



# MS *news*

Autumn / Winter 2020

Issue  
109



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Celebrity Ultimate  
Hell Week



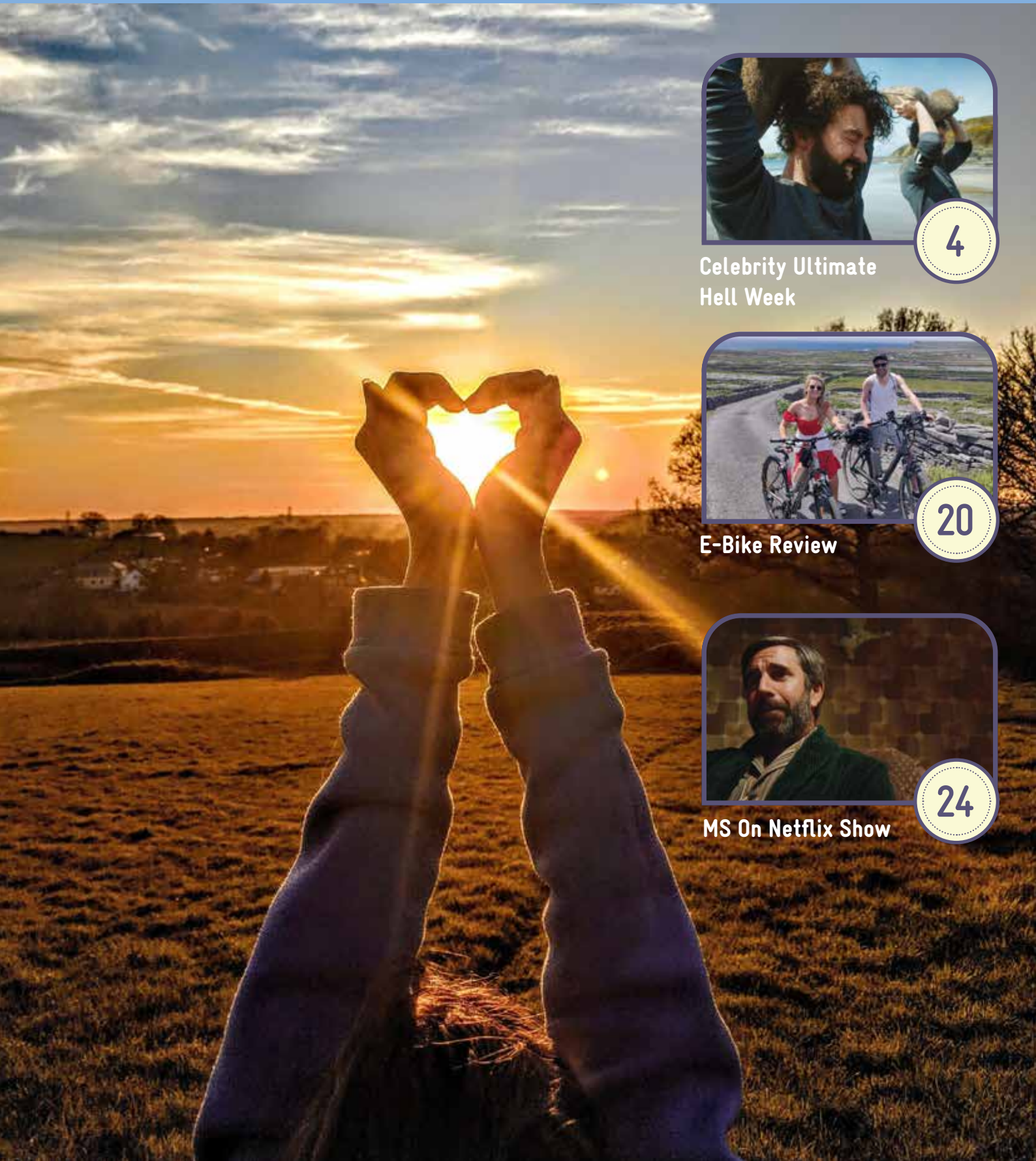
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E-Bike Review



24

MS On Netflix Show





Dear Friends,

At the beginning of the COVID-19 pandemic, MS Ireland had to adapt some of the projects that we normally work on. The pandemic had an impact on our ability to carry out various fundraising activities and this resulted in a decision to scale back some of the projects we normally work on to ensure the sustainability of our organisation. One of those projects was MS News. We decided to share MS News in digital format only, in 2020 but are happy to be returning to physical print as we know that some of you may not have access to the internet. MS News uses considerable resources in terms of creating, printing and posting. We are currently reviewing this part of our work and assessing its relevance to our community. We would love to hear from you on this. On **page 35** you will find a short survey which we would greatly appreciate you completing and returning to us. Alternatively, you can email your feedback or suggestions to the editor, Aoife Kirwan – [aoifek@ms-society.ie](mailto:aoifek@ms-society.ie).

