

NOTES FOR PRESENTATION WITH PETER NORTH AND GILLIAN FRY AT BRAIN DAY, 23 MARCH 2013 BY DUILIA RENDALL.

Multiple sclerosis is a funny disease so I often think how fortunate I am to have a good sense of humour and a well developed sense of the ridiculous especially in my day to day life. With the symptoms so varied and of greater or lesser duration, what is possible one day may be impossible the next. And when you add in the fact that our brains and dream lives so often do not coincide with reality, the person with multiple sclerosis (pwms) can have some fun just living. As an example, I spent three hours trying to put down masking tape on teeny tiny area that needed a few addition brush strokes of paint. What between balance problems, legs not working etc getting to the floor was number one problem, followed by number two problem, the tremor which immediately appeared in my hand to ensure that the masking tape could not go down straight. I ended up laughing as my neighbour did it for me in about five minutes! And don't ask me about the number of times I have dreamt about vacuuming, washing floors, tidying cupboards when (praise be) I haven't done these things for nigh on fifteen years.

The person I am today is due, I believe, to the beneficial effects of disease modifying drugs. I have now been on one drug or another for more than ten years and can testify to a slow but sure improvement in almost every aspect of the effects on me of ms. For the first three or four years I was on a drug called Beta Interferon which I injected every second day into my skin – sub cut to the knowledgeable, but otherwise known as a subcutaneous injection. I managed this for a few years but then developed reactions at the injection sites which took weeks to heal. As a result I became loathe to continue injecting myself, so the wonderful, kindly and ever helpful district nurses began giving me my injections.

I now use a drug called Avonex which is given by way of a weekly intramuscular injection. I see a district nurse once a week who comes to give me my injection. I believe that I am most fortunate to be on a disease modifying drug as it has (over time) cut the attacks of ms, reduced my symptoms to a more than manageable level and allowed me to have a very near normal life..

The path to diagnosis can be long and tortuous. I thought I must be the world's greatest hypochondriac or going mad when the path from initial symptoms was to diagnosis took about thirty one years. I felt joyous relief when told I had multiple sclerosis, an explanation for the myriad of symptoms I had had over the years.

One current concern though, is that with the earlier diagnosis, some individual pwms are making life altering decisions which are sometimes justified but sometimes not. I do not envy those learning in their twenties that they have ms, when the reality is they may well have a near normal life. Still again, they may not. Unfortunately, no-one, not our doctors, specialists, nurses or our field workers can tell us what the future holds.

Peter will be talking about symptoms and how he copes with them but I would like to say a few words about fatigue, a symptom I have met with a number of times. With fatigue, you may need to rest sometimes up to twenty hours a day. It is more than being tired. It is being exhausted by the effort of going to the toilet, let alone showering and dressing. I was often too tired to read and sometimes it seemed too tired to sleep even. (Now there's a contradiction, but that's how I felt.)

However effective for me disease modifying drugs have been, I would not get by without the assistance of many, many people. My daughter, her husband and my grandchildren are the top of my list, but my friends and neighbours, my care givers, the ms field workers and even people such as the taxi drivers, all contribute hugely to me living independently in my own home.

Thank you.