

Secondary Progressive MS: From Diagnosis to Management



A Series by [REALWORLDHEALTHCARE.org](https://www.RealWorldHealthCare.org)

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Secondary Progressive MS can be difficult to diagnose and challenging to treat. It is a common progression of the disease, but it often sets off alarm bells among patients and their loved ones.

Secondary Progressive MS: From Diagnosis to Management is a recently published series of articles that highlights organizations dedicated to helping patients receive accurate, timely diagnosis and practical techniques to help them manage the disease. Please accept this complimentary copy as our way of thanking you for your commitment to raising awareness for Secondary Progressive MS and advocating for healthier futures.

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Update Your Outlook on Progressive MS

By Rosalind Kalb, PhD, Senior Programs Consultant, Can Do MS & Patricia Kennedy, RN, CNP, MSCN

Editor's Note: Friday, March 1, marks the start of MS Awareness Month, and Real World Health Care will be focusing on Secondary Progressive Multiple Sclerosis through the end of the month.

This article is reprinted, with permission, from Can Do MS. To read the original article and learn about additional resources for people with multiple sclerosis and their caregivers, [click here](#).

The words “progressive MS” can set off alarm bells. No one wants to hear that his or her MS is, or has become, progressive. The term “progressive MS” applies to different aspects of the disease, and it helps to know how it is being used. Approximately 85% of people are initially diagnosed with relapsing-remitting MS (RRMS).

At some point in their disease course, typically after 10-15 years, relapses become less frequent or stop occurring completely, the disease progresses more consistently but not necessarily more rapidly, and changes in function become more pronounced. When that happens, the person is said to have transitioned to secondary progressive MS (SPMS). Approximately 15 percent of people are initially diagnosed with primary progressive MS (PPMS). This group tends to experience gradual changes in symptoms and function over time with very few or no defined relapses. It is important for people to have an understanding of what these terms mean so that if they receive the word that they have progressive MS, they can begin to think about how to plan for any changes that may occur.



Rosalind Kalb, Can Do MS

When symptoms worsen and abilities are affected, it can feel frustrating and frightening, particularly when a person feels he or she has been doing everything possible to manage the disease. Just when one seems to have a handle on MS and its symptoms, changes can occur, making the playing field feel totally different. Some people express fear of the future, seeing only a downhill slope. Others are disheartened and lose the oomph they need to try new ways to solve problems. This is a time when anger, grief, and anxiety may feel more intense. We urge all of you –

individuals with MS, support partners and other family members – to step back and rethink the future. There are exciting research developments in the area of progressive MS, and there are many things you CAN do to optimize your health and well-being with progressive disease.

Managing Your MS – Using a Team Approach

Disease-modifying therapies (DMTs) are an important component of care for people with progressive MS. Most of the available DMTs are approved for relapsing forms of MS, which included those individuals with SPMS who continue to have occasional relapses. In addition, mitoxantrone is approved for SPMS and ocrelizumab is approved for PPMS. If you have been diagnosed with a progressive form of MS, be sure to discuss these treatment options with your healthcare provider.



Patricia Kennedy

Comprehensive MS care for a person with progressive disease also involves ongoing symptom management; rehabilitation to enhance function, comfort and safety; adaptive equipment to optimize mobility, independence and participation; and careful attention to optimizing mood and cognition.

Your best strategy is to assemble a team of professionals you trust and with whom you can communicate comfortably whenever there are changes in function and/or new symptoms. Your neurologist, nurse, physical or occupational therapist, and mental health professional can help you evaluate those changes and identify treatments, tools and resources to improve the situation. MS is a journey you do not need to travel alone.

Enhancing Your Health and Wellness

You are more than your MS – and your health and wellbeing are about more than treating your MS.

A healthy diet, regular exercise geared to your abilities and limitations, effective coping and stress management strategies and care attention to your mood are all essential to your overall quality of life. If you smoke, you have one more reason to quit: the research clearly shows that people who smoke have an increased risk of disease activity and progression.

There is now ample evidence that people with MS are more likely than the general population to have additional ('co-morbid') health conditions that impact their overall health and their MS. In particular, vascular conditions – including high blood pressure,

high cholesterol, heart disease, diabetes – can accelerate the progression of MS and shorten a person’s lifespan. Therefore, prompt diagnosis and treatment of these conditions is important to comprehensive MS management. Regular check-ups and preventive screening as recommended for your age group can help you stay healthy and well.

Maintaining a Balanced Relationship

Healthy relationships with care partners are built on open communication and mutual give and take. Each person in the relationship needs to feel like a valued contributor. If your partnership starts to feel out of whack – with one person taking on too much of the doing and giving and the other feeling increasingly like a non-contributor, it’s time to talk about a redistribution of responsibilities. If your MS symptoms are making it difficult for you to do the things you used to do for your relationship and your household, think about swapping some things around.

