

FOR VETERANS WITH ALS

Disclaimer: This information is a guide to help you make decisions about your care and benefits. Benefits change as often as Congresses, so the information here is not flawless; it should be used as a guide.

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SECTION ONE: INTRODUCTION TO THE VA

1. OVERVIEW FOR VETERANS

The Department of Veterans Affairs is a cabinet-level department of a quarter million employees in hundreds of facilities throughout the United States, answering directly to the President. It is not a military service. Its mission is to fulfill President Lincoln's promise "to care for him who shall have borne the battle, and for his widow, and his orphan" by serving and honoring the men and women who are America's veterans.

VA can provide ALS veterans with all your healthcare, excellent compensation, modifications to your home and vehicle, burial and survivor benefits. First, you need to apply.

If your non-VA neurologist diagnosed you, ask for a letter stating your diagnosis. You'll need this to claim your benefits. It may be helpful to ask your doctor to fill out the VA's Disability Benefits Questionnaire (DBQ) form 21-0960C-2 found at [this list of DBQ's](#).

As a minimum, you should get a copy of your interpreted EMG results and send those to the VA along with your letter of diagnosis. If you're new to VA, send your DD-214 as well.

As your ALS progresses, you'll become eligible for increased amounts of Special Monthly Compensation (SMC) as you lose the use of one limb, then two, then more. Also, you'll become eligible for compensation to pay for your Aid and Attendance. Eventually you'll be eligible for Housebound compensation.

VA also pays for hospice in the community or at home. They will also reimburse up to \$2000 of your funeral expenses and provide a burial plot and marker. Your dependents can apply for lifetime Dependency Indemnity Compensation, government health insurance, and Dependents Education Assistance. There are more benefits. Read on.

2. GETTING STARTED WITH THE DEPARTMENT OF VETERANS AFFAIRS

Military veterans tend to get ALS more than civilians. For this reason, the government has decided to consider ALS as a "presumptive" condition for veterans with 90 days or more of continuously active service in the military. Unless your ALS has a clear non-service-connected cause (such as a family inherited genetic mutation), your ALS will be "presumed" to be 100 percent service connected.

Any veteran with ALS should apply for Disability Compensation and VA health care. Call the VA at 1-800-827-1000. (ALS cases are fast-tracked).

On your first visit to your local VA Medical Center, see the Eligibility Office to register for health benefits, see the Paralyzed Veterans of America office to get help filing your paperwork, and visit your State Veterans Affairs Office for additional benefits available to families and survivors of P&T veterans.

Speak to the Paralyzed Veterans of America at 1-866-734-0857. They are very well informed on VA issues for ALS. Many veterans use the PVA rep as their Veteran Service Organization, a convenient interface with the VA. They can help you apply for benefits. These benefits and compensation moneys are all tax free and are not subject to income limits.

3. SOCIAL SECURITY EFFECTS

VA compensation does not affect your Social Security benefits. You should apply for those as well. (Additionally, the SS office will give you Medicare A [hospital benefits] free of charge, and will offer

you Medicare B [medical benefits not hospital] at about \$100 monthly. Call Social Security at 1-800-772-1213. There is no waiting period for Medicare benefits; you get MC as soon as you receive SS, typically four months after applying.

4. ELIGIBILITY

Military veterans diagnosed with ALS who have served at least 90 continuous days active duty and discharged other than dishonorably will be considered service connected for ALS. This is the case regardless of when or where a veteran served in the military and regardless of the length of time between discharge from the military and a diagnosis of ALS.

Service connection opens many benefits to veterans. As a quick summary, service connection allows a veteran to receive compensation for disability, as well as grants for housing and/or vehicle modifications and much more. A veteran's spouse and dependents also may be eligible for benefits.

Service connection also qualifies a veteran for enrollment in the VA health care system, which provides coverage for medications, equipment and other health services. Medications such as Rilutek and equipment such as power wheelchairs that are directly related to a service connected condition like ALS are covered in full.

5. P & T VETERANS (Remember that abbreviation)

Once the VA determines that you are Permanently and Totally (P&T) disabled and the reason is 100 percent Service Connected, you'll receive a big thick envelope with the award letter. This rating letter is important, because although health care is provided to veterans diagnosed with ALS, the most expensive benefits are only available to veterans rated 100 percent service connected. It may take several months to be approved, but benefits are retroactive to the date of application, so don't delay.

6. BARS TO BENEFITS

Eligibility for most VA benefits is based upon discharge from active military service under other than dishonorable conditions. Dishonorable and bad conduct discharges issued by general courts-martial may bar VA benefits. Veterans in prison and parolees must contact a VA regional office to determine eligibility. VA benefits will not be provided to any veteran or dependent wanted for an outstanding felony warrant.

