

# Ask the Experts: Navigating Medicare, Medicaid, & Social Security Benefits

Our Ask the Experts: Medicare, Medicaid & Social Security session was shaped by questions submitted directly by the MSA community through MSA Connect. To help address these important topics, Mission MSA partnered with experts from the Social Security Administration and the Patient Advocate Foundation, who provided guidance on common questions, key considerations, and available resources for individuals and families navigating benefits and coverage.

Mission MSA has created brief summaries of the experts' responses in this document for a quick, easy-to-reference overview. These summaries are intended to highlight key takeaways but do not capture every detail shared during the discussion. To hear the experts' full responses and additional context, we encourage you to watch the complete video session [\*\*here\*\*](#).

## **Q: When should someone with MSA begin applying for Social Security Disability benefits, and what benefits should they consider soon after diagnosis?**

A: If you believe you may qualify for Social Security disability benefits, it's important to apply as soon as possible, as the process can take time. The easiest way to apply is online through the Social Security Administration, though you can also apply by phone or schedule an appointment to complete the application with a representative. Starting the process early can help avoid delays in accessing benefits.

After submitting an application, you can expect to receive updates and notifications as it moves through the review process. Creating a my Social Security account is strongly encouraged, as it allows you to track your application status, view notices, and quickly respond to any requests for additional information. Paper notices are also mailed, but an online account can help you stay informed in real time.

## **Q: How does the disability application process work for people with MSA, including Compassionate Allowance eligibility?**

A: The disability determination process is designed to carefully evaluate each application and can take time, especially since every case is unique. In some situations, individuals with serious medical conditions may qualify for compassionate allowance, which can help speed up the process.

Once an application is submitted, Social Security reviews work history, medical conditions, medications, providers, and how symptoms impact a person's ability to work. Medical records are gathered and reviewed, and in some cases, additional information or appointments may be needed before a decision can be made.

While timelines vary, the goal is to make decisions as quickly and accurately as possible. If an application is denied, applicants still have options and may appeal the decision. Often, additional medical documentation or clarification can help strengthen a case during the appeals process.

**Q: In the disability application process, what documentation is most important, and what should people do if they are denied?**

A: Strong medical documentation is one of the most important parts of a Social Security disability application. Applicants should provide detailed and up-to-date records from healthcare providers that clearly explain diagnoses, symptoms, treatments, medications, and, most importantly, how the condition limits the ability to work and perform daily activities. Documentation that demonstrates progression of symptoms and functional limitations can help strengthen an application and give reviewers a clearer picture of how the condition impacts everyday life.

If an application is denied, it's important not to get discouraged, as denials are common and there is an appeals process. Individuals have the right to request reconsideration or appeal the decision, and additional medical evidence or updated documentation may improve the outcome. Staying engaged with healthcare providers and responding promptly to requests for information can also help support a stronger case during the appeals process.

**Q: Do short-term disability or long-term disability benefits through an employer affect when or how someone should apply for SSDI or SSI?**

A: Employer-provided short-term or long-term disability benefits generally do not prevent someone from applying for Social Security Disability Insurance (SSDI). SSDI is based on a person's work history and inability to work due to a disabling condition, so receiving disability insurance through an employer does not automatically disqualify someone. In fact, because SSDI can take time to process, individuals may want to consider applying sooner rather than later if they believe they will be unable to return to work.

However, Supplemental Security Income (SSI) works differently because it is a needs-based program that considers income and financial resources. Receiving short-term or long-term disability payments may affect eligibility or the amount someone can receive through SSI. Because every situation is different and rules can be complex, individuals are encouraged to contact the Social Security Administration directly to better understand how their specific benefits and income may impact eligibility.

**Q: Can someone receive Social Security Disability benefits while also receiving other benefits (such as VA disability, private disability insurance, or retirement benefits)?**

A: In many cases, individuals can receive Social Security Disability Insurance (SSDI) alongside other benefits, such as VA disability compensation or private disability insurance. These benefits often operate independently, meaning one does not automatically prevent eligibility for another. However, the type of benefit matters, and each program has its own rules regarding eligibility, payment amounts, and how benefits may interact.

