



CURE SMA

CHOICE AND CONNECTION TO CARE

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



Make today a
breakthrough.

INTRODUCTION

When caring for a loved one with SMA or when faced with a new SMA diagnosis, the decisions ahead can seem overwhelming—particularly when navigating health insurance and predicting your healthcare costs. Learning more about the resources available and how to navigate them is a foundational first step toward ensuring you have the most effective, appropriate, and comprehensive care for your situation.



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

- The different types of health insurance available.
- Resources to help you understand different types of health coverage and related terms.
- The insurance eligibility profile for families impacted by SMA.
- How coverage works and what insurance may cover.
- How to calculate estimated costs.
- How to find help to cover costs that may not be covered by traditional health insurance plans.
- How to talk to insurers about insurance options and new treatments.



Many of the terms used in this booklet are defined in the glossary that begins on page 12. Terms that are defined in the glossary are bolded the first time they appear in the text.



HEALTH INSURANCE AT-A-GLANCE

Current law incentivizes Americans to buy health insurance. Having health insurance is the best way to protect your family from high medical bills and avoid this penalty.

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 **Social Security, Medicare, Medicaid**, or the **Children's Health Insurance Program (CHIP)**.

MEDICARE? MEDICAID?

What's the difference?

Medicare is a federal government program that provides coverage for individuals older than 65 years and for those with certain disabilities.

Medicaid and the Children's Health Insurance Program (CHIP)

are stateadministered programs that provide coverage for low-income individuals and for children with disabilities and special needs.

To learn more about government-funded health insurance, and to determine your eligibility, visit **CMS.gov**.



ABOUT PRIVATE HEALTH INSURANCE

- There are many different types of private health insurance plans, also known as commercial health insurance. Each insurance plan is unique and offers different degrees of coverage. Your insurance will differ in **premiums, out-of-pocket costs, out-of-network providers** available, and other items. Call your insurer to learn more about what your insurance plan covers.



ABOUT GOVERNMENT-FUNDED HEALTH INSURANCE

Many people receive health insurance through programs funded by federal or state governments, including programs such as:

- Medicaid
- Medicare
- CHIP
- **TRICARE** (through the U.S. Department of Defense)
- **VA Care** (through the U.S. Department of Veterans Affairs)

Determining the right health coverage for you and your family 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 your family, some first 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?



SECURING GOVERNMENT-FUNDED HEALTH COVERAGE

You and your family may already have private health insurance at the time of an SMA diagnosis. 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. In most states, if a person with SMA is eligible for **Supplemental Security Income (SSI)** benefits, he or she is automatically eligible for Medicaid.



TO APPLY FOR SSI BENEFITS

If your child has SMA, review the Social Security Child Disability Starter Kit at ssa.gov/disability/disability_starter_kits_child_eng.htm. This kit answers common questions about applying for SSI benefits for children and includes a worksheet that will help you gather the information you need.

1. Contact Social Security right away to find out whether your income and resources are within the appropriate eligibility limits and to start the SSI application process. You can call toll-free at 800.772.1213.
2. Fill out the online Child Disability Report at ssa.gov/childdisabilityreport. At the end of the report, Social Security will ask you to sign a form that gives the child's **primary care provider(s)** permission to offer information about your child's diagnosis. This will allow them to make a decision on your claim.

Visit socialsecurity.gov or call toll-free at 800.772.1213 or at the Social Security TTY number, 800.325.0778, to learn more about your **eligibility**. You can also visit ssa.gov/ssi/text-child-ussi.htm.



SUPPLEMENTAL SECURITY INCOME (SSI)

SSI makes monthly payments to people who have limited income (money received) and resources (owned items/property), and who are:

- Age 65 or older;
- Blind; or
- Disabled.

Income includes money you receive in the form of wages from an employer, Social Security benefits, or pension payments. Income also includes such things as food and shelter. The amount of income you can receive each month and still be eligible for SSI depends partly on where you live.

Call Social Security at 800.772.1213 to find out the income limits in your state. Resources used in deciding if you qualify for SSI include real estate, bank accounts, cash, stocks, and bonds. You may be able to receive SSI if your resources are worth \$2,000 or less or—if you are a couple—\$3,000 or less. To learn more about SSI eligibility requirements and benefits, visit [socialsecurity.gov](https://www.socialsecurity.gov).

