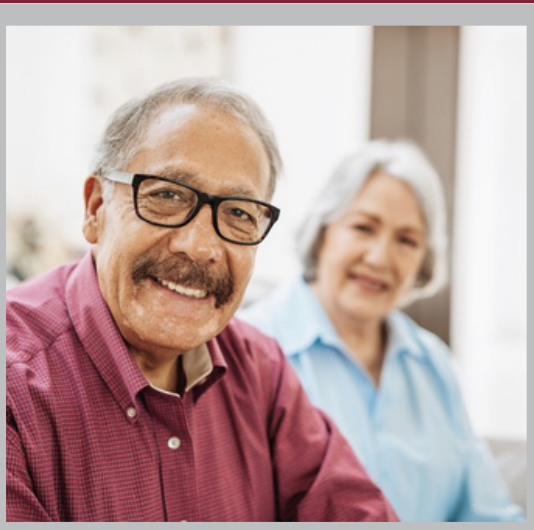








TRIAGE HEALTH

Practical Guide to Navigating Health Care with Amyloidosis

Navigating Employment, Insurance, & Finances



Triage Health provides free education on legal and practical issues to help you navigate health care, through resources, materials, and events. This is especially important when navigating an amyloidosis diagnosis.
Triage Health is a program of Triage Cancer®.

What are Health Care Rights?



Health care rights include a number of separate areas of law, including employment, insurance, government benefits, consumer rights, and estate planning. Some of the topics discussed in this guide are not even thought of as legal issues by most people, such as health insurance. But getting health insurance coverage, consumer protections in the use of coverage, and the right to appeal denials of coverage are all rooted in laws. Lack of awareness of the law and failure to recognize its power to help is a barrier to getting needs met, and contributes to the financial burden of a chronic or serious medical condition, like amyloidosis.

An understanding of your rights can help you get access to the care you need, improve your quality of life, reduce stress and anxiety, and can be the difference between losing your job, your health insurance, or even your home. This guide is meant to serve as an introduction to some of the health care rights topics that most people have questions about after the diagnosis of a chronic or serious medical condition: employment, insurance, and finances.

The details about these laws and programs change frequently. The most up-to-date information about these topics and many others can be found at TriageHealth.org.

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Disclaimer: This guide is intended to provide general information on the topics presented. It is provided with the understanding that Triage Cancer® is not engaged in rendering any legal, medical, or professional services by its publication or distribution. Although this content was reviewed by a professional, it should not be used as a substitute for professional services. © Triage Cancer®

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Health Insurance Basics

Health insurance can be confusing. To understand your options and find coverage that is appropriate for you, there are some health insurance basics that are helpful to know.



Types of Health Insurance Plans

There are two main payment systems when you receive medical care:

- **Fee for service**: A health care provider is paid a fee for each service provided. With these plans, you can go to any provider willing to see you. You pay for a portion of your care and the insurer pays the rest.
- **Managed care**: Health care providers contract with a health insurance company to be a part of its network. If you go to a provider in the network, the provider has agreed to a certain payment rate for treating you (i.e., allowed amount). Regardless of what the provider bills, it's that "allowed amount" that will determine your final cost. You typically pay a percentage of the allowed amount, depending on your plan.

Common types of managed care plans are:

- **Health Maintenance Organizations (HMOs)**: Your health care services start with your primary care physician, and you usually need a referral to see another health care provider, except in an emergency. For example, if you have a skin rash, you first go to your primary care physician. If needed, that physician will refer you to a dermatologist in your network. Generally, HMOs have smaller networks of providers, and providers outside of your network will not be covered by your HMO. While you may have less choice in providers, HMOs are often less expensive.
- **Exclusive Provider Organizations (EPOs):** Generally, you do not need to start with your primary care physician. Typically, EPOs have larger provider networks than HMOs, but will not pay for any services that you get outside of the plan's network.
- **Preferred Provider Organizations (PPOs):** These plans have the largest network of providers, and generally you do not need to start with your primary care physician. While most PPOs have some out-of-network coverage, staying inside your network means lower out-of-pocket costs. Typically, PPOs cost more than HMOs, but you have more choice and control.

When choosing a plan, you should consider your personal needs and the options available in your area. If you may need care at an amyloidosis specialty center outside your area, it is helpful to understand how each plan type handles that.

Terms Used to Understand Health Insurance Costs

Here are terms related to the cost of health insurance that you should understand.

- **Monthly premium:** what you pay each month to have coverage; you pay these costs even if you never receive medical care. It's similar to paying for car insurance but never filing a claim.

Health Insurance Basics

- **Out-of-pocket**:
  - **Annual deductible**: the amount you have to pay out-of-pocket each year before your health insurance policy kicks in. This fixed dollar amount could be any amount, such as $500 or $5,000. Some plans have a $0 deductible.
  - **Co-payment**: a fixed dollar amount you pay when you get medical care. For example, when you visit the doctor, you might have a $20 co-payment; if you go to see a specialist, you might have a $40 co-payment. You usually pay co-payments at the time you receive care.
  - **Co-insurance (aka cost-share)**: a percentage difference in what the insurance company pays for your medical expenses and what you pay for your medical expenses. For example, if you have an 80/20 plan, the insurance company pays 80% of your medical expenses and you are responsible for 20% of your medical expenses.
  - **Out-of-pocket maximum:** a fixed dollar amount that is the most that you will have to pay for your covered medical expenses out-of-pocket during the year. Your out-of-pocket maximum will depend on your plan. It is a very important thing to find out! Generally, you reach your out-of-pocket maximum by paying your deductible, plus any co-payments that you make during the year, plus any co-insurance payments you make. So, it's everything that you pay, except your monthly premiums. Once you reach your out-of-pocket maximum, your insurance pays 100% of your medical expenses for the rest of the year. Most insurance companies only count expenses toward the out-of-pocket maximum that are from in-network providers. Also, some employer-sponsored plans may carve out expenses from the out-of-pocket maximum (e.g., co-payments won't count toward your out-of-pocket maximum).

Example: Out-of-pocket Maximums

Mark was in an accident. He went to the emergency room and then spent a week in the hospital that is in his plan's network. Mark ends up with a $102,000 hospital bill. His health insurance plan has an emergency room co-payment of $250, a deductible of $2,000, an 80/20 co-insurance, and an out-of-pocket maximum of $4,000. How much of that does Mark actually have to pay?

- Mark pays his co-payment of $250 at the time of his emergency room visit, which leaves $101,750.
- Then he has to pay the rest of his $2,000 deductible ($2,000-$250=$1,750), which leaves $100,000.
- Then the insurer will pay 80% of the bill. Mark is responsible for 20% of $100,000, which is $20,000.

However, Mark's plan has an out-of-pocket maximum of $4,000. Because he has already paid his $2,000 deductible out-of-pocket, Mark only needs to pay another $2,000 to reach his $4,000 out-of-pocket maximum and the health insurance company will pay the rest.



Prescription Drug Terms

Here are some helpful terms to understand prescription drug coverage:

- **Brand-name drugs**: A prescription drug with a specific name from the company that sells the drug. A generic version of a drug may be available and sold by other companies, usually after a patent expires.
- **Generic drugs:** A prescription drug that contains the same chemical substance as a brand-name drug.
- **Specialty drugs:** Prescription drugs that have a high cost, high complexity and/or require a high touch.
- **Formulary:** A list of prescription drugs that a health plan will cover and for how much. Using a plan's formulary will help you save money on medications. Some plans have formularies with two or more cost levels, known as tiers. A drug on a higher tier will have higher out-of-pocket costs for you. The highest tier in most formularies is the "specialty" tier. The co-payment and co-insurance amounts will depend on the tier of the prescription drug you are taking. For example, a tier 1 drug may have a $10 co-payment, while a specialty tier drug may have a 30% co-insurance amount.

Generally, if a drug isn't on formulary the insurance company will not cover it. But you may be able to file an appeal called an "exception request" based on medical necessity. There are different types of exception requests:

- Nonformulary drug exception: ask to cover a nonformulary drug.
- Tier exception: ask to treat a drug as if it were in a lower tier, reducing your out-of-pocket costs.
- Brand exception: ask to cover a higher-cost brand name drug even if a generic is available.

Example: Prescription Drug Costs

Noah's Plan:
Deductible = $1,000 / Co-payment = $50 / Co-insurance = 70/30 plan / Out-of-pocket max = $1,500

If Noah has a prescription for a drug that costs $10,000, how much does he pay?

- His co-payment of $50: $10,000 - $50 = $9,950 left
- His remaining deductible of $950: $9,950 - $950 = $9,000 left
- His co-insurance amount of 30%: 30% of $9,000 = $2,700



But his out-of-pocket max is only $1,500. So, after paying the $50 co-payment and the remaining $950 of the deductible, he has paid $1,000 in out-of-pocket expenses and only needs to pay another $500 of the $2,700 co-insurance amount to reach his $1,500 out-of-pocket maximum. His plan will pick up the rest of the costs.

- What does Noah pay next month for his prescription? $0

Health Insurance Basics

Picking a Health Insurance Plan

Finding the right health insurance plan can feel overwhelming. There are a few key things to consider when picking a health insurance plan:

- What will the plan actually cost me?
- Are my health care providers and facilities included in the plan's network?
- Does the plan cover my prescription drugs and the pharmacies I use?

When comparing plans, it can be tempting to just choose the one with the lowest monthly premium. But to figure out the total cost for the year in a worst-case scenario, including your out-of-pocket expenses, you have to do some math:

(Plan's monthly premium x 12 months) + Plan's out-of-pocket maximum = Total Annual Cost

Choosing health insurance is not a one-time activity. You should review your options every year to ensure your plan meets your needs. A plan that met your needs in the past may not meet your needs in the future as your health changes over time. Open enrollment is the time of the year when you can change plans without penalty. The dates for open enrollment will depend on what type of health insurance coverage you have. For example, if you have an employer plan, it will vary, but many employers have open enrollment in the fall for the plan year to start on January 1.

Example: Picking an Insurance Plan

- *Plan A* is an HMO with a monthly premium of $25, an annual deductible of $2,500, a 70/30 co-insurance and an out-of-pocket maximum of $7,000.
- *Plan B* is a PPO with a monthly premium of $100, an annual deductible of $1,500, an 80/20 co-insurance and an out-of-pocket maximum of $4,000.



At first glance, it may seem that Plan A is less expensive because of its low monthly premium. But you have to do the math!

- *Plan A*: ($25 premium x 12 months = $300) + out-of-pocket maximum of $7,000 = Total cost of $7,300.
- *Plan B*: ($100 premium x 12 months = $1,200) + out-of-pocket maximum of $4,000 = Total cost of $5,200.

After doing the math, *Plan B* is actually the more affordable plan if your medical expenses reach the out-of-pocket maximum.

Health Insurance Options

The health insurance options available to you depend on where you live, your age, your employment, your income level, and a number of other factors. Here are some of the main options for health insurance coverage.



Health Insurance Marketplaces

The Patient Protection and Affordable Care Act (ACA) created a new way to buy private health insurance coverage for individuals and families: through state health insurance marketplaces. Originally called “exchanges,” the term “marketplace” refers to a place where you can find health insurance options from private insurance companies. These marketplaces have been compared to an insurance shopping mall. The marketplaces for most states are operated by the federal government at HealthCare.gov. Some states run their own marketplaces.

There are real benefits to shopping for coverage through the marketplace.