From various consultations with our community we know that there is value in sharing personal stories about living with MS. In this edition, we have created extra space to give people living with MS the opportunity to share elements of their stories and details of their activities with us. You will find personal pieces on **pages 14, 20, 24, 28 and 31**. Additionally on **page 11** we have a piece by a young writer in their early teens which explains their perspective as a child of someone living with MS

As we face into yet another year with COVID-19 we have provided a summary of where we are now regarding risks, vaccines and protecting ourselves and others from the spread of the virus. This can be found on **page 12**.

While 2021 has been challenging in many ways, there were some good news stories and positive developments for the MS community this year including positive reimbursement outcomes, the expansion of services in some areas and even the establishment of the All Ireland MS Research Network. Details of these can be found from **page 4 – 10**.

In 2021 we have also been blown away by the incredible support from our community. Details of some of the extraordinary challenges people took on to support us as well as some of the wonderful sponsorship we have received this year can be found on **page 32**.

In this edition of MS News, we want to make our content more interactive, engaging and accessible. To do this, we are trialling the use of QR codes. There are a series of little black and white squares, similar to a barcode. To use the QR codes, simply open the camera on your smartphone. Hold the camera over the code as if you are going to take a photo of it – ensure the four corners of the code are visible on your screen. Your phone should automatically scan the code and provide a link which you can click, taking you directly to the item we provide the code for!

In the coming weeks our Information Line number is changing. The service will remain the same but you will need to use the new number. As of January 1st 2022, you will no longer be able to use 1850 233 233 instead you will need to dial 0818 233 233.



**Ava Battles**  
**Chief Executive**



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'MS News' is the magazine of MS Ireland. It exists to foster informed debate and comment about all issues relating to MS. The view of contributors are not necessarily those of the Society. No treatments or therapies should be attempted or products used without qualified medical or professional advice.

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## CONNECT WITH US



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## Celebrity Ultimate Hell Week



MS Ireland was delighted that Weatherman and TV presenter, Deric Ó h'Artagáin took part in the latest series of Celebrity Ultimate Hell Week on RTÉ one. Celebrity Hell Week takes a group of celebrities and places them in a series of gruelling exercises and challenges used as a test for those entering military service.

Each participant represented charity of their choice and we were thrilled that Deric chose to support MS Ireland. The series, which was recorded in West Cork and its surrounds followed 18 well known Irish personalities as they were put through a series of difficult tasks typical of the special forces selection process.

During each episode, the public were encouraged to support one of the 18 chosen charities by donating €4 to the charity selected by their celebrity.

Our many thanks to Deric for taking on this very difficult challenge to support our organization. Deric displayed amazing courage, bravery and resilience through Celebrity Ultimate Hell Week and we were blown away by his determination.



## MS EXPLORED THE PODCAST

**IN SEPTEMBER**, MS Ireland in collaboration with Novartis launch a podcast series to support people living with multiple sclerosis in Ireland. Hosted by MS Ireland's Aoife Kirwan, the series features top healthcare experts including as well as people with lived experience of MS. Three episodes were released, covering important topics relating to the life of someone living with MS and potential challenges. Below is an outline of each episode in the series.

### Episode 1: MS the journey

A diagnosis of MS can be overwhelming, and the treatment journey is different for every person with MS. In the first episode of MS Explored – The Podcast, host Aoife Kirwan is joined by Consultant Neurologist, Dr. Lisa Costello and Laura Lee who was diagnosed with MS ten years ago, to break down a diagnosis of MS, discuss what the future might look like and how to best manage the condition.

### Episode 2: Family Life & MS

Having MS doesn't just affect the person living with it, it can hugely impact the lives of families and loved ones too. In this episode of MS Explored – The Podcast, Aoife Kirwan is joined by Sharon Henvey who is living with MS, MS Fellow Dr. Maria Gaughan, MS Nurse Specialist, Sinead Jordan and Clinical Psychologist Dr. Eddie Murphy to explore the challenges faced by people living with MS and how they can communicate their diagnosis to loved ones.

