



When good doctors aren't enough

By Judi Hasson | June 1, 2016

When I was diagnosed with multiple sclerosis nine years ago, I didn't know what it was and couldn't even spell it. I was frightened and desperate, looking to health care professionals for comfort and information that would calm my fears.

By now, that's what I have: caring doctors and plenty of knowledge. But as I've navigated the challenging world of chronic illness, I've learned that I need more. At every step along the way, I've confronted emotional, physical and day-to-day issues that lie outside the scope of ordinary medical practice, but affect my well-being – and no one in the medical system has been fully equipped to help me face them.

This is life as a patient with a chronic disease, and it highlights the blind spots in our disconnected health care system. Medical organizations are beginning to shift toward caring for populations. As they do, the experience of a patient like me ought to be their guide.

It starts with diagnosis – and how hard it can be to get one. A year before my world collapsed, I had complained to my primary care doctor that my hands and feet were always cold (a possible MS symptom), and that I sometimes lost my balance and

was often fatigued. But she didn't probe deeply or make any connections to MS.

Shortly thereafter, I was hit with a vertigo attack (another possible MS symptom). The same doctor treated my ailment, but did not look further to investigate the cause.

I got sucked even further into the medical vortex as my body continued to exhibit warning signals. Six months after the vertigo, I was undergoing physical therapy for a back injury, but I wasn't getting better.

An astute physical therapist walked me down the hall to a neurologist for a consult. She took one look at me, put all the pieces together, and ordered an MRI and a spinal tap. At last, the verdict was clear: I had relapsing remitting MS.

But the next step in this medical maze was not clear at all. There was no one to help me navigate the system. Pretty daunting, that's for sure.

So I used Google and put together a list of neurologists who specialized in treating MS patients in Northern Virginia where I live. Several weren't taking new patients. (After all, it's a time

commitment. I'm not a 15-minute kind of patient). Several others only had appointments available six months out.



Finally, I found an MS specialist who had just recently opened a new office only a few miles from my home. I thought I was set, but it was just the beginning of my marriage to the medical profession and a host of other needs.

On my very first visit, my doctor recommended a biologic medicine, taken by injection once a week, that hopefully would slow the progression of the disease and cut down on relapses. I took this medicine for five years, but my condition continued to deteriorate. Finally, my doctor recommended that I switch to a twice-a-day pill, a new entry in the treatment market. But I became allergic to that after two years. Now, I'm on a hiatus and carefully looking for the next solution.

My neurologist is great. She usually spends an hour or more with me during my visits every six months. She has recommended a urologist to treat my frequent urinary tract infections – another MS side effect – and to a physical therapist who specialized in treating patients with neurological disorders.

But there have been many critical issues that my MS physician and my primary care doctor, whom I still see for routine medical issues, could not solve.

This included finding reliable and competent home care when I lost my ability to walk; getting counseling to cope with my radically changed circumstances; locating contractors to help me make my house handicapped accessible as well as locating a durable medical equipment supplier to purchase a motorized wheelchair and teach me how to use it.

In other words, I had no single care manager, no one who could deal with the whole person, and no one to truly help a patient like me navigate numerous and often unexpected challenges.

If I could start a health care system from scratch, that's what I'd wish for.

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