

I'm a Veteran Diagnosed with ALS — Where Do I Begin?



A Guide for Veterans Living with ALS and Those Who Love Them

By the I Am ALS Veterans Team

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IAM ALS

About this Document

The I AM ALS Veterans Team wrote this guide to help veterans diagnosed with ALS navigate the complex worlds of veteran benefits and the veteran healthcare system. Lack of knowledge of the VA system can result in frustration and delays in service. Because ALS can progress rapidly, delays should be avoided at all costs. This document aims to help veterans and their loved ones by providing a step-by-step guide on navigating the VA system.

The I AM ALS Veterans Team consists of veterans living with ALS and their loved ones - all of whom are volunteers. They have many years of experience navigating the VA and know firsthand what you're going through. Breathe. You don't have to go through this alone. Contact the I AM ALS Support Team online at iamals.org/reach-out or through email at gethelp@iamals.org or email community@iamals.org to reach the I AM ALS Veterans Team. Please email if you discover additional benefits that can be added to this guide or if any information is no longer valid.

This document does not contain medical advice. Any treatment options or equipment decisions must be made in consultation with your medical team.

Two Distinct and Separate Agencies: VBA and VHA

It's important that you understand that you will be working with two VA systems. The Veterans Benefits Administration (VBA) provides the disability rating, monthly disability compensation, and other non-healthcare benefits. The Veterans Health Administration (VHA) provides healthcare, equipment, and supplies. You will have to apply and go through the intake process for both agencies.

The VHA is the largest integrated healthcare system in the US and serves 9 million veterans annually. There are approximately 170 medical centers (VAMCs) and 1,100 outpatient centers across 18 Veteran Integrated Service Networks (VISNs). Many VAMCs provide excellent care and services for ALS while other VAMCs fall short.

Advocating for Yourself within the VHA

Every facility is required to follow [VHA Directive 1101.07 The ALS System of Care \(click this link for a downloadable copy\)](#). This directive lists all responsible parties and the care, services, and equipment they are required to provide. It can be a powerful advocacy tool if you are denied access to something listed in the directive. Some VA personnel are unaware of the directive or the unique needs of veterans living with ALS and will deny services or equipment. Don't take "no" for an answer. Ask for the name and contact information of your ALS Coordinator. Every VAMC is required to have an ALS Coordinator to assist you. If you receive inadequate equipment or are denied access to services or medication, use the chain of command to escalate your request. Contact your congressional representative if you are repeatedly ignored. If you are in a crisis situation, call the White House VA hotline at 1-855-948-2311.

Using this Document

This document is designed to be used online rather than in a printed form and is organized around a Master Checklist. This Master Checklist is constructed to allow veterans to get information based on where they are currently in their ALS journey. There are two major categories: 1) things you need to do when you are newly diagnosed and 2) things you need to do as your ALS begins progressing. The Master Checklist contains links to sections for all Master Checklist items. Each section consists of steps you will need to complete and a link to return to the Master Checklist. The document also contains a section of additional resources you can access and a list of mobility equipment and recommended manufacturers.

ALS progresses differently for every person. Most progress fairly rapidly, but some progress more slowly. But in all cases, progression will happen, and you need to be ready. It is extremely important that you try to stay ahead of your needs as much as possible. For example, don't wait until you can't walk to order a power wheelchair. Order it as soon as you have indications that you are having trouble with your legs and feet. This document will help you through this process.

Master checklist

As Soon As You Are Diagnosed (Like Immediately)...

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- ☐ [Establish Your Healthcare and Medical Team](#)
- ☐ [Get your Affairs in Order](#)

Other Benefits You Can Access When You Have Time...

- ☐ [VA Benefits If You Need Assistance At Home](#)
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As Your ALS Progresses...

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Resources

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Assemble Documents And Get Your Benefits

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This checklist details how to get started accessing your VBA benefits. There are two VA agencies you will need to apply to.

1. The Veterans Benefits Administration (VBA) will review your application for disability compensation and will grant you a 100% disability rating. This rating is very important because it determines your priority access to ALS-related healthcare within the Veterans Health Administration (VHA)
2. The Veterans Health Administration (VHA) will review your application and enter you into the VA Healthcare system. You can apply for the VHA before you receive your VBA rating, but you won't receive ALS-related healthcare benefits until you get your rating.

To begin this process, you will need a *definite* diagnosis of ALS. A probable diagnosis will not be enough to get benefits. This will need to be in the form of a document provided by a neurologist. This can often be hard to get as most neurologists do not want to give this diagnosis. We suggest going to an ALS clinic or treatment center to get your diagnosis. I AM ALS has a list of ALS clinics and treatment centers here: [ALS Clinics and Treatment Centers](#). Here is a map of all [VA Medical Centers and Clinics](#).

Contact your local Paralyzed Veterans of America (PVA) and set up an appointment. You can find your local PVA chapter [here](#).

Detailed Checklist

Step 1 - Documents you will need before applying for benefits

Item	Description	Who Do I Contact?	How Long?
Intent to file a claim for compensation and/or pension, or survivors pension and/or DIC	VA Form: 21-0966 You should file this form as soon as your neurologist suspects that you have ALS. This form simply declares your intention to file for a disability claim. This form establishes the date when your disability started and requests retroactive pay from that date.	PVA	
Definite ALS diagnosis	You will need a definite written diagnosis of ALS. A probable diagnosis will not be enough to receive benefits. This will need to be in the form of a document provided by a neurologist.	Neurologist	
DD-214 (discharge orders)	You will need a valid DD-214. If you don't have one, you can order one here from the Department of Defense (DoD).	DoD	1-2 Weeks

Assemble Documents And Get Your VA/Non-VA Benefits Cont...

