



Tips for Military Veterans, Families and Survivors Fighting ALS



The ALS Association wants to make sure that every veteran is given the tools that they need to fight back in the war against ALS. This disease has taken too many of our heroes' lives.

A 2007 study concluded that people who have served in the military are at a greater risk of developing ALS and dying from the disease than the general public. ALS can attack all veterans - regardless of the branch of service, regardless of where they were stationed, regardless of whether they served in the Persian Gulf War, Vietnam, Korea, or World War II, and regardless of whether they served during a time of peace or a time of war.

The ALS Association, key members of congress and the Department of Veterans Affairs have worked together to make important progress in expanding benefits for veterans and advancing the search for a treatment with increased Department of Defense dollars for ALS specific research - BUT more must be done!

We need to learn why our heroes are at greater risk and take action to protect them. We need to educate the veteran's medical community so that veterans receive the care and benefits they deserve and have earned. And we need to find a treatment! The ALS Association will continue to advocate for our military heroes each and every day until we can solve these pieces of the ALS puzzle.

As of September 23, 2008, ALS was listed as a disease entitled to presumptive service connection. This means that if a veteran is diagnosed with ALS his or her condition will be presumed to have occurred during or been aggravated by military service and as such be entitled to service connection and full benefits. **All veterans with ALS automatically will be eligible for benefits; no matter when or where they served and no matter how soon after discharge they were diagnosed. You must have served on Active Duty for a minimum of 90 days and discharged under Honorable conditions.**

These regulations provide veterans diagnosed with ALS and their survivors' access to benefits that will help maximize their functional capabilities, preserve their dignity, and increase their quality of life. It will provide support after the veteran's journey with ALS is over.

These benefits include but are not limited to:

- Monthly monetary disability compensation
- Medical care, DME, and adaptive devices
- Adaptive housing and vehicle grants
- Aide and attendant home care assistance
- Death and burial compensation
- Survivors benefits

Please join our roll of call of veterans at <http://capwiz.com/alsa/mlm/signup/>. We want to make sure every veteran counts and that the nation has a true representation of how ALS affects military families.

Your ALSA case manager can work closely with you to ensure that you receive benefits, medical care and outline program benefits for those left behind.

As you read forward you will see that the PVA and the VA will be your primary contacts. However, your ALSA case manager can make recommendations for in home devices, and assistance to help expedite your care and the care of your loved ones.

Together we can make a difference.

What You Need To Apply For Benefits

- DD214 Discharge orders
- If married- marriage license
- If you are a surviving spouse- a copy of the veteran's death certificate that lists ALS as the cause of death

The veteran's administration will ask for the original of the above documents. These documents will be returned once your claim has been processed.

Who Can Help You With Enrollment Benefits?

Assistance From The Paralyzed Veterans Of America (PVA)

The ALS Association advises that veterans with ALS should contact their local PVA organization office once a diagnosis has been made for assistance in obtaining benefits. At any time, should you have difficulty, please contact the PVA – they will be your best advocate within the VA system.

PVA, National Service Office
Fred Bradley, Senior Benefits Advocate
400 South 18th Street
St. Louis, MO 63103
314-552-9887 or 1-800-795-3614

Rodney Harris, Senior National Service Officer
314-894-6467 or 866-328-2670
VA Medical Center 128/JB, Bldg. 52, Room 2 South 25
#1 Jefferson Barracks Drive
St. Louis, MO 63125

Mr. Bradley and Mr. Harris are advocates for all veterans, especially those with ALS. The St. Louis branch of the PVA is the preferred contact person for all veterans diagnosed with ALS in the chapter's entire service area. If they cannot directly serve you, they will refer you to the proper person. In 2009, Mr. Bradley was awarded the St. Louis Regional Chapter's Advocate of the Year Award.

Medical Care

To find the nearest VA Medical Center near you: www.va.gov or call the chapter office for a listing of VA Hospitals/Clinics within the service area.

Most Veterans will treat directly at a VA medical center. However, you can treat at a certified ALS multi-disciplinary clinic locally and still receive benefits. You must be seen at the VA once a year for medical benefits to continue.