Note: If you receive SSDI (Social Security Disability Insurance), you will be automatically enrolled in Medicare after two years for inpatient and outpatient hospital bills and other medical services.

It is important to note, even if you do not qualify for Social Security benefits, you may be eligible for other government assistance, such as Medicaid. (See next page.)

What constitutes income?

Social Security uses different types of income to calculate your SSI payment and determine whether you meet the SSI resource limit.

Earned income is 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.

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

In-kind income (income in kind) is 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.

Deemed income is the portion of your ineligible spouse's income and resources that are considered to be yours, if you're married.

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. For families who have a loved one living with SMA, Medicaid benefits may include healthcare provider visits, medical testing, hospital visits, and transportation to visits, equipment, and other services, depending on the specific benefits and services covered by the program in your state.

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 [healthcare.gov/lower-costs/](https://www.healthcare.gov/lower-costs/) to find out if you are eligible based on income alone. Under “spend-down” rules, you are able to subtract your medical expenses from your income to become eligible for Medicaid. Find out if you qualify by visiting [medicare.gov/your-medicare-costs/get-help-paying-costs/medic](https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/medic)

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 1619b. If you are eligible for SSI, have Medicaid for your health insurance and are employed, 1619b allows you to work and to keep Medicaid coverage without a Medicaid spend-down. You can continue to be eligible for Medicaid coverage until your gross annual income reaches a certain amount (income threshold varies annually by state). Exceptions to this work incentive are if you no longer need Medicaid, or if you accumulate more than your state’s Medicaid resource limit.

Visit www.ssa.gov/disabilityresearch/wi/1619b.htm to learn more about Section 1619(b). See if your income falls within the eligibility range for Medicaid by visiting [healthcare.gov/lower-costs](https://www.healthcare.gov/lower-costs). Even if you don’t qualify based on income alone, it is recommended you apply.

MEDICAID WAIVER PROGRAMS

People living with SMA and their loved ones may qualify for other Medicaid assistance not based on income alone. Medicaid waivers can help provide additional services and wraparound Medicaid coverage so you or your loved one can receive long-term care in your own community.

Not all states have the same rules and benefits. The federal government allows states to apply for waivers from the traditional Medicaid rules, so they can offer a range of innovative options in their state. To learn more about waivers available in your state, **visit [medicaid.gov](https://www.medicaid.gov)**. Then, under the Medicaid drop down, select “State Waivers” under the “Section 1115 Demonstration” section.

[Kidswaivers.org](https://www.kidswaivers.org) is another helpful resource to learn more about available Medicaid waivers.

Moving and Medicaid Waivers

Because Medicaid waivers are state-based, note that waiver services will not transfer to other states and many states have people already on a waiting list for waiver services.

Eligibility for Medicaid & CHIP

Eligibility for Medicaid and CHIP varies from state to state. Note you can only be eligible for Medicaid OR CHIP, not both. You can apply for Medicaid or CHIP in two ways:

- Through the Health Insurance Marketplace by creating an account to submit an application: [healthcare.gov/create-account](https://www.healthcare.gov/create-account).
- Through your state Medicaid agency. Find contact information for your state at [healthcare.gov/medicaid-chip/getting-medicaid-chip](https://www.healthcare.gov/medicaid-chip/getting-medicaid-chip).

There is also no limited enrollment period for Medicaid or CHIP. If you/your loved one qualify, coverage can begin immediately at anytime of year.

Note, in some states, there is no difference between Medicaid and CHIP in terms of benefits and eligibility requirements. In other states, CHIP is a separate program from Medicaid, covering children who are older or children from families with incomes above the state’s Medicaid eligibility ceiling.

Learn more about Medicaid and CHIP in your state by visiting [medicaid.gov/medicaid/by-state/by-state.html](https://www.medicaid.gov/medicaid/by-state/by-state.html)



MEDICARE

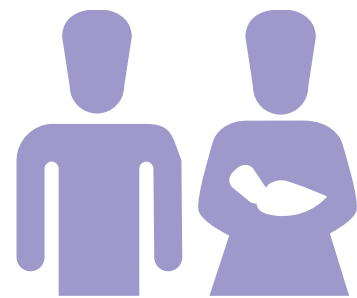
Medicare is a federal health insurance program that provides coverage for individuals who are 65 or older and for those under 65 who have certain disabilities like SMA.