7. APPLYING FOR BENEFITS

You'll need the applications listed below, plus your DD-214 (discharge paper). If you don't have a DD-214, request one [from the Archives](#) or by calling 1-314-801-0800.

You can apply by yourself, but it is highly recommended that you apply through your Veteran Service Organization, such as the PVA. They understand your benefits very well and have contacts in the right places at the VA Regional Office. Contacts for the PVA are found [at this page](#).

Online applications are available for [healthcare](#) and [service connection](#).

SECTION TWO: BENEFITS and COMPENSATION

8. LIFE INSURANCE FOR SERVICE-DISABLED VETERANS

Service-Disabled Veterans Insurance (S-DVI) is a life insurance benefit for Veterans who have service-connected disabilities who are otherwise in good health. S-DVI is available in a variety of permanent plans as well as term insurance. S-DVI policies are issued for a maximum face amount of \$10,000. To obtain S-DVI, you must meet ALL of the following criteria:

- you were discharged from service after April 25, 1951 under other than dishonorable conditions, AND
- VA granted service connection for any disability (even if evaluated at zero percent), AND
- you applied within two years from the date VA notified you of that new service-connected disability, AND
- you are in good health, except for any service-connected conditions.

Veterans who are granted service-connection for a disability will receive VA form 29-4364, Application For Service-Disabled Veterans Life Insurance, along with their Notice of Disability Rating. You must apply within two years from the date VA notifies you that you have been granted a new service-connected disability. You may also apply for S-DVI online.

Another program exists to help increase your life insurance coverage. It's called Supplemental S-DVI. Supplemental S-DVI is additional supplemental insurance coverage if:

- you have an S-DVI policy, AND
- VA is waiving the premiums on your basic coverage due to total disability, AND
- you apply for Supplemental S-DVI within one year of being notified of the waiver, AND
- you are under 65 years of age

The insured has up to one year after being notified of his/her eligibility for waiver on the basic policy to apply. No waiver of premiums due to total disability can be granted on Supplemental S-DVI coverage.

The premium you pay for S-DVI coverage depends on your age, type of plan (term or permanent), and the amount of coverage. If you are a Veteran eligible for basic S-DVI coverage and are totally disabled, then you may apply to have your premiums waived.

To apply for Supplemental S-DVI, you must file VA Form 29-0188, Application for Supplemental Service-Disabled Veterans (RH) Life Insurance or send a letter requesting this insurance over your signature. You must apply for the coverage within one year from being notified by VA of your S-DVI premium waiver.

9. VETERANS DISABILITY COMPENSATION

Veterans with ALS are normally approved initially at the 100 percent service connected level, regardless of the actual level of physical disability. As your ALS progresses, you'll be eligible for Special Monthly Compensation.

10. SPECIAL MONTHLY COMPENSATION (SMC)

Special Monthly Compensation is a monetary compensation (paid in addition to the regular VA Disability Compensation) to a veteran who, as a result of military service, incurred the loss or loss of use of specific organs or extremities. These might include:

- loss, or loss of use, of a hand or foot
- immobility of a joint or paralysis
- inability to communicate by speech (complete organic aphonia)

VA will pay higher rates for combinations of these disabilities such as loss of use of the feet, legs, hands, and arms, in specific monetary increments, based on the particular combination of the disabilities. SMC levels range from K through T.

VA will pay SMC for being Bedridden, Housebound, or in need of the Aid and Attendance of another person. Work with your VSO or call VA at 1-800-827-1000.

11. AID & ATTENDANCE COMPENSATION

When you require the aid and attendance of another person, you may be eligible for additional monetary payment if:

- you require the aid of another person in order to perform personal functions required in everyday living, such as bathing, feeding, dressing, toileting, adjusting prosthetic devices, or protecting yourself from the hazards of your daily environment, OR
- you are bedridden, in that your disability or disabilities requires that you remain in bed, OR
- you are a patient in a nursing home due to mental or physical incapacity.

12. HOUSEBOUND COMPENSATION

This increased monthly amount may be added to your monthly amount when you are substantially confined to your immediate premises because of permanent disability. You may apply for Aid and Attendance or Housebound benefits by writing to the VA regional office where you filed a claim for pension benefits. If the regional office of jurisdiction is not known, you may file the request with any VA regional office. You should include copies of any evidence, preferably a report from an attending physician validating the need for Aid and Attendance or Housebound type care.

13. CLOTHING ALLOWANCE

Veterans who have unique clothing needs as a result of a service-related disability or injury may receive an annual supplement to their disability compensation. This includes vets whose clothes are deteriorated by use of prosthetics or a wheelchair. This allowance is worth several hundred dollars per year. Apply to your Prosthetic Department at your VAMC with VA form 10-8678. The applications are accepted all year, and the disbursement is made during September and October.

