



A Caregiver's Guide to Understanding Health Insurance Options for Spinal Muscular Atrophy



Using this guide

Facing a diagnosis of spinal muscular atrophy (SMA) for your child can feel overwhelming. A diagnosis of SMA means there is a lot of information to think about, including understanding the different health insurance options and programs that are available to support your child's care. Learning about the choices that are available and determining which ones best fit your child's needs is important to beginning the path to coordinated care from your child's healthcare team.

This guide will help you learn more about



Different types of health insurance (also called *health plans* in this guide)



What to consider when choosing a health plan



What your plan may cover



What you may pay



How coverage works



Finding help to pay for your child's care



Resources to support children with SMA and their caregivers



Coverage questions to ask your health plan



Insurance words you should know

Definitions for words in bold can be found on pages 22-23.

Table of Contents

1. Understanding the different types of health insurance.....	4
2. Health insurance coverage considerations for patients with SMA	11
• What to consider when choosing a plan	
• Plan coverage	
• What you may pay	
• Understanding how coverage works	
3. Finding help to pay for your child’s care.....	17
4. Resources to support families living with SMA.....	18
5. My health insurance worksheet	20
6. Important health insurance terms you need to know.....	22

Understanding the different types of health insurance

Types of insurance options

There are many different types of health insurance options that may help cover the cost of care for people with SMA. They may provide different levels of coverage and operate in different ways. These types of insurance include

- **Private health insurance, also called *commercial health insurance***

There are many types of private health insurance plans, such as

- Health Maintenance Organization (HMO)
- Exclusive Provider Organization (EPO)
- Preferred Provider Organization (PPO)
- Point-of-service (POS) plan
- Indemnity, also called *fee-for-service*
- High **deductible** health plan
- Tiered **provider network**

- **Government-funded health insurance**

This is insurance that is funded by the state or federal government and includes

- **Medicaid**
- Children's Health Insurance Program (CHIP)
- **Medicare**



You may be able to get one or more of these types of health insurance to help cover the cost of your child's care.

About commercial health insurance

There are many different types of commercial health insurance plans. Each type of plan provides varying levels of coverage and operates in a unique way. You may get commercial health insurance from your employer or union, but you can also purchase it from a private insurance firm or an insurance exchange.

Commercial health plans are all different and may have their own specific costs for **premiums, out-of-pocket costs, out-of-network providers**, and much more. Call your health insurance plan to learn more about the services your plan covers.

What are the different types of commercial health insurance plans?

The table below can help you understand generally how each type of commercial health insurance plan works.

	Has a network of providers?	Need a referral to see a specialist?	What happens if I need out-of-network care?
Health Maintenance Organization (HMO)	Yes	Yes	HMOs cover out-of-network care if <ul style="list-style-type: none"> • The HMO's network of doctors do not have the experience to treat a certain health problem • A network doctor refers you to an out-of-network doctor • You have an emergency
Exclusive Provider Organization (EPO)	Yes	No	EPOs do not include out-of-network care, even when the plan's doctors do not have the experience to treat a certain health problem. EPOs must pay for out-of-network care if you have an emergency.
Preferred Provider Organization (PPO)	Yes	No	PPOs provide out-of-network care but may not pay for the full cost of treatment. If you choose to see an out-of-network doctor, you may have to pay for some of your treatment, even if you have an emergency.
Point-of-service (POS) plan	Yes	Sometimes	POS plans provide out-of-network care, but you may have higher costs for out-of-network providers.
Indemnity, or fee-for-service	No	No	Not applicable.

Other types of health plans you may need to know

High deductible health plan. This type of plan has a higher deductible than other types of plans; however, its monthly premium is usually lower. A higher deductible means that you will have to pay more money out of your pocket before the insurance plan will pay for any healthcare expenses. There are ways to help pay for the expenses in a high deductible health plan, such as health savings accounts or a health reimbursement arrangement, which puts aside pretax money to pay for some medical expenses.

