

# Understanding Insurance And Benefits When You Have ALS



LIVING WITH ALS  
RESOURCE GUIDE



# Understanding Insurance and Benefits When You Have ALS

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**A NOTE TO THE READER:** The ALS Association has developed the *Living with ALS* resource guides for informational and educational purposes only. The information contained in these guides is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.



# Introduction

Navigating the maze of health insurance and benefits can be overwhelming, to say the least. Many people living with ALS describe it as a full-time job. This resource guide provides guidelines and helpful information to assist you along this journey so you can get on with living instead of wasting time and energy stuck in a web of insurance and benefits.

Covered in this resource guide:

- Questions to ask about your health insurance
- Planning and organizing your insurance and care needs
- Veterans' Benefits
- Social Security Disability
- Supplemental Security Income
- Short- and Long-Term Disability Insurance
- Long-Term Care Insurance (LTC)
- Medicare
- Medigap/Supplemental Insurance
- Medicaid
- Loan forgiveness

# Questions to Ask Your Health Insurance Provider

After receiving a diagnosis of ALS, many people ask, “Where do I begin? What will I need? What does my insurance cover?” Below is a list of questions to help get you started:

## General Health Insurance Questions

- Is there an annual deductible?
- Is there an annual out-of-pocket expense limit or maximum? If I meet my limit, does my coverage increase and to what extent?
- Do I have a major medical plan? Is there an annual or lifetime maximum?
- Do I need to complete any claim forms?
- Am I subject to pre-existing condition regulations?
- For what services do I need pre-authorization?
- What does insurance cover/not cover that a person with ALS needs?

## Durable Medical Equipment (DME) Questions

- Does my plan cover DME? What about ventilator and non-invasive ventilator coverage (i.e., BiPAP); are they under respiratory equipment or DME?
- What is my coverage for a complex power wheelchair and/or speech generating device?
- What is the percentage of my coverage?
- Is there a preferred provider I must see?
- Is pre-authorization or a medical review required?

### Prescription Questions

- Does my plan cover prescription drugs? What are the terms of this coverage, and is coverage different based on using brand-name versus generic drugs?
- Is there a specific pharmacy/supplier network I must use?
- Is there a limit on the amount of prescription drugs I can get through this plan?
- Is there coverage for all FDA-approved drugs, or is coverage provided only for those listed on your formulary (a list of drugs that an insurance policy covers)?
- Does my plan offer a mail-order pharmacy option?

### Home Health Questions

- Does my plan have home health coverage?
- Do I have coverage for a home health aide (for skilled or custodial care)?
- Is there a preferred home healthcare agency I must use? Is there private duty nursing coverage at home?
- Does my plan offer case management? At what point does case management get involved and for how long?
- Does my plan have hospice coverage? Describe this benefit.
- Is there a preferred hospice agency that I must use?
- Is there insurance coverage for ventilator dependents at home?

Questions Specific for Health Maintenance Organization/  
Preferred Provider Organization (HMO/PPO) Subscribers:

- Is my ALS neurologist, or other ALS specialist, a member of the network or a participating provider?
- What is the referral process? Do I need a referral from my primary care physician every time I go to the neurologist or other specialist; is there a limit to the number and frequency of referrals?

## Planning and Organizing

Planning and organizing are key to managing insurance and care needs when living with ALS. One option is to keep a **3-ring binder** with all business cards, documents and paper for keeping notes regarding appointments, service/equipment delivery, medical records and deadlines. With current technology, many people prefer to have all this information right at their fingertips on an **electronic device**.

Whatever way you are most comfortable, whether it's a handwritten calendar or online calendar and notes, it's recommended to keep this information organized. Some people take pictures of business cards with their cell phones and enter the information right into their contacts. As care needs increase, it will be helpful to keep track of who is assigned what tasks and when they will be completed. There are various websites, such as The ALS Association's Care Connection Program site <https://www.als.org/navigating-als/for-caregivers/als-association-care-connection> and [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com), that can assist with this. Please check these sites to see how they can help you plan and stay organized.

# Veterans' Benefits

## VA Service-Connected Benefits

### ELIGIBILITY

Thanks to the efforts of The ALS Association, key members of Congress, advocates and the Department of Veterans Affairs, **ALS is now a disease entitled to presumptive service connection.** This means that if a service member is diagnosed with ALS, their 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. These benefits are described briefly below.

***The benefits listed below apply to service-connected individuals only.***

**VA compensation.** 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 is paid monthly and varies with the degree of disability and the number of veteran's dependents.



All veterans with ALS are automatically rated at 100% disability if they have served 90 consecutive days of active duty. 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/>.

