Kristina, living with ALS.

UNDERSTANDING HEALTH INSURANCE

A Resource to Help You Answer Questions from People Living with ALS and Their Caregivers

AMYLYX®
Rooted in Connection

How to Use this Guide

A Diagnosis of ALS Can Be Overwhelming for People Living with ALS and Their Caregivers

Many healthcare decisions will need to be made. People living with ALS and their caregivers need to build their support network, which may include case workers or disability services in addition to a core medical team.

In memory of Mick, a husband and father, who was a gifted tattoo artist and musician.

This guide is intended to help you engage in conversations about available healthcare resources and planning for current and future healthcare needs. This guide will also provide important information about the health insurance options available to most people diagnosed with ALS. Specifically, the Inflation Reduction Act (IRA) of 2022 ushered in sweeping changes to Medicare. In 2024 and 2025, these changes may significantly reduce out-of-pocket (OOP) prescription drug costs to people living with ALS.[1]

Health plans are structured to cover services through either a medical benefit or pharmacy benefit. It is helpful to consider and distinguish medical and pharmacy needs when reviewing different health plans and what they offer.

As part of a support team, and as an advocate for a person living with ALS, you are in a unique position to identify and discuss ALS-specific types of healthcare and support that will be needed in the days, months, and years ahead.

People living with ALS and their caregivers may have many healthcare insurance options from which to choose

The key to making good health insurance choices is in identifying the immediate and future healthcare needs in the context of financial and other individual circumstances. Healthcare needs should be evaluated annually, as health plans can change what they offer, including prescription drug coverage.

To help people living with ALS make informed choices about health insurance, encourage them to consider a number of factors.

You'll find a comprehensive list of questions on page 13 of this guide. You can also share this helpful **Insurance Guide** provided by Amylyx for people living with ALS and their caregivers. There, they can find information on a variety of insurance topics discussed in this guide.

- What is the current health status of the person living with ALS?
- What is their age and working status?
- What is the current insurance plan?
- What ALS-specific services does the plan cover or not cover?
- Is it possible to make a change in health insurance plans now?
- If not, when?

Medicare

Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services (CMS). Medicare is available for persons aged 65 and older and some people under age 65 with disabilities.[2]

Medicare Eligibility for People Living with ALS

People living with ALS do not have to be age 65 to qualify and they do not have to wait 24 months to be eligible.[2]

- As soon as they qualify and receive their Social Security Disability Insurance (SSDI), people living with ALS are eligible for Medicare[3]

There is no SSDI waiting period for people diagnosed with ALS, which provides quicker access to Medicare services.[3]

SSDI supports individuals who are disabled and have a qualifying work history either through their own employment or through a family member (spouse/parent).

The Parts of Medicare

Part A | Free for those receiving SSDI[2]

Hospital insurance helps pay for:

- inpatient care
- skilled nursing facility care
- hospice care
- some home health care

Part B | There is a monthly premium for Part B[4,5]

Medical insurance helps pay for:

- other medical services not covered by Part A, such as physical therapy and some home health care
- physician services
- outpatient hospital care
- durable medical equipment
- some provider-administered medications

Medicare Parts A and B may be referred to as Original Medicare, Traditional Medicare, or fee-for-service Medicare. Some may also refer to it as "the red, white, and blue card."[6,7]

Optional Coverage

Part D | Drug coverage

Helps cover the cost for prescription drugs and can be purchased from a private health insurance company that adheres to Medicare rules. Read more about Medicare prescription drug coverage on page 4.

Medicare Supplemental Insurance (Medigap)

Extra insurance that can be purchased from a private health insurance company to help pay for OOP costs associated with Medicare Parts A and B (Original Medicare). Medigap plans help cover OOP costs including copayments, coinsurance, and some deductibles. Medigap does not cover prescription drug costs and is only available to individuals enrolled in Original Medicare.

There are 10 standardized Medigap plans available in most states. For people under 65 who have ALS, access to Medigap plans varies among states.

