



**Understanding
Insurance Options
for Patients With
Spinal Muscular Atrophy**

USING THIS GUIDE

Facing a diagnosis of spinal muscular atrophy (SMA) for you or your child can feel overwhelming. No matter where you are on your journey, there are many decisions to make. Your health plan choices are very important. Your plan can help cover the cost of doctor visits, SMA treatments, and **medical equipment**, if needed. Biogen has created this booklet to help you understand the coverage that may be available for you or your loved one.

This guide will help you learn more about



Different types of health insurance (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 or your loved one's care



Coverage questions to ask your health plan



Resources to support individuals with SMA and their caregivers



Health plan terms you should know



Definitions of terms shown in bold gray can be found on pages 44 to 47.

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Coverage

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HEALTH PLAN BASICS

SECTION 1

HEALTH PLAN BASICS

You may already be familiar with how your health plan works. However, when it comes to treating SMA, there may be more you need to know about. This section reviews health plan coverage as it relates to SMA.



What is an Open Enrollment period?

Each year, usually from October to December, you may make changes to your health or drug plan for the next year. This is called **Open Enrollment**. Open Enrollment lets you review your plan benefits. You can keep your current plan. You can also compare plans to find one with better coverage. Make sure the plan you choose covers the health services and drugs you will need next year.



Understanding the medical benefit and the pharmacy benefit

Depending on the type of medication you take, your treatment may be covered by your health plan with a medical benefit or a pharmacy benefit.

Medical benefits cover drugs that are injected or infused by your doctor in the office, infusion center, or hospital outpatient center.

Pharmacy benefits cover drugs that you or your loved one can administer at home, including those that are oral or self-injectable.



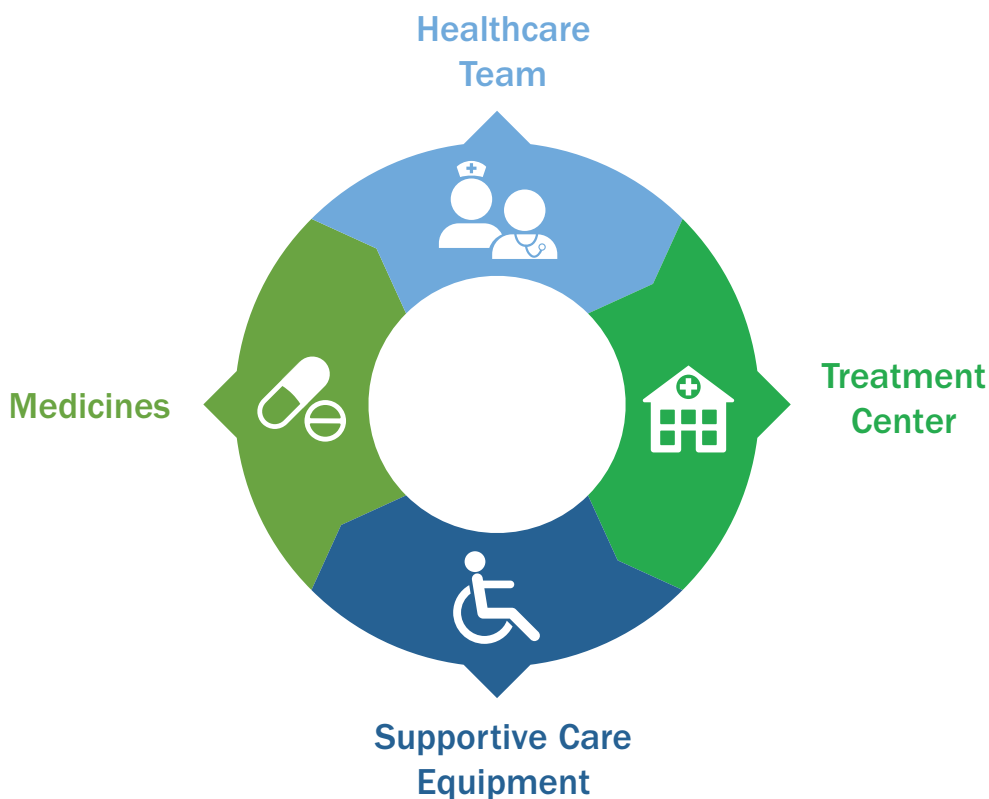
What is a specialty pharmacy?

Specialty pharmacies manage drugs that need special handling or storage. These drugs may not be available at your local pharmacy or through mail order. Your doctor's office will order these drugs for you. Also, specialty pharmacies may offer support services, such as answering questions about your treatment.

If treatment for SMA includes a specialty drug, you may get a call from the specialty pharmacy to confirm the order. **It is very important to answer this call and talk with the specialty pharmacy.** If you don't, there may be a delay in scheduling your treatment.

Health plan considerations for individuals with SMA

SMA is a very complex disease. Care for SMA often requires a healthcare team, equipment, and medicines. All of these are important factors to consider when choosing a health plan.







It is important to think about the needs for SMA that you or your child may have. Talk to your health plan representative about how those needs may be covered.

Understanding the cost of coverage

Health plans may typically assume 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**. The health plan pays a portion of the cost and shares the remaining cost with the patient.

There are many types of 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.

Understanding cost sharing

	Costs that patients may be responsible for (cost sharing)	Explanation	Example
	Deductible	The amount you pay for the healthcare services covered by your plan before it begins to pay for the services.	If you have a yearly deductible of \$1000, you will need to pay the first \$1000 out-of-pocket (OOP) before your insurance will cover any costs.
	Coinsurance	The share (percentage) you pay of the cost of a covered healthcare service.	If your specialist billed you \$250 and your coinsurance rate is 20%, you will pay \$50 and your insurance company will pay \$200.
	Copayment	A set amount you pay for healthcare services covered by your health plan.	If your specialist billed you \$250, a \$20 copayment means that you pay your healthcare provider \$20. Your insurance company would then pay \$230.
	OOP maximum	The money you pay for your healthcare costs that is not paid back by your health plan. The OOP maximum is the most you will have to pay during your policy period (usually 1 year). After you pay that amount, your health plan covers all costs.	A patient may have an OOP maximum of \$6000. This means that once the OOP share of covered costs reaches \$6000, the health plan will pay the full cost of covered services for the rest of the year.

How much does health insurance cost?

Finding a health plan that is affordable starts with knowing the real costs of coverage. Monthly **premiums**, deductibles, and medication costs all need to be considered. Sometimes the plan that seems the cheapest may end up costing you more. It may not give you enough coverage for your medical needs. This table shows some examples of coverage and costs.

Note: These numbers are just examples. They are not meant to show actual plan coverage and costs. OOP maximum amounts may vary between individual family members and total OOP maximum amounts under a family plan. Please consult individual plan guidelines. Contact your health plan for actual coverage, health plan benefits, and estimated costs.

	Monthly premium (individual)	Patient copay for 1 doctor visit	Deductible/ coinsurance/ OOP maximum*	Copay for 1 specialty drug	Cost for other medical services per month
Plan A (high deductible/ low premium)	\$260	\$50	\$2000/20%/\$6000	\$400	\$250
Plan B (low deductible/ high premium)	\$350	\$15	\$500/30%/\$4000	\$400	\$250

*This example reviews expenses for services covered within a network. Be sure to find out the OOP maximum when choosing a plan. This is the amount you will pay before your health plan covers the rest of the balance.



Most of the healthcare costs for people with SMA come from deductibles, copays, or coinsurance. They also include the full cost for any benefits that aren't covered or are excluded. It is important to ask your health plan representative how cost sharing will apply to coverage and treatment for you or your child.

Sample health plan costs

To understand the difference in total costs between the 2 types of plans explained on page 8, let's look at what you would pay if you had



12 months of premiums



8 doctor visits in 12 months



4 doses of 1 specialty drug



Tests and other medical services



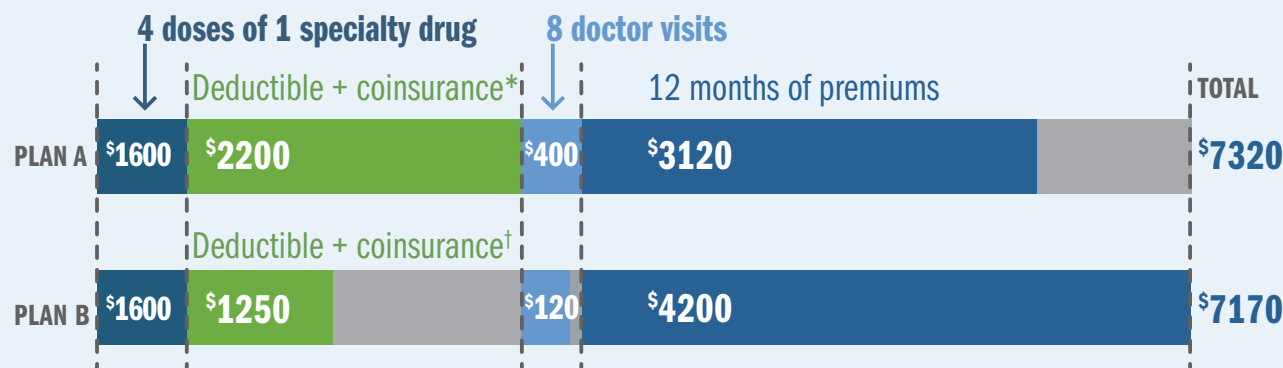
Drug administration



Medical equipment used at home

Estimate \$3000 in total costs for these services

Sample OOP costs for 1 year for Plan A and Plan B



*You pay a \$2000 deductible, then the plan covers 80% of the remaining \$1000. You pay \$200 in coinsurance.

†You pay a \$500 deductible, then the plan covers 70% of the remaining \$2500. You pay \$750 in coinsurance.

Note: These numbers are just examples. This example reviews expenses for services covered within your network. They are not meant to show actual plan coverage and costs. Going outside of network usually results in higher costs. Contact your insurance plan for actual coverage and costs.

In this example, a **high-deductible health plan** (HDHP) with a lower premium (Plan A) would cost you \$150 more than a plan with a lower deductible and a higher premium (Plan B). Before you choose a plan, it is important to think about all of your healthcare costs.

My Health Plan Worksheet

Questions to ask your health plan

This worksheet may be helpful when you talk to or email your health plan. Use the lines below to fill in the information your plan shares with you so that you can refer to it in future.

Representative name and ID number: _____

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

What, if any, **medical policies** have been established? _____

- Outpatient physician care _____
- Specialist visits _____
- Prescription drugs/administration _____
- Medical equipment used at home _____

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

If so, what documentation is required? _____

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

What benefit limits apply to the following?

- Physical therapy _____
- Occupational therapy _____
- Respiratory therapy _____
- Home care _____
- Nutritional support _____
- Medical equipment used at home _____

What is considered to be medically necessary? _____

- What supporting documents are needed? _____

Questions to ask your health plan (cont'd)

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? _____

Do any coverage restrictions apply to my doctors? _____

If coverage is denied, what is your **appeals** process? _____

What should I know about the coverage renewal process? _____

My costs

Write the costs you will pay and the OOP maximum for your plan.

Costs to consider	What you will pay Use this column to describe your deductible, coinsurance (percentage) or copay	What is the OOP maximum?
Monthly health plan premium		Not Applicable
Visits to the primary care doctor and specialists		
Physical therapy		
Occupational therapy		
Respiratory therapy and equipment used at home		
Home care		
Nutritional support		
Other medical equipment used at home		
Prescription drugs, including specialty drugs		
Prescription treatment that is given at my doctor's office or hospital		
Other		

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HEALTH PLAN COVERAGE

SECTION 2

HEALTH PLAN COVERAGE

Your health plan's medical policy



A **medical policy** is a set of guidelines. A health plan uses it to make treatment coverage decisions. A plan may restrict a treatment or procedure based on its policy.

Medical policies are created from different types of support. Clinical studies are used. Also, guidelines or support by societies help create a policy. Policies may differ from one health plan to another.

Health plans often review and update their policies. This makes sure that they meet the latest medical support.



How your health plan's medical policy affects coverage

Medical policies may limit coverage. For example, the plan can limit it based on the type of SMA or age of the patient. Or medical policies may set a limit for the number of copies of the survival motor neuron 2 (*SMN2*) gene. Also, where you or your loved one is treated may be included in the policy. Some plans may limit it to an in-network doctor's office or hospital.



If the SMA treatment your doctor prescribed is not covered, there are many support services available. See page 41 of this booklet for more information.

Understanding your medical policy

It is important to know your health plan's medical policy before starting SMA treatment. If you or your loved one is getting treatment at a doctor's office, clinic, or hospital, call your health plan. Ask your plan representative to send your health plan's medical policy for the treatment. Many health plan medical policies are also available online.

What to do if your medical policy has restrictions on treatment

Even if your health plan has restrictions on SMA treatment, there are things that you can do.

- Talk with your doctor about a waiver, or **medical exception**. Your doctor can write a letter to your plan about why the treatment is necessary
- Contact your health plan. Be an advocate for yourself or for your loved one
- If you are insured through an employer, contact your employer's human resources department. Ask them to advocate on your behalf. Your employer may have contacts at the insurance company
- If the company that makes your treatment has a family representative or case manager, call him or her. Your case manager can help answer questions. He or she also may connect you with support services and patient advocacy groups

What to do if coverage is denied

There are many reasons an insurer may deny coverage. But there are things you can do to seek a reversal of this decision.

- Your doctor can request a medical exception. This is a written request for a treatment that your doctor believes is the right choice for you or your loved one
- If the medical exception is denied, then you and your doctor can file an appeal. You and/or your doctor may contact your insurer and request that it reconsider its decision
- If coverage is still denied, the second-level appeal is usually reviewed by a medical director who was not involved in the original decision made by your health plan. The goal of the second-level appeal is to prove that the coverage you or your loved one needs can be accepted within the coverage guidelines
- If the second-level appeal is denied, you have the right to request an independent third-party review of the plan's decision



If your treatment is not covered on your plan's medical policy, it is still important to try to get it approved for coverage. Health plans need to know that patients are asking for a treatment that is prescribed by their doctor.

Frequently asked questions about medical policies and SMA treatment coverage

Q

How can I get my health plan's medical policy?

A

You can get your health plan's medical policy by calling your health insurance company at the customer service phone number on your insurance ID card. Many health plans post their policies online. You can download its policy by visiting your health plan's website. Your insurance ID card will also have your insurance company's website address.

If you are insured through an employer, contact your employer's Human Resources department. They may be able to provide you with the medical policy.

Q

What happens if my treatment is not covered by my insurance?

A

Contact your health plan and explain that you need help getting coverage. Don't give up. If your insurance plan is through your employer, contact the Human Resources department and ask them to reach out to contacts they may have with your health plan to help you get the coverage you need.

Many drug companies have support programs. These can help patients with insurance coverage for the treatment they are prescribed. Contact the company that makes your treatment. Also see page 41 for community resources for individuals with SMA.

Q

What happens if my coverage for a treatment is denied?

A

It is important to know that there are things you can do if coverage for a treatment is denied. Your doctor can file a medical exception that requests the treatment. If your health plan denies the medical exception, you and your doctor can file a series of appeals. More information about this process is found on page 14.

WHAT ARE YOUR HEALTH PLAN OPTIONS?

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SECTION 3

WHAT ARE YOUR HEALTH PLAN OPTIONS?



Types of health plan options

There are many types of commercial (also called private) health plans and **government-funded health programs**. These help to cover the cost of care for individuals with SMA. They may provide different levels of coverage. They also operate in different ways.



**Commercial (private)
health plans**



**Government-funded (public)
health programs**



Types of commercial health plans

- **Health maintenance organizations (HMOs)**
 - Exclusive provider organizations (EPOs)
 - **Preferred provider organizations (PPOs)**
 - **Point-of-service (POS) plans**

Other types of commercial health plans

- **High-deductible health plans (HDHPs)**
- Tiered **provider networks**
- **Health insurance marketplace**, also called **exchange**
- Indemnity plans, also called **fee-for-service (FFS)**



Government-funded health programs

- Medicaid
- **Medicare**
- **Children's Health Insurance Program (CHIP)**
 - Department of Defense (DoD)/TRICARE®
 - Veterans Affairs (VA)

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

HOW IS COMMERCIAL INSURANCE DIFFERENT FROM GOVERNMENT PROGRAMS?

	Commercial	Government programs	
		Medicaid	Medicare
Who funds it?	Funded by employers, unions, or trade groups; people usually pay some cost sharing to have a commercial plan.	Funded by the federal government and/or your state.	Funded only by the federal government.
How does coverage work?	Coverage is based on the benefits package provided by your employer.	Helps low-income or disabled individuals and families by providing free or low-cost care based on income and family size. May be an option for people with SMA. Learn more on page 25.	All people aged 65 years or older are eligible, as well as certain younger people with disabilities and people with end-stage renal disease. May be an option for people with SMA. Learn more on page 33.
Who is eligible?	Only available to people who have a job that offers health insurance.	Only available to people with certain incomes or disabilities.	Only available to people who qualify based on age or health needs.

What are the different types of commercial health plans?

There are many different types of commercial health plans.

Types of commercial health plans	Has a network of providers?	Need a referral to see a specialist?	What happens if I need out-of-network care?
HMO	Yes	Yes	HMOs cover out-of-network care if <ul style="list-style-type: none"> • The HMO's network of doctors does 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
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.
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.
POS Plan	Yes	No	POS plans provide out-of-network care, but you may have higher costs for out-of-network providers .
Indemnity or FFS	No	No	Not applicable.

Considerations When Choosing a Commercial Health Plan

Self-funded (self-insured) health plan

In a self-funded plan, the employer pays all the costs for healthcare benefits for its employees. These plans can differ greatly because the employer makes the coverage decisions. It's important to understand the coverage provided by an employer plan. A key step is to identify a person at the employer who can provide information on coverage details and process. This is typically someone in the Human Resources department.

Some self-insured employers process healthcare claims in-house. Others choose to hire a third-party administrator (TPA) to do this for them. TPAs are companies that process claims for an employee benefit plan. They are used by the health plan, but are not associated with the plan or the employer.

Stop-loss insurance protects against catastrophic or unpredictable losses. It is also called "excess insurance." Employers that self-fund their employee benefit plans, but who do not want to assume 100% of the liability for losses, may choose to buy this type of insurance. Under a stop-loss policy, the insurance company covers losses that go beyond certain limits. These limits are called deductibles.

High-deductible health plan

This type of plan usually has a lower monthly premium. But 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 an HDHP. These include a **health savings account** (HSA) or a health reimbursement arrangement (HRA). The money in these accounts is tax-free. It can be used to pay for some medical expenses.

Flexible spending account

A flexible spending account (FSA) is an account that you set up through your job to help pay for healthcare costs. This type of account can be used with any health plan. It is not linked to an HDHP. FSA funds expire at the end of the year. You may not be able to roll over any money you haven't spent to the next year. As with HSAs and HRAs, the money in an FSA is tax-free.

Tiered provider network

This type of plan ranks doctors based on quality and costs. A patient may pay less when treated by a network provider that offers high-quality care at lower cost.



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

Health insurance marketplace

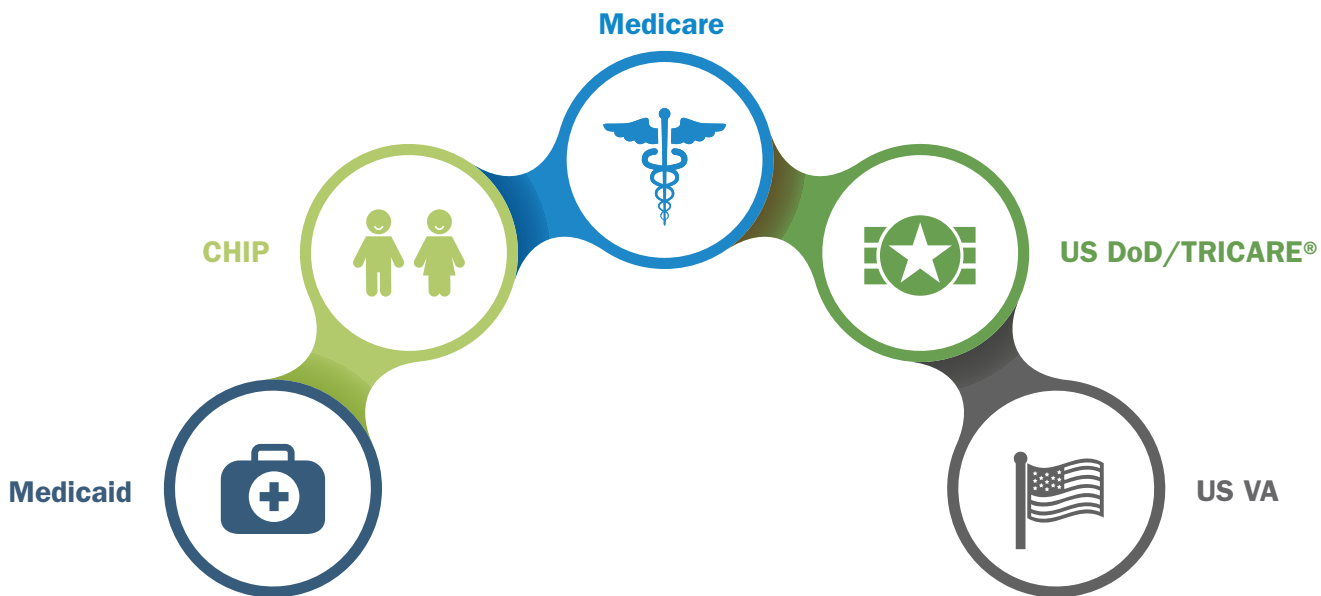
The health insurance marketplace, also known as the exchange, began with the Affordable Care Act. It offers health plans for people who cannot get them otherwise. The marketplace helps provide health plans to people who don't have an option through their employer or another government-funded source.

For more information about what the marketplace offers, go to www.healthcare.gov.



Government Programs

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



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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 even if you have a commercial plan. See pages 25-31 for more about these programs.

Medicare may be an insurance option for adults with SMA who receive disability benefits from **Social Security**. For more about Medicare, see page 33.

TRICARE and the VA provide health coverage for US military service members, veterans, and their families. TRICARE may cover the cost of treatment for a child with SMA if a parent has TRICARE coverage for the family.

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SECTION 4

MEDICAID ELIGIBILITY FOR INDIVIDUALS WITH SMA

What is 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 covering



Hospital visits



Doctor or nurse visits



X-rays



Home healthcare



Medical tests



Transportation to medical care

The Medicaid program is run by each state. Each state has different requirements. They include how much money you make, the number of people in your household, family status, and other factors. Your state may also help pay for other care for SMA such as



Medicines



Breathing care



Occupational therapy



Medical equipment and procedures



Case management



Physical therapy



Medicaid provides coverage for many people with severe disabilities such as SMA, including children from families with low incomes.

Medicaid waiver programs

People living with SMA who do not qualify for Medicaid based on their income alone may be able to get benefits through Medicaid waivers. Medicaid waivers may pay for needed benefits, such as long-term care, that may not be covered by **private insurance**.

The federal government allows states to apply for waivers from the Medicaid rules. This lets states offer more options to help patients. To learn about waivers available in your state, visit www.medicaid.gov/medicaid

- Select “Section 1115 Demonstrations”
- Select “State Waivers List”

Another helpful resource to learn more about Medicaid waivers for children is www.kidswaivers.org.

Enrolling in Medicaid

How to apply

Contact your state Medicaid office to learn about how to apply for Medicaid. To get the phone number for your state office, visit www.Medicaid.gov or call **1-877-267-2323** and follow the prompts.

Information you need to provide

Each state has different Medicaid application requirements. Check with your state office to see what you will need before you apply. You may be asked to provide



Understanding commercial insurance and Medicaid together

People with SMA may have **commercial insurance** at the time of diagnosis. Many individuals with SMA may also get Medicaid to help pay for costs that commercial insurance does not cover.

For example, you may consider applying for Medicaid if your commercial plan provides little or no coverage for visits to specialists, in-home care, or medical equipment. Supplementing your commercial plan with Medicaid can help fill in coverage gaps.

The first step to getting Medicaid is to see if you or your child meet Social Security's definition of disability. In many states, a person with SMA who qualifies for **Social Security Disability Insurance** (SSDI) benefits is automatically enrolled in Medicaid.



Once approved, Medicaid can help pay for some costs that may not be covered by commercial insurance.

Supplemental Security Income

Supplemental Security Income (SSI) is a federal program that provides monthly payments to adults and children with disabilities who have limited income.

SMA is a condition that fits the criteria for disability to qualify for SSI. This includes adults and children younger than 18 years who meet the Social Security definition of disability. This means that they have a physical or mental condition that



Very seriously limits their activities



Has lasted, or can be expected to last, for 12 months or more



Can lead to death

SSI also considers income (money you receive) and resources. If you have a child under the age of 18 years with SMA, SSI will look at a portion of the income and resources for you and your spouse to see whether your child qualifies.

Qualifying for SSI

What SSI looks at to see if you qualify	Description
Income	<ul style="list-style-type: none"> • Includes your salary, 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 <ul style="list-style-type: none"> – You current home and its land – Your main vehicle – Household goods – Personal property (such as wedding rings) – Any educational funds (such as grants or scholarships) • Resource limits are \$2000 or less for an individual/child and \$3000 or less for a couple



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

How to apply for SSI benefits



For you

1. If you apply online, gather the information you need to complete the application before you start.
2. If you call, you will be asked to make an appointment to complete your application over the phone or at a local Social Security office.



For your child

1. Review the Social Security Child Disability Starter Kit at www.ssa.gov/disability/disability_starter_kits_child_eng.htm. This kit answers questions about applying for SSI benefits for children with rare diseases like SMA. It also includes a worksheet to help you gather the information you need.
2. To start the SSI application, contact Social Security at **1-800-772-1213** to find out if your income and resources are within the limits for your state.
3. To fill out the online Child Disability Report, visit www.ssa.gov.
 - Scroll down the page to select “Forms”
 - Select “Disability Report - Child.”At the end of the report, you will be asked to sign a form that gives your child’s primary doctor permission to provide information about your child’s diagnosis. This will allow Social Security to make a decision on your claim.

Once you or your child is accepted for SSI, you may also be eligible for other government programs such as Medicaid, food stamps, and other social services.

Children's Health Insurance Program (CHIP)

CHIP provides low-cost coverage for children in families that earn too much money to qualify for Medicaid but cannot afford to buy private health insurance. Children with SMA who are younger than 19 years may be eligible for CHIP.

Children who qualify for CHIP will get free or low-cost insurance. This covers a wide range of benefits. These benefits can include doctor visits, checkups, immunizations, medicines, dental and vision care, hospital visits, medical tests, X-rays, and 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.

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MEDICARE FOR INDIVIDUALS WITH SMA

SECTION 5

MEDICARE FOR INDIVIDUALS WITH SMA

Medicare is an optional insurance plan offered by the government. A person may be able to get Medicare if



He or she is younger than 65 years and receives SSDI benefits



He or she could be currently working or has worked to earn Social Security benefits



He or she is 65 years or older

All individuals with SMA who receive SSDI are eligible for Medicare after 2 years. Enrollment in Medicare is automatic.

How to qualify for SSDI benefits:



You have a past work history



You can no longer work due to your disability

See page 28 for more information about SSI.

When is Medicare an option to cover SMA?

Medicare may be a health plan option if you are an adult with SMA who is working or has worked. To learn about disability benefits through Social Security, contact **1-800-772-1213** or visit www.ssa.gov.

How does Medicare work?

Medicare has 4 parts to help cover services. These 4 parts are

- A** **Part A**, hospital insurance (hospital visits, nursing homes, hospice, some home healthcare services)
- B** **Part B**, medical insurance (doctor visits, visits to infusion or hospital clinics for treatments you receive from your doctor, some home healthcare services, medical equipment, wellness services, lab tests, preventive screenings)
 - Parts A and B are known as “Original Medicare”
- C** **Part C**, Medicare Advantage plans
 - A Part C plan is also called a Medicare Advantage plan. It is another way to get Medicare coverage. Part C covers everything in Part A (hospital insurance) and Part B (medical insurance). It also may include prescription drug coverage.
- D** **Part D**, prescription drug coverage
 - Part D covers drug costs (pills that you swallow, injections you give yourself, inhaled treatments)

Part A covers a treatment for SMA that you are given as an inpatient during a hospital stay.

Part B covers a treatment for SMA that you get as an outpatient, for instance, at an SMA treatment center.

Getting help to pay for out-of-pocket costs for Medicare

You may consider enrolling in a supplemental plan to help cover Medicare out-of-pocket costs.



Medicare does not cover all healthcare expenses. If you have Original Medicare (Parts A and B), see if you are eligible for other benefit options to help pay for costs (see page 37). If you do qualify for other benefit options, you will be responsible for 20% of the cost of a Part B service after your deductible is met. However, there is added insurance coverage that you can buy. It's called a **Medigap** policy or Medicare supplemental insurance. This is a plan from a private insurance company and can cover what Medicare does not.



The best time to buy a Medigap policy is during an Open Enrollment period. You must enroll in Part B to buy a Medigap policy. If you do not enroll in a Medigap policy during Open Enrollment, it may not be available later or may cost more.



Some states may not have Medigap policies available to Medicare recipients who are younger than 65 years. If you have Original Medicare and would like to learn if your state offers a Medigap policy, contact Medicare directly or call your state's insurance department.



Medicare may not be your only health plan option for coverage for your SMA. If you are currently working, you may have commercial insurance, you may also qualify for Medicare because you receive SSDI. One health plan will be the primary payer and pay first, while the other plan will be the secondary payer. There are rules about which insurance pays first. For more information, visit [Medicare.gov/publications](https://www.medicare.gov/publications) to view or print the booklet “Medicare and Other Health Benefits: Your Guide to Who Pays First,” or call **1-800-MEDICARE**.



If you are already receiving Medicaid, you may be eligible to also receive Medicare. This is referred to as **full dual eligible**. The Medicare-Medicaid Coordination Office of the Centers for Medicare & Medicaid Services makes sure the 2 programs work together to improve care and potentially lower costs. If you qualify for both, Medicare is the primary payer. Medicaid then pays for all other eligible costs not covered by Medicare. For more information, call **1-800-MEDICARE**.



Did you know? If you have original Medicare, OOP costs are capped in the hospital outpatient setting. This means that OOP costs may be limited to the Medicare Part A deductible. Contact Centers for Medicare & Medicaid Services to find out if this applies to you.

Other benefit options to help pay Medicare

Medicare Savings Programs are offered through your state's Medicaid program that help pay for

- Medicare premiums
- Part A and Part B deductibles
- Part A and Part B coinsurance
- Part A and Part B copays for your SMA care

Depending on your income and resources, you may qualify for one of these 4 programs:

- Qualified Medicare Beneficiary program
 - Helps pay for Part A and/or Part B premiums, copayments, coinsurance, and deductibles
- Specified Low-Income Medicare Beneficiary program
 - Helps pay for Part B premiums
- Qualifying Individual program
 - Helps pay for Part B premiums
- Qualified Disabled and Working Individuals program
 - Pays the Part A premium for some people who are working and have disabilities

If you are receiving help to pay for your health care costs through a Medicare Savings Program, then you are **partially dual eligible**.



Even if you think you may not qualify for a Medicare Savings Program, it is important to apply. Contact your state Medicaid office for more information. You can find the appropriate Medicaid phone number for your state at www.medicare.gov/contacts. You can also call **1-800-MEDICARE (1-800-633-4227)**

How to apply for Medicare

Most people with SMA who are receiving SSDI benefits are automatically enrolled in Original Medicare (Parts A and B)

- You will be enrolled after 2 years of receiving SSDI. You will get your Medicare card in the mail
- You also get a yellow notice in the mail about your Part D drug plan. It will tell you how to review or change it



If you are disabled and have received SSDI for 24 months, you will automatically be enrolled in Original Medicare (Parts A and B).

If you are not disabled, you will need to enroll in Medicare. You can sign up in 2 ways:

- Call the Social Security office at **1-800-772-1213**.
- Sign up online at **www.ssa.gov/medicare**.

Medicare enrollment periods

For some people, there are special times set aside for enrolling in Medicare. These are usually the times when you also can change your Medicare plan (Part C or Part D).

- Open Enrollment period: You can change your Medicare plan (Part C or Part D) during Medicare Open Enrollment. This happens every year from October 15 to December 7. For more information about Medicare plans, go to **www.medicare.gov**
- Special Enrollment period: When certain events happen in your life, such as a move or the loss of a health plan, you can make changes to your Medicare Part C or Part D plan. There are many different situations when a Special Enrollment period may apply. Call **1-800-MEDICARE (1-800-633-4227)** to learn more

Continuing your treatment when your insurance changes

It is important to track and understand changes in your health insurance if they occur. For example, there may come a time when you move from Medicaid to Medicare. In that case, Medicare becomes your primary insurance plan and Medicaid becomes the secondary insurer.

- Some health plans require you to get an authorization for your treatment. If your insurance changes, you will need to find out if an authorization is required
- If your primary insurance plan changes and you submit a claim to the wrong primary plan, it will likely be rejected and you will need to resubmit the claim to the right insurer. This can cause a significant delay in getting reimbursed

How much Medicare covers depends on whether it is your primary or secondary insurance plan

- If Medicare is your primary insurance, it pays up to the limits of its coverage
 - Hospital coverage (Part A)
 - Doctor visits, outpatient services, and drugs administered by a healthcare provider (Part B)
 - Prescription drugs that you administer yourself (Part C)
- There are still coverage gaps if Medicare is the primary insurance plan
 - You can cover these gaps with secondary or supplemental insurance (for example, a health plan through your employer or a Medigap policy)
- If Medicare is your secondary insurance plan
 - The main role of Medicare is to close the gap in your OOP expenses
 - It pays only for costs that are not covered by the primary insurance plan
 - It may not pay all of the uncovered costs
 - It covers claims when payment by your primary insurance is delayed or in dispute



If you have Original Medicare, you may want to also enroll in a Part D plan. A Part D plan will cover prescriptions that are not given at a doctor's office or SMA treatment center.

Health
Plan Basics

Health Plan
Coverage

Health Plan
Options

Medicaid, Social
Security, and CHIP

Medicare

SMA Support
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Important Terms

SMA SUPPORT RESOURCES

SECTION 6

SMA SUPPORT RESOURCES

Here is a list of groups in the SMA community that may be able to offer help to you and your family.

<p>Cure SMA</p>		<p>The advocacy organization Cure SMA provides a nationwide support system to the SMA community. For those newly diagnosed, it offers 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 of SMA and patients of all ages. Cure SMA hosts the largest annual SMA conference in the world for individuals with SMA and their families, and members of the scientific community.</p> <p>www.curesma.org</p>
<p>Muscular Dystrophy Association (MDA)</p>		<p>MDA is a source for news and information about neuromuscular diseases, research, treatments, cures, and services. MDA funds worldwide research and provides support to families nationwide by 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>

EveryLife Foundation for Rare Diseases		<p>The EveryLife Foundation for Rare Diseases is dedicated to accelerating biotech innovation for rare disease treatments through science-driven public policy. It also works to fulfill the unmet needs of patients with rare diseases and to empower the community.</p> <p>www.everylifefoundation.org</p>
FightSMA		<p>Created in 1991, the mission of FightSMA is to strategically accelerate the search for treatments and a cure for SMA by raising disease awareness and funding research.</p> <p>www.fightsma.org</p>
Global Genes		<p>Global Genes is a nonprofit 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>
SMA Foundation		<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 SMA.</p> <p>www.smafoundation.org</p>



**There may be more groups that provide SMA support.
Talk with your healthcare team to learn about all of your options.**

IMPORTANT HEALTH PLAN TERMS YOU SHOULD KNOW

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Health Plan
Coverage

Health Plan
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Medicaid, Social
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Medicare

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Important Terms

SECTION 7

IMPORTANT HEALTH PLAN TERMS YOU SHOULD KNOW

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

Children's Health Insurance Plan (CHIP): Low-cost government-funded health insurance for children up to age 19 years whose families earn too much money to qualify for Medicaid.

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

Commercial insurance: Health insurance coverage, offered to groups or individuals through private insurers. Commercial insurance policies may be purchased through an employer, a broker, or a public health insurance marketplace (also known as an insurance exchange). Individuals may choose different types of commercial insurance plans.

Copayment (copay): A set amount a patient pays for a healthcare services covered by insurance.

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 your insurance plan begins to pay for the services.

Fee-for-service (FFS): A structure in which you and your health plan pay a portion of your costs at each visit or service. These plans often offer more flexibility in choice of providers or hospitals, but they tend to cost more. FFS is also known as indemnity insurance.

Flexible spending account (FSA): An account that you set up through your job to help pay for healthcare costs. You don't pay taxes on this money, but if you don't spend all of your FSA money by the end of year, you lose the money that is left. In some cases, your job may provide a grace period to use the rest of the money in your FSA. Your job may also let you carry over up to \$500 to use in the following year, but is not required to.

Formulary: A list of prescription drugs covered by a health plan.

Full dual eligible: An individual who receives both Medicare and Medicaid.

Government-funded health programs: Health insurance benefits provided through programs funded by each state or the federal government, such as Medicare, Medicaid, CHIP, TRICARE®, or VA Care.

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Health insurance marketplace: Also called “Exchange.” A government-sponsored resource where you can choose a health plan. It also provides information on programs that offer financial help for insurance coverage.

Health maintenance organization (HMO): A type of plan in which you get care from a network of providers. Your primary care doctor coordinates all of your care.

Health savings account (HSA): An account you set up with your employer to save money for medical expenses. Like an FSA, you don’t have to pay taxes on this money. Unlike an FSA, money can be carried over to the next year if you don’t use it.

High-deductible health plan (HDHP): A healthcare plan with a higher deductible than a traditional healthcare plan. The monthly premium is usually lower, but you pay more healthcare costs yourself (your deductible) before the insurance company starts to pay its share.

In-network provider (or preferred provider): Doctors, hospitals, or other providers that participate in your health plan. You can get care outside of the network, but you’ll pay less if you use in-network providers.

Managed care plan: Plans that include a network of doctors, hospitals, and other providers to coordinate care.

Medicaid: A health insurance program run by each state for people with low incomes, disabilities, and special needs. People enrolled in Medicaid get their care mainly from private providers, community health centers, and managed care plans that contract with Medicaid to provide needed services.

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

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

Medical exception: A request to use a drug even though the drug is not covered by the health plan.

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.

Medical policy: Set of guidelines a health plan uses to make treatment coverage decisions. A health plan may restrict a treatment or procedure based on its medical policy.

Medigap: A health insurance policy sold by private insurance companies. Medigap policies help pay some of the healthcare costs that the Original Medicare plan does not cover.

Network: The facilities, providers, and suppliers your plan works with to provide healthcare services.

Open Enrollment: A set period of time (usually from October to December) during which people can choose to make changes in their insurance coverage for the coming year.

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

Out-of-pocket (OOP) cost: The amount an individual may have to pay for covered healthcare services over the course of a year. The portion you pay may include your plan's deductible, copays, and/or coinsurance.

Out-of-pocket limit or maximum: The money you pay for your healthcare costs that is not paid back by your health plan. The OOP maximum is the most you will have to pay during your policy period (usually 1 year). After you pay that amount, your health plan covers all costs.

Partially dual eligible (or partial dual): An individual who receives both Medicare and Medicaid (dual eligible) and qualifies for Medicaid to pay some of the costs for Medicare, such as Part B premiums and cost sharing.

Point-of-service (POS) plan: A plan that coordinates care with a primary care doctor. It allows for more flexibility in choice of doctors and hospitals than an HMO.

Preferred provider organization (PPO): A plan that contracts doctors and hospitals to create a network of providers. You can get care outside of the network, but you'll pay less if you use in-network providers.

Premium: The amount that must be paid by a family or an individual to get coverage. For some people with commercial insurance, a portion of the health plan premium is paid by their employer.

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 an HMO and a PPO.

Primary insurance (or primary payer): The health plan that pays for claims first. This can be a commercial plan, Medicare, or Medicaid.

Prior authorization (or preauthorization or precertification): The process of getting a health insurer to agree that a treatment, medicine, or healthcare service is medically necessary before a patient can receive it.

Private insurance: Any health plan bought by an employer or by an individual directly from a private insurance company.

Provider network: A group of healthcare providers (such as doctors), facilities (such as hospitals), and suppliers (such as pharmacies) that work 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 health insurance marketplace may be eligible for government subsidies to help reduce premiums, cost sharing, or both.

Referral: Permission that patients need to get from their primary care doctor in order to get health insurance coverage for specialty care. For example, some individuals with SMA 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 1 source of health insurance, this is another plan that pays for the services or costs not covered by the primary health plan.

Social Security: A United States program of social insurance and benefits. Social Security's benefits include retirement income, disability income, and death and survivorship benefits.

Social Security Disability Insurance (SSDI): Benefit program by Social Security paid by the federal government for people who cannot work because they have a long-term medical condition or a condition that will result in death.

Specialty pharmacy: A type of pharmacy that coordinates medication delivery and offers support services for drugs that treat complex conditions, such as SMA.