### Episode 3: Work and education

Living with MS can have a big impact on work-life and/or the education journey. In this episode of MS Explored – The Podcast, Aoife Kirwan is joined by Lauren McCauley and Keith Byrne who are both living with MS, and by Career Psychologist Sinead Brady to discuss the supports and resources that are available to people living with MS, as well as tips on how and when to talk to your employer about your diagnosis.

The podcasts can be found on MS Ireland's website, or wherever you normally listen to podcasts.

## WORLD MS DAY PODCAST

To mark World MS Day, the Mid West Region released three podcasts in which three people living with MS reflect on their experiences since being diagnosed with MS. They offer insights into how they have learned to deal with symptoms and they reflect on how their connections within the MS community have helped them.

### EPISODE ONE

In the first episode, Clare spoke about her newly-diagnosed self and the lessons she has learned in the 20 plus years since diagnosis. What has helped, who has helped and what she has learned to dismiss. She talks about her MS related challenges and the importance of connection.

### EPISODE TWO

In the second episode, Seamus likens his journey with MS to a battle and explores his resolve in managing the challenges that arise for him on an often-daily basis. He speaks of the impact of MS on his worth as a person, and as a father. He reveals what supports him to keep going, and the lessons he has learned in the 16 years since diagnosis. He shares how his connection with himself through art and poetry has also been a platform from which he can reach out and connect with other people living with MS, sharing his experiences and learnings.

### EPISODE THREE

In the third episode, Shirley talks about her MS diagnosis 4 years ago and the emotions and feelings that went with it. She talks about the impact her diagnosis had on those closest to her, as well as the reactions of people in the wider community to her diagnosis. She reflects on how she coped with peoples' reactions and also how she adapted her work and family life to accommodate her symptoms. Shirley also discusses the advice she would now give to her newly diagnosed self and the importance to her of following her own path and finding the right supports suited to her individual needs.

## UNDERSTANDING MS@WORK

Understanding MS@Work, a dedicated resource for people living with MS and their employers to become more informed on the daily impact of MS was recently released. A survey conducted by MS Ireland this year revealed the impact of COVID-19 on employment, and how working life with MS can be better understood by employers. 80% of people with MS said the way they work has changed as a result of the pandemic.



**Simone Feresin, Roche Products, John Lee, Teacher Donahies Community School and Ava Battles, CEO MS Ireland at the launch of Understanding MS @Work**

9 out of 10 people (90%) living with multiple sclerosis (MS) in Ireland say that the COVID-19 pandemic has helped, or could help, steer conversations with their employer about how working from home could benefit them in the long-term. The survey results also showed that (64%) of respondents say that working from home has benefitted them over the past 18 months. Although the majority of respondents (85%) say that their employer knows they are living with MS, more than one-fifth (21%) of respondents cited 'lack of understanding/empathy' as the issue that most impacts their working life.

Understanding MS@Work, which is supported by Roche Products (Ireland) Ltd., aims to encourage and enable people living with MS to have beneficial conversations with their employers about their working environment. Videos of people with MS talking about their careers and their conversations



with employers have been created along with advice on working during the pandemic. Sections have also been developed for employers so that they can become more informed and aware of the potential challenges faced by people living with MS and emphasize the benefits of providing a flexible work environment for employees with MS and other chronic conditions.

For more information about MS and to learn more about working with MS visit Understanding MS@Work here: [www.ms-society.ie/understanding-ms-work](http://www.ms-society.ie/understanding-ms-work)

## LAUNCH OF NAI REPORT ON ONLINE SERVICE PROVISION ACROSS NEUROLOGICAL CARE IN RESPONSE TO COVID19



On World Brain Day, 22nd July the Neurological Alliance of Ireland (NAI) launched their report on online service provision across neurological care services. When the pandemic hit in 2020, many services moved online resulting in significant changes for both service users and service providers. The survey aimed to examine the experiences of online service provision within neurological care services in response to COVID-19. The report is a culmination of a series of investigations and engagement with various stakeholders including service users and healthcare providers.

### The survey found that;

**75%** of service users said they would use online services into the future

**74%** of service users would like a combination of face-to-face and online services going forward

**26%** of service users said poor broadband was a barrier in accessing online services

**60%** of NAI member organisations provided an average of 60% of services online compared to 8% pre-COVID

The full report including observations and recommendations can be found here:

[www.nai.ie/assets/2/3E0C2446-80E4-4825-9CE95636F81C30B8\\_document/Online\\_Report\\_FINAL.pdf](http://www.nai.ie/assets/2/3E0C2446-80E4-4825-9CE95636F81C30B8_document/Online_Report_FINAL.pdf)

## PROF. ALAN THOMPSON CHARCOT AWARD



**Winner of the  
2021 Charcot Award**

**Professor  
Alan Thompson**



MS Ireland was delighted to congratulate Prof. Alan Thompson on winning the 2021 Charcot Award. The Charcot Award recognises a lifetime achievement in outstanding research into understanding and treating MS. Prof. Thompson who is the Dean of the Faculty of Brain Sciences at UCL in the UK, is a long-time supporter of MS Ireland who has focused his 40-year career on the care and treatment of people living with MS.

