MS Fear and How to Overcome It

by ABIGAIL BUDD

Dealing With "The Fear"

Many people with multiple sclerosis (MS) will experience “the fear” at various stages of their journey. Fear is omnipresent and there are many layers I feel, but if I gave in to it all the time I’d never get out of bed, push myself, or get anything done. Giving in to fear lets MS win, so we need to develop strategies for dealing with fear and coming out on top.

What Are We Afraid Of?

There are many different types of fear when dealing with MS:

Diagnosis

Cast your mind back to the weeks and months before the neurologist finally confirmed your worst fears and told you it was MS. That was a pretty scary time for me and I fought this particular fear with denial.

I buried my head firmly in the sand and refused to acknowledge my symptoms might be something serious. Many people find diagnosis a relief after the months of uncertainty, but for me it was a bombshell that blew up in my face and forced me out of my comfortable denial.

The Future

Many people don’t know anything about MS when they’re diagnosed, and researching the prognosis can be terrifying. Every relapse gives us a glimpse of what might happen in the future as disability sets in and the fear of progression is always with us.

I remember waking up in the middle of the night in a cold sweat worrying about the future and stressing about what may or may not happen. This can be a frightening, lonely place we all revisit from time to time even when we’re feeling good.

New Situations

Any new situation sets the fear off in me! What if I can’t park? What if I can’t get my scooter out of the car? What if there are no toilets nearby? I’ve canceled plans so many times due to rising panic that normally starts a few days before I have to face a new situation or place, leaving me feeling like a failure and missing out.

Humiliation

This is a particularly worrying fear that links in with the fear of new situations. Many of us with bladder and bowel problems live in constant fear of having accidents outside the safety of our homes. This has never actually

happened to me, but the fear of it happening has definitely kept me awake at night!

I also worry about falling over in public and not being able to get up again. My friend had this happen to her at work and needed to be heaved up by several colleagues. Oh the humiliation!\

Next page: how to deal with MS fear and move forward with life

What Are We Afraid Of?

Fatigue

How many of us avoid situations due to the fear of overdoing it and being enveloped by fatigue? I am in constant fear of this and miss out on so much because of it.

Dealing With the Fear

What can we do to combat all this fear? How do we get up and keep going with all this negative energy floating around?

Educate Yourself

The more I learned about MS by reading trusted websites and connecting with people on social media, the more I began to fear the future less. MS is not a death sentence, we just have to learn to live with it and manage as best we can.

No two people with MS are the same, so you'll never know what your prognosis is. There is no point worrying about the future — the best thing you can do is give yourself the best chance by eating well and keeping as active as possible rather than shutting yourself away in terror.

Stay engaged with your healthcare team and take an active role in your medication and care. It's important to stay proactive and learn to face up to MS instead of living in denial.

Planning and Preparation

This is essential if you want to avoid canceling engagements and missing out. If you're going somewhere you've never been before, make sure you call in advance and find out about the venue.

Ask about parking, washrooms and stairs so you know what you're dealing with. There are some places I can't go because the washrooms are downstairs or there isn't any parking, but that's OK because there are plenty of places I can go. I always tell people I use a mobility scooter and usually the reaction is positive and they can't do enough to help.

Push Yourself

Sometimes we have to take a leap of faith (not literally, or we'd be falling all over the place). I did a lecture at a university recently and refused to let the fear stop me. I found it difficult, but I didn't wet myself in public and I didn't fall over.

I was fairly tired afterwards but I managed it and got some great feedback. The best thing was the sense of achievement I felt and the feeling of having triumphed over MS fear!

I still feel fear most days, but I won't let it stop me moving forward with my life — and you shouldn't either.