Building Your Support Network – family, friends, medical team, employer, colleagues

Family, friends, colleagues, as well as your healthcare care team, are all essential parts of your support network. Stay connected with others, even if it means finding new activities, interests and opportunities for engagement; isolation isn’t good for your emotional or physical health!

Research in Progressive MS

Major clinical trials are underway, testing novel approaches to treating all forms of MS, including progressive MS. Scientists are learning new information about how MS damages the nervous system and cells and factors involved in the body’s ability to recover from injury. Early human trials of new therapies to repair myelin are already under way.

The International Progressive MS Alliance is focusing new resources on finding the answers that will lead to new treatments and ultimately, end progressive MS.

Studies are providing new evidence that exercise and rehabilitation can improve many functions and even help rewire and possibly build areas of the brain, and researchers are pursuing these leads to find the best ways people can maximize quality of life.

The journey with progressive MS will be different for every individual and will need to be managed differently. Success lies in building a support network, using all of the tools and resources available to you, and being creative and flexible in your problem-solving. You may need to do things differently than you did them before, but there’s no reason to sit on the sidelines. Be your own cheerleader but invite others onto your squad. It may feel difficult to cheer if the game isn’t going well, but on a basketball

court, the cheerleaders don't sit down if the score is not favorable. They cheer louder and get the fans involved too.

About the Authors

Rosalind Kalb, PhD, is a clinical psychologist who has specialized in MS care, support and education for over 30 years. She began her career in MS providing individual, group, and family therapy at the Medical Rehabilitation Research and Training Center for MS at the Albert Einstein College of Medicine and then at the MS Comprehensive Care Center in White Plains, NY. Dr. Kalb joined the National MS Society in 2000, creating online resources and educational materials for individuals and families living with MS and healthcare professionals until 2017. She continues her resource development work for the Society as a consultant. Dr. Kalb has written or edited multiple books including *Multiple Sclerosis for Dummies* (2nd ed.), *Multiple Sclerosis: Understanding the Cognitive Challenges*, *Multiple Sclerosis: The Questions You Have; The Answers You Need*, now in its 5th edition, and *Multiple Sclerosis: A Guide for Families*, now in its 3rd edition. Dr. Kalb has served as a Can Do program consultant since 2001.

Patricia Kennedy, RN, CNP, MSCN, a former Nurse Educator for Can Do MS, worked in the field of MS since 1987. For most of her MS career, she provided patient care. She served on the Board and was president of the International Organization of MS Nurses, served as a clinical consultant for the National MS Society and was a member of the Client Education Committee. She also was active in the Consortium of MS Centers and was on the editorial board of the International Journal of MS Care. She is the author of *The Can Do Multiple Sclerosis Guide to Lifestyle Empowerment* and is now retired.

Categories: General, Secondary Progressive MS

Tags: MS, Multiple Sclerosis, myelin, secondary progressive MS

Navigating Secondary Progressive MS

By Real World Health Care Editorial Staff

Real World Health Care continues our observance of Multiple Sclerosis Awareness Month by shining a spotlight on the [National Multiple Sclerosis Society](#). We spoke with Kathy Costello, MS, ANP-BC, MSCN, associate vice president of [Healthcare Access](#) for the National MS Society, about the Society's [MS Navigator](#) program and strategies that patients with [Secondary Progressive MS](#) can adopt to help them manage their disease and its impact on their daily lives.

Diagnosing Secondary Progressive MS

Real World Health Care: Secondary Progressive MS (SPMS) can be difficult to diagnose. Why is that?

Kathy Costello: SPMS is an MS disease course that follows Relapsing Remitting MS (RRMS). Most people diagnosed with RRMS will eventually develop SPMS within about 15 years of their initial MS diagnosis. A patient needs to go through about six months of observed progression of neurologic symptoms, in the absence of a relapse, before SPMS is considered to be the disease course.



Kathy Costello, National MS Society

Because the transition from RRMS to progressive MS is gradual, physicians may not be able to tell exactly when it occurs. If the worsening symptoms are left over from the last relapse, with permanent but stable damage that remains after the inflammatory attack has ended, the patient is considered to be experiencing an RRMS disease course. However, if the disease continues to worsen even though the person is no longer experiencing inflammatory relapses, they have transitioned to SPMS. Diagnosis takes on further nuances when you consider that some patients with SPMS may still experience relapses from time to time and may demonstrate new inflammation in their brain and spinal cord, though this doesn't occur as frequently as during RRMS

Impact of Progressive MS on Daily Life

RWHC: Is there a difference between SPMS and other stages of MS in terms of its impact on a patient's daily life?