He is a leader in research efforts, especially in progressive MS. His work has helped to understand the complexities of progressive forms of MS. Prof. Thompson has been involved in advances in rehabilitation strategies, developing measures for a number of symptoms such as spasticity and pain as well as the impacts of disability. In addition to being an impassioned advocate of the voice of people impacted by MS. Prof. Thompson has led as a teacher, mentor and advisor on a global level. He has served on multiple national and international scientific boards and committees including the International Progressive MS Alliance.

## TYSABRI INJECTIONS LICENSED IN EUROPE

The MHRA (Medicines and Healthcare Products Regulatory Agency) and European Commission have granted marketing authorisation for an under-the-skin injection of Tysabri. Tysabri is a disease-modifying therapy for highly active relapsing-remitting MS.

Until this development, Tysabri was administered via IV in a number of hospitals in Ireland. These injections are given by a health professional but are faster to administer and may be a preferable administration method for some people living with MS.

Clinical trials have shown that monthly subcutaneous injections of Tysabri are as effective as monthly infusions at reducing relapses and lesions seen on MRI scans. About 7% of people experienced mild or moderate injection site reactions when having a subcutaneous injection of Tysabri.

## Mayzent (siponimod)

Earlier this year, MS Ireland was made aware that the National Centre for Pharmaco-economics (NCPE) made a negative recommendation regarding the reimbursement of siponimod. MS Ireland was, however, delighted to learn that the HSE Drugs Group have since made a positive recommendation meaning this product will be reimbursed. We are awaiting an official reimbursement date and we will share this on our social media and in eNews once it is confirmed.

Mayzent (siponimod) is a disease-modifying therapy (DMT) for people living with active secondary progressive MS who continue to have either have relapses or radiological evidence of disease activity. It is a pill once daily to slow progression of disability.



Patients Deserve Better Campaign – Neurology Nurses

## Patients Deserve Better Campaign – Neurology Nurses

The Neurological Alliance of Ireland, of which MS Ireland is a member, has recently launched a new campaign aimed at highlighting the lack of neurology nurses across Ireland. 100 extra neurology nurses are required across the country in order to reduce waiting lists and deliver improvements to neurology patients. Currently, there are almost 24,000 people waiting for a neurology appointment and over 8,500 of these individuals have been waiting more than 18 months for an appointment. MS nurses are one of specialist services that is lacking. This campaign aims to highlight the shortfall. Virtual events have taken place across the country, with people living with MS having their voices heard by decision makers in their area.



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Advanced Nurse Practitioner in MS, Sinéad Jordan described the role of the MS nurse and the support they can provide to people living with MS. She said “My role is to provide education and support to both patients and their families and to liaise with primary care services in order to facilitate supports they may need in their local area”. Sinéad also spoke about the importance of the service to people living with MS, outlining some of the many ways in which MS nurses can support people living with MS and their families saying that “...if they (people living with MS) have any symptoms, or any concerns, or worries or medication issues they can contact us directly”. She also spoke about how the MS nurse can provide support to those experiencing an MS relapse by carrying out a neurological assessment and providing steroids if needed.

Mark Mitchell who lives with MS, took part in the campaign and outlined the support his MS nurse provides. “When I meet with my nurse specialist, she goes through all of my medications, my home situation, aids, facilities, et cetera, and may make suggestions or recommendations for me... My life is so much better having access to an MS nurse specialist and going forward everyone should have access to one.”

We encourage our members to visit [www.patientsdeservebetter.ie](http://www.patientsdeservebetter.ie) to support this campaign and to learn more about this issue.

## Celebrities living with MS

Over the past number of years, the profile of MS has been raised by the inclusion of characters living with the condition being included on screen as well as a number of high-profile celebrities choosing to publicly share their diagnosis.

In 2018, actress **Selma Blair** shared that she had been diagnosed with MS in an Instagram post. She has also starred in ‘Introducing Selma Blair’, a documentary that provides viewers with a very raw account of diagnosis and the actions Blair took to help get MS under control. This documentary is available on Discovery+.