- **Out-of-pocket maximum cap**: There is a cap on the out-of-pocket maximum for plans sold through the marketplace, which may be lower than some employer plans. Also, out-of-pocket maximums for all marketplace plans must include everything you spend for deductibles, co-payments, and co-insurance for in-network providers.
- **Standardized plans**: Plans sold through the marketplace are standardized by their level of cost-sharing:
  - **Bronze plans** have a 60/40 cost-share, meaning that the insurance company pays for 60% of your covered medical expenses and you are responsible for 40% of your medical expenses. Bronze plans generally have lower monthly premiums but higher out-of-pocket costs.
  - **Silver plans** have a 70/30 cost-share.
  - **Gold plans** have an 80/20 cost-share.
  - **Platinum plans** have a 90/10 cost-share, with higher monthly premiums but lower out-of-pocket costs.
- **Financial assistance**: Based on your household income level, you may qualify for one or both types of financial assistance. You may receive “premium tax credits,” which lower your monthly premium based on the plan you choose. And “cost-sharing subsidies” can lower out-of-pocket costs, like co-payments, deductibles, and co-insurance amounts.

The marketplace open enrollment period is usually from November 1 to December 15 for plans that begin the following January 1. States that run their own marketplaces may have open enrollment periods that last longer.

Note: marketplace plans may look substantially different in 2027, based on proposed changes to the law.

If you lose coverage or have a life-changing event, you may qualify to enroll during a special enrollment period. You can enroll in a marketplace plan through a 60-day special enrollment period for reasons that include:

- Loss of health insurance (including coverage through work; end of COBRA; or loss of eligibility for Medicaid, Medicare, or Children's Health Insurance Program).
- Loss of coverage through a family member.
- Change in residence (e.g., moving to a new ZIP code or county, or moving to/from school).
- Changes in household.
- Marriage (choose plan by last day of month and coverage will start first day of next month).
- Birth of a baby, adoption of a child, or placement of a child in foster care (coverage starts day of event, even if you enroll in plan up to 60 days later).
- Divorce or legal separation (if this results in losing health insurance).
- Death of someone on your marketplace plan.

If you lose employer-sponsored coverage, you may have a number of options for comprehensive health insurance coverage, even if you have a pre-existing medical condition. These options include a marketplace plan, COBRA, another group health plan, Medicaid, or Medicare. Because you may be eligible for more than one of these options, it is important to compare your options to determine which plan is best for you.

COBRA

COBRA is a federal law that allows eligible employees to keep their existing employer-sponsored health insurance plan after experiencing a "qualifying event." Table 1 lists the qualifying events that may entitle you to continue coverage under COBRA and the maximum length of time you can keep your plan.

COBRA applies to private employers with 20 or more employees and to state and local governments. Federal employees have similar protections under a different law. Many states also have a COBRA law that covers employers with two to 19 employees.

A main barrier to COBRA coverage is cost. Typically, you pay 100% of what your employer was paying for your coverage, plus a possible 2% administrative fee (for a total of 102%). But there may be some benefits to COBRA. For example, if you are in the middle of treatment, with COBRA coverage, you wouldn't have to find a new insurance plan that has the same coverage for your doctors, hospitals, and prescription drugs. Also, if you have already met your out-of-pocket maximum or deductible for the year, it may be less expensive to pay the COBRA premiums and not have any out-of-pocket costs for the rest of the year. You should do the math to figure out which option would cost you less.

Table 1. Qualifying Events for COBRA Coverage

COBRA Qualifying Event	Max COBRA Coverage*
Employment ends or hours reduced	18 months
Loss of dependent child status (i.e., turning 26)	36 months
Covered employee enrolls in Medicare	36 months
Divorce or legal separation from covered employee	36 months
Death of covered employee	36 months

**There are two times when you may be able to extend COBRA coverage. There are also a few times when COBRA coverage may end early, such as when an employer stops offering health insurance coverage to all employees or when an employer goes out of business.*

Health Insurance Options

You must choose COBRA within 60 days of your qualifying event. If you wait until the 59th day, you may have to back pay the premiums for the two prior months, but any medical care that you received during that time should be paid for by your COBRA plan. If you need financial assistance to pay your COBRA premiums, some states have a Medicaid Health Insurance Premium Payment Program that may help. If you qualify for Medicaid, but have access to a group plan through an employer (e.g., COBRA), Medicaid may pay your monthly premium for the group plan.

Another Group Health Plan

You may be eligible for a special enrollment period to move to a group plan that is available to you through another job that you might have, your spouse's group plan, or a parent's group plan (if you are under 26). Check the employer's plan for additional rules.



Medicaid

You may be eligible for Medicaid in your state. Medicaid is a federal health insurance program that provides coverage to individuals with a low income level. If you live in a state that expanded its Medicaid program under the Affordable Care Act and you have a household income under 138% of the federal poverty level (FPL), you may be eligible for Medicaid. If you live in a state that has not expanded Medicaid, eligibility is based on having a low income level, having a low resource level (e.g., assets), and meeting another category of eligibility, such as receiving SSI. Currently, 40 states and Washington, DC, have expanded Medicaid and 10 states have not. Medicaid applications are accepted year-round.

Qualifying for Medicaid Coverage Based on Income Level
If you live in a state (or Washington, DC) with expanded Medicaid, and your household income is:

- Up to 138% of the FPL: You have access to Medicaid.
- Between 138% and 250% FPL: You have access to marketplace premium tax credits and cost-sharing subsidies (if you pick a silver health insurance plan).
- Between 250% and 400% FPL: You have access to marketplace premium tax credits.
- Above 400% FPL: You can buy a marketplace plan, but you do not qualify for financial assistance in most states. Some states provide additional assistance.

If you live in a state without expanded Medicaid, and your household income is:

- Between 100% and 138% FPL: You have access to cost-sharing subsidies (for silver plans only).
- Between 138% and 250% FPL: You have access to marketplace premium tax credits and cost-sharing subsidies (if you pick a silver health insurance plan).
- Between 250% and 400% FPL: You have access to marketplace premium tax credits.
- Above 400% FPL: You can buy a marketplace plan but do not qualify for financial assistance.

Note that the FPL numbers for the current year are used to determine Medicaid eligibility. The FPL numbers for the previous years are used to determine marketplace financial assistance.

Health Insurance Options

Medicare

Medicare is a government health insurance program. To be eligible, you must be 65 or older, have collected SSDI benefits for more than 24 months, or have been diagnosed with end-stage renal disease or amyotrophic lateral sclerosis. There are about 70 million Americans enrolled in Medicare.

Medicare coverage is broken down into four parts:

- **Part A: Hospital Insurance**. Includes hospital care, skilled nursing facilities, hospice care, and limited nursing home and home health care.

- **Part B**: **Medical Insurance.** Includes outpatient care from doctors, preventive care, lab tests, mental health care, ambulances, and durable medical equipment.

- **Part C: Advantage Plans**. An alternative to Parts A and B, it includes the benefits and services covered under Parts A and B, and usually Part D. You can select a PPO or HMO plan that is run by a Medicare-approved private insurance company.

- **Part D**: **Prescription Drug Coverage.** Plans have options depending on where you live, with different premiums and formularies offered by private insurance companies.

Parts A and B together are referred to as Original Medicare.



Medicare Costs

- **Part A:** If you have paid into Medicare while working over your lifetime, the monthly premium is free. If you didn't pay into the system, you will pay a monthly premium. There is an annual deductible. You may also be responsible for paying a co-pay, depending on the number of days spent in a hospital.

- **Part B:** There is an annual deductible plus a monthly premium that is based on your income. The cost-share for Part B is 80/20, which means that once you have paid your deductible, Medicare will cover 80% of your Part B health care costs and you will be responsible for 20%. With Part B, there is not an out-of-pocket maximum. If you enroll in Part B late, there will be a 10% penalty for each year you wait to enroll. (Example: Phil's initial enrollment period ended December 1, 2023, but he waited until December 1, 2025, to sign up for Part B. His Part B penalty is 20%). You also may have to wait until the general enrollment period to sign up.

- **Part C:** The premium cost for Part C is at least the same as Part B or more, but varies based on the plan you choose. The deductibles, cost-share, and out-of-pocket maximums will vary.

- **Part D:** The premiums for prescription drug coverage vary by plan and are higher for people with higher income levels. After paying the annual deductible, you pay 25% of the cost of your covered drugs until you reach a certain amount in total out-of-pocket drug costs. In 2027, that amount is $2,400. At that point, you enter "catastrophic coverage," and you are no longer required to pay anything towards the cost of your covered drugs. If you are having trouble paying for your prescriptions under Part D, you can enroll in the Medicare Prescription Payment Plan. If you do not sign up for a Part D plan when you are first eligible, there are other enrollment periods you may use to sign up, depending on your situation. But you may pay a late enrollment penalty for life.

Example: Prescription Drug Out-of-Pocket Costs

Jamie is nearly 65 years old and is taking an oral amyloidosis medication, which has a cost of $20,000 a month. Because she takes the medication by mouth, at home, it will be covered under Medicare Part D. Her Part D plan has a $34.50 monthly premium. What would be her total out-of-pocket costs?

- Part D monthly premium: $34.50 per month x 12 = $414.00
- Part D deductible: $700
- Part D co-insurance: ($20,000 x 25% = $5,000) x 12 months = $60,000
- Actual cost for Part D and treatment co-insurance = $60,414
- **But, Part D has a $2,400 out-of-pocket maximum (2027), so Jamie will only pay $2,814 for all of her medications for the year.**

If Jamie cannot afford to pay the entire $2,400 in January, she can enroll in the Medicare Prescription Payment Plan (MPPP) to spread out her costs over several months.

MPPP Enrollment	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total Paid
Jamie does not enroll in the MPPP	$2,400	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	**$2,400**
Jamie enrolls in the MPPP in January	$200	$200	$200	$200	$200	$200	$200	$200	$200	$200	$200	$200	**$2,400**

If Jamie is interested in the MPPP, she can sign up with the health insurance company that sold her the Part D plan. Moving forward, she will pay nothing at the pharmacy when she picks up her medication. Instead she will receive two monthly bills from her Part D insurance company, one for her premium and one for her payment plan amount. She can also unenroll from the payment plan at any time. There is no interest charged on the payment plan.

Medigap Plans

A Medigap plan is a supplemental insurance plan that will help pay for your deductibles, co-payments, and cost-share amounts. Plans are labeled A through N, and each plan with the same letter must offer the same basic benefits in most states. The premiums and deductibles vary for each plan. If you choose Original Medicare (Parts A and B), there is a 20% cost-share amount for Part B, so a Medigap plan can help pay for that expense. If you have Medicare Part C, you are not eligible to buy a Medigap plan.

