

# Living a meaningful life after a multiple sclerosis diagnosis



MARY O'CONNOR

**When Shona McEachern was diagnosed with multiple sclerosis in 2019, she found it very difficult to tell her family and friends. She was worried the news would upset them or that they would treat her differently. Most of all, she did not want to see pity on their faces, she says.**

At that stage, Shona, then aged 59, who is from the Scottish Highlands but now lives in Galway, was walking with the aid of a stick.

"I remember visiting a cousin in hospital and telling her I had a 'form of MS'. You either have [MS] or you don't! I was just trying to soften the blow. [Another time] I was at a friend's birthday party complete with my stick, and told everyone that I had a problem with my ankle (which was true, in part). An old friend, who knew me well, said: 'Come on Shona, what's actually going on?' Normally, I'd have been up there on the dance floor but my balance prevented it."

She had been experiencing symptoms since at least 2015. "Looking back, I had had a few trips and falls and tingling in my right leg after driving. I was forever adjusting my car seat thinking that was the issue. With the gift of hindsight, I'm so glad I didn't know what fate awaited me."

She and her husband were living in the UK then. They moved to Galway in 2019 after he was offered a position at the then NUI Galway. "Literally two weeks after that, I developed foot drop - I was walking with a very pronounced limp in my right leg. My MS playing his tricks and wreaking havoc with the future we had planned."

Initially, her GP thought it might be a trapped nerve in her spine. "I waited seven months to see the NHS

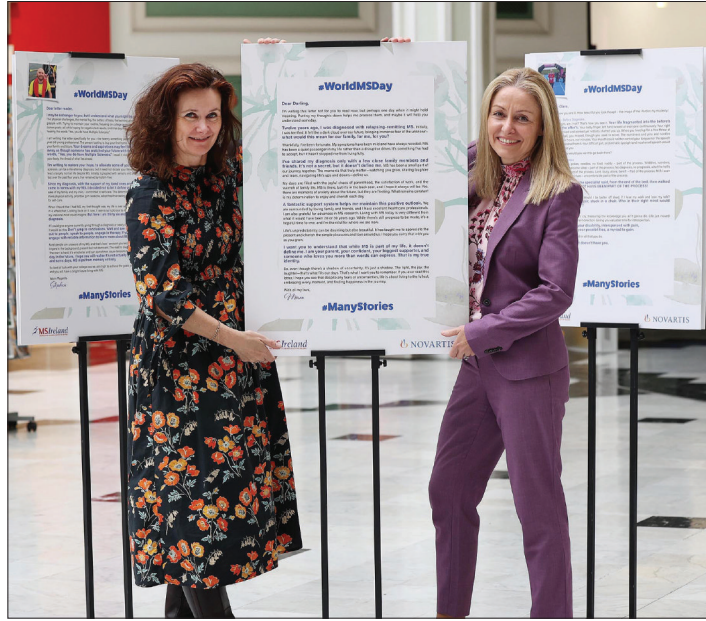
specialist as they also queried an undetected broken ankle. I spent a fortune on private physio before seeing the NHS consultant who ruled out the ankle but thought it might be a trapped nerve. It was at this stage I first heard the words 'neurological' mentioned. It could be many more months waiting to see the NHS neurologist, so we decided to go private."

She was diagnosed in the UK with primary progressive multiple sclerosis, which is quite rare, on July 4, 2019 following tests, X-rays, and a series of dead-ends, she says. "The irony of the date of US Independence Day was not lost on me! I was just shy of my 59th birthday when diagnosed which is pretty old for an MS diagnosis. Thankfully, I was not aware how great my loss of independence would be. Even for that type of MS, mine is particularly aggressive."

## Choppy waves

Shona, a university graduate who previously worked as a librarian and archivist at the Royal Observatory of Edinburgh, before relocating to South Wales to work as an advocate in residential care settings, says she was relieved to get a diagnosis. "I know that many of my MS friends in Ireland had felt the same reaction. I compare it to sitting in a boat with waves gently lapping at the sides. I'm no longer directionless, I know what course I'm steering in but I've no idea how choppy those waves can get."

She has gone from being "fiercely independent" to being "totally dependent" on personal assistants (PAs) who call to her home four times a day. "The bulk of my care rests with my poor husband and for that I feel intensely guilty even though I know it's all down to a condition which I have no control over. Gone also is my immersion in nature through my hour-long dog walks, for which my aged dog is intensely grateful! Gone, too, are the days of forcing myself to the gym three times a week. I think that's a plus, although I miss coffee and cake with friends afterwards."



**Susanne O'Reilly, country communications, public affairs and advocacy head at Novartis (left) and Ava Battles, the chief executive of MS Ireland, pictured as MS Ireland and Novartis hosted a letter writing display earlier this week ahead of World Multiple Sclerosis (MS) Day 2024, which takes place today (Thursday). As part of a new campaign, called 'Many Stories', six people with MS reflected on their experiences of diagnosis by writing letters to friends and family to thank them for their support.**

Shona is sharing her story because she is keen to make people aware of what it is like to live with MS. She is determined it will not defeat her, try as it may. She says the "positives" the condition has brought into her life are "precious".

