

Media review



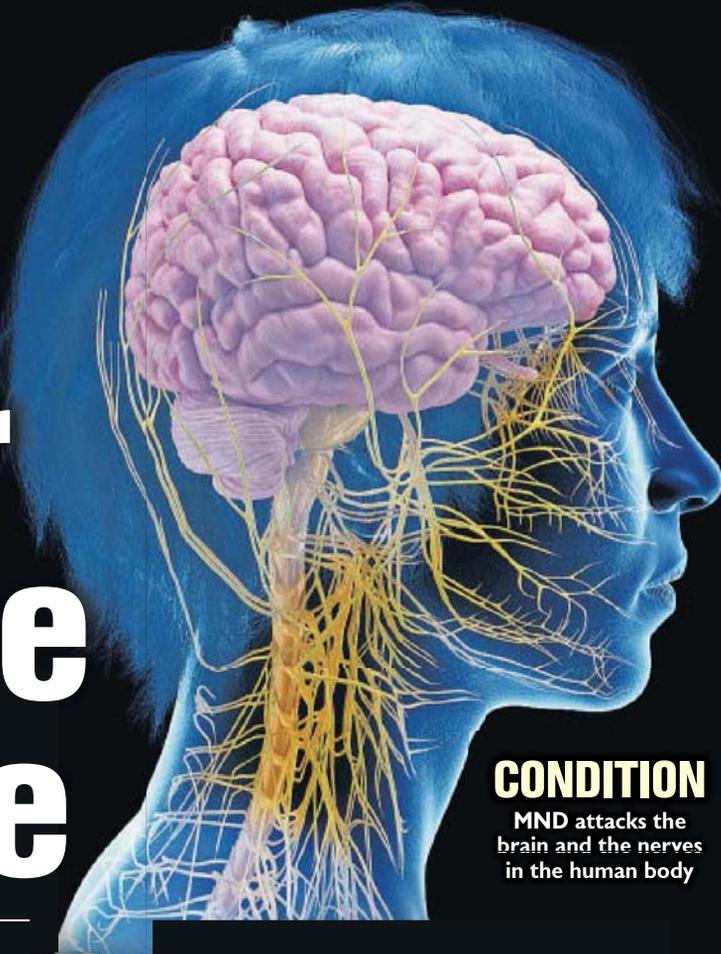
Table of contents

Life with motor neurone disease
The Sun (Eire) - 05/03/2024

3

PATIENTS ON ILLNESS DIAGNOSIS

Life with motor neurone disease



CONDITION

MND attacks the brain and the nerves in the human body

ONE Irish person is diagnosed with motor neurone disease every two days.

That is the stark figure from the charity that represents the 450 people currently living with the condition in this country.

TV presenter Charlie Bird, *left*,

has been public about his battle with the condition, and Coronation Street fans will have watched as the disease continues to affect the character Paul on the show.

The Irish Motor Neurone Disease Association has launched their nationwide campaign to raise awareness and funding – Drink

Tea for MND. It asks people to host a tea morning and help pals and colleagues understand that many of those with MND can no longer do the simple things such as have a cup with friends.

Here, two Irish sufferers tell The Irish Sun about their respective experiences with the condition.

OLIVER JOHNSON

‘I was shell-shocked. I knew nothing about MND before then’

OLIVER, 48, had been working for Irish Rail for 25 years when his symptoms first started to show.

He was an intercity train driver and it was at work he noticed the first telltale sign.

Oliver explained: “I was experiencing some weakness in my right hand when writing for work.

“Following two GP visits and an MRI, I was getting worse, and around the time of Storm Debi in November of 2023, I was given a diagnosis of motor neurone disease. You could say the real storm had just begun for me.

“I was shell-shocked. I knew nothing about the disease and how it would affect me. I was never sick before, I had my appendix removed as a teen but never ever had anything worse than a cold or a flu or a sore back.

“Today, just a few months on, I have a lot of weakness in both hands continuing up into the arms. The simple things we take for granted are no longer simple, like putting on socks, getting dressed, opening bottle tops,



zips, buttons, laces, turning a key, brushing your teeth, putting gel in your hair – these are some of the negatives.”

Dad-of-four Oliver was a train driver at the Westport station in Mayo until he stepped down in September last year. He is of a fourth generation working on the rails and now his twin sons, Aaron and Dylan, are following in his footsteps.

But while the diagnosis has affected every aspect of his life, he is determined to focus on the positives.

He said: “I can still walk, I can still drive, I can still plan for the weeks and months ahead. I’m getting married next month and planning a holiday in March.

“My dream always was to do Route 66 and I hope to accomplish that this year too.

“My life has been good, I have wonderful parents, five brothers and a sister, four great sons and a loving, caring, strong fiancée who will soon be my wife.

“There are many wonderful things to keep looking forward to in this life, so I’ll stay strong and stay positive and battle on for me and my family.”

DIARMUID HICKEY

‘Every day brings new challenges – but we get through it’

DIARMUID, 56, is a deputy principal at Cork’s Coachford College, where he has worked for 32 years.

Before his diagnosis, he led a very active lifestyle and had completed 20 marathons before the pandemic hit.

But in January 2022, he started to notice difficulty getting his right hand to do simple things, like use nail clippers or clothes pegs.

That led to a weakness in his shoulder, but tests on the GP seemed clear.

It was a neurologist in Kerry who eventually confirmed he had MND.

He said: “I took the decision to continue working for the time being, bearing in mind the advice ‘don’t make big decisions when big things happen’.

“I am conscious that the nature of my job allowed me this choice and not everyone is afforded this privilege.

“My life continued pretty normally for the 2022-23 school year with the gradual failure of my right hand and a slight limp being the main symptoms.

“There was considerable progression over the

next summer, particularly in my back, and I returned to school in August with a walking stick.

“I didn’t return to solo teaching, unfortunately, but have adapted well otherwise.

“I became slower and slower, and then when I requested it, the fairy god-mother that is the **IMNDA**, provided me with the use of a powered wheelchair.

“I am back on the corridors with a vengeance. The chair was named ‘The Hawk’ in honour of the late, physicist Stephen Hawking.

“We are lucky that the whole family is in Ireland. We take every day as it comes and make it as good as it can be.

“Every day brings new challenges, it’s the nature of the beast that is MND. It is all about finding silver linings, day by day, week by week, and they’re there.”

● **TO** support the **IMDNA**, their website, **imnda.ie**, has information on how you can host a tea day, or if you can’t organise one, you can also donate €4 by texting **MND4** to 50300.