In 2021, **Christina Applegate** shared on Twitter that she had been diagnosed with MS, describing it as a ‘...tough road’. The actress who starred in *Married with Children*; *Anchorman* and more recently in the Netflix series

“Dead To Me” said that she was touched by the support she had received from the MS community.



CNN’s “Inside Politics” host **John King** announced his diagnosis during a live segment in October. He shared it while discussing the importance of COVID-19 vaccines and mask mandates to protect the immunocompromised. Later, he was interviewed and revealed that he has

been living with the condition for 13 years and had chosen not to share his diagnosis beyond a handful of people up to that point.

## Societal Cost of MS Survey Launch

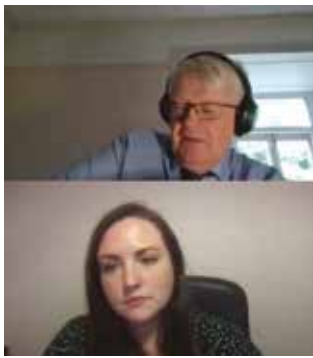
MS Ireland in collaboration with Novartis have reconducted the Societal Cost of MS survey. This research was originally carried out in 2015. Conducting this research again will provide MS Ireland with new information on the true cost of MS. Figures from the 2015 study revealed that MS costs Ireland EURO 429 million per year. We learned that the cost of relapse is EURO 16.9 million and that the estimated savings from avoiding relapses would be approximately EURO10 million. Conducting this survey again will allow MS Ireland to update these figures and also allow for a comparison to be made to the previous version, which will help us to identify what has changed or remained the same since then. The updated report will be made available in 2022.

## Medical Cannabis Access Programme

MS Ireland welcome the news that a reimbursed product is now being dispensed to people living with MS through community pharmacies as part of the Medical Cannabis Access Programme (MCAP). This programme allows access to accepted cannabis-based products on a named patient basis, for medicinal use. If an individual experiencing MS-related spasticity does not respond to standard therapies and interventions, they may be able to access a cannabis-based product through the MCAP. To access this programme, an individual, consultant neurologist must apply to register the individual on the Cannabis for Medicinal Use Register. The application must be completed by the prescribing consultant as well as the person who will be using the product.



## Webinars



Dr Brian Sweeney and MS Ireland's Aoife Kirwan during the webinar on Current and Emerging Treatments in MS

Over the past year, MS Ireland has been busy ensuring we are providing our community with expert information in an accessible way. While in the past, we would have held physical information events, holding them online has allowed us to create an information resource that people can access from the comfort of their own homes. In 2021, MS Ireland hosted 27

webinars. Where permission could be sought, these webinars were recorded and have been added to an online video catalogue on our website. This allows our community to engage with content and information as and when they wish. During the year we have had the opportunity to cover a wide range of topics including fatigue management, relationships, self-care for carers and specifically tailored events for International Women's Day and International Men's day.

We are thrilled to be able to provide this information as a permanent resource for our community. We are currently planning webinar topics for 2022. If you would like to make a suggestion for a specific topic you feel would make for an interesting or informative webinar, please email your suggestion to Aoife Kirwan – [aoifek@ms-society.ie](mailto:aoifek@ms-society.ie)

To view the video catalogue visit [www.ms-society.ie/what-we-do/video-catalogue](http://www.ms-society.ie/what-we-do/video-catalogue)

## Progressive MS Series



Dr Jonathan Egan, Progressive MS Series regular with Host Robert Joyce

This year, MS Ireland were delighted to launch a new video series on Progressive MS. The series aimed to help discover new tools and learnings on how you can be more resilient and provide you with resources for managing Progressive MS. The series

is hosted by MS and Me blogger Robert Joyce, who has delved into a variety of topics around progressive MS. Recordings of this series are available on MS Ireland's online video catalogue. Audio recordings are available here <https://shows.acast.com/multiple-sclerosis-society-of-ireland-podcast/about> or from Robert's podcast, A 30 Minute Life <http://a30minutelife.com>

## Most Googled Questions about MS



Dr Karen O'Connell

It is important to MS Ireland that people living with MS and their families have access to reliable and valuable information. We know that Google is a popular place to turn when you have a burning question so we found the questions that were being searched most often and out them directly to a neurologist who could provide accurate and accessible responses.