"Finding out the true nature of friendship - who has been there for me and who hasn't. Love of family which has dug deep and shown me love beyond compare. Strangers who have become supportive friends. Unbounded joy, love, and laughter, particularly my wonderful PAs who have opened up a whole new world to me through their many kindnesses that go beyond the call of duty."

"My diagnosis more or less coincided with lockdown and the emergence of the power of Zoom. As well as being an aid to keeping in contact with friends and family, it linked me with others, who, like me, have had MS thrust upon them. I truly value their support and friendship and for bearing with me as my condition deteriorated, especially my speech. Only they, truly understand what living with MS is truly like."

The 63-year-old, who

loves nature, reading, and socialising with family and friends, says everyone's MS journey is different. "I've been unfortunate that it's totally impacted on my daily life and that of my husband. Until recently, there has been no real treatment for my type of MS. I was amongst the first to be given Ocrevus treatment in the UK and continue to receive it now that it is available in Ireland. The jury is still out on its success."

Her advice to anyone newly diagnosed with the condition is to take each day as it comes. "Don't compare yourself with others - their journey will be completely different. Embrace and acknowledge the positives, for there will be many. You'll be amazed at how strong you can be. Reach out for the support on offer and don't hide away from the world or let that pesky MS rule your life. There is still a fulfilling life post-diagnosis."

## What is MS?

Every five minutes, someone in the world is diagnosed with multiple sclerosis. The people who get this life-changing news are usually aged 20 to 40 years and are three

times more likely to be women. More than 10,000 people in Ireland are living with this complex neurological disorder which affects the central nervous system (CNS) - the brain and the spinal cord.

The CNS controls the motor, sensory, and cognitive functioning of the body by processing and transmitting messages through a network of nerves. These are covered by a fatty substance called myelin, which helps to conduct the messages. MS develops when the body's immune system mistakenly attacks the myelin, thinking it is a foreign substance.

In normal circumstances, the body is able to distinguish between its own cells and those that have invaded the immune system. However, in some circumstances, it is unable to recognise one from the other and begins to attack the body's healthy cells. While the initial attack may not last long, scar tissue forms over the area. This can be viewed as the white spots on an MRI scan, commonly referred to as plaques or lesions.

The time around

diagnosis can be difficult and emotional, according to MS Ireland, which provides a range of services to thousands of people with MS and their families.

"Prior to this, there can be a lot of frustration due to unexplainable symptoms. You may have gone to the doctor with something you think can be treated easily. Instead, a long agonising wait and a batch of tests confirm MS. You may have put 'multiple sclerosis' into an internet search engine and read lots of information that may have increased your anxiety. You may also have done this all on your own and now are now wondering who to turn to for support."

Discovering you have MS can give rise to many feelings. Some people are shocked or angered. Others feel relieved that they know why they have been unwell and are able to start dealing with it. Some more, deny that they have this condition, which affects over 2.9 million globally, and try to carry on as if nothing has happened.

All these feelings are normal; it is part of coming to terms with the diagnosis, says a spokesperson for MS Ireland. "Go with the feelings and take your time to let your diagnosis settle in your head. However, many of these feelings and reactions can be damaging in the long run so at some stage you may need to find a way to accept your MS and decide how you can manage it. This process may take weeks, months, or, for some, years."

Some of the symptoms of the condition are immediately obvious. Reduced mobility is often the most visually apparent. Others, such as fatigue, changes in sensation, memory, and concentration problems are often hidden and can be difficult to explain to others. These symptoms not only affect the functioning of your body physically, emotionally, and cognitively, they can also affect your work, family and social life.

While treatments exist, there is no cure for MS. Managing symptoms is not just about drug treatments, many people find a healthy lifestyle

also helps. A balanced diet, appropriate exercise, and minimising stress can give your body and mind the best chance to deal with symptoms. Some people with MS find complementary therapies helpful. Many of these promote wellbeing holistically; the focus being on the person and not just the symptoms. MS Ireland recommends that people speak to their doctor before starting any alternative therapies.

## Where to go for help

MS Ireland provides in person and online services to people with multiple sclerosis and their families. These include a community worker, wellness and symptom management programmes, exercise and physical activity courses, information, advocacy, and research services, and respite care at its MS Care Centre.

The MS organisation is spearheading a new campaign called Many Stories, which is supported by the pharmaceutical company, Novartis. Five people with MS wrote letters to family, friends, healthcare providers, and decision-makers to heighten awareness about the condition by sharing their personal journeys. The letters are displayed today (Thursday), which is World MS Day, at St Stephen's Green Shopping Centre in Dublin. MS Ireland is encouraging people to join in, express their thoughts, and tag MS Ireland on social media at 9.30am, 1.30pm, or 5pm.

MS Ireland is also hosting an information event, supported by Novartis, which will explore the uncertainty that often accompanies an MS diagnosis. The talk will feature expert insights from neurology and psychology experts as well as a personal perspective on moving forward in life after challenges, including an MS diagnosis. The event will be live streamed on Facebook live - <https://www.ms-society.ie/world-ms-day-information-event>

For further information, telephone (01) 6781600 or email [info@ms-society.ie](mailto:info@ms-society.ie)