

## TRAVELING THE BYWAYS: A Personal Account of Living with Multiple Sclerosis

Roaming the aisles of a local bookstore, Annette found herself thumbing through the books on multiple sclerosis (MS). The words on the pages seemed foreign as the reality of her diagnosis set in. With each syllable, the hopes and dreams she had for her future seemed to fade away. When first diagnosed, she had been relieved to have an explanation for her symptoms. However, relief morphed very quickly into fear and despair. All the information she could find, including what was in the books in her hand, painted a picture of a life seemingly not worth living. She recalled, "What I read was nothing but gloom and doom. I was scared."

That was Annette's reality nearly 30 years ago. Looking at her today, no one would know that she has MS. Like so many of the 2.5 million people living with MS worldwide, Annette does not resemble the patients described in those books she read all those years ago. Today she truly embodies the MS TeamWorks mantra, **"I have MS. I have a team. I have a future."** But that wasn't always the case.

### DETOUR

Annette's journey with MS began in her twenties. She was engaged to be married and traveling eagerly toward her future when a series of diverse symptoms broke her stride, rerouting her on a convoluted path to diagnosis.

"At first, I thought I had the flu," Annette recollected. "I slept through an entire weekend." Over the next few months, Annette experienced headaches, back pain, and problems with bladder control and memory. "I saw multiple doctors," she said, recounting primary care and chiropractic visits. Doctor visit after doctor visit, Annette would leave without any answers. One after another, each symptom or occurrence was treated as a separate event. As time passed and as her health continued to decline, she became distraught. "I knew something was wrong, and I didn't understand what was happening to my body," she said.

After what seemed like an eternity at the time Annette eventually saw a neurologist and had an MRI. "The neurologist told me I had MS and sent me home with a prescription for Xanax (alprazolam) to keep me calm," said Annette, quick to acknowledge how the treatment of MS has changed since then, which was before any of the current treatments were available. "That's pretty much all that could be done at the time."

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Annette remembered the overwhelming but fleeting sense of relief she had experienced initially, realizing that she finally had an explanation for her symptoms. She was told that MS had caused her symptoms by damaging the myelin sheath, which is the layer of insulation that surrounds nerves and facilitates conduction of signals from the brain. "I understood the explanation and that it was a life-long diagnosis, but I couldn't wrap my mind around what it truly meant."

That's when Annette started questioning her future. Would she get married? Would her fiancé choose to stay with her when this disease would undoubtedly be a challenge for them both? Would they be able to have children? Even today, when there is so much more hope for patients who are diagnosed with MS, these are very common questions for patients.

### TREACHEROUS CONDITIONS

Unfortunately, soon after learning of her diagnosis and long before she had recovered from the shock, Annette's symptoms intensified. "I was having trouble walking, and that was when my family realized there was a serious problem," said Annette. The weeks that followed were filled with events and details that elude Annette's memory to this day.

"I just remember how terrified I felt," she said, referring to the 8 days she had spent lying in a hospital bed unable to walk. Her family later told her that she was slipping into a coma. "I declined so rapidly," she remarked. "Even though the doctors were pretty sure I had MS, they were testing me for all sorts of other things because my symptoms were so unusually severe."

## PATH TO RECOVERY

After extensive testing failed to uncover an alternative cause for her severe symptoms, Annette was treated with intravenous gamma globulin, which was one of the only treatments for MS available at the time. "It was considered an experimental treatment," she said, recalling how the doctors had described it.

Shortly after receiving the gamma globulin, Annette began a long course of physical rehabilitation, the expected outcome of which was uncertain. "I remember being told that there was a 10% chance I might not recover the ability to walk. I felt as if I'd been told there was a 100% chance I'd never walk again," she said, awed by how overwhelming the news had been. "I was petrified."

Annette did regain her footing, first using a walker and then a cane. After several weeks, she was walking without any assistance. One of the advanced practice nurses involved in her care referred to her recovery as a miracle. Annette then went on to walk down the aisle on her wedding day, which for a short time she had feared would never happen.

## SPOTTERS & ROADSIDE ASSISTANCE

Now, having lived with MS for many years, Annette has "nothing but gratitude" for the treatments and care she has received. "I feel so lucky," she declared. "I owe my survival to that gamma globulin treatment and to the doctors and nurses who helped me recover."

Not long after her initial harrowing ordeal, the first of the disease-modifying therapies that are commonly used today became available. Literally through the luck of a lottery drawing, Annette began treatment with an injectable beta interferon therapy, which she still takes to this day. "I remember praying that my number would be called," she said, reminded of the role luck has played in her journey and grateful for the benefits of medication.

Annette's gratitude extends to the many individuals who have helped her along the way, from the coworker who wisely suggested she see a neurologist for her puzzling symptoms, to the competent and compassionate team of medical professionals at her specialized MS care center. She is also thankful for her staunchly supportive family and friends, who have helped her "in every way imaginable."

## COBBLESTONES & UNPAVED TRAILS

While she considers herself lucky in many ways, Annette admits she lives with uncertainty and fear. "With this diagnosis comes fear of the unknown," she said, relaying stories of how other people she knows with MS have been affected differently by the disease. "I live with a big question mark. That cloud of doubt is always there."



**"I am much more hopeful now than I was years ago"**

In the face of doubt and fear, Annette draws strength from many sources. She relies on her family, friends, and trusted medical care team for support, while crediting her spirituality for her ability to be optimistic about her future. "I am much more hopeful now than I was years ago," said Annette, commenting on how much has changed since she was diagnosed. "MS is not the disease it used to be. We know so much more now, and treatments have come so far."

## STEADIER GROUND

A journey that began with so many unknowns followed by despair for Annette is now guided by hope. Having navigated some difficult terrain, Annette knows the course can be rocky. But the byways are passable and replete with rest stops and refueling stations.

Reflecting on what she has learned over the years, Annette remarked that she knows better now how to manage her symptoms and minimize exacerbations. "I try my best to do my best," she said, emphasizing the importance of having a medical care team that she trusts, staying informed and involved in her own care, and being diligent about taking her medication. While her journey continues, Annette happily reported that in spite of her disease she is living a very active and fulfilling life with her husband and her children.

By sharing her story, Annette hopes to help others who are affected by MS, especially her fellow travelers, each trekking along his or her own unique journey.