

Aging with MS



Learn to distinguish symptoms of progressing MS from normal aging—and from other health conditions.

by Aviva Patz

Thanks to newer medications and treatments, people with multiple sclerosis are living longer than ever before—just seven years less, on average, than people without MS, according to a study published in **Neurology** in May 2015. The challenge is that with longevity comes aging and all the symptoms associated with it.

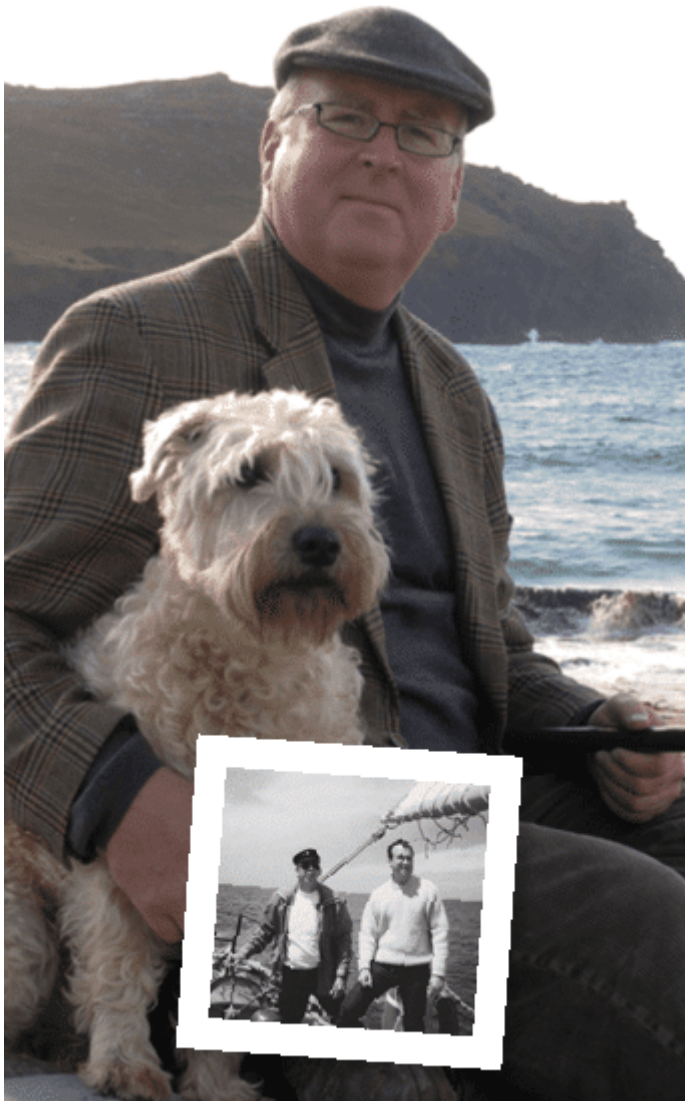
“Everybody loses a certain percentage of muscle mass, bone density and brain volume in their later years,” explains Michelle Ploughman, PT, PhD, assistant professor of physical medicine and rehabilitation at the Memorial University of Newfoundland in Canada. “But if you have MS, you’ve already lost a percentage, and now you’re losing more.” So with bone density, for example, you will meet your threshold for fracture sooner than someone without MS. “When aging and MS are happening together,” Dr. Ploughman says, “one compounds the other.”

With some 1 in 10 people with MS now over age 65—and many more soon joining their ranks—knowing what to expect going forward can help you make sound medical and lifestyle decisions and better prepare for what’s to come. Here’s what you need to know.

Changing symptoms

As people who live with MS age, they may find its effects changing, particularly if they’ve been living with the disease for decades. “Symptoms of MS are quite variable at any age and

they can change over time,” says Kathleen Costello, an MS nurse practitioner at the National MS Society. Although the progression of MS slows somewhat once you reach your 50s—lesions on the brain remain fairly stable, Dr. Ploughman says—the disease does march on, with 80 percent of all people with relapsing-remitting MS eventually advancing to the secondary-progressive form of the disease.



