

A new phase



A diagnosis of secondary progressive MS can be scary, but there are strategies to help you live a full life.

by Vicky Uhland

More than two decades ago, before medications for multiple sclerosis emerged, there was no formal definition for the secondary progressive stage of the disease.

“We didn’t talk about the types of MS. You just had MS,” says Rosalind Kalb, PhD, a clinical psychologist who consults with the National Multiple Sclerosis Society. “But when clinical trials for disease-modifying therapies began, they had to identify the stages of the disease.”

What followed was the creation of four courses of MS: relapsing-remitting, secondary progressive, primary progressive and progressive relapsing. And if people didn’t have the relapsing-remitting form of MS, they couldn’t get into the clinical trials, Kalb says. “Suddenly, the term ‘secondary progressive’ became a very scary thing.”

It’s not that secondary progressive MS (SPMS) didn’t exist 20, 50 or 100 years ago. But previously, it was just seen as a natural progression in how the disease manifests. When it was given a name, it acquired significant psychological baggage.

“In my experience, people diagnosed with secondary progressive MS tend to feel frightened because they feel like there is nothing much to help them,” Kalb says. “They feel like they’ve reached a point of no return, and that results in not only fear but also sadness.”



Dara Brown was diagnosed with RRMS in 2006. Her disease progressed so rapidly that she had transitioned to SPMS by 2012. Photo courtesy of Dara Brown

That was the case for Dara Brown of Baltimore. In 2006, at age 30, she was diagnosed with relapsing-remitting MS (RRMS). Her disease progressed so rapidly that, by 2012, she had transitioned to SPMS. Mobility and balance issues required her to quit her job as an accountant two years later. Today, Brown uses a wheelchair and no longer drives.

“When I was diagnosed with secondary progressive, I felt a little sad because I didn’t get to meet my husband yet,” she says. “I spend a lot of time in the house, so unless my husband-to-be knocks on the door, I’ll have a hard time meeting him.”

But with better understanding of how SPMS manifests, new medications in the pipeline and more advanced treatment plans, MS specialists believe this is a time of hope for Brown and other people living with SPMS.

“If you are secondary progressive, you are not forgotten,” says Mary Hughes, MD, a neurologist with Premier Neurology in Greer, South Carolina, and a Society board member. “SPMS does not mean: ‘Go sit down; nothing can be done.’ I’m optimistic that the breakthroughs we’ve seen with progressive and relapsing-remitting MS will soon be seen with secondary progressive MS.”

Here’s how you can navigate this next phase of your journey with MS, and what you can expect physically, mentally and emotionally. “The key message is this is not the end of the road—it just means more strategies can come into play to help you maintain a full life,” Kalb

says.

SPMS 101

Simply put, SPMS occurs when the inflammatory phase (relapsing remitting) of MS is much less prominent or stops, and the disability caused by the neurodegenerative process becomes more prominent. This often means no new lesions or “white spots” will show up on your MRI, Dr. Hughes says.

There is no definitive test to diagnose SPMS, although some tests that measure functions such as cognition or hand dexterity may provide clues. Generally, a person is thought to have SPMS when they stop having disease exacerbations—although Dr. Hughes says there are some forms of SPMS in which there are still occasional relapses.

In most cases, SPMS usually manifests as an increase in existing symptoms. And that increase can be slow or rapid, Dr. Hughes says. Or sometimes, your MS symptoms could simply plateau. “The variable nature of MS is not any less apparent in the progressive phase,” she says.

Prior to the availability of MS medications, studies showed that 50 percent of people diagnosed with RRMS would transition to SPMS within 10 years, and 90 percent would transition within 25 years. But the 2017 update of the Multiple Sclerosis Coalition paper “The Use of Disease-Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence,” makes it clear that those numbers have changed.

The paper cites a study of 517 people with RRMS and clinically isolated syndrome MS (the first episode of MS neurologic symptoms). At almost 17 years after disease onset, only 18 percent of the study participants had transitioned to SPMS.

