

Planning Guide for Loved Ones of a Veteran with ALS

When your loved one, who is a veteran, is diagnosed with ALS, it is normal to feel overwhelmed, uncertain, and afraid. As a caregiver, you'll experience many different emotions along this journey. Some days will be harder than others. Remember, in those overwhelming moments, sometimes the best thing to do is slow down and remember to breathe.

So what does it mean to be a caregiver for a veteran living with ALS? With so much to learn plus the shock of diagnosis, it can feel like you're lost in an unknown city without a map. Here you'll find practical information to help you plan ahead. This list has been prepared by people who have experienced the loss of a spouse, parent, or family member(s) with ALS and want to make it easier for those currently going through this process.

If you need emotional or social support, or help with this paperwork, please reach out to [I AM ALS' ALS Support team](#) at gethelp@iamals.org or [through this form](#).

After a veteran is diagnosed with ALS the following will be beneficial in future planning:

1. Apply for the free \$10,000 life insurance policy provided by the VA and apply for additional life insurance through the VA if needed.
2. Keep all important documents in a safe location. Make sure loved ones know where the documents are located and how to access them. Important documents and information might include:
 - Insurance policies
 - Investment account statements
 - Tax returns (from the past seven years)
 - Deeds
 - Social Security card
 - Marriage and birth certificates

- Passport
 - Military discharge papers and records
 - Motor vehicle titles
 - Names of extended family members to be notified of the veteran's death
 - Veteran's given name
 - Veterans Administration records and identification card
 - A Will, Power of Attorney, and Medical Directive
3. Prepare a "call list" with the names and contact information of key people to call upon the veteran's death, such as your lawyer, accountant, and financial advisor.
 4. Have a list of passwords to cancel or delete accounts, such as social media and email.
 5. Make sure you know how all of your bills are paid and pay them until the estate is settled.
 6. For information on navigating and accessing benefits through the VA, see the following:
 - VA Checklist for Veterans Living with ALS
 - A Guide for Veterans Living with ALS and Those Who Love Them

After your veteran loved one has passed, use the rest of this guide to navigate next steps.

Death Certificate: Obtain at least five (5) original death certificates. Some agencies do not accept copies. You might need less or more original certificates depending upon your situation. For example, your insurance brokers, mortgage company, bank, and credit card companies might need originals, or they might accept copies.

If people ask for a death certificate, request that they make a copy of the original and return the original to you. This might not be possible in all situations, but if they do make a copy it will save you from having to get more original death certificates.

Note: *ALS must be listed as the primary cause of death on the death certificate to qualify for certain benefits.*

Actions to take once you have the death certificate:

- Make an appointment with the Social Security office. You are entitled to a one-time payment of \$255.
 - **This entitlement is paid to a loved one in the following priority order:**
 - A surviving spouse who lived in the same household as the deceased person at the time of death.
 - A surviving spouse is eligible for or entitled to benefits for the month of death.
 - A child or children eligible for or entitled to benefits for the month of death.
 - **Your loved one must have credit for work covered by Social Security, ranging from 1.5 to 10 years, depending on their age at death. Those who may receive monthly benefits are:**
 - A widow or widower age 60 (50 if disabled) or older or at any age if caring for an entitled child who is under 16 or disabled.
 - A divorced widow or widower age 60 (50 if disabled) or older if the marriage lasted 10 years or if caring for an entitled child who is under 16 or disabled.
 - Unmarried children 18 years old or younger (19 if they are attending a primary or secondary school full-time).
 - Children who were disabled before reaching 22 years old, as long as they remained disabled.
 - Dependent parent or parents 62 years old or older.
- Contact your loved one's workplace:
 - Check to see if your loved one had a life insurance policy through work.
 - Check to see if you are eligible for a portion of your loved one's pension.
- Assess your loved one's assets to determine what was owned in their sole name (not joint ownership) which must be transferred as part of the probate process. (A jointly held asset automatically goes to the survivor.) This applies regardless of whether your loved one had a Will.

- Transfer the titles to any joint bank accounts to the joint owner. If your loved one signed a payable on death (POD) designation during their lifetime, transfer the affected accounts to the designee.
- Transfer title to any IRAs or investment accounts for which there is a named beneficiary.
- Apply for survivor benefits to which you may be entitled under state law, such as a partial or full exemption from payment of real estate taxes.
- Contact the Veterans Administration regarding the benefits listed below.

VA Benefits

Veteran's monthly benefit - As a surviving spouse, you are entitled to receive the benefit for the month of the veteran's death. Typically, the VA will withdraw the last payment made and issue a check/direct deposit for the monthly amount.

Burial Allowance - [VA Form 21P-530](#) A one-time benefit payment payable toward the expenses of the funeral and burial of the veteran's remains. Burial includes all legal methods of handling the veteran's remains including, but not limited to, cremation, burial at sea, and medical school donation.

Plot or Interment Allowance - A one-time benefit payment payable toward expenses incurred for the plot or interment if the burial was not in a national cemetery or another cemetery under the jurisdiction of the United States. "Plot" means the final disposition site of the remains, whether it is a grave, mausoleum vault, columbarium niche, or similar place. "Interment" means the burial of casketed remains in the ground or the placement of cremated remains into a columbarium niche.

Transportation Expenses - The cost of transporting the body to the place of burial may be paid in addition to the burial allowance when:

- The veteran died of a service-connected disability or had a compensable service-connected disability and burial is in a national cemetery; OR
- The veteran died while in a hospital, domiciliary, or nursing home to which they have been properly admitted under the authority of VA; OR
- The veteran died en route while traveling under the prior authorization of VA for the purpose of examination, treatment; OR
- The veteran's remains are unclaimed and burial is in a national cemetery.

Life Insurance - If you applied for life insurance (see 5 above on page 1), file [VA Form 29-4125](#) to claim your One Sum Payment Government Life Insurance of \$10,000. If you purchased additional Life Insurance through the VA or elected to keep your veterans' Group Life Insurance (VGLI) you should contact your representative from [Paralyzed Veterans of America](#) (PVA).

Dependency and Indemnity Compensation - If you are the surviving spouse, child, or parent of a service member who died in the line of duty, or the survivor of a veteran who died from a service-related injury or illness, you may be able to get a tax-free monetary benefit called VA Dependency and Indemnity Compensation (DIC). [VA Form 21-534EZ](#) for the spouse or child of the veteran. [VA Form 21-535](#) for a parent of the veteran.

Veterans Mortgage Life Insurance (VMLI) - [VA Form 295E-VMLI](#) This insurance can only be purchased after the Special Adaptive Housing (SAH) remodeling has started. It will be applied to the mortgage of the residence of the veteran. The maximum amount is \$200,000. If you are in the middle of the remodel, it should be completed and any leftover funds applied to the mortgage.

Government Headstone or Marker - [VA Form 40-1330](#) The veteran is entitled to a headstone or marker.

State Appropriation for Burial of Veterans - State Form 49890 payment of \$100 made to the surviving spouse.

CHAMPVA - VA Civilian Health and Medical Program shares the cost of medical services for eligible dependents and survivors of certain veterans. If you are interested in this program, contact the PVA.

Survivors' & Dependents' Educational Assistance - [VA Form 22-5490](#) VA's Survivors' and Dependents' Educational Assistance (Chapter 35) program provides education and training opportunities to eligible dependents and survivors of veterans with a service-connected disease.

Home Loan Guaranty - [VA Form 26-1817](#) VA guarantees loans to eligible surviving spouses to purchase a home, condominium, or manufactured home, and for refinancing purposes. The loans are actually made by private lenders but the VA guarantee generally means the lender will not require any down payment.