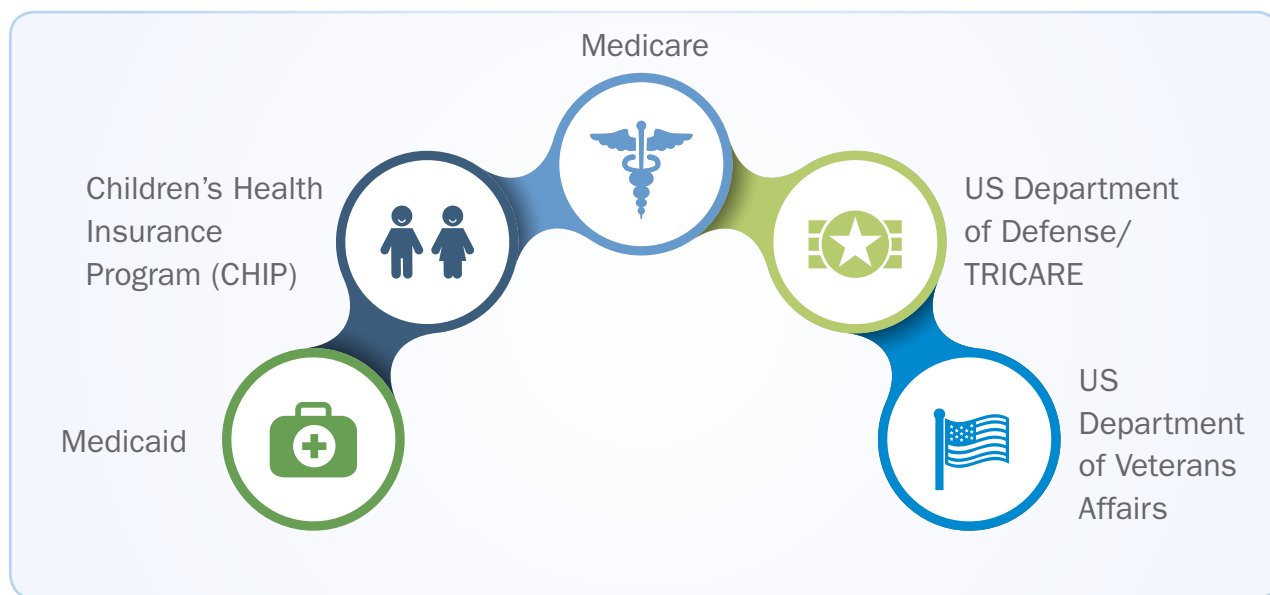
Tiered provider network. This type of plan separates healthcare providers (HCPs) based on quality and costs. For example, a patient may pay less when they are treated by an HCP that has a higher quality and lower cost.



Call your health insurance plan to learn more about the services your plan covers. The number to call is on the back of your insurance card.

Government-funded health insurance

Many people get health insurance through a program that is funded by the state or federal government. These programs include



If you have a child with SMA, Medicaid or CHIP are the programs that will most likely help you pay for the cost of your child's care.

Medicaid

Medicaid provides low-cost or free health coverage to millions of Americans, including



People with low income



People with disabilities



Pregnant women

Medicaid can help you afford medical costs for SMA and other conditions by offering



Hospital visits



Home healthcare



Doctor or nurse visits



Medical tests



X-rays



Transportation
to medical care

Medicaid is administered by your state. This means that each state has different requirements for income, the number of people in your household, family status, and other factors. Your state may also help pay for other care, such as



Medicines



Breathing care



Physical therapy



Occupational
therapy



Chiropractic
services



Prosthetics



Case management



Medicaid provides coverage for many people with severe disabilities, including children who live in families with a low income.

Supplemental Security Income

Supplemental Security Income (SSI) is a federal income supplement program that helps adults and children with disabilities who have limited income.

SMA is a condition that fits the criteria for disability to qualify for SSI, which includes children younger than age 18 with a physical or mental condition that

1. Causes serious functional limitations
2. Can lead to death
3. Has lasted, or can be expected to last, for 12 months or more

SSI also considers income and resources. As parents of a child with SMA, SSI will look at a part of the income and resources of you and your spouse to see if your child can qualify.