Make sure your treating neurologist works directly with a primary care physician at the VA so that benefits continue. It is important that all supporting documentation is provided for disability ratings, prescriptions for medicine, equipment and home care be completed correctly.

The requirement to provide income & net worth information does not apply if a veteran has an adjudicated service connected, which applies to ALS patients.

For ALS patients, unless they have low income or are in urgent need of medicine, supplies, prosthetics, it is generally best to wait until they have been adjudicated as service connected for ALS. This process can take up to 3 weeks.

Primary Care Physician (PCP)

Once a patient is enrolled, a Primary Care Provider is assigned either at the clinic or a VA Medical Center. The PCP would be responsible for ordering medications, submitting requests to Prosthetics for supplies, durable medical equipment, oxygen, etc.

If a private doctor writes a script for anything, it must be given to the PCP to have it re-written. The PCP is not obligated to prescribe what the private doctor wrote out, especially if the veteran is not actually treated by the VA doctor. However, most PCPs will consider the needs of the ALS patient and the recommendations of the treating team.

The SLU ALS Certified Center has a contract with the VA to expedite orders.

The PCP is ultimately responsible for all in home needs. DO NOT HESITATE TO ASK FOR WHAT YOU FEEL YOU NEED AND DESERVE!

Medical Expenses

The VA should cover all the medical expenses related to care of veterans with ALS. This includes in home therapy, medication, medical equipment, and all services. If you are being treated at the VA your copay will be exempt since you are awarded 100% on the initial claim for ALS.

If bills are received or are denied, send a copy of them to:

VA Medical Center, 1 Jefferson Barracks

Attn: Feebase 04 @ Jefferson Barracks

Fax: 314-845-5018

Phone: 314-894-6600.

Disability Rating System

All veterans' with ALS are rated at a 100% disability rate automatically once the claim for service connection has been processed. This does not consider how the illness impacts your life. The more specific you are how the illness impacts your life, the higher the rating will be and benefit eligibility will increase. This disability rating should be performed at each significant progression of the illness. The veteran or caregiver

should notify PVA whenever there is a significant change in the patient's condition. The veteran can receive payments at much higher rates than 100% when loss of use of extremities, speech, PEG tube, ventilator etc are involved. VA will not automatically review them to see if an increase is warranted. The veteran or PVA service officer must initiate the claim.

Disability Compensation

Included in your package of benefits, will be a monthly monetary stipend. Disability compensation is a monetary benefit paid to veterans who are disabled by an injury or disease that was incurred or aggravated during active military service. These disabilities, including ALS, are considered to be service-connected. Disability compensation varies with the degree of disability and the number of veteran's dependents, and is paid monthly. Veterans with certain severe disabilities may be eligible for additional special monthly compensation. The benefits are not subject to federal or state income tax. Tables listing current compensation levels are available at: <http://www.vba.va.gov/bln/21/Rates/>.

Durable Medical Equipment & Adaptive Devices

The prosthetics department within the VA is assigned to ordering and approving all adaptive equipment and special devices, including automobiles, wheelchairs, and adaptive devices within the home - with an order from the PCP.

It is advised to discuss your in home needs with your ALSA case manager and obtain DME from the VA whenever possible. A copy of the chapter's loan closet and recommendations for adaptive devices is available on the website.

The VA and the chapter have worked together to educate local providers on the needs of patients so that veterans get the best care possible.

It is recommended that all veterans with ALS receive a PERMOBIL wheelchair. The VA has a contract directly with Permobil and an evaluation will be completed at the VA center that you are treated at.

Do not purchase a van prior to obtaining the type of wheelchair that will be provided for you. Tie down systems, entry way, and head space must be considered and adapted if necessary.

What To Do When You Need Equipment: You need to get an order/prescription from your PCP or private doctor & contact the Prosthetics Dept at the VA Medical Center. You will need to provide Prosthetics a copy of VA award letter to confirm you are service connected for ALS.

In Home Services

Your PCP will be responsible for ordering of all services to be delivered in your home including: therapies, home care, and hospice.

Therapies: In home therapy is recommended at each significant progression point of the illness.