14. VEHICLE MODIFICATION GRANT

The VA will grant moneys toward the purchase of an accessible vehicle. There are prerequisites that must be met. Prior to purchasing a handicap accessible vehicle, you might want to contact your local ALS Association Chapter or the Veteran Service Organization of your choice (Paralyzed Veterans of America, American Legion, or Disabled American Veterans) to discuss your options. The modified vehicle grant is processed through the VA Driver Training Program at your VAMC.

15. STATE VEHICLE LICENSING

Many states give free or discounted vehicle licensing to disabled veterans.

16. HOME IMPROVEMENT STRUCTURE ALTERATION GRANT

HISA is a grant that, based on 100 percent Service Connection, entitles the veteran to a predetermined amount of money towards home modifications that meet the Americans with Disabilities Act to allow the veteran to live independently in the home environment. Currently the grant is quite large. Apply at your VAMC Prosthetics Department.

17. SPECIAL ADAPTIVE HOUSING GRANT

The SAH grant entitles the veteran to money to modify or build an accessible home. It's currently over ten thousand dollars. Different than the HISA grant, you must apply for SAH through your VA Regional Office.

18. DEPENDENTS EDUCATIONAL ASSISTANCE PROGRAM

Survivors' and Dependents' Educational Assistance Program (DEA) provides education and training opportunities to eligible dependents of veterans who are permanently and totally disabled due to a service-related condition, or who died while on active duty or as a result of a service related condition. These benefits may be used for degree and certificate programs, apprenticeship, and on-the-job training. If you are a spouse, you may take a correspondence course. Remedial, deficiency, and refresher courses may be approved under certain circumstances.

Entitlement: 45 months. (Maximum of 48 months if eligible for more than one benefit chapter.)

How long do you have to use up this benefit? Child: 8 years; Spouse: 10 years; Surviving Spouse: 10 years. 20 years if death while on active duty.

Use the Application for Benefits VA Form 22-5490

19. STATE EDUCATIONAL AID TO CHILDREN

Ask your state veterans affairs department (they might have an office at your VAMC) what benefits are available to various classes of veterans. Many states will give educational benefits to children of P&T veterans, 100 percent service-connected veterans, and veterans who died from service connected causes.

20. CHAMPVA HEALTH INSURANCE FOR DEPENDENTS

Upon receiving 100% service connected status, the veteran's spouse and children are eligible for consideration for healthcare insurance. (Used to be called CHAMPUS.)

21. MORTGAGE INSURANCE

Veterans' Mortgage Life Insurance (VMLI) is mortgage protection insurance that can help families of severely disabled servicemembers or veterans pay off the home mortgage in the event of their death. VMLI is only available to servicemembers and veterans with severe service-connected disabilities who:

- received the Specially Adapted Housing (SAH), AND
- have the title to the home, AND
- have a mortgage on the home

VMLI provides a significant but limited amount of mortgage life insurance and is payable only to the mortgage holder (i.e., a bank or mortgage lender), not to a beneficiary. The amount of coverage will equal the amount of the mortgage still owed, but there is a maximum limit. VMLI is decreasing term insurance which reduces as the mortgage balance declines. VMLI has no loan or cash values and does not pay dividends. Veterans must apply for VMLI before their 70th birthday.

22. BURIAL BENEFITS

Effective July 7, 2014: VA can pay, without a written application, most eligible surviving spouses basic monetary burial benefits at the maximum amount authorized in law through automated systems rather than reimbursing them for actual costs incurred. The burial allowance for a non-service-connected death is several hundred dollars, and a couple thousand for a death connected to military service, such as ALS. Keep your paid receipts. If the veteran is buried in a VA national cemetery, some or all of the cost of transporting the deceased may be reimbursed.

NOTE: VA does not pay burial benefits if the deceased:

- died during active military service, OR
- was a member of Congress who died while holding office, OR
- was a federal prisoner

Other information regarding VA burial benefits such as flags, headstones and markers is provided by the National Cemetery Administration. Find your regional office at [this link](#).

23. DEPENDENCY AND INDEMNITY COMPENSATION

DIC is a tax free monetary benefit paid to eligible survivors of military servicemembers who died in the line of duty or eligible survivors of veterans whose death resulted from a service-related injury or disease.

To qualify for DIC, a surviving spouse must meet the requirements below.

The surviving spouse was:

- married to a servicemember who died on active duty, active duty for training, or inactive duty training, OR
- validly married the veteran before January 1, 1957, OR
- married the veteran within 15 years of discharge from the period of military service in which the disease or injury that caused the veteran's death began or was aggravated, OR
- was married to the veteran for at least one year, OR
- had a child with the veteran, AND
- cohabited with the veteran continuously until the veteran's death or, if separated, was not at fault for the separation, AND
- is not currently remarried

Note: A surviving spouse who remarries on or after December 16, 2003, and on or after attaining age 57, is entitled to continue to receive DIC.