Last month, MS Ireland shared a video in which Dr Karen O'Connell provides answers to the most 'googled' questions about MS from Ireland including

- What is multiple sclerosis?
- What is an MS relapse?
- What causes MS?
- Can MS go away by itself?
- Can people living with MS have intimate relationships?
- What's the best treatment for MS?
- You can watch the video here [www.ms-society.ie/news/most-googled-ms-questions](http://www.ms-society.ie/news/most-googled-ms-questions)

## CNS for the South East

MS Ireland was delighted to learn that University Hospital Waterford has recently welcomed Neurology Clinical Nurse Specialist (CNS) Máire Hayes to their team and are planning to expand their MS service. Máire is a great supporter of MS Ireland. Last year, she took part in a number of videos in which she answered community generated questions about COVID-19. We greatly look forward to seeing how this service develops and benefits people living with MS in the South East.



## AIMS RESEARCH NETWORK

A new research network, focused on Multiple Sclerosis (MS), was launched in February 2021. The All-Ireland MS Research Network (AIMS-RN) brings together researchers in the Republic of Ireland and Northern Ireland, that share a common interest in the disease. The central mission of the network is to support collaborative research across the island of Ireland that holds potential to limit the progression of MS, to train future generations of MS researchers and to contribute to global MS research. Involvement of people with MS in the activities and research of the network is a core principle of the network.

This initiative, which had been in discussion between the founding members for some time, was galvanized, and formally became AIMS-RN, during 2020. Indeed, all pre-launch planning meetings were held remotely and an incredible amount of work from the founding members ensured that the network could launch in the original timeframe of early 2021. The founding members lead MS research teams in NUI Galway, Royal College of Surgeons in Ireland and Queen's University Belfast. The core leadership of AIMS-RN has reached out to a range of other researchers involved in MS research in Ireland to form the initial membership of the network, which they anticipate will grow year on year.

There are four main areas of focus through which the mission of the network will be accomplished. The first goal is to deliver cutting-edge research that focuses on limiting the progression of disease as this holds potential for all individuals diagnosed with MS. The second area of focus is to train future researchers and research leaders in the field of MS. The third focus area is to communicate MS research discoveries and results to the public, to the

research community, and to key stakeholders. The fourth area of focus is to collaborate on research programmes, both nationally and internationally to achieve the mission of the network, working with people with MS as primary partners.

The network has already had an exciting launch in February 2021, and has already delivered its first training activity, the AIMS-RN Summer Studentship Program. Through this program, which had over 70 applicants from across the island of Ireland, four undergraduate students were selected to undertake collaborative research projects over the summer of 2021. These projects had to involve collaboration across at least 2 separate laboratories of AIMS-RN members and, so far, has been a tremendous success. The programme will culminate in an online Summer Student Research Symposium at the end of August 2021.

Since the launch of AIMS-RN, the founding committee have been meeting monthly to develop a strategy for the development of the network. This strategic plan will be reviewed by the expert advisory panel that have kindly agreed to support the mission of AIMS-RN. The expert advisory panel consists of world leading experts in Ireland, the UK and France, that have experience in both clinical and biomedical MS research. In 2021, the network also launched its website ([www.aims-rn.org](http://www.aims-rn.org)) and communicates regular updates via Twitter [@aims\\_rn](https://twitter.com/aims_rn). Members of AIMS-RN are excited about developing MS research and helping train and mentor the MS research leaders of the future across the island of Ireland.

For more visit <https://aims-rn.org>



### Founding investigators

Prof. Denise  
Fitzerald

Dr. Yvonne  
Dombrowski

Dr. Alerie Guzman  
de la Fuente

Dr. Claire McCoy

Dr Una Fitzgerald

Dr. Jill McMahon



## Having a Mam with MS

*In this piece, a young guest writer who wishes to remain anonymous shares their perspective and experience as a child of someone living with MS.*

My Mam was diagnosed with MS when I was very small and before I remember, so it has always been part of our lives and I always knew about it as long as I can remember. My Mam never makes a big deal out having MS and most of the time, it's just something we know about but doesn't really interfere with our life. I do think that my life has been a little bit different to other people my age because I sometimes have more responsibilities because Mam needs help doing housework or she might not be feeling very well all of the time. I feel bad for my Mam that she has to put up with all of the symptoms she gets. She has numbness sometimes and she has to be careful when she is drinking things because sometimes if her lip is numb, the drink just pours out a little where the cup isn't fully touching her mouth. Especially with hot drinks, you need to be careful with those. That didn't happen too much though and it went away, so it's not a problem at the minute.

