



MS, Walking Sticks, Waterboarding and Much More

MULTIPLE SCLEROSIS (MS) is an insidious disease. The changes that it brings about can seriously affect your life, without you immediately realising. For me, the first and possibly hardest change to come to terms with was needing assistance to be able to get around. For context, I was a reasonably fit 50-year old man who would walk approximately five miles a day. I loved to walk.

I've always tried to preserve some sense of humour when dealing with MS and its sackful of issues. I probably laugh at things that I shouldn't, say things that cause friends to look at me and I suspect silently tut. Consultants and nurses roll their eyes, but I usually get a laugh and that's what matters. It's my chronic illness and I'll take whatever pleasure I can from it.

Anyhow, jump ahead a couple of years and I'd started to find walking difficult and falls were becoming more frequent. My legs had stiffened up, controlling them was becoming ever more wearisome. The usual tests; two consultants, plus an MRI and I'm awarded the title of 'MAM w PPMS (Middle Aged Man with Primary Progressive MS)'. Hurray! I remain disappointed that there isn't a badge, some form of certificate and media recognition.

With legs that were always tired, I elected to use a stick to help me keep mobile and hopefully more stable. Rather than burden the NHS and innumerable physiotherapists and Occupational Therapists, who I suspected have better things to do, I ordered

an adjustable stick through the Internet. It arrived and it was reasonably successful in enabling me to walk short distances. Accepting I was now 'MAM w PPMS Who Needs a Stick' was slightly harder to come to terms with. I needed to shake off this pride thing. It seems this is a common experience and is the subject of many 'do whatever you need to do to get by and stay strong' articles all over the Internet. Due to a rapidly weakening left leg, I soon became MAM w PPMS Who Needs Two Sticks. Isn't life grand?

Walking short distances was now possible, although my mean minded MS, probably reasoning that I was getting around far too well with my two sticks (with cushioned hand grips no less), elected to introduce severe vertigo for good measure. So, I now find I'm walking with two sticks across the deck of a ship, during high seas, wearing roller skates. Superb. Incidentally, I was once visiting our Doctor, with my two sticks and severe vertigo, for a series of blood tests. I was discussing weight gain with the nurse and the fact it's hard to exercise when you have two sticks, weak legs, and vertigo, as you do when someone is sucking buckets of blood out of your arm. "Have you tried a treadmill?" says the nurse. Fortunately, she'd finished extracting blood and was concentrating on filling buckets and applying a useless cotton wool bandage to each of my shoulders, so didn't see my wide-eyed stare and, although I do say so myself, magnificent eye

roll, combined with my mutter of 'jesusssssssssss' under my breath. Some people have very little idea of how lucky they are to go home without having been hit by an office chair.

So, MAM w PPMS Who Needs Two Sticks now has a further issue. Stairs. I have come to detest stairs. They have the ability to hurt my knees in a uniquely painful manner. I attempt to minimise this by using my arms on the bannisters to take some of my weight. This only really works on the way down. On the way up it's more a matter of hauling myself along whilst trying to lessen the weight on my legs and the searing pain in my knee joints which it causes. I can't use my sticks as I need to hold on to something, remember the vertigo. I suppose I could try a treadmill...

'You need a stairlift.'

'What is it I now need?'

'A stairlift'

So MAM w PPMS Who Needs Two Sticks becomes MAM with PPMS Who Needs Two Sticks and a Stairlift. Excellent. To be fair, I rate the stairlift as one of the best inventions mankind has ever come up with. OK, there's the wheel, the car, sliced bread, gin, and the Internet but really, I can now get up and down the stairs. It does however come with a few tiny issues.

Issue one, stairlifts are generally designed for the elderly and even more infirm than I. Their operation reflects this. Incidentally, I have nothing against the elderly. Some of my oldest friends are elderly and I hope to survive to join their ranks one day, PPMS permitting. Anyway, I press a button to go upstairs and (pause

to count grains of sand) nothing happens for what I'm told is five seconds. It seems infinitely longer. Nothing, apart from a very loud screech from the unit, no doubt to warn any other passing elderly persons in the vicinity that something is about to happen and that they should dive for cover. This screech is loud enough to hurt my ears. Dogs run down our road to get away from the sound, whilst bats, no doubt attracted by the high frequency, try to get in the windows. Being of a practical nature, I've removed the cover, voided the warranty and unceremoniously jammed an earplug into the speaker. It's dulled the screech a bit, but I can still hear it, as I suspect all the dogs in the neighbourhood can.