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Step 2 - Forms you will need to complete and submit *immediately* (with help from the PVA) to apply for VBA benefits

Item	Description	Who Do I Contact?	How Long?
Fill-out disability application	<p>VA Form: 21-526EZ This is the main application for disability compensation (include a copy of your DD-214 and definite ALS diagnosis). It's important that the PVA attempt to get you the highest Special Monthly Compensation (SMC) possible given your current condition. SMC rates are confusing, but the PVA can work with you on asking for the maximum amount. As you progress, you can apply for higher levels of SMC. This process is explained below. Here is a list of current SMC rates and descriptions.</p> <p>Note: The requirement for the VA to service connect your ALS diagnosis is 90 continuous days of active duty service. If the veteran served in the National Guard or Reserves and does not meet the 90-day requirement, contact your PVA service officer for guidance.</p>	PVA	N/A
Fill-out statement in support of disability claim	<p>VA Form: 21-4138</p> <p>This is a statement in support of your disability claim.</p>	PVA	N/A
Fill-out VSO representative form	<p>VA Form: 21-22</p> <p>This appoints a Veteran Service Organization VSO (the PVA) as your representative</p>	PVA	N/A

Fill-out diagnosing physician authorization form	VA Forms: 21-4142 and 21-4142A The contact information of the physician who diagnosed you and authorizes them to disclose medical information to the VA.	PVA	N/A
Fill-out and submit your dependent declaration form	VA Form: 21-686C This form allows your spouse and dependents to access a number of benefits that are covered later in this document. Make sure you include supporting evidence: marriage/birth certificates, divorce decrees, & court orders for adult-dependent children or parents.	PVA	N/A
Submit above documents	At this point you will need to wait for the VA to review and approve the application and give a rating of 100% permanent and total service-connected disability. ALS applications are fast-tracked, but if you don't receive notification within 1-2 weeks, contact the PVA to help expedite this process. If a month passes with no decision, you should consider contacting one of your federal senators and ask for help getting your paperwork through the system. Once you get your rating, you should get your first payment within 15 days.	PVA	2-4 Weeks

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Step 3 - Steps you need to take immediately after you receive your 100% service-connected, total and permanent disability rating, your SMC, and a packet from the VBA detailing your additional benefits

Item	Description	Who Do I Contact?	How Long?
Intake appointments for VBA	After you receive your rating, the VA will contact you and schedule an intake appointment. This is where you meet an intake doctor to verify your disability. At this point, you can also try and upgrade your SMC level if you think the initial rating was too low.	VA will notify you	N/A
Apply for VHA healthcare benefits	<p>VA Form: 10-10EZ</p> <p>After you get your rating and are in the VBA system, you need to apply for healthcare benefits with the VHA.</p> <p>When you fill out your 10-10EZ, make sure to check the box next to “Do you have a va service-connected rating?” and put a “100” next to “What is your rated percentage” in the military history section. This is the key to getting approved quickly for full benefits. Fill out the form completely and provide all requested documents using the instructions on the website or form instructions.</p>	Submit form and VHA will contact you	1-2 Weeks
Fill out and submit Your request for permanent aid and attendance	<p>VA Form: 21-2680</p> <p>This form requests the VBA to add monetary benefits to your disability pension due to your being homebound and needing help with basic functions such as eating, dressing, etc.</p>	Submit form	N/A

Additional benefits you will receive in your packet	<ul style="list-style-type: none"> • DoD ID Card • Commissary and Exchange Privileges • Free National Park Access • Access to Military Installations 		
Enroll to access two online portals	Ebenefits.va.gov to manage benefits online Myhealthvet to manage healthcare online		

Assemble Documents And Get Your VA/Non-VA Benefits Cont...

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Step 4 - Non-VA steps you need to take after you receive your diagnosis from your Neurologist

Item	Description	Who Do I Contact?	How Long?
Social security benefits	Apply for Social Security Disability Benefits (SSDI) immediately after your diagnosis. In 2020, the mandatory five-month waiting period for disability approval for people with ALS was waived, so the process has been reduced to days or weeks rather than months. You can start the process online here .	Social Security Administration	1-2 weeks
Short term disability insurance (STD)	If you are employed at the time of your diagnosis, you may qualify for Short Term Disability. As soon as you feel uncomfortable or incapable of doing your job, you should contact your employer about this option. This usually lasts for up to a year. It will require documentation from your doctor and employer.	Employer	2-4 Weeks
Long term disability (LTD)	If you are part of a pension or other retirement program through your employer, you may qualify for Long Term Disability benefits. Contact your employer for more information	Employer	2-4 Weeks

Assemble Documents And Get Your VA/Non-VA Benefits Cont...

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Step 5 - Additional steps you should take after you receive your 100% service-connected, total and permanent disability rating, your disability amount, and a packet from the VBA detailing your additional benefits

Item	Description	Who Do I Contact?	How Long?
HISA grant	VA Form: 10-0103 This form is for the Home Improvements & Structural Alterations (HISA) grant. This grant gives veterans up to \$6,800 (as of 2021) for accessibility modifications to your home. This includes modifications for safe entry and exit, bathroom and/or kitchen remodeling, and modifying your home's electrical system to support medical devices. Applicants may apply for this grant multiple times, but one cannot receive more than \$6,800 across multiple uses of the grant. There are limits on what the HISA grant can be used for.	Your occupational therapist (OT) or your local VA's prosthetics department. Visit this website for more information	2-4 Weeks
SAH grant	VA Form: 26-4555 This form is for the Specially Adapted Housing (SAH) grant, which is limited to \$101,754 (2022 amount) to make the home more accessible. This may include creating additional rooms, modifying bathrooms or electrical systems, widening hallways and doors, replacing windows, and other home modifications. Veterans living with ALS may apply for this grant six times if they do not receive more than \$101,754 across multiple uses of the grant.	You can find out how to apply here . You can also call toll-free at 800-827-1000, Monday through Friday, 8:00 a.m. to 9:00 p.m. ET. Ask to have a claim form mailed to you.	3-9 Months

	<p>Veterans who received this grant get a cost of living increase each year, so even if all of the grant is used in a single year, the veteran living with ALS may be able to access the additional increased amount in future years. This grant is much larger and the process is much more involved than the HISA grant. You will be assigned a case manager who will guide you through the process, discuss your options, and recommend local contractors. We recommend that you think carefully about how you want to use this grant. Exhaust all other avenues (HISA, Safe Egress from House, etc) before using this grant. Consider hiring a designer to give you some ideas on how to maximize this grant.</p>		
VMLI	<p>VA Form: 29-8636</p> <p>This form is for the Veterans Mortgage Life Insurance (VMLI) benefit. The veteran must use the SAH grant to get this benefit. In the event of the veteran's death, this insurance will pay up to \$200,000 of the primary residence mortgage. This costs approximately 16% of the payoff amount the veteran chooses. This amount will be directly deducted from the veteran's VA disability benefits. For example, if the veteran chooses to purchase the entire \$200,000 of coverage, it will cost approximately \$325 per month. Do the calculations to determine if this is a good fit. Consider that after an ALS diagnosis the veteran living with ALS has a preexisting condition and is no longer eligible for any other life insurance. This insurance can be used if the veteran purchases a different primary residence.</p>	<p>Your SAH case manager should help you with this when you are approved for the SAH grant.</p> <p>Documentation such as a deed of trust, mortgage statement, etc. are required.</p> <p>You can find more information here.</p>	2 - 4 Weeks