Retirement benefits can be more complex, particularly depending on a person's age and whether they are receiving Social Security retirement or disability benefits. Additionally, Supplemental Security Income (SSI) may be affected by other income sources because it is a needs-based program. Since every situation is unique, individuals are encouraged to speak directly with the Social Security Administration to better understand how their specific combination of benefits may impact eligibility or payment amounts.

**Q: What happens to Social Security Disability benefits when someone reaches retirement age? How are payments affected?**

A: When someone receiving Social Security Disability Insurance (SSDI) reaches full retirement age, their disability benefits generally automatically convert to Social Security retirement benefits. In most cases, this transition happens without the need to reapply or take additional action, and benefit payments typically remain the same amount. The primary change is the classification of the benefit, from disability to retirement, rather than a change in payment.

Because retirement age can vary depending on birth year, individuals may want to review their specific Social Security account or speak with the Social Security Administration to understand what to expect. For most people, however, reaching retirement age does not result in an interruption of benefits or a reduction in monthly payments solely because of the transition.

**Q: What options exist for people living outside the U.S. who receive Social Security benefits and later develop MSA? Are there any additional disability-related benefits or reporting requirements?**

A: In some cases, individuals living outside the United States may still be eligible to receive Social Security benefits, including disability benefits, but eligibility and payment rules can vary depending on factors such as citizenship, immigration status, and country of residence. People already receiving Social Security benefits who later develop MSA may be eligible for disability-related benefits, but it is important to notify the Social Security Administration of significant changes in medical status, work ability, or living arrangements when required.

Because rules for receiving benefits abroad can be complex and vary by country, individuals living outside the U.S. are encouraged to contact the Social Security Administration directly to understand their specific eligibility, reporting requirements, and any potential impact on payments. Reviewing available international Social Security agreements and keeping personal information up to date can also help avoid disruptions in benefits.

**Q: How should people evaluate whether to keep employer/private insurance, transition to Medicare, or use both? How does coordination of benefits work when someone has multiple insurance plans?**

A: The right choice depends on your individual situation, including your healthcare needs, costs, and what your current insurance covers. Before making a decision, compare your options carefully to understand what each plan covers and whether keeping employer or private insurance alongside Medicare makes sense for you.

If you have more than one insurance plan, coordination of benefits determines which plan pays first and how the remaining costs are covered. Because this can vary depending on the type of coverage you have, it's important to contact your insurance provider or Medicare directly to understand how your specific plans work together and avoid unexpected costs or coverage gaps.

**Q: How can people bridge the insurance gap during the two-year Medicare waiting period after qualifying for SSDI? What coverage options should they explore?**

A: If you are in the two-year waiting period for Medicare after qualifying for SSDI, it's important to explore other coverage options so you do not experience a gap in care. Depending on your situation, options may include staying on employer-sponsored insurance, joining a spouse or family member's plan, purchasing coverage through the Health Insurance Marketplace, or exploring Medicaid eligibility.

Because eligibility and costs vary based on income, household situation, and state-specific programs, it's important to review your options carefully and ask questions early. Connecting with a benefits counselor, patient advocate, or insurance representative can help you better understand what coverage may be available during the waiting period.

**Q: How can people ensure their Medicare coverage includes access to specialized MSA care centers, out-of-network providers, or major hospital systems? What should they look for when comparing plans?**

A: When comparing Medicare plans, it's important to carefully review provider networks to make sure your neurologist, specialists, preferred hospital systems, or MSA care centers are covered. Before enrolling, check whether your providers are in-network, ask about referral requirements, and understand how out-of-network care is handled if you may need to travel for specialized treatment. You should also review costs such as premiums, deductibles, and out-of-pocket expenses, since access to specialized care can vary significantly between plans.