I think the worst part though is when Mam is really tired. I know this upsets her the most because it can sometimes stop her from doing the things she wants to do. Like for example I could want to go cycling with her and Mam might have to say she can't because she is too tired. I know that she doesn't like it when she has to say no to doing things like that together and I think it makes her feel a bit guilty sometimes. But I have the best Mam in the world and I know that when she can't do something, she just really can't. It's never that she doesn't want to and when she can then she will. We do spend good time together doing other things when she can't do activities or sports anyway. We watch some series on Netflix together. Sometimes we will play video games together when she is tired too. I know she is putting in an effort because she keeps trying even though she is not great at video games and she never plays them unless its with me, so I know it's for me and so that we can spend some time together doing something fun. Our family is really good and they help when

Mam is tired or not feeling well. They might bring me to school if Mam can't or they might make dinner for us. They always make sure that we are always okay and I think we are really lucky for that. We are nice to them too and we help them out in lots of ways. Sometimes we need some help and sometimes they need it and we help each other. That's what families are for.



I sometimes worry about my Mam and if she will get worse but I know she is doing her best and she has good doctors who are helping to make sure it doesn't get too bad. Hopefully it won't get worse. I wish my Mam didn't have MS because it's not fair on her but for me she is still the best Mam in the world.

Best  
Mom  
Ever!

## COVID-19

### Where are we now?



Over the past 21 months or so, it has been challenging to keep up with changes regarding COVID-19. From the development of vaccines to the emergence of new variants, we have found ourselves in an ever-changing landscape where some things remain consistent and others are changing.

### What do we know about COVID-19 and MS?

Current evidence shows that having MS does not make you more likely to develop, become severely ill with or die from COVID-19 than the general population. You are at the same risk as anyone else. However, various factors can increase the risk of a more severe case of COVID-19. These include; being on certain disease-modifying therapies (DMT's)\*; being over 60 years of age; having an EDSS score of 6 or above. People living with MS and diabetes, obesity or disease of the heart or lungs are also at increased risk.

\*Studies are producing reassuring results which show no additional risk of COVID-19 severity for people living with MS from most DMT's. The possible exception being anti-CD20 monoclonal antibodies which include ocrelizumab and rituximab.

**If you have concerns about your risk level, your healthcare provider should be able to help provide information based on your individual case. It is important not to stop your MS treatment unless you have been advised to do so by a member of your healthcare team.**

### What about vaccines?

It is recommended that people living with MS receive a COVID-19 vaccine. The vaccines are not live and so they cannot cause

COVID-19. Some DMT's may reduce antibody production following COVID-19 vaccination which may reduce the effectiveness of the vaccines. This includes fingolimod, Siponimod, ocrelizumab, rituximab and ofatumumab. **It is still recommended that those on these medications receive a vaccine.**

Currently, the rollout of both boosters and extended primary vaccinations or a third dose are ongoing. Some people use the term booster and extended primary vaccination or third dose interchangeably but the intention behind giving them is different. An extended primary vaccination or third dose is given with the aim of completing a primary vaccination. Essentially, it 'tops-up' the vaccination. This is used for people who may not have mounted an optimal immune response after their first two doses. A booster is a dose that is given to extend the length of protection.

At the moment, you must wait at least 5 months after completing your primary vaccination to receive a booster. Those who received a single-dose Janssen vaccine need to wait at least 3 months after their vaccine to receive a booster.

In recent days, the National Immunisation Advisory Committee (NIAC) signed off on the use of COVID-19 vaccines in children aged between 5 and 11 years. Vaccine rollout for those ages 12 years + have been ongoing through 2021. NIAC have strongly recommended that children aged 5-11 years with an underlying condition; living with a younger child with complex medical needs; living with an immunocompromised adult should receive a COVID-19 vaccine.

Exactly how long a person is protected from COVID-19 after being vaccinated remains unclear. Repeated doses of the COVID-19 vaccines may be required in future.

### What if I get COVID-19?

If you are confirmed to have COVID-19 you should contact your healthcare team who can provide individualised advice for you. The Association of British Neurologists (ABN) Guidelines state that people taking Avonex, Aubagio, Betaferon, Brabio, Copaxone, Extavia, Plegridy, Rebif, Tecfidera or Gilenya do not