What SSI assesses to see if you qualify	Description
Income	<ul style="list-style-type: none"> • Includes your pay, Social Security benefits, pensions, food stamps, and nonprofit housing • Amount is set by each state
Resources	<ul style="list-style-type: none"> • Includes bank accounts, cash, investments such as stocks and bonds, and real estate (except your current home) • Does not include your current home and the land it is on, your primary vehicle, household goods, personal property (such as wedding rings), and any educational funds (such as grants or scholarships) • Resource limits are \$2,000 or less for an individual/child and \$3,000 or less for a couple

Once you are accepted for SSI, you may also be able to get other government programs such as Medicaid, food stamps, and more social services.



Signing up for SSI will help you get enrolled in Medicaid and other programs. To learn more about SSI, visit www.socialsecurity.gov or call 1-800-772-1213.

Children's Health Insurance Program

Children's Health Insurance Program (CHIP) provides low-cost coverage for children in families that earn too much money to qualify for Medicaid but cannot afford other health insurance plans. Children who qualify for CHIP will not need to buy an insurance plan. If your child is younger than age 19 and has SMA, he or she may be able to get CHIP.

CHIP can help you afford medicines and treatments for medical conditions by covering

- ✓ Doctor's visits
- ✓ Checkups
- ✓ Immunizations
- ✓ Medicines
- ✓ Dental and vision care
- ✓ Hospital visits
- ✓ Medical tests
- ✓ X-rays
- ✓ Emergency services

Not all doctors accept patients who have Medicaid or CHIP. You may want to ask the office staff if they accept Medicaid or CHIP when you make an appointment. If you have trouble finding a doctor, your CHIP plan can help you.



CHIP provides health insurance for children. To learn more about CHIP, visit www.medicaid.gov.

Understanding commercial insurance and Medicaid together

People with SMA may have commercial health insurance at the time of diagnosis. Many children who have been diagnosed with SMA can also get Medicaid to help pay for costs that commercial health insurance does not cover.

If your commercial insurance plan does not cover certain medical costs or equipment, you may consider applying for Medicaid to help address those coverage limitations and exclusions. The first step in becoming eligible for Medicaid is an official verification of your child's disability by Social Security (see page 8). In most states, if a person with SMA is eligible for SSI benefits, he or she is automatically enrolled in Medicaid. If your state does not automatically enroll your child in Medicaid, you will need to apply with another agency. Social Security will direct you to the appropriate office.

If you need to enroll in Medicaid

How to apply: Contact your state Medicaid office to determine how to apply for Medicaid. You can find your state Medicaid office by visiting [Medicaid.gov](https://www.Medicaid.gov) or by calling 1-877-267-2323 and following the prompts to get the phone number for your state's office.

What you need to have available: Each state has different Medicaid application requirements, so you should check with your state office. There is general information that will be required, such as

- Your child's name and date of birth
- Documentation of disability status from Social Security
- Social Security numbers for your child and both parents
- Information about your current commercial health insurance
- Information about incomes from work and any other source

