Raising MS Awareness

by ABIGAIL BUDD

The Importance of Raising Awareness

March is MS Awareness Month and the internet is awash with orange to mark events and awareness campaigns. Social media is such a powerful tool to spread the word about MS and share pictures, stories.

I've always been a bit dismissive of MS awareness campaigns, thinking to myself: "I'm painfully aware of MS, thank you very much!"

That was back when I shunned the MS community though, refusing to acknowledge that I was part of it. Now I think, "If you can't beat them, join them," and I like to be involved.

This got me thinking about awareness campaigns and why they're important. Around 2.3 million people worldwide suffer from this disabling, unpredictable condition and although we, and those close to us, come to understand the beast, it is widely misunderstood among the general public.

MS Ignorance

I remember my own ignorance when I was diagnosed — I'd certainly heard of MS but didn't have a clue what it was. I began climbing a steep learning curve and I'm discovering new things all the time as my condition changes, improves and takes a nosedive whenever it feels like it.

Other people are astonishingly ignorant too. I remember being at a party once and one of the host's friends sidled up to me, eyed me sympathetically and said, "I'm sorry to hear about your diagnosis, my father had motor neuron disease too, you must be gutted." I smiled back wearily, sparing him the embarrassment of a correction. Many people don't know the difference between ALS and MS.

Work colleagues don't have a clue either, and why should they? I was talking the other day about when I used to go swimming four times a week. One lady looked at me suspiciously and said, "Did you have equipment to get you in and out of the pool then?" She hadn't realized that I used to be able bodied and fit!

The worst one is when friends presume I'm going to get worse and worse until I die! MSers need to hang on to the fact that this is not necessarily the case or suicidal tendencies can easily kick in!

Next page: the flaw in many MS awareness campaigns, and reaching ordinary people.

The Flaw in Many MS Awareness Campaigns

So, anything that raises more awareness of MS has to be a good thing then right? Awareness will allow people to realize it's not a death sentence and sufferers can lead full and satisfying lives. The problem with lots of

awareness campaigns, though, is the people they chose to represent the MS community.

It seems to me that the “face” of MS is either the over-achiever who runs marathons to raise money or climbs Everest solo! The other side is images of tragic people who can’t do a thing for themselves and live miserable existences, needing full time carers and being a burden to their loved-ones. Why do these two extremes seem to be the only way to represent MS?

The problem for me as an MSer is I don’t relate to either of these representations of MS. I can’t walk well enough to contemplate running, the results would be carnage. And I can’t lift my legs high enough to climb the stairs, let alone a mountain — but I’m not living a miserable life either! I work, I’m a mother, a wife and a good friend and I make the most of what I can do rather than focus on what I can’t.

The difficulty is that no two people with MS are the same — it’s hard to raise awareness of such a random, unpredictable condition in a way that all of us can relate to. I talk to other MSers all the time and sometimes I don’t recognize the condition they’re describing. Those who can walk normally but are crippled with fatigue or cognitive problems, for example. We have the same condition but totally different experiences of it.

This is what campaigns need to address — the fact that MS can strike in so many different ways and no two people are the same. There are millions of people out there just getting on with life in an unremarkable way, except they live with MS too. Everything is harder for us, from work to shopping to going on holiday to looking after children, but we do it because we have to. We are not heroes or “brave,” we just get on with the cards we’ve been dealt.

Reaching Ordinary People

Awareness campaigns are vital to attract the attention of ordinary people who don’t have a clue about what we’re all living with. Research needs to be funded somehow, so anything that raises awareness has to be a good thing. If this means some of the representations in the media are extreme, then so be it! If that is what gets the attention of the public and makes people more aware, then we have to get behind campaigns and support them.

One day, with enough awareness and support they will find a way to cure, reverse or prevent the effects of MS, and I hope I’m around to benefit from it. So spread the word and raise awareness.