Now and then: Trevis Gleason shown above with his dog, Sadie, in County Kerry, Ireland; and inset (he’s on the right) with his dad in 1989 on the Appledore III, when Gleason was a U.S. Coast Guard navigator. Fourteen years after his diagnosis, Gleason can tell from various physical changes that his MS has progressed. Photos courtesy of Trevis Gleason

As it turns out, people with MS who are over age 55 are more likely to have the secondary-

progressive form of MS, according to a 2015 Multiple Sclerosis International Federation (MSIF) survey of 1,948 people with MS from 70 countries. They're also more likely to have a greater level of significant disabilities that require help from carepartners and healthcare professionals. Nearly 70 percent of survey respondents agreed that their MS had changed as they got older. "This often means more problems over time with any symptoms, and particularly with memory, fatigue, endurance, gait and strength," Costello says.

Indeed, people with MS confirm that their disease has morphed over the years. "Fourteen years after diagnosis, and likely 30 years from my first symptoms of MS, I can say that the disease has progressed," says Trevis Gleason, 49, formerly of Seattle, and now living in Ireland. "I have regained and then lost again much of the function on my left side, and more parts of my body and mind are now affected by the disease—my vision, bladder, bowels and several sensory pathways," says Gleason, author of **Chef Interrupted: Discovering Life's Second Course in Ireland with Multiple Sclerosis** (Coffeetown Press, 2015).

The toll of aging

People with MS are reaching disability milestones later in life than in previous times, according to a 2012 study in the **Journal of Neurological Science**, which means they can expect to enjoy a better quality of life for longer.

At the same time, older age brings greater disability, and the lines between aging and MS can easily become blurred. "As I've gotten older, it's sometimes hard to tell if what's happening is because of my MS or just aging," says Cathy Chester, 56, of Kinnelon, New Jersey. She was first diagnosed with MS in 1986 and is no longer able to walk as far as she used to.

She's not alone. "I'm weaker in the last few years, and my balance has become worse. I can't tell if it's aging or the MS," says Jeanne Long, 85, of Phoenix, who was diagnosed in her 20s.

When it's something else

If it wasn't challenging enough to have your MS finally diagnosed, other conditions can have remarkably similar symptoms, which may also be mistaken for aging and/or MS progression. Read "[When it's something else](#)," to learn more about "MS mimics."

The confusion is not surprising, notes Costello, because aging and MS share many overlapping symptoms: vision changes, cognitive impairment, diminished muscle strength, balance problems, weakness, fatigue, reduced sensation, alterations in bowel and bladder function, and depression and anxiety. Some differences can help distinguish the symptoms:

Vision changes. Presbyopia, a natural, gradual loss of the eyes' ability to focus on nearby objects, is often confused with optic neuritis, which is associated with MS. While both may

cause blurry vision, here's one way to tell the difference: With presbyopia, the problem often affects both eyes, is painless and is easily corrected with glasses. Optic neuritis, on the other hand, usually affects only one eye and can come with pain upon eye movement.

Cognitive impairment. It's not unusual for older adults to have mild memory lapses ("senior moments"), like forgetting names and words and even appointments. In MS, people may experience short-term memory changes, but more commonly, the problem is with the speed of processing new information, like instructions that the doctor may provide. "That slowing of thinking is very characteristic of MS, but not age-related dementia," Dr. Ploughman says.



Jazz singer Rosemary Conte pictured today (above) and in a photo from the cover of the album, "But Beautiful" (inset), which she recorded in 1987. Fatigue is an issue for Conte, who has MS. She has learned to prioritize tasks in her life. Photos courtesy of Rosemary Conte

Diminished muscle strength. Everyone loses muscle mass and function, a process called sarcopenia, with age. Even if you're active, the loss begins around age 30 and accelerates around age 75. The problem is compounded for people with MS because the nerve cells responsible for sending "get moving" signals from the brain to the muscles aren't reaching their target in a timely way. Rosemary Conte, of Matawan, New Jersey, was not diagnosed with MS until age 72. Now 74, she sees an occupational therapist for increasing muscle weakness. "She tells me I'm getting weaker—the muscles have atrophied from MS," Conte says.

With sarcopenia, muscle loss is milder—the main effects being added stress on joints such as knees, and a greater risk of developing arthritis or falling. Needing a cane, rolling walker or wheelchair because of muscle weakness is more likely to reflect MS.