**Q: What services are typically covered by Medicare, Medicaid, or supplemental plans for people with progressive neurological diseases (home health, caregiving, communication devices, therapies, durable medical equipment, etc.)? What common gaps should families plan for?**

A: Coverage for services such as home health, therapies, durable medical equipment, and communication devices can vary significantly depending on whether you have Medicare, Medicaid, supplemental insurance, or a combination of plans. Some services may be covered if they are considered medically necessary and prescribed by a provider, but coverage often depends on the specific plan, documentation requirements, and whether providers or equipment suppliers are in-network.

Families should be aware that there are often coverage limitations and gaps, particularly around long-term caregiving and in-home support. Understanding what your plan does and does not cover early on and asking detailed questions about prior authorizations, visit limits, equipment coverage, and out-of-pocket costs can help families better prepare and avoid unexpected expenses as care needs change over time.

**Q: How does Medicaid work for long-term care and home care needs, and when should families begin planning for Medicaid eligibility?**

A: Medicaid can play an important role in helping cover long-term care and certain home- and community-based services, but eligibility rules and available benefits vary by state. Because Medicaid is income- and asset-based, planning ahead is important—especially as care needs increase over time. Families are encouraged to begin exploring eligibility requirements early, understand what services may be available in their state, and ask questions before a crisis situation arises so they are better prepared for future care needs.

**Q: What long-term care options exist for people with MSA, and what financial considerations should families prepare for as care needs increase?**

A: Long-term care options for people with MSA may include in-home care, adult day programs, assisted living, memory care, skilled nursing facilities, or hospice and palliative care as needs change over time. Many families find themselves relying on a combination of paid caregivers, family caregiving, and community supports. The right option depends on a person's symptoms, level of independence, safety needs, and available support system.

Financially, it's important to plan early, as long-term care can be expensive and coverage is often limited. Medicare generally does not cover long-term custodial care, while Medicaid may help cover certain long-term services for those who qualify. Families should think ahead about out-of-pocket caregiving costs, home modifications, transportation, respite care, and whether private long-term care insurance or other financial resources may be available to help meet growing needs over time.

**Q: Are there programs that help pay family caregivers or provide caregiving support for people with significant disability?**

A: In some situations, programs may be available to help support family caregivers or offset caregiving costs, but eligibility and available services vary depending on factors such as insurance coverage, income, disability status, and state programs. Medicaid programs in some states may offer caregiver support or home- and community-based services, and families may also be able to access respite care or local caregiving resources. Because options differ widely, it's important to ask questions early and explore what programs may be available in your state or through your insurance coverage.

**Q: What advocacy resources, case management programs, or patient navigation services are available to help people manage doctors, prescriptions, insurance denials, and complex care needs?**

A: If you are feeling overwhelmed managing appointments, insurance, prescriptions, or denials, there are organizations and patient navigation services that may be able to help. Case managers, social workers, patient advocacy organizations, and groups like the Patient Advocate Foundation may be able to assist with insurance appeals, care coordination, financial challenges, and navigating complex healthcare systems. Reaching out early and asking for help can make it easier to manage changing care needs and reduce some of the burden on patients and care partners.

**Q: What are some of the biggest insurance or benefits challenges facing people with rare diseases like MSA today, and what changes are being discussed to improve access to care?**

A: One of the biggest challenges for people living with rare diseases like MSA is navigating complex insurance and benefits systems while trying to access specialized care. Coverage rules, prior authorizations, denials, provider network limitations, and the cost of treatments, equipment, and caregiving can create significant barriers. Because MSA is a rare condition, families may also face challenges finding providers who understand the disease or securing approval for services that are medically necessary but not always straightforward to obtain.

There are ongoing conversations around improving access to care, reducing barriers to coverage, and strengthening patient protections for people with complex medical needs. Advocacy organizations, patient groups, and policy leaders continue to discuss ways to improve care coordination, expand access to specialists and services, and make insurance and disability systems easier to navigate for individuals living with serious, progressive diseases.

## **More Resources**

Video Tutorial for Creating Your ID.me account with the Social Security Administration: <https://www.youtube.com/watch?v=SESbUu2hY84&authuser=0>

Learn more about the Patient Advocate Foundation:  
<https://www.patientadvocate.org/>

Watch the full Q&A: <https://youtu.be/GI5e4a61lpE>