Medicare Coverage Options

There are two ways to access Medicare coverage. When an eligible individual first signs up for Medicare and during certain times of the year, they can choose[6,8,9]:

Original Medical	Includes Part A and Part B Does not include Part D
OR	
Medicare Advantage (also known as Part C)	Includes Part A and Part B and usually Part D May have extra benefits such as vision, dental, and hearing

Coordination of Benefits

Some Medicare beneficiaries will also have other types of health insurance coverage, including a commercial plan through an employer. Coordination of benefits (COB) allows plans that provide health and/or prescription coverage for a person with Medicare to determine which insurance plan has the primary payment responsibility and the extent to which another plan will contribute.

Drug Coverage Under Medicare

Under Medicare, drug coverage is an optional benefit and is provided through private insurance companies.

There are two ways to access Medicare drug coverage. Eligible individuals can:

Enroll in a Medicare Advantage plan that offers Part D drug coverage

Includes Part A and Part B, and most plans provide Part D coverage

OR

Join a Part D stand-alone prescription drug plan

Coverage added on to Original Medicare (Part A and Part B)

Medicare Prescription Drug OOP Costs

OOP costs for prescription drugs in Part D plans may include premiums, coinsurance, and copays. Costs will vary based on the chosen type of coverage.[11]

With any Medicare Part D or Medicare Advantage plan, formularies (the drugs that the plan covers) and OOP costs will vary by insurance plan and may change every year.

People living with ALS and their caregivers can learn more about getting Medicare prescription drug coverage at **Medicare.gov**. For more information, they can also download this helpful **Insurance Guide**.

Inflation Reduction Act (IRA) of 2022

Provisions in the IRA may significantly reduce OOP drug costs in 2024 and beyond. The IRA of 2022, signed into law on August 16, 2022, includes several provisions to lower prescription drug costs for people with Medicare. Lower prescription drug costs may result in lower total OOP costs to Part D enrollees.[1,15]

In 2023, there is a $505 deductible. After enrollees spend $3,100 in OOP costs, they pay a 5% coinsurance for the remainder of the year.[1]

In 2024, there will be a $3,300 OOP cap on prescription drug costs and the 5% coinsurance requirement will be eliminated.[1]

Once they reach the OOP cap, Part D plan enrollees will not pay any additional prescription drugs costs for the year.

Looking ahead to 2025, OOP drug costs will be capped at $2,000 and enrollees will have the option to spread those costs throughout the year.

Provisions in the IRA for Medicare Part D enrollees may bring lower OOP costs to prescription drugs for people living with ALS.[1]

Medicaid

Medicaid provides free or low-cost health insurance to eligible low-income people, families and children, pregnant women, elderly people, and people with disabilities. Medicaid is jointly funded by federal and state governments. Eligibility, benefits, and other details vary greatly by state.[16,17]

Medicaid Eligibility

Eligibility for Medicaid is based on Modified Adjusted Gross Income (MAGI). MAGI is used to determine financial eligibility for Medicaid, the Children's Health Insurance Program (CHIP), and premium tax credits and cost-sharing reductions available through the Health Insurance Marketplace®.[16]

Medicaid Benefits

Every state establishes and administers their own Medicaid program and determines the type, amount, duration, and scope of services within broad federal guidelines.[17]

Federal law requires states to provide certain mandatory benefits, including[18]:

- inpatient and outpatient hospital services
- laboratory and x-ray services
- physician services
- home health services

Optional benefits include[18]:

- prescription drugs (currently included in all state programs)
- physical therapy
- case management
- occupational therapy

Medicaid Prescription Drug Benefits

Although pharmacy coverage is an optional benefit, currently all states provide some level of coverage for outpatient prescription drugs. OOP costs are minimal for Medicaid beneficiaries.[64,65]

Medically Needy Programs

Some states have "medically needy programs" for people with significant health expenses who earn too much to qualify for Medicaid. In states with a medically needy program, the individual will use incurred medical expenses to reduce, or "spend down," income to qualify for Medicaid. After each spend-down period, the individual must re-qualify for Medicaid. Spend-down periods range from 1 to 6 months.[16,19]

Medicaid offers benefits not normally covered by Medicare, including nursing home care and personal care services.[20]

People living with ALS and their caregivers can learn more about qualifying at **HealthCare.gov**. For more information, they can also download this helpful **Insurance Guide**.