The best treatment is exercise. A huge body of research shows that activity—resistance training in particular—builds and strengthens muscles. Exercise also seems to extend longevity among people with MS. In a 2015 study, people with MS who exercised once or twice weekly had a 36 percent lower risk of death than non-exercisers. And people with MS who exercised more than three times a week slashed their mortality rate in half.

Balance. Walking and balance change with MS. "Your balance relies on sensation, motor control and strength," Dr. Ploughman says. "With MS, you can have effects on both those systems." So if you already have problems in those areas, as you get older, your sensory system is even less robust and muscles get weaker. If you've been using a cane, you may need to upgrade to a walker.

"My balance is really bad now—it's hard to walk without falling," says Anna Pearl, 53, of northern New Jersey, who was diagnosed 19 years ago at age 34. "Now I don't go out without hiking sticks or a rolling walker, so I don't have to think about where my next fall is going to be." How to know if changes to your balance are due to aging or a flare-up of your MS? If the change has been very gradual, it may be aging. If it's abrupt, look to the disease.

Fatigue. Some 80 percent of people with MS report fatigue that is often so significant that they have to stop working, according to the Society. MS-related fatigue may occur early in the morning, even after a restful night's sleep; it tends to worsen as the day progresses; it can be aggravated by heat and humidity; it comes on easily and suddenly; and it is generally more severe than normal fatigue, interfering with daily responsibilities. Fatigue tends to worsen as both MS and age progress. Conte says she needs 11 to 12 hours of sleep these days—as "everything is exhausting."

Reduced sensation. Altered nerve impulses often cause mild or severe numbness of the face, body, arms or legs in people with MS. That was the first sign of MS for Pearl. "Over time, the numbness and tingling has spread from my feet to my ankles all the way up to my waist," says the former policy analyst. Heat seems to magnify her symptoms. "My legs break down when I get hot—they don't want to move, they don't want to bend," Pearl says. There's no

treatment for numbness and tingling, but if it's very severe, a neurologist can prescribe a brief course of corticosteroids, which may temporarily restore sensation.

Wisdom for the ages

Coping skills and life lessons that keep people with MS going strong:

- **“Don't sweat the small stuff.** You're going to move on.” —Jeanne Long, 85
- **“I've become more selective about what I do,** where I go and who I'm with, because I don't have enough energy or strength to do everything. I can't do two things in one day because I get too exhausted. Each day, I have to prioritize. But that means that what I choose to do is very valuable to me. I appreciate my priorities more.” —Rosemary Conte, 74
- **“Were I to dig down into the sack of coping mechanisms that I've tried to employ over the years, I think that coming to the realization that control is an illusion has served me best.** The only things over which I truly have any control are my reactions and my responses. I respond more thoughtfully, I react less harshly, and I assuredly laugh at myself more heartily than ever in my life.” —Trevis Gleason, 49
- **“I try to find the silver lining in every difficult situation.** I learned how to practice mindfulness by being grateful for the blessings in my life instead of dwelling on what's negative. I try to meditate during times of stress. And I surround myself with what makes me happy—an old movie or a classic TV show; a walk in nature; or spending time with my family, my friends or my cats. Find what makes you feel good and surround yourself with it.” —Cathy Chester, 56
- **“I tell myself that I'm not any different.** I still have the same relationships with people, and I still do many things I want to do—I just have to think about ways to make it easier. Like I use hiking poles to walk and I wear a utility belt with ice packs to stay cool. Ask yourself: How can you make your life better today?”
— Anna Pearl, 53

Bladder and bowel changes. “This is a normal part of aging, especially for women who've had children,” Dr. Ploughman says. “Their muscles are weaker, and they can get leakage,” like losing a few drops when sneezing or laughing. But bladder issues also affect 75 to 90 percent of people with MS.

It happens when MS lesions block or delay transmission of signals along the central nervous system that control the bladder and urinary sphincters. The result may be an overactive bladder that can't hold the normal amount of urine, or a bladder that doesn't empty completely, causing symptoms such as urge incontinence, frequent nighttime urination, hesitancy in starting urination and frequent bladder infections. It's important to see a doctor to determine if the problem is a weak pelvic floor (from aging, childbearing or both), or if it's neurological. Many bladder and bowel symptoms can be treated with interventions such as

lifestyle modifications (for example, changes to diet and fluid intake and physical activity), pelvic floor physical therapy or medication as needed.



