

ALS & MONEY

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 or financial advice. Talk to your ALS care team and your financial team before making any decisions about your health or treatment. Together, you and your team can determine a plan that works for you.

Last Reviewed: March 6, 2026

An ALS diagnosis can bring a lot of unexpected changes – not just physically and emotionally, but financially, too. People living with ALS need a significant amount of medical care and support, and the costs can add up quickly. *But you're not alone.* There are resources and people who can support you – financial counselors, ALS care teams, and nonprofit organizations that understand what you're going through. Planning ahead may help you tap into grants, low-interest loans, or assistance programs that can help to offset the costs of living with ALS.

Common expenses for people living with ALS

ALS affects everyone who has it differently, and everyone's financial situation looks different, too. But there are some common expenses that many people living with ALS need to pay for. It's helpful to learn about these expenses so you can get a sense of what to expect.

Home Modifications

Many people living with ALS make modifications (changes) to their home to make their living space more accessible. Home modifications are not usually covered by health insurance.

Common modifications include:



Installing ramps



Remodeling bathrooms



Widening doorways



Moving bedrooms to the ground floor

Equipment

Some of the medical equipment you need may be covered by insurance. Ask your health insurance company what is covered under your plan. You can also look for equipment loan closets in your area. Loan closets provide donated or refurbished medical or assistive devices for free or at a low cost.

Health insurance plans typically place limits on how often and how much they will pay for medical devices. If you need to get a new medical device, check with your ALS care team for advice on navigating insurance limits and getting the best value for your money.

Transportation

Common transportation expenses for people living with ALS include:



Buying an accessible van



Modifying a vehicle you already own to make it more accessible



Getting a parking placard or a special license plate so that you can use accessible parking spaces for people with disabilities

Medical Expenses

Medical care for people living with ALS is very expensive. Health insurance helps to cover the cost of services that many people living with ALS may need, such as:



Breathing support,

like non-invasive ventilation (NIV) and tracheostomy and mechanical ventilation (MV)



Nutrition support,

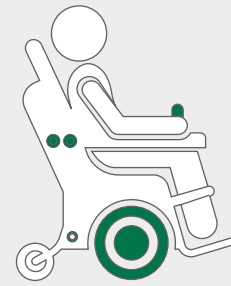
like a feeding tube



Assistive devices



Genetic counseling and testing



Many insurance plans will only cover a new wheelchair once every 5 years. The quality of your power wheelchair can make a big difference in your daily life, so it makes sense to use your health insurance to get the highest quality power wheelchair you can.

For equipment that you won't use as often (like a manual wheelchair, for example), consider going to a loan closet or paying out of pocket, so that the device won't count toward your health insurance plan's limit.



When you have ALS, it's especially important to choose a health insurance plan that meets your needs.

To learn more about choosing and using health insurance, check out our companion guide, [ALS & Health Insurance](https://lesturnerals.org/als-health-insurance-guide) lesturnerals.org/als-health-insurance-guide

However, you will still need to pay part of the cost for your doctor's visits, medications, and other health care services and equipment. Some pieces of equipment, like NIV devices and hospital beds, come with rental fees. Additionally, there are some types of services that health insurance does not typically cover, like caregivers, nursing care, or home health services.

Medicaid can help to cover the cost of services that aren't 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."

Participating in clinical research

Some people with ALS choose to participate in clinical research studies. You do not have to pay to participate in a study, but you may need to cover costs like:



Traveling to appointments during the study



Taking time off work to attend your appointments



Paying a caregiver to support you during the study

Home health versus caregiving services

Many people living with ALS benefit from home health and caregiving services. At first glance, these services might sound similar, but insurance handles them differently.



Home health includes services like having a nurse come to your home to provide wound care or change a needle in your port. These services are typically covered by insurance.



Caregiving services – like hiring a caregiver privately or through an agency – are typically not covered by insurance. However, Medicaid may cover some of these services. Long-term care insurance can also help to cover the cost.

If you're interested in learning more about clinical research, check out these resources:



ALS & Participation in Clinical Research Guide
lesturnerals.org/als-participation-in-clinical-research

MY ALS DECISION TOOL

My ALS Decision Tool™
Participating in ALS Clinical Research
lesturnerals.org/clinical_research/0_about-this-tool

Unfortunately, people who have been diagnosed with ALS are not eligible to purchase long-term care insurance. But if you already have a long-term care policy, check with your insurance company to find out what caregiving services are covered.

Hospice Services

Hospice support can also help you feel more comfortable near the end of life. Hospice services are typically covered by insurance. Check with your health insurance company and your ALS care team to confirm exactly what is covered under your plan. Medicare covers 100% of the cost of hospice services, but some private insurance companies only cover a portion of the cost (e.g., 80%) or a specific timeframe of hospice care.

Financial assistance

There are programs that provide financial assistance for people living with ALS to help you pay for the health care and support you need.

Social Security Disability Insurance (SSDI) benefits

SSDI is a United States government program that provides benefits to people with disabilities. If you are interested in getting health insurance through Medicare, you will need to apply for SSDI first.