Vehicle grant	<p>VA Forms: 21-4502 and 10-1394</p> <p>This grant allows the veteran to purchase a wheelchair-adapted vehicle. There are two forms. VBA-21-4502 allows a one-time grant of \$21,488 to purchase a vehicle. VBA-10-1394 authorizes the VA to pay for the conversion of the vehicle to an adapted vehicle. The VA will only purchase a vehicle once, but they will pay for the conversion of a new vehicle approximately every two (2) years. You can often trade in your current accessible vehicle for a new one every two years for minimal out-of-pocket expenses. There are dealers nationwide who specialize in working with the VA in this regard.</p>	<p>Your occupational therapist (OT) or your local VA prosthetics department.</p> <p>A discussion on types of vehicles is available here.</p>	1-2 Months
Clothing allowance	<p>VA Form: 10-8678</p> <p>This grant gives the veteran an annual clothing allowance of approximately \$750. The deadline for this grant is July 31st every year.</p>	<p>Contact your VA prosthetics department and/or your OT. You will need to fill out VA Form 10-8678 and submit it annually to the prosthetics department.</p>	Usually paid out in October with an end of July application deadline
Bank your voice	<p>While you still can talk, it is a very good idea to “bank your voice.” This means recording your voice and having those recordings turned into a digital version of your voice that you can use if you ever use a text-to-speech communication device. This typically involves around 6-8 hours of speaking phrases and words into a voice modeling software.</p>	<p>Modeltalker is the most popular software for this and the process is free.</p> <p>https://www.modeltalker.org/</p>	

Safe egress from your house	This is not a specific grant but is something your prosthetics department will do for you. The VA will want to ensure that you have at least two safe ways to exit the home in case of an emergency. This usually means threshold ramps, ramp systems to navigate, stairlifts, and/or vertical platform lifts (VPL). The VA will only pay for one major entry system (modular ramp, stairlift, or VPL), but should put threshold ramps on at least two entries or exits.	Contact your OT or local prosthetics department	1-4 Months
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Establish Your Healthcare And Medical Team

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Once you have been accepted into the VHA system, you will have some choices about how you want to receive your care and who you want to direct your care. This is an important distinction. You want the VA to **administer** your care, but you may want a medical team who specializes in ALS to **direct** your care.

Who Do You Want To Direct Your Care?

What do we mean by *direct your care*? You will want a team experienced with ALS who knows the challenges you face, who stays on top of your progression, who lets you know when to consider procedures or equipment, and who gives you targeted information on what to expect going forward. We recommend that you find an ALS multidisciplinary clinic to direct your care. Most multidisciplinary clinics are composed of teams of specialists, including neurologists, respiratory therapists, occupational therapists, speech therapists, physical therapists, dieticians, and social workers. They are trained in the needs of people living with ALS. I AM ALS has a list of ALS clinics and treatment centers here: [ALS Clinics and Treatment Centers](#). Clinic staff will help you to request treatment, equipment, and procedures from the VA. Many times, the VA will pay for your visits to these clinics.

How Do You Want The VA to Administer Your Care?

Some Veterans Affairs Medical Centers (VAMC) have ALS teams, while others do not. Here is a list of all [VAMCs](#) in the U.S. You have two different options on how you receive care:

1. You can request Home Based Primary Care (HBPC). HBPC consists of a team of physicians, nurses, and specialists who will come to your house to administer care that does not require a trip to the VAMC. Not all VAMCs support HBPC and it can be more difficult to get if you live in a rural area. We highly recommend using HBPC, if possible.
2. You can set up appointments with staff at your local VAMC yourself. Some care will have to be done at the VAMC or a local VA Clinic, regardless of which option you choose.

Get Your Affairs In Order

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You don't know how fast your disease will progress, so it's important that you get your affairs in order as soon as possible. This includes:

- Ensuring that your will or living trust is accurate and up to date.
- Ensuring that your finances, insurances, and mortgages are well organized and managed.
- Discuss and plan with family members what steps you wish to take and those you wish not to take as your disease progresses. This may include filling out a do-not-resuscitate order (DNR).
- Establishing a medical and financial power of attorney for someone you trust who is nearby in case you become incapacitated and are unable to make decisions on your own. This should include instructions on your wishes as well as authorization for someone else to make decisions.

VA Benefits If You Need Assistance At Home

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If you need assistance bathing, dressing, eating, doing light household duties, and/or skilled nursing care due to a tracheostomy, the VA will provide assistance in your home. The type of in-home assistance and the number of hours authorized vary widely depending upon the VA medical center. If you are not authorized for the hours you need you can keep asking up the chain of command. At this point, there are no hard and fast rules. Don't accept "no" for an answer until your needs are met. **No matter your disease progression, you have the right to be cared for in your home with adequate in-home care.** Contact your social worker or primary care physician for a home care referral.

Item	Description	Recommended Hours
Certified nursing assistant (CNA)	CNAs help with personal hygiene, dressing, meal preparation, and light housekeeping.	16 hours a week
Skilled nursing by a licensed vocational nurse (LVN) or registered nurse (RN)	Skilled nursing services are provided in-home when a veteran has a tracheostomy and is dependent on a ventilator.	16 hours a day
Community care contracted services	Typically, CNA and skilled nursing services are contracted with home care services like Bayada or Maxim.	
Veterans directed care	Veterans Directed Care is a program that gives the veteran control over how care dollars are directed. Carefully consider long-term needs and the number of hours afforded in this program.	
Residential care facilities	Sometimes veterans living with ALS are best served in a residential facility. This decision should be made by the veteran and their loved ones. Read more about VA residential settings and nursing homes.	