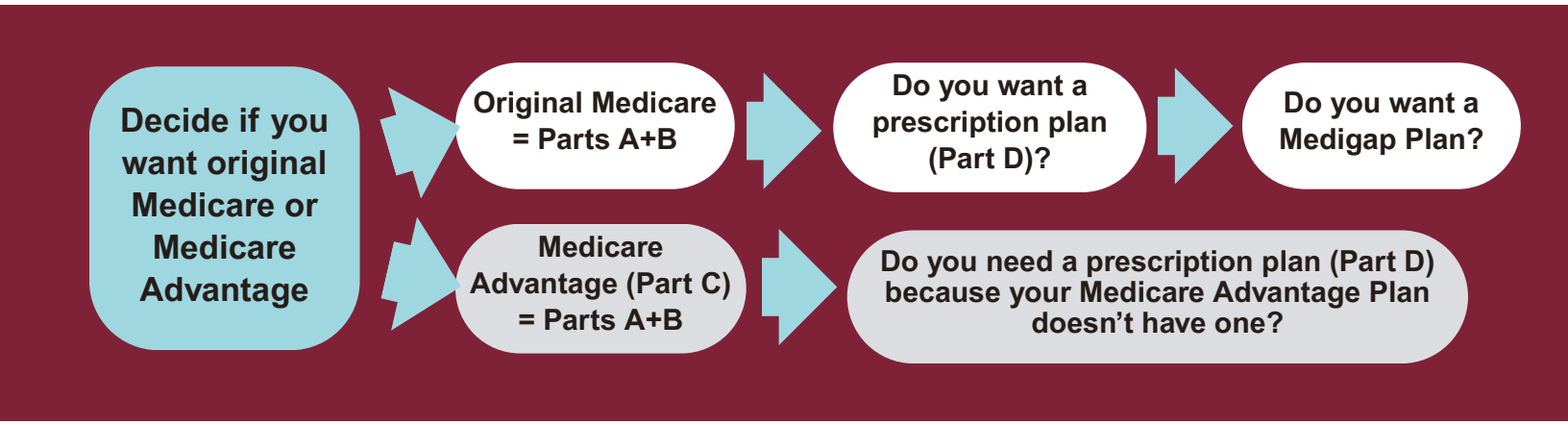
How to Enroll

You can sign up for Medicare during a seven-month initial enrollment period, which begins three months before the month you turn 65, includes the month you turn 65, and ends three months after the month you turn 65. If you do not sign up for Medicare when you are first eligible, during your initial enrollment period, there are other enrollment periods you may use to sign up, depending on your situation. However, you may pay a late enrollment penalty for life.

Health Insurance Options

You can buy a Medigap plan during your Medicare IEP. If you sign up for a Medigap plan during the IEP, you cannot be denied coverage. But if you wait to buy a plan outside of the IEP, you may face a pre-existing condition exclusion period up to 6 months and/or the plan may cost more. Depending on the rules in your state, you may be denied a Medigap plan outside of the IEP, or a special enrollment period.

Renewing a Medigap Plan
Once you have a Medigap plan, it is automatically eligible for renewal each year, regardless of any health problems you may have. Your Medigap plan can only be canceled if you fail to pay the premiums. If you are under 65, and have Medicare because of a disability, your state may not require insurance companies to sell you a Medigap plan. Visit TriageHealth.org/StateLaws for more information.



Considerations for Picking a Medicare Plan
Finding the right Medicare plan can feel overwhelming. There are generally 2 lanes to choose from:

- Original Medicare with Parts A and B, then you can decide if you would like a Part D plan, and then you can decide if you want a Medigap plan.
  - In this lane you can go to any provider around the country that accepts Medicare.
- Medicare Advantage plan (Part C) that includes the benefits of Parts A and B, and usually Part D. If the Advantage plan does not include Part D, then you can also decide if you would like a Part D plan.
  - In this lane you will be limited to a specific network of providers.

There are a few key things to consider when picking a Medicare plan:

- What will the Medicare plan actually cost me?
- Do my health care providers and facilities take Medicare, and if I choose a Medicare Advantage plan, are they in the plan's network of providers?
- Does the Part C or Part D plan cover my prescription drugs and pharmacies I use?

When comparing plans, it can be tempting to just choose the one with the lowest monthly premium. But, to figure out the total cost for the year, including your out-of-pocket expenses, you have to do some math:

(Plan's monthly premium x 12 months) + Plan's out-of-pocket maximum
= Total annual cost

Example: Picking a Plan

Jamie is nearly 65 years old and will also need 1 year of IV treatments, which will cost $10,000 a month. Because the IV treatment will be provided in the doctor's office, it will be covered under Medicare Part B. What would be her out-of-pocket costs?



Option 1: Original Medicare

- Part B monthly premium: $202.90 per month x 12 = $2,434.80
- Part B deductible: $283
- Part B co-insurance (just for her IV treatment): ($10,000 x 20% = $2,000) x 12 months = $24,000
- **Total for Part B and treatment cost-share = $26,717.80**

Option 2: Original Medicare + Medigap Plan G (costs $300/month based on her age and where she lives).

- Part B monthly premium: $202.90 per month x 12 = $2,434.80
- Part B deductible: $283
- Part B co-insurance (just for her IV treatment) = $0 (paid for by Medigap plan)
- Medigap plan G monthly premium = $300 x 12 months = $3,600
- Total for Part B + Medigap Plan G = $6,317.80

Although there's an additional monthly cost to buy a Medigap plan, it can save someone with an expensive medical condition thousands of dollars each year.

Option 3: Medicare Advantage plan with drug coverage (costs $83/month based on where she lives). This plan has an out-of-pocket maximum of $4,758.

- Part B monthly premium: $202.90 per month x 12 = $2,434.80
- Medicare Advantage monthly premium = $83 per month x 12 = $996
- Medicare Advantage co-insurance (just for her IV treatment) = ($10,000 x 20% = $2,000) x 12 months = $24,000 (but she only has to pay up to her out-of-pocket maximum of $4,758)
- **Total Medicare Advantage (MA) Plan and treatment cost-share = $8,188.80**

Although the MA plan is less expensive than Original Medicare (Option 1), Jamie is limited to only going to in-network providers.

Assuming Jamie is interested in Original Medicare with a Medigap plan (so that she can go to any provider around the country that accepts Medicare), she can also do the math to understand the maximum amount she would pay out-of-pocket for *all* of her health care for the year

Maximum Annual Cost	
Original Medicare + Medigap Plan G	$6,317.80
	+
Part D	$2,814.00
Maximum annual cost	= $9,131.80

Health Insurance Options

Evidence of Coverage Documents (EOCs)
If you are enrolled in Medicare coverage, you should receive an "evidence of coverage" (EOC) document each year. The EOC is an important document to help you understand your Medicare plan. It provides an overview of your current coverage, including what your plan covers and how much you pay. Usually, this document arrives during the fall, so you can use it to prepare for the open enrollment period beginning October 15th.

Medicare Savings Programs
You may qualify for one of the four Medicare Savings Programs. Each program has different income and resource limits and provides different levels of help.

- **Qualified Medicare Beneficiary Program**: This program has the lowest income limits but covers the most out-of-pocket costs. It helps pay for Part A premiums, Part B premiums, deductibles, co-insurance, and co-payments.
- **Specified Low-Income Medicare Beneficiary Program:** This program only helps pay for Part B premiums, but has slightly higher individual and married couple income limits than the Qualified Medicare Beneficiary program. It helps pay for Part B premiums.
- **Qualifying Individual Program:** To qualify for this program, you must apply every year. Applications are approved on a first-come, first-serve basis, but individuals who received benefits in the previous year are prioritized. If you qualify for Medicaid, you cannot qualify for this program. This program has higher monthly income limits than the Specified Low-Income Medicare Beneficiary and Qualified Medicare Beneficiary programs. The Qualifying Individual Program helps pay for Part B premiums.
- **Qualified Disabled and Working Individuals Program**: This program accepts applicants who are working, have a disability, and under 65; have lost their premium-free Part A after returning to work; are not getting medical assistance from their state; and meet the income and resource limits for their state. This program has higher income limits than other programs, but lower resource limits. It helps pay for Part A premiums.

The **Extra Help Program** helps individuals with limited income and resources pay Medicare's prescription drug program costs, such as premiums, deductibles and co-insurance. Extra Help also is referred to as the low-income subsidy. If you qualify for the Specified Low-Income Medicare Beneficiary or Qualifying Individual programs, you automatically qualify for Extra Help. In addition, you may be able to receive Medicare and Medicaid, depending on your income and resources.

Medicare and Retirement Plans
If you choose to retire and have Medicare and a retiree group health plan from a former employer, it is important to understand how these plans will work together to pay for your medical expenses. Some retiree plans will require you to also have Medicare Part A and/or Part B. You may also need a Part D plan to cover your prescription drugs. Generally, Medicare will pay first for your medical expenses, and the retiree plan will pay second. Employers are not required to provide retiree coverage, and benefits and premiums can be changed at any time. For more information about your retiree plan, ask your employer or contact your employer's retiree plan.

For more information, visit: TriageHealth.org/HealthInsurance, TriageHealth.org/Medicare, or TriageHealth.org/Medicaid

Accessing Medical Records

It is important to have a complete copy of your medical records. Having a copy will help you ensure the information in your records is correct, coordinate your medical care between your different providers, share information with your family and caregivers, and appeal denials of health insurance coverage.



When Can I Request My Medical Records?

HIPAA is a federal law that gives you the right to receive, inspect and review copies of your medical records and billing records from health plans and health care providers that are covered by HIPAA. You can request a copy of your medical records from your health care provider and/or health plan at any time, for any reason. A health care provider may not withhold access to your medical records even if you have an outstanding medical bill. Under HIPAA, providers must provide a patient with a copy of their medical records within 30 days of their request, or 60 days if records are kept off-site. If the provider cannot either respond or provide the records within this time frame, they can use one 30-day extension.

How Much Does it Cost to Request a Copy of My Medical Records?

HIPAA allows providers to charge reasonable, cost-based fees related to providing you with a copy of your medical records (including the cost of supplies, labor, and postage). You may not be charged if someone else searches for your medical records. Per page fees are not allowed if records are stored electronically. Note: some state laws also allow for fees, and the amounts vary by state.

What Do I Do if I Want to Correct Something in My Records?

If you think there is information in your medical or billing record that is incorrect, you can ask your health care provider or health plan to make a change to your record. Your health care provider or health plan must respond to your request and make the change or addition. If they refuse, you have the right to submit a statement of disagreement that the provider or plan must add to your record.

Who Do I Contact if Denied Access to My Medical Records?

If a health care provider or health plan denies you access to your medical records, contact the U.S. Department of Health & Human Services' (HHS) Office for Civil Rights at (800) 368-1019.

Getting the Right Diagnosis & Specialty Care

Managing a serious condition like amyloidosis often means working with more than one provider, and sometimes getting care or a second opinion at a specialty center far from home.



A few things help keep your care coordinated when more than one provider is involved: keeping a complete copy of your medical records and sharing them with any new provider, getting a second opinion when you want one, and making sure your providers can communicate with each other.

Getting a Second Medical Opinion

Wanting to get a second medical opinion is common, especially for a serious medical condition like amyloidosis. A second medical opinion helps you make informed decisions about your health care, and ensures you receive the most accurate diagnosis and appropriate treatment options available to you. You always have the right to get another opinion about your medical care. You may even be able to get a third or fourth opinion if that is important to you.

How Do I Get a Second Medical Opinion?

- Talk to your current doctor about why you would like a second medical opinion. Your doctor is unlikely to be surprised or offended. Some doctors may even recommend that you get a second medical opinion. Ask your doctor for referrals for another doctor or specialist who can provide a second medical opinion.
- Contact patient advocacy organizations that specialize in amyloidosis. They may have recommendations on how to find another doctor or specialist.
- Contact your insurance company.
  - Ask what their process is to get a second medical opinion. For example, do you need to get prior approval from the insurance company (i.e., a pre-authorization)?
  - Confirm that the referred doctors and specialists are in-network for your health insurance plan.
  - Request a list of in-network providers if you have not found a doctor or specialist who can provide a second medical opinion.
- Request a copy of your medical records from your current health care team and provide them to the provider who is giving you the second medical opinion. Records may include: medical history; imaging tests; biopsy slides; pathology reports; discharge summaries (if you have received inpatient care); a list of all drugs and dosages taken, and a summary of the proposed treatment plan(s)
- Before attending your second opinion appointment, write a list of any questions you have.
  - You may want to ask: How did you arrive at your conclusion? What were the most important factors you considered? How does this compare with other cases you've seen?

Will My Health Insurance Cover a Second Medical Opinion?

