of any age. Homemakers and Home Health Aides are not nurses, but they are supervised by a registered nurse who will help assess the Veteran's daily living needs.

This program is for Veterans who need personal care services and help with activities of daily living such as bathing and dressing. This program is also for Veterans who are isolated, or their caregiver is experiencing burden.

Homemaker Home Health Aides work for an organization that has a contract with VA. Homemaker or Home Health Aide services can be used as a part of an alternative to nursing home care, and to get Respite Care at home for Veterans and their family caregiver. The services of a Homemaker or Home Health Aide can help Veterans remain living in their own home and can serve Veterans of any age.

Homemaker and Home Health Aide services can be used in combination with other Home and Community Based Services. Services may vary by location and are designed to change overtime, depending on the Veteran’s needs. Veterans should discuss their home health care needs with their ALS Coordinator.

To learn more:

- VA Geriatrics and Extended Care
    - Website: https://www.va.gov/GERIATRICS/pages/Homemaker_and_Home_Health_Aide_Care.asp

Skilled Home Health Care

Skilled Home Health Care is for Veterans needing short-term care as they are moving from a hospital or nursing home back to their home. It can also be used to provide continuing care to people with ongoing needs.

The program is for Veterans who need skilled services such as: skilled nursing, case management, physical therapy, occupational therapy, speech therapy, wound care, or IV antibiotics. For Veterans who have a need for tracheostomy with ventilator care, the VA is able to provide ventilator trained nursing support for the purpose of caregiver support and respite.

Skilled Home Health Care can be used in combination with other Home and Community Based Services. The care is delivered by a community-based home health agency that has a contract with VA.

Services may vary by location and are designed to change overtime, depending on the Veteran’s needs. Veterans should discuss their home health care needs with their ALS Coordinator.

To learn more:

- VA Geriatrics and Extended Care
    - Website: https://www.va.gov/GERIATRICS/pages/Skilled_Home_Health_Care.asp

Talk with your VA ALS Team about any help you need.

Private Duty

Veterans and caregivers should discuss their home health care needs with their ALS Teams. In some cases, Veterans and caregivers may choose to explore in home care in addition to the care provided by VA home health care. Veterans and caregivers can choose to pay out of pocket for additional caregiving support. Veterans and caregivers are encouraged to utilize the maximum available home health care supports available through the VA before considering this option for additional support.

Assisted Living/ SNF Care with VA

Skilled Nursing Facility (SFN) care may be provided by the VA in a VA Contract bed in a community facility for the following individuals with skilled needs: those with 70% or more service connected, those with 60% or more service connected and rated unemployable, those whose service-connected disability is precipitating SNF placement, and patients requiring hospice services. The VA does not provide SNF placement for all other patients.

- VA does not provide for assisted living care in residential care homes or Assisted Living Facilities.
- Although wait times for assisted living and nursing home level of care vary, you may also complete application for wait list at the state Veterans Homes which are a system of live-in, residential care facilities offering a comprehensive plan of medical, dental, pharmacy, rehabilitation services and social activities within a homelike, community environment.

VA Homemaker Home Health Aid (H/HHA)

H/HHA care can include non-skilled in-home caregiving. Care can include ADLS (e.g., bathing, dressing, personal hygiene care) and IADLs (e.g., cooking, laundry), To apply discuss with your doctor who can request a consult. To apply, discuss with your care team to determine eligibility.

VA Adult Day Health Care (ADHC)

The VA can pay for ADHC services. ADHC's are day programs providing activities and lunch, for individuals with cognitive and physical impairments who require these services as an alternative to nursing home placement. To apply, discuss with your care team to determine eligibility.

VA Home Safety Evaluation and Purchase Skilled Home Care

The VA can arrange for an occupational therapist to visit Veteran's home to do a safety assessment and facilitate installation of necessary safety equipment within certain service areas. Limited skilled care due to a medical condition can also be arranged to homebound patients only. To apply, discuss with your care team to determine eligibility.

VA Home-Based Primary Care (HBPC)

Home-Based Primary Care (HBPC) is a program for Veterans who are homebound and unable to make it to the VA or regular appointments. Primary care physicians or providers and an interdisciplinary team of staff provide primary care services in their home. To apply, discuss with your care team to determine eligibility.

VA Freedom Alert/ Guardian Alerts Plus

An alert system can be installed in the home for Veterans to utilize in case of emergency. The system is free to all Veterans who are at risk for falls, are hard of hearing, and have upper extremity impairment. To apply, discuss with your care team.

Veteran Directed Care

Veteran Directed Care provides Veterans of all ages the opportunity to receive the Home and Community Based Services they need in a consumer-directed way. This program is for Veterans who need personal care services and help with activities of daily living. Examples include help with bathing, dressing, or fixing meals. This program is also for Veterans who are isolated, or their caregiver is experiencing burden. Veterans in this program are given a budget for services that is managed by the Veteran or the Veteran's representative. With the help of a counselor, Veterans hire their own workers to meet their daily needs to help them live at home or in their community. Services are based on your assessed needs. Talk with a VA social worker to find out what specific help you may be able to receive. As a part of this program, Veterans or their representatives receive help developing a spending plan and hiring workers (which might include their own family member or neighbor) to help Veterans live independently in the community. Veterans are eligible for either the support of Veteran Directed Care or VA Home Health Care Benefits. Veterans and caregivers are encouraged to discuss these options with their ALS Teams to learn more about their local VA's programs and services and for help in deciding which VA program would best meet their needs.

To learn more:

- VA Geriatrics and Extended Care
    - Website: https://www.va.gov/GERIATRICS/pages/Veteran-Directed_Care.asp

Skilled care can help you to feel your best and fill the gaps where you need assistance.

ALS: Children and Family Support

All family members are affected by a Veteran’s diagnosis of ALS. When working with the Veteran and their family, it is important that Coordinators and ALS Teams learn about the Veteran’s family support system. The needs of children, teens, and young adults should be considered. Common areas of support include supporting the Veteran and Caregiver in communicating the diagnosis of ALS, identification of age-appropriate resources, understanding the role of children as family caregivers, support in the school setting, and resources for grief.

To learn more:

- National Alliance for Children’s Grief
    - Website: https://nacg.org/
- I AM ALS
    - Website: https://www.iamals.org/get-help/resources-for-kids-and-teens/
- Les Turner ALS Foundation
    - Websites:
        - https://lesturnerals.org/als-children-guide/
        - https://www.youtube.com/watch?v=RCI_1jN5TyU
- Hope Loves Company
    - Website: https://www.hopelovescompany.org/

Transportation

Driver Rehabilitation and Training

Driving is an important part of our lives and, for many, represents freedom and independence with activities of daily living. ALS may significantly impact your driving abilities and result in transportation needs that you had not anticipated. Your primary care provider may refer you to a driver rehabilitation specialist who will evaluate your safety and need for adaptive controls to drive and assist with vehicle modifications you may need as a driver or passenger.

Driving Safety and Legal Considerations

You are required to notify your state Department of Licensing of your change in medical status. Your state may require your physician or provider to complete a form to medically clear you for driving. Once the form is submitted, you may request, or the state may require you to be reexamined for your ability to safely drive your vehicle. Given the progressive nature of ALS, caution should be taken when your muscle strength and function begins to change. For example, you may begin to have difficulty with moving your leg or foot to use the gas and brake pedals, grasping the steering wheel, or sitting upright and holding your head up to see the road. Driver rehabilitation specialists are available to assist you by evaluating your safety and ability to drive, and to determine whether or not adaptive controls are appropriate for continued driving.

Driving Assessment

Your team will determine the best time for you to be referred to have a driving assessment. However, if you or a family member has concerns about driving safety, or notices changes in your driving abilities, you should request a referral to driver rehabilitation. A driver rehabilitation specialist will provide an evaluation of your driving skills to determine your safety with driving. Driver rehabilitation programs are available at many rehabilitation centers and VA Medical Centers.

The evaluation process includes an in-person assessment of your vision, visual perception, cognition, spatial orientation, muscle strength, range of motion, sensation, balance, coordination, and reaction time. If appropriate, an on-road test will also be completed to test your skills in real life situations and to observe your safety awareness, insight, judgment and your ability to operate a vehicle. The driver rehabilitation specialist will provide you with the results of the evaluation, including your current ability to drive and recommendations regarding driving limitations. Due to the progressive nature of ALS, frequent monitoring and reevaluation of driving skills are recommended.

Driving Training

Driving training provides a range of services, from recommendations for limitations with current driving environments to behind-the-wheel training with adaptive controls. You may have a narrow window of opportunity to train and drive with adaptive controls, depending on the rate of progression of the ALS. It is highly recommended that you meet with the driver rehabilitation specialist early in the disease process to have an open discussion about what to expect and whether driving with adapted controls is appropriate for you. At some point, you will need to stop driving—discussing this with your family, ALS team, and driver rehabilitation specialist early on will also help you to transition from driver to passenger and identify alternative transportation options.

Accessing Your Vehicle

While you are able to walk, getting in and out of your vehicle may not be a concern. As your mobility changes you will need to consider what equipment and, potentially, which vehicles can best meet your needs. There is a large range of equipment options for supporting driving while it is appropriate and traveling as a passenger. Based on recommendations from your driver rehabilitation specialist, modifications can be made to most vehicles. Vehicle modifications and adaptive equipment are expensive, and the progression of your ALS should be one of the primary considerations when making decisions about purchasing equipment and driving.

Transporting You and Your Wheelchair

You will need to determine if you will be traveling in your wheelchair or if you are able to transfer into the passenger or driver seat. If you are able to transfer, a six-way power seat base (one that moves forward, backward, up, down and swivels) can be installed to assist you from your wheelchair to the passenger or driver seating.

In all cases of transporting your wheelchair inside the vehicle, tiedowns are required to secure the device in place; wheelchair brakes alone are not a strong enough securement system in the event of an accident. Additionally, if you are sitting in your wheelchair in the vehicle, your wheelchair should be secured facing the front of the vehicle using a tiedown or lockdown system, and an occupant seatbelt system is required.

Tiedown and docking systems secure the wheelchair to the floor of the vehicle and may include manual tiedowns, semi-automatic and electric docking systems.   If you decide not to install an electric docking system, a four-point manual tiedown system is required to secure your wheelchair. Tiedowns should be attached to the frame of the wheelchair base and not to any adjustable or removable parts. Most power wheelchairs have tiedown loops welded to the frame for a four-point tiedown system. You should review tiedown locations and securing the wheelchair using this technique with your mobility expert.