Getting Help with Costs: Dual Eligibility, Extra Help, and MSP

Medicare and Medicaid Together (Dual Eligibility)

People who are dually enrolled in both Medicare and Medicaid are known as dually eligible beneficiaries. These individuals may either be enrolled first in Medicare and then qualify for Medicaid, or vice versa.[2]

Coordination of Benefits for Dual-Eligible Individuals

For dually eligible beneficiaries, Medicare will function as the primary payer. Medicaid functions as the secondary payer and is sometimes referred to as the "payer of last resort." People who are dually eligible are automatically assigned to a Medicare prescription drug plan (Part D). This plan covers drug costs instead of Medicaid.[21]

Dual-Eligible Special Needs Plan (D-SNP)

A special needs plan (SNP) is a Medicare Advantage coordinated care plan (CCP) designed to provide targeted care and limit enrollment to special needs individuals.[22]

A D-SNP is a type of SNP that may be available to dual-eligible beneficiaries. A D-SNP coordinates Medicare and Medicaid benefits to make them easily accessible to people who have both. States decide what types of D-SNPs health plans can offer and may review the specific benefits provided.[23]

Other SNPs include:

- **Chronic condition SNPs (C-SNPs)** restrict enrollment to special needs individuals with specific severe or disabling chronic conditions, including ALS[24]
- **Institutional SNPs (I-SNPs)** restrict enrollment to those who, for 90 days or longer, have had or are expected to need the level of services provided in a long-term care setting[25]

Medicare Savings Program (MSP)

Medicare Savings Programs (MSPs) are cost-savings programs administered by individual states. Some Medicare beneficiaries may qualify for one of the 4 MSPs, which can help with Medicare Part A and Part B deductibles, coinsurance, and copayments. Beneficiary income and resources must be below a certain limit.[21]

Learn more

Low-Income Subsidy (LIS)/Extra Help

The LIS, referred to as "Extra Help," is available under the Medicare Part D prescription drug program to help people with limited income and resources pay for prescription drugs.[26]

Program highlights

- Extra Help eligibility is based on income and assets. Extra Help may cover some or all of Part D costs, including premiums, deductibles, and copayments, depending on income and assets[26]
- Dually eligible beneficiaries or those eligible for an MSP automatically qualify for "Extra Help"[21,26]

Prescription costs (as of 2023) with Extra Help will be either $0 or[27]:

Up to $4.15 for each generic drug

Up to $10.35 for each brand-name drug

Qualifying for dual eligibility, Extra Help, or an MSP will depend on the financial circumstances of the beneficiary.[2,21,26]

Commercial Insurance

Commercial health insurance, often referred to as private insurance, is health insurance provided and administered by non-governmental entities. The commercial health insurance market includes both the group market, largely made up of employer-sponsored insurance plans, and the non-group market, referred to here as the individual market.[28]

Health insurance coverage varies by plan; however all plans must include a set of 10 categories of services. These include doctors' services, inpatient and outpatient hospital care, prescription drug coverage, pregnancy and childbirth, and mental health services.[66]

Group Market: Employer-Sponsored Insurance

Many people have health insurance through their jobs. Employers commonly offer group health coverage to employees and their family members.[29]

Should a person living with ALS decide to stop working for any reason, coverage can be continued under The Consolidated Omnibus Budget Reconciliation Act, better known as COBRA. COBRA requires group health plans to provide continued coverage when an employee loses said coverage due to a qualifying event.[30]

If a person living with ALS has a self-funded employer insurance plan (the name of the employer may be on the top of the insurance card) and coverage for treatment is denied, if they are comfortable doing so, they may consider contacting their human resources department to see if anything can be done to help.

Individual Market: Direct Purchase or Marketplace® Plans

People living with ALS may purchase coverage directly from an insurance company or through a federal or state Marketplace.[28,31]

The Health Insurance Marketplace® is sometimes referred to as the federal "Marketplace" or "exchange." Both federal and state Marketplaces provide health plan shopping and enrollment services through websites, call centers, and in-person help.[31,32]

- In most states, the federal government runs the Marketplace
- Some states run their own Marketplaces at different websites
- Marketplace enrollees may qualify for a premium tax credit, which reduces the monthly premiums for insurance coverage; enrollees may also qualify for a cost-sharing subsidy, which is designed to minimize OOP costs for medical services

If a person with ALS has Medicare, or other government insurance, they are not eligible for a Marketplace plan.[33] Medicare beneficiaries may have other, non-Marketplace types of commercial insurance.[14]

People living with ALS and their caregivers can learn about health coverage options at **HealthCare.gov**, a one-stop clearinghouse to check eligibility and benefits for Marketplace plans and Medicaid. For more information, they can also download this helpful **Insurance Guide**.

