



MEET STACEY



At age 23, Stacey began experiencing numbness and tingling in her lower extremities. She went to see a neurologist who diagnosed her with multiple sclerosis (MS). She decided to get a second opinion. Through an MRI scan, the second doctor verified the reason for her symptoms: Stacey had MS.

In the beginning, Stacey's symptoms were mild and consisted of sensory disturbances, sensations of numbness and tingling in her legs. These episodes, known as relapses, would subside for a while, and then the symptoms would return. This disease pattern of relapses followed by partial or complete recovery is known as relapsing-remitting MS (RRMS). In 1990, after having her first child, Stacey had another relapse. The symptoms were again mild and her treatment consisted of regular doctor follow-up appointments. With no disease-modifying drugs available to assist in slowing the progression of MS at that time, medication wasn't part of Stacey's treatment between 1987 and 1993.

Then in 1994, Stacey began developing more significant symptoms, one of which was brainstem seizures. These new symptoms were scary for her as the seizures would last as long as 90 seconds and made her appear as though she were having a stroke. Along with the brainstem seizures, Stacey

suffered from optic neuritis, the swelling of the eye's optic nerve that can impact sight. She also began losing her sense of taste. These changes happened within just a few months. That same year, Stacey was selected from a pool of patients to begin taking a new immunosuppressive drug. After beginning this treatment, Stacey's MS went into remission, and for the next 18 years, she experienced no symptoms.

While Stacey credits the medication with helping her live with MS, she believes her attitude and outlook on life has also contributed to her well-being and ability to carry on. From day one, Stacey has remained optimistic about life with multiple sclerosis. She was understandably frightened by the diagnosis, especially when her first neurologist told her she'd be in a wheelchair within 10 years. Stacey decided that the unpredictable nature of the disease was a positive thing. Her journey would be unique, and having the disease has led her to live in the moment and focus on making the most out of every day. She went from a rather bad prognosis at the outset to almost no symptoms. Stacey is only reminded that she has MS when she needs to take a shot.

Living with the condition has taught Stacey the importance of managing her stress. In 2017, she



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had a high-pressure job that elevated her stress level, causing flare-ups and exacerbating her symptoms. Stacey began to manage her stress level better and to focus on eating and exercising appropriately.

Stacey has a large support network of people that she relies on. Foremost, she has a very close relationship with her children and her husband. Stacey works as a child therapist and has many colleagues who are experienced in supporting others. She also has a close group of friends, which she has known since she was five years old. These childhood friends can sense if Stacey is feeling tired and it is time to rest or take a break from whatever activity they are doing. Paying attention to the signals that your body is giving you is a learned skill, and Stacey feels blessed that her friends and family are so understanding and help her to manage her illness.

Acknowledgment, encouragement, and empathy are powerful sentiments and can help motivate Stacey to keep going when she's having a rough day. She believes that when people living with an illness are acknowledged by those around them saying something as simple as, "That must be hard." - that interaction does something in their brains to help them to cope more effectively.

In her 30s and 40s, Stacey was an avid biker and runner. Since being diagnosed with MS, most of

Stacey's symptoms have been benign, allowing her to continue as a runner for much of her adult life. She competed in and finished three triathlons, which is unusual for someone living with MS.

In addition to multiple sclerosis, Stacey faces several other health challenges, including lupus, a disease where the body's immune system attacks its tissues and organs and psoriatic arthritis, a type of inflammatory arthritis that occurs in some patients with psoriasis. She also developed low platelet levels meaning it's harder for her blood to clot. In 2019, Stacey suffered from vertigo that left her incapacitated for some time. While she faces many health challenges, Stacey remains positive and focuses her time on stimulating activities such as writing and researching. She is the author of several child therapy textbooks.

Stacey participates in healthcare market research studies because she believes it is important to tap into the experiences of patients to bring awareness to their journey living with an illness. She believes gathering the patient perspective is especially important for a disease like MS that is so variable and unpredictable.

Throughout her life living with MS, Stacey has seen a change in the approach to treatment and the medications available to patients. In the late 80s and early 90s, she was encouraged by her neurologist to tolerate her symptoms to the best



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of her ability. Doing her best to be a good patient, Stacey learned to ignore any numbness or tingling that she felt.

The neurologist that Stacey currently sees had to re-condition her to be more open about how she was feeling and the symptoms she was experiencing. Stacey was surprised when her doctor suggested a disease-modifying treatment because she was having very minimal symptoms even though the disease was progressing. Stacey's doctor recommended they take an aggressive approach to treatment and that she begin taking a disease-modifying drug in this early stage. Stacey attributes her ability to manage her MS to the fact that she started treatment in her twenties.

One aspect of MS treatment that Stacey thinks about often is the vulnerability of her immune system while taking disease-modifying medicine. She recently endured a terrible case of cellulitis, a painful bacterial skin infection that started from a tiny scratch. While Stacey is concerned about being on the medication for the rest of her life and wishes there was a way to be less vulnerable, there is no way she would stop taking the shots because it has made a drastic difference in her life.

To those who have been diagnosed with multiple sclerosis, Stacey recommends writing down how you feel because you can easily lose track. Keep a journal and fill it up. Being able to characterize

the course of your disease at different points in time helps you and your doctor discuss treatment options and expected outcomes. Stacey also encourages others with MS to stay positive and remain hopeful because the trajectory of the disease is unknown and varies from person to person. While Stacey is certainly familiar with the fear that comes along with having a new symptom and the question of 'What's going to happen next?', she encourages others to try to live in the moment.

In addition to eating healthy and exercising, Stacey recommends partnering with your physician and getting access to disease-modifying drugs. She has heard from others with the disease that they want to deal with it naturally. But, Stacey firmly believes that the research is clear: aggressive treatment, meaning the use of disease-modifying drugs, is your best chance of managing the disease and living your fullest life.