Home Care: There are three main in home care programs provided for service connected Veterans

- **Aide and Attendance:** A veteran who is determined by VA to be in need of the regular aid and attendance (care) of another person, or a veteran who is permanently housebound, may be entitled to additional disability compensation or pension payments. A veteran evaluated at 30 percent or more disabled is entitled to receive an additional payment for a spouse. Veterans with ALS are granted 100% on the initial claim.

Criteria for determining need for aid and attendance and "permanently bedridden." - A broad, general terms, the need for aid & attendance is met when a patient needs assistance with some or all activities of daily living such as feeding, bathing, dressing, transferring in/out of wheelchair, unable to protect themselves from the hazards of daily living, permanently bed-ridden. Not all of the conditions need to be met to qualify.

Aide and Attendance: is a monetary benefit paid to you - to pay a provider of your choice.

- **Community Health:** Non skilled services, 5-7 days a week no more than 2 hours per day, usually 3 days a week. Services including light housekeeping, cooking, etc.
- **Respite Program-** 180 hours a year used in 6 hour increments. If it is at home, the VA Medical Center would pick the agency. Respite care can be provided in a VA Medical Center. Normally, it is for a 7 day period and must be scheduled in advance. This should be done through a VA social worker. Exceptions are if the care-giver has a medical need or medical emergency, natural disaster where the home may not be safe, damage from fire, etc. The criteria for Respite Care means the person needs to be in an environment than can care for his/her medical needs.

Hospice: in home, facility, and a hospice house are the options for veterans with the chapter's service area.

Home Modification Grant Program

VA has three main grant programs to assist disabled veterans with necessary home modifications.

- **Specialty Adapted Housing Grant:** Veterans who have specific service-connected disabilities may be entitled to a grant for the purpose of constructing an adapted home or modifying an existing home to meet their adaptive needs. The goal of the Specially Adapted Housing (SAH) Grant Program is to provide a barrier-free living environment which affords the veteran a level of independent living that he or she may not have otherwise enjoyed. The SAH grant is generally used to create a wheelchair accessible home.
- **Special Home Adaptation Grant:** Veterans who have specific service-connected disabilities may be entitled to a grant for the purpose of modifying an existing home to meet their adaptive needs. In the case of ALS, loss of use of hands is required. The Special Home Adaptations (SHA) grant is generally used to assist veterans with mobility throughout their homes. This grant is currently limited to \$13,511.00 effective October 1, 2013.
- **Home Improvements and Structural Alterations Grant:** Under the Home Improvements and Structural Alterations (HISA) program, veterans with service-connected disabilities or veterans with non-service connected disabilities may receive assistance for any home improvement necessary for the continuation of treatment or for disability access to the home and essential lavatory and sanitary facilities. A HISA grant is available to veterans who have received a medical determination indicating that improvements and structural alterations are necessary or appropriate for the effective and economical treatment of his/her disability. A veteran may receive both a HISA grant and either a SHA or SAH grant. Home improvement benefits up to \$6,800.00 for service-connected veterans.

In order to apply, the Veteran must send VA Form 26-4555, Veterans Application in Acquiring Specially Adapted Housing or Special Home Adaptation Grant to the VA Regional Office in the state you reside or to your Paralyzed Veterans of America National Service Officer for them to submit. It should be sent to the PVA Service Office in the state the veteran resides. They can submit it which helps prevent it getting lost. If PVA is not their representative, they can send it to the VA Regional Office in their state ATTN: Special Adapted Housing Coordinator. However, there is a risk that it may not arrive to the coordinator.

Home Improvement Structural Alteration Grant: You should request your VA Primary Care Physician to submit the request to Prosthetics and what modifications you want to make. Prosthetics will require 3 contract bids, and a home visit for approval.

It is not uncommon for the 1st application to be denied. They should tell you why it is denied and what is needed to get it approved. It is usually something lacking in the bids that needs to be clarified. If it is denied for something like a lack of medical need, then that would need to be addressed by a VA physician or they can call a PVA service officer for guidance.

Automobile Grant Program

Financial assistance is available to purchase a new or used automobile (or other conveyance) to accommodate a disability for a veteran with ALS. The veteran may only receive the automobile grant once in his/her lifetime. The grant is paid directly to the seller of the automobile. The amount of the grant is \$19,817.00 effective October 1, 2013. The van must be co-titled in the veteran's name at time of purchase.