**Special Monthly Compensation (SMC) for Serious Disabilities.** VA can pay additional compensation to a veteran who, as a result of military service, incurred the loss or loss of use of specific organs or extremities.

**Death and Indemnity Compensation (DIC).**  
A monthly payment to survivors, if eligible.

**Specially Adapted Housing grant (SAH).** Certain veterans and service members with service-connected disabilities may be entitled to a Specially Adapted Housing (SAH) grant from VA to help build a specially adapted house or buy a house to be modified to meet their disability-related requirements. Eligible veterans or service members may now receive up to three grants, with the total dollar amount of the grants not to exceed the maximum allowable.

**Automobile grant.** Financial assistance is available to purchase a new or used automobile (or other conveyance) to accommodate a disability for a veteran or service member with certain disabilities that resulted from an injury or disease incurred or aggravated during activity military service. The veteran or service member may only receive the automobile grant once in his/her lifetime. The grant covers \$19,817 toward the purchase of a vehicle and your local VA pays for all of the adaptive equipment that makes the vehicle accessible.

**Adaptive equipment.** The purchase of adaptive equipment and funding for repair, replacement or reinstallation of adaptive equipment required for a disability or for the safe operation of a vehicle purchased with VA assistance.

**Clothing allowance.** Any veteran with a service-connected disability for which they use prosthetic or orthopedic appliances may receive an annual clothing allowance.

**Aid and attendant allowance.** A veteran who is determined by VA to need the regular aid and attendance 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% or more disabled is entitled to receive an additional payment for a spouse who needs the aid and attendance of another person.

**Healthcare benefits.** The VA also offers a full range of healthcare benefits, which may include medical and respite care and prosthetic items, such as wheelchairs, walkers and canes. Prescriptions and medical supplies also may be included, as well as a Home Improvement and Structural Alteration (HISA) grant. More specifically, the following services are covered:

#### Preventive Care Services

- Immunizations
- Physical Examinations
- Healthcare Assessments
- Screening Tests
- Health Education Programs Ambulatory (Outpatient) Diagnostic and Treatment Services
- Emergency outpatient care in VA facilities
- Medical
- Surgical (including reconstructive/plastic surgery as a result of disease or trauma)
- Chiropractic Care
- Mental Health
- Bereavement Counseling
- Substance Abuse

## Hospital (Inpatient) Diagnostic and Treatment

- Emergency inpatient care in VA facilities
- Medical
- Surgical (including reconstructive/plastic surgery as a result of disease or trauma)
- Mental Health
- Substance Abuse

## Medications and Supplies\*

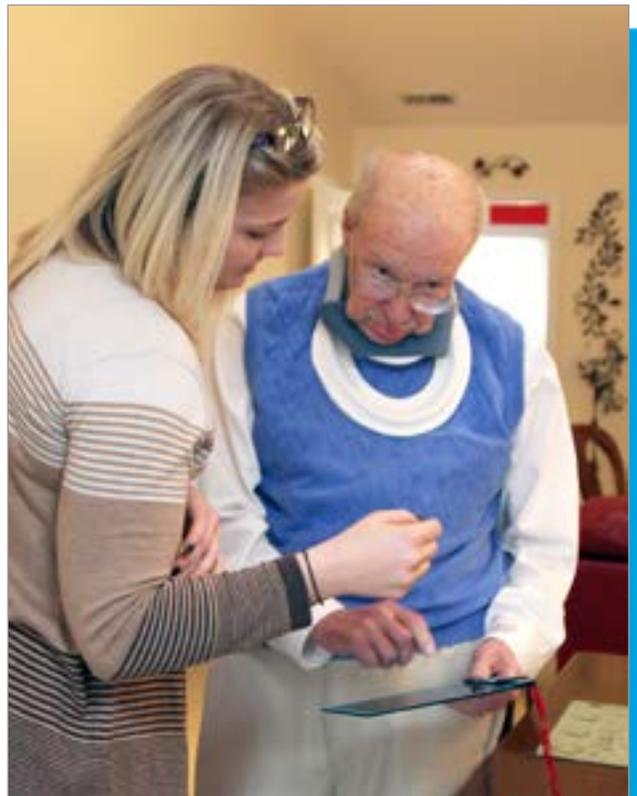
- Prescription medications
- Over-the-counter medications
- Medical and surgical supplies

\*Generally, they must be prescribed by a VA provider and be available under VA's national formulary system.