VA Benefits For Your Dependents And Family Caregivers

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Your dependents and spouse will be significantly impacted by your disease. If your spouse is your primary caregiver, they may have to quit their job or change their career trajectory. The list below lays out some steps you can take to get benefits for your dependents.

Item	Description	Who Do I Contact?
Survivors and dependents educational assistance program	<p>This benefit includes the spouse and any dependents between ages 18 and 26. The program can help cover:</p> <ul style="list-style-type: none">• Associates, undergraduate, or graduate degree programs• Career-training certificate courses• Educational and career counseling• Apprenticeships• On-the-job training <p>These benefits are for 36 months of education and can be used within 10 years starting from the time the veteran gets their disability rating.</p>	<p>Once you are identified as a dependent, you should receive a letter granting these benefits. You will need to take this letter to the school of your choice and ask for the veterans certifying official. They will help submit your enrollment certification to the VA.</p> <p>Go to this site for more information.</p>
Program of comprehensive assistance for family caregivers (PCAFC)	<p>This program gives substantial financial benefits to the primary caregiver of a disabled veteran. This currently applies to veterans who were actively serving and who incurred or aggravated a serious injury (including a serious illness) in the line of duty in the active military, naval, or air</p>	<p>This process is long and includes multiple steps that you have to go through.</p>

	<p>service on or after September 11, 2001, or on or before May 7, 1975.</p> <p>This program will expand to all service eras in October of 2022.</p> <p>This program pays a monthly stipend directly to the Primary Caregiver based upon a pay rate of a GS rate at Grade 4, Step 1. The amount varies depending on where you live.</p> <p>There are two levels of pay based upon the ability of the veteran to “self-sustain in the community.” Level 1 is when the veteran can, to some level, “self-sustain in the community.” Level 2 is when the veteran is unable to “self-sustain in the community.” Almost all veterans living with ALS will qualify for level 2. Here is a fact sheet that explains this stipend.</p>	<p>Go to this site to start the process.</p>
Survivor life insurance	<p>Survivor Life Insurance is a \$10,000 policy for the surviving beneficiary. The premium is waived for veterans living with ALS. Make sure to ask for this waiver when enrolling.</p>	<p>This should be automatic once your disability rating is received. You will get a letter from the VA explaining the benefits and statements quarterly.</p>
Service-disabled life insurance (S-DVI)	<p>This is an additional \$20,000 in life insurance that <i>must</i> be activated within 1 year of receiving Survivor Life Insurance. This premium cannot be waived.</p> <p>Important note: Once diagnosed with ALS, the veteran won't be able to get other life insurance.</p>	<p>You must sign up for this within 1 year of activating the Survivor Life Insurance, you will get a letter from the VA that directs you to enroll in Service-Disabled Life Insurance.</p>

Dependency and indemnity compensation (DIC)	Dependency and Indemnity Compensation (DIC). This is a survivor benefit, in the event of the veteran's death, of \$1,356 per month which is adjusted annually for cost of living. If the veteran lives for more than 8 years with a 100% disability rating, the surviving spouse is awarded an additional \$256 per month. Dependent children are also awarded a monthly benefit amount.	This benefit will be approved once the veteran is diagnosed and receives their 100% disability rating.
CHAMPVA medical and dental benefits	VA Form: VBA-10-10d Spouses and dependent children are able to receive free medical care through the CHAMPVA program. This benefit continues even after the veteran passes away. Dental care can be purchased through this program at a discounted rate. CHAMPVA is considered secondary insurance. If you have other insurance or Medicare, CHAMPVA will be the secondary payer. If you don't have other insurance, CHAMPVA will also act as primary insurance coverage.	Fill out VBA-10-10d to enroll. Once accepted, you should also get the option to buy dental care at a group rate. Refer to this site for information on benefits, limits, and copays: https://www.va.gov/health-care/family-caregiver-benefits/champva/
Bowel and bladder stipend	The Primary Caregiver for the veteran may qualify for a bowel and bladder stipend. This stipend varies depending on the amount of bowel and bladder assistance required. If your caregiver has to help you with a substantial portion of your bowel and bladder care, they may qualify for this stipend. This will be approximately \$1,200 a month, although the amount will vary depending on how many hours per day you are authorized. Unlike most benefits, this stipend is taxable. You become a VA vendor and will be subject to all withholding and applicable tax rates.	To start this process, consult your assigned social worker or occupational therapist at your VAMC's spinal care unit. There are various steps including filling out a vendor request form, filling out a W9, and getting a

		National Provider Identification (NPI) number.
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Other Benefits (Local, State, And Federal)

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Item	Description	Who Do I Contact?
Property tax discount	Forgiveness of a specific percentage or set dollar amount of your property tax bill.	Contact the local tax assessor's office. To receive this forgiveness, veterans living with ALS are required to provide disability documentation and fill out a form provided by the tax assessor's offices. Tax forgiveness is only applicable to primary residences. The forgiveness amount varies from state to state.
Vehicle registration exemption	Forgiveness of registration fees for vehicles transporting disabled veterans.	Contact the local Department of Motor Vehicles and inquire if they forgive or reduce vehicle registration taxes for a vehicle used to transport a disabled veteran. This is not available in all states. The VA provides veterans living with ALS a letter to submit to the local DMV.
Forgiveness of student loans	Total and Permanent Discharge (TPD) forgives federal student loan debt.	TPD pays off the entire student loan debt. Go to this site to learn more: https://www.disabilitydischarge.com
Utility benefits	Veterans living with ALS may be eligible for a	Contact your local electrical provider.

	reduced rate on electrical service. This varies depending on where you live. Also, due to living with a disability that requires life-saving medical equipment, veterans living with ALS may qualify for priority restoration during power outages.	
Free or discounted entry to state parks	Discounted or free admission to state parks (varies per state).	Contact the state directly and provide documentation that the veteran living with ALS is a service-connected disabled vet. Most states offer free or discounted admission.

ALS Progression And The Importance Of Staying Ahead Of The Disease

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The one thing each ALS progression has in common is that your body will lose its ability to do things you once took for granted. There is virtually no way to know how slowly or quickly this loss will progress. There are equipment and services that can help alleviate the loss, but it's important to be as mentally, emotionally, and physically prepared.