Illustration by Roy Scott

Depression and anxiety. Both are really common in people with MS. In fact, depression in many people with MS is thought to be part of the disease process itself. Don't brush these symptoms off, Dr. Ploughman urges. Not only can they be treated and even cured, but if you don't seek help, they may influence the decisions you make about your health—you might exercise less, smoke more, drink more alcohol—all things that will worsen your disease, she says. In addition, depression can worsen other symptoms of MS, including cognition, and makes other symptoms, such as pain and fatigue, feel worse.

"Accumulating evidence suggests that health behaviors influence the severity and progression of MS in the long term," Dr. Ploughman says. And untreated depression can be life-threatening, as it is a major risk for suicide.

Additional concerns

Few people have bulletproof plans for their golden years, and those with MS are no exception. In the MSIF survey, only 5 percent of respondents said they felt "very prepared" for getting older. The majority were much less confident. "People with MS may have more financial worries, job-related worries, relationship worries and housing worries," Costello says. "People may be worried that they won't be able to work as long as someone who does not have MS, and this may cause financial concern. What's worse, people worry that they will experience progression that causes a loss of independence and thus require assistance with daily activities."

In fact, in the MSIF survey, when asked which aspects of aging they were most concerned about, three-quarters of respondents ranked losing their independence as fear No. 1. Nearly 50 percent were worried about developing memory issues, and nearly 40 percent were concerned that they would require help at home or in a care facility.

Taking action

If you wake up with any new pain, ache or spasm, don't shrug it off. "It's important to not say, 'This is normal for my age,' or 'It's just my MS,'" Dr. Ploughman says, since effective treatments are available for many symptoms.

If you begin noticing changes in your symptoms or daily functioning, reach out to your MS healthcare provider promptly. Only after discussing your symptoms and undergoing a thorough evaluation can your doctor determine the best management strategies.

"Sometimes a change in symptoms may come from new MS-related inflammatory changes and require a discussion about a change in disease-modifying therapy, for example," Costello says. "Other times, a symptom may be due to a mood disorder such as depression, which may affect a multitude of symptoms such as cognitive function, overall energy, sleep, pain and endurance."

Dr. Ploughman agrees. "Just because you have MS doesn't mean you can't also have a stroke," she says. Studies show that people with MS develop the bigger health problems—high blood pressure, high cholesterol, heart disease and diabetes—at about the same rate as the rest of the population.

Fortunately, treatment is available even when symptoms are due to progression. Rehabilitation strategies and exercises can improve mobility, fatigue, strength and endurance, and will likely have a positive effect on cognitive function and mood, Costello notes. For other symptoms, there are a host of new medications and treatment options. "I was diagnosed during the Dark Ages of MS—there were no approved medications like there are today," says Chester. "We should all feel very positive about being able to find better ways to manage our MS."

Dr. Ploughman's own research focuses on "successful aging" with MS. Her team found, in studies published in 2012 and 2014, that people with MS who were 80 or older exercised more, drank less alcohol and smoked less than other people their age without MS. "They said that paying attention to their health as they got older was key to healthy aging," Dr. Ploughman says. They also used self-determination, social support, strong problem-solving abilities and collaborative relationships with health professionals to better adapt and cope with their disease.

Dr. Ploughman sums up the mentality as "survivor attitude" or resilience. "When faced with a challenge, a resilient person will say, 'There must be another way to do this.' " For example, when going down stairs, says Dr. Ploughman, "a resilient person might go down on their

bottom if balance is an issue, but a not-resilient person would just give up, and over time, they would lose their ability to use the stairs, and become less independent.”

We can choose to be resilient, Dr. Ploughman says, which can help us stay strong and healthy down the line. “Our data show that having a survivor attitude influences the decisions you make, which can then impact the course of your disease.”

Aviva Patz is a freelance writer in Montclair, New Jersey.

Clarification: Dr. Ploughman’s studies should have been described as conducted on people age 55 or older, not 80 or older. However, Dr. Ploughman confirms that unpublished findings suggest that “the oldest old” in the studies displayed the same healthy behaviors.

Visit the National MS Society’s [Aging with MS resources page](#) for more information.