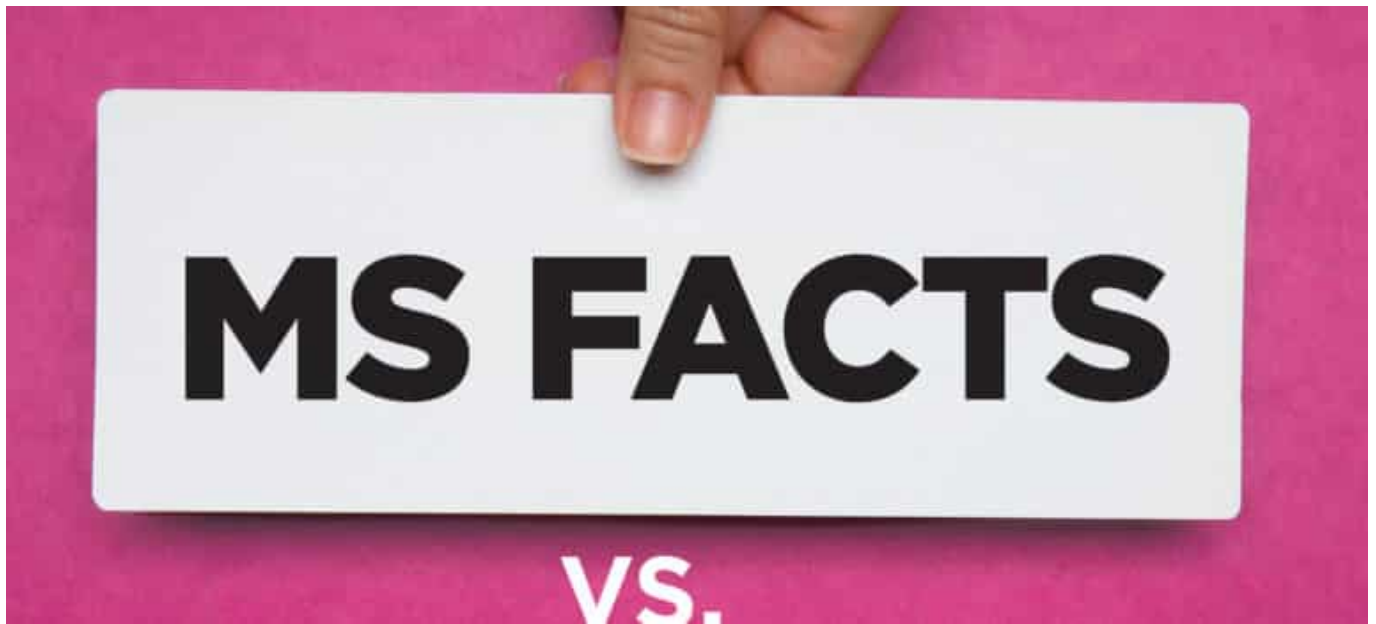


MS facts vs. myths



Don't let these common misconceptions keep you from getting the best treatments and having the greatest possible quality of life.

by Aviva Patz

When Najia Chafai, 55, of Detoin, Morocco, first learned she had multiple sclerosis in 2014, she recalls saying, "My life is over." She'd had a friend in France who died shortly after receiving the same diagnosis. And yet, eight years later, Chafai is still very much alive, living with her husband and volunteering for MS organizations.

Personal experience with friends or family members living with MS can lead people to form opinions about the disease — some of them inaccurate. On top of that, MS has an unpredictable clinical course. "You can imagine that someone tries a novel therapeutic approach and their disease gets better, but it might have gotten better anyway," explains Caroline Whitacre, PhD, retired senior vice president for research at Ohio State University and chair of the National Multiple Sclerosis Society's Scientific Advisory Committee. "That leads to anecdotal myths." Whitacre has been around long enough to recall when the Society had a 120-page book called "Therapeutic Claims in MS," which listed many possible therapeutics for MS, some of which were quite unusual, including bee stings and a grapefruit diet.

Reliable, up-to-date scientific information can help people with MS minimize their symptoms and maximize their quality of life. Read on as the experts dispel some of the most common misconceptions about MS.

MYTH: MS is contagious

TRUTH: It's not. "There's lots of evidence from people living in the same household that it doesn't get transmitted that way," Whitacre says. One of the reasons for this myth is the relationship of MS with the Epstein-Barr virus (EBV). A 2021 study in JAMA Network Open showed that people who had infectious mononucleosis, which is commonly caused by EBV, as children were nearly twice as likely to develop MS. For people who got mono as teens, the risk was three times higher. "There is some relationship — but there hasn't been any evidence that's a direct cause and effect." Also, Whitacre adds, "A lot of people get mono. That doesn't mean that they will go on to develop MS — it's just a higher likelihood."

