Learning About MS

by ABIGAIL BUDD

Knowledge Is Power When Diagnosed With MS

Denial is a powerful force and I was firmly stuck in this stage of accepting my condition for a number of years. I refused to tell friends and family about my diagnosis, preferring to delude myself that it wasn't happening to me. I stubbornly refused to engage with my MS nurse, feeling that treatments didn't apply to me as my symptoms were invisible.

As my symptoms worsened over the years though I had no choice but to start learning as much as I could about my condition. One particularly bad relapse in 2009 left me literally dragging my right leg behind me. I hadn't disclosed my condition to work at that point and went to work, hoping no one would notice! My boss noticed and it forced me to tearfully spill the beans in his office and start engaging with my MS nurse.

I started Disease Modifying Drugs (DMD's) shortly after the leg dragging episode and my condition stabilized nicely for a few years and this is when I faced up to my diagnosis. Current research suggests that the earlier you start DMD's the more effective they are in preventing long term disability so my pig headed denial didn't do me any favors! If I'd found out as much as I could about my condition at the beginning I would have known this and started treatment straight away. This may have prevented or delayed the onset of my disability so I learned the hard way how important it is to learn as much as you can about your condition.

Knowledge is power. How else can we have any control over an otherwise uncontrollable disease? How can we arm ourselves against what's happening if we don't know the best ways to fight it? Below are some of the things I've learned about my condition along the way.

No Two People Are the Same

It's no use comparing your MS with someone else's as we all experience MS in different ways. Learn as much as you can about the symptoms that affect you and then you can manage them more effectively. Never become obsessed with symptoms you may get in the future as it may not happen to you. Concentrate on what's happening now.

Diet

Amazingly, most MS specialists know little about diet and nutrition and the effect food has on our bodies. Nutrition won't be part of the care you receive after diagnosis and it's baffling that most MSers stumble across this as they go along. I've cut out gluten and dairy from my diet and the effect has been amazing. Gluten makes fatigue so much worse for me. If I so much as look at pasta fatigue descends like a fog and claims the rest of the day. Dairy makes my tingly hands worse and I feel the difference almost immediately.

As above, no two people are the same and there are numerous MS diets out there to learn from. I'd never considered how much diet an influence how we feel generally so learning as much as you can and doing your

research helps you make informed decisions about what to eat. I've also lost a great deal of weight as a result which means there's less of me to lug around which can only be a good thing! Heaving myself up from a fall is also easier for me and those round me.

Exercise

Many years ago it was believed that people with MS shouldn't exercise as the effort would make symptoms worse. It is now widely known that exercise can alleviate symptoms and improve fatigue so do as much as you can to prevent further disability and improve fatigue.

MS Specialists

You'd be forgiven for assuming that everyone diagnosed with a chronic condition such as MS would get to see someone who knew the best ways of treating them. You'd be wrong in this assumption though. It took me 8 years of fighting to finally see the MS specialist in my area. Different countries have different health care systems so find out about yours and the best way to see someone who knows what they're doing. This is another reason to learn as much as you can about your diagnosis so you can challenge and question the care you receive. Don't blindly assume the people in white coats know about the latest treatments or have the best advice. Go to appointments armed with questions and take someone with you so you don't forget the answers or misunderstand what's being said to you. I can't stress how important this is.

Don't Worry About the Future

As I mentioned above, there is no point worrying about what might happen to you. No two people are the same so horror stories about what might happen years down the line are an unnecessary stress you can do without.

So, knowledge is definitely power when it comes to MS. Learn as much as you can about your diagnosis. Read about new treatments and research, connect with other people and share experiences as doing so will give you back a sense of control that can often be swallowed up by the enormity of the diagnosis. Don't bury your head in the sand like I did as it could affect what happens in the long run.