Veterans Health Administration

The Veterans Health Administration (VHA) is part of the United States Department of Veterans Affairs (VA) and provides health services to veterans. The Veterans Benefits Administration (VBA) provides a variety of benefits and services to servicemembers, veterans, and their families and can help veterans living with ALS to access health service coverage.[34]

VA's prescription benefit program is part of its comprehensive medical benefits package and not a separate, stand-alone program.[67]

Eligibility for VA Service-Connected Benefits

Veterans living with ALS may be entitled to full benefits under the VHA.

The VA recognizes ALS as a service-connected disease, which means that the VA provides financial and medical support to veterans with at least 90 continuous days of active duty. All veterans with ALS are automatically rated at 100% disability if they have served 90 consecutive days of active duty.[3]

When a servicemember is diagnosed with ALS, their condition will be presumed to have occurred during, or been aggravated by, military service and they are therefore entitled to full benefits.[3,35]

VA Service-Connected Benefits[3]

Service-connected veterans living with ALS may receive disability compensation, paid monthly, but this varies depending on the degree of disability and the number of dependents.

Veterans with ALS may be eligible for additional special monthly compensation or grants for Specially Adapted Housing (SAH). Other benefits may include financial assistance for automobiles with accommodations for disability, aid and attendant allowance, medical support and supplies, and other potential support.

VA Benefits and Other Insurance

People living with ALS may have VA benefits and other forms of health coverage, including a commercial insurance plan, Medicare, Medicaid, or TRICARE.[36]

- TRICARE is the healthcare benefit program for active-duty personnel, retirees, National Guard and Reserve personnel, and their family dependents and survivors[37]
- TRICARE provides prescription drug coverage with most TRICARE health plans[68]

People living with ALS who have VA benefits and Medicare are covered by both, depending on where the services are delivered.[36,38]

- To use VA benefits, care must be obtained at a VA medical center or other VA location[39]
  - Pre-authorized services in a non-VA hospital or other care setting may be covered under certain circumstances
- In a non-VA care facility, Medicare may pay for healthcare services, depending on the specific Medicare plan. People living with ALS and their caregivers should check with their Medicare plan to coordinate the best use of benefits[36]

All VA medical centers are required to have an ALS coordinator. The coordinator is the point of contact for veterans with ALS and their caregivers. Their role is to track available resources, help with scheduling, and provide education and tools for navigating VA ALS benefits.[40]