Electric docking systems allow the wheelchair user or caregiver to drive the wheelchair into a floor-mounted device. After you receive your wheelchair, a bracket and docking pin will be attached under your wheelchair. The vendor installing your lockdown system can tell you whether your wheelchair is compatible with this type of securement system.

Vehicle Selection

Selecting an accessible vehicle is an important and expensive decision and it is essential to be a savvy consumer. Talking to qualified mobility experts and driver rehabilitation specialists is highly recommended. These experts can provide information on the best vehicle conversion that will assist with transporting you and your wheelchair. ADED and the National Mobility Equipment Dealers Association (NMEDA) can assist with finding mobility experts and driver rehabilitation specialists in your area.

Determining the best vehicle for you will depend on the type of wheelchair you have—manual or electric—and the seating system on the wheelchair. You should have someone assess your overall height, wheelchair width, and your overall length while seated in your wheelchair. If possible, visiting a mobility dealer in your wheelchair is recommended to test out entering/exiting different types of vehicles. Most individuals select a van for modification that will enable them to enter/exit the vehicle and ride in it while seated in their wheelchair.

Determining if you need a minivan versus a full-size van will depend on personal preference as well as lifestyle needs and wheelchair specifications. Full-size vans may require a raised roof, raised door, and wheelchair lift for you to enter. A minivan conversion requires a lowered floor and ramped entry.

Vehicle Lifts for Mobility Devices

There are many vehicle lift options that may be compatible with the make and model of your vehicle. Your vehicle will need to be rated or classified to accommodate the weight and size of your issued mobility device. The VA will provide a vehicle lift if you are issued a VA mobility device and your vehicle meets the lift classification requirements for the device.

External vehicle lifts:

External lifts are installed either in the bed of a truck, or on the back of the vehicle. These lifts are most appropriate if you are still able to walk and can transfer in and out of your vehicle.

Internal vehicle lifts:

Internal lifts are installed in the trunk or rear storage area of your vehicle. These lifts are usually most appropriate for transporting manual wheelchairs and lighter-weight power wheelchairs. Installation location varies based on the model of lift and may require removal of the back seats and/or drilling into the back interior of the vehicle.

Platform wheelchair lifts:

Platform lifts are mechanical platforms that raise and lower to allow a wheelchair and individual to enter and exit a vehicle from the side or the back. These types of lifts have a greater lift capacity and are most suitable for full-size vans.

Work with your ALS Care Team on a plan for your transportation.

Travel and Leisure Time

Spending time engaged in leisure and recreation interests is not only desirable, but also part of leading a healthy life! You most likely have several leisure interests that you currently enjoy participating in or used to participate in. Depending on the types of activities you enjoy (active vs. passive), you may soon experience difficulty remaining involved in these activities due to physical limitations, such as decreased hand function, mobility, or endurance.

If requested, a recreation therapist will meet with you to explore current or past leisure interests and identify barriers to participation. From this, the therapist will offer solutions, if available, to remain engaged in your current leisure interests or provide guidance in exploring new leisure opportunities.

Most people are able to remain involved in leisure interests either by adapting how they do the activity, or through the use of adaptive leisure and recreation equipment. Your recreation therapist can assist with obtaining adaptive leisure equipment, if needed. Some examples are:

- Bowling – ramp, mouth stick (a device that is placed in a Veteran's mouth to push a bowling ball off a bowling ramp)
- Hunting/shooting – gun mounts, mouth trigger mechanisms
- Computer/technology – voice-activated or motion-activated controls

Recreation therapy also offers opportunities to engage in adaptive sports and recreation at both a local and a national level with support and assistance provided. Though the way you engage in leisure and recreation activities may change with the progression of ALS, there are still ways to remain involved in those activities that are important to you.

Air Travel

Pre-plan

It is always a good idea to call your airline prior to your trip to determine their policies on how they accommodate for passengers with disabilities.

Arrival

It is suggested you arrive at least two hours early—keep in mind that if using a manual chair or power chair, you will automatically be searched when going through security screeners. Most security lines have a wheelchair access lane to get up to a TSA Security employee who will check your plane ticket and valid ID; you usually do not have to wait long in line if using this lane.

Carry-on baggage

Always pack enough clothes, necessities, and medicines for a day or two in your carry-on bags in the event your checked luggage is lost. Always keep your medicines with you.

Liquids and gels

You may bring medically necessary liquids, medications and creams in excess of 3.4 ounces in your carry-on bag. It is recommended that medication be clearly labeled to facilitate the screening process. Remove them from your carry-on bag to be screened separately from the rest of your belongings.

Cruises and International Travel

Some airports, particularly overseas, may have more stringent security standards. Always check ahead before travel to ensure there are no restrictions on medications, devices, or liquids at your destination. Additionally, cruise lines may require a “fitness to travel” letter from your doctor, check with the cruise line.

Your rights

Be aware of your rights as a person flying with a disability—there are some exceptions that apply to you that don’t apply to other passengers, including:

You are allowed one extra piece of luggage for medical equipment; this is outside of your original one or two pieces. Usually, people pack medical equipment into a large box and transport it that way, counting it as their third piece of luggage; mark the outside of the box with the words “medical equipment.” When you bring your box to the check-in desk, employees may ask to look inside the box, so bring extra tape to reseal the box.

If you carry tools with you for your wheelchair or power chair in case of a need for emergency repairs, you ARE allowed to take these tools on board with you. Contact TSA prior to travel.

Getting on the plane

You should stay in your personal wheelchair or power chair until you get to the opening of the airplane. There is pre-boarding available for people who need extra time or assistance. If you are able to walk on the plane safely, you can do so. You have the option of being transferred to an “aisle chair” by airline staff or the caregiver travelling with you. If you need assistance with transfers, please do not hesitate to direct the staff on how to transfer you safely! If you do not know how to direct people to transfer you safely, contact your physical therapist, occupational therapist, or recreation therapist for information. Your personal wheelchair or power chair will be marked with a special gate tag and taken below the airplane. You will then be taken onto the airplane and transferred from the aisle chair into a regular airline seat. Upon arrival at your destination, airline staff will bring your wheelchair or power chair directly to the gate, where you will transfer from the aisle chair back into your personal chair. People with disabilities are the first to board the plane, and the last to get off.

Once transferred into an aisle chair, remove all removable parts from your wheelchair or power chair and take them with you on the airplane (i.e., arm rests, side guards, joy sticks, head rests, footrests, etc.). This decreases the chance of the airline misplacing or losing removable wheelchair parts.

For power chair users, you may use bubble wrap and tape to cover/secure/protect your arm rests and control devices from damage.

Road Travel

Almost every city has accessible transportation for people with disabilities, whether by transit bus or paratransit.

Transit Bus

Check with your county transit authority to determine if the route close to your home has a lift-equipped bus. Buses often have stairs that fold out flat to make a ramp, enabling people with walkers, wheelchairs, and power chairs to access the bus. Most counties also offer reduced fare permits for seniors or for people with disabilities, reducing full fare to a discounted fare. Some transit programs offer free training on how to use the bus. Your recreation therapist can also provide bus training.

Paratransit

Check with your county transit authority to determine if they offer paratransit, or lift-equipped shuttles that provided door-to-door transportation services for people with disabilities using walkers, wheelchairs, and power chairs. Ask if you are eligible to receive these services; they may require you to complete an application for eligibility. Your recreation therapist can assist you with obtaining and completing the application.

Disabled Parking Placards

Talk to your ALS physician or provider if you think you would benefit from a disabled parking placard. In addition, some VA medical centers offer additional accessible parking to Veterans with ALS in designated Spinal Cord Injury and Disorders (SCI/D) spaces.

Rental Car Companies

To inquire about renting a vehicle with hand controls or other accessibility features, it is recommended that you contact local and national rental car companies for further information, including prices and availability.

Make time for leisure, travel, and fun!

Emergency Preparedness

Veterans and families affected by ALS need tools to face unexpected challenges head-on. ALS is a progressive neurodegenerative disease that requires comprehensive care and planning, especially in the face of emergencies. ALS requires a proactive approach to ensure safety, comfort, and well-being during unexpected events. Having an emergency preparedness guide helps Veterans to navigate the complexities of emergency planning and empowers them to confidently respond to whatever comes their way, ensuring the highest level of preparedness and peace of mind in the face of adversity.

Disaster Planning and Readiness

Living with ALS changes many aspects of daily life, but how does it change how you would handle a disaster or emergency? Here are some things to think about and ways to prepare for situations where your disease may affect your ability to react or respond.

Have a Plan

Problems such as inaccessible evacuation routes, roads blocked by downed trees or flooding, utility outages, and overloaded communication lines all need to be considered in planning your responses to various disasters and emergencies.

- Figure out an evacuation route out of your house in case of a power outage.
- Notify your police, fire, and emergency departments of your diagnosis and how it may impact you in an emergency.
- Notify your utility companies of your diagnosis so they are prepared in the event of a loss of power, water, or other service.
- Establish an emergency meeting place and emergency contact in case the Veteran and caregiver are separated (e.g., the caregiver is at work and the Veteran is at home alone or with a home health aide).

- Have an emergency contact outside of the local area as well as someone close by, in case communication within the affected region is blocked, but calls or texts to outside areas can go through.

Gather Information

What information would you need and where would you need it in a disaster? Gather the following information for both the Veteran with ALS **and the caregiver** and keep it in several secure places – on the refrigerator (vital for home health aides and other caregivers); in a fireproof, waterproof safe and your car glovebox; at a family member's house; and in your disaster kit.

Be sure to keep in mind the need for securing personal identifying information; don't display it where others can see it unless it is necessary.

- Medical information – diagnoses, allergies, blood type
- List of medicines (and prescriptions, if possible)
- Contact information for your primary care physician, rehab doctor, neurologist, pulmonologist.
- A list of emergency contacts – family member, emergency caregiver, someone outside the state (in case of a regional disaster or emergency)
- Copies of your advance care directive, living will, DNR
- A copy of your POLST
- A copy of your DPOA

Create a Disaster Kit

A disaster kit for a Veteran with ALS and their caregiver needs the usual components – water, food, clothing, etc. – but beyond that, consider your changing needs as the disease progresses and be sure to have a disaster kit that meets those needs as they increase.

