## **That Was Then, This is Now**



I first heard the words, "You have multiple sclerosis," in 1986. I had no idea what that was or how I got it. How could this happen to me at the age of 28? I had my whole life in front of me. What would become of me? How will my life change? Will my boyfriend still love me? Will I die from it?

I had so many questions, and there were not many answers.

I refer to that time as the Dark Ages of MS. There were no medications or internet — no directories to find others who were living with the disease and little information about what MS was. I was frightened, alone, overwhelmed and angry.

That was then. Today, there are many approved treatments and countless ways to discuss the illness and socialize both online and in person. There's a growing amount of research, and a shift in perspective about the disease.

I often tell newly diagnosed patients they are ironically diagnosed at a "good" time, despite the news itself not being "good." Why you ask? Let's see some of the advances since I was diagnosed:

**THEN**: In 1986, there were no FDA approved medications. The standard protocol for treating an exacerbation was the use of steroids, either Solu-Medrol (injectable) or Prednisone (oral) to reduce inflammation. It's a speedy method to fight a flare-up, with many risks of difficult side effects.

**NOW**: There are more **FDA approved medications for MS** than ever. For the first time, there are DMTs for pediatric and progressive forms of MS as well.

**THEN**: There were three types of MS: relapsing-remitting, primary progressive and secondary progressive.

**NOW:** Today there are four types of MS: clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), secondary progressive MS (SPMS), and primary progressive MS (PPMS). Read more about them on the National Multiple Sclerosis Society's **website**.

**THEN**: Information about MS was scarce. The local library was a fair choice to find information, but if your library was anything like mine, books and periodicals were outdated.

**NOW:** Once the internet became accessible and user friendly, the sky was the limit for finding credible information.

**THEN:** I clearly remember a visit to my neurologist when I asked if they'd recommend trying yoga, acupuncture, massage and herbal supplements. Without hesitation — no discussion, no explanation — the response was a clear and adamant **no**.

**NOW:** Slowly but surely, the medical community recognized the benefits of complementary medicine (a range of medical therapies that fall beyond the scope of scientific medicine that are used alongside treatments to emphasize a more holistic, patient-focused approach of care to treat the whole person). There are endless possibilities for complementary medicine to help a patient, and with more research focusing on this growing area, patients will continue to benefit by exploring integrative medicine (**read more about complementary medicine**).

**THEN:** I was about to be engaged to my boyfriend when I was diagnosed, so I asked if I could still start a family and what was the likelihood that my child could inherit the disease. I was told there was less than a 1% chance of passing MS from mother to child. There were no support groups for children or parents of children with MS in my area.

**NOW:** According to the **National Multiple Sclerosis Society**, "The risk for a child with one parent who has MS is approximately 2%." Also: "Approximately 3-5% of all individuals with **MS experience disease onset before age 16.** Two recent consensus reports – one by neurologists in the United States and one by the International Pediatric MS Study Group (IPMSSG) – provide helpful insights into the management of MS in the pediatric population."

There are now self-help groups for families dealing with pediatric or young adult MS.

**THEN:** After my diagnosis I was told to go home, rest and call the doctor if I had an exacerbation. I quit my job, gave up my apartment and moved back home with my parents.

My doctor offered no hope or sage advice except to say not to overdo any exercise program by getting overheated.

**NOW:** Exercise is not only encouraged but <u>recommended for people living with MS.</u> Any amount of exercise is better than none and can lead to improved overall health.

These are just a few of the many developments that took place over the last 30+ years to try and improve the lives of people with MS. I have great hope that the next 30 years will see extraordinary changes in ways that we can't even imagine right now, including a cure.

Editor's Note: This blog was originally published on July 16, 2019 and updated on April 11, 2023.