

Profile of a Person with Multiple Sclerosis

Julie C, Biogen Idec

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- What is MS?
 - Nerves in your brain are like a phone cords, carrying messages within your brain or from your brain to your body. With MS, part of the insulation on that cord is stripped off and the signal is sporadic, scrambled, or just doesn't get through.
- What is having MS like for you?
 - Julie was in the military. After many "mystery illnesses." She received a medical discharge. All along the way her doctors kept treating symptoms without finding any main cause.
 - For example: One day Julie woke and noticed she had kind of a blurry spot in her peripheral vision, just out of the corner of her left eye – almost like the snow on a television screen that is getting bad reception. Through the day, the snowy area gradually closed in to a tunnel around what she could see through her one eye. Then gradually, the snow completely obscured her vision. Of course, this was a bit scary, so she went to the doctor. The diagnosis? A migraine headache...her vision gradually came back, but to this day she has no peripheral vision in that left eye. Migraines are known to cause vision problems, like an "aura," but this was different. This is a classic early symptom of Multiple Sclerosis called optical neuritis.
 - Later, after her discharge, Julie was home cleaning her house one day and saw one of her friends. Her friend commented on a slight limp that Julie hadn't noticed and asked about it. Julie thought little of it, but the limp continued. After a little time, she thought perhaps it would help if she got more exercise. So, she asked her husband if he would go for a little walk with her. About half way along the walk, one of her legs suddenly stopped listening to her- it was like she had forgotten how to walk! Her husband ended up carrying her home, but asked, "How can you just forget how to walk?" She was able to walk around fine when she got home, strangely enough, so, back to the doctor! A different one this time.
 - The doctor asked her many questions, including whether she had ever had any problems with her vision. Once he heard her answers, he recommended she get an MRI (magnetic resonance image) scan to look at her brain. When he got the results back, he realized that she had multiple sclerosis and that there were many lesions in her brain.
 - At first, Julie didn't really want to think about it too much. She said to herself, "I had this yesterday and I have it today, nothing has changed," and tried to continue on with her life. With the support of her family, she has come to understand that this illness will continue to impact and affect her life and that it won't be the same, but that she will continue to work and keep going as long as she is able.

- What have you done to treat your MS?
 - When Julie was first diagnosed, there were few medicines to treat MS, and many of them could potentially damage other parts of your body, like your heart, if you took them for a long time. Even though she knew what she had, she had some bad days. Some days, she couldn't even get out of bed. One day, she had a fever and chills so bad that she shook like she was having a seizure. Her husband tried to help her get warm by wrapping her up in blankets and carrying her downstairs to lie by the fire in the fireplace. Eventually, she was worn out and went to sleep. When she woke up, she couldn't move. She was like a floppy rag doll and could only move her head around. Fortunately, after a little panic, she and her husband realized that her body had just gotten too hot, even though she had felt like she was cold. He wrapped cool towels around her and after 20 minutes, she could stand on her feet again, after 45 minutes, she could walk again and after an hour, she seemed fine, like none of it had ever happened.
 - After discussing options with her doctor, she chose to take Avonex, which helped. Then later a new medicine came out, called Tysabri. She said since the short time she has been on it, "Good things have happened for me."
 - Once a month, Julie has to go to an infusion center where the medical workers give her fluids intravenously with Avonex and Tysabri in the fluids. She said, "Once a month I leave work a little early and get to take a nap in the middle of the day," while she gets her infusion. She talks to other people before it is her turn. Some are worse off than her, in a wheelchair or using a walker, but some of them don't look sick at all.
 - She still has to get MRI's regularly, at least once a year, to see if she is getting any new lesions. She still has to monitor and talk to her doctor about any new symptoms. But Julie is able to go to work, garden with her husband and do many of her hobbies. She was even able to walk three miles in the last MS walk she went to, she'd had to work up to that!
- What are your symptoms?
 - Since there were many lesions in her brain when she started taking medication, Julie still has symptoms from her condition. Currently, there is no cure for Multiple Sclerosis or other autoimmune disorders where your immune system attacks your own body. But her treatments are slowing down the formation of new lesions in her brain and spinal cord.
 - Julie gets tired easily, experiencing fatigue. It is hard for her to stay awake during a movie unless she is doing something. Sometimes the fatigue can be a good thing, because it makes it easy for her to take a nap when she is getting an infusion or having an MRI done.
 - Sometimes she has trouble walking and has to carry a cane just in case.
 - Sometimes she has pain- as if an Olympic dart team is all throwing darts at some part of her body, often one of her hip joints. The thing is- there isn't really anything physically wrong with that part of her body- her brain just thinks there is – which is really worse because rubbing the spot or putting heat on it won't help at all. Some pain medications can help, somewhat.

- One time she is driving and couldn't for the life of her remember the next turn ahead, even though she took that road home every day. Once she saw it, she remembered it, but it was pretty scary not being able to remember what came next on the road. Especially when she knew that she *did* know it, but that she just couldn't remember it.
- Really, any part of your body that relies on a signal coming from your brain to make something happen can be affected by MS. Anything from walking to breathing to thinking one thing and not being able to say it the way you thought it.
- Julie said that the keys for her dealing with her MS are really having the support of her family and co-workers; having a strategy to cope with her symptoms; and having something to occupy her and help her feel like she is doing something worthwhile with her life. It can be hard if a new symptom appears, because she has to figure out how to cope with it, but thankfully she does have a lot of support.
- Biopharmaceuticals like Tysabri and Avonex really represent a good hope for people who have MS and other autoimmune diseases like Julie. Early detection helps ensure that progression can be stopped before too much damage is done. In the past, many doctors didn't really worry about diagnosing this condition, because the prognosis was very poor. But today there is hope that the disease can be slowed down or stopped, and some medicines in may someday even be able to reverse some of the damage, reducing symptoms or maybe eliminating them entirely.
- More information about multiple sclerosis can be found at:
 - www.msfocus.org
 - www.nationalmssociety.org