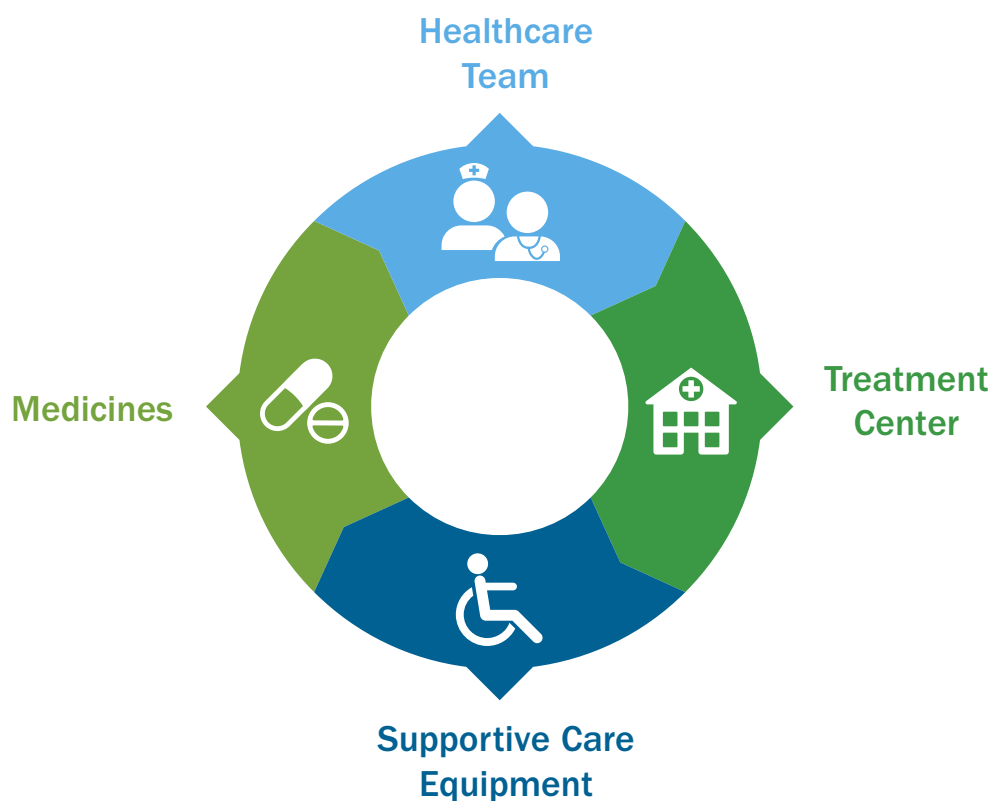


Many families can get Medicaid to help pay for costs that are not covered by commercial insurance.

Health insurance coverage considerations for patients with SMA

There are many considerations for health insurance for patients with SMA

SMA is a very complex disease. If your child has SMA, he or she may need a healthcare team, medical devices, and medicines. All of these are important factors to consider when choosing health insurance.



It is important to think about the needs your child may have and talk to your health insurance plan about how those needs may be covered.

What to consider when choosing a plan

What does my plan cover? What does it not cover?

Typically, insurers cover general categories of healthcare services, including doctor visits, medical tests, and treatments. Each plan may have different rules about the management of SMA. Talk to your plan representative about the specifics of your plan.

Which doctors, hospitals, and pharmacies are in my plan?

Your insurance provider is likely to have a **network** of providers who have agreed to provide healthcare services to its members under certain terms. The out-of-pocket cost for seeing an **in-network provider** is typically lower than out-of-network providers. In some cases, if you choose to see an out-of-network provider you may be responsible for 100% of the provider's bill depending on the type of coverage you have and the specifics of your plan.

People with Medicaid are often limited to seeing participating providers in their state. People who have Medicaid Managed Care might also be limited to seeing in-network providers within their state.

People with SMA often have to travel long distances or out of state, or both, to access treatment centers that specialize in SMA. This means that these people will need to receive care from out-of-state or out-of-network providers. Generally, states must pay for the out-of-state services to the same extent that an in-state service would be paid if

- You have an emergency
- You need medical services while you are out of state and your health would be endangered if you needed to travel back to your home state
- The state decides that the needed services are more easily available in another state
- People in your area often use an out-of-state provider—for example, in areas that border another state

What you may pay





What do I pay versus what my health insurance company will pay?

Health insurance companies take on most of the burden of the cost of medical care and medicines, but not all of it. Often the patient must pay some of the costs. This is called **cost sharing** because the insurance plan pays a portion of the cost and shares the remaining cost with the patient.

There are many terms for cost sharing, such as deductibles, **coinsurance**, and **copayments**. Some preventive services that you get with in-network providers do not require cost sharing. In addition, people who have Medicaid often pay a lower amount in cost sharing.



There are organizations and resources to help you pay for the cost of SMA care. See page 17 for more information.

Costs that patients may be responsible for (cost sharing)	Example
 <p>Deductible If you have a high deductible health plan, you will have to pay your full deductible before your plan begins to pay for healthcare expenses.</p>	<p>If you have a yearly deductible of \$1,000 in 2016, you will need to pay the first \$1,000 out-of-pocket before your insurance will cover any costs.</p>
 <p>Coinsurance</p>	<p>If your specialist billed you \$250 and your coinsurance rate is 20%, you will pay \$50 and your insurance company will pay \$200.</p>
 <p>Copayment</p>	<p>If your specialist billed you \$250, a \$20 copayment means that you pay your healthcare provider \$20. Your insurance company would then pay \$230.</p>
 <p>Out-of-pocket limit</p>	<p>An individual with private insurance may have an annual out-of-pocket limit of \$6,000 in 2016. This means once that individual's share of covered costs reaches \$6,000, the insurer will pay the full cost of covered services and products for the rest of 2016.</p>

See pages 22-23 for definitions of these terms.

Understanding how your coverage works

If your child has SMA, you may need to work with your plan's representatives to learn more about how the medical care your child needs is covered and what your costs may be. This section gives you an introduction to some of the terms you may hear during this process.



What is considered to be medically necessary? What supporting documentation is required?

Your insurer may not cover care that is not believed to be medically necessary. For example, your insurer may not cover **durable medical equipment** (DME), such as a wheelchair or respiratory assistive device, if your insurer believes that it is not medically necessary. You may need a letter from your doctor (clinical documentation) to prove **medical necessity**. If you believe you have been denied coverage of care that is necessary, you can **appeal** (see page 15 for more information).



What is a benefit referral?

Some insurers, including commercial HMO plans and Medicaid, may not cover specialty care unless you receive a letter, or referral, from your **primary care provider**. Your insurer may also require that you get some services and medicines only after a **prior authorization** or precertification is approved. Insurers often make these rules in order to be able to review medical necessity before providing coverage.



What is a benefit exclusion or limit?

Most plans have coverage limits or services and treatments they do not pay for. Some services, such as physical therapy, DME, or home healthcare may be subject to a limit or benefit exclusion. For example, a health plan may not cover long-term home care services or may limit the number of times you can receive physical and occupational therapy (such as 30 visits a year).

What is the exemption process for out-of-state and out-of-network care?



People with SMA may need to travel a long distance to reach doctors who specialize in caring for people with SMA and often times these doctors may not be part of your insurance network.

If you need to go outside of your state to see a doctor for medical care, you may need an exception for out-of-state or out-of-network care. As part of this process, you may need to provide documentation to show that the services are medically necessary. If your claim is denied, follow up with your case manager to find out why and begin the appeals process.

What is the appeals process?

Sometimes, even if your care is medically necessary, your coverage may still be denied. If your insurer denies coverage of care, you can appeal. This may mean that you need to fill out paperwork and provide detailed documentation. You also need to communicate with your insurer, your HCP, and any other providers or groups involved.

Here are several things you need to know to navigate denials and the appeals process:



Find out why your claim was denied. You have the right to know why your claim was denied. Your insurance company must tell you why they have denied a claim and how you can appeal.



Appeal the decision. If your insurance company denies your claim for coverage of care or equipment, you have the right to an internal appeals process. An internal appeals process is a process in which you ask your insurance company to reconsider its decision. For urgent cases, your insurance company may speed up its appeals process.



Ask for an independent review. In most cases, you should be able to resolve coverage denial during the internal appeals process. If you cannot resolve the denial with your insurance company, you have the right to request an independent third-party review of your insurance company's decision. This is called an independent review. This is helpful for people with SMA because it means your insurance company will no longer have the final say regarding your benefit and coverage.

What should I know about renewing my coverage?



It is important to know that your insurance company cannot deny you coverage or refuse to renew your coverage because of your diagnosis. Your insurance company also cannot charge you a greater premium because of SMA.

Your insurance company can only legally change your health insurance coverage at the time of renewal. If your insurer renews your coverage with changes or ends your coverage, they must provide written notification. If your insurer changes your plan during renewal, they must provide the following:

1. Information about your premium for the next policy year
2. Information about significant changes to your coverage
3. Information about health coverage options and how you can get new insurance coverage
4. A phone number for you to call with any questions

If your insurance company decides to end your coverage, they must provide the following:

1. A statement that your coverage has been ended
2. If the insurance company is automatically moving you from one insurance product to a new product, and information about how that changes your benefits
3. Information about health coverage options, and how you can get insurance coverage
4. A phone number for you to call with any questions



If your insurance company denies your coverage renewal or ends your coverage, you have the right to know why and you have the right to appeal that decision.

Finding help to pay for your child's care

Programs that can help you pay for SMA care

There are several government and private programs that may be able to help you manage the costs of SMA. These programs may also direct you to other resources that can help you and your child.

Medicaid provides coverage for many people with severe disabilities, including many children who live in families with a low income. To learn more about Medicaid, see page 7. You can sign up for Medicaid at www.medicaid.gov or by calling 1-877-267-2323.