Issue two, after the five second delay and the ear drums have perforated, we're moving. As far as I can detect, there are three 'speeds': very slow, slow, and a bit less slow, like my walking these days. When the engineer came to fit and program the unit, I was watching as it made its way leisurely up and down the stairs, configuring the motor for all of the climb and corners. "Can you make it go any quicker?" "Nope, sorry. That's it." I'm in no position to argue. Without it I'm confined to one floor, admittedly it would be one of my choosing.

Third issue, speaking to the company which makes the stairlift. Again, don't get me wrong here, I know they'll have a specific demographic they target for sales and that's grand. What they do not appear to acknowledge is that not everyone who needs a stairlift is stone deaf and has a man with a red flag to walk in front of their car. Indeed, I have the hearing of a bat and until recently owned an extremely large and very fast motorcycle. That

was another casualty of the MS progression. Anyway, I digress. An example would be the call to let me know when the engineer was arriving to install the stairlift.

“Hello, is that Mr Daly?” The lady is speaking clearly, and louder than I would have ordinarily expected.

“It is”. I find myself shouting a little, as if trying to join in.

“Mr Daly, we’re arranging for our engineer Adam (not his real name,) to attend tomorrow. Would you prefer an AM or PM visit?”

“AM please”

“Great, would eleven o’clock be a good time? That should give you plenty of time to get washed and dressed and have your breakfast”.

“Err... OK that’d be fine”. I am not used to this level of interest or consideration. Like most people, I normally have to endure the: “We’re unable to give you a time, am or pm is the best I can do”. Appointment fixed, I wonder if I have time to nip out to get the engineer a gift. Nothing extravagant you understand, just a token.

“When Adam arrives he’ll show you his identification badge. If you’re not completely happy please give us a ring to confirm his ID is genuine. He won’t mind waiting”.

“If I’m not happy I’ll bounce Adam down the drive”.

“I beg your pardon”.

“Nothing. Eleven o’clock tomorrow then”.

You see, everyone must be elderly if they have a stairlift. I’ve done the thing where you ask for a note to be put on your account. You know the sort of thing; please do not treat **Ian** as an elderly gentleman. He is not elderly, neither is he a gentleman.

This makes not a blind bit of difference. It is extremely annoying though until, that is, there’s a problem or you need something.

About a year ago I was cruising up to the first floor, coffee in one hand, motorcycle helmet on, in order to deaden the sound and my finger on the requisite button. I arrived upstairs where I spent some time playing with the Internet and drinking coffee. On attempting my return journey, nothing. The whole thing was as dead as a Dodo. So I telephoned the company to advise them of my dilemma.

“I’m trapped upstairs.” I thought I’d go straight for the dramatic introduction that would raise a level of medium to high panic.

An eminently reasonable and professional sounding lady began to slowly talk me through a list of resolutions that must have previously worked. Not today though.

“Are you able to get downstairs, Ian?”

“Of course”. My sarcasm nerve has now kicked in. “That’s why we spent four and a half grand on a stair lift”.

“I beg your pardon?”

“Nothing, just thinking out loud. Not really, I’m pretty stuck here”.

“OK, there’s something we can try”.

The fix turned out to be opening the footrest and then slamming it closed “as hard as you can”.

“Really?”

“Yes, really”

This I did. Everything lit up like a Christmas tree and the

MS A Funny Thing (well s🤔metimes!)

warning bleep felt compelled to join in. All sorted. Well almost. Adam Not His Real Name turned up the next day to replace the main circuit board, and at a pre-arranged time.

After a lot of inane rambling my message here is that if there's something, anything, which can make your life a little easier, then for the love of God go for it. Walking sticks, crutches, stairlifts, car adaptations, grab rails, false limbs, parachutes, they're all there to enable you to be you, or at least a semblance of you. Use them. Walk or shuffle to the park, point at pigeons with your stick, make sarcastic comments to call centre staff. The possibilities are endless. Life with MS is hard enough.

I was showering the other morning and dropped the soap. Such a trivial thing for a non MAM with PPMS. It's only a small shower cubicle, so I bent double to pick up the soap, slipped and became wedged, corner to corner and, to all intents and purposes, upside down. It was like being water boarded. If it wasn't for the grab rail I'd have probably drowned. How my partner and I laughed.

Ian Daly.

A Middle Aged Man with PPMS Who Needs Two Sticks, and a stairlift, and a non-slip mat in the shower, and grab rails in said shower, plus a grab rail to get on and off the toilet and a stool for the shower.