Generally, most health insurance plans will cover a second opinion from an in-network provider. Some health insurance plans may even require a second opinion before beginning treatment. However, coverage does depend on the type of health insurance that you have:

- **Medicaid**: Will cover a second opinion for medically necessary surgery that is not an emergency.
- **Medicare**: Will cover a second opinion for medically necessary surgery that is not an emergency. Medicare will also help pay for a third opinion if the first and second opinions are different.
- **Private insurance** (e.g., employer-sponsored or marketplace plans): Will generally cover a second opinion from an in-network provider. If there is no in-network provider to provide a second opinion, you may request a network gap exception from your insurance company to see an out-of-network provider. It will be determined by your insurance company on a case-by-case basis.
- **TRICARE**: You may be able to access a second opinion if you go to your Primary Care Manager (PCM), explain your situation and any questions you may have about the first specialist's suggested care, then ask your PCM to coordinate a referral to another specialist and request a referral from your regional contractor, if necessary.

Clinical Trials

A clinical trial may be an option to discuss with your care team. Clinical trials test new screenings, treatments, or procedures and confirm that they are safe, and for a rare condition they can be a route to newer options. Your care team, the trial site, and amyloidosis organizations can help you find and understand specific trials. You can also search ClinicalTrials.gov.

Qualifying for a Trial

Being eligible does not guarantee you will be accepted, because some trials accept only a set number of people. If you are not eligible for a trial you want to join, you can ask your doctor to request a special exception, though if you are approved that way your results may not be included in the study. The Food and Drug Administration also runs an Expanded Access program that can allow access to drugs or devices that are not yet FDA approved.

Will Insurance Cover a Trial?

This is where people are most often caught off guard, so talk with both the trial site and your insurance company before you enroll. A trial usually has two kinds of costs. Research costs, such as the study drug and study-specific tests, are usually covered by the trial. Routine costs, meaning the regular office visits, blood tests, and scans you would get as standard care anyway, are usually billed to your insurance.

- The Affordable Care Act requires most private plans to cover the routine costs of a qualifying clinical trial, and your plan cannot drop your coverage or refuse to let you take part.
- Plans are generally not required to cover care from doctors or hospitals outside their network if the plan does not normally cover out-of-network care. Some plans cover it at a lower rate, which means higher out-of-pocket costs.
- Government programs follow different rules, so check separately if you have Medicare, TRICARE, or VA coverage.
- Since January 1, 2022, Medicaid covers the routine patient costs of clinical trials and cannot deny coverage based on the state where the trial takes place or whether the provider is in network for Medicaid.

If your plan denies a routine cost it should cover, you can appeal. (See Understanding Appeals.)

Other Things to Think About

Beyond coverage, consider where the trial is located, whether you will have travel or lodging costs, the time commitment, and how it may affect your ability to work or care for your family. If travel is a barrier, help may be available. (See Financial Assistance).

Understanding Appeals

At some point, you may experience a denial of coverage from an insurance company, whether for an imaging scan, prescription drug, treatment, procedure, or genetic test. And, many of us take “no” for an answer. But those who don’t accept the denial and file an appeal may actually win and get coverage for the care prescribed by their health care team.



There are different rules for filing appeals depending on the type of health insurance coverage that you have. Medicare, Medicaid, military, and veterans plans all have specific rules. If you have a private individual health insurance policy or a health insurance policy through work, you generally have two opportunities to appeal a denial of coverage using an internal appeal and an external appeal.

Internal Appeal

When an insurance company has denied coverage for care, you can file an “internal appeal” within your insurance company. Each insurance company has its own internal appeals process, so contact your insurance company for details or look for instructions on how to file an appeal on your denial letter. There are time frames related to filing an internal appeal. If your insurance company denies your internal appeal, you can request an external appeal.

External Appeal

Under the Affordable Care Act, all states must have an external appeals process; this is sometimes referred to as an External Medical Review or Independent Medical Review. State insurance agencies or the HHS administer external appeals through independent review organizations that decide if the insurance company should pay for your medical care. Decisions are binding on the insurance company. If urgent, reviews can be expedited, filed at the same time as an internal appeal and decided within 72 hours, at the latest. The HHS process is free, but states can’t charge more than $25 for an external appeal.

Appeals Timing

Type of Appeal	Reason for Appealing	When Patient Should Submit Appeal	Timeline for Decision from Insurer
Pre-Authorization Appeal	Denial before services rendered. Denial prevented patient from receiving care	Within 180 days	Within 30 days of initial appeal
Post-Treatment Appeal	Denial for payment of care received meaning patient is 100% responsible for any charges	Within 180 days	Within 60 days of appeal
Urgent Care (or Expedited) Appeal	Delay in treatment would seriously jeopardize life/overall health, affect your ability to regain maximum function, or subject you to severe and intolerable pain	Within 180 days But if urgent can ask for external review at same time as internal review	Within 72 hours of receiving appeal

Understanding Appeals

Appeals Before Care Versus After Care

You can file appeals both before and after you receive medical care. The processes for filing an appeal before care and after care are slightly different. An example of when you might get a denial of coverage before you even receive care is when your insurance company requires a pre-authorization before getting care. If your insurance company denies pre-authorization, you can appeal that decision.

Getting Out-of-Network Care Covered

Sometimes the care or specialist you need is out of network. This is common when the nearest amyloidosis specialist or specialty center is not in your plan's network. Two tools can help you get that care covered at your in-network cost, so you pay your regular co-pay or cost-share.

A gap exception is generally used when there are no in-network providers who can meet your needs. The plan may agree to cover an out-of-network provider at the in-network rate, often as a temporary solution until it can add a provider to fill that gap.

A Single Case Agreement (SCA) is a one-time contract between your plan and an out-of-network provider that lets you use your in-network benefits to see them. An SCA is usually the tool when in-network providers exist but don't offer the same specialty, or are too far away, or when you're already in treatment with an out-of-network provider and switching would disrupt your care. An SCA typically lasts only for the length of your treatment.

To request one, start by asking the out-of-network provider if they're willing to work with your insurance company, since they have to agree. Then call the number on your insurance card, ask about a gap exception or Single Case Agreement, and be ready to explain why you need this provider: that you're already in their care, that no one in-network has the same specialty, or that the nearest provider is too far. The plan reviews the request and, for an SCA, negotiates with the provider. If approved, you can see the provider at the in-network rate for a set period or course of treatment.

Rules vary by plan and state. Some state Medicaid programs allow SCAs, and you may have to show the care is medically necessary, so check with your state Medicaid agency or managed care plan. Original Medicare doesn't use SCAs, because you can already see any provider who accepts Medicare, but a Medicare Advantage plan with a provider network may. If your request is denied, you can appeal, using the internal and external appeal steps above.

Tips for Successful Appeals:

- Understand the reason for the denial
- Get full plan benefits language from your insurance company (i.e., Evidence of Coverage)
- Gather evidence of medical necessity
- Enlist the help of your health care team
- Keep track of all phone calls and communications
- If it is urgent that you receive care, file an internal appeal at the same time as the external appeal

Step Therapy Protections

If you are diagnosed with amyloidosis, it is likely, at some point, that you will be prescribed a brand-name medication by your health care team. Your health insurance plan may require you to participate in a process called step therapy. Step therapy means you have to try a lower-cost version of the prescribed drug before "stepping up" to the more expensive drug. If the cheaper drug does not work or you have a bad reaction, you may then be allowed to try the more expensive medication. If your insurance company uses step therapy, it is important to work with your health care team to show that taking a specific drug is medically necessary for you and why the insurance company should make an exception for you.

Though there are currently no federal protections in place against the use of step therapy, many states have their own step therapy protections. States use three kinds of protections: override / exception determination processes; prohibiting step therapy (in some states, or for certain diagnoses); and other protections, such as requiring that step therapy be handled like a preauthorization request or barring insurers from making patients repeat a step therapy they already failed. For an up-to-date list of state laws, visit TriageCancer.org/State-Laws/Health-Insurance-Step-Therapy.

Medicare Part D Prescription Drug Exception Requests

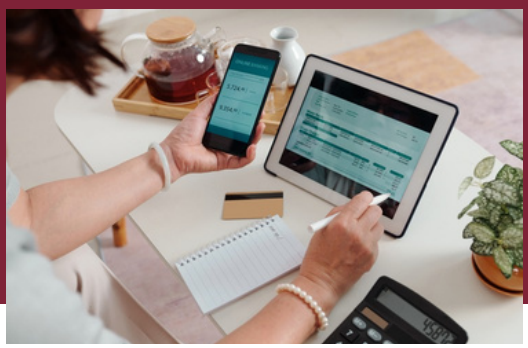
At some point, you may find that a prescription drug you need is not part of your Medicare Part D drug plan's formulary, or that it is on the formulary but carries coverage restrictions (such as quantity limits, prior authorization, or step therapy). In that situation you can ask your plan to make an exception and cover the drug you need.

- **Understand your options first**. Ask your provider whether another formulary drug would work; if you were already taking the drug and the plan no longer covers it, you can request a one-time "transition fill" (at least a 30-day supply) during your first 90 days in a new plan or in a new plan year; and check whether you have an enrollment period to change plans.
- **Know the two exception types**. A tier exception asks that a higher-tier drug be covered at a lower tier's cost. A formulary exception asks that a non-formulary drug be covered, or that a coverage restriction be waived.
- **Get a "supporting statement" from your prescriber**. The provider who prescribed the drug must submit a statement explaining why the drug is medically necessary for you (and, for a tier exception, why lower-tier drugs would be less effective or cause adverse effects).
- **Submit it and, if needed, ask for a fast decision**. You or your provider can make an expedited request if the standard timeframe would jeopardize your life, health, or ability to regain maximum function.
- **Know the timeframes**. Once the plan receives the supporting statement, it must give written notice within 72 hours for a standard request, or within 24 hours for an expedited request. If granted, the plan generally cannot make you re-request the same drug for the rest of the plan year, as long as you stay in the plan, your provider keeps prescribing it, and it remains safe for you.
- **Appeal if denied**. If your exception request is denied, you can appeal and ask your plan to reconsider.

For more information, visit:
TriageHealth.org/HealthInsurance
TriageHealth.org/Appeals

Managing Medical Bills

Medical treatment is expensive. But here are key tips on how to manage your medical bills to help you avoid unnecessary expenses.



Ways to Avoid Higher Medical Bills Before Care

While it is impossible to completely avoid out-of-pocket medical costs related to a medical diagnosis, you can take steps to avoid higher-than-necessary medical bills.

- **Have the right insurance.** Avoid looking only at a plan's monthly cost when choosing a health insurance plan. You should also look at the out-of-pockets costs that you have to pay when you get medical care, such as co-payments, deductibles, and out-of-pocket maximums. You also need to make sure the plan covers your providers, hospitals, and prescription drugs. Reviewing your health insurance coverage is something you should do each year to make sure you have the best coverage for your current needs.
- **Discuss costs with your health care team before treatment.** Your health care team may have suggestions for reducing costs; for example, grouping appointments together helps you avoid extra co-payments for office visits. You might be able to negotiate your medical bill before you receive care. Ask for upfront pricing for all nonemergency tests and procedures and ask if there are any discounts available.
- **Get any necessary pre-authorization.** Many health insurance companies require you to get prior approval (also called pre-authorization, prior authorization, or pre-certification) before you get medical care. If you don't get the pre-authorization, your health insurance company may deny your claim. Make sure your health care team contacts your health insurance company before treatments, testing, surgery, or hospitalization to check if you need a pre-authorization. If your health care team does not request a pre-authorization for you, you are responsible for getting approval from your insurance company. Also, even if you receive approval, it does not guarantee that your insurance will cover your care.
- **Go to in-network providers when possible.** To be a part of a plan's network, doctors and facilities contract with the plan and agree to accept a specific rate for their services under the plan. These doctors and facilities are considered "in network." Doctors and facilities that do not have a contracted relationship with an insurer are considered "out of network." Some PPO plans have limited coverage for out-of-network providers (e.g., 50%). Most HMO and EPO plans pay 0% for out-of-network providers.
- **Leverage out-of-pocket maximums.** If you've reached your maximum for the year, consider getting any other health care you need, rather than waiting until the new plan year, where you will have to meet your deductible and out-of-pocket maximum again.