KC: No matter what type of MS someone has, impacts are the result of damage in the central nervous system. The central nervous system is our command center: the spinal cord governs our movement and other functions, while the brain manages higher level functions and interprets messages. MS interrupts those functions, which translate into symptoms such as generalized fatigue, slowed thinking, changes in vision, coordination problems, weakness, walking difficulties and even loss of bladder and bowel control.

With progressive forms of MS, including SPMS, those symptoms will worsen over time. Patients will experience more fatigue and more difficulty walking, for example. These worsening symptoms make it harder to participate in work, social life and activities of daily living at home. It's important to note, however, that MS is heterogeneous. No two people with SPMS will be exactly the same. One person may have a tremendous amount of impairment while another may have far less, or may have a different type of impairment. When people hear the word "progression," it can be frightening and can conjure images of wheelchairs, dependency and an inability to participate, but that's not always the case.

RWHC: It sounds like the progression of MS affects not only the person with MS, but also the people around them as well.

KC: True, especially when it comes to the patient's family. Most families and households have defined roles and responsibilities. When MS symptoms start to interfere with a patient's activities, those roles may need to change. Frustration, anger and feelings of guilt can exist on both sides: from the patient who can no longer participate as she/he did before MS, and from the family members, who may need to assume more household or other roles over time.

The financial burden of MS can also put a strain on family dynamics, especially if the patient can no longer work or has a reduced earning potential because of MS symptoms. MS is remarkably expensive, even with insurance, which may not cover the entire cost of medications, rehabilitation or assistive devices like walkers and wheelchairs.

SPMS Treatments and Management

RWHC: Are there any treatments on the horizon for SPMS?

KC: There is an enormous amount of research going on in progressive forms of MS. One medication for SPMS, siponimod, has completed its clinical trials and is currently under review by the FDA. A decision on approval is expected very soon. Other treatments, including high-dose biotin, also are being studied.

With \$32 million dedicated to research in 2019, the National MS Society is the largest private funder of [MS research](#), and 94 percent of our research portfolio is relevant to progressive MS. In addition to treatment research, we are also funding research into

better understanding the disease process, as well as lifestyle and rehabilitation-related management strategies.

We're also a founding member of the [International Progressive MS Alliance](#), which is accelerating research with an eye toward appropriate measurement metrics during clinical trials, how imaging or blood tests may be used to identify someone at risk for progression, and treatments that can slow or halt the process of progression. Of course our ultimate goal is a cure.

Support for SPMS Patients

RWHC: How is the National Multiple Sclerosis Society helping to support patients with SPMS?

KC: Among the many services and programs we have nationwide, our flagship programs here at the National MS Society is our [MS Navigator](#) program. The program matches patients with highly skilled, compassionate professionals who can connect them to the information, resources and support they need to meet the many challenges imposed by MS. MS Navigator offers a live, online chat function as well as a toll-free phone number at 800-344-4867. Patients can also connect [via email](#) and through our [MSconnection.org community discussion board](#).

If our MS Navigators identify someone with highly complex needs, we refer them to our case management program, the [Edward M. Dowd Personal Advocate Program](#). This program connects patients with case management organizations and individuals in the patient's local community. We help to train those case managers so they are highly knowledgeable about MS, and we help them work toward solutions for patients.

I would also like to point out our Healthcare Access team, who work with healthcare professionals to ensure providers of all disciplines become more knowledgeable about MS and the services and expertise we offer. The National MS Society funds a number of programs to ensure the workforce of the future including a [medical student mentorship program](#) to foster interest in a career in MS care, [clinical fellowships](#) for physicians who wish to specialize in MS care, and an MS track in 3 doctoral level physical therapy programs.

The National MS Society encourages SPMS patients to be as proactive as possible in mitigating the effects of MS. The disease gets worse when people develop co-morbid conditions such as cardio-vascular disease, so it's important to follow a healthy eating plan, stay as active as possible, maintain a healthy weight and quit smoking. Depression is common in MS patients, and mood disorders can keep people from staying on their medications and participating in a healthy lifestyle. Above all, don't suffer in silence. Speak up about any symptoms of stress or depression so that effective interventions can begin.

Categories: [General](#), [Secondary Progressive MS](#)

Tags: [caregiving](#), [Central Nervous System](#), [MS](#), [Multiple Sclerosis](#), [secondary progressive MS](#)

MS Care Partners Crucial to Circle of Support

By Real World Health Care Editorial Staff

This week, Real World Health Care closes our observance of [MS Awareness Month](#) by highlighting the [Multiple Sclerosis Association of America](#) (MSAA) and the full circle of support it offers to patients and their care partners. We spoke with Angel Blair, MA, client services specialist, who stressed the importance of understanding that while MS has a big impact on patients, it also impacts the patient's entire family.