Those qualified for the automobile grant may also qualify for the adaptive equipment grant. Adaptive equipment includes, but is not limited to, power steering, power brakes, power windows, power seats, and special equipment necessary to assist the eligible person into and out of the vehicle.

Contact should be made with the Prosthetic Department prior to purchasing any equipment. You will need a prescription from your PCP for application.

The adaptive equipment grant may be paid more than once, and it may be paid to either the seller or the veteran directly.

How Can I Apply for an Automobile and/or Special Adaptive Equipment Grant?

Complete VA Form 21-4502, Application for Automobile or Other Conveyance and Adaptive Equipment. The instructions on the VA Form 21-4502 contain a list of adaptive equipment that has been pre-approved for particular disabilities.

Clothing Allowance Program: Any veteran who is service-connected for a compensable disability for which he or she uses prosthetic or orthopedic appliances may receive an annual clothing allowance. In order to apply a VA Form 10-8678 needs to be submitted and sent to Prosthetic that issued the equipment or to Prosthetics nearest the VA facility where they receive care. An example would be a veteran who lives in north Arkansas and uses the VA Medical Center Poplar Bluff, MO. It should go to Prosthetics at Poplar Bluff.

Independent Living Program Benefit

A program through the Department of Vocational Rehabilitation can supplement the VA care and provide an alternative resource for service connected veterans. This can provide a resource for recreational aids, adaptive devices, and unusual requests.

Criteria that needs to be met to utilize the program:

- * At least rated 20% disability rating for VA Voc Rehab. It is not likely a veteran with ALS will be approved for Voc Rehab.

- * Apply for the HISA grant - Medical need must exist. Usually, use of a wheelchair is required, or loss of use of hands when speaking about ALS.

- * Apply for the Home Modifications grant – A recent change in law now allows VA to grant entitlement to Special Adapted Housing/Special Home Adaptation grant on the initial claim for ALS. VA will no longer require loss of use of the feet, hand and foot or both hands on ALS cases.

How To Apply:

Complete Form 1900 under the Voc Rehab section at www.va.gov and ask your ALSA case manager for contact information of the counselor at the Voc Rehab.

Death and Burial Benefit Programs

VA will pay up to \$2,000 toward burial expenses for deaths. If the veteran is buried in a VA national cemetery, some or all of the cost of transporting the deceased may be reimbursed, and \$300 for plot assistance.

How Can You Apply?

You can apply by filling out VA Form 21-530, *Application for Burial Benefits*. You should attach a copy of the veteran's military discharge document (DD 214 or equivalent), death certificate, funeral and burial bills. They should show that you have paid them in full. You may download the form at <http://www.va.gov/vaforms/>

Surviving Spouse and Dependant Benefits Programs

Contact you local PVA Rep to set up a meeting to complete all necessary paperwork and to overview all eligible benefits. The PVA can track and assist the claim for expedition.

The law for service connection of Amyotrophic Lateral Sclerosis (ALS) became effective September 23, 2008. Therefore, if a veteran passed away from ALS before September 23 2008, the effective date is September 23, 2008. Otherwise, when a surviving spouse submits a claim within one year of veteran's death; the claim will be effective the date of death. If the claim is submitted after the one year period of date of death, the claim will be effective the date of claim.

Death and Indemnity Compensation (DIC) – The DIC benefit is a monthly monetary award that is paid the first of every month for the previous month of benefit. Currently that amount is \$1215.00 for a survivor without children effective December 1, 2012.

Insurance benefits for your dependents

Survivors' & Dependents' Educational Assistance

45 months of educational cost paid in a state approved school. Spouses and surviving spouses have 10 years from the date VA establishes eligibility to use the benefit. Children must be between the ages of 18-26. There are many other programs that veterans may have taken advantage of or may be eligible for. Please check with your PVA on all eligibility programs. PVA has their own Voc Rehab program to help veterans and their dependents find work. It is called PAVE.

Monetary awards disclosed in this document were accurate at the time of writing of November 1, 2013. These amounts vary year to year. Please verify it with the PVA rep at the time of program application.

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