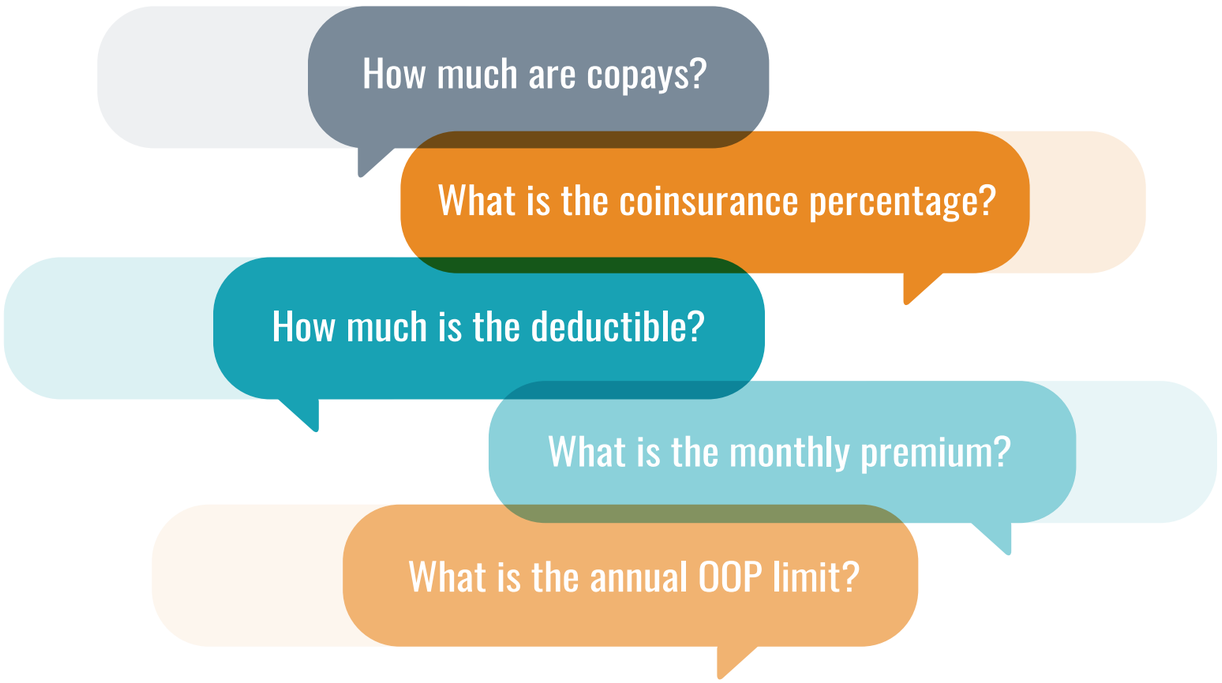
The VHA will cover healthcare needs for veterans living with ALS, while the VBA provides access to non-medical benefits granted for military service and an ALS diagnosis.[34]

Veterans can learn more about VA benefits at VA.gov. For more information, they can also download this helpful Insurance Guide.

Out-of-Pocket Costs and Health Plan Choice

People living with ALS and their caregivers should consider patient cost share, that is, the share of costs covered by the plan that patients pay out of their own pocket, or OOP, when shopping for and selecting among different health insurance insurers and plans.[41]

Patient cost share usually includes copayments, coinsurance, deductibles or similar charges; however, it does not include premiums (the exception is with Medicaid plans where premiums count toward allowable OOP costs), balance billing amounts for non-network healthcare providers, or the cost of non-covered services.[41]



Cost Considerations for Some of the Most Common Patient Cost-Share Methods

Copayment (copay)

Although it varies by plan, copays are generally a fixed amount that a patient pays for a covered healthcare service ***after*** their plan deductible has been paid. Patients should always refer to their summary of benefits for exact copay amounts.[41-44]

Example

The health plan allowable cost for office visit = $100 and the plan's copay = $20.

- If the patient met their deductible, they will pay a $20 copay at the time of visit
- If the patient has not met their plan deductible, they will pay $100, which is the full amount allowed for the office visit

Cost Considerations

- Copayments can vary for different services within the same health plan, eg, medications, lab tests, and specialist visits
- Health plans with lower monthly premiums often have higher copayments, whereas plans with higher monthly premiums, often have lower copayments

Coinsurance

Percentage of costs of a covered healthcare service that a patient pays ***after*** they have paid their deductible.[42,43,45]

Example

Health insurance plan's allowable amount for an office visit = $100 and the patient's coinsurance is 20%.

Cost Considerations

- If the patient met their deductible, they pay 20% of $100, or $20, and the health plan pays the remaining 80%, or $80
- If the patient has not met the deductible, they pay the full allowed amount, which is $100
- Health plans with low monthly premiums often have higher coinsurance, whereas plans with higher monthly premiums often have lower coinsurance

Out-of-Pocket Costs and Health Plan Choice

Deductible

The amount a patient pays for covered healthcare services ***before*** the health insurance plan starts to pay.[46]

Example

A health plan's deductible is $2,000. The patient pays the first $2,000 of covered services. Once the deductible is met, the patient typically pays only a copayment or coinsurance for covered services, and the insurance company pays the rest.

Cost Considerations

- Some health plans may pay for certain services before the deductible is paid, eg, checkup, disease management program, preventive services (eg, blood pressure, depression screening, fall prevention). Patients/caregivers should check their plan details
- Some plans have separate deductibles for specific services, such as prescription medications
- Family plans often have both an individual deductible, which applies to each person, and a family deductible, which applies to all family members
- Health plans with lower monthly premiums often have higher deductibles, whereas plans with higher monthly premiums often have lower deductibles

Premium

The amount a patient pays to their health insurance plan each month for coverage.[47]

Example

The premium for this health insurance plan is $300 per month, or $3,600 for the entire year.