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.

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.

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

Private disability insurance

You may be able to get disability insurance through your employer (if you are working) or your partner's employer. There are 2 types of disability insurance: short-term disability and long-term disability. Both types pay you a percentage of your salary when you are unable to work because of a disability like ALS.

In most cases, employers will ask you to apply for SSDI at the same time that you apply for long-term disability insurance. This way, your employer will pay less out of pocket for your disability coverage. Keep in mind that any money you get from disability insurance may be taxable, depending on who paid the premiums.

HealthWell Foundation

HealthWell Foundation assists with copays, premiums, deductibles, and out-of-pocket expenses for essential treatments and medications. To learn more and find out if you qualify for assistance, visit healthwellfoundation.org.

Grants

Some federal, state, and nonprofit programs offer grants to help cover the cost of home modifications, equipment, and respite care. For help finding grants, ask your ALS care team or reach out to an ALS foundation near you. Check out the Les Turner Foundation's list of trustworthy ALS organizations at lesturnerals.org/trusted-resources-to-learn-about-als.



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.



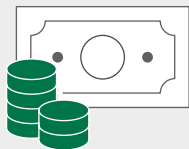
Legal planning

ALS may change your ability to communicate or make decisions later. Taking time to make important legal decisions and share your wishes now can help you protect your choices.

Planning ahead can make things much easier for you and your family. There are 3 essential legal documents you need to create:

Power of Attorney (POA)

Power of Attorney (POA) is a document that lets someone else make decisions for you when you are no longer able to do so. There are 2 types of POA:



Financial POA allows someone to make decisions about your finances and business for you.



Medical POA allows someone to make medical decisions for you. Keep in mind that medical POA only goes into effect once a medical professional approves your documentation.

Why do people living with ALS need POA?

ALS may affect your ability to write or to speak clearly. You may also need someone to handle health insurance paperwork or medical bills.

Advanced Directives

Advanced directives are documents that tell your doctors what medical care you want if you can't communicate. There are 3 different types of advanced directives:



A **Living Will** tells doctors what treatments you want or don't want.



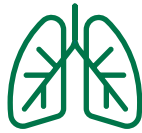
A **Do Not Resuscitate (DNR) Order** tells emergency workers not to try to restart your heart if it stops.



A **Physician/Practitioner Order for Life-sustaining Treatment (POLST)**, also called a **Medical Order for Life-sustaining Treatment (MOLST)** in some states, tells doctors whether you want to receive life-sustaining treatment (often called life support).

Why do people living with ALS need advanced directives?

As your ALS progresses, you may face difficult decisions about your health care, like:



Do you want to use a machine to help you breathe easier, like non-invasive ventilation (NIV) or tracheostomy and mechanical ventilation?



Do you want doctors to place you on life support?



Do you want to use a feeding tube?



Do you want someone to give you CPR if your heart stops?

ALS may affect your ability to speak or write – making it hard or impossible to communicate what you want when the time comes. That’s why it’s important to tell your family and your ALS care team what you want ahead of time, so they won’t need to guess later.



It’s okay to change your mind at any time. Just keep your family and ALS care team in the loop about your decisions.



Here are a few resources to help you plan ahead and communicate your wishes:

- To learn more about advanced directives, visit [fivewishes.org](https://www.fivewishes.org)
- To learn more about POLST, visit [polst.org](https://www.polst.org)
- For guidance on having these important conversations with your loved ones, visit [lesturnerals.org/difficult-conversations-can-be-some-of-the-most-important/](https://www.lesturnerals.org/difficult-conversations-can-be-some-of-the-most-important/)

Wills and trusts

Wills and trusts are two types of legal documents that allow you to decide what will happen to your money and assets after your death. Here's how they work:



A **will** is the simplest way to communicate your wishes. In your will, you can state where you want your money and property to go after your death. You can also name an executor (a person to manage your estate after your passing) and name guardians for your children.



If you own property (a home or land), it's a good idea to create a **trust** in addition to a will. A trust gives you more control over when and how your assets, including property, will be distributed to other people. Plus, if you have a trust, your property will not have to go through probate court after your death.

An attorney who specializes in estate planning can help you make a plan that's right for you and create the legal documents you need.

Why do people living with ALS need a will and trust?

Because ALS is a terminal illness, it's important to think through what you want to happen after your passing. By making a will and trust, you can control what happens to your money, your belongings, and any property you own.

If you don't have a will, your state will decide who gets your money. Similarly, if you own property and you don't have a trust, your property will go to probate court. The state or court's decisions might not align with your wishes — and this can create extra stress and legal costs for your family. Having a will in place will make things much easier for your family during this difficult time.

Life insurance

A life insurance policy pays money to your family when you die.

Why do people living with ALS need life insurance?

Life insurance provides income to your family after you pass away. Additionally, some life insurance policies let you use the money while you're still alive. This could help to cover the cost of health care, medical equipment, and other care needs.



