

Losing Control

Hiya as the title states, this is what it feels like sometimes and yesterday was no different. Elaine asked me to sit down and help fill in a large form concerning direct payments for my care. I wasn't too sure what it all meant (and to be honest I'm still not 100% now)

As Elaine started to ask me the first few questions it quickly became clear that we both have a different view of this disease. It was questions all about my personal care, safety assessments and the likes and the big question about being left on my own for too long.

I could feel myself getting more emotional as it soon became very very clear I wasn't as Independent as I thought I was. I could hear myself saying "Of course I can still do that!! Of course I can still do this, to which Elaine would reply gently "When do you think you last did this and that? Sadly her answer was a million miles away from mine. I could feel the concrete overcoat (my depression) descending over me like an unwanted friend who calls at the most inopportune time. I suddenly realised that things weren't quite as good as I thought they seemed.

By the end of it, if I am brutally honest, I felt totally useless at the thought of being unable to do some of the most menial tasks, and yet, according to Elaine I hadn't done them for some time anyway!! When you are diagnosed NOBODY tells you that you have to go through this!! Nobody tells you that when you thought that your world had some kind of stability that it would be ripped from under you, more than once and all this had to be dealt with at some stage.

I regard myself as a very lucky man, even with this awful illness, because Elaine and me are just not lifelong partners and soul mates but we are also the best of friends, and we talk, we talk openly and honestly, always have, so this was no different. Probably a good thing as well as I couldn't imagine anyone else being as honest with me, and me taking it as well as I did (If you can call it that) Without a doubt, if it had been anyone else telling me all hell would have let loose!! Then came the heartache and tears, floods of them, I felt as if I had stepped over the line and there was no coming back from this. Was this the point of no return or not?? Well, what do you think?? Once I had stamped my feet YET AGAIN!!! And threw

Thoughts by Norrm's Mcnamara

my usual tantrum (yes even I have them LOL) Elaine explained to me that by doing all this and sorting all this out, my future wasn't set in stone (As they WILL FIND A CURE one day !!) but my future was a little more secure and it was one less thing for "My Angel" to worry about.

Admittedly it has taken me a little time to come to terms with this as a voice in my head keeps shouting "I AM ONLY 53!!" and will take a bit more time to get used to, but one thing I have learned and would like to share with you all is, when the time comes for you to face the same dilemma please take care and think about how you are going to deal with it. It needs careful wording, compassion, a lot of listening after, and most of all a whole lot of love. What you are about to say is absolutely devastating, I know, but at least I am lucky enough to be able to tell you how I feel about it, some are not that lucky. BUT!! That doesn't necessarily mean they haven't understood what you have told them, please remember this, I hope this helps, very best wishes, Norrms and family xxxxxxxxx

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