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Learning About Multiple Sclerosis (MS) on the Internet: *What Works and What Doesn't?*

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If you have multiple sclerosis there is a lot that *doesn't work*. And what isn't working is both unpredictable and constantly changing. MS affects everyone differently. And it's a very *wide range* of different. While one person may have sensory issues (perhaps a leg is always numb), another person may have movement issues (like muscle weakness or spasticity), and yet another person may be unable to leave bed. You may even know someone who has MS and not realize it. That's how variable this disease can be.

It's because of this variability that learning about the disease can be really tough. As you can imagine, learning about what may never happen to you can create tons of anxiety, and this emotional state is not conducive to learning and empowerment.

What works and what doesn't when trying to learn about MS on the Internet is like a moving target. What a person needs to know changes as the disease progresses over time. And while anxiety is common for the newly diagnosed, even people who have been living with MS for many years go through changes in both the everyday symptoms and the course of the disease.

It's also important that those who care about a person with MS know what is happening to their loved one so that they can be supportive and understand what he/she is going through. It's hard enough to live with this disease; to be doubted brings the stress to a whole new level.

The Internet has helped people who are affected by MS in many different ways. Through social networking and the most current information about the disease, the online MS community is an active and interactive space that can help even those who are living with very limited mobility to become informed e-patients and advocate for themselves. And that's very important.

But the existing websites (and there are more MS sites than there are noises in an MRI tube ☺) don't go as far as they can in helping people with MS learn all that they need to. The sites that provide information can't meet an e-patient's individual learning needs or consider the emotional state they are likely experiencing. It's no secret that learning about MS (in a meaningful way) is critical while coping with MS. It's good to find control – considering MS is all about losing control – where you can.

When I was diagnosed with MS in 1988, it was long before the Internet was available or the FDA had approved any disease-modifying drugs. I was flailing. It was the Stone Age in isolation compared to the connectivity we have today, and I struggled to learn about my version of MS using printed materials and support groups, both of which triggered so much anxiety and fear it was, in and of itself, immobilizing. I vowed to avoid information and just wait and see how *my* MS would play out. Looking back, it's clear that this was my only choice at the time.

Then the Internet came to be, and everything changed. Well, not everything.

In 2006, I got my Masters in educational design and studied cognitive science and learning theory. I had an epiphany. There is a way to use the existing Internet technology to make for a personalized, self-directed learning experience that greatly reduces anxiety.

That's when I founded MSSoftServe, a non-profit organization that aims to revolutionize how patients learn about their diseases on the Internet. The vision is that people with MS will be able to create a web space that is all their own, ensuring that their emotional and intellectual needs will be considered as an individual person, rather than taking the cookie cutter approach that current information sites offer. The site will be personalized so that people with MS will be able to learn about their unique version of MS their way. By establishing preferences, people will be able to control the information they receive. It will be a site like no other and, once produced, it will take full advantage of the capabilities the Internet offers.

Today, I know that change is possible for the 350,000+ Americans who have been diagnosed with MS and the 200+ individuals who are newly diagnosed every week. There is no reason that people who have a disease like MS should feel the same way I did when I was diagnosed 26 years ago. MSSoftServe will give patients what they truly need, not what someone else thinks they do.

Bringing MSSoftServe to life is no small task. Meeting the diverse needs of the MS population requires more content production and more complex site design than other websites. Through www.mssoftserve.org, we are spreading the word about the initiative, raising the required funding, and reaching out to the MS community to find out how to meet their learning needs so that MSSoftServe can help them cope with their version of the disease. Please take a moment to check out the site to learn more about this effort and spread the word to those who will benefit.

Have you or a loved one been diagnosed with MS or any other chronic disease? What would you want to learn on a site that could be customized for you?

Share your insights in the comments section.

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