

## Life changing MS diagnosis hasn't stopped Waterford woman

When Passage East woman, Karen Doyle, started to experience tingling down the left side of her face and ear, she explained it away as being part of working in a call centre and having to use a headset during the course of her work. Around the same time the avid walker started to notice her balance wasn't what it should be, again explained away by thinking it was her runners. "I was feeling really unwell. I couldn't pinpoint exactly what it was. That was going on for a few months. It wasn't going anywhere. It was constantly there and it was really strange. I remember thinking are my features changing? Is this just a phase in life that you go through? This went for maybe 5 months."



Karen Doyle

It wasn't until the itching in her left arm became so unbearable and a friend suggested that she go have it checked out that the realisation that there was something more serious happening with her body started to unfold. In October 2015, the results of an MRI scan, catapulted the then 36-year-old Karen into a whole new world, as she received a diagnosis of Multiple Sclerosis (MS). Not knowing what this meant or how it would affect her life, Karen describes the time around her diagnosis as 'isolating, lonely, confusing and worrying.'

"I knew nothing about MS. I knew the term and that was as far as it went. I was given steroids intravenously for three days. I really thought that was it. I just wasn't aware of the enormity of it at all but my left arm had lost pretty much all use. I wasn't driving. I didn't drive for 8 months at this stage."

"The MRI showed that there were lesions, which I had no clue what that meant. It was a very surreal moment. I was admitted to hospital and a lumbar puncture was taken that evening. It was confirmed from that it was MS. I could hear it being said but it felt outside of me."

In the weeks and months that followed Karen learned to self-administer medication and she slowly started to adjust to living with MS. "I went through a tough tough time. A nurse came for five weeks to help me to get used to injecting. I went through an awful two years. I wasn't sure if I was doing the right thing or the wrong thing. I had five days of side effects and then knowing that I had to do this again in two days. I would feel really dizzy, weak and nauseous."

The neurologist was really slow to make a change to Karen's medication until he could see an MRI. "Twelve months after I was diagnosed Dr O'Connor ordered an MRI and I'm still waiting. That was December 2017."

"I did not want to go and jump the list in a public hospital because I was lucky enough to get a loan to do it privately. That's why I went to Whitfield. I made a conscious decision about that. I think a two tier health system is just horrendous." In October 2018 Karen had her second MRI at a cost of €400 and only a two week wait. At that point she was waiting nearly two years on the public system. "The second MRI showed that things were balanced. The lesions weren't active. So it would seem that the hard two years of medication was worth it," she said. The MRI gave Karen reassurance and peace of mind to know that her MS is remitting rather than relapsing and she continues to take medication.

## **Living well with MS**

Having almost completed her Masters of Cognitive Behavioural Therapy and Motivational Interview Practice through WIT part-time over two years, Karen has learned to live with her MS and not allow it to define her. "I walk a lot. I eat well enough and relax."

"I was studying and working part-time when it all began. I had to give up everything. I had to deregister from doing my masters. It was heartbreaking. The second year after being diagnosed I applied again but I knew I wasn't well enough. I am really determined to carry on but sometimes the condition takes over. I felt lucky to be able to go back to college this time and it's part-time and they are so supportive." Karen also attends the weekly yoga session run in conjunction with MS Ireland, "I feel that yoga has become my support group. It's a group of people who have one tiny thing in common and at the same time there is so much more to that. It's just so relaxing, it's lovely just to appreciate the things that you can do. It is after strengthening me and improving my posture and just helped me physically."

## **Newly diagnosed**

To people who have recently been diagnosed with MS, Karen has this to say, "first of all stay off the internet. No Dr Google. MS Ireland is the recommended website to get your information from. You are already overwhelmed and we all learn and do things differently. Sometimes it's just too much. "Don't go through it alone. Loved ones and friends and family are great if you're lucky enough to have them. Either way reach out. Talk to somebody. It could be the community worker, it could be counselling. Just talk to people. It might be a case that I'll get on with things but in the background it's there." "I was very

aware that I needed to be strong for everyone else. I was very aware on the affect this might have on other people, like my mam and my friends. It's been tough for my mam. She has been so supportive. Family and friends have taken a lot of the daily stresses away for me. They have sheltered me from financial stress and I am very grateful. Without them I wouldn't be doing as well."

## **Service deilivery**

Speaking about the need for change in service deilivery for people with MS, Karen feels very strongly about a number of issues. "Delays with MRIs are going to have huge consequences. People don't know if they are on the right medication. People don't know if the medication is working."

In terms of supporting people to live in their own home as people's needs change, Karen feels that, "home support really needs to be improved. It is the first preference for most people. The most expensive care is all that's available. Carers have to do so much in such a short space of time. To try and build a relationship with someone who is already vulnerable."

She also feels that "Fair deal needs to be expanded for home care - it shouldn't even be up for debate. Why should the most expensive insitulionalised care be the only option if you're at that point. Where's your autonomy?"