# What Happens When I Stop Working?

## Social Security Disability

When you have a diagnosis of ALS, making the decision to stop working and apply for Social Security Disability can be a difficult one, but the process for applying for Social Security Disability and Medicare benefits should be relatively easy. You can file an application



for benefits once you are no longer able to work or your current Substantial Gainful Activity (SGA) is below the allotted amount. <http://www.ssa.gov/oact/cola/sga.html>

The easiest way to file for Social Security Disability is to do so online at [www.socialsecurity.gov](http://www.socialsecurity.gov). You will need the names and addresses of your doctors and a very brief outline of the work you have done in the last 15 years. If you are unable to apply online, you can apply by calling Social Security at 1-800-772-1213, or by visiting your local social security office. To find your local office, visit [www.socialsecurity.gov/locator](http://www.socialsecurity.gov/locator).

ALS is on the Social Security Administration's list of Compassionate Allowances meaning that **Social Security will grant you disability status immediately once an application is filed. The ALS Disability Insurance Access Act of 2019 eliminates the required five-month SSDI waiting period for ALS applicants approved for benefits on or after July 23, 2020.** The new law, however, does not affect your disability application or determination process.

Another requirement for meeting the minimum qualifications for Social Security Disability is having paid enough into Social Security to satisfy the quarters of coverage requirements <http://www.ssa.gov/oact/ProgData/insured.html>:

- One quarter of coverage is earned for every \$1,510.00 (as of January 2022) you earn in a calendar year to a maximum of four quarters per year.
- One quarter of coverage gives you one credit.
- Adults over the age of 31 will need 40 lifetime credits.
- In addition to meeting the minimum number of credits to qualify for disability, 20 of those credits must have been earned in the 10 years immediately prior to the onset of the disability.

For most adults who have worked immediately prior to becoming ill, having the appropriate number of credits is not an issue.

**Once you are approved for benefits you will receive monthly monetary payments for you and, in most cases, your minor children and a spouse who cares for your children under age 16.**

The amount of your monthly benefit depends on the amount you have paid into Social Security over your working life. Visit <http://ssa.gov/myaccount/> to obtain your Social Security statement and an online benefits estimator. Once you are approved for Social Security Disability, you will also be entitled to Medicare.

## **DO YOU NEED TO HIRE AN ATTORNEY TO APPLY FOR SOCIAL SECURITY DISABILITY?**

Absolutely not! While applying for benefits may sound complicated, it is a relatively easy process which can be done without paying for an attorney. If you have questions, your ALS Association care team may be able to refer you to a legal professional who you can talk to free of charge.

## **HOW DOES SOMEONE APPLY FOR SOCIAL SECURITY DISABILITY PROGRAMS?**

Individuals can apply for Social Security benefits by telephone or in person. To apply via telephone, you can call toll free at 1-800-772-1213, Monday–Friday, 7 a.m.–7 p.m. Eastern Time. To apply in person, an individual may go to their local Social Security Administration (SSA) office to schedule an appointment. For information regarding the SSA office nearest you, go to [www.ssa.gov](http://www.ssa.gov). For assistance with making an application to Social Security, an individual may also contact the A.C.C.E.S.S. program at 1-888-700-7010.

The representative will ask for the applicant's social security number, name and address. Additional information the applicant will eventually need to provide to SSA includes, but is not limited to:

- Birth certificate
- Names and addresses of hospitals and physicians
- Medications
- Marriage information
- Dependent children's names, addresses and social security numbers
- Employers over the last 15 years
- Income

**Note:** SSA has an expedited procedure for processing terminal illness cases to ensure that a favorable decision can be made quickly.

## WHAT IF AN APPLICANT IS DENIED SOCIAL SECURITY BENEFITS?

Individuals might be denied SSDI benefits for a number of reasons including:

- Not enough time worked and paid into Social Security
- Not a U.S. citizen
- Not considered disabled
- Failure to cooperate with SSA

**A person who is denied benefits from Social Security has appeal rights with strict time limitations.** Please consider referring to the A.C.C.E.S.S. program at 888-700-7010 for free representation or advice. You may also contact The ALS Association's Advocacy Department for potential congressional support at 877-444-ALSA (2572) or [advocacy@als.org](mailto:advocacy@als.org).

# Supplemental Security Income (SSI)

**Supplemental Security Income (SSI) provides cash to meet basic needs for food, clothing and shelter to those age 65 and over, blind or disabled who have little or no income.** Individuals

and their children may be eligible for SSI even if they have never worked or have an insufficient insured status for SSDI.

SSI is a federal income supplement program funded by general tax revenues, not Social Security taxes. Each person who applies for SSDI is also screened for SSI benefits. Those eligible for SSI may also be automatically eligible for Medicaid benefits.

