Why Coping With MS Requires Emotional Support

by ABIGAIL BUDD

Coping With MS

A life-changing diagnosis can feel like you've been hit by a train at high speed. One minute you're happily plodding along through life and the next minute; bang and you're floored!

That's what it felt like for me anyway. I'd just had a baby and had been promoted at work, much to my delight and surprise. I was engaged to a wonderful man, and we'd moved to a larger house so life was exciting and I had high hopes for our future.

Although I'd had some troubling symptoms I never really believed anything was seriously wrong so my world turned upside down when the neurologist broke the news to me.

At first, I coped with it well – probably due to the power of denial. It's easy to deal with it well when the symptoms are slight, and you can hide it from most people but the worse it got, and the more people knew about it, the harder I found it to cope with. I felt like it challenged the core of my being and my sense of myself.

In my head, I still felt like the person I'd always been, but in the eyes of people around me, I thought I saw a disabled woman who ought to be pitied.

I'm sure my experience isn't unusual, and my guess is that many of us with MS have needed to seek emotional support to cope with it but what stages do we go through and what help is available?

Coping With an MS Diagnosis

Even if you've been waiting months or years for a diagnosis and it's a relief to know what you're finally up against and it can still be a stressful time. And this is a time where emotional support is needed.

In the UK, diagnosis is handled by a neurologist before they refer you to a specialist MS nurse. Initially, I found my nurses support invaluable.

The nurse steered me through the minefield of treatment options and support available and even visited me at home a few times while I got my head around it. This was ten years ago though, and budget cuts and financial issues have led to a marked difference in the support offered.

It seems that MS nurses have impossibly large caseloads so trying to get through on the phone is a challenge! If I have a question, I usually email her and get a response a week later so I can't rely on her for immediate emotional support.

She's also offered me three monthly appointments before but the effort involved in parking at the hospital, getting my scooter out of the car and attending the appointment outweigh any benefits of going. It's not her fault, but it's a shame she doesn’t have the time, and I’m glad I’m not newly diagnosed.

I also find the 20-minute appointment every six months with my neurologist inadequate – in terms of support – and usually talk to him about symptoms and treatments options only.

It’s important to remember that reaching or coping with an MS diagnosis is a rollercoaster of emotions for the sufferer and those around them, but once the dust settles there are other stages to go through.

Dealing With Grief and Loss With MS

Although MS isn’t a death sentence, there are still important stages of grief and loss we must go through to reach acceptance of our new normal. We grieve for the loss of everything we used to be able to do and everything we won’t be able to do in future, but with the right support, we can get there.

The Four Stages of Grief

- **Denial** – thinking it’s a mistake or simply refusing to face up to it. I was guilty of this for years and refused to tell anyone at first, so I wasn’t forced to confront it.
- **Anger** – we’ve all shouted, screamed and cried right?
- **Bargaining** – we tell ourselves that if we’re a better person our symptoms won’t get worse or find ourselves praying for a miracle.
- **Sadness and depression** – once it hits us we can feel miserable, and this can lead to depression if we’re not careful.
- **Acceptance**- this is when you come to terms with what’s happened and get on with it!

Finding Emotional Support With MS

So, whatever stage of acceptance you think you’re at there’s emotional support available and I’ve tried most of them.

- **Social media** – I love twitter and facebook groups as I like getting support from real people with MS. When I’m feeling low or have had a great day despite MS sharing this can be good for the soul, and I’ve learned so much!
- **Online support** – find trusted websites such as MS Trust or MS society as they have tips on dealing with MS and accessing support. Online communities such as this are pretty cool too!
- **Support groups** – I have an MS treatment center near me that offers support groups where you can meet people face to face.
- **Friends and family** – talking to people close to you aren’t always ideal. I find I have to manage how they’re dealing with my MS as well as how I’m dealing with it, but sometimes I can get great support close to home.
- **Counselors** – A while ago I realized I wasn’t dealing with MS very well and found myself snapping at my family and feeling generally angry and unpleasant. It didn’t work for me, but I think that was the particular therapist I was seeing and if I’d shopped around more it would have been a more positive experience.

It’s important to remember you’re not alone and finding it hard it inevitable but once you reach acceptance, it gets a little easier.