Cost Considerations

- In addition to the monthly premium, patients often have many other costs for healthcare such as deductible, copayments, and coinsurance
- If a patient has coverage through a Marketplace health plan, they may be able to lower their costs with a premium tax credit
- A plan with the lowest monthly premium may not be the best option for some patients. If a patient requires or expects to require substantially more healthcare, a plan with a slightly higher premium but lower deductible may save them money

OOP limit/ maximum

This is the most that a patient would have to pay for covered services in a plan year. Once the patient spends this amount on deductibles, copayments, and coinsurance for in-network care and services, their health plan pays 100% of the costs of covered benefits.[48]

Example

The OOP limit for Marketplace plans varies but cannot exceed a set amount each year. For the 2024 plan year: The OOP limit for a Marketplace plan cannot exceed more than $9,450 for an individual and $18,900 for a family.

Cost Considerations

The OOP does not include the following:

- Monthly premiums
- Money spent on services that are not covered by the health plan
- Out-of-network care and services
- Costs above the allowed amount for a service that a healthcare provider may charge

People living with ALS and their caregivers should consider all of their options. While some health plans may have lower premiums, they may have higher OOP costs or a narrower provider network.[43]

Plans with broader networks may provide patients with more choices, although they may be more expensive.[43]

Enrolling or Making Changes in Health Insurance

People living with ALS and/or their caregivers should review the enrollee's health plan at a minimum of once per year. Many health insurance plans change coverage and premium costs on an annual basis.[49]

When it is time to renew, people living with ALS and/or their caregivers should check that the enrollee's preferred healthcare providers still participate in the health plan network, and they should review any changes to health insurance–related costs.[43,50]

There are 2 situations that allow for enrolling in or making changes to health insurance plan[43,50]:

Open Enrollment Period

- Time when patients can enroll in or change their health plan
- Occurs every year

Special Enrollment Periods

- If a patient experiences a life change, such as a new job, job loss, marriage, or divorce, they may enroll in or change their health plan outside of the open enrollment period

People living with ALS and their caregivers should check what the health plan open enrollment periods are to ensure they do not miss the deadline for open enrollment or renewal.[43,49]

Knowledge is key to selecting the most appropriate health insurance plan. As covered on page 3, patients who are diagnosed with ALS are eligible for enrollment into Medicare the first month they receive SSDI.[51]

Most health insurance plans have specific enrollment dates that should be noted to ensure timely coverage[50, 52-55]:

Plan	Open Enrollment Period	Coverage Begins
Commercial or private health insurance	Patients should check with the plan as dates can vary; usually enroll between September and December	
Health Insurance Marketplace®	November 1 – December 15	January 1
	December 15 – January 15	February 1
Medicare	October 15 – December 7	January 1
Medicare Advantage (Part C) (for those already enrolled in a Medicare Advantage plan)*	January 1 – March 31	First of the month after the plan gets the request
Medicaid	Patients can sign up at any time; plan renewals, which can vary by state, must be completed in a timely fashion to avoid coverage gaps and loss of benefits	

*During this time, people who are already enrolled in Medicare Advantage may[53]:
- Switch to a different Medicare Advantage plan
- Drop their current Medicare Advantage plan and go back to Original Medicare (Parts A & B)
- Enroll in a Medicare Part D PDP if they are going back to Original Medicare

Support for Prescription Drug Coverage

There are several ways healthcare providers and their office staff help to ensure people living with ALS can access prescription drugs. These include:

Benefits Investigation[56]

- Review medical and pharmacy benefits through the patient's health insurance plan(s) to determine the cost to the patient, prior authorization requirements, level of eligibility of the practice or facility to treat, as well as the requirements of the healthcare provider

Submitting the Prior Authorization (PA) Form[57,58]

- To avoid authorization denials and treatment delays, ensure the information is accurate, includes any necessary supporting documentation, and is submitted according to the health plan directions

Requesting a Tier Exception (if Necessary)[57]