Communication about Medical Bills

The amount of paperwork generated each time you receive medical care can be overwhelming. Each time you get medical care, you can expect to receive some, or all, of the following items listed below in the mail, by email, or posted in your online insurance account or online electronic medical record offered by your provider.

Managing Medical Bills

From the health insurance company, you may get:

- A letter indicating it has received a claim from the health care provider.
- A letter saying it is processing the claim.
- An EOB (Explanation of Benefits), which details the claim received, how much the provider charged for the particular service (e.g., an X-ray), what the health insurance company is going to pay the provider and what the patient may owe the provider (often called the "patient responsibility"). Generally, EOBs are identified by the statement "THIS IS NOT A BILL" somewhere on the page.

From the health care provider, you may get:

- The bill with an amount that the patient is responsible for paying.

You should wait to send in a payment to your provider until you receive your insurance EOB to make sure that the bill and the EOB match and that they are correct. If you're concerned about missing the due date on the bill while waiting for your EOB, contact your provider and let them know that you are waiting for your EOB.

Reviewing your Medical Bills

Once you've received a medical bill, it's important to review it to make sure it's accurate. Don't be afraid to ask your providers to explain codes or descriptions of services you received. Small errors, such as a wrong number or code, can make a big difference in your bill. Ask for an itemized list of charges, request a copy of your medical records and pharmacy ledgers, and check that everything matches up. If you need help managing your medical bills, consider asking family and friends for help. They can open mail, match EOBs to bills and put payment due dates on your calendar.

Getting Organized

There are many tools available to keep track of your medical bills, EOBs, medical records, and other paperwork related to your medical care. But the key is to use the tool that makes it easier for you to stay organized, whether that is a box with file folders or a three-ring binder. You also should keep track of any communications that you have with your provider and health insurance company. One reason it is important to stay organized is that tracking all of your expenses related to your medical and dental care (including meals, lodging, and travel expenses related to medical care) could save you money. These expenses may be tax deductible, or possibly paid for through a Health Savings Account (HSA) or Flexible Spending Account (FSA).

Paying Your Medical Bills

If you receive a medical bill that you are unable to pay, it is important not to ignore it. Consider contacting your provider to ask for more time or see whether your provider would be willing to negotiate a payment plan or accept a lower lump-sum payment. It is important not to wait too long to contact your provider about an unpaid medical bill. Contacting your provider before unpaid bills get sent to collection agencies can help protect your credit score. Be careful when you're considering paying medical bills with credit cards; they usually have high interest rates, and you could end up spending more than necessary. You should also be careful when considering taking out a home loan to pay off medical debt. Using your home as collateral transfers the debt from being unsecured to secured, which means that the lender could take your home if you are unable to make payments. You may be able to qualify for financial assistance programs to help you pay your medical bills.

For more information, visit:
TriageHealth.org/Financial

Financial Assistance

An amyloidosis diagnosis can create costs that insurance does not fully cover, including copays and coinsurance for high-cost medications, travel to specialty centers, and everyday expenses during treatment. Several types of programs may help.



Copay and Premium Assistance Foundations

- **Patient Advocate Foundation (PAF).** Provides financial assistance for people with chronic and serious conditions.
- **The Assistance Fund (TAF)**. May help with the cost of medications when you cannot afford them; funds are not always open, and patients must meet eligibility criteria.
- **HealthWell Foundation**. Offers disease funds for out-of-pocket treatment costs when a relevant fund is open.
- **Blood Cancer United**. Provides assistance, including financial help, for people with certain types of amyloidosis, and runs a Co-Pay Assistance Program. Eligibility is diagnosis-specific, so confirm whether your diagnosis qualifies.

Manufacturer Support Programs

Drug manufacturers often run patient support programs that may include help navigating insurance, copay support for people with commercial insurance, and patient assistance for eligible uninsured or underinsured patients. Eligibility rules vary, and copay support from manufacturers generally cannot be used by people enrolled in Medicare or other federal programs. Ask your care team or the manufacturer of the specific therapy you are prescribed whether a support program exists.

Travel, Lodging, and Everyday Costs

Because amyloidosis care is often concentrated at distant specialty centers, help paying for travel and lodging can be useful. Nonprofit programs may arrange free or reduced-cost medical air travel and ground transportation, and some hospital-affiliated “hospitality house” programs provide low-cost lodging near treatment centers for patients in active outpatient treatment.

Medicare’s Extra Help Program

If you have Medicare Part D and a limited income, you may qualify for Medicare's Extra Help program, also called the Part D Low-Income Subsidy, which helps reduce your prescription drug costs. You may automatically qualify or need to apply through the Social Security Administration at ssa.gov or by calling 1-800-772-1213.

For more information, visit:

TriageHealth.org/Financial

Your Rights at Work

If you have been diagnosed with amyloidosis or if you are a caregiver to someone with amyloidosis, you may need to figure out how to continue working, take time off, return to work, or even retire. Understanding employment laws and your employer's policies can help you navigate these options and make the best decisions for you.



Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal law that provides eligible individuals with disabilities protection against discrimination. Title I of the ADA protects individuals with disabilities and caregivers from discrimination at work and gives individuals with disabilities access to reasonable accommodations.

Employers Covered by Title I of the ADA

- Private employers with 15 or more employees
- Employment agencies, labor organizations, and joint labor-management committees
- State and local governments of any size
- Employees of the federal legislative branch (e.g., employees of the Senate, House of Representatives, and agencies that support Congress)
    - Note: Employees of the federal executive branch (e.g., United States Postal Service, federal agencies) are covered by the Rehabilitation Act of 1973 (similar to ADA)

Requirements for Employees Covered by the ADA

- Must be "qualified" (i.e., you can perform essential functions of the job, with or without reasonable accommodations) **and**
- Must have a disability (i.e., a physical or mental impairment that substantially limits one or more major life activities)

Major life activities, according to the ADA, are "activities that an average person can perform with little or no difficulty." Activities include physical activities (breathing, hearing, seeing, talking, walking, other motor movements), mental activities (concentrating and learning), and social/professional activities (working or caring for oneself).

When Are You Protected by the ADA?

The ADA provides protections during all phases of employment (including during the job application process) and when all employment-related decisions are being made, including hiring, firing, promotions, pay, benefits, job assignments, bonuses, training opportunities, and leaves of absence.

You are protected against discrimination at work, if you:

- currently have a disability
- have a history of having a disability
- employer regards you as having a disability
- have a family, business, social, or other relationship with a person with a disability (e.g., you are a caregiver).

You also are entitled to reasonable accommodations if you currently have a disability or you have a history of a disability.

Your Rights at Work

What Are Reasonable Accommodations?
According to the ADA, "an accommodation is any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities." Reasonable accommodations are anything that can help you continue to do your job, return to work, or take time off, such as:

- Changing work schedule (e.g., flex time, additional breaks)
- Changing workspace (e.g., telecommuting, ergonomic chair, hand controls on cars, different office)
- Using technology (e.g., tablet, smartphone, screen reading software, speak-type software)
- Changing workplace policies (e.g., allowing an employee with a scar to wear a scarf or hat, allowing more breaks)
- Shifting nonessential job duties to other employees
- Moving to a vacant position, if one is available *(Note: employers are not required to create a new position for an employee with a disability, but you still may make a request).*

The reasonable accommodations that will work best for you will depend on the side effects that you are experiencing, your job responsibilities, and your workplace. Remember that when thinking about accommodations you may need, they must still be "reasonable." One accommodation might not address all of the challenges you are facing, so you can receive more than one accommodation.

Does an Employer Have to Provide a Reasonable Accommodation?
Yes, if you are eligible under the ADA or a state fair employment law. However, an employer does not have to accommodate you if the employer can show that the accommodation you are requesting would be an undue hardship or would pose a direct threat. An undue hardship is when providing the reasonable accommodation would cause the employer significant difficulty or expense. A direct threat is when there is a "significant risk of substantial harm to health or safety of self or others that cannot be eliminated or reduced by reasonable accommodation."

How Should You Ask for a Reasonable Accommodation?
The ADA does not require that you ask for a reasonable accommodation from a specific person, such as a supervisor, another superior, or a human resources (HR) representative. However, it is a good idea to check your employer's policies, often found in an employee handbook, to see whether your employer has a specific process to request reasonable accommodations.

When you make your request, you do not have to specifically mention the ADA or use the words "reasonable accommodation." Your request does not need to be in writing, but having a written record of your request, either by following up the conversation with an email or formal letter, confirming what was agreed upon, may be useful for future reference. Remember, your current supervisor may not always be your supervisor.

Once you make a request, you and your employer should engage in the "interactive process," which involves negotiating and agreeing on an effective reasonable accommodation.

Your need for an accommodation may change over time. For example, you may need a flexible work schedule while in treatment, but after treatment you may need more rest periods during the day. You and your employer should monitor accommodations to make sure they are still working for you. If not, restart the process.



When Should You Ask for a Reasonable Accommodation?
Generally, you should ask for a reasonable accommodation when you realize that you need help to effectively complete your job responsibilities. If you delay the request and your job performance suffers, your employer may decide to let you go based on your poor job performance. But you may avoid this situation if you ask for a reasonable accommodation to help you effectively complete your job responsibilities.

Is Your Request for Reasonable Accommodations Confidential?
Generally, your employer cannot share information about your medical condition or why you have asked for, or received, a reasonable accommodation. But keep in mind that if you ask your supervisor for an accommodation, your supervisor may need to take your request to HR. And, in turn, HR might share information with company leaders, as appropriate. If you start with HR, because you do not want your supervisor to know about your medical condition, then HR can only share with your supervisor that you are getting an accommodation, not why. Coworkers may ask why you are receiving an accommodation, but your employer can only share that you are getting an accommodation, not share information about your medical condition.

Are Caregivers Eligible for Reasonable Accommodations?
Employers are not legally required to provide reasonable accommodations to employees who are caregivers. However, many employers recognize the benefit of keeping a valued employee and avoiding the costs associated with finding a replacement. Therefore, many of the strategies discussed above can be useful options for caregivers as well.

State Fair Employment Laws
Most states have a state fair employment law. Many provide similar protections to the ADA, but some have a broader definition of disability, and some cover private employers with fewer than 15 employees. Below is a chart that lists the states that cover private employers with fewer than 15 employees, as well as how many employees the state requires them to have to be covered.

If a state is not listed here, the state fair employment law is the same as the ADA and requires an employer to have 15 or more employees. Visit TriageHealth.org/StateLaws to learn about the laws in your state.