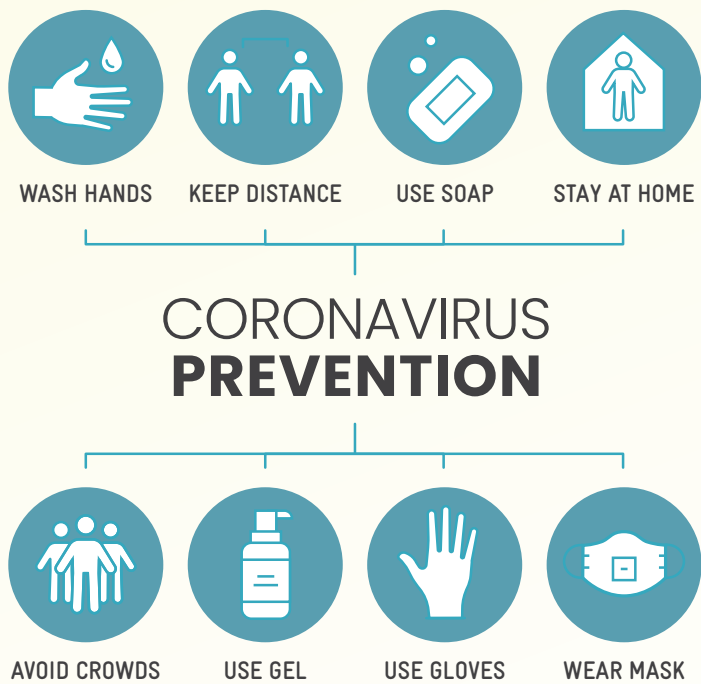


need to stop their treatment if they have mild symptoms of COVID-19. Those being treated with Tysabri, Ocrevus, Lemtrada or Mavenclad should have treatments delayed until their COVID-19 symptoms are resolved.

In the case of severe COVID-19 infection, your MS team will likely recommend stopping or delaying your treatment. In order to avoid rebound MS activity, where possible, Gilenya and Tysabri should be restarted within 8 weeks.

It is still important to adhere to public health advice and take precautions to prevent the spread of COVID-19.

## What can I do to avoid catching or spreading COVID-19?



Each of us has a responsibility to reduce the spread of COVID-19. It is important to keep yourself up-to-date with current public health advice. This enables you to make informed choices. Currently, the advice from the HSE to protect yourself and others from COVID-19 includes:

- Self-isolate and get a PCR test if you have symptoms of COVID-19
- Get a COVID-19 vaccine
- Keep up-to-date with and follow Government guidance

- Follow the latest travel advice when travelling to Ireland
- Wash your hands properly and regularly (for at least 20 seconds)
- Let fresh air into your home by opening windows, doors and air vents as much as possible if you have visitors
- Check that visitors to your home or workplace do not have symptoms of COVID-19, colds or flu
- Try to avoid crowded places where you cannot social distance
- Wear a face mask in crowded places outdoors and when you move around in public indoor spaces
- Use the COVID Tracker app for contact tracing and to store your EU Digital COVID Certificate
- Cover coughs or sneezes with a tissue or your sleeve – put used tissues into a bin and wash your hands
- Clean objects and surfaces that other people touch
- Don't touch your eyes, nose or mouth if your hands are not clean
- Do not share objects that touch your mouth, for example, bottles or cups
- Do not shake hands or make close contact with other people, if possible
- Do not wear gloves instead of washing your hands – your hands can get contaminated when you take them off

### Further information is available from:

[https://cdn.ymaws.com/www.theabn.org/resource/collection/6750BAE6-4CBC-4DDB-A684-116E03BFE634/21.10.26\\_ABN\\_Guidance\\_on\\_DMTs\\_for\\_MS\\_and\\_COVID-19.pdf](https://cdn.ymaws.com/www.theabn.org/resource/collection/6750BAE6-4CBC-4DDB-A684-116E03BFE634/21.10.26_ABN_Guidance_on_DMTs_for_MS_and_COVID-19.pdf)

<https://www2.hse.ie/conditions/covid19/preventing-the-spread/>

MS Ireland has a dedicated COVID-19 information centre that can be accessed here [www.ms-society.ie/covid-19-and-ms](http://www.ms-society.ie/covid-19-and-ms)

## MS, Grief and Creativity

By Eimear Lawlor



In July 1999, the buzz words at the time were Eircom shares. I lay in bed at Waterford regional hospital eight months after the birth of my second child Ciara, at the age of twenty-eight, listening to nurses talking that they got loans from the credit union to

buy Eircom shares. I had double vision. Initially, I thought it would pass and wasn't concerned as I didn't feel unwell, but after a few days, I finally went to see my GP, who sent me to Waterford Regional Hospital.

After a few tests, I was discharged from the hospital. They didn't give a diagnosis but arranged that I go to Beaumont for an MRI. At the time, I couldn't understand the fuss, but of course, they suspected MS. It would have been in my doctors' notes I had been to the doctor the previous month about numbness in my right leg.

After my MRI, my GP called me into his surgery to say that there were plaques on my brain, and it was probably Multiple Sclerosