CURE SMA CARE SERIES BOOKLET

A HEALTH INSURANCE ROADMAP FOR PEOPLE LIVING WITH SPINAL MUSCULAR ATROPHY (SMA) AND THEIR CAREGIVERS

CHOICE AND CONNECTION TO TREATMENT AND CARE

Last updated September 2025

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INTRODUCTION

Navigating health insurance and predicting your healthcare costs can be overwhelming.

This toolkit is designed to be a roadmap for understanding your health coverage and helping to ensure it meets your needs. It offers an overview of:

- Different types of health insurance available.
- Resources to help you understand different types of health coverage and related terms.
- How coverage works and what insurance may cover.
- What to look for and ask about when reviewing policy information.
- How to talk to insurers about insurance options and new treatments.
- How to navigate insurance denials and appeals.
- How to find help to cover costs that may not be covered by traditional health insurance plans.

Many of the terms used in this booklet are defined in the glossary that begins on page 18.

HEALTH INSURANCE AT-A-GLANCE

Health insurance helps protect both your health and your finances. With coverage, you can get the care you need while lowering the risk of high medical bills.

In the United States, there are two major types of health insurance:

- **Private health insurance** (also known as commercial health insurance), which is any health insurance plan privately purchased; often private health insurance is available through an employer.
- **Government-funded health insurance**, which means insurance benefits provided through a government program such as Medicare, Medicaid, or the Children's Health Insurance Program (CHIP).

Determining the right health coverage is important. If you or someone in your household is living with SMA, you may have multiple insurance plans to choose from depending on where you live and your income/resource eligibility.

To find the insurance plan that works best for you and/or your family, some questions to ask and answer are:

- Am I or my loved one eligible for government insurance?
- (If employed) What insurance is offered through my employer?
- (If married) Is my or my spouse's insurance the better option for my family?

ABOUT PRIVATE HEALTH INSURANCE

There are many different types of private health insurance plans. Each insurance plan is unique and offers different levels of coverage. These are often provided through an employer or purchased directly by individuals or families.

- How to Qualify: You can sign up through your employer, the **Health Insurance Marketplace**, or directly through an insurance company.
- What it Covers: Coverage depends on the plan, but may include doctor visits, hospital care, medications, transportation assistance, therapies, and specialists.

ABOUT GOVERNMENT FUNDED INSURANCE

Government-funded insurance programs are designed to help the elderly, people who may have lower incomes, and individuals with disabilities get the care they need. At the time of an SMA diagnosis, you may already have private health insurance. However, you may also be eligible for government programs to help pay for expenses not covered by your private health insurance. The first step in becoming eligible for government assistance is receipt of an official verification of an SMA diagnosis by the U.S. Social Security Administration. To learn more about this process, contact your state's Disability Services Office.
The following are government-funded insurance programs you may qualify for.

MEDICARE

Medicare is a federal health insurance program for people aged 65 and older, and for those under 65 who have certain disabilities like SMA. It can be used together with Medicaid or private insurance.

- How to Qualify if under 65: If you have a qualifying disability like SMA, you may become eligible after receiving Social Security Disability Insurance (SSDI) for two years. SSDI is a program that provides monthly payments to those who have a qualifying diagnosis that affects their ability to work. See if you qualify by visiting **Medicare.gov/eligibilitypremiumcalc**
- What It Covers: Hospital stays, doctor visits, equipment, and preventive care.
- How to Apply: Learn more at **medicare.gov**

MEDICAID

Medicaid is a state-run program funded with both state and federal funds. Medicaid provides low-cost, sometimes free, health coverage to individuals with limited income and resources, people living with disabilities, and pregnant women.

- How to Qualify: Rules vary by state. You may qualify through income limits or disability status. To find out more about income and resource eligibility, visit www.medicaidplanningassistance.org/medicaid-eligibility-income-chart. In some states, you may be automatically eligible for Medicaid if you receive Supplemental Security Income (SSI). Some states also offer options that count medical expenses toward eligibility.
- What It Covers: Doctor visits, hospital care, medical testing, equipment, therapies, caregiver services, and even transportation to appointments.

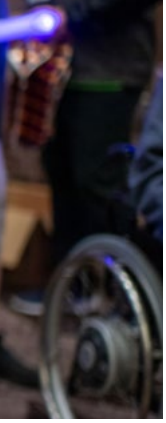
HOW TO APPLY:

- Apply through your state's Medicaid office or HealthCare.gov. There is no limited enrollment period for Medicaid. If you/your loved one qualify, coverage can begin immediately at any time of year. Because Medicaid rules vary by state it may be helpful to talk with your healthcare provider, a Medicaid case worker, or local support program to understand what you may be eligible for and what steps to take.

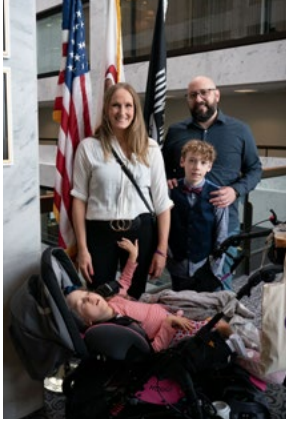
MEDICAID "SPEND-DOWN" RULE

Even if your income exceeds traditional eligibility income levels, you may be able to qualify for Medicaid under Medicaid expansion, or through "spend-down" rules. Some states have expanded Medicaid coverage to include residents with household income below 133% of the federal poverty level.

Visit www.medicaid.gov/medicaid/eligibility-policy to find out more about eligibility requirements . In addition, it is possible to receive an income and maintain both SSI eligibility and Medicaid benefits for health insurance, up until a specified earnings threshold via Section 1619(b). If you are eligible for SSI, have Medicaid for your health insurance and are employed, 1619(b) allows you to work and to keep Medicaid coverage without a Medicaid spend-down. To learn more about Section 1619(b), including eligibility and exceptions to the rule, please visit www.ssa.gov/disabilityresearch/wi/1619b.htm.







CHILDREN'S HEALTH INSURANCE PROGRAM

CHIP offers low-cost health coverage for children in families that exceed the income eligibility for Medicaid but cannot afford other health insurance. Families who qualify for CHIP will not need to buy a private health insurance plan.

- How to Qualify: Each state sets its own rules based on family income and your child's age. Contact your local state Medicaid office for more information.
- What it Covers: Doctor visits, medications, hospital care, therapies, and equipment related to SMA.
- How to Apply: Apply through your state Medicaid office or HealthCare.gov. There's no enrollment deadline, but CHIP can't be used at the same time as Medicaid. The program may have a different name in your state.

ABOUT GOVERNMENT FUNDED PROGRAMS

In addition to government-funded insurance like Medicaid and Medicare, there are other helpful programs that may support individuals or families affected by SMA. These programs don't replace your insurance but can provide extra help like financial support, access to care, or coverage for services not included in your main health plan. This section introduces programs you may qualify for.

SOCIAL SECURITY INCOME (SSI)

SSI is a federal program that provides monthly cash payments to help individuals with limited income that are aged 65 or older, blind, or living with a disability such as SMA.

- How to Qualify: A person must meet income and resource limits. The amount of income you can receive each month and still be eligible for SSI depends partly on where you live. However, a single person usually must have resources worth $2,000 or less ($3,000 or less for couples). Resources include things like savings, investments, or property (but not your home or car in most cases).
- What It Offers: Monthly cash payments to help with basic needs like food, clothing, and shelter.

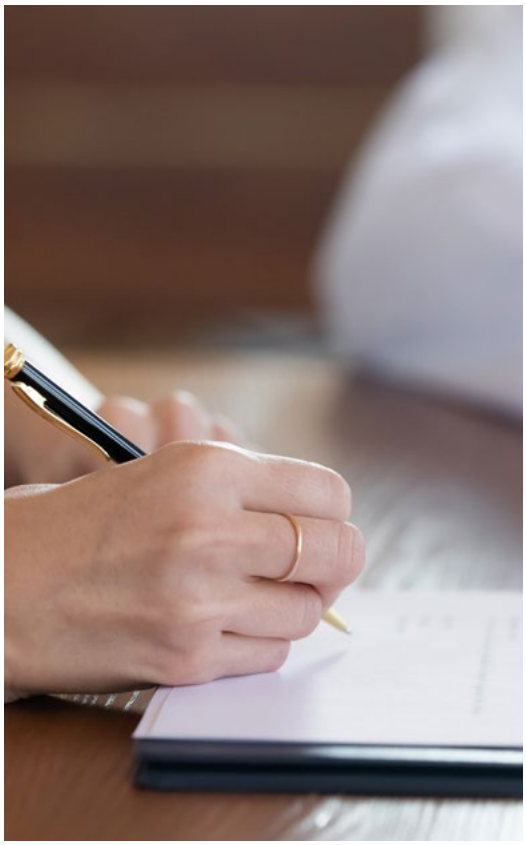
HOW TO APPLY:

- As a Child: Review the Child Disability Starter Kit at www.ssa.gov/pubs/EN-64-112.pdf to prepare you to complete the Child Disability Report by calling SSA at 1-800-772-1213 or by completing the report online at www.ssa.gov/childdisabilityreport.
- As an Adult: Review further details and complete the online application at www.ssa.gov/ssi or by calling 1-800-772-1213.
- If you feel you need additional assistance with the SSI application process, you're not alone. You can search for your state's *Vocational Rehabilitation Services Office* or your local *Disability Services Office* for help. Your healthcare provider may also be able to guide you or connect you with someone who can assist.

MEDICAID WAIVER PROGRAMS

Medicaid waiver programs provide extra services for people with disabilities who need daily or special care at home or in the community. These programs often offer more than regular Medicaid. Please note, because Medicaid waivers are state-based, waiver services will not transfer to other states, and many states have people already on a waiting list for waiver services.

- How to Qualify: Not all states have the same rules and benefits. Eligibility is often based more on medical needs than income.
- What It Covers: Services like home health care, therapies, adaptive equipment, and support programs that help with everyday life.
- How to Apply: Waiver programs vary by state. To learn more about waivers available in your state, visit medicaid.gov. Then, under the Medicaid drop down, select "Section 1115 Demonstration".



KNOW YOUR RESOURCES

Navigating insurance and healthcare can feel overwhelming, but you don't have to do it alone. There are people and programs available to support you along the way.

Cure SMA Insurance Resources Page

- ✓ State Resource Guides
- ✓ Letter of Medical Necessity Checklist
- ✓ Insurance Appeal Process Checklist

Support Services for SMA Treatment

- ✓ Evrysdi®
- ✓ Spinraza®
- ✓ Zolgensma®

UNDERSTANDING WHAT HEALTH INSURANCE COVERS

All health insurance plans are different, and many factors can affect what services, treatments, and equipment are covered. Because managing you or your loved one's care can be complex, it's important to know where to go for information—and to keep an ongoing dialogue with your employer and your insurance provider.

Most plans come with a summary—sometimes called a *Summary of Benefits and Coverage*—that gives you a quick look at what the plan includes. This is a great place to start when trying to understand your benefits. You can also call the insurance company's customer service line to ask questions.

If you get insurance through your job, you may also talk with your employer. They can provide an overview of the plan, including what it covers and how much it costs. You may request an Employer Plan Document that defines the benefits offered to an employee. This provides more detailed information than the summary about the benefits offered. They may also have someone in human resources (HR) or a contact person at the insurance company who can help answer questions.

To better understand what's covered, review your plan details and think about the services, treatments, and equipment that matter most to you or your loved one—especially those you use often. Be sure to consider:

- What medical services do we use most often?
- Are the specialists we see (like neurologists or pulmonologists) covered by this plan? Are they in-network or out-of-network?
- Will the plan cover physical therapy, occupational therapy, and speech therapy?
- Does the plan cover the treatment options we need?
- Will we be able to continue the treatments we're already using?
- Does the plan cover durable medical equipment (DME) like wheelchairs or breathing devices?
- Is there a specific pharmacy we need to use? Can we fill our prescriptions there?

WHAT INSURANCE MAY COVER

Health insurance can help pay for many types of care—like doctor visits, medicines, equipment, and therapies. Common types of coverage include:

MEDICAL SERVICES

This includes doctor visits, specialists, hospital stays, rehabilitation, and home health care. Some of these may need a referral from your primary care provider or prior approval from the insurance company. Medical services also include important testing—like genetic testing to confirm diagnosis, breathing tests, imaging, or nutrition checks to monitor care over time.

PRESCRIPTION COVERAGE (PHARMACY BENEFIT)

Prescription coverage helps pay for medicines you usually get from a pharmacy. Some treatments—like injections at a clinic or infusions at home—may be covered under medical services instead of pharmacy. If you're not sure where the medication is covered, it's a good idea to check both parts of your plan or ask your insurance provider.

MAJOR MEDICAL

Major medical is the part of your insurance plan that helps pay for large or ongoing healthcare needs like specialists, surgical procedures, emergency room and urgent care visits, or inpatient hospital stays. Not all insurance plans are the same so it's a good idea to check your plan or contact your insurance provider to find out what's covered under your major medical benefits.

DURABLE MEDICAL EQUIPMENT (DME)

DME is equipment that supports safety, independence, and comfort at home. For people with SMA, this might include wheelchairs, Bi-level Positive Airway Pressure (BiPAP or BPAP) machines, bath chairs, adaptive seating, braces, and standers. Insurance often covers DME when it's prescribed and medically necessary, but your provider may need to submit paperwork to explain why it's needed.

From there ask your employer and/or your insurance provider the following questions to be sure the plan supports your care:

- Are there rules or steps required to meet "medical necessity" for the treatments we receive?
- Do we need a referral or prior approval before we receive certain care or treatment?
- Does the plan offer support for rare disease?
- Are there out-of-pocket costs for our medical equipment or treatment?

ACCESING COVERED SERVICES

Even if your insurance plan covers a service or treatment, you might need to take a few extra steps before it's approved. Here are some of the common steps your care team may help with:

Referral Requirements

A referral is an order or recommendation provided by the primary care provider for a patient to receive care from a specialist, like a neurologist. Some insurance plans require referrals for specialty care. Without a referral, your plan might not cover the service — or may charge you more.

Prior Authorization Requirements

Prior authorization (also called pre-approval) means your doctor needs to ask your insurance for permission before you receive certain treatments or services. Prior authorization requirements are common for:

- SMA treatment
- Medical equipment (DME)
- Genetic testing

If approval isn't given ahead of time, your insurance might deny coverage.

Letter of Medical Necessity

A Letter of Medical Necessity is a note from your doctor explaining why a specific treatment, medicine, or piece of equipment is important for your health. This letter is often used to:

- Support prior authorization requests
- Help appeal an insurance denial

For guidance on what to include within a letter of medical necessity please visit the **Cure SMA Insurance Resources page**

UNDERSTANDING INSURANCE CLAIMS, DENIALS, AND APPEALS

When you or your loved one gets medical care, the doctor or hospital sends a claim to your insurance company. This claim is a request for your insurance to help pay for the service.

Federal law requires your health insurer to respond to a health insurance claim. Required response times are:

- Within 15 days if you are seeking authorization ahead of treatment, usually referred to as "prior authorization";
- Within 30 days for medical services you've already received; and
- Within 72 hours for urgent medical matters

Sometimes, the insurance company may deny the claim, meaning they decline to pay for all, or part of the services received. This can be frustrating—especially when the service is needed and recommended by your healthcare provider. If a claim is denied, insurance companies will send a denial letter.

Common reasons for treatment denials include:

- Lack of Medical Necessity
  - › Insurers may say the treatment isn't needed based on their guidelines. This determination may be based on your age, genetic test results, SMN2 copy number, or how severe your symptoms are.
- Non-Formulary Drug
  - › Insurance plans often have a preferred drug list (called a "formulary"). If a medication is not included, they may deny coverage.
- Duplicative Therapy or Concurrent Therapy Not Allowed
  - › Some insurance plans will only cover one treatment at a time for specific conditions. They may deny coverage if you're prescribed more than one treatment.

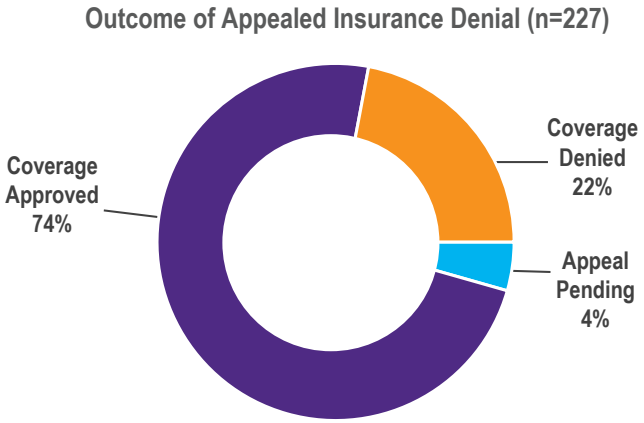
WHAT TO DO WHEN A CLAIM IS DENIED

If a claim is denied, you have the right to appeal.
An appeal is a formal request to an insurance company to reconsider a decision to deny a claim.
Insurance denials for SMA treatment are common. However, we encourage you to consider filing an appeal. As reported within the 2023 State of SMA, the majority of appeals for SMA treatment are successful.

INSURANCE DENIALS AND APPEALS

55%

of individuals treated with an SMA therapy have received an insurance denial related to SMA treatment coverage



After appealing initially denied coverage, nearly three-quarters of individuals received approval for SMA treatment.

When stratified by age, similar appeal outcomes were seen between both pediatrics and adults.

Insurance Denials and Appeals for SMA Treatment. Adapted from 2023 State of SMA by Cure SMA, 2024

In general, if your claim is denied you can formally submit an appeal by following these key steps:

Step 1

Before you start an appeal: Talk to your healthcare team. Most clinics have staff available to help you better understand the process and can submit the appeal on your behalf.

To work with your healthcare provider on the appeal you will need to provide:

- A copy of your denial letter
- Any documentation from your conversations with the insurance company
- Any medical information you may have

Sometimes, your healthcare provider can speak directly with a doctor from the insurance company to explain why the treatment is needed. This option, called a peer-to-peer, is not available with all insurance companies, but it can speed things up. You or your healthcare provider may contact your insurance company to see if this is an option that may be used for an appeal.

You can also reach out to your insurance provider to ensure you comply with their appeal requirements. It is recommended that conversations with insurance companies be documented: write down the date, time, length, and details of the conversation as well as the name and/or any identification number of the individual with whom you speak. Creating a paper trail can be helpful when filing appeals.

Step 2

Internal Appeal: To file an internal appeal, you and/or your healthcare provider must provide an appeal letter to your insurer demonstrating why a particular service, treatment or equipment is medically necessary. Appeals usually need to be submitted within a set timeframe—often 180 days. For guidance on what to include within an appeal letter, please visit the Cure SMA Insurance Resources page. Pharmaceutical companies also offer resources to support appeals for SMA treatment.

- ✓ Evrysdi®
- ✓ Spinraza®
- ✓ Zolgensma®

Step 3

External Appeal: If the internal appeal is denied, you or your provider may help request a review by someone outside the insurance company.
The third-party review is usually handled by a state or federal agency. A written request for an external review must be filed within 60 days after the internal appeal is rejected. It is important to request an expert in the specific area related to the denial.

COVERED BY EMPLOYER-BASED INSURANCE?

If your insurance says no to a treatment or service, it can feel frustrating. But it's important to know that the insurance company might not be the only one making the decision. In many cases, the rules about what's covered are set by your employer, not the insurance company.
If you're unsure why a claim was denied, review your plan documents or talk to your human resources or benefits department. They can explain what your plan includes.

UNDERSTANDING AND MANAGING HEALTHCARE COSTS

When it comes to paying for your health insurance, it helps to have a sense of the costs you will incur. There are tools to help you estimate and compare costs associated with your health insurance, including coinsurance, copayments (copays), and deductibles. In addition to budgeting apps you can download on your smart phone, organizations like Fair Health Consumers provide a calculator to help estimate costs for medical procedures and services in the zip code where you receive care. Whether you are insured or uninsured, the cost estimate you receive will show how much you may be asked to pay for your care.
Learn more at fairhealthconsumer.org/

OUT-OF-NETWORK

Because SMA is considered a rare condition, it can be difficult to find a provider that knows the ins and outs of the disorder and its related challenges. That is why it is important to know which healthcare providers and facilities are covered by your health insurance plan.

Insurers manage and predict costs by creating provider networks (i.e., contracts with doctors, hospitals, and other health professionals the expectation to provide care at negotiated rates). Visiting a healthcare provider or hospital in your insurance network (in-network provider) has several benefits, including lower out-of-pocket costs and more generous insurance benefits. However, insurers have been narrowing networks in recent years to keep costs low. As a result, it is likely that not every doctor, hospital, or medical treatment facility will be covered by your health insurance plan. Your insurer offers provider directories to help you understand what healthcare providers and hospitals are included in your network.

OUT-OF-POCKET

Many health insurance plans are now charging higher premiums and imposing larger out-of-pocket costs on patients, placing greater burdens on people living with SMA and caregivers. However, there are resources available to help you predict and manage healthcare costs. Know that your insurance company cannot deny you coverage, refuse to renew your coverage, or charge you a higher premium because of SMA.

Out-of-pocket costs are your expenses for healthcare that aren't directly reimbursed by insurance, including:

Premium: the amount you pay each month to have health insurance, regardless of whether you use your insurance plan.

Deductible: the amount you must pay for healthcare services covered by your insurance plan before insurance starts to pay.

Coinsurance: the percentage you pay for the cost of a covered healthcare service after paying any applicable deductible.

Copayment/Copay: the fixed dollar amount you pay for a covered healthcare service.

Under most health insurance plans, there is an out-of-pocket maximum you must pay for covered services in a plan year. How you reach that maximum depends on your deductible and coinsurance percentage.

SUPPORT FOR OUT-OF-POCKET TREATENT COSTS

Even when a treatment is approved, you may still have an out-of-pocket cost. If you're facing high costs, here are some options that may help:

- Companies that make SMA treatments offer patient assistance programs to help with the cost. These programs may provide financial help, discounts, or even free medication for those who qualify. Please review the links provided to learn more about each program and how to apply.
  - ✓ Evrysdi®
  - ✓ Spinraza®
  - ✓ Zolgensma®
- Consider reaching out to nonprofit organizations that offer copay assistance programs such as:
  - › PAN Foundation: https://www.panfoundation.org
  - › Patient Advocate Foundation CoPay Relief Fund: https://copays.org/
- Check for state programs or Medicaid waivers that could give you more support or coverage.
  - › You can request further information about state funded insurance by completing this Cure SMA Request Form and clicking on State Specific Resource Guides:
- Look into prescription discount cards online. They can sometimes lower the prices of certain medications at your pharmacy.

GLOSSARY

Appeal: A request for a health insurance plan to reconsider denying coverage for a specific service or product.

Children's Health Insurance Plan (CHIP): Low-cost health coverage for children in families that exceed the income eligibility for Medicaid but cannot afford other health insurance plans.

Coinsurance: The percentage you pay of the cost of a covered healthcare service after paying any applicable deductible; e.g., 5 percent of the allowable amount paid to a physician.

Copayment (copay): A fixed dollar amount you pay for a covered healthcare service; e.g., $20 per physician visit.

Cost sharing: The share of costs of care that must be paid for by the individual.

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

Deemed income: The portion of your ineligible spouse's income and resources that are considered to be yours.

Dually eligible (dual-eligible beneficiary/ies, dual eligible/s): Being dually eligible—or a dual-eligible beneficiary or dual eligible—describes people eligible for both Medicare and Medicaid. The term includes individuals who are enrolled in Medicare Part A and/or Part B and receive full Medicaid benefits and/or assistance with Medicare premiums or cost sharing through one of the following Medicare Savings Program (MSP) categories:

- **Qualified Medicare Beneficiary (QMB) Program** – Helps pay for Part A and/or Part B premiums, deductibles, coinsurance, and copayments.
- **Specified Low-Income Medicare Beneficiary (SLMB) Program** – Helps pay for Part B premiums.
- **Qualifying Individual (QI) Program** – Helps pay for Part B premiums.
- **Qualified Disabled Working Individual (QDWI) Program** – Pays the Part A premium for certain people who have disabilities and are working.

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

Earned income: Income derived from wages, salaries, tips, and other taxable employee pay; union strike benefits; long-term disability benefits received prior to minimum retirement age; and net earnings from self-employment.

Government-funded health insurance: A broad category of health insurance programs through which insurance benefits are provided (e.g., Medicare, Medicaid, and CHIP).

In-kind income (or income in kind): Income other than money. It includes many employee benefits and government-provided goods and services, such as toll-free roads, food stamps, public schooling, or socialized medicine.

In-network provider (or preferred provider): A provider who has been contracted by an insurer to provide healthcare services to an insurance plan's members or policyholders.

Medicaid: A health insurance program that is administered by 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** – a payment model where services are unbundled and paid for separately.
- **State Medicaid** – a single statewide program operated by the state government.
- **Medicaid Managed Care** – a system in which patients agree to visit only certain doctors and hospitals, and in which the cost of treatment is monitored by a managing company. This program is operated by private health insurance contracted by your 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, disorder, disease, or its symptoms.

Medicare: A government health insurance program that provides coverage for individuals 65 or older and for those under 65 who have certain disabilities. Medicare consists of four parts:

- **Part A** – Hospital insurance (inpatient hospital care, inpatient care in a Skilled Nursing Facility, hospice care, and some home health services).
- **Part B** – Medical insurance (physician services, outpatient care, durable medical equipment, home health services, and many preventive services).
- **Part C** – Medicare Advantage (MA) (Medicare-approved private insurance companies provide all Part A and Part B services and may provide prescription drug coverage and other supplemental benefits).
- **Part D** – The Prescription Drug Benefit (Medicare-approved private companies provide outpatient prescription drug coverage).
    - Medicare beneficiaries who meet certain income and resource limits may qualify for the Extra Help Program, which helps pay for monthly premiums, annual deductibles and copayments.

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

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

Out-of-pocket costs (sometimes called OOP): The amount of money an individual may have to pay for the cost of covered healthcare services, which can vary based on the health insurance plan and can include deductibles, coinsurance, and copayments.

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

Premium: The amount that must be paid by a family or an individual to obtain coverage, usually payable on a monthly basis.

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

Privately held health insurance: Also known as commercial insurance, a broad category of health insurance coverage where benefits are purchased directly from a health insurance plan or through an employer, a broker, or a public health insurance marketplace (also known as an insurance exchange).

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 health insurance plan that, before coverage is allowed, decides if a treatment or medication is medically necessary.

Provider network: A group of healthcare providers, healthcare facilities, and suppliers contracted by an insurer to provide services and products.

Government-funded 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.

Reasonable and customary fees: Charges made by your health insurance plan for a particular medical service or treatment; fees considered reasonable and customary match the general prevailing cost of that service within your geographic area, calculated by your health insurance plan.

Referral: An order, permission, or recommendation provided by the primary care provider for a patient to receive 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 one source of health insurance, an additional source of coverage that pays for the services or costs not covered by the primary health insurance.

TRICARE: A healthcare program for uniformed service members, which includes active duty and retired members of the U.S. Army, U.S. Air Force, U.S. Navy, U.S. Marine Corps, U.S. Coast Guard, the Commissioned Corps of the U.S. Public Health Service and the Commissioned Corps of the National Oceanic and Atmospheric Association, as well as their families around the world.

- Retired soldiers may be eligible for both TRICARE and VA Care benefits.
- Service members who separate due to a service-connected disease or disability may be eligible for VA benefits and certain TRICARE benefits.

Unearned income: Income derived from other sources other than work, including income from owning property (known as property income), inheritance, pensions, investments, interest, and payments received from public welfare.

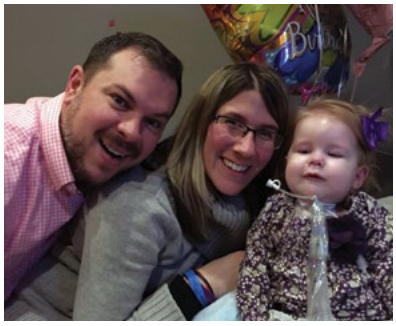
VA Care: Healthcare benefits for people who served in any of the armed forces and were separated under any condition other than dishonorable.

- Current and former members of the Reserves or National Guard who were called to active duty by a federal order and completed the full period for which they were called or ordered may be eligible for VA health benefits, as well.
- Retired soldiers may be eligible for both TRICARE and VA Care benefits.
- Service members who separate due to a service-connected disease or disability may be eligible for VA benefits and certain TRICARE benefits.

CURE SMA

Cure SMA is a non-profit organization and the largest worldwide network of families, clinicians, and research scientists working together to advance SMA research, support affected individuals/caregivers, and educate the public and professional communities about SMA.

Cure SMA is a resource for unbiased support. We are here to help all individuals living with SMA and their loved ones, and do not advocate any specific choices or decisions. Individuals and caregivers make different choices regarding what is best for their situation, consistent with their personal beliefs. Parents and other important family members should be able to discuss their feelings about these topics, and to ask questions of their SMA care team. Such decisions should not be made lightly, and all options should be considered and weighed carefully. All choices related to SMA are highly personal and should reflect personal values, as well as what is best for each individual and their caregivers.



Cure SMA is here to support you. To continue learning, please see available Care Series booklets:

- Breathing Basics
- Caring Choices
- Genetics of SMA
- Musculoskeletal System
- Nutrition Basics
- Understanding SMA

OUR MISSION IS TO DRIVE RESEARCH FOR TREATMENTS AND A CURE FOR SMA, AND TO SUPPORT AND EMPOWER EVERYONE IMPACTED BY SMA TODAY.

Follow us on social media to stay up-to-date with news and stories!