Being prepared to live with ALS means getting equipment and lining up services well before you actually require them to function. For example, if you are becoming unstable when walking, but can still walk with relative safety, continue walking as long as you can safely. However, order a scooter or wheelchair so you have it there when you need it, and can practice using it before you need it. Your ALS multidisciplinary clinic can help you with this by monitoring your progression and suggesting when to have certain procedures performed and when to get certain equipment.

The following pages will describe stages in your progression and help you be proactive and avoid crisis situations. Each page will:

- Detail a specific type of functionality loss
- Give you a checklist of equipment and/or services to consider for each type of loss
- Link you to a list of equipment or services to consider including who to contact to order, estimated lead time to receive and recommendations
- Note: Once you start getting electronic equipment that you depend on, consider getting a whole house generator or backup system. You can use the SAH grant for this. You will want to make sure you can power your equipment in case of an outage.

Some of the stages may be happening at the same time. For example, if you are losing the ability to walk, you might also be losing the ability to transfer in and out of your bed. In those cases, just look at the actions for all the stages that are applicable to your situation.

Things To Do If You Have Trouble Standing, Walking, Transferring, Or Moving In Bed

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I Am Starting To Have Trouble With Balance And Stability, But Still Walking

At this point, you want to take steps to minimize your chances of falling and sustaining injury. Below are some actions you should consider taking. For other actions you should take, please see the [Equipment List](#) for mobility devices

Action To Take	Description	Who Do I Contact?	Lead Time
Safe exits from your house	Now is the time to get this process started. You want to minimize the risk of falls when navigating steps or stairs. At a minimum, you need to minimize the number of steps you have to navigate.	Your OT or prosthetics department	1-4 months

Access the vehicle grant	Since a power wheelchair is most likely in your future, it would be smart to start the process of finding an accessible vehicle.	Your OT or prosthetics department	2-4 months
Access the HISA grant	It would be a good idea to fast-track getting a bathroom remodel to have a zero barrier, roll-in shower.	Your OT or prosthetics department	1-2 months

I Am Starting To Have Trouble Bearing Weight, Standing, Walking And Transferring

At this point, you are well on your way to needing a mobility device so that you can maintain independent mobility. Hopefully, you have received your power wheelchair, have safe exits from your house, and have purchased your accessible vehicle. The risk of falling is probably reaching its highest point, so you need to take steps to minimize that risk. Below are some actions you should consider taking.

Action To Take	Description	Who Do I Contact?	Lead Time
Things you should already have on hand	<p>You should already have the following on hand or ordered:</p> <ul style="list-style-type: none"> • Power wheelchair or scooter • Accessible vehicle • Safe exits from your house <p>If you haven't ordered these items, do so immediately.</p>		
Order a portable hoyer lift and/or a ceiling lift	<p>A portable Hoyer lift allows your caregivers to safely lift you in and out of bed and in and out of your wheelchair. The portable lifts are also capable of breaking down so you can take them with you when you travel.</p> <p>A ceiling lift is a lift that is installed on your ceiling and goes from set points in</p>	<p>Your OT or prosthetics department</p> <p>See Equipment List</p>	2-4 weeks

	<p>your bedroom. These lifts save space in your room.</p> <p>The VA will get you one or both.</p>		
Get fitted for an ankle foot orthosis (AFO)	An AFO is designed to provide additional support for your feet, ankles, and lower leg. It can help you bear weight and continue standing. It can also be helpful if you are experiencing foot drop.	Your OT or prosthetics department	2-4 weeks
Order a reclinable shower chair	If you are having trouble showering yourself or sitting on the toilet, consider requesting a reclinable, rolling shower chair with a headrest and armrests.	<p>Your OT or prosthetics department</p> <p>See Equipment List</p>	2-4 weeks

I Am Starting To Have Trouble Adjusting Myself And Rolling Over In Bed

If you get to the point where you can no longer move to adjust yourself in bed, your caregiver will be getting up often at night to roll you from side to side for your comfort and to avoid pressure sores. See [Hospital Beds](#) for next steps.

Things To Do If You Have Trouble With Your Arms And Hands

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When your progression moves into your arms and hands, you will need some specific equipment to help you replace that function as much as possible. Below are some actions you should consider taking.

Action To Take	Description	Who Do I Contact?	Lead Time
Order a computer	The VA will pay for a computer that will allow you to use your eyes to control	Your speech therapist, OT	2-4 weeks

with eye gaze technology	functionality - once you begin losing functionality. Get your eye gaze equipment before you need it so you can practice in a low stress environment. Don't be afraid to try new technology! It can open up a whole world for you. Be patient with yourself. You can do it.	or prosthetics department See Equipment List	
Request eye-drive technology	Once you are confined to a power wheelchair you can use your eye gaze enabled computer to control your wheelchair. This is called eyedDrive technology,	Your OT or prosthetics department See Equipment List	2-4 weeks

Things To Do If You Have Trouble Swallowing And Speaking

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When your progression moves into your throat and starts affecting your swallowing and speaking, you are at risk of aspirating (breathing in liquid or solid objects) when eating or drinking. You may also be struggling with communicating. Below are actions you should consider taking.

Action To Take	Description	Who Do I Contact?	Lead Time
Procedures to discuss with your medical team	<p>This document doesn't suggest if or when to get medical procedures, but we want to list some things to discuss with your medical team.</p> <ul style="list-style-type: none"> Feeding Tube 	Medical Team	
Install your banked voice on your text to speech device	If you banked your voice using ModelTalker or some other speech-to-text software, now is the time to install it and to start using it.	N/A	

Things To Do If You Have Trouble Breathing

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When your progression starts affecting your breathing, you will need ventilation to help you breathe. Below are some actions you should consider taking.