MYTH: MS is a young white woman's disease

TRUTH: MS does affect more women than men, at a rate of 3-to-1, even 4-to-1 in some populations, according to Mitzi Williams, MD, medical director at Joi Life Wellness MS Center in Atlanta. "But most autoimmune diseases are more prevalent in women," she adds. What's false is that it affects fewer people of color. A 2022 study in the journal Neurology that looked at more than 2.6 million adults from the multiethnic community of Kaiser Permanente Southern California found that MS prevalence was "similarly high in white and Black and significantly lower in Hispanic and Asian persons." It also found that the ratio of women to men with MS was higher among Black individuals with MS than those of white or Hispanic background. "The risk of MS, at least in the US, is possibly 47% higher in Black women," Williams adds. "These are populations that have been historically underrecognized and underdiagnosed."

MYTH: You're going to end up in a wheelchair

TRUTH: "Even though people with MS may have difficulty walking, the vast majority do not use wheelchairs," Williams says. While everyone's rate of disease progression differs, making it difficult to predict their degree of disability, studies show that 15% of people with MS tend to need walking assistance within a year of diagnosis. And after 45 years with MS, some three-quarters require aid with mobility—but that can be a cane or a walker, Whitacre notes. It's not necessarily a wheelchair.

MYTH: If you have MS, don't be physically active

TRUTH: It was once thought that physical activity speeds up the autoimmune disease process, but being active is now known to be one of the best ways to stay healthy and delay disability," Whitacre says. And while exercising can make you more tired initially, you'll actually increase your energy if you stick with it. A 2020 meta-analysis (a review of existing research) in BMC Neurology confirmed that physical activity "significantly reduces fatigue" in MS. The same journal reported on a Phase 2 trial exploring the neuroprotective effects of exercise in progressive MS, noting that in healthy people, endurance training has been shown to build grey- and white-matter volume in the brain and boost levels of brain-derived neurotrophic factor (BDNF), which is strongly linked to cognitive function. Healthcare professionals now recommend that people with MS engage in regular physical exercise to the best of their ability.

MYTH: You shouldn't have children

TRUTH: You absolutely can. "The disease was once thought to get worse during pregnancy, but it actually gets better," Whitacre explains, "especially during the third trimester." And there's no greater risk of preterm delivery, birth defects, C-section or miscarriage. MS can relapse about three months after delivery as the body's changing hormones affect the immune system, Whitacre adds, but then the disease activity settles back down.

"Neurologists are now saying if you want a family, go ahead, just be aware of the risks," Whitacre says. The way MS is treated during pregnancy is changing as well, according to Williams. "We used to take everybody off meds while they were trying to get pregnant. Now there are some therapies you can use until conception or even the third trimester," she says. "And we're learning more about medications and breastfeeding. We're being more conscious of when to stop and restart therapy."

MYTH: For DMTs, wait and see...

TRUTH: A common misconception in MS is that not everyone needs to take a disease-modifying therapy (DMT). Some people hope they will have a benign or mild course that does not require treatment. Studies have shown that people do best when they start a DMT immediately. "We want to intervene as early as possible," while people do not have physical limitations, Williams says. "Because even if you don't have another episode for several years, all that time you could be developing new lesions that can cause damage later."

MYTH: You have one type of MS or another

TRUTH: "We used to think about relapsing-remitting and primary progressive MS as finite, but in the last 25 years we've started looking at it as a progression," Whitacre explains, noting that relapsing-remitting MS can progress to secondary-progressive MS over time, and that people with primary progressive MS tend to progress a little faster, with no intermissions. Williams sums up the shift in thinking this way: "The current subcategories of MS are still the accepted categories, but everybody doesn't fit into a neat box like that," she says. "There's often relapses and progression going on simultaneously from the beginning, which is why we want to treat patients early to prevent as many symptoms as possible."

MYTH: Since there's no cure, there's nothing I can do

TRUTH: Besides getting treated early, there are risk factors people can control, says Whitacre. "Stop smoking, stay at a healthy weight and keep up your vitamin D levels," she advises, adding: "Pregnancy is OK, employment can be helpful and MS is not just a white women's disease. And don't wait to start the DMTs!"

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