It's not possible to get a new life insurance policy after you have been diagnosed with ALS, but if you already have a life insurance policy, check on this important information:



Who is named as the beneficiary on your policy? (The beneficiary is the person who will get the payment after you pass away.)



Are the payments up to date?



Do you have life insurance through your employer? If you stop working, you may lose access to this policy.

Developing financial strategies

Here are a few ways to make managing your finances less stressful.

Take inventory of your finances

Here's how to get started:



List every source of income.



Keep track of your spending.



List your debts.



Make arrangements for ongoing financial responsibilities. Decide who will pay the bills and manage the accounts.

Make a plan

Once you have identified a financial problem, it's time to make a plan and put that plan into action. There are many free or inexpensive online tools that can provide a good framework to help you manage your money. You can link your bank accounts, set goals, and monitor your progress. Most importantly, don't get derailed by setbacks.

Review your statements

When you get explanation of benefits (EOB) statements from your insurance company, set aside time to review them. If you feel overwhelmed or need help organizing your statements, ask a trusted family member or friend for help.

Keep important details together

Create a document to keep track of important personal and financial details in one place, so that your loved ones can quickly find this information if needed. There are free templates available online that can help you get started. Here are a few key pieces of information you may want to include:



Contact information, birth dates, and Social Security numbers for yourself and your family members



Key information about your bank accounts, credit cards, life insurance, and investments (like banking institutions and account and card numbers)



Contact information for anyone else who helps you manage your money and legal affairs (like a financial advisor or an attorney, for example)



Bill due dates and automatic payment (autopay) details



Instructions on how access safe deposit boxes



Login information for your online accounts, like banking websites or apps, patient portals, and Apple or Microsoft accounts.

Tip: Be sure to include the email address or username for each account, along with passwords and answers to security questions.



Locations of important documents like your will, advanced directive, or power of attorney

Coping with financial stress

If you're feeling overwhelmed, you're not alone. Financial stress is incredibly common, especially when you're also managing something as challenging as ALS.

Keep in mind that your journey is your own. There's no "right" way to handle the financial aspects of living with ALS, and you don't have to solve or complete everything today. The good news is there are steps you can take to manage financial stress.

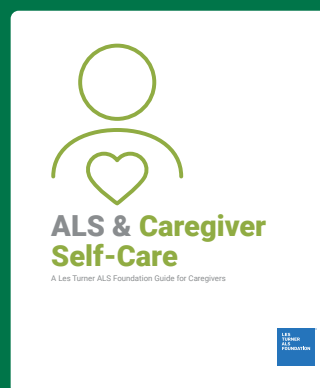
Talk to someone

Money is deeply personal, and it's okay to ask for help. Find someone to talk to about the financial challenges of living with ALS. This could be a mental health professional or counselor, a family member, or a friend. Don't isolate yourself — staying connected to the people you care about can help you feel better.



Take care of yourself

Now more than ever, it's important to be gentle with yourself and keep stress in check. To learn about ways to take care of yourself, check out our self-care guide:



lesturnerals.org/als-caregiver-self-care-guide

Building your team

It's helpful to connect with people who can provide legal, financial, and insurance assistance. Think of them as your team of experts.



Attorney

Look for an attorney who specializes in estate planning, understands the complexities of living with a terminal illness like ALS, and knows about health insurance (especially Medicare and Medicaid). An attorney can help you create a living will and advanced directives. If you're interested in finding an attorney who specializes in elder law, visit naela.com.



Certified Public Accountant (CPA)

An accountant can help you with filing taxes, getting tax benefits, and planning for the future.



Certified Financial Advisor

A financial advisor can help you with investing, managing required minimum distributions for retirement plans and IRAs, and choosing or updating beneficiaries.



Les Turner ALS Foundation Support Services Coordinator

If you attend the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine, our support services coordinators can assist you with SSDI, Medicare, Medicaid, and veterans' benefits. They can also help with advanced directives.



Patient Advocate Foundation

Patient Advocate Foundation is a national nonprofit organization that provides patient services and support to people with complex health conditions like ALS. They also offer a plethora of educational resources, like this helpful guide to Medicare: patientadvocate.org/medicare.



Paralyzed Veterans of America (PVA)

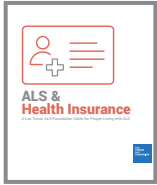
If you served in the military for 90 or more consecutive days of active duty and have been honorably discharged, you will likely be eligible for a variety of service-connected benefits from the U.S. Department of Veterans Affairs (VA). Paralyzed Veterans of America (PVA) can help you get the benefits 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.



State Health Insurance Assistance Program (SHIP)

For help with enrolling in 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.

Additional resources



ALS & Health Insurance Guide

Health insurance helps to cover the cost of medical care for people living with ALS. To learn more about choosing and using health insurance, check out our companion guide, [ALS & Health Insurance](#)



Veterans' benefits webinar

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



Advanced directives webinar

Watch this video from our ALS Learning Series to learn more about creating advanced directives: lesturnerals.org/support-services/als-learning-series-navigating-advanced-directives

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 and 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.