Action To Take	Description	Who Do I Contact?	Lead Time
Procedures to discuss with your medical team	<p>This document doesn't suggest if or when to get medical procedures, but we want to list some things to discuss with your Medical Team.</p> <ul style="list-style-type: none">• Non-invasive ventilation (mask)• Cough assist• Tracheostomy and invasive ventilation	<p>Medical team</p> <p>See Equipment List</p>	
In-home nursing care	<p>When your breathing numbers drop below a certain point, you will need to decide if you want a tracheostomy and invasive ventilation. Post tracheostomy, you will need 24/7 care. You will then be eligible for in-home skilled nursing care. The number of hours you get varies widely between VA Medical Centers. You need to advocate for a minimum of 16 hrs a day to reduce the strain on your primary caregiver.</p>	<p>Your social worker and medical team</p>	<p>1-4 weeks post tracheostomy.</p>

What To Do To Increase Your VA Disability SMC Benefits

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As your disease progresses and more areas of your body are affected, you will become eligible for a higher rate of Special Monthly Compensation (SMC). This is unusual in that many veterans receiving SMC were injured during war time and have fairly fixed disabilities that do not progress with time. ALS is different because loss of functionality does progress. The rules about different SMC rating levels are very

complex. When you lose more functionality, review your SMC with your medical team and the PVA to determine if you qualify for higher compensation. The amount of increased monthly compensation can be very significant, so don't hesitate to apply for a higher rating as your disease progresses. Go [here to view current SMC rates and descriptions](#).

Equipment List

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This section contains a list of equipment you can receive from the VA. It is organized by type of equipment and includes recommendations (if we have any). These are common manufacturers used by the VA, but this is not an exhaustive list of all devices.

Mobility Devices

The VA will pay for a wide range of mobility devices. As your disease progresses, you will need more devices. You will probably start with a walker or rollator and then progress to a power wheelchair. Below are some of the devices you may need. Contact your VA occupational therapist (OT) in consultation with the prosthetics department at your VISN for all mobility devices. Some devices require fitting or evaluation visits to determine the correct device and configuration before ordering.

Equipment	Description	Recommendations	Lead Time
Cane	A cane can help you to maintain balance and give you stability when walking. You can contact your OT or prosthetics department for this item.	N/A	2 weeks
Walker/ rollator	A walker can help you maintain balance and stability when walking. Consider getting one with a seat, a cup holder, and a basket for storing things. A collapsible walker can be stored in a vehicle. You can contact	N/A	2 weeks

	your OT or prosthetics department for this item.		
Manual wheelchair	Used when you are struggling to walk and/or tire easily and need to rest frequently. Also used when you will have to walk long distances and need help. Also used as a stop gap while waiting for your power wheelchairs (PWC). Usually a manual wheelchair is a stop-gap until you can get a power scooter or wheelchair. You can contact your OT or prosthetics department for this item.	N/A	2-4 weeks
Scooters	Used when you are only able to walk short distances. Scooters have a smaller footprint and some can be folded to fit into the trunk of a car. Most times, however, you will need to get a vehicle lift installed on the back of your vehicle or a fully accessible vehicle to transport the scooter. Scooters have a smaller footprint than a PWC and are easier to get into and out of tight spaces. However, they are probably a stop gap at best for people living with ALS who generally move to a power wheelchair fairly quickly. Although you may not need it yet, we would recommend going straight to a wheelchair as a scooter may not be viable for long. These can take months to receive, so don't wait. You can contact your OT or prosthetics department for this item.	Golden Technologies Pride Mobility Drive Medical	2-4 months
Power wheelchairs (PWC)	Used when you are unable to walk or need the extra support and flexibility of a full chair. Gives you independence because you are not	Permobil Quantum Rehab Pride Mobility	2-4 months

	<p>dependent on others to push you in a manual wheelchair. Usually provides more functionality (can be moved into different levels of support), more comfort and support, and more driving options. You will need to get an accessible vehicle to transport the PWC. These can take months to receive, so don't wait to order. You can contact your OT or prosthetics department for this item.</p> <p>Here are some features to consider:</p> <p>Turning radius - How tight a chair can turn is usually a matter of how the wheels are configured</p> <p>Comfort and support of the seat - The standard seat may not be the best one for you. ROHO seats cushion and support you with inflatable/deflatable air fingers.</p> <p>Standing features - Some chair models can be configured to allow a person to stand vertically and support them if they can't bear weight on their legs.</p> <p>Speed - Standard speed for a PWC is around 5 mph. However, some can be configured to go as fast as 7-8 mph.</p> <p>Lateral supports - If you need extra lateral supports, you might consider a chair back that is molded to provide extra lateral support. Many chairs also can add lateral supports later.</p>		
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	<p>Head support - If head support is important, consider the ability of the chair to have extra head support beyond the headrest.</p> <p>Alternate drive systems - If you are losing the use of your arms and hands, you may not be able to use the standard drive joystick configuration. In this case, make sure that the chair can be configured with alternative drive systems such as eye drive, chin controls, etc. Also consider chairs that allow attendant controls so that your caregiver can drive the chair for you. Attendant controls work best when the caregiver controls the chair from behind.</p> <p>Expandability and Add-ons - Most top of the line have this built-in, but make sure you can add things to your wheelchair like cupholders, inverters to power your computer, USB ports, cell phone holders, storage, etc.. You may get to the point where you might need to bring your ventilator or other equipment with you, so make sure that the chair can be expanded to allow these devices to be attached.</p> <p>The VA will generally replace an old wheelchair every 5 years, but you can get a new one before that if you can make the case that your progression requires the features only found in a new chair.</p>		
AFO	If you suffer from foot drop or other ankle or foot weaknesses that make	N/A	

	<p>it difficult to bear weight or are causing pain or deformity, an ankle foot orthosis (AFO) device can make it easier to bear weight and keep the ankle and feet in a proper configuration. An AFO is designed to provide additional support for your feet, ankles, and lower leg. It can help you bear weight and continue standing. Getting fitted for an AFO can be requested through your OT or prosthetics department, and lead time is about 2-4 weeks.</p>		
Recreational mobility	<p>If you wish to enjoy the beach or a pool, but are unable to keep yourself above water, the VA may purchase a floating wheelchair so that you can safely enjoy the water.</p> <p>Get a wheelchair that allows the user to recline and elevate their legs, balloon wheels so it can go on sand and contains a floatation system so it can go into the water and float.</p> <p>You will most likely have to fight a bit for this with your OT. Arguments can be the therapeutic value of being in the water, equity in access to the water, etc.</p>	Water Wheels	

Adaptive Transportation

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The VA will pay for an adapted vehicle to transport you when you are in your wheelchair via the Vehicle Grant. The VA will only purchase a vehicle once, but they will pay for the conversion of a new vehicle approximately every 2 years. Many times you can trade in your current accessible vehicle for a new one every two years for

minimal out of pocket expenses. There are dealers nationwide who specialize in working with the VA in this regard. If you can still use your arms and hands, the vehicle can be fitted with hand controls and so you can continue driving yourself. If you cannot use your hands and arms, it can be configured so you ride in the passenger seat. Below are some of the vehicles you can request. Contact your VA occupational therapist (OT) in consultation with the prosthetics department at your VISN for all vehicles. They can give you a list of local dealers who will guide you through the process.