Physical and Emotional Support for MS Patients

Real World Health Care: What are some of the biggest challenges facing family care partners of people with MS?

Angel Blair: Family care partners often need to address a variety of challenges, from helping their loved one with activities of daily living such as cooking and bathing, to managing care decisions and financial issues, to making modifications within the home, such as adding entrance ramps, stair lifts or roll-in showers. If their loved one has mobility issues, they may need to help them with moving from one place to another – such as physically transferring them into and out of a wheelchair or driving them to appointments.

Many care partners faced with these challenges find that time management becomes a big issue, especially if they are working outside of the home. They also tend to neglect their own physical and emotional well-being, which is pushed aside to focus on their loved one.

These stresses of providing physical and emotional support to their loved one become acute when the care partner is the sole caregiver, with nobody else to rely upon. That is why care partners must seek out additional resources for help. Seeking help should not be seen as a sign of weakness, but rather a sign of strength.

RWHC: How can MSAA help care partners get the support they need?

AB: Our bi-annual magazine, [The Motivator](#), regularly addresses topics for care partners. We host a number of [educational programs](#) around the country for patients and their care partners. Our web site contains on-demand [videos and webinars](#) as well



Angel Blair, Multiple Sclerosis Association of America

as our [MS Conversations blog](#). Plus, we have a number of ways people can access live help from an MSAA client service specialist: through our toll-free Helpline (800-532-7667, extension 154), a dedicated [email](#) address for MS-related questions, and [online MS chat](#) feature.

Through these various touchpoints, we can help care partners find resources and assistance in their local communities, whether that be financial assistance programs, respite care services, home care waiver programs, assistive equipment services, support groups or counseling services.

We also help to connect care partners with others who are experiencing similar issues through our online [My MSAA Community](#) forum, a peer-to-peer online forum for individuals with MS, their families and their care partners to share information and their experiences in a friendly, supportive and safe community.

MS Awareness Month

RWHC: Have you been doing anything special for care partners during MS Awareness Month?

AB: Yes. This year we are particularly focused on the theme of “[MS and the Family](#)” and have highlighted issues of particular interest to care partners, with webinars, podcasts, and “Ask Me Anything” online events. For those who may have missed the live events, everything is archived on our [MS Awareness Month web site](#).

Progressive MS

RWHC: How do caregiver challenges change when the loved one’s disease course progresses, for example to Secondary Progressive MS?

AB: In many cases, it’s an issue of the same challenges, just more of them. When MS progresses, it’s important for care partners to work with their loved ones and their health care team to re-assess the current level of at-home care and determine if it is appropriate. Their loved one may need more assistive equipment or additional home modifications if their mobility decreases, for example.

Discuss issues openly and honestly. Are cognitive problems increasing? Can the loved one be left alone for extended periods of time? Can the care partner physically help to move their loved one in and out of bed, in and out of the bath, and in and out of the car? Answers to these questions will help the loved one and their care partner decide if additional assistance is needed.

MS progression also may require additional medications and therapy services and involve more paperwork and financial commitments. The cost of these additional treatments, coupled with the cost of nursing or home care and additional respite services for the care partner, often lead to stress for all parties.

Stepping in to Care for an MS Patient

RWHC: What are some of the signs that it is an appropriate time for a family member or loved one to step in and become an active care partner for someone with MS?

AB: MS affects every patient and family in a unique way, so there is no one universal “sign.” However, care partners should pay close attention to their loved one’s behavior. If they become particularly depressed, agitated or forgetful, it may be an appropriate time for the family to step in. If they start to have trouble caring for themselves or their home, they may need assistance. If their symptoms result in balance or mobility issues and they start to have accidents, that’s another indication.

It’s crucial at these early stages for the patient to be directly involved in decisions around family caregiving. They should provide input on how they’re feeling, ask questions, and be clear about the level of independence they’re comfortable with. Many people with MS find it’s helpful to focus on the things they *can* do rather than the things they can’t do. Some even look at it as an opportunity to learn or try new things or pursue new activities or hobbies.

Care partners must remember to not push if their loved one doesn’t accept help right away. Instead, meet their loved one where they are in the moment, letting them know that help is available when, where and how they need it.

The Multiple Sclerosis Association of America (MSAA) is a national, nonprofit organization founded in 1970. It is dedicated to improving lives today through ongoing support and direct services to individuals with MS, their families, and their care partners. For more information, visit <https://mymsaa.org>.

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