How to Find Support on the Journey of Accepting Your MS Diagnosis

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Emotional Support for MS

Being diagnosed with any life-changing condition requires emotional support, but how you cope with it all depends how accepting you are of the diagnosis.

When I received the news from my neurologist, I remember feeling numb, and coped by smoking copious amounts of cigarettes and drinking a large glass of wine. Probably not the most effective coping strategy, but I was also in denial for years, so I was determined to carry on as I had before.

I refused to accept the situation and didn't identify with the chronically ill or disabled community. I didn't see myself that way and didn't want to join their club! I hid my condition from family, friends and colleagues and soldiered on, carrying the burden myself with no support.

This was unsustainable in the long term and I eventually started telling people as I began to accept my situation.

Ironically, it was the worsening of my disabilities that led to acceptance and finding emotional support. When I could no longer hide my mobility problems and needed to use walking sticks, for example, it became obvious I was suffering from MS, so I had to open up more. I am now an active member of the MS community and have accepted this part of myself, which means I can help support other people to find acceptance.

Different Types of Support

Counselling

Around four years after diagnosis I tried counselling. I realized I wasn't coping with it very well and it was affecting my relationship with my husband. I was pregnant with my second child and was short tempered and difficult to live with, so I contacted a counselor through my local MS treatment center. It wasn't the best experience, but mainly because it was cognitive behavioral therapy (CBT), which I was familiar with through my work so was resistant to it. There are lots of different types of counselling though, so I should have given it more of a chance. Finding a style of counselling that's a good fit can be beneficial, so it's worth shopping around and getting recommendations.

Support Groups

I'm lucky enough to live close to an MS treatment center, where they offer all sorts of therapy and support. I used to attend regularly for Pilates and other fitness classes, but worsening disability and a busy home and work life have made this more difficult. They also offered a number of different support groups, but I wasn't ready at that time. I still didn't see myself as part of the MS club and was trying to carry on as if I didn't have it! Now that I've fully accepted my condition and would benefit from a support group, I can't easily attend, which is a shame.

Websites

Luckily, there are some great websites offering support, but I would stick to the ones you trust and try not to get side-tracked online. I like msociety.org.uk, mstrust.org.uk and nationalmssociety.org.

Online Support

We are lucky that we live in the age of social media and I don't know where I'd be without it. As my MS has got worse, I've become more isolated due to not being able to be independent. But being able to access support through twitter has been a lifeline for me. There is a huge community of people with MS online and I can call some of them friends even though we've never met. Facebook also has support groups and other platforms such as Instagram have a huge MS presence.

Friends and Family

Now that I'm able to open up and be more honest about my MS, I find I get lots of support from my friends and family. They're unlikely to understand if you don't explain yourself though, so you need to be honest.

Coping with MS and Covid-19

The current global situation with Covid-19 is making us all feel vulnerable and isolated. My mental health is usually fairly stable, especially since I've accepted my situation, but these are not usual times.

A few weeks ago, I noticed my mental health deteriorating, I was tearful and anxious most of the time and felt fearful and alone. I found myself glued to rolling news and scrolling through twitter for updates, but instead of offering support this was making me feel worse. I now avoid TV for most of the day and tune in to the daily government briefing instead. This is where I find out the latest statistics and scientific advice and learn about what my family and I need to do to support the national effort.

There is a "clap for the NHS" event every Thursday evening where people stand outside their homes and clap and cheer for our health workers. This way we feel connected and supported by our community and gain strength and support.

All the usual emotional support for MS above is available during this difficult time and being socially isolated is, unfortunately, something people with MS have a head start on! You can learn more about coping and staying positive with MS here.