The key is that all of these people were taking MS therapies that slowed or stopped their disease exacerbations. “Clearly, the medications are having an impact. It’s thought that starting disease-modifying therapies very early in the disease course delays the progression to secondary progressive,” Kalb says.

Medications may also delay awareness of the transition from RRMS to SPMS. Think of it as a chicken-and-egg scenario: Are you no longer having relapses because of the medication, or because you’ve transitioned to SPMS? Also, “it’s less likely a person with MS might notice a slow transition to SPMS because they’re living with the disease every day,” Kalb says. “The transition could take months or even years.”



Paul Smith believes he may have been transitioning to SPMS slowly over the years, but was unaware of it due to his MS medication. Photo courtesy of Paul Smith

That was the case for Paul Smith, a Mullica Hill, New Jersey, resident who was diagnosed with MS in 1996 when he was 43 years old. After he began taking medications eight years after his diagnosis, Smith says he “went for quite a few years where nothing happened—no relapse events. But when I look back on a yearly basis, I realized there was a very small progression” in his symptoms, which include mobility and strength issues in his legs.

Was he transitioning to SPMS during that time? Smith likens the experience to the old joke about a guy standing on a corner in New York City, doing a frenetic dance. “When people asked him what he was doing, he said, ‘Scaring away elephants. And see, it works!’” Smith says.

“Who knows how many relapses I would have had if I wasn’t ‘scaring them away’ with Copaxone? I probably went to secondary progressive a long time ago but had no way of knowing it.”

Five years ago, following three annual MRIs that showed no changes in his brain lesions, Smith and his neurologist jointly agreed that he had transitioned to SPMS. Because Smith was starting to get more permanent injection-site reactions from his RRMS medication, he and his doctor decided he should stop using it. Today, Smith says his symptoms are progressing “very, very slowly.”

“I just keep doing what I like to do to the best of my ability, and when I can’t do that, I rechannel my energies into something that keeps me happy,” says Smith, who stopped water skiing about eight years ago and snow skiing three years ago, but spends his time doing other things he enjoys like traveling, woodworking and swimming. “For people heading into secondary progressive, it might be useful to hear it’s not the end of the world.”

Physical symptom management

Dr. Hughes says common symptoms that occur during SPMS include spasticity, walking and gait issues, bladder and bowel control issues, and fatigue. But there can also be cognitive and other mental issues, along with every other type of MS symptom. “You usually don’t develop new symptoms, but minor ones may become more prominent,” Dr. Hughes says.

Because SPMS tends to occur in older people, Dr. Hughes says it’s important to make sure your healthcare practitioners don’t mistake MS symptoms for symptoms of aging-related conditions like post-menopausal constipation, arthritis, type II diabetes and thyroid issues. And vice versa—your joint pain or memory loss may actually be attributable to advancing years rather than MS.

“This is a time when people need their MS specialists more than ever,” Dr. Hughes says. “They are very aware of the symptoms and challenges people with SPMS face, and are equipped to manage a wide scope of symptoms.”

There is one medication specifically approved for people with SPMS who do not experience relapses: mitoxantrone (Novantrone). But Dr. Hughes hesitates to prescribe it because it’s been linked in several studies to cardiac events in MS patients. In the latest treatment guidelines from the American Academy of Neurology, mitoxantrone is not recommended due to the potential for severe adverse events.

She is excited about a new medication, siponimod, which is in phase III of the Food and Drug Administration (FDA) approval process. Data published in March 2018 in *Lancet* showed a 21 percent decrease in the risk of MS progression in people with SPMS. In addition, the study showed that siponimod resulted in a 23 percent reduction in brain volume loss. There was also a 26 percent decrease in disease progression, and a 29 to 33 percent drop in sustained disability progression after six months of siponimod use. Novartis, manufacturer of siponimod, announced it planned to seek FDA approval of the drug in the first half of 2018.

In the meantime, Kalb says Ocrevus, a medication approved to treat people with primary progressive MS and RRMS, may also be effective for people with SPMS who still have relapses, or for those transitioning between RRMS and SPMS. So might any other medication developed for RRMS.