- Each health insurance plan has its own process to request a tier exception override so that the patient can obtain a higher-tier medication at a lower cost
- Certain specialty medications may not be eligible for tier exception overrides
  - The healthcare provider, office staff, or patient/caregiver may contact the specialty pharmacist or health plan to determine whether a tier exception override is possible
  - If it is not, other cost-saving options may include patient copay or other assistance programs

Appealing a Health Insurance Denial[57,59,60]

- If a health insurance plan denies treatment coverage, after troubleshooting common reasons for a denied claim (eg, PA form was not submitted, step-through therapy is required, prescribed treatment is off-formulary), an appeal may be submitted to the health plan for reconsideration
- Healthcare providers, office staff, and specialty pharmacies are instrumental in helping patients get access to their medications by gathering additional documentation, speaking with the health plan, following up on appeals, identifying drug substitutions, or contacting human resources for support in getting treatment covered (applies to denials from self-funded employer insurance plans)

Help with Prescription Affordability[61-63]

- **Websites of prescribed medications** often have information about financial support programs
- **Extra Help/Part D Low-Income Subsidy** is available for those financially eligible
- **A tiering exception request** could be made to lower patient costs if a patient has a higher-tier Medicare Part D–covered medicine and their copayment is not affordable
- **State Pharmaceutical Assistance Programs (SPAPs)** are offered by many states to help pay for prescription drugs. Each state program has different program rules

Patients should not assume they are not eligible for assistance programs, even if they have insurance.

Specialty drug manufacturers may provide patient support services. Services may include helping with enrollment in copay programs, performing benefits investigations, educating on the process for submitting PAs, and appealing denied claims.[59]

Key Considerations for Choosing Health Insurance

People Living with ALS and Their Caregivers Should Review and Compare Health Insurance Options Every Year During Open Enrollment

General questions to consider when comparing plan options

- [ ] Does the plan include pharmacy benefits?
- [ ] What are the monthly premiums, annual deductibles, copayments/coinsurances, and maximum OOP costs?
- [ ] Where does the patient reside, and does that impact coverage?

Medically related questions to consider

- [ ] Are the preferred providers in the health plan network?
  - [ ] Is a referral needed to see specialists?
- [ ] Is pre-authorization or a medical review required for certain services?
- [ ] What is the percentage of coverage for each of these services?
- [ ] Will Durable Medical Equipment (DME) be needed, and does the plan cover it? (Anticipate future DME needs for upcoming year)
- [ ] Will ventilator and noninvasive ventilator coverage (ie, BiPAP) be needed and are these covered as respiratory equipment or DME?
- [ ] Will a power wheelchair and/or speech-generating device be covered?

BiPAP, bilevel positive airway pressure.

Pharmacy-related questions to consider

- [ ] Does the plan cover prescription drugs? What are the terms of this coverage, and is coverage different based on using brand-name or generic drugs?
- [ ] Is there a specific pharmacy/supplier network?
- [ ] Does the plan cover the specific prescription drugs prescribed?
  - [ ] Are the drugs on the plan's formulary? (Review plan's upcoming year's formulary, rather than the current year as they can change yearly)
  - [ ] If on formulary, what tier?
  - [ ] What are the OOP costs?
- [ ] Is there a limit on the amount of prescription drugs allowed in the plan?
- [ ] Is there coverage for all FDA-approved drugs, or is coverage provided only for those listed on the plan's formulary?

Home health–related questions to consider

- [ ] Does the plan have home health coverage?
- [ ] Is there coverage for a home health aide (for skilled or custodial care)?
- [ ] Is there a preferred home health agency?
- [ ] Is there private duty nursing coverage at home?
- [ ] Does the plan offer case management?

To help people living with ALS and their caregivers evaluate their options, they can download this helpful **Insurance Guide**.