- Enough food and water **for each person** for at least 3 days
- Clothing and blankets for each person, sufficient for all seasons
- All necessary medicines
- Extra supplies for catheter and/or feeding tube, if using one
- Dietary supplement, if applicable, e.g., Ensure
- Incontinence briefs or pads, if needed
- Emergency generator for suction, pump, BiPAP or ventilator
- Mobility aides, as needed – AFOs, cane, walker, manual wheelchair.
- Portable (i.e., not permanently installed) transfer aides, as needed – belts, board.
- Assistive devices for communication, if needed – pad and paper, letter board

To learn more:

- VA Caregiver Support Program – Disaster and Emergency Preparedness
    - Website: https://www.caregiver.va.gov/Emergency_Preparedness.asp

Symptoms that Mean You Should Call Your ALS Team

- A fever
- Significant change in breathing or shortness of breath
- Productive cough with colored sputum (yellow or green)
- New or significantly worse confusion
- New or increased falls
- Significantly decreased appetite or oral intake
- Significant weight loss (more than 10 pounds in a month)
- Intolerance of tube feeds (nausea, vomiting, diarrhea, constipation, bloating, abdominal pain)
- Increased coughing with solids, liquids, or medicines
- New difficulty communicating with loved ones.
- If your medical equipment malfunctions or is broken and in need of immediate repair
- If you have new difficulty getting into or out of bed
- If you have new difficulty or fatigue with walking
- If you need additional home health care support
- If you are seen in an emergency room or admitted to the hospital

Genetics, Registries, and Clinical Trials

ALS and Genetics

About 10% of people diagnosed with ALS have a family history of the disease. Studies of these people and their family members have identified several gene variants that cause ALS. And studies in people with ALS, but no family history of the disease, have led to the identification of several gene variants that increase the risk of developing ALS.

This research has led to insights into the potential causes of ALS, but more importantly, has led to the development of new treatments for those with ALS gene variants, including Tofersen, an FDA-approved treatment for individuals with ALS and disease-causing mutations in the SOD1 gene.

Genetic testing for ALS is available through several companies. Testing is typically done using a panel approach – that is, the sequence of genes known to harbor variants that can cause ALS is analyzed in DNA isolated from the blood or saliva of an individual. This is helpful in determining whether someone is a candidate for a gene specific treatment and can also potentially provide useful information for family planning.

Because disease causing gene mutations can be found in 5-10% of people with no family history of ALS, genetic testing does not need to be restricted to those with a family history.

To learn more:

- Les Turner ALS Foundation
    - Websites:
    - https://lesturnerals.org/als-and-genetics/
    - https://lesturnerals.org/genetic/about-this-decision-tool/

- The ALS Association
    - Websites:
    - https://www.als.org/research/als-research-topics/genetics
    - https://www.als.org/understanding-als/who-gets-als/familial
- VA Office of Research and Development
    - Website: https://www.research.va.gov/topics/genomics.cfm
- End The Legacy
    - Website: www.endthelegacy.org

Clinical Trials and Research

Ongoing research efforts both within and outside of the VA healthcare system are directed towards understanding ALS and identifying new treatments. Because ALS is a rare disease, clinical trials often struggle to find enough participants. For most drug trials, participants will receive the investigational drug or a placebo. New trial designs now can provide an increased likelihood that a participant will receive an investigational drug. Inclusion in drug trials will depend on meeting eligibility criteria which includes both inclusion and exclusion criteria.

Individual VA Healthcare centers and/or their academic affiliates are often involved in ongoing research studies. In addition to clinical trials, in which a drug or other intervention is given, there are opportunities to participate in observational and cohort studies.

Research into the causes and treatment of ALS is varied and ongoing. It’s important to ask your local ALS Clinic for any current or upcoming opportunities to participate in clinical trials. Included in this page are links to several reputable ALS Clinical Trial resources.

It’s worth noting The ALS Association has an excellent introduction to clinical trials for patients, which includes definitions of different trial phases, the differences between observational studies and clinical trials, as well as more definitive answers on “What to expect” when joining a clinical trial. More information can be found at this link: https://www.als.org/research/clinical-trials-for-patients

The Northeast Amyotrophic Lateral Sclerosis (NEALS) Consortium is another great resource. They identify their primary mission as “rapidly translating scientific advances into clinical research and new treatments for people with ALS and motor neuron disease.” They have clinical trial liaisons whom can be contacted via: alstrials@neals.org or 855-437-4823.

Below are links to nationally known/reputable websites for ALS-specific clinical trials:

This Active Clinical Trial Studies page by the CDC provides links to 20 or more ongoing ALS Clinical Trials, including the study name, institution conducting research, and links to enroll. This list is not exhaustive and is changing as older studies end and new studies begin enrollment.

https://www.cdc.gov/als/abouttheregistrymain/active-alsclinicalresearchnotification.html

ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world. You can search by disease/condition or location to find either 'All Studies' related to a condition, or search by whether or not a study is currently recruiting. Since some clinical trials listed on this website have already finished, there are sometimes links to published research studies for those interested.

https://clinicaltrials.gov/search?cond=ALS&city=

To learn more:

- I AM ALS
  - Website: https://www.iamals.org/get-help/als-signal-clinical-research-dashboard/
- Northeast ALS Consortium
  - Website: https://neals.org/als-trials/als-clinical-research/
- Your ALS Guide
  - Website: https://www.youralsguide.com/research-and-clinical-trials.html
- Food and Drug Administration
  - Websites:
  - https://www.fda.gov/news-events/public-health-focus/expanded-access
  - https://www.fda.gov/media/133864/download
- National Library of Medicine
  - Website: https://clinicaltrials.gov/
- ALS Therapy Development Institute
  - Website: https://www.als.net/als-trial-navigator/

Million Veteran Program

The VA Million Veteran Program (MVP) is one of the world's largest databases of health and genetic information. The purpose of the MVP is to learn how genes affect health and to improve health care for Veterans and all Americans. MVP is one of the largest databases of genetic, military exposure, lifestyle, and health information. Research findings based on MVP may lead to new ways of preventing and treating illnesses in Veterans and all Americans.

Veterans diagnosed with ALS may voluntarily join MVP and potentially contribute to research done for understanding ALS and developing new or revising current treatment options. To participate, the Veteran would be asked to complete online or mailed surveys about their health, lifestyle habits, military experience, and personal and family history. Additionally, the Veteran will need an MVP visit to provide a blood sample for genetic analysis and agree to future MVP contact.

The Veteran participating in the MVP program will not receive individual results. The intent of the program is aimed at improving the health of future generations. MVP will not provide any information that will directly benefit the participating Veteran.

To learn more:

- VA Million Veteran Program
    - Websites:
    - https://www.mvp.va.gov/pwa/
    - https://www.youtube.com/watch?v=ZPftNsGVFu0

VA Biorepository Brain Bank

The Department of Veterans Affairs ALS Biorepository Brain Bank (VABBB) is a human tissue bank that collects, processes, stores, and gives out research specimens for future scientific studies. The ALS VABBB provides biological samples, including central nervous system (CNS) tissues/biofluid and health information to scientists studying ALS and related disorders.

Currently, the VABBB is enrolling Veterans with ALS and without ALS (as controls) in the biorepository, collecting biological samples and related health information from Veterans. Veterans have been found to have an increased risk of developing ALS, but the reasons for this increased risk are undetermined. Researchers are studying environmental, toxic, genetic, and other military-related factors and influences as possible contributing causes to the development and progression of ALS.

Veterans with ALS may contribute to advancing ALS research. If Veterans are interested in the VABBB program, they will be asked to sign a consent and complete a survey about their health history. The VABBB will contact the Veteran approximately every six months to ask if there were any changes in their life or health history. The VABBB will collect antemortem (before death) biofluid and postmortem (after death) tissues. The VABBB team will work with the Veteran’s next-of-kin to coordinate the body tissue donation. All costs associated with organ donation, including transportation of the body to and from the hospital or facility where the body tissue donation will be collected, are covered by the VABBB program. Diagnostic neuropathological evaluation and genetic analyses, such as whole genome sequencing, will be conducted on the donated samples.

All data/information collected will be stored in a secure location or in a VA secure research server. The VABBB complies with the requirements of the Health Insurance Portability and Accountability Act (HIPAA) and its privacy regulations and all other applicable laws that protect participants’ privacy.

To learn more:

- VA ALS Biorepository Brain Bank
  - Websites:
  - https://www.research.va.gov/programs/tissue_banking/als/default.cfm
- Federal Practitioner
  - Website https://www.mdedge.com/fedprac/avaho/article/206097/oncology/genomic-medicine-and-genetic-counseling-department-veterans

CDC National Registry

ALS Research depends on people living with ALS joining the National ALS Registry. The National ALS Registry allows people with ALS to provide information about themselves and their disease through the completion of a series of surveys. The goals of the Registry include:

- Estimating the new number of ALS cases diagnosed each year.
- Estimating the number of people who have ALS at any given time.
- Improving the understanding of who gets ALS and what factors affect the disease.
- Enhancing research that could improve care for people with ALS.

The Registry provides many opportunities for Veterans with ALS to advance research including participation in the National ALS Biorepository which collects and stores samples of biological material. Specimens may be collected via in-home collection and/or postmortem.

To learn more:

- National ALS Registry - CDC
  - Websites:
  - https://www.cdc.gov/alsresearch/Default.html
  - https://www.cdc.gov/als/ALSNationalBiorepository.html
- The ALS Association – The National ALS Registry
  - Website: https://www.als.org/research/participate-als-research/registry

Understanding VA Benefits

Entitled VA Benefits

VA automatically presumes that certain disabilities were caused by military service. This is because of the unique circumstances of a specific Veteran's military service. If a presumed condition is diagnosed in a Veteran within a certain group, they can be awarded disability compensation. If a Veteran served continuously for at least 90 days and is diagnosed with amyotrophic lateral sclerosis (ALS) after discharge, they can establish service connection for the disease. If a Veteran has a presumptive condition, they do not need to prove that their service caused the condition. They only need to meet the service requirements for the presumptive condition. Veterans diagnosed with ALS are granted the maximum service-connected benefits and are automatically rated 100%. In addition to eligibility for service-connected disability benefits, Veterans with ALS are eligible for many significant benefits through both Veterans Benefits Administration (VBA) and Veterans Health Administration (VHA). Through VBA, Veterans are eligible for the Special Adaptive Housing Grant, Automobile Allowance, VA Life Insurance, Special Monthly Compensation, CHAMPVA, Veterans Readiness and Employment Independent Living Grants, and Veterans Mortgage Life Insurance.

VA Healthcare Basic Eligibility

A person who served in the active military, naval, or air service and who was discharged or released under conditions other than dishonorable may qualify for VA health care benefits. Reservists and National Guard members may also qualify for VA health care benefits if they were called to active duty (other than for training only) by a federal order and completed the full period for which they were called or ordered to active duty.