CHIP provides health insurance for children. To learn more about CHIP, see page 9. You can sign up for CHIP at www.medicaid.gov or by calling 1-800-318-2596.

SSI is a federal income supplement program to help people with disabilities who have little or no income. To learn more about SSI, see page 8. You can also learn more at www.socialsecurity.gov or by calling 1-800-772-1213.

Early intervention program for infants and toddlers with disabilities helps children with disabilities from the time they are born until they turn 3 years old. The program pays for evaluation, assessment, service coordination, and the development and review of an Individualized Family Service Plan at no cost. To be part of this program, your child must be under the age of 3 and must have a developmental delay. The condition must be physical, cognitive, social, emotional, or related to self-help or communication. To learn more about your local early intervention program, contact your state's Early Intervention Program Coordinator. A list by state can be found at www.ectacenter.org/contact/ptccoord.asp.

Pharmaceutical-sponsored programs are patient assistance programs developed by pharmaceutical companies to help eligible families with financial need purchase necessary medications and supplies. If you are having problems covering the financial cost of your treatment plan, reach out to your pharmaceutical or medical supply manufacturer to learn if it has a patient assistance program that you may qualify for.

Facing SMA with support

There are many resources available to people with SMA and their caregivers to help them navigate the world of SMA and health insurance.

<p>Cure SMA</p>		<p>Cure SMA provides a nationwide support system to the spinal muscular atrophy community. For those newly diagnosed, they offer a number of resources, including care packages, information packets, and a family support staff. Cure SMA funds a comprehensive research program focused on developing treatments for all types and ages of SMA. They host the largest annual SMA conference in the world for families and members of the scientific community.</p> <p>www.curesma.org</p>
<p>EveryLife Foundation for Rare Disease</p>		<p>The EveryLife Foundation for Rare Disease is dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy. It also works to fulfill the unmet need for patients with rare disease and to empower the community.</p> <p>www.everylifefoundation.org</p>
<p>FightSMA</p>		<p>Created in 1991, the mission of FightSMA is to strategically accelerate the search for a treatment and cure for spinal muscular atrophy by raising disease awareness and funding research.</p> <p>www.fightsma.org</p>
<p>Global Genes</p>		<p>Global Genes is a non-profit patient advocacy organization working to eliminate the challenges of rare disease by building awareness, educating the global community, and providing critical connections and resources, that equip advocates to become activists for their disease. Numerous tools, resources, and educational events can be found on the Global Genes website.</p> <p>www.globalgenes.org</p>

<p>Muscular Dystrophy Association (MDA)</p>		<p>MDA is a source for news and information about neuromuscular disease, research, treatments, cures, and services. They fund worldwide research, providing support to families nationwide and rallying communities to fight back through advocacy, fundraising, and local engagement.</p> <p>www.mda.org</p>
<p>National Organization for Rare Disorders (NORD)</p>		<p>NORD, established in 1983, is the leading advocacy organization addressing the challenges faced by patients and families impacted by rare diseases and the organizations that serve them. NORD, along with its more than 250 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.</p> <p>www.rarediseases.org</p>
<p>SMA Foundation</p>		<p>The SMA Foundation has invested millions in the development of critical validated research tools and other drug discovery resources. It was established in 2003 by Loren Eng and Dinakar Singh, parents of a child with spinal muscular atrophy.</p> <p>www.smafoundation.org</p>



This list is not inclusive of all organizations that may provide assistance related to your child's SMA. Talk with your healthcare team to see if there may be other organizations available to help.

My health insurance worksheet

Questions to ask your health insurance plan

This section may be useful to start a conversation with your health insurance plan about your benefits. Use the lines below to fill in specific information that your plan's representative shares with you. You can refer back to this section if you need to have any follow-up discussions with your insurer.

Representative name and ID number: _____

What does my plan cover? What does it not cover? _____

Outpatient physician care? _____

Specialist visits? _____

Prescription drugs? _____

Do I need a referral, precertification, or prior authorization for treatment?

What is covered by **primary insurance** versus **secondary/supplemental insurance**?

What benefit exclusions or limits apply to physical, occupational, respiratory therapy, home care, nutritional support, and DME?

What is considered to be medically necessary? What supporting documentation is required?