Eligibility (Surviving Child):

- not included on the surviving spouse's DIC, AND
- unmarried, AND
- under age 18, or between the ages of 18 and 23 and attending school.

To apply for DIC, complete VA Form 21-534, "Application for Dependency and Indemnity Compensation, Death Pension and Accrued Benefits by a Surviving Spouse or Child and mail to your VA regional office.

SECTION THREE: VA HEALTHCARE FOR ALS

24. SPINAL CORD INJURY AND DISORDERS CLINIC

Upon diagnosis, expect to be referred to the SCI&D clinic. SCI&D serves veterans with Spinal Cord Injuries, MS and ALS. The SCI team includes a neurologist, physiatrist, physical therapist, nurse and social worker.

25. PHARMACY DEPARTMENT

All VA prescribed medications are free of charge for 100 percent service connected veterans. You might want to ask your PCP to prescribe RILUTEK/RILUZOLE, which is reported to extend the lives of persons with ALS.

26. PROSTHETICS DEPARTMENT

At the beginning of your disease, you may need things to help you walk: an Ankle Foot Orthosis (AFO), cane, or walker. This office also administers the Home Improvement Structure Alteration grant and the Clothing Allowance program.

27. PHYSICAL THERAPY

A professional PT specialist can come to your home and train your caregiver to help you with Range Of Motion exercises to reduce the joint pain that prolonged immobility can cause.

28. OCCUPATIONAL THERAPY

OT can help address needs for bathing, feeding, dressing and toileting; wheelchairs and power wheelchairs; and the HISA home modification grant. These include shower chairs, hand held showers, portable commodes, grab bars, and a shower chair that transfers the patient over a bathtub wall.

- OT can issue manual and power wheelchairs.
- OT can assess the need for adaptive feeding equipment including built-up handled utensils, adaptive drinking devices and special plates to increase independence and safety for feeding.
- OT can assess the need for grooming and toileting aides including items to perform shaving, brushing teeth and cleaning your bottom.

29. SPEECH THERAPY

There are several devices that the Speech Therapist can consider as communication challenges arise. These include voice banking for computerized devices as well as eye gaze controlled computers and low tech items to increase communication.

30. PALLIATIVE CARE CLINIC

At some point, your PCP will coordinate your care with the Palliative Care Clinic. Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression. The team includes a physician, nurse, social worker, and chaplain. You will continue to see your primary care provider.

31. HOME BASED PRIMARY CARE PROGRAM

HBPC is for Veterans who have trouble coming to the clinic because of their health care problems. In HBPC, your main care provider is a Nurse Practitioner who sees you at your home. Other members of the team that come to your home are a nurse, social worker, mental health provider, and dietitian. Ask your PCP when you need to be set up with the HBPC program.

32. HOMEMAKER/HOME HEALTH AID PROGRAM

This program sends an aide to the home to help with bathing and dressing. The aide can also do light housework. The VA works with home care agencies in the community to offer this service.

33. COMMUNITY NURSING HOME CARE

VA pays for nursing home care for veterans who are highly service connected. Staff visit Veterans in nursing homes to make sure their needs are met.

34. ADULT DAY HEALTH CARE

Veterans who have no caretakers at home during the day might ask if the VAMC has ADHC available. The centers provide care during the day, nursing, meals and snacks, and socializing.

35. COMMUNITY HEALTH NURSE

VA Nurses arrange for Veterans who are home bound to receive nursing and therapy services from community home health agencies. Your PCP refers Veterans for this type of care.

36. RESPITE FOR CAREGIVERS

This service provides caregivers with a short-term break from the daily demands of caring for a chronically ill Veteran. Veterans may stay at a VA community living center or attend an Adult Day Health Care setting for up to 30 days per year. Space is very limited, so arrange this well in advance.

37. COMMUNITY LIVING CENTER

Vets with no family might want to live in a VA nursing home. Contact your VAMC CLC to see if they can care for you in their nursing home.

38. NON-VA EMERGENCY CARE (FEE BASIS)

When you have an emergency, go to the nearest ER. When a P&T veteran goes to a non-VA emergency room, the hospital patient accounts office should bill the nearest VA Medical Center. The VAMC Fee Basis office will pay for emergency treatment for P&T veterans if a VA ER is not feasibly available.

39. HOSPICE CARE

Hospice is comfort care in the home for veterans who are near the end of life. Typically, a doctor will certify that the patient has less than six months to live. VA staff will set up care with hospice programs in the community. You might choose to have hospice care in your home or in a nursing home. You won't see your PCP while you're in hospice; they have their own doctor who specializes in hospice care. Also, there might be rules against going to the ER while you're in hospice. Ask your hospice provider.