Minimum Duty Requirements: Veterans who enlisted after September 7, 1980, or who entered active duty after October 16, 1981, must have served 24 continuous months of the full period for which they were called to active duty in order to be eligible. This minimum duty requirement may not apply to Veterans discharged for hardship, early out or a disability incurred or aggravated in the line of duty.

To learn more:

- VA.gov
    - Website: https://www.va.gov/health-care/eligibility/

Service-Connected Disability

Disability compensation is a monetary benefit paid to Veterans who are disabled by an injury or illness that was incurred or aggravated during active military service. These disabilities are considered to be service connected. To be eligible for compensation, the Veteran must have been separated or discharged under conditions other than dishonorable. All Veterans who develop ALS at any time after separation from service may be eligible for compensation for that disability. To be eligible, the Veteran must have served a minimum of 90 consecutive days of active service.

To learn more:

- VA.gov
    - Website: https://www.va.gov/disability/

Special Monthly Compensation and Aid and Attendance

VA disability compensation offers a monthly, tax-free payment to Veterans who got sick or injured while serving in the military and to Veterans whose service made an existing condition worse. Establishment of service connection for ALS warrants a minimum rating evaluation of 100%. There is also potential for additional payment of various levels of special monthly compensation (SMC) dependent on the severity of ALS and its complications. SMC is an additional tax-free benefit that can be paid to Veterans, their spouses, surviving spouses and parents. For Veterans, SMC is a higher rate of compensation paid due to special circumstances or complications. Complications of ALS that may warrant various levels of SMC include, but are not limited to, upper or lower extremity impairment resulting in loss of use of one or both hands or feet, speech impairment resulting in constant inability to communicate by speech, loss of sphincter control, and erectile dysfunction. Entitlement to SMC may also be warranted if ALS complications that cause the Veteran to be housebound or to require aid and attendance.

VA considers the following disabilities for Special Monthly Compensation (SMC):

- Loss, or loss of use, means no effective remaining function of an extremity or organ.
- Loss, or loss of use, of a hand or foot
- Immobility of a joint, resulting in functional loss of use
- Paralysis of an extremity, resulting in functional loss of use
- Loss of sight of an eye (only seeing light)
- Loss, or loss of use, of a reproductive organ
- Complete loss, or loss of use, of both buttocks
- Deafness of both ears (no air and bone conduction)
- Inability to communicate by speech (complete organic aphonia)
- Loss of a percentage of tissue from a single breast, or both breasts, from mastectomy or radiation treatment.

SMC can also be increased if the Veteran is determined by the VA to be in need of regular aid and attendance by another person, or a Veteran who is permanently housebound, may be entitled to additional disability compensation through Special Monthly Compensation (SMC):

- Housebound
- Bedridden
- Requires the aid and attendance of another person.

ALS disease progression will result in the Veteran’s eligibility for additional SMC benefits to increase over time. To ensure that Veterans receive these additional monetary benefits in a timely manner, Veterans, ALS Teams, ALS Coordinators, and appointed Veteran Service Officer should work collaboratively to ensure an ongoing review of entitled benefits.

To learn more:

- VA.gov
    - Websites:
    - https://www.benefits.va.gov/compensation/docs/ALS_Lou_Gehrigs_Disease.pdf
    - https://www.va.gov/disability/compensation-rates/special-monthly-compensation-rates/

CHAMPVA

The Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) provides health care coverage for medical services and supplies that are medically necessary for the spouse/surviving spouse and eligible family members of an eligible Veteran. However, there may be limitations on certain care, and some care is not covered at all.

A Veteran’s spouse and eligible family members who are *not TRICARE-eligible* should be informed that they may be eligible for CHAMPVA benefits, if the Veteran meets one of the following criteria:

1) Rated permanently and totally (P&T) disabled for a service-connected disability by a VA regional office (VARO), without regard to percentage of disability.
2) Died from a VA-rated service-connected disability.
    - At the time of death was rated (P&T) disabled from a service-connected disability
    - Died in the line of duty, not due to misconduct; however, most of these family members qualify for TRICARE instead of CHAMPVA.
3) CHAMPVA may also provide benefits to the Primary Family Caregiver. For more information, refer to the Caregiver Support Program webpage on VA.gov.

By law, CHAMPVA is a secondary payer whenever a beneficiary has other health insurance (OHI), to include Medicare. However, CHAMPVA is always the primary payer when the beneficiary also receives health care benefits through Medicaid, CHAMPVA supplemental policies, State Victims of Crime Compensation programs, or Indian Health Services (IHS). If eligible for Medicare, the beneficiary must maintain continuous enrollment in Medicare Part B to retain CHAMPVA benefits. CHAMPVA can serve as the primary coverage until the family member becomes eligible for Medicare benefits.

To learn more:

- VA.gov
    - Website: https://www.va.gov/COMMUNITYCARE/programs/dependents/champva/index.asp

Life Insurance & Mortgage Life Insurance

VA offers quality life insurance at competitive rates that can help cover end of life costs, provide financial support to spouses or children, and cover any outstanding debts such as a mortgage balance. VA currently offers three types of life insurance programs tailored to fit the needs of Veterans and their families: Veterans Affairs Life Insurance (VA Life), Veterans' Mortgage Life Insurance (VMLI), and Veterans' Group Life Insurance (VGLI).

VA Life is a guaranteed acceptance whole life policy with no health review required and, for those age 80 and under, no time limit to apply. It provides maximum coverage of $40,000, in increments of $10,000. Premium rates are based on age at the time of application and will not increase through the life of the policy. There is a two-year waiting period in order to receive the full coverage, however, if an insured passes away within the two-year period, all premiums plus interest is paid to their named beneficiary.

VMLI offers reduced term mortgage protection insurance to the families of Veterans under age 70 with severe service-connected disabilities who've received a Specially Adapted Housing Grant to adapt a home to fit their needs. Up to $200,000, or the balance of the mortgage, whichever is less, in mortgage life insurance is available and is paid directly to the bank or other lender that holds the insured's mortgage at time of death. Premiums are determined by your age as well as the outstanding balance of the mortgage at the time of application, the level of coverage, and the number of years remaining on the mortgage.

To learn more:

- VA.gov
  - Websites:
  - https://www.va.gov/life-insurance/options-eligibility/valife/
  - https://www.va.gov/life-insurance/options-eligibility/vmli/
  - https://www.va.gov/life-insurance/options-eligibility/vgli/
  - https://www.va.gov/life-insurance/options-eligibility/sgli/

HISA Benefit

A Home Improvements and Structural Alterations (HISA) benefit provides assistance for any home improvement necessary for treatment or disability access. The HISA benefit is available through Veterans Health Administration (VHA) and is managed through your location's Prosthetics Service. The Veteran is eligible for one HISA benefit per lifetime.

To learn more:

- VA.gov
  - Websites:
  - https://www.prosthetics.va.gov/psas/HISA2.asp
  - https://www.prosthetics.va.gov/psas/Documents/HISAProcess.pdf

Specially Adaptive Housing

The primary goal of the Specially Adapted Housing (SAH) Grant is to provide eligible Veterans and Service Members with severe, permanent-and-total service-connected disabilities (permanent-only in the case of eligible blindness) with a barrier-free living environment. Eligible Veterans can use their grant to buy or build a home with specially adapted features or adapt an existing home to meet their needs and live more independently. Adapting or modifying a home might involve installing ramps, widening doorways, or modifying a bathroom or kitchen to meet the Veteran’s needs. Adaptations may also include special equipment needed in the home (i.e., home generators, vertical power lift or stair glides, etc.), or other adaptations to assist with the Veteran’s specific needs.

Amyotrophic Lateral Sclerosis (ALS) is currently the only presumptive diagnosis for SAH, meaning Veterans with an ALS diagnosis are generally assumed to be entitled. Knowing that ALS conditions generally progress more rapidly than other conditions, the SAH program has incorporated provisions to expedite final grant approval for diagnosed Veterans. In addition, it’s imperative that care teams assist diagnosed Veterans to engage the SAH program as soon as possible to allow time for coordinating necessary adaptations. Adapting or modifying a home can be complex, and although our SAH agents are trained to assist the Veteran and their family members throughout the entire process, time is of the essence.

To learn more:

- VA.gov
    - Websites:
    - https://www.va.gov/housing-assistance/disability-housing-grants/
    - https://benefits.va.gov/WARMS/docs/admin26/m26_13/sah-2022-update-26-13.pdf
    - https://www.youtube.com/watch?v=EN5QMihyuhY

Veterans Readiness and Employment Independent Living Track

Veteran Readiness and Employment (VR&E) offers a range of services to assist Veterans with increasing independence within activities of daily living through the Independent Living (IL) track. Initially, a Veteran must complete a VA Form 28-1900, Application for Veterans Readiness and Employment for Claimants with Service-Connected Disabilities and attend the initial entitlement meeting with a Vocational Rehabilitation Counselor (VRC). During this meeting, the VRC will review the information available from the VR&E questionnaire and determine entitlement to VR&E benefits. If a Veteran's service-connected disability limits their ability to perform activities of daily living (like bathing, dressing, accessing the community and interacting with others) and they aren't able to return to work right away, the Veteran may qualify for independent living services through the Independent Living track.

Additional entitlement determinations include that the Veteran meets all the requirements listed below.

All of these must be true:

- The Veteran has a serious employment handicap (SEH), **and**
- The Veteran's disabilities prevent them from looking for or returning to work, **and**
- The Veteran is in need of services to live as independently as possible.

Please note: Having an employment handicap means the Veteran's service-connected disability limits the Veteran's ability to prepare for, obtain, and maintain suitable employment (a job that doesn't make the disability worse, is stable, and matches the Veteran's abilities, aptitudes and interests).

The VRC works with the Veteran to select the track that will benefit the Veteran. When the IL track is selected, additional assessments may be required such as a preliminary independent living assessment and a comprehensive independent living assessment. The assessments will assist the VRC and Veteran to identify barriers within the home impacting Veterans with ALS. The VRC may create a referral to the Specially Adapted Housing (SAH) program, within VA's Loan Guaranty Service, that manages home adaptations on behalf of the VR&E program. Home adaptations up to the maximum VR&E 2102B housing adaptation grant amount may be provided as part of an approved rehabilitation plan. The Veteran is responsible for selecting a builder and coordinating with the SAH agent on the necessary steps for processing the VR&E 2102B housing adaptation grant.