Equipment	Description	Recommendations
Adaptive van	An adaptive van is a van that has been modified to allow a wheelchair to be loaded into the van in either a passenger or driver configuration. Generally, loading is done from the side door, but you can get configurations where the chair is loaded through the back. A row of seating is lost to give the wheelchair room to maneuver. It is easiest for a disabled driver to navigate into and secure themselves. Since a power wheelchair is most likely in your future, it would be smart to start the process of finding an accessible vehicle by accessing the Vehicle Grant. You can find more information from your OT or prosthetics department, and lead time is about 2-4 months.	BraunAbility
Truck or SUV	All-terrain conversions (ATC) take a different approach. They modify SUVs and Trucks and install a gull-wing door and a platform lift on either the driver or passenger side. The main benefit of an ATC conversion is that you retain all the conventional seating. You lose a row of seating with a van.	ATC Conversions
Vehicle lift	A vehicle lift is used when a person can still walk short distances, but they still need to transport a scooter or a wheelchair to use at their destination. Vehicle lifts are uncommon for people living with ALS because of the progression of the disease.	Bruno Harmar

Hospital Beds

The VA will pay for a hospital bed if you need the extra support and are unable to roll over or adjust yourself in bed. The VA will want you to try a standard medical bed at first, maybe with an air mattress with oscillating inflation and deflation to simulate side to side moving. In our experience, these beds are not adequate for the needs of people living with ALS. You will need to advocate for a recommended bed because they are more expensive than standard beds. Below are some of the beds you can request. Contact your VA occupational therapist (OT) in consultation with the prosthetics department at your VISN for all beds.

Equipment	Description	Recommendations
Advanced hospital bed	<p>You should request a hospital bed that can roll a person from side to side throughout the night. This has multiple benefits. It saves your caregiver from getting up multiple times a night to adjust you, it reduces the danger of pressure sores and it reduces the danger of pneumonia. An advanced hospital bed has all the functionality of a standard hospital bed such as raising the bed vertically and raising the head and legs.</p> <p>Many veterans struggle with this step because it means you are no longer sleeping in the same bed with your spouse, but the risks are too great not to consider this step. Do not accept a low-end hospital bed. They are uncomfortable and not adequate for ALS. You can learn more from your OT or prosthetics department. Lead time is 2-4 weeks.</p>	<p>ProBed Hill Rom</p>

Compression Devices

Many times, your legs and arms and hands can develop edema (excess fluid in an area of the body) and swelling from lack of support and movement. Much of this can be avoided by keeping your legs and arms elevated, but this isn't always possible. The VA will pay for devices that will help manage edema and swelling.

Equipment	Description	Recommendations
Pump driven compression sleeves	Pump driven compression sleeves - These are very effective in reducing swelling. They consist of leg and arm length sleeves that connect to an electric pump and can be programmed to apply specific amounts of pressure and for specific amounts of time. These devices generally oscillate by applying pressure and then relieving to massage your limbs.	BioTAB Healthcare

Bathing and Toilet Aids

The VA will pay for equipment that will help you to use the toilet or shower, including when you need help to perform these functions.

Equipment	Description	Recommendations
Simple shower chair	If you can still transfer and bathe yourself, but find it hard to stand for the entire shower, these chairs allow you to remain seated while you bathe yourself. They are generally very light weight and can be easily moved in and out of the shower if necessary. They usually don't have wheels and are not mobile.	N/A
Advanced shower chair	If you cannot transfer and/or bathe yourself and require help for bathing and/or toilet activities, a rolling and reclining shower chair is recommended. These chairs generally have much more comfortable seating and leg support. Most also come with the ability to insert and remove a bedpan bucket if you need assistance with the toilet and cannot transfer. You can request one from your OT or prosthetics department. The lead time is about 2-4 weeks.	RAZ Design

Grab bars and handles	Grab bars and handles to increase stability while in the shower or tub	N/A
Toilet modifications	The VA will generally install raised toilets if needed so people don't have to sit down as far as a normal toilet. These are generally only useful for people who can still transfer and handle toilet activities themselves.	N/A

Transfer Devices

Transfer devices are generally people lifts. A lift is an assistive device that helps safely move a person from one area to another. Generally, this is from bed to a power wheelchair or shower chair but can also be to a sofa or chair.

Equipment	Description	Recommendations
Floor lifts	<p>A floor lift is a lift that can be moved to a person and used to lift, move, and then lower a person to a new location. There are various types of floor lifts.</p> <p>Hoyer lift with a sling - These devices consist of a lift that attaches to a sling that you place around the person. These lifts generally have wheels and can be moved to various places in the house. There are also portable Hoyer lifts that can be taken with you if you travel. A portable Hoyer lift allows your caregivers to safely lift a person in and out of bed and in and out of their wheelchair.</p> <p>Sure-hands lift - This device is generally for people who still have some core strength, particularly in their waist and shoulders. These lifts do not use a sling and are generally quicker and easier to use than a Hoyer and sling. They can also be used by the person living with ALS independently if</p>	<p>MoLift Sure Hands</p>