1	2	4	5	6	8	9	12
AK, CO, CT, DC, HI, IL, ME, MI, MN, MT, NJ, NY, ND, OK, OR (but 6 for RAs), SD, VT, WI	WY	DE, IA KS, NM, OH, PA, RI	CA ID VA	IN (but 15 for RAs), MA, MO, NH	KY, TN (but 15 for RAs), WA	AR (but 15 for RAs)	WV

Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a federal law that allows eligible employees to take up to a total of 12 weeks of unpaid, job-protected, and health insurance-protected leave per year:

- For their own serious medical condition
- For the care of a parent, child, or spouse with a serious medical condition
- For the birth of a son or daughter, and for bonding time with that child
- For placement of a child with the employee for adoption or foster care, and for bonding time with that child
- For any qualifying exigency (such as deployment) when a spouse, son, daughter, or parent is a military member on covered active duty or call to covered active-duty status
- For any combination of the qualifying reasons above

Example: Reasonable Accommodations

Jenny has been working during her chemotherapy treatment, but has been finding it hard to concentrate and remember things. She is concerned it is affecting her work. Jenny works for a sales company and her desk is in a cubicle on a floor of the building with an open floor plan with offices circling the cubicles. There are 2 desks per cubicle with low partitions between the cubicles. What reasonable accommodations could help Jenny continue to do her job effectively?

Jenny may be able to continue her job effectively with the following reasonable accommodations:

- Move to an office with a closed door
- Move to a desk in the corner of the floor plan with less surrounding noise
- Have one desk in the cubicle, instead of two
- Create higher partitions (e.g., wall or bookcase)
- Wear noise-cancelling headphones
- Allow headphones if not normally allowed
- Allow access to an office regardless of seniority
- Telecommute (work from home)
- Shift work hours to 7am to 3pm, when the office is quieter and has fewer distractions



Employers Covered by the FMLA

- Private employers that have or had 50 or more employees during 20 or more workweeks in the current or preceding calendar year
- Public agencies, including local, state, or federal agencies, regardless of number of employees
- Public or private elementary or secondary schools, regardless of the number of employees

Employees Eligible for Leave Under the FMLA

- Work for an employer that has at least 50 employees within 75 miles of the employee's worksite; and
- Have worked for the employer for at least 12 months in the last seven years (note: the 12 months don't have to be in a row); and
- Have worked at least 1,250 hours for the employer during the 12 months immediately before taking leave

What Activities Count as Caregiving?

Caregiving can include helping with activities of daily living, such as:

- providing basic medical, hygienic, nutritional, or safety needs
- providing transportation to and from medical appointments
- providing psychological comfort
- assisting with housework or paperwork
- organizing prescription medication or grocery shopping
- assisting in chores



What Happens to Your Health Insurance if You Take Time Off Under the FMLA?
If you receive health insurance coverage from your employer, your employer must continue to offer you that coverage under the same terms and conditions that were in place before taking leave. For example, if your employer pays 50% of your monthly premium while you are working, they must continue to do so while you are on FMLA leave.

When Should You Ask for FMLA Leave?
Generally, employees should request FMLA leave as soon as they know they need time off work. If the need for leave is foreseeable, employees must provide employers with at least 30 days' notice. If the need for leave is unforeseeable, employees must provide employers with notice "as soon as practicable," usually within one to two days of when the need for leave arises. You should follow your employer's rules for absences unless you are receiving emergency medical care.

How Do You Ask for FMLA Leave?
Check your employee handbook to see if your employer has a process for requesting FMLA leave. Your request for leave does not necessarily have to mention a medical diagnosis, but does need to contain enough information so the employer can determine if you are eligible for FMLA leave. See the following section on disclosure.

If you are eligible for FMLA leave, your employer cannot interfere with your right to take leave. An employer cannot retaliate against you because you are taking FMLA leave. An employer cannot use your FMLA leave against you in decisions related to your job, such as attendance policies, promotion, or discipline.

How Does the FMLA Work With Other Types of Leave?
The ways that federal laws, state laws, and employer policies work together are similar to puzzle pieces fitting together. Except that everyone's puzzle looks different, depending on which laws apply to you, which state you live in, and what benefits are offered by your employer. When thinking about taking time off work, you may have multiple options available to you.

- Some states have passed leave laws, which may offer more protection than the FMLA.
- Your employer can require you to substitute unpaid leave under the FMLA with paid leave or disability insurance benefits that you have available. Even if your employer does not require that you use your paid time off at the same time as the FMLA, you have the option to do so.

The FMLA and the ADA also can work together to give you time off work. For example, if you have used up your 12 weeks of FMLA leave during a 12-month period, you may be eligible for additional time off as a reasonable accommodation under the ADA. Court cases have suggested that additional time off as a reasonable accommodation will be considered reasonable only if the additional leave is for a definite period of time. How long is considered reasonable will depend on your job responsibilities and your workplace. The ADA only applies to private employers with 15 or more employees, as well as state or local governments. If you work for a smaller employer, you may be covered by a state fair employment law.



Your Rights at Work

What Can You Expect When You Return to Work from FMLA Leave?
When you return from FMLA leave, your employer must reinstate you to the same or an "equivalent" job. An equivalent job is one with the same responsibilities, pay, and benefits as the original job.

Your employer can require a medical certification that you are able to return to work, as long as that requirement would be applied to any employee in a similar situation. If at the end of 12 weeks of FMLA leave you are not ready to return to work, you may be able to request additional time off as a reasonable accommodation under the ADA or state fair employment law.



Disclosure, Privacy, & Medical Certification Forms

Choosing to disclose your medical diagnosis in the workplace is a personal decision and should be made only after thoughtful consideration. Some individuals feel very comfortable that sharing their diagnosis in the workplace and in other arenas is right for them. Others have concerns about sharing their diagnosis for a variety of reasons. There is no "one size fits all" answer to disclosure.

- **Online**: Social media platforms and online tools can be a source of information and support. However, it is important to remember that disclosing a medical diagnosis online makes the information public, and many employers search social media platforms and the internet in order to research job applicants and employees.
- **With family, friends, and others**: Once you decide with whom to share your diagnosis, you should consider telling family and friends your preferences about what you are choosing to disclose, so that they don't share your information with others against your wishes. An example of when these disclosure decisions come up is when a family member or a friend wants to host an online fundraiser for you. While crowdfunding may be a useful tool to cope with the financial burden of a medical condition, there are some possible ramifications to consider before starting a campaign, including privacy and keeping access to government benefits.
- **At work**: Whether you already have a job or are looking for a job, you need to make some decisions about what, if anything, you will share at work. Making educated, proactive decisions about disclosure is one way to regain some of the control you may have felt you lost when you were diagnosed.

Legal Protections
You have privacy rights related to your medical information, and these laws protect your rights in different ways:

- **Health Insurance Portability and Accountability Act (HIPAA)**: a federal law that requires your health care providers to get your permission before giving your personal health information to third parties.

Your Rights at Work

- **ADA:** The ADA has specific rules about an employer's access to your medical information. Before making a job offer, potential employers may not ask any questions about your medical condition or general health. After a job offer has been made, employers are allowed to ask you questions about your health history or to complete a medical exam, but only if they would be required of anyone entering a similar job. Employers are not allowed to rescind a job offer based on the results of a medical exam, unless the results show that you cannot perform the essential functions of that job, with or without a reasonable accommodation. Once you are working for an employer, you can be asked only to complete a medical exam or answer questions about your health history when it is "job-related and consistent with business necessity" or if there is a "direct threat" (e.g., requiring an eye exam for a school bus driver).

Your employer is entitled to medical certification from a health care provider to show why you need a reasonable accommodation. But your employer doesn't necessarily need to know about your medical diagnosis if you don't want to share that information. Your employer only needs as much information as necessary to show that you are eligible for a reasonable accommodation. For example, if you are experiencing neuropathy as a side effect, the health care provider could focus on discussing the neuropathy on the medical certification form and not include information about your medical diagnosis.

- **FMLA:** Your employer is entitled to medical certification from a health care provider to show you are eligible for FMLA leave. Again, your employer doesn't necessarily need to know about your medical diagnosis if you don't want to share that information.

Be careful of medical certification forms created by employers, which may request more information than what they are entitled to, such as a specific diagnosis. The U.S. Department of Labor has model forms that can be used for guidance as to what information an employer can request. Note that even the model form asks for the specialization of the health care provider completing the form. So, if you prefer to keep your medical diagnosis confidential, you may not want to have your oncologist complete the form. Under the FMLA, there are multiple health care providers who can complete the form, including primary care physicians or clinical social workers.

Note: Employers may contact the health care provider who completed the medical certification form, as long as the employee's direct supervisor is not the one contacting the health care provider. But the employer is only allowed to ask the health care provider for clarification (e.g., what does line two say) or authentication (e.g., did you sign the form) of the certification form. The employer is not entitled to additional information other than what is included on the certification form.

For more information, visit:

TriageHealth.org/Employment

TriageHealth.org/Caregiving



Disability Insurance

If you have been diagnosed with a chronic or serious medical condition and are undergoing treatment, you may find that you are no longer able to work and earn a living the way that you did before your diagnosis. Disability insurance may provide you with income if you are unable to work because of your medical condition. Disability insurance benefits are offered by the federal government, some state governments, and through private insurance companies.



Federal Disability Insurance

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are federal programs that provide financial assistance to individuals with disabilities. Both are administered by the Social Security Administration (SSA).

If you qualify for disability benefits from the SSA, you must have a disability within the SSA's definition of disability:

- You cannot do your job; **and** you cannot adjust to a new job; **and** your disability has lasted, or is expected to last, for at least one year or will result in death.

SSA uses this process to see if you qualify for disability benefits:

- Step 1: Are you working and is your earnings average more than the Substantial Gainful Activity (SGA) threshold this year? If yes, you will not be considered disabled for SSDI. If no, proceed to step 2.
- Step 2: Is your medical condition severe? If yes, proceed to step 3. If no, you will not be considered disabled.
- Step 3: Is your medical condition found in the list of disabling conditions/impairments? If yes, then you are considered disabled. If no, then the SSA will look at the severity of your condition. If the SSA decides the condition is severe enough, you are considered disabled. If the SSA does not decide the condition is severe enough, proceed to step 4.
- Step 4: Can you do the work you did previously? If yes, you will not be considered disabled. If no, proceed to step 5.
- Step 5: Can you do any other type of work? If yes, you will not be considered disabled. If no, you will be considered disabled.

SSI

You may qualify for SSI benefits if you have a low income level (income limit can vary) **and** are 65 and older, **or** blind, **or** "disabled." The monthly payment for SSI is capped. Most states provide a supplemental payment in addition to that amount. You will receive payments beginning the first full month after becoming disabled. Some states automatically provide Medicaid to individuals who are eligible for SSI. You may be able to receive both SSDI and SSI benefits at the same time.

Disability Insurance

SSDI

You may qualify for SSDI benefits if you are "insured," meaning that you have worked long enough and have paid Social Security retirement taxes to earn work credits. SSDI work credits are based on your total yearly wages or self-employment income. You can earn a total of four credits each year. You can register for a "My SSA" account online to track your credits at ssa.gov/myaccount. Your SSDI monthly benefit is proportional to your salary history, but it is capped at a certain amount each month.

Can You Receive Back Payments or Retroactive Payments?

The approval process for SSDI and SSI can take several months. To make up for the time it takes to approve an SSI or SSDI application, SSA makes back payments, which cover the time between the application date and the approval date. SSA also understands that individuals may not apply until after their disability began, so it also provides retroactive payments for SSDI. Retroactive payments cover up to 12 months from the date of application back to the disability onset date, after a five-month waiting period.

Do You Have to Pay Taxes on Social Security Disability Benefits?

SSI payments are not taxed. You may be responsible for paying income taxes on SSDI benefits, depending on your total household income level.



Can You Receive SSDI and Private Long-Term Disability Insurance?

If you have a private long-term disability insurance policy (LTD) that you either bought directly from an insurance company or that you have access to through an employer, that LTD policy may require you to apply for SSDI. Usually, the LTD policy will begin paying benefits before the SSA decides whether you are eligible for SSDI. If you are denied SSDI benefits, the LTD company may offer to help you with the appeals process, including hiring an attorney for you.