To learn more:

- VA.gov
    - Websites:
    - https://www.va.gov/careers-employment/vocational-rehabilitation/programs/independent-living/
    - https://www.va.gov/careers-employment/vocational-rehabilitation/apply-vre-form-28-1900/start
    - https://www.vba.va.gov/pubs/forms/VBA-28-1900-ARE.pdf

Automobile Grant

When VA establishes service connection for ALS, this automatically entitles a Veteran to a certificate of eligibility for financial assistance in the purchase of one automobile or other conveyance and necessary adaptive equipment. A Service member on active duty who has ALS incurred during active service is also eligible for the automobile allowance and adaptive equipment.

Veterans can pursue adaptive equipment with the goal of being a driver or a passenger. When the Veteran's goals are to continue driving, a driving assessment and adaptive equipment will be provided through the VA Driver's Rehabilitation Program. Given the progressive nature of ALS associated weakness, ALS Veterans will often transition from driving to becoming the passenger and therefore Veterans who are driving will benefit from ongoing assessment and discussion regarding their goals and needs.

The VA provides necessary equipment such as platform wheelchair lifts, UVLs (under vehicle lifts), power door openers, lowered floors/raised roofs, raised doors, hand controls, left foot gas pedals, reduced effort and zero effort steering and braking, and digital driving systems. Additionally, VA's program provides reimbursements for standard equipment including, but not limited to, power steering, power brakes, power windows, power seats, and other special equipment necessary for the safe operation of an approved vehicle.

To learn more:

- VA.gov
    - Website: https://www.va.gov/disability/eligibility/special-claims/automobile-allowance-adaptive-equipment/

Caregiver Support

Caregivers of eligible Veterans (of certain specific service eras) seriously injured in the line of duty in active military who has a single or combined service-connected disability rating of 70% or more, and who is in need of in-home personal care services from a caregiver on a regular basis for a minimum of 6 continuous months may be eligible for:

- Monthly Caregiver Stipend
- CHAMPVA health insurance (if no other health insurance is available)
- Mental Health Counseling
- Respite Care of no less than 30 days per year.
- Travel, lodging and per diem during mandatory caregiver training and during Veteran medical appointments.
- To APPLY: www.caregiver.va.gov 1-855-260-3274

General Caregiver Program

Caregivers of Veterans of all eras are eligible for:

- Education and Training
- Individual counseling related to the care of the Veteran.
- Support Services to include VA and Community Based Care including respite care.
- National VA Caregiver Support Program website: www.caregiver.va.gov 1-855-260-3274

To learn more:

- VA Caregiver Support Program
    - Websites:
    - https://www.caregiver.va.gov/
    - https://www.caregiver.va.gov/Care_Caregivers.asp
    - https://www.caregiver.va.gov/support/support_benefits.asp
    - https://www.caregiver.va.gov/REACH_VA_Program.asp
    - https://www.caregiver.va.gov/help_landing.asp
    - https://www.caregiver.va.gov/support-line/presentations.asp

Resources for Home Modifications

It has been found that people who have a physical disability are more likely to receive better care, maintain function longer, and have better quality of life if they are able to receive treatment and remain in their own home. In order to remain at home, most people with ALS in time will likely need some type of home modification to accommodate the use of a wheelchair. Initial changes usually include providing you with adaptive equipment to make daily activities easier. Unlike home modifications, adaptive equipment (i.e., walkers, bath bench, and transfer pole) are able to be moved in the home and are not permanently attached to the walls or other structures in the home. Home modifications may involve: 1) adjusting the location of items (e.g., moving furniture); 2) installing special equipment (e.g., grab bars and handrails); and 3) making changes or additions to the structure (e.g., widening doorways, adding a first-floor bathroom or a ramp). Planning for use of a wheelchair in your home before it happens can reduce stress and ease the transition while maintaining your independence. It is helpful to review each room in your home to determine whether you need to use the room, how you will use the room, and what changes need to be made for this. Veterans are encouraged to check with their ALS Team about the options for home evaluations to assist with home modification planning. Veterans with ALS are eligible for several benefits that assist with home modifications including the HISA Benefit, Specially Adapted Housing Grant, and Veteran Readiness and Employment Independent Living benefits.

To learn more:

- The ALS Association
    - Websites:
    - https://www.als.org/navigating-als/living-with-als/adapting-your-environment
    - https://www.als.org/navigating-als/resources/fyi-home-adaptations

    - https://www.als.org/blog/living-als-making-sure-your-home-environment-safe-and-livable
- Your ALS Guide
    - https://www.youralsguide.com/home-modifications.html
- The Les Turner Foundation
    - https://lesturnerals.org/als-home-modifications-guide/

Planning for the End of Life

Disease Specific Goals of Care

Goals-of-care conversations help individuals with serious illness clarify what they value most, consider their wishes regarding medical decisions, and ensure goal-consistent care. Understanding your goals related to ALS is considered an essential component of high-quality care. Conversations regarding your goals should occur early and often. Early discussions to understand your goals result in a positive impact on quality of life and Veteran and caregiver satisfaction. There are many health care decisions Veterans with ALS will make throughout their diagnosis. Two significant decisions include the decision to pursue feeding tube placement and deciding how to manage respiratory changes, specifically your wishes regarding invasive ventilation. Veterans and caregivers benefit from education and support from their ALS Teams as they carefully consider their goals and preferences.

To learn more:

- VA Geriatrics and Extended Care
    - Websites:
    - https://www.va.gov/geriatrics/pages/advance_care_planning_topics.asp
    - https://www.va.gov/GERIATRICS/docs/What_Matters_Most_questionnaire.pdf
- Les Turner ALS Foundation:
    - Website: https://lesturnerals.org/my-als-decision-tool/
- The Conversation Project
    - Website: https://theconversationproject.org/

End of Life

ALS Teams can assist Veterans and caregivers in planning for the later stages of ALS and provide guidance and assistance with reaching end of life decisions. It is important that you have the opportunity to learn about end-of-life care, ask questions of their medical team, and include their loved ones in discussions regarding their wishes. Proactive discussions regarding end-of-life care help to ensure that planning is not done during a medical crisis and can ease the burden of decision making on your loved ones.

To learn more:

- The ALS Association
  - Websites:
  - https://www.als.org/navigating-als/end-of-life-plans
  - https://www.als.org/sites/default/files/2022-10/Resource-Guide-11.pdf

Hospice and Palliative Care

Hospice and Palliative Care play important roles in providing support and comfort to Veterans living with ALS and their caregivers. Both Hospice and Palliative Care provide specialized care that focuses on comfort, quality of life, and prioritize understanding and honor the Veteran's wishes and goals of care. Hospice care is a specific type of palliative care that provides care to individuals who have an estimated life expectancy of six months or less. Your ALS Team will provide education regarding these care options and help you access the right care, at the right time.

To learn more:

- I AM ALS
  - Website: https://www.iamals.org/get-help/palliative-and-hospice-care-for-als/

- Your ALS Guide:
    - Website: https://www.youralsguide.com/hospice-care.html
- VA Geriatrics and Extended Care:
    - Websites:
    - https://www.va.gov/GERIATRICS/pages/Palliative_Care.asp
    - https://www.va.gov/GERIATRICS/pages/Hospice_Care.asp

Funeral Planning

Funeral preplanning is the process of arranging your burial, service and any other end-of-life ceremonies while you're still alive and able to express your wishes.

This may seem uncomfortable, but making these decisions in advance can provide peace and comfort you your loved ones. It can save money and ensures your wishes are recognized.

Funeral preplanning is a compassionate gesture that can benefit you and your loved ones in several ways:

- **It saves your family money.** Prepaid funerals allow the ability to honor your memory and won't impact your family financially.
- **It helps avoid family conflict and stress.** With the choices premade, your family will be able to spend more meaningful time grieving instead of stressing to make arrangements.
- **Your wishes will be honored.** When you plan your funeral in advance, you can have peace of mind knowing that your funeral will be handled in a way that reflects your life and personality.
- **It gives you time to prepare financially.** Knowing your exact funeral costs way in advance helps you plan for them, so your family won't be impacted. Even if you don't pay for your funeral in advance, you'll have time to save and earmark funds in a payable on death (POD) account or purchase burial insurance.

Important steps in planning your funeral:

1. **Decide how your remains should be handled.**
    - Consider whether you prefer traditional burial (underground or mausoleum), cremation, green burial, donation to science or some other option.
    - If you opt for burial, you'll need to purchase a burial plot or mausoleum space.
    - If you opt for cremation, you can choose to have your ashes buried, saved with a loved one in an urn, placed in a columbarium niche as a few examples.

2. **Decide what type of service you prefer**. Your memorial gathering will be specific to you, but it will probably fall into one or more of these basic categories:
    - Funeral. This is a traditional service with the body present, either in an open or closed casket (or urn). You can choose to have a wake, viewing or reception held before or after your service, or have a mourning event specific to your religion or culture.
    - Graveside service. These take place at the body's final resting place, such as a cemetery, and are often held in addition to a funeral.
    - Memorial. This is a service without the body present that takes place after cremation or burial.
    - Celebration of life. This is a more joyful event that honors the life of the deceased.

3. **Choose your funeral home and service venue**. The right funeral home for you can meet your needs, align with your personal taste and will work within your budget. Here are some ways to find one:
    - Contact your local Funeral Consumers Alliance for a comparison of prices in your area.
    - Visit funeral homes near where you live in person to get detailed quotes and see which one meets your preferences.
    - Read online reviews of potential funeral homes on their websites and with the Better Business Bureau.

You can have your service at the funeral home that handles your remains, but you might also choose to have it at a house of worship, family home, cemetery, park, beach, garden, community hall or other public venue.

4. **Consider payment and contract options.**
    - You can pay for a funeral upfront, purchase final expense insurance, establish separate account or trust, or pay gradually through an installment plan.

5. **Communicate and share details with your family**.
    - Make sure to communicate your funeral preplanning with your loved ones. You can give your family physical copies of receipts and contracts, share them online or use an end-of-life planning service.
    - Designate someone to be in charge; recommend selecting one or two family members/loved ones to manage the preplanned arrangements.
    - Ensure they have accessibility to your preplanned arrangements for easy accessibility.

VA Burial Benefits

A Veteran who served in the active military, naval, air, or space service and was discharged or released under conditions other than dishonorable may be entitled to burial benefits the Veteran's death is impacted by a service-connected condition. VA burial benefits can help Service members, Veterans, and their family members plan and pay for a burial or memorial service.

