



ALS & Health Insurance

A Les Turner ALS Foundation Guide for People Living with ALS

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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

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How health insurance works

People living with ALS need a lot of medical care to treat their symptoms and take care of their health. This care can be very expensive — but the good news is that health insurance helps to pay for the medical care you need.

Here's how health insurance helps to pay for the cost of your medical care:



You pay a **monthly fee called a premium** to have coverage under your health insurance plan. (You still need to pay your premium every month, even if you don't get any medical care that month.)



You pay the full cost of your medical care **until you reach a limit called your annual deductible**. Your deductible starts over with each new year.



Once you've met your deductible, you and your health insurance plan will **share the cost of your care**. Here's what to expect:



When you get health care services, you will pay a set dollar amount called a copay or a percentage called coinsurance. *For example, you may be asked to pay \$20 each time you go to the doctor or 30% of the cost each time you go to the hospital.* Then, your insurance plan will pay the rest. For example, let's say you go to the doctor and your visit costs \$100 total. You pay a \$20 copay, and your insurance pays the remaining \$80.



If you use a lot of health care services in one year, you may reach a limit called your **out-of-pocket maximum**. Once you have reached your out-of-pocket maximum, your health insurance will cover the **entire cost** of your medical care for the rest of the year.



Closer look: Deductible vs. out-of-pocket maximum

Both your deductible and your out-of-pocket maximum are limits that start over with each new year. Here's how they are different:

After you meet your deductible, the plan will pay part of the cost of your medical care for the rest of the year.

Your out-of-pocket maximum is usually much higher than your deductible. If you meet your out-of-pocket maximum, the plan will pay the full cost of your medical care for the rest of the year.

Health insurance options for people living with ALS

Since medical care for people with ALS can be so expensive — up to hundreds of thousands of dollars — it's important to choose a health insurance plan that meets your needs. Here are a few options to consider.

Private health insurance provided by an employer

You may be able to get health insurance through your employer (if you are working) or through your partner's employer. This is called private health insurance. The cost of private health insurance plans can vary widely, so take time to shop around and compare your options.

Employers typically have an open enrollment period — a few weeks, usually in the fall, when employees are allowed to enroll in their health insurance plan or add a partner or child to their coverage. You may be able to enroll at other times of the year if you experience certain life changes, like getting married or divorced or losing health insurance coverage from another source.

Cobra continuation coverage

If you or your partner need to stop working, you will need to consider other options for health insurance coverage. COBRA continuation coverage is one option that can help you fill the gap temporarily.

With COBRA, you and your dependents can stay on your employer's health insurance plan for a short period of time after leaving the company, typically up to 18 months. You'll keep the exact same coverage, and if you've already met your deductible or out-of-pocket maximum for the year, those limits will not reset. However, your monthly premiums will cost more than they did before.

To learn more about COBRA continuation coverage, visit <https://inspirafinancial.com/individual/resources-education/health-benefits/cobra-101>. Keep reading to learn about long-term health insurance options.



Health insurance marketplace plans

If you are a United States citizen, you may be eligible to get health insurance through a government resource called the Health Insurance Marketplace. (The Marketplace goes by different names in different states, and you may hear it called the Exchange, too.) It's a website where you can explore individual and family health insurance plans that are available in your state and sign up for the plan that's right for you. Depending on your income, you may qualify for a subsidy, meaning the government will cover part of the cost of your monthly premiums.

You can sign up for a Marketplace plan during the annual Open Enrollment period each fall. You may be able to enroll at other times of the year if you experience certain life changes, like getting married or divorced or losing health insurance coverage from another source.

To explore your plan options on the Health Insurance Marketplace, visit healthcare.gov.

For step-by-step instructions on how to get health insurance through the Marketplace, check out this article: healthcare.gov/quick-guide/getting-marketplace-health-insurance

Medicare

If you qualify for Social Security Disability Insurance (SSDI), you can get health insurance through Medicare.

Keep in mind that you cannot cover your partner or children under your Medicare plan unless they also qualify for Medicare.

What services does Medicare cover for people living with ALS?

There are a few different parts of Medicare that cover different types of health care services. Here's what you need to know.

Medicare Part A

Medicare Part A helps to cover the cost of services including:



Inpatient care at hospitals



Care at a skilled nursing facility (including overnight and longer stays)



Hospice care



Home health services after a hospital stay (see details below)

How does Social Security Disability Insurance (SSDI) work?

SSDI is a United States government program that provides benefits to people with disabilities. The Social Security Administration (SSA) decides if you qualify for SSDI based on your work history. SSA calculates how many "work credits" you have earned based on how long and how recently you have worked in the United States. To learn more about SSDI eligibility, visit ssa.gov/benefits/disability/qualify.html.

You will need the following information to apply for SSDI:

123-45-6789

Your Social Security number



Your work history



Medical records and contact information for all your health care providers



A list of your medications

To apply for SSDI, visit ssa.gov, call 800-772-1213, or visit your local Social Security office.

For tips on applying for SSDI, visit lesturnerals.org/3-tips-for-people-with-als-applying-for-ssdi.

Once your SSDI application is approved, you can sign up for Medicare right away.