Common Terms

Assignment of benefit	A healthcare provider agrees to accept payment from a health insurance company first and then bills the patient for any remaining balances.
Catastrophic coverage	Once a Part D beneficiary is out of the coverage gap phase, they enter the "catastrophic coverage" phase, which assures payment is needed only for a small coinsurance percentage or copayment for covered drugs for the rest of the year.
Claim	The information billed to the insurance company for services provided.
Coordination of benefits	A method to determine who pays first when 2 or more health insurance plans are responsible for paying the same medical claim.
Cost-sharing subsidy (cost-sharing reduction)	A discount that lowers the amount patients have to pay for deductibles, copayments, and coinsurance. In the Marketplace®, cost-sharing reductions are often called "extra savings." If a patient qualifies, they must enroll in a plan in the Silver category to receive the extra savings.
Coverage gap (donut hole)	In Medicare Part D, there is a temporary limit on what the drug plan will cover for prescription drugs. The coverage gap begins after the beneficiary and the Part D prescription drug plan have spent a certain amount for covered drugs within a calendar year.
Deductible	The amount a patient pays for covered healthcare services before the health insurance plan starts to pay after the deductible is met.
Durable medical equipment (DME)	Equipment and supplies ordered by a healthcare provider for everyday or extended use. Coverage for this type of equipment may include oxygen equipment, wheelchairs, walkers, crutches, or blood testing strips.
Formulary	A continually updated list of medications and related products that a health plan covers. The primary purpose of the formulary is to encourage the use of safe, effective, and affordable medications.
Formulary tier	The formulary is usually divided into tiers or levels of coverage based on the type or usage of the medication. Each tier will have a defined out-of-pocket cost that the patient must pay before receiving the drug.
Health insurance	A contract that requires a health insurer to pay some or all of an enrollee's healthcare costs in exchange for a premium.
Home healthcare	Healthcare services and supplies patients receive in their home under their healthcare provider's orders. These services may be provided by nurses, therapists, social workers, or other licensed healthcare providers.
Initial coverage period	In a Medicare Part D prescription drug plan, once a patient meets their deductible, the plan will help pay for their covered prescription drugs. The plan will pay some of the cost, and the patient will pay a copayment or coinsurance.
Medical necessity	Medical necessity is a term used by health insurance companies to describe the coverage that is offered under a benefit plan. The policy and benefit summary will describe what is covered under that insurance plan and will generally describe benefits that are available "when medically necessary."
Mandatory generic substitution	The practice of dispensing a generic version of a prescribed brand-name medication without advanced approval of prescriber. Mandatory substitution requires pharmacists to use the generic as a default.
Medical policy	A type of policy that is typically based on the highest level of evidence available and addresses new or evolving technologies, drugs, services, or supplies. The policy usually establishes medical necessity or investigational status for the service, drug, or device being addressed.
Network limitations	Health insurance plans may offer coverage within a limited network of physicians, hospitals, labs, and other healthcare services. If a patient visits a healthcare provider outside of this network, they may have to pay more or all of the provider's billed amount.
Payer	A third-party entity, most often a commercial or government health insurance plan, that pays medical and pharmacy claims.
Pre-determination	A formal review of a patient's requested medical care compared with their health plan's medical and reimbursement policies to determine if the intended care meets the plan's medical necessity requirements.
Premium tax credits	Financial help that lowers a patient's taxes to help them or their family pay for private health insurance. Patients may receive this type of assistance if they get health insurance through the Marketplace® and their income is below a certain level.
Prior authorization (PA)	Health plans and pharmacy benefit managers (PBMs) require prescribers to receive pre-approval for certain prescription medications to qualify those medications for coverage under the terms of the plan's benefit.
Quantity limit	A health plan may limit coverage of a prescription medication to a certain amount over a certain time interval, such as 30 pills per month.
Step therapy	A patient is required to use a certain (usually preferred) therapy before another treatment.

For more information, please consult the following:

ALS Association

ALS Medicare Resource Line

als.pafcareline.org | 1-844-244-1306

ALS Care Services Support Directory

alsa.org/als-care/resources/resource-directory

Medicare

www.medicare.gov

Medicaid

www.medicaid.gov

Social Security

www.ssa.gov

Centers for Medicare & Medicaid Services

www.cms.gov

Veterans Health Administration

www.va.gov/health

Healthcare.gov

www.healthcare.gov

State Health Insurance Assistance Program

www.shiphelp.org

ACT™ Amylyx Care Team

Visit: AmylyxCareTeam.com

Call ACT: 866-318-2989

The above resources are provided by independent third-parties or government agencies.

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