Possible benefits include:

- VA burial allowance for burial and funeral costs
- VA plot or internment allowance for the cost of the plot (gravesite) or internment
- VA transportation reimbursement for the cost of transporting the Veteran's remains to the final resting place.

VA provides burial benefits for all legal burial types, including cremation and burial at sea. VA also provides burial benefits for donating the Veteran's remains to a medical school.

Please note: While there's no time limit to file for a service-connected burial, plot, or interment allowance, a claim for a non-service-connected burial allowance must be filed within 2 years after the Veteran's burial. If a Veteran's discharge was changed after death from dishonorable to another status, their survivors must file for an allowance claim within 2 years after the discharge update.

To learn more:

- Va.gov
    - Websites:
    - https://www.benefits.va.gov/compensation/claims-special-burial.asp
    - https://www.va.gov/burials-memorials/
    - https://www.benefits.va.gov/compensation/claims-special-burial.asp
    - https://www.cem.va.gov/cem/burial_benefits/index.asp

    - https://www.va.gov/burials-memorials/what-to-expect-at-military-funeral/
    - https://www.cem.va.gov/VLM/index.asp
    - https://www.cem.va.gov/resources.asp

DIC Benefits for Survivors

The Veterans' Benefits Administration's (VBA) commitment to serving those who served does not end with the death of the Veteran. Surviving spouses, dependents, and parents of a Veteran who died from a service-related injury or illness may be eligible to receive a tax-free monetary benefit called Dependency and Indemnity Compensation (DIC). DIC may also be granted for survivors of certain Veterans who had a service-connected disability that was rated totally disabling for either: a continuous period of 10 or more years immediately preceding death, not less than five years from the date of a Veteran's discharge or other release from active duty, or not less than one year immediately preceding death if the Veteran was a former prisoner of war.

DIC is a tax-free monthly benefit paid to eligible survivors of a Veteran or Service member who died in the line of duty, from a service-connected injury or illness, or who met certain criteria if they were service-connected.

To learn more:

- Va.gov
    - Websites:
    - https://www.va.gov/disability/dependency-indemnity-compensation/
    - https://benefits.va.gov/BENEFITS/factsheets/survivors/dic.pdf

Additional Tools

Glossary of Terms

Amyotrophic Lateral Sclerosis (ALS), Lou Gehrig's is a progressive disease that affects nerve cells (or neurons) in the brain and the spinal cord. These neurons reach to the muscles throughout the body. Without proper nerve stimulation, the muscles cannot respond, and they weaken.

APAP, BPAP, VPAP, CPAP are machines that provide air pressure to assist breathing. They are non-invasive respirators. The machine hose connects to a mask then to the nose and mouth or just to the nose. **APAP** automatically adjusts the amount of pressure needed. **VPAP** or **BPAP** provide two level pressures: inspiratory positive airway pressure (IPAP) for breathing in, and a lower expiratory pressure (EPAP) for breathing out. BiPAP® is a brand name for this type. **CPAP** delivers a constant inward pressure. It keeps the airway open in people who have obstructive sleep apnea.

Aphonia, Dysphonia: **Aphonia** is reduced voice loudness due to vocal cord weakness. Complete aphonia is when no sound can be made. **Dysphonia** is a voice disorder that results in hoarse, breathy, coarse or nasal sounding voice.

Bulbar palsy is an impairment of certain cranial nerves that serve the muscles of the mouth and throat. This can make it hard to speak, chew, and swallow.

Doctor of Osteopathy (DO) is a medical doctor who has a holistic approach to medicine and sees the body as an integrated whole. DOs receive extra training in the musculoskeletal system.

Dysarthria is a problem forming words due to weak facial, mouth or tongue muscles. Speech may be slow, slurred or not precise.

Dysphagia is a term that describes difficulty in swallowing.

Dysphagia Diet uses foods that are easier and safer to swallow if you have problems swallowing.

EMG (Electromyogram) is a test that measures nerve conduction and stimulation of the muscles. EMG is used to detect neuromuscular abnormalities.

Esophagram, Video Swallow Study are tests that look at how you swallow food or liquids. They show how well your mouth and throat work and if food leaks into your airway (aspiration) instead of going to your stomach.

Frontotemporal Dementia (FTD) is type of dementia that affects the part of the brain that controls behavior, insight and reasoning. There may be changes in personality, ability to concentrate, social skills, motivation and reasoning. Some people with ALS develop mild to severe forms of this dementia.

Home Care is care provided in your home. It may include help with bathing, getting dressed, housecleaning, laundry, and cooking meals. This care is often provided through an agency using health aides supervised by a registered nurse. Home care may include a nurse for medication management, treatments and monitoring.

Hospice Care is concerned with the quality of life of the terminally ill. It focuses on relief of pain and symptoms and reducing emotional and spiritual suffering. Hospice care is available in your home or in a health care facility.

Hoyer Lift is equipment used to transfer a person to or from bed to chair, toilet or shower.

Neurologist is a doctor who specializes in diagnosing and treating neurological disorders. These include diseases of the brain, spinal cord, nerves and muscles.

Nurse Practitioner (NP) is a nurse with advanced training in a Masters or PhD program. NPs can meet most of a patient’s health care needs. They promote a comprehensive approach to health care with an emphasis on the overall health and wellness of their patients.

Palliative Care emphasizes comfort and quality of life. The focus is on relieving symptoms, pain, and the stress of illness.

PEG (Percutaneous Endoscopic Gastrostomy) G-tube, G-J tube are feeding tubes inserted directly into the stomach through the abdominal skin. The tube allows feeding directly into the stomach or the intestinal tract, bypassing the mouth. A person may still eat by mouth and use the feeding tube only for extra nutrition or hydration.

Psychiatrist is a medical doctor who specializes in diagnosing and treating mental and behavior disorders.

Psychologist has a PhD and is trained help people learn to cope more effectively with life issues and mental health problems. Psychologists consider the individual’s values, goals, and circumstances.

Physiatrist is a doctor who specializes in rehabilitation and musculoskeletal problems. Physiatrists, or rehabilitation physicians, are nerve, muscle, and bone experts. They treat injuries or illnesses that affect how you move.

Pseudobulbar affect (emotional lability, labile affect, or emotional incontinence) is involuntary crying and/or laughing. The emotional response does not always match how the person is feeling.

Pulmonary Function Tests are tests that measure force and the amount of air breathed in and out. Sniff Nasal Inspiratory Pressure (**SNIP**) is a simple procedure that indicates inspiratory muscle strength by measuring maximal nasal sniff pressure through one nostril.

PVA (Paralyzed Veterans of America) is a national advocacy group serving Veterans who have spinal cord injuries and disorders, including ALS.

Quad Cough or Assisted Cough is used by people who cannot clear respiratory secretions. The person coughs while an assistant exerts gentle upward and inward pressure with both hands on the abdomen. This produces a more forceful cough.

Reflux, GERD (gastroesophageal reflux disease) occurs when stomach acid or stomach contents, flow back up into the food pipe (esophagus). The backwash (reflux) irritates the lining of the esophagus and may reach into the throat.

Rollator is a walker that has wheels and a pouch or basket for carrying items. It may also have a place to sit.

Sialorrhea is too much saliva.

Spasticity is involuntary muscle contraction or muscle cramping.

Tracheostomy or Tracheotomy is an opening surgically made in the neck into the trachea (windpipe). It provides an airway and an access to remove secretions from the lungs. Breathing is done through the tracheostomy tube rather than through the nose and mouth. A breathing machine can be used to help the person breathe.

Transfer is the movement of a person from one place to another; for example, transfer or move from chair to bed.

Navigating VA Benefits Checklist

Navigating a new diagnosis of ALS and understanding your associated VA benefits can be overwhelming. This checklist was developed to help guide some of the important steps you will need to take to establish your care and benefits. Please use this checklist as a starting point and partner with your VA ALS Clinic Coordinator for help understanding benefits and resources that may be unique to your specific needs and location.

Disability Compensation

- ☐ Contact a Veteran Service Organization, such as Paralyzed Veterans of America to request their assistance with applying for VA benefits.
  - Website: https://pva.org/find-support/national-service-office/
- ☐ Special Monthly Compensation may increase as your level of disability from ALS increase. If you have experienced a significant change in function and require more assistance for mobility and daily activities, ask your Veteran Service Officer if you may apply for an increase in benefits.

Access to VA ALS Clinics

- ☐ Talk to your local VA ALS Coordinator to learn more about local regional options for VA ALS Interdisciplinary Care.

Copayment Exempt Healthcare

- ☐ Talk with your ALS Coordinator about pathways to applying for copay exempt care until your Service Connected Disability rating is awarded. The VA Hardship Application and/or Application for Catastrophic Disability may be solutions to ensuring copay exempt care.
- ☐ Once your VA Service Connected Disability rating is established, if you have received any VA copayment bills, please reach out to the VA Health Eligibility Center at 1-800-812-0318. You may be eligible for refund of copays that occurred from your established date of service-connected disability.

Home Health Care Benefits

- ☐ If you need assistance with your daily self-care, you may be eligible for VA funded home health care services. Talk to your ALS Coordinator about how to access this care locally.

Caregiver Support and Caregiver Stipend Benefits

- ☐ As your need for daily assistance increases, talk to your ALS Coordinator about eligibility for the VA Caregiver Support Program and Caregiver Stipend. Learn your eligibility requirements and discuss a recommended timeline for applying for these benefits.

Home Modification Benefits

- ☐ Talk to your ALS Team about recommendations for home modifications, and to find out what resources are available in your community to get advice on the most important modifications to make your home accessible.
- ☐ Learn about available home modification benefits including the:
    1) Home Improvements and Structural Alteration (HISA) Benefit
    2) Specially Adapted Housing Grant
    3) Veterans Readiness and Employment (VR&E) Independent Living Grant
- ☐ Talk to your appointed Veteran Service Organization to ensure that the application for SAH and VR&E are completed and submitted on your behalf. This is most commonly included with the initial application for disability compensation.

CHAMPVA Benefits

- ☐ Learn more about the CHAMPVA benefit that provides health insurance for eligible dependents.
- ☐ Talk to your appointed Veteran Service Organization to ensure that the application is completed and submitted on your behalf. This is most commonly included with the initial application for disability compensation.

