

VA Checklist for Veterans Living with ALS

Thank you to Chris Mullholland, a veteran living with ALS, who developed this document for other veterans living with ALS.

The Veterans Administration (VA) recognizes the rapidity of ALS, and while applications are often fast tracked, it is important to not delay submitting your application. This checklist includes tasks that will be helpful for you to complete upon receiving an ALS diagnosis.

As soon as possible after you receive an ALS diagnosis, contact [Paralyzed Veterans of America](#) (PVA) for assistance with applying for VA benefits. Their phone number is **866-734-0857**. You will need to fill out and submit the following forms to the VA through your PVA representative:

- [VBA-21-526EZ](#): Application for disability compensation (include copy of DD-214)
- [VBA-21-4138](#): Statement in support of claim
- [VBA-10-10EZ](#): Application for health benefits
- [VBA-21-22](#): Appoint the PVA as claimant's representative
- [VBA-21-4142](#) and [21-4142A](#): Contact information of physician & authorization to disclose information to VA
- [VBA-26-4555](#): Application for Specially Adapted Housing (SAH) grant
 - [VA Form 26-6807](#): Financial statement
 - [VA Form 29-8636](#): Veterans mortgage life insurance statement
- [VBA-10-0103](#): Application for Home Improvements & Structural Alterations (HISA) (provides up to \$8,000 for other modifications not covered by the SAH grant)
- [VBA-21-4502](#): Application for specially equipped vehicle
- [VA-29-4364](#): A \$10,000 life insurance policy
- [VBA-10-1394](#): Application for adaptive equipment for your motor vehicle

- [VBA-21-2680](#): Application for examination for housebound status or permanent need for regular aid and attendance
- [VBA-21-686C](#): Application to add and/or remove dependents (if applicable) [include supporting evidence: marriage/birth certificates, divorce decrees, and court orders for adult-dependent children or parents]

If you are still working and have disability insurance through your employer, apply for the following if you feel uncomfortable with continuing your job or are ready to retire:

- Short Term Disability (STD); this will require documentation from your doctor,
- Long Term Disability (LTD); this is important after STD ends,
- Social Security Disability Insurance (SSDI); learn more about SSDI and eligibility requirements [here](#).

When your VA disability status has been approved, fill out and submit:

- [VBA-10-10CG](#): Application for comprehensive assistance for family caregivers

When you receive the VA disability confirmation letter, bring a copy to:

- Local tax office for full or partial exemption from property taxes;
- Department of motor vehicles for vehicle tax exemption and apply for a disabled veteran (DV) license plate

As soon as the home modification grant is approved, ask the VA for a list of contractors previously used. Generally, three bids are required. Call at least three to conduct surveys and develop proposals. You should ask for:

- Handicap accessible bathroom
- Roll-in shower with handheld sprayer
- Disabled (taller) toilet with bidet seat
- Grab bars throughout
- Accessible sink (shower/wheelchair fits underneath)

- Widened doorways throughout
- House access (2 ramps, or 1 ramp and 1 wheelchair lift) – If a multi-story home, also ask for stair-lift

As soon as a handicap vehicle grant is approved, ask the VA for a list of approved local dealers. Call each and ask what vans are available or can be ordered. You will need to decide on a specific make, model, type of entry system (ramp/lift, rear/side) etc.

After your disability status has been approved, ask for the following assistive technology. It is not guaranteed that you will receive the items listed below although all are items that we recommend you ask for.

Communication

- Voice banking assistance – We recommend doing this as early as possible. Contact [Team Gleeson](#) for details.
- Eye controlled technology (e.g. [Tobii](#), [Eyespeak](#), etc.)

Daily Living

- Grabber/reacher
- Sock/stocking dressing assist
- Adaptive dinnerware/utensils/ silverware
- Electric recliner (may or may not be approved)
- Robotic arm Automated multi-directional feeding system food transfer system
 - OBI (<https://meetobi.com>)

Home Support

- Transfer pivot disk
- Transfer gait belt/sling, mobility assistance belt
- Mobile (and/or ceiling-mounted) electric Hoyer lift
- Automatic bed (that rolls to prevent bed sores) such as, but not limited to:

- Pro-Bed (www.pro-bed.com)
- Hill-Rom (www.hillrom.com)
- Walking cane (adjustable length)
- Walker
- Powered wheelchair w/ Savant headrest
- Transport chair
- Alternating pressure pad (for traveling)

Hygiene

- Rolling shower chair (that tilts) & Roho pad
- Urinary system:
 - Afex (penis)
 - Purewick (vulva)

Respiratory Care

- Non-invasive Ventilator (BiPAP, Trilogy)
- Cough assist machine
- Portable phlegm suction machine

We know that this process can feel overwhelming. We recommend contacting one or more of the following organizations to learn more about whether their services may be helpful for you:

- [Paralyzed Veterans of America](#)
- [Local ALS clinic](#)
- [I AM ALS](#)
- [Team Gleason](#)
- [ALS Association](#)

Below is a list of other important actions that are not specific to the VA. Many are related to end-of-life planning, which can be difficult to think and talk about. Take time to process how you're feeling as you go through this, and [ask for help](#).

- Talk to someone you trust about being your power of attorney, and prepare the documents. There are different types of power of attorney, such as financial, general and medical. While general is typically inclusive of many if not all types of power of attorney, it is important to look up the rules by state. [This guide](#) on Choosing A Healthcare Proxy from The Conversation Project may be helpful as you prepare to have these conversations.
- Decide on whether or not to fill out a do not resuscitate (DNR) form. The name of the form may vary by state.
- Meet with a lawyer or tax professional to discuss establishing a trust to simplify the settling of your estate
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- Meet with a funeral home or other memorial agency. Ask that they help ensure ALS is listed as the cause of death and see if they would be willing to submit the following forms to cover the following expenses:
 - [VA Form 40-1330](#) (headstone)
 - [VA Form 21P-530](#) (burial)

Other helpful resources:

- [Thinking Through VA Benefits and VA Care: A Resource for Veterans with ALS and Their Caregivers](#) by Mary Hahn Ward and Lara Garey

This is a personal and practical guide to accessing veterans resources/benefits when diagnosed with ALS. Based on first hand experience by the authors, this book informs and educates veterans and their caregivers on the many VA benefits and care available to a veteran living with ALS.

- [The Veterans Health Administration's Electronic Benefits and Service Portal](#)

This portal is a one-stop shop to apply for and manage documents, services, and benefits from the Veterans Benefits Administration and Veterans Health Administration. Start by clicking the "Register" button at the top right corner of the screen.

- [The Veterans Health Administration's My HealtheVet Patient Portal](#)

This online portal allows you to access and manage your veteran healthcare resources, including prescriptions, appointments, health records, and medical supplies. It also allows you to securely communicate with health care staff. Start by clicking the "Register" button at the top right corner of the screen.