Larry Myers, diagnosed with RRMS in 2004 and SPMS in 2015, with his wife. Photo courtesy of Larry Myers

Of course, not every MS medication is going to be effective for everyone. Larry Myers, a Lothian, Maryland, resident who was diagnosed with RRMS in 2004 and SPMS in 2015, when he was 58, tried several RRMS medications before he joined a siponimod trial shortly after his SPMS diagnosis. People who participated in the trial had the option to continue on the drug after the trial was over, and Myers opted to do so in early 2016.

“We all thought I was on the drug, so it was logical to continue,” he says. But he later found out he had been in the placebo-controlled arm of the study. He took siponimod for 11 months before discontinuing it. “I was up and down health-wise with various illnesses and side effects until I lost the ability to walk by the end of December 2016,” he says. “I have not regained the ability to walk since and now use a scooter to get around.”

Now, Myers takes Ocrevus. “I’m counting on it to keep me going long enough so I will benefit from the cure for MS that I’m sure is just around the corner,” he says.

Kalb and Dr. Hughes agree that the lack of medications for SPMS highlights the importance of other treatment strategies.

“Symptom management is critically important when MS is progressing—not only for preventing an increase in disability but also because rehabilitation becomes a significant part of the disease-management strategy,” Kalb says. “And if you have more health and wellness options, you feel more empowered and better able to manage your well-being. This is the time to use your full range of healthcare providers.”

Both Kalb and Dr. Hughes recommend visiting a physical therapist to find out which exercises will work best for managing or improving your specific symptoms.

“This is the time to focus on wellness,” Dr. Hughes says. “If you’re ever going to exercise, now is the time. If you ever going to eat well, now is the time.”

Lynne Notari, a Jefferson, New Hampshire, resident who was diagnosed with MS at age 30, a year after the last of her six children was born, believes she transitioned to SPMS in 2003. Now, at age 70, her standing stamina only lasts about 10 minutes. She has a doctor’s prescription to do therapy-pool exercises once a week, and she also walks half an hour a day around her home and does leg bridges in bed.

“If I don’t do all of this, I can feel my legs being weaker,” she says. “I also try to diet to keep my weight down. I figure the less my legs weigh, the better.”

Psychological symptom management

Debra Kos felt she had been managing her MS pretty successfully since she was diagnosed in 1995. “But about three years ago, all of a sudden I got what I assumed was a relapse, which was weird because I hadn’t had a relapse for 10 years,” she says. However, Kos’ neurologist told her she had no new lesions on her MRI, so it probably hadn’t been a relapse. “He told me it could have been something that sent me into a ‘new spin of going downhill.’”



Debra Kos’ transition to SPMS was sudden and unexpected, which has been a difficult adjustment for her. Photo courtesy of Debra Kos

Kos was angry and upset. She had previously been told by her neurologist that she had a mild form of MS and hadn't taken any medications for the disease for 18 months. She and her husband had just bought a new walk-out rambler-style home in Lake City, Minnesota. But she soon began feeling more and more pain, spasticity, weakness and heaviness in her legs.

"For the past year and a half, I have barely been able to walk, and my symptoms are worsening quickly. And it's hard to get information about how my MS will progress," Kos says. "I had read a few things on secondary progressive, but I thought I was doing so well, and I got cocky. I thought I wouldn't get it, and no doctors warned me."

Transitioning to SPMS has been as much an emotional and mental adjustment as it has been physical, Kos says. "My relapses had been nasty when they happened, but I came out of them. I would tend to think: 'This is what's happening today, but maybe in three weeks, it will be better.' Now, knowing that I'm not going to get better is hard to accept."

When people undergo a transition to SPMS, it's important that they take care of their mental and emotional symptoms just as much as their physical symptoms, Kalb says. "The idea of healthy grieving is important. You need to grieve over what MS takes from you" before you move onto problem-solving for the new phase of your disease. A therapist can help with both of those aspects, Kalb says.

Susie Ulrey, a Tampa, Florida, resident who was diagnosed with RRMS in 2001 at age 24 and transitioned to SPMS in 2015, uses both psychological therapy and music to help her cope with worsening spasticity, numbness, tingling and weakness in her legs and feet.

"The turning point for me emotionally was between 2013 and 2015, when I got a van with a wheelchair ramp and also started using my scooter inside the house full time," Ulrey says. "I became very depressed." But, in 2014, she also began playing guitar with the band she had been a member of before she was diagnosed with RRMS.

"I'm writing a lot more music now and have worked out a lot of issues," Ulrey says. "What's been helpful for me is to take control over what I can, and music helps me with that. And I'm 100 percent convinced that playing music has helped me with memory and cognition."

A new normal

Ulrey's first record in 22 years was released in September 2018. She and the band have been touring around Florida and are thinking about doing a European gig in the spring of 2019. It's not easy performing in a wheelchair, but Ulrey has figured out how to make it work. "I got a pedal board that I can successfully hit, and our drummer carries me to the stage," she says. She also exercises two to three times a week and started eating more healthily, which she said has made her feel stronger.

For others, a SPMS diagnosis can mean the end of their career or a change in their relationships.



Debbie Bright, diagnosed with SPMS in 2010, and her granddaughter. Photo courtesy of Debbie Bright

Less than two years ago, Debbie Bright was working as a program specialist for the Department of Justice's violence against women initiative. "I was really proud of that job. I loved it," she says.

After Bright's SPMS diagnosis in 2010 at age 48, she began experiencing more gait and balance issues, along with numbness and burning sensations from the waist down. But it was the fatigue that really affected her job. She stopped commuting from her home in Baltimore to her job in Washington, D.C., and began teleworking. But by 2017, she was so fatigued that she could no longer work a full day even from her home office. So, she retired from her job.

"It's been difficult to give it up," Bright says, especially in a time in which violence against women is getting more publicity. "I'm still grieving at some level that I'm just not who I used to be." To compensate, Bright has been trying to "reinvent" herself. She's thinking about volunteering for a domestic abuse hotline and has been researching and writing about violence against women and crime in Baltimore.

Bright also has more time to spend with her mother, daughters and granddaughter, who all live nearby. But her friendships have changed because it's harder for her to go out in the evenings. Even her MS support groups have been affected by her SPMS diagnosis.

"There's been some segregation. Some people with relapsing-remitting don't want to see the progression of the disease staring them right in the face," Bright said. "My advice for other people with SPMS is to find a support group you feel comfortable with, or online resources that make you aware of how many people are in the same situation."

Kalb says friends, neighbors, family and even support group partners can feel awkward when

someone is diagnosed with SPMS because they don't know what to do. In those cases, "you can't sit back and wait for them to figure it out," she says. "You have to teach them about your disease and what you need in the way of help."



Linette Gray-Goodman was diagnosed with RRMS in 1990 and SPMS in 2014. Photo courtesy of Linette Gray-Goodman

That was the case for Linette Gray-Goodman, who was diagnosed with RRMS in 1990, when she was 38, and transitioned to SPMS in 2014. That year, her 28-year-old son, Michael Goodman Jr., moved back into her Weymouth, Massachusetts, home to be her care partner.

"When I learned that my mother had SPMS, I knew as her son and caretaker that my responsibilities would increase, and I wanted to obtain as much knowledge as possible to ensure that I could do everything necessary for my mother," Goodman says. "But she's taught me that MS has a mind of its own, every day is different and there are events you just can't prepare yourself for. But you can do meditation, prayer and other types of self-care."

Gray-Goodman says SPMS has been a challenge, but she can still do everything she did before her diagnosis—just a little bit slower.

"My advice to those who are concerned about the secondary stage of MS would be the same I would give for the [relapsing-remitting] stage," she says. "Stay positive and don't let the MS be in front of anything you want to do. Because if you put it in front of you, you will not live a normal life."

Vicky Uhland is a writer and editor in Lafayette, Colorado.

Learn more about [Secondary progressive MS \(SPMS\)](#).