See if you qualify for Medicare by visiting [Medicare.gov/eligibilitypremiumcalc/](https://www.medicare.gov/eligibilitypremiumcalc/)



CHILDREN'S HEALTH INSURANCE PROGRAM (CHIP)

CHIP offers low-cost health coverage for children in families that exceed the income eligibility for Medicaid, but cannot afford other health insurance. Children who qualify for CHIP will not need to buy a private health insurance plan. Similar to Medicaid, CHIP can help you pay for equipment, treatment, and services needed for SMA care.



For families with a child living with SMA, Medicaid and CHIP are the programs that will most likely help you pay for the cost of your child's care. You can learn more about these programs at [medicaid.gov](https://www.medicaid.gov).



Medicaid and CHIP programs may be called something else in your state. Learn the names of these programs in your state healthcare at [healthcare.gov/medicaid-chip-program-names/](https://www.healthcare.gov/medicaid-chip-program-names/).



UNDERSTANDING WHAT HEALTH INSURANCE COVERS AND HOW INSURERS REJECT /APPROVE CLAIMS

All health insurance is different and many factors can impact what services, treatment, and equipment are covered. Because managing your or your loved one's healthcare can be complex, it's helpful to have an ongoing dialogue with your insurer about coverage.

To fully understand what's covered—and help predict and avoid any claims denials—be sure to ask the following questions:

- On average, are claims for [SERVICE/TREATMENT/EQUIPMENT] generally approved under my health insurance plan?
- In general, what is your process for determining if treatment or equipment is **medically necessary**?
What specific information and/or documentation is needed to determine if a treatment or equipment is medically necessary?
- Do you provide any exceptions for rare disorders? If so, can you give examples of such exceptions?
- If I make multiple claims for treatment or equipment, will this affect my monthly premium?
- Do you cover durable medical equipment (DME)?

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

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** for claims denials.



WHAT TO DO WHEN A CLAIM IS DENIED

Insurance denials happen for a variety of reasons. Your insurer is likely to deny a claim for anything not deemed as medically necessary. For example, a wheelchair or respiratory assistive device may be rejected if your insurer believes that **durable medical equipment (DME)** is not a medical necessity.

Receiving a notification that your insurer won't pay for treatment or equipment can be both frustrating and frightening. However, there are protections and laws in place that allow you to dispute your insurer's decision and demonstrate that a treatment and/or medicine is medically necessary.

While the following steps generally apply to most insurance plans, we suggest reaching out to your insurer to ensure you comply with any specific appeals requirements. Doing so can help ensure you meet their requirements, which can be critical to the appeals process.

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

- **Step 1: Internal Appeal.** Following the initial denial, you should be able to request an internal appeal. To file an initial appeal, write a letter to your insurer demonstrating why a particular treatment or equipment is medically necessary. Tip: Appeals that come from your doctor using the term "medically necessary" are usually more successful.
- **Step 2: External Review.** If your insurer denies the internal appeal, you have the right to seek an "external review" in which an independent medical professional will review your case. You must file a written request for an external review within 60 days after your internal appeal was rejected.
- **Step 3: Expedited External Review.** If you or your loved one is facing an urgent health situation, you may ask for an external review at the same time as an internal review to speed up the process. Each state has different rules for the external review process. The Centers for Medicare & Medicaid Services—the federal agency that oversees government-funded healthcare—provides an overview of the guidelines in your state.

What is durable medical equipment (DME)?

DME is medically necessary equipment that your doctor prescribes for use in your home. Only your doctor can prescribe medical equipment for you. DME meet these criteria:

- Are durable (can withstand repeated use)
- Used for a medical reason
- Not usually useful to someone who isn't sick or injured
- Used in your home
- Have an expected lifetime of at least three years

Examples of DME specific to people living with SMA include:

- Adaptive Strollers
- Bath Chairs
- Bi-level Positive Airway Pressure (BiPAP or BPAP)
- Braces
- Standers
- Respiratory Assistive Device
- Wheelchairs



UNDERSTANDING & MANAGING HEALTHCARE COSTS

When it comes to paying for your health insurance, it helps to have a sense of the costs you and your family 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/medicalcostlookup.php.

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 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 your family's 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.

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



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