Durable Medical Equipment and Assistive Technology

- ☐ Talk to your ALS Team about the availability of VA issued durable medical equipment and assistive technology. Your team can help you better understand what options you have and help you determine the best timing to obtain equipment based on your unique needs. Check with your VA Team prior to purchasing medical equipment to determine if it can be provided by the VA.
- ☐ Explore community partner resources to learn more about the types of equipment and assistive technology that may help meet your future needs.
  - ALS Equipment Guide - Your ALS Guide
    - Website: www.youralsguide.com
  - ALS & Activities of Daily Living - Les Turner ALS Foundation
    - Website: https://lesturnerals.org

Automobile Grant

- ☐ Talk to your appointed Veteran Service Organization to ensure that the application is completed and submitted on your behalf. This is most commonly included with the initial application for disability compensation.
- ☐ Talk with your ALS Team about vehicle modification options and to explore local vendor options. Your ALS Team may refer you to the VA Drivers Rehab/Training Program for support.

Explore State Specific Veteran Benefits

- ☐ Contact your local tax office to learn about your states benefits for disabled Veterans that could impact your property taxes.
- ☐ Contact your local Department of Motor Vehicles to learn about your states license plates and parking benefits.
- ☐ Contact your local state Department of Veterans Affairs to learn about additional benefits your state offers for disabled Veterans.

Recreation Therapy and Adaptative Sports

- ☐ VA offers recreation therapy, access to adaptive sports, and creative arts services. Talk to your ALS Team about what services are available locally.

MyHealth*e*Vet

- ☐ Register for a MyHealth*e*Vet account. This is the VA's Patient Portal and is an excellent tool for communication with your team, viewing your upcoming appointments, ordering medication refills, and accessing your medical records. Please refer to instructions in this Handbook for creating and authenticating your account. Visit: www.myhealth.va.gov

Navigating Other Areas of Care Checklist

Social Security Benefits

- ☐ Apply for Social Security Disability Benefits immediately. The mandatory five-month waiting period for disability approval for people with ALS is waived.

Short or Long Term Disability Benefits

- ☐ Work with your current or prior employer to determine if you have any eligible short or long term disability insurance benefits. These benefits will require documentation from your doctor and employer.

Advance Care Planning

- ☐ Talk with your ALS Coordinator and/or Social Worker about their recommendations regarding completion of legal documents including an Advance Directive, Living Will, and/or the completion of Power of Attorney documents.

Explore Support Group Opportunities

- ☐ You may find it valuable to connect with an ALS Support Groups. Support groups can occur in person and/or online. Some groups are for individuals living with ALS, for caregivers, or created specifically for Veterans. Contact your ALS Coordinator to learn more about local options.
- ☐ Explore support group opportunities through community partners:
    - ALS Support Groups | The ALS Association
        - Website: www.als.org
    - I AM ALS Support Groups - I AM ALS
        - Website: www.iamals.org
    - Free ALS support groups • Les Turner ALS Foundation
        - Website: https://lesturnerals.org

Clinical Trials

- ☐ Learn more about the tools and resources available to help you understand your clinical trial options and have informed discussions with your ALS Team.

        - ALS Trial Navigator: Empower Your Clinical Trial Search | ALS Therapy Development Institute
            - Website: www.als.net

Genetics

- ☐ Regardless of your family history or clinical presentation, talk to your ALS Team about the option of genetic counseling and genetic testing to learn more.
- ☐ Explore the My ALS Decision Tool on Found on https://lesturnerals.org

Community Partners

The VA partners with many organizations in our community to enhance support for Veterans and families. Here are just a few of our community partners that you may be interested in learning more about. Please refer to our VA ALS website for further information about our community partnerships:
https://www.va.gov/health/als.asp

- **ALS Association:** the largest, national non-profit organization dedicated to ALS. They aid people with ALS through a nationwide network of chapters, coordinating care through certified clinical care centers.
  - Website: http://www.alsa.org/

- **ALS United**: a national collaborative of ALS organizations across the United States dedicated to supporting individuals with ALS and their families
  Website: https://www.alsunited.org

- **CreATe:** the goal of the Clinical Research in ALS and Related Disorders for Therapeutic Development (CreATe) Consortium is to advance therapeutic development for ALS.
  - Website: https://create.rarediseasesnetwork.org/

- **I AM ALS:** is a patient-led community that provides critical support and resources to persons with ALS, caregivers, and families.
  - Website: https://www.iamals.org/

- **Les Turner ALS Foundation**: provides comprehensive ALS care and support services in the Chicagoland area and at Northwestern Medicine.
  - Website: https://lesturnerals.org/

- **MDA ALS:** supports muscular dystrophy and related life-threatening diseases such as ALS through its national network of clinics.
  - Website: https://www.mda.org/disease/amyotrophic-lateral-sclerosis

- **Northeast ALS Consortium (NEALS)**: supports ALS research and clinical trials through its network of ALS partners.
  - Website: https://neals.org/

- **Your ALS Guide:** a website that offers content from ALS professionals, provides resource information, and expands your support network.
  - Website: https://www.youralsguide.com/

- **Roon:** a website that brings together ALS experts to answer questions about ALS. Experts ranging from physicians, pALS, researchers, and caregivers provide video answers to common questions about ALS.
  - Website: https://www.roon.com/als/home

Paralyzed Veterans of America

Paralyzed Veterans of America, a congressionally chartered Veterans service organization founded in 1946, has developed a unique expertise on a wide variety of issues involving the special needs of our members – Veterans of the armed forces who have experienced spinal cord injury or dysfunction.
Veterans with Spinal Cord Injury and Disease (SCI/D), Multiple Sclerosis (MS), Amyotrophic Lateral Sclerosis (ALS), and other service-connected injuries or conditions can seek help by contacting the Veterans Benefits Department within one of the PVA National Service Offices.
PVA's extensively trained Service Officers will use their expertise in the VA claims process to secure Veterans benefits—from disability compensation to adaptive automobile equipment. They also assist service members with discharges and pending discharges due to injury. PVA specializes in complex cases and advocacy for Veterans with disabilities.

Other benefits include:

1. Vocational rehabilitation for Veterans facing barriers to employment.
2. Housing and auto grants for Veterans with qualifying disabilities
3. VA Pension for eligible low-income Veterans with disabilities
4. Life insurance at lower premiums—or in some cases free
5. Burial and survivor benefits and more.

To locate your PVA Veteran Service Officer: https://pva.org/about-us/national-service-officers/

When Emergency Medical Care or Hospitalization Occurs

Checklist: What to Bring to the Hospital/Emergency Room

- ○ Advanced Directives-Including your DPOA for Health Care and Living Will
- ○ POLST/POST or DNR
- ○ Your noninvasive respiratory equipment
- ○ Cough assist
- ○ Communication Board
- ○ ALS Association pocket card for medical emergencies

Pro Tips:

- For chest pain, shortness of breath, loss or decreased consciousness, or any other worrisome or possible life-threatening emergency symptoms, please **GO TO THE CLOSEST EMERGENCY ROOM** for urgent medical attention.
- As many facilities don't treat a lot of persons with ALS, you may need to SPEAK UP for yourself or your loved one.
- Please bring an ALS Association pocket emergency card and/or the ALS Association Medical Information packet- also available online: www.alsa.org
- Please tell the staff the **best way to communicate** with you or your loved one.

What to Bring with you to the Hospital:

1. Always bring your respiratory equipment (Bipap, cough assist, suction machine) with you to the hospital. Your own equipment is set up just for you and is better than using generic equipment that may not be available right away.
2. Bring a copy of your Physician Orders for Life-Sustaining treatment (POLST/POST) form and/or advanced directives and durable power of attorney for healthcare (DPOA)

Outside Hospital Admission

1) Call the ALS nurse coordinator and/or social worker and let us know! Please also contact the VA Notification line (844-724-7842) within 72 hours if you want and qualify for the VA to pay for your hospitalization. Or you can report via this online portal: **https://emergencycarereporting.communitycare.va.gov/request**
2) If you would like to be transferred to our hospital, let the team at the outside hospital know. They will contact the VA to notify them of your request to transfer.

My Health*e*Vet

www.myhealth.va.gov

Learn how to get a My HealtheVet Premium Account

Get a My HealtheVet Premium account online.

1. On the My HealtheVet Sign In page, sign in to your My HealtheVet account using the Login.gov, ID.me, or DS Logon account you used to complete identity verification.
2. If you don’t have a My HealtheVet account, complete the prefilled registration form to create one.
3. If presented, review and accept the My HealtheVet Terms and Conditions.
4. You’ll be signed in to your My HealtheVet Premium account.

Verify your identity in person to get a Premium account.

You can upgrade your My HealtheVet account to Premium in person at a VA health facility where you are registered as a VA Patient. You'll need to bring this form of ID with you:

- **A government-issued photo ID.** This can be either your Veteran Health Identification Card or a valid driver’s license.
- **Note:** If your primary ID information does not match your official VA medical record, bring a secondary card such as your social security card.

Verify your identity in person via a video visit to get a Premium account.

You can upgrade your My HealtheVet account to Premium in person via a video visit where you are registered as a VA Patient. Contact your VA health care team to set up a video visit. You'll need to present this form of ID:

- **A government-issued photo ID.** This can be either your Veteran Health Identification Card or a valid driver’s license.

Note: If your primary ID information does not match your official VA medical record, present a secondary card such as your social security card.

How to Refill Medicines

The VA uses a mail system that is cost effective and efficient.

The day you get a prescription fill, order the next refill. It may seem too early, but the computer will time it to mail out about 2 weeks before your next fill is needed.

Automated Prescription Refill Telephone Line

Please call: ____

Availability: 24/7, 365 days a year.

You can refill your VA prescriptions. Other pharmacy services may be available depending on your location.

Who will I speak with?

Generally, you won't speak with anyone as long as the system is able to complete your request successfully. If not, the system will offer to transfer you to a VA pharmacy technician.

Online Refill Request

Prescriptions may also be refilled online using VA's My Health*e*Vet program. Please allow for 10 days processing time so that you will receive your medications on time.

Questions about your medicines?

Please call: ____

No more refills?

Please call: ____

Release of Information

A Release of Information (ROI) is a document that gives you the opportunity to decide what is communicated and released to whom from your medical file. It states the duration that the information can be released, who can get that information and under what conditions it is given. It is a written authorization that is dated and signed by you, the patient. The document is used to protect the privacy and confidentiality of your information.

Your ALS Coordinator and team may provide you with an ROI form in order to discuss care with:

- Family/Friends/Caregivers that you authorize
- Referral to community partners
- Collaboration with other medical teams

Knowing Your Transportation Resources

Veterans Transportation Service

The Veterans Transportation Service (VTS) provides safe and reliable transportation to Veterans who require assistance traveling to and from VA health care facilities and authorized non-VA health care appointments. VTS also partners with transportation services in local communities to serve Veterans' transportation needs.