Medicare Part B

Medicare Part B helps to cover the cost of services including:



Many preventive care services, like checkups and vaccines



Durable medical equipment (wheelchairs, hospital beds, and other devices you may need at home)



Medically necessary home health services (see details below)



Services from doctors and other health care professionals (like office visits and tests)



Outpatient care

Medicare Part D

Medicare Part D helps to cover the cost of prescription drugs. Medicare plans that offer prescription drug coverage (Part D) are run by private insurance companies that follow rules set by Medicare.

To learn more about these plans, visit [cms.gov/medicare/health-drug-plans/medicare-prescription-payment-plan](https://www.cms.gov/medicare/health-drug-plans/medicare-prescription-payment-plan).

How are home health services covered under Medicare?

Home health services are covered under Medicare Part A and Part B. In general, Part B covers medically necessary home health services, while Part A may cover home health services after you come home from a hospital stay of at least 3 days. Exactly what is covered will depend on your specific situation.



Medicare Advantage (Medicare Part C)

You may have heard about Medicare Advantage plans, also called Medicare Part C. Medicare Advantage plans usually aren't the best fit for people with ALS because these plans often require pre-authorization (meaning you and your doctor have to complete an approval process before you can get care).

Additionally, they tend to deny coverage for health care services at high rates. If the plan denies coverage for services you need, you have the right to file an appeal – but all these factors can cause delays in your care.

The process of enrolling in Medicare can be confusing. For help with navigating Medicare, contact the State Health Insurance Assistance Program (SHIP) in your state. SHIPs provide free counseling to people who are eligible for Medicare and their families and caregivers.

To find your SHIP, visit [shiphelp.org](https://www.shiphelp.org).



Medicare Savings Programs

If you choose to enroll in Medicare, signing up for a Medicare Savings Program can help you save money on health care expenses. Medicare Savings Programs help to pay for costs like your premiums, deductibles, and copays or coinsurance.

To learn more about these programs, contact the SHIP in your state. Find your SHIP at shiphelp.org.

Medicare Supplement Insurance (Medigap)

Medicare Supplement Insurance, often called Medigap, is a type of supplemental health insurance that you can get if you are enrolled in Medicare.

Medigap plans help to cover certain gaps in Medicare coverage, so you'll pay less for health care services. Here's how it works:



You get a health care service that is covered under Medicare Part A or B.



Medicare pays part of the cost of the service.



Then, your Medigap plan pays an additional portion of the cost — so you'll pay less out of pocket.

Keep in mind that if a health care service is not covered under Medicare Part A or B, it will not be covered by Medicare Supplement Insurance, either.

Eligibility for Medigap plans varies based on where you live. In some states, these plans are only available to people over age 65, and they can be expensive. Search for "Medigap plans" and the name of your state to learn about your options.

Veterans' Benefits

If you've been diagnosed with ALS, served in the military for 90 or more consecutive days of active duty, and have been honorably discharged, you will likely be eligible for a variety of service-connected benefits from the U.S. Department of Veterans Affairs (VA).

These benefits may include:



Medical care at VA facilities



Monthly disability compensation, with special compensation for severe disabilities



Equipment and adaptive aids



Prescription medications



Housing and vehicle grants



Home-based or preventive services



Respite care



Survivor support

If you served in the military, visit va.gov/health/als.asp to learn more about veterans' benefits available through the VA.



Paralyzed Veterans of America (PVA) can help you get the benefits you have earned. PVA's National Service Officers know how to navigate the VA, and they're here to help you learn about and apply for all the resources available to you. To connect with PVA, visit pva.org.

Additional Resources

An ALS diagnosis can bring a lot of unexpected changes – not just physically and emotionally, but financially, too.

For guidance on managing money with ALS, check out our companion guide, [ALS & Money](#).



Watch this recorded webinar to learn more about important things to consider as you choose a health insurance plan: lesturnerals.org/support-services/open-enrollment-matters-health-insurance-considerations-for-people-diagnosed-with-als.



Watch this recorded webinar to learn more about veterans' benefits for people living with ALS who have served in the military: lesturnerals.org/support-services/als-learning-series-veterans-helping-veterans-with-als-department-of-veterans-affairs-benefits-advocacy.



Patient Advocate Foundation is a national nonprofit organization that provides patient services and support to people with complex health conditions like ALS. Learn more about Medicare from PAF: patientadvocate.org/medicare.

Medicaid

If you have limited income and assets, you may be eligible for Medicaid. If you qualify, Medicaid can cover the cost of medical care that is not covered by other insurance.

Medicaid goes by different names in different states, and each state has its own requirements.

To learn more and find out if you're eligible, search for name of your state and "Medicaid requirements."

Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, lesturnerals.org/resources.

My ALS Decision Tool™

If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options. To learn more, visit: alsdecisions.org.

**MY ALS
DECISION
TOOL**

ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research, visit: alslearningseries.org.

**ALS
LEARNING
SERIES**

My ALS Communication Passport to Quality Care

My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit: lesturnerals.org/passport.

**MY ALS
COMMUNICATION
PASSPORT
TO QUALITY CARE**

Support Groups

We facilitate support groups to provide people living with ALS, their caregivers and family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS. To find out more, visit: lesturnerals.org/support-groups.