If you qualify for SSDI, you may be eligible for back payments or retroactive payments. If an LTD policy has been paying benefits to you for the same months that SSDI makes back payments or retroactive payments, then the LTD policy will likely require you to repay them for those months. So, it is important for you to wait to see if you need to pay back your LTD policy before spending the back payments or retroactive payments from SSDI.

It is possible to receive benefits from both SSDI and a private LTD policy. However, the amount received from the private policy will be prorated. For example, if your LTD policy pays 80% of your salary and the amount that you receive from SSDI is only 60% of your salary, then moving forward, SSDI will pay 60% of your salary and the LTD policy will pay 20%.

Can You Apply for Social Security Disability Benefits and Unemployment Benefits?

Generally, you cannot be eligible for both Social Security disability benefits and unemployment benefits. Every state's unemployment program requires individuals to certify that they are able to work and actively looking for work, while the SSA requires individuals to be unable to work because of a medical condition. But there are limited exceptions where you may be able to receive both.

Disability Insurance

Are There Programs to Help You Return to Work?
Some individuals who receive SSDI or SSI have concerns about trying to return to work but being unable to work at the same capacity they could prior to a chronic or serious medical diagnosis. They also may be concerned how that will affect their disability and health insurance benefits. SSA has programs to help you try to return to work while protecting your access to disability benefits and the health insurance programs that are tied to those benefits. These programs are called "work incentives," and they vary depending on whether you are receiving SSI or SSDI. The programs include a trial return to work period, vocational rehabilitation, and the Ticket to Work Program.



What Happens When You Reach Retirement Age?
For most SSDI beneficiaries born after 1960, full retirement age is 67. Once you turn 67, your benefits will switch from SSDI to Social Security retirement benefits. In most cases, the amount will remain the same.

Do You Have to Report Changes to SSA?
If you are receiving SSDI or SSI, you are responsible for reporting any changes in your situation to SSA as soon as possible and no later than 10 days after the end of the month in which the change occurred. The types of changes that should be reported to SSA include any changes in work status, household size, address, immigration status, income, marital status, or health status. Failing to report changes in a timely manner could result in underpayment, overpayment (which must be paid back plus a penalty), or payments withheld by the SSA for up to 12 months.

What Happens if Your SSDI or SSI Application Is Denied?
Many applications are initially denied. You can appeal the denial, but make sure to follow the instructions for appealing and any deadlines. Work with your health care team to gather information for your appeal. If you lose your first appeal, there are three additional levels to the appeal process.

State Disability Insurance

California, Hawaii, New Jersey, New York, Rhode Island, and Puerto Rico offer short-term disability programs that last from six to 12 months. You may be able to receive both SSDI and state disability, but check your state rules.

Private Disability Insurance

You can purchase short-term and/or long-term disability insurance directly from a private insurance company. Private disability insurance also may be offered by your employer as an employee benefit.



For more information, visit:

TriageHealth.org/DisabilityInsurance

TriageHealth.org/Caregiving

Retirement Options

There are many reasons why someone might decide to retire early. Health concerns, employment changes, and finances could all play a factor in this decision.



There are some key things to consider when deciding whether to retire, including being able to pay your living expenses, accessing health insurance coverage, and how it affects the taxes that you owe. Some people may also weigh retiring against applying for disability benefits, if the need to leave work is due to amyloidosis. It may be helpful to speak with a financial planner and an accountant before making any decisions about retiring, to help you make the best decisions for you.

How Do You Decide Whether to File for Disability Benefits or Retire?

Based on your age when you stop working, you may be eligible to receive retirement benefits. Retirement benefits typically come from the SSA, a private account, or through an employer pension. You may have access to one or more of these options. Consider speaking with an accountant or financial planner to help you make the best decisions for you.

If you paid Social Security taxes while you were working, you may be able to begin collecting Social Security retirement benefits. Your monthly retirement payment depends on what you have earned over your work history and when you decide to retire: at your full retirement age, before your full retirement age, or after your full retirement age. If you retire early, your monthly payment will be lower than if you wait until your full retirement age. If you wait to retire until age 70, your monthly payment will be higher than if you retire at your full retirement age. You can visit ssa.gov/myaccount to see the amount of your monthly payments if you were to apply for Social Security disability benefits, retire early, retire at your full retirement age, or retire later. You can also call SSA at (800) 772-1213.

Note: You cannot collect Social Security retirement benefits and SSDI. If you are at your retirement age, the SSA will consider your benefits as retirement benefits.

If you have a private retirement account not related to your employer, you should contact the investment company to understand when you can take money out of the account, how much you will receive monthly, and how it will impact your taxes. If you retire after age 59½, the IRS allows you to begin taking distributions from your 401(k) without paying a 10% early withdrawal penalty. If you meet the IRS's definition of having a disability, you can withdraw funds from your retirement account early without the 10% penalty. If you are at least 55 years old, you can withdraw money and avoid the 10% penalty if the 401(k) is from your most recent employer.

If you have a pension, ask your employer about your vested percentage, how the distribution will be made (e.g., monthly, quarterly), and what income taxes you can expect to pay. If you need access to retirement funds early, you may have options, including withdrawing funds from an employer retirement plan through a loan or a hardship distribution, or taking funds out of an IRA, but there are rules and tax implications for these withdrawals.

For more information, visit:

TriageCancer.org/Cancer-Finances **TriageHealth.org/NavigatingFinances**

Other Topics

Learn about some other topics that you may have questions about, such as home modifications, accessing long-term care, and hiring caregivers.



Housing Accommodations and Modifications

If you are diagnosed with amyloidosis and are undergoing treatment, or have completed treatment, you may experience short- or long-term side effects that impact the way you access and use your home.

The Fair Housing Act (FHA) is a federal law that prohibits discrimination in the sale, renting, or financing of housing, to people on the basis of race, religion, national origin, gender, and disability. The FHA defines a person with a disability as an individual with a physical or mental condition that substantially limits one or more major life activities like: walking, seeing, speaking, hearing, breathing, caring for oneself, concentrating, sleeping, or operation of major bodily functions. It also includes individuals with a history of having such a medical condition or being regarded as having such a medical condition. If you are eligible for protection under the FHA, you have the right to request reasonable changes related to housing (reasonable accommodations and reasonable modifications).

Reasonable Accommodations

A reasonable accommodation is the term for changes, exceptions, or adjustments to rules, policies, or practices that can give you “full enjoyment” of the premises. Full enjoyment means that you can have the same benefit from the place you live, as people without disabilities. Generally, the housing provider will cover the cost of a reasonable accommodation.

If you are renting, or you live in a development with an association, a mobile home park, or an apartment complex, you may be helped by a change to, or exemption from, certain rules and policies as a reasonable accommodation. Renters might also benefit from changes to the physical space of their property. Some possible reasonable accommodations in housing include:

- More time to make a payment
- Moving to a ground-level unit or a unit closer to the elevator
- Changing when payments are due to accommodate when you receive income
- Allowing an applicant to submit a housing application a different way
- Allowing an assistance animal, even when the property has a “no pets” policy
- Allowing a caregiver to stay overnight despite restrictions in a lease

Reasonable Modifications

A reasonable modification is the term for physical changes to your private living space or to the common areas that are made to give you full enjoyment of your private space (inside and outside) or the common areas of a multi-unit building. Possible reasonable modifications include:

- Installing a ramp into a building
- Lowering the entry threshold of a doorway or creating wider doorways
- Installing grab bars in a bathroom or hallway
- Lower sinks and countertops

While the law prevents a housing provider from refusing a reasonable request, you will likely have to pay the cost of any physical changes. In addition, the provider might require you to cover the cost of removing the changes when you move out. However, providers may have to cover the cost if they receive government funding to provide housing. If you cannot afford the modification, community resources may be available. For more information about housing rights and resources, visit: TriageCancer.org/Cancer-Finances-Housing.

Long-Term Care

The need for long-term care may arise after an individual has been diagnosed with amyloidosis. This individual may find that they need assistance in performing daily tasks. The need for long-term care may develop gradually as an individual grows older, or may come suddenly after an event like a heart attack or car accident. Long-term care includes various services that help individuals live as independently as possible, even if they are not able to perform everyday activities on their own. Long-term care services may include: home health aides; assisted living facilities; nursing homes; and personal, or custodial, care. Personal, or custodial, care includes services that help individuals with everyday activities, such as bathing, grooming, eating, and transportation.

Individuals can receive long-term care in their home, or in a facility such as a nursing home or assisted living facility. Each of these options has different benefits. Many individuals feel more comfortable staying and receiving care in their own homes. At-home care may be provided by a paid or unpaid family member or friend, or provided by a paid professional caregiver. Individuals may also choose to participate in adult foster care, which allows a person to live in a home environment with a small number of other individuals who need care. Those who participate in adult foster care are cared for by a live-in professional caregiver.

Research has shown that some people who stay in their own homes, have better health outcomes and quality of life, than if they were to move into a facility. However, some people want or need to get care in a nursing home or assisted living facility, which have specialized staff to assist with long-term care needs.

Health insurance does not typically cover long-term care expenses. For example, if you have a private health insurance plan, you will be responsible for covering 100% of the costs of long-term care services. Medicare will only cover short-term or limited amounts of home health care services. Neither private health insurance, nor Medicare, will cover personal care services. This is why people buy long-term care insurance directly from a private insurance company. But when it comes to pre-existing conditions, there aren't the same protections in place in the long-term care insurance arena that there are for health insurance. This means that long-term care insurance companies look at your health history and medical conditions when deciding whether to give you a plan.

- A pre-existing condition is a health problem an individual has before coverage begins. Preexisting conditions can include diabetes, high blood pressure, high cholesterol, and nicotine/tobacco use. Having a pre-existing condition does not automatically bar you from being able to buy long-term care insurance, but it can be an obstacle. The more serious your pre-existing medical condition is, the more likely you are going to get denied. Having a chronic or serious medical condition is not an immediate disqualifier, but it is better to buy long-term care insurance while you are healthy.
- If you buy your long-term care insurance before you develop one of the health conditions listed above, then your policy will cover the care you need for that condition.

If you currently need long-term care and have a preexisting condition, your options to buy long-term care insurance will be limited. One option that you may have is to qualify for long-term care coverage through Medicaid. To learn more about long-term care, visit: TriageCancer.org/Cancer-Finances.

Hiring a Caregiver

Individuals may find that they would benefit from having a caregiver after being diagnosed with a chronic or serious medical condition. If an individual qualifies for Medicaid, they may also qualify for in-home support services that will pay for a caregiver to help at home. Some states also allow for those services to be performed by family members, and then the family members will be paid as caregivers through the program. To find the rules in your state, visit TriageHealth.org/StateLaws.

Support for Caregivers

Caring for someone with amyloidosis can affect your own job, finances, and time. Caregivers have rights and support options of their own.



This section highlights the main ones. For detailed guidance, including a state-by-state look at paid leave, see the full Practical Guide to Caregiver Rights at TriageHealth.org/Guide-Caregiver.

Caregiver Protections at Work

The Americans with Disabilities Act protects caregivers from discrimination through its "association" provision: you are protected against discrimination at work if you are caring for a loved one with amyloidosis. However, employers are not legally required to provide reasonable accommodations to employees because they are caregivers. Even so, many employers recognize the benefit of keeping a valued employee, so it can be worth asking whether flexibility (such as a schedule change) is possible.

The Family and Medical Leave Act allows eligible employees to take up to 12 weeks of unpaid, job-protected leave to care for a parent, child, or spouse with a serious medical condition. FMLA leave can be flexible: you are not required to use all 12 weeks at once. You may be able to take leave in increments as small as a few hours at a time, for example to take a family member to a medical appointment.

Paid Leave Options for Caregivers

Whether any of your leave is paid depends on your state and your employer. Three kinds of state laws can help: kin care laws (which require that, if an employer offers paid sick leave, an employee can use it to care for a family member); general paid leave laws (which require paid leave that can be used for any reason); and paid family and medical leave (PFML) programs (state insurance programs that pay a portion of your wages while you care for a family member). A growing number of states, plus Washington, DC, have PFML programs, and the details, eligibility, benefit amounts, and job protection vary widely. For your state's specifics, see the full Caregiver guide at TriageHealth.org/Guide-Caregiver and the Triage chart of state laws at TriageCancer.org/State-Laws/Taking-Time-Off.

Being a Prepared Caregiver

As a caregiver, you may need to communicate with the care team when the person is in the hospital, help file an insurance appeal, manage medical bills, negotiate payment plans, or submit a disability application on their behalf. Providers, insurers, and agencies may want proof that you are authorized to act for the person you are supporting. A HIPAA authorization form lets you receive medical information and communicate with the care team, and a power of attorney lets you handle financial or medical decisions if the person cannot. It also helps to make sure the person you are caring for has their wishes about medical care and finances in writing, in case they become unable to make those decisions. The Planning Ahead section covers these documents in more detail.

Respite Care and Caregiver Support

Caregivers sometimes need a break. Respite care can come from family, friends, or neighbors, or from professional services such as in-home care agencies, adult day services, and facilities that allow short-term stays. Caregiving can also be stressful, and support is available.

For more information, visit:

TriageHealth.org/Caregiving

Planning Ahead

Estate planning is a process that involves thinking about your wishes related to your health and finances, and then documenting those wishes to ensure that they will be carried out.



Most people think that you only need to plan your estate if you have a lot of money or property. But really, estate planning can be useful for every adult over the age of 18. Although it can be difficult to think about your mortality, creating an estate plan allows you to express your deeply held values and personal preferences. Thinking about these decisions and preparing in advance can provide you with the peace of mind that your loved ones will know your wishes. Although estate planning plays a crucial role in financial and health care decisions, many people do not have the most basic document, a will. But there are a number of documents that could make up an estate plan.

Wills

A will is a legal document that provides instructions for what an individual would like to have happen to their property upon death. A will is also a place where parents can name a guardian for any minor children or adult children with developmental disabilities. Each state has different rules about how to create a valid will, so it is critical to check the rules in your state. There are different types of wills:

- **Written:** Most states require that:
  - your will be in writing;
  - you be of "sound mind;" "Sound mind" generally means you have an understanding of what you are doing.
  - you sign the will; and
  - it be witnessed by an "uninterested party" (i.e., someone who is not getting anything in the will).
- **Statutory:** Some states (California, Maine, Michigan, New Mexico, and Wisconsin) have a statutory will form, which can be filled in with the details of your estate plan and your wishes. Will forms are free and you don't have to hire an attorney. But, they can't be customized, so they are better for simpler estates.
- **Oral:** Generally, oral wills are only allowed in very limited and unusual circumstances (e.g., statements made on one's deathbed).

There are several do-it-yourself will options, if you have a relatively simple estate, or cannot afford an attorney. There are online services, books, and computer software that can cost anywhere between $35-$200.

You may also want to consider hiring an estate planning attorney, especially if you have a complicated estate. When an attorney helps you create a will, you will typically be charged a flat fee or an hourly rate. How much it costs depends on factors such as the size of your estate or how complicated your wishes are. There are legal aid organizations that provide free or low-cost legal services for people with low and moderate-income levels.

When you write a will, you should also consider who you want to be the executor of your will. This is the person who will make sure that your property is distributed according to your will.

You can change or revoke (cancel) your will at any time, as long as you are of sound mind. A codicil is a legal document that you can use to make changes to your will, and can be used for minor changes (e.g., adding a particular gift or updating the legal name of one of your beneficiaries after they get married). Codicils must be executed in the same way that wills are in your state. For example, if a state requires that a will be signed by two witnesses, the codicil must also be signed by two witnesses.

If you need to make more substantial changes (e.g., completely removing a beneficiary or adding a new child as a beneficiary) you may want to consider revoking (cancelling) your current will and writing a new one. Generally, if you create a new will, you should destroy any older versions to avoid any confusion or doubt.



Trusts

A trust is a document that allows you to hold assets for one or more beneficiaries. A beneficiary is a person who receives the benefit of the assets in the trust. You can choose a "trustee" to oversee the assets in the trust, or you can act as your own trustee during your lifetime. Property that can be placed in a trust includes real estate, cars, bank accounts, stocks, art, and jewelry. When you place property into a trust, legal ownership is transferred from you to the trust itself. Then the trustee has a legal responsibility to manage the property in the trust the way that you specified in the trust document. The most common types of trusts are:

- **Living trust:** created while you are alive and is revocable until your death. Typically, you act as your own trustee, and while you are alive, you can make any changes for any reason.
- **Testamentary trust**: used to provide for individuals who need help managing their assets. Testamentary trusts can be especially useful to parents who have young children and want to provide for future education, health care, or general support. They may also be helpful in meeting ongoing expenses for dependent adults with special needs while safeguarding their government benefits (e.g., Medicaid).
- **Irrevocable trust:** cannot be changed or revoked once created but may provide some tax benefits and protection from legal action or creditors.
- **Special needs trust**: can be used to meet the needs of an individual with a disability. The advantage of these trusts is that the assets in the trust are not considered "countable assets" for purposes of qualification for certain governmental benefits (e.g., Supplemental Security Income (SSI) or Medicaid). If you are considering creating a trust, you should consult an estate planning attorney who is experienced in your state's trust and tax laws to ensure that your trust is set up properly.

Powers of Attorney for Financial Affairs

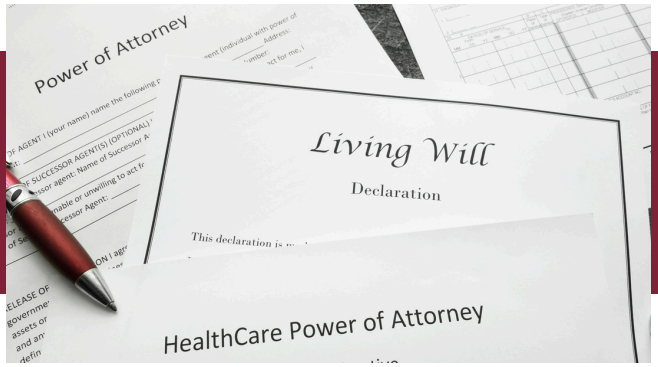
There may be a time when you become unable to make financial decisions for yourself and you may need help. A Power of Attorney for Financial Affairs is a legal document where you can authorize a trusted adult to make financial decisions for you. Those decisions could be as simple as depositing or withdrawing funds from a bank account, or handling other personal matters, such as receiving mail or making travel arrangements. A durable Power of Attorney for Financial Affairs takes effect when you sign it and stays in effect even if you become incapacitated in the future, but it ends when you pass away. That is when your will takes over. A springing Power of Attorney for Financial Affairs "springs" into effect only if you become incapacitated.

Advance Health Care Directive

There may come a time when you can no longer express your wishes about your medical care. An advance health care directive is a legal document in which you can share your preferences and provide written instructions about your medical care, if you become unable to communicate.

You can make decisions about whether or not you want to stop medical treatment at a future time when treatment may not be useful (e.g., stopping chemotherapy once it stops working). However, they can also be used to ensure the start or continuation of treatment at a future time when you may not be able to verbalize your consent (e.g., starting artificial hydration). You can also appoint a trusted adult to make medical decisions for you in the event you are unable to communicate.

When making decisions about end-of-life care, there are other resources that might be useful. The POLST (Physician Orders for Life Sustaining Treatment) Paradigm encourages patients to talk with their health care providers about the kind of care they want. After talking, they document those decisions in a POLST Form, which can be used by emergency health care providers if patients are unable to speak for themselves. Depending on the state that you live in, a POLST Form might be called by another name.



HIPAA Forms

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that protects the privacy of your health information. HIPAA does allow your protected health information to be shared with your personal representative who has authority to make health care decisions for you (i.e., your health care agent or proxy). To guarantee your agent's access to information, a HIPAA authorization form must be signed and dated by you. Also, it must identify the information to be disclosed, the purpose of the disclosure, the recipients of the information, and an expiration date. This means that any advance health care directives should be clear about the scope of your agent's authority to receive protected health care information.

There are some other key reasons why it can be helpful to have a HIPAA authorization form. For example, if you have children over the age of 18, they may want you to be involved in their medical care, or have access to their medical information. Once your child turns 18, you no longer have the authority to make medical or financial decisions on their behalf. Your child could sign a HIPAA form to give you access to their medical information and communicate with your health care team. Also, if you are in a relationship with another person who is not your spouse, and that person would like you to have access to their medical information, they should have a HIPAA form. Or, perhaps your best friend would like you to be able to communicate with their health care team. In that case, their HIPAA form should give you that ability.

As an agent, you should make sure that you know where important documents (e.g., advance health care directive or will) are kept as well as how to access accounts, safety deposit boxes, and storage units, if relevant.

Hospital Visitation Directives

Most hospitals are required by federal law to have written rules that give patients the right to choose their own visitors. But, in a crisis, or a moment when you are not able to communicate your decisions, it can be helpful to document your wishes about who you would like to visit you in a hospital. You can do that by creating a Hospital Visitation Directive. This document tells your health care providers to allow your chosen visitors to visit you. It can be a separate document or part of another document, like an advance health care directive. You can also use this document to exclude certain individuals if that is your choice.

Life Insurance

Life insurance is insurance that individuals can buy to provide a specific amount of money to a person (or persons) of their choosing, in the event of their death. A main purpose of life insurance is that individuals can ensure that their loved ones are taken care of financially when they pass away. It can be difficult to purchase life insurance after an individual has been diagnosed with amyloidosis, but not impossible. Life insurance companies are permitted to refuse to sell policies to people with pre-existing medical conditions. Because life insurance consumers do not have the same protections that are available in the health insurance arena, it is left up to each insurance company to decide if, or when, they will insure someone who has been diagnosed with a serious medical condition.

There are many companies in the United States that offer some level of coverage to individuals diagnosed with a serious medical condition. The only way to know which companies sell those policies is to contact the insurance companies that offer policies in your state and ask them. You can find which companies sell life insurance policies in your state by contacting your state's insurance agency here: TriageHealth.org/StateResources. Some state insurance agencies list the life insurance companies on their website.

Sometimes, there are other options available for getting a life insurance policy, such as getting a group policy through an employer, a professional association, or an alumni association, where they may not ask medical questions and do not impose pre-existing condition exclusions.

For more information, visit:
TriageHealth.org/EstatePlanning

Conclusion

This practical guide addresses the most common issues that arise after an amyloidosis diagnosis. However, it only scratches the surface of the legal and practical issues that patients and their caregivers may have to address. Triage Health provides information and resources on all of these topics and more for free.

We believe that when patients, their caregivers, and their health care professionals have a better understanding of how to obtain and use insurance coverage, appeal denials of coverage, take time off work, access workplace protections and accommodations, plan ahead, and manage other financial issues associated with medical care, quality of life and outcomes improve.

Everyone should have access to the resources they need to manage their life beyond diagnosis - regardless of their medical condition, where they live, or their financial situation.

TriageHealth.org

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