**Note:** SSA can make a determination of “presumptive disability” for SSI benefits. This provision allows SSA to pay up to six months of SSI payments before they make their disability determination, based on the finding that there is a high probability that the applicant is disabled. Therefore, persons with ALS, especially those with significant bulbar signs or gross disturbance of gait, should inquire about this provision at the time of application. (SSA does not provide for presumptive payments to individuals applying for SSDI benefits.)

## Short-Term and/or Long-Term Disability Through an Employer

**It is crucial to determine what your benefits are from your employer’s Human Resources department.** If you have Short- and/or Long-term Disability, what are the parameters of these plans—until a certain age, a certain number of years or until death? You can also inquire if there is an open enrollment period where you can apply for these or additional benefits.



# Long-Term Care Insurance (LTC)

Long-term care insurance is a private policy purchased that covers care generally not covered by health insurance. Contact your LTC provider before initiating a claim to gain a better understanding of your benefits. Here are questions to ask:

- What are the parameters of the policy?
- What is the elimination period?
- Is there a lifetime limit?
- Is there a home modification rider?

## Medicare

### Medicare Waiver

Due to the tireless lobbying efforts of The ALS Association, other groups and individuals with ALS and their families, Congress passed landmark legislation in July 2001 benefiting the ALS Community. The usual 24-month waiting period for Medicare was eliminated for SSDI recipients disabled by ALS. Medicare entitlement now begins the first month the recipient receives cash benefits.

### What is Medicare?

Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services (CMS). Medicare is available to the following groups of individuals:

- Persons age 65 and older and their spouses.

- Persons eligible for SSDI (and some disabled civil service workers not eligible for SSDI due to not having paid FICA taxes). Incidentally, individuals with end stage renal disease may also be eligible for Medicare.

Medicare has two parts, **Part A and Part B**.

**Part A (Hospital Insurance)** helps pay for:

- Care in hospitals as an inpatient, skilled nursing facilities, hospice care and some home health care. This coverage is free to SSDI recipients.

**Part B (Medical Insurance)** helps pay for:

- Doctors' services, outpatient hospital care, and some other medical services that Part A does not cover, such as physical and occupational therapy and some home healthcare. **Part B helps pay for these services and supplies when they are medically necessary. There is a monthly premium for this coverage.** If an individual is also a Medicaid recipient, their monthly premium for Medicare may be paid by their Medicaid benefits.

Medicare Parts A and B pay for the first 80% of services and "Medigap" or supplemental plans (which we will soon discuss) pick up the other 20%.

Since Medicare coverage is subject to change, please refer to the official Medicare website for the most up-to-date information at <http://www.medicare.gov/Coverage/Home.asp> or call 1-800-MEDICARE.

## Medigap/Supplemental Insurance

As a person with ALS, a key piece of your healthcare planning is selecting the best health insurance for you!

The advocacy efforts of The ALS Association came to fruition in 2002 with the passing of legislation that waived the 24-month

waiting period for Medicare coverage for persons with ALS. This means that those who qualify for Social Security Disability Insurance (SSDI) now qualify sooner for Medicare Insurance. This eligibility for Medicare brings with it a set of additional decisions to make:

- Should I also purchase Medicare Part B?
- Should I purchase a Medicare Supplement?
- What about a prescription plan?
- Will a Medicare Advantage Plan save or cost me money over time?

To make your journey with ALS a little easier, we highly recommend discussing your health insurance options with an **insurance counselor** and reviewing insurance related publications on The ALS Association website. By thinking through and planning for what your coverage needs may be, you will be able to make choices that will provide you the most appropriate coverage when you need it.

For the best guidance possible, it is essential to be very clear with the insurance counselor about your condition, prognosis and anticipated needs. Please consider and discuss the answers to the following questions:

- What medications do I currently take/plan to take in the coming year?
- How might my ALS progression over the next year impact my need for:
  - Durable medical equipment, such as a power wheelchair or hospital bed?
  - A communication device (a machine that helps an individual verbally communicate)?
  - Office visits to the ALS clinic or other physicians?

The decisions you make about your insurance plan will directly impact your coverage for these items. For information about what your needs may be as your disease progresses, we encourage you to consult with your ALS physician and/or your ALS clinic team.

Your State Health Insurance Counseling Program (SHIP) has expert volunteers who can assist you free of charge. To locate your area SHIP agency, call 1-800- 677-1116 (Eldercare Locator) or go to <https://eldercare.acl.gov/Public/Index.aspx>.

## Medicaid

Medicaid provides health insurance for low-income and needy parties. It covers children, the aged, blind and/or disabled individuals. Medicaid is jointly funded by federal and state governments.