	they retain strength in their hands and arms. The VA is able to get you this item. Learn more from your OT or prosthetics department. Lead time is about 2-4 weeks.	
Ceiling lifts	A ceiling lift is a lift that is installed on your ceiling and goes from set points in your bedroom, or other specific points in your house. These lifts save space in your room taken up by a portable lift. Transfer usually takes place in a sling, but a sure-hands ceiling lift is available also. The limitations to these lifts are that the ceiling must be able to handle the weight and the ceiling where the tracks go must be level without obstructions to the tracks. The VA is able to get you this item. Learn more from your OT or prosthetics department. Lead time is about 2-4 weeks.	Handicare Hill Rom
Vertical platform lifts (VPL)	Vertical platform lifts (VPL) are used when the structure's entry height is too high for a reasonable length of ramp or where the area around the entry doesn't provide adequate space to deploy a ramp system. VPLs are like wheelchair elevators. They consist of an enclosed platform where the people using mobility devices can safely sit while the lift is in operation. VPLs can be installed in a garage or outside for access to a deck or elevated patio. The VA will only provide a VPL to gain access to a structure, not to an outside deck or patio that doesn't allow access to a structure.	Bruno Harmar
Threshold ramps	Threshold ramps are used at the thresholds of entrances to structures when the incline is less than 4 inches. They are usually rubber material and can be connected together as needed for the appropriate height.	EZ-Access
Modular ramps	Modular ramps are used when the entry point to the house is higher than 6 inches	EZ-Access

	and there is adequate space to install a ramp system. They consist of stainless steel ramps with handrails. Usually, there is at least one level platform that the ramps connect to - typically at the entrance to the structure. They are all-weather. They are set up to have one foot of ramp for every inch of elevation. So, if you have a 12-inch step to get into a structure, you will need to have 12 feet of ramp, plus a 5ft x 5ft platform at the entry to the structure.	
Transfer boards	Allows a person to slide on a board between two chairs. Usually used when moving into the shower or tub.	N/A
Transfer sheets	Used when dressing or undressing a person in bed. Allows for easy sliding movement when moving a person from side to side and is easy to remove from underneath the person when finished.	N/A
Transfer/lift belts	Used by a caregiver to help maintain a person's stability when they are transferring them between two areas. They are usually used when moving a person from bed to chair or chair to toilet. This device is only useful when a person is still mobile, but lacks stability.	N/A

Respiratory

The VA will pay for devices that will assist in breathing and swallowing. Contact your primary care doctor to get a referral to the pulmonology department. You will have a breathing and swallowing evaluation. Equipment and supplies are generally contracted out to a local company.

Equipment	Description	Recommendations
Non-invasive BIPAP/ventilator	A ventilation device used with a nose or full face mask for breathing assistance. Most people living with ALS begin using ventilation	Trilogy Astral VOCSN

	<p>at night and then as they progress use it all the time.</p> <p>Non-invasive ventilation is pre-tracheostomy.</p> <p>Generally, when your Forced Vital Capacity (FVC) numbers start dropping below 60, a BIPAP or ventilator is needed, but consult your neurologist about appropriate timing. This is something to discuss with your medical team.</p>	
Invasive ventilators	<p>If you decide to get a tracheostomy, you may need a ventilator 24 hours a day. This is a more invasive process where the ventilation hooks to a tube in the trachea. This procedure is usually considered when your FVC drops into the 30's. Consult your neurologist about appropriate timing.</p> <p>Post tracheostomy, you will need 24/7 care. You will then be eligible for in-home skilled nursing care. The number of hours you can get varies widely between VA Medical Centers. You need to advocate for a minimum of 16 hrs a day to reduce the strain on your primary caregiver. You can learn more from your social worker or medical team. Typically, this type of equipment becomes accessible 1-4 weeks following a tracheostomy.</p>	Trilogy Astral VOCSN
Cough assist device	<p>A cough assist device is used to help clear mucus from the lungs and assists in the coughing process. It can also be used for breathing exercises.</p>	Phillips
Suction device	<p>Used to suction mucus and saliva from the mouth and throat</p>	N/A
Percussion vest	<p>Used to break up mucus and fluid in the lungs</p>	N/A

Computer Technology

The VA will pay for computers that will allow you to use your eyes to control functionality - once your arms and hands are no longer functional.

Equipment	Description	Recommendations
Eye-gaze enabled computer	<p>Computers that can be controlled using eye movements.</p> <p>The VA will pay for a computer that will allow you to use your eyes to control functionality - once you begin losing functionality. Get your eye gaze equipment before you need it so you can practice in a low stress environment. Don't be afraid to try new technology! It can open up a whole world for you. Be patient with yourself. You can do it. You can learn more about this from your speech therapist, OT, or prosthetics department. Lead time is about 2-4 weeks.</p>	<p>Tobii Dynavox EyeGaze EyeSpeak</p>
Eye-drive technology	<p>Once you are using a power wheelchair you can use your eye gaze enabled computer to control your wheelchair. This is called eye-drive technology.</p> <p>You can learn more about this from your OT or prosthetics department. Lead time is about 2-4 weeks.</p>	<p>AbilityDrive</p>

Augmented Communication Devices

The VA will pay for devices to help you communicate when your voice has degraded to the point where you aren't able to communicate effectively without assistance.

Equipment	Description	Recommendations
Speech generation device	Smartphones and tablets have apps that will speak what you type. A high-end device such as a Tobii-Dynavox can be controlled by typing with your fingers or eyes.	N/A
Speech board	A board that allows the veteran to use their eyes to spell out words. Slow, but workable.	N/A
Erasable writing pad	An erasable writing pad is used by veterans who have lost their voices, but can still use their hands to write.	N/A

Feeding

The VA will pay for devices that will help you feed yourself when your arms and hands have declined to the point where you have limited or no functional use.

Equipment	Description	Recommendations
Obi robotic feeder	This is a robotic system that allows a veteran with minimal arm and hand functionality to control the pace at which they are fed. It works best for soft foods. It consists of four "bowls" and a robotic arm with a spoon attached. The veteran can control the use with a small pad that activates the device.	Obi
Adaptive cups	Cups that are easier for someone with reduced arm and hand function to use.	N/A
Adaptive silverware	Silverware that is easier for someone with reduced arm and hand function to use.	N/A

Other Resources

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Here are some other resources that will help you in your ALS journey:

- [Thinking Through VA Benefits and VA Care: A Resource for Veterans with ALS & Their Caregivers](#). This is a must read! Written by Mary Hahn Ward and Lara Garey, it contains a ton of excellent information on how to navigate the VA.
- [ALS Untangled](#) is a website that reviews off-label and alternative treatments.
- [ALS from Both Sides](#). A website from a neurology nurse living with ALS.
- [Kinda Ugly](#). This is a personal story of one man's journey with ALS.
- [ALS Guide for PALS and CALS](#). This is a book written by Sarah Rozenzweig and contains many tips and helpful suggestions for people living with ALS and caregivers.