Which doctors, hospitals, and pharmacies are in my plan?

Will I have to change doctors?

If care needs to be provided out-of-network and/or out-of-state, what is the exception process?

Which coverage and out-of-pocket cost restrictions apply for my HCPs?

If coverage is denied, what is your appeals process?

What should I know about the coverage renewal process?

What will be the cost? _____

- Monthly premium? _____
- Out-of-pocket expenses? _____
- Deductibles or copays, or both? _____
- Out-of-pocket maximum? _____

Important health insurance terms you need to know

Appeal: A request for a payer to reconsider its decision to deny coverage for a specific healthcare service or product.

Coinsurance: The share (percentage) you pay of the cost of a covered healthcare service.

Copayment (copay): A fixed amount you pay for any covered healthcare service.

Cost sharing: The share of costs covered by an individual's insurance plan that must be paid for by the individual.

Deductible: The amount you have to pay for the healthcare services covered by your insurance plan, before it starts to pay for these services.

Durable medical equipment: Equipment and supplies ordered by a healthcare provider for everyday or extended use, such as a wheelchair or respiratory assistive device.

Government-funded health insurance: A broad category of health insurance coverage, under which insurance benefits are provided through a government program, such as Medicare or Medicaid.

In-network provider (or preferred provider): A provider who has been contracted by an insurer to provide healthcare services to its members.

Medicaid: A health insurance program that is administered by the state government to provide coverage for individuals with low incomes or for children with disabilities and special needs. In most states, Medicaid beneficiaries are typically covered by one of the following programs:

- Fee-for-service state Medicaid, which is operated by the state government as a single statewide program
- Medicaid Managed Care, which is operated by private health plans contracted by the state

Medical necessity: Healthcare services or supplies that meet the accepted standards of care and are needed in order to prevent, diagnose, or treat an illness, injury, condition, disease, or its symptoms.

Medicare: A government health insurance program that provides coverage for individuals older than 65 years and for those younger than 65 with certain disabilities.

Network: The institutions (hospitals, labs, etc), providers (doctors, etc), and suppliers your plan works with to provide healthcare services.

Out-of-network provider (or nonpreferred provider): A provider who is not in your plan's network.

Out-of-pocket cost (sometimes called OOP): The amount of money an individual may have to pay for the cost of covered healthcare services. OOP costs vary depending on the type of cost-sharing structure of the health plan benefit.

Out-of-pocket limit: The maximum you have to pay over the course of a year (usually) before your plan begins paying 100% of your costs.

Premium: The amount that must be paid by a family or an individual to obtain coverage. For some people with private commercial coverage, their employer may pay for at least a portion of the health insurance premium.

Primary care provider: A healthcare professional that provides care and coordinates your access to a wide range of healthcare services.

Primary commercial insurance: A broad category of health insurance coverage, under which benefits are privately purchased directly from a health plan or through an employer, a broker, or a **public health insurance** marketplace (also known as an insurance exchange). Individuals with private commercial insurance may have a range of benefits, including

- Health maintenance organization, where coverage is typically granted only if patients use in-network providers
- Preferred provider organization, where patients may use out-of-network providers, but at a higher out-of-pocket cost

Primary insurance (or primary payer): For people with more than one source of health insurance, primary insurance is their main source of coverage that pays first, unless a particular healthcare service or product is not covered.

Prior authorization (or preauthorization): The requirement by a plan that, before coverage is allowed, must decide that a treatment or medication is medically necessary.

Provider network: A group of healthcare providers (such as physicians), facilities (such as hospitals), and suppliers (such as DME suppliers) that are contracted with an insurer to provide services and products to its members.

Public health insurance: A public entity that facilitates the purchase of private commercial health insurance when employer-sponsored insurance is not available or is unaffordable. Individuals with limited income who obtain coverage through the public insurance marketplace may be eligible for government subsidies to help reduce premiums or cost sharing, or both.

Referral: An order or permission granted by the primary care provider for a patient to receive specialty care. For example, some individuals with spinal muscular atrophy may need a referral to see a specialist such as a pulmonologist or an orthopedist.

Secondary/supplemental insurance (or secondary/supplemental payer): For those with more than one source of health insurance, this is an additional source of coverage that pays for the services or costs not covered by the primary health insurance.