Certain states may have different Medicaid programs available for those who are not as financially needy, such as programs designed for catastrophic or high monthly out-of-pocket costs. A person who has any financial hardship should contact their state's Medicaid program for information. For contact information for a specific state, you can go to <https://www.medicaid.gov/about-us/contact-us/index.html>.

## Loan Forgiveness for Parent Plus Loans

If you (the person living with ALS) have taken out a PLUS Loan to help pay for your child's education, all or part of it may be cancelled (discharged) for several reasons. Cancellation is different from forgiveness in that forgiveness is an incentive for borrowers working in certain fields. Cancellation relieves the borrower from repayment obligation for extenuating circumstances.

### **You may qualify for total or partial loan discharge if:**

- The school closed within 90 days of your child's enrollment, and they were unable to finish their program of study.
- The school did not properly qualify your child's status before they began studies.

- You did not receive a refund that was due to you.
- Your signature was forged.
- The school did not properly evaluate your child's ability to benefit from the coursework before beginning studies.
- You become totally and permanently disabled.
- You or the dependent for whom the loan was borrowed dies.
- Your loan is discharged due to bankruptcy. (Typically, student loans cannot be discharged in a bankruptcy.) Consult your legal counsel regarding your situation.

## Summary Statement

Understanding insurance and benefits may feel overwhelming, but hopefully the information we've provided will simplify this process for you. We have included several websites and phone numbers to access this information. Take the opportunity to use the check lists included at the end of this resource guide to assist you along this journey. One relates to summary points about Social Security Disability, Medicare and Short- and Long-term Disability Insurance; and the other, tips on finding in-home care. Contact your ALS Association care team or ALS center or clinic social worker to help you navigate this process. **Know that you are not alone.**

# What Happens When I Stop Working?

## Applying for Social Security Disability (SSD)

- Three ways to apply: online [www.ssa.gov](http://www.ssa.gov); call to schedule a telephone interview 1-800-772-1213; or apply in person at your local office.
- Keep it simple: ALS is a presumptive diagnosis, so with this diagnosis and meeting SSD guidelines for work credits, you should be eligible for SSD. No need to put any other diagnoses you may have.
- Benefits begin once approved.
- You should not need a disability lawyer to apply for benefits.

## Medicare

- When your SSD benefits begin you should be eligible for Medicare.
- Medicare B premium is automatically deducted from your SSD check. This covers the initial 80%.
- You will need to purchase a supplemental plan to cover the other 20% and a prescription plan as well.
- You can check out [www.Medicare.gov](http://www.Medicare.gov) or your local county Office on Aging to determine supplemental Medicare and prescription plans in your area.

## Short- and Long-Term Disability

- Check with your employer's Human Resources Department to determine what benefits you have and the parameters of these plans for long-term planning.
- Most Long-Term Disability plans require you apply for SSD and deduct the amount of that benefit from what they pay you monthly.

# How To Find Care At Home

- At some point in your journey with ALS, you may require additional help with bathing, dressing and activities of daily living beyond what your caregiver can provide.
- This type of care is NOT covered by Medicare, Medical Assistance or private medical insurance on an ongoing basis.
- It is important to explore options for in-home care as early as possible. Begin talking honestly about the help you as the patient need and you as the caregiver can realistically provide.
- Insurance may cover limited short-term home health services if there is a skilled need, such as a feeding tube placement or PT/OT evaluation, but once the skilled need is met, the home health aide services will end.
- Check your local county Area Agency on Aging and/or local Office of Disability to see if you are eligible for any programs or services.
- Often, county and state funded programs have lengthy application processes or waiting lists, so be proactive so you don't find yourself in an emergency.

- Veterans: If you are 100% service connected, you may be eligible for an Aid and Attendance grant which is additional income to your monthly compensation to be used to pay for help at home.
- Veterans: In addition, most VA Hospitals offer 10 hours per week of a home health aide. Check with your local VA.
- Private Pay: You can check with your local Area Agency on Aging or your ALS Association Social Worker for local agencies to pay privately for in-home care.
- Word of mouth/referrals: Talk to family and friends that have had help for a loved one. Check within your community if there are experienced aides looking for work. This may be less expensive than going through an agency.
- Some people have been successful looking into local nursing or physical therapy (PT)/occupational therapy (OT) schools to hire students who are hoping to gain experience. Again, this could be less expensive.

***For additional assistance, contact your local ALS Association care team.***







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#### **About The ALS Association**

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of care and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association is working to make ALS a livable disease while urgently searching for new treatments and a cure.