Beneficiary Travel

The Beneficiary Travel (BT) program reimburses eligible Veterans for costs incurred while traveling to and from VA health care facilities. The BT program may also provide pre-approved transportation solutions and arrange special mode transportation (SMT) such as wheelchair vans or ambulance services when requested by the VA. Veterans may be eligible for common carrier transportation (such as bus, taxi, airline or train) under certain conditions.

Please talk to your ALS Team and Coordinator about local transportation options. Resources may exist for standard vehicle transportation, wheelchair accessible transportation, and ambulance transportation when needed. Please familiarize yourself with the process for initiating these requests and the timeline for submitting the request prior to your appointment.

To schedule standard vehicle transportation please call:

____

To schedule wheelchair accessible or ambulance transportation, please call:

____

VA Resource Navigator

Scan QR codes, visit popular links to trusted VA websites, or call the MyVA411 hotline at (800) 698-2411 to learn more about VA resources.

VA.gov is the gateway to access and manage your VA benefits and health care.
www.va.gov

The VA Welcome Kit provides an overview of benefits and services.
www.va.gov/welcome-kit/

With the official **VA: Health & Benefits** app, you can manage your VA health care, benefits, and payments from your mobile phone or tablet.
www.mobile.va.gov/app/va-health-and-benefits

My HealtheVet is a free online tool to manage your health care. Refill and track prescriptions, access your medical records, and communicate with your health care team.
www.myhealth.va.gov

How to scan a QR code with your smartphone camera

1. Open your smartphone's camera app or QR code scanning app.
2. Hold your device so that the single QR code appears on your smartphone's screen.
3. Once the QR code is centered on your smartphone's screen, your device will recognize the QR code and show a notification.
4. Tap the notification to open the link associated with the QR code.
5. Still having trouble? See additional tips on page five.

Veterans Crisis Line

Contact the Veterans Crisis Line. Available 24/7 via phone, text, and online chat.

Receive crisis support

The Veterans Crisis Line provides confidential crisis support for Veterans and their loved ones. You don't have to be enrolled in VA benefits or health care to connect.

Crisis Hotline: **Dial 988 (then press 1)**

Text Hotline: **Text at 838255**

www.veteranscrisisline.net/get-help-now/chat/

For phone numbers listed in this resource, dial 711 if TTY-based Telecommunications Relay Services are needed.

Health Care

Apply for VA health care, find out how to access services, and manage your health and benefits online.

Apply for VA health care

Apply for health care benefits for Veterans and transitioning service members.

Health Care Hotline: **(877) 222-8387**

www.va.gov/health-care/how-to-apply/

Manage your appointments online

Schedule, cancel, and manage health appointments online.

www.va.gov/health-care/schedule-view-va-appointments/

Pay copays and use multiple insurances

Check your balance for medical services and prescription copays, request help, or dispute charges.

Pay by Phone: **(888) 827-4817**

www.va.gov/health-care/pay-copay-bill/

Apply for travel pay

Request reimbursement for travel expenses to and from approved health care appointments.

Travel Pay Call Center: **(855) 574-7292**

www.va.gov/health-care/get-reimbursed-for-travel-pay/

Explore long-term care

Learn about assisted living, residential, and home health care.

Health Care Hotline: **(877) 222-8387**

www.va.gov/health-care/about-va-health-benefits/long-term-care/

Learn about qualifying for VA dental care

Find out if you qualify for dental care benefits.

MyVA411: **(800) 698-2411**

www.va.gov/health-care/about-va-health-benefits/dental-care/

Learn about your VA primary care team

VA takes a team approach to health care with you at the center. Research shows this kind of approach leads to better quality care, more satisfied patients, and fewer hospital visits.

Health Care Hotline: **(877) 222-8387**

www.va.gov/health-care/about-va-health-benefits/your-care-team/

VA Health Connect Clinical Contact Centers

VA Health Connect provides Veterans with access to health care via virtual clinical contact centers that are available 24/7/365. Veterans can access VA Health Connect by calling their local medical center to schedule primary care appointments, speak to a nurse, meet with a clinical contact center medical provider, and check on their medications.

Fill in your VA Contact Center phone number:

Find urgent and emergency care

If you are having a medical emergency, dial 911.

Have a plan of where to go for urgent and emergent care.

www.va.gov/initiatives/emergency-room-911-or-urgent-care/

Explore Community Care/MISSION Act

Access other providers when VA cannot provide the care needed.

Community Care National Contact Center
(877) 881-7618

www.va.gov/communitycare/

Find VA Locations

Find a VA location or in-network community care provider.

www.va.gov/find-locations/

Disability

File a claim for disability compensation for conditions related to your military service and manage your benefits over time.

Learn about the PACT Act

Learn how the PACT Act expands VA health care and benefits for Veterans exposed to burn pits, Agent Orange, and toxic substances.
MyVA411: **(800) 698-2411**
www.va.gov/resources/the-pact-act-and-your-va-benefits/

Apply for an initial disability rating or increase

Learn how to file a claim for a disability related to military service.
VA Benefits Line: **(800) 827-1000**
www.va.gov/disability/how-to-file-claim/

Find local Veteran Service Organizations (VSO)

Get help from an accredited representative.
MyVA411: **(800) 698-2411**
www.va.gov/get-help-from-accredited-representative/

Education and Training

Apply for and manage your GI Bill and other education benefits to help pay for college and training programs.

Continue education with the GI Bill

Explore how VA can help pay for education.
Education Contact Center
From the U.S.: **(888) 442-4551**
From Overseas: **001-918-781-5678**
www.va.gov/education/about-gi-bill-benefits

Housing Assistance

Find out if you're eligible for a VA-backed home loan. If you have a service-connected disability, see if you qualify for a housing grant to help you live more independently.

Apply for housing assistance

Learn more about home loans and other benefits that can help you improve, build, or keep your current home.
Regional Loan Center: **(877) 827-3702**
www.va.gov/housing-assistance/

Receive help for homelessness and housing instability

Get connected with housing solutions and community services.
Call Center: **(877) 424-3838**
www.va.gov/homeless/

Careers and Employment

Apply for Veteran Readiness and Employment (VR&E), get support for your Veteran-owned small business, and access other career resources.

Prepare for careers and employment

Receive support for education, training, and credentialing needed for employment.
MyVA411: **(800) 698-2411**
www.va.gov/careers-employment

Veteran Readiness and Employment (VR&E)

Service members and Veterans with service-connected disabilities may qualify for VR&E, also known as Chapter 31.
www.va.gov/careers-employment/vocational-rehabilitation/

Pension

Apply for monthly payments for wartime Veterans and survivors with limited or no income who meet certain age and disability requirements.

Apply for supplemental income

Learn how pensions provide supplemental income for some wartime Veterans and their survivors.

VA Benefits Line: **(800) 827-1000**

www.va.gov/pension/

Fiduciary Program

The fiduciary program provides oversight for VA's most vulnerable beneficiaries who are unable to manage their own VA benefits.

Fiduciary Line: **(888) 407-0144**

www.benefits.va.gov/fiduciary/

Family Member Benefits

Learn about the benefits you may qualify for as a spouse, dependent, or survivor. Find out what else you may be eligible for as a family member caring for a Veteran with disabilities.

Caregiver support program

The VA Caregiver Support Program offers services to caregivers of eligible and covered Veterans enrolled in VA Health Care.

(855) 260-3274

www.caregiver.va.gov

Benefits for Spouses, Dependents, Survivors

Learn about life insurance, money for school, survivors pension, and other benefits you may qualify for.

www.va.gov/family-and-caregiver-benefits/

VA Benefits Hotline: **(800) 827-1000**

Find and use counseling services

Access counseling, outreach, and referral services for eligible active duty service members, Veterans, and their families.

Vet Center Line: **(877) 927-8387**

www.vetcenter.va.gov

Connect with social workers

VA social workers assist with resource navigation, crisis intervention, advocacy, case management, benefit assistance, mental health related interventions, treatment for substance use dependence, food insecurity, and support for those facing housing instability and homelessness.

Health Care Hotline: **(877) 222-8387 (press 0)**

www.socialwork.va.gov

Fisher House™ Program

Located within walking distance of the treatment facility, a VA Fisher House™ provides temporary accommodations at no cost for Veterans, service members, their families, and caregivers while the Veteran or service member receives treatment at major military and VA medical facilities.

Current Fisher House locations. www.socialwork.va.gov/fisher.asp

VA Fisher House™ phone numbers available at www.socialwork.va.gov/Fisher_House_Locations.asp

Burials and Memorials

Get help planning a burial in a VA national cemetery, order a headstone or other memorial item to honor a Veteran's service, and apply for survivor and dependent benefits.

Schedule a burial for a Veteran or family member

Get step-by-step guidance on how to request and apply for a burial in a VA national cemetery or in a state or tribal government Veterans cemetery.

National Cemetery Scheduling Office
(800) 535-1117
www.va.gov/burials-memorials/schedule-a-burial/

Honor a Veteran or Reservist with memorial items

Find out how to apply for markers, medallions, headstones, Presidential Memorial Certificates, and other memorial items to honor a Veteran's service.

Headstones and Markers: **(800) 697-6947**

www.va.gov/burials-memorials/memorial-items/

Veterans Legacy Memorial (VLM)

VLM is an online memorial that honors Veterans interred in VA National Cemeteries, VA grant-funded cemeteries, DOD-managed cemeteries (including Arlington National Cemetery); U.S. Park Service National Cemeteries, and thousands of private cemeteries where Veterans have received a VA-provided gravesite marker since 1996.

www.vlm.cem.va.gov

As you discover more contacts, list them below.

Name	Office or Department	Contact Information

Having trouble scanning the QR code? Try these tips!

Turn up your screen brightness
Make sure the screen showing the QR code is bright enough for the camera to register the code. This will also make it easier for you to see the hyperlink when it appears.

Find the right distance
If the camera on your smartphone is too close or too far from the QR code, the camera might not be able to scan it. Keep the QR code in the camera's viewfinder while you try different distances.

Square up your smartphone
Keep the smartphone camera parallel to the QR code when scanning. If your smartphone is tilted, you may have trouble scanning the code.

Stay safe online - confirm your link leads to a trusted website
Ensure that the link which appears in your camera leads to a trusted website (e.g. "va.gov" or "veteranscrisisline.net"). Using your camera to access official VA sites is free and does not require any additional app downloads.

Important Contact Information

Specialty	Phone Number	Location

Additional Notes