Two Extremes: The Portrayal of MS in the Media

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Representation of MS in the Media

The first time I became aware of multiple sclerosis in the media was watching daytime TV eight years ago. I was on maternity leave with my first baby and was also awaiting the results of my first MRI scan. I was vaguely aware of a lady on a chat show taking about the law on assisted dying and how this needs to be clarified in the UK and other countries.

My ears pricked up when she started describing her initial symptoms of MS. She might have been describing me! It was terrifying. What was worse for me though was how she described how she wanted the law clarified so her husband could avoid prosecution if he assisted her to die, if and when her condition became intolerable.

For someone newly diagnosed it's frightening enough without horror stories in the media. I remember seething with anger at how irresponsible it was to portray MS in this way. I needed hope, not misery.

The lady on TV was UK 'right to die' campaigner Debbie Purdie. I followed her story with interest over the years and was dismayed to find out that she died on December 23, 2014. It was widely reported that she died in a hospice and spent the last year of her life refusing food in order to take her own life. She showed astonishing strength and determination and played a key role in forcing debate about the issue and clarifying the law.

Although I admire and respect her courage enormously, I can't help worrying about all the MSers who have been affected by her story. Do they feel pressure to think about the issue when they might not have such strong feelings and may be quite happy despite their condition? I also worry about the message this is sending to the general public: "MS is so bad that sufferers will want to end their lives." This is simply not true of the MSers I've come across and it's not true of me. I don't identify with Debbie Purdie's story at all.

Another MSer in the media recently was *People's Strictly* contestant Trishna Bharadia who was diagnosed with MS in 2008 but could still dance well enough to compete on national TV. Good for her, but I struggle to identify with someone who can dance that well and seems to have no problems with mobility, balance or foot drop that a lot of MSers face, not to mention cognitive problems that would make remembering the steps impossible.

I can't help feeling slightly bitter about the fact I'd struggle to stand up for the length of the dance let alone be able to do it myself! This representation also puts pressure on MSers who aren't achieving such impressive goals. Are they lazy? Are they unfocused? What message does this send to the general public about MS? "MS is no big deal, get off your backside and get dancing."

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Representing the Middle of the Spectrum

These two extremes can be useful in raising awareness for much needed research funding but I don't find them helpful. They both make me miserable for different reasons, one for the sheer terror of how things might be in the future and one for the able-bodied dancer I used to be.

This got me thinking about how I would like MS to be represented in the media. The trouble with MS is that no two people are the same. You can talk to different people with the same diagnosis who experience the disease very differently.

This is what makes it difficult to represent MS accurately in the media, but I would like to see the millions of people in the middle of the spectrum represented – those like me with mobility issues who still drag themselves to work every day or look after children; those doing normal, every-day activities without asking for recognition or a medal!

I'd love to see MS quietly represented on popular soap operas. A few years ago there was an HIV story line on a popular British soap opera and after the initial bombshell was dropped the character just quietly got on with his life.

Every now and again they revisited his diagnosis and explored issues such as dating or medication, but it sent out a crystal clear message that a diagnosis of HIV is not the end of the world and it doesn't even have to lead to AIDS.

I'd like to see a main character struggle with an MS diagnosis and the journey to acceptance, but then just live with it as we all do without high drama! Maybe the character could live a long and happy life with a few flare-ups along the way, which is much more representative of the MS millions of us around the world live with.

I suppose this kind of representation isn't attention grabbing enough though; it doesn't sell newspapers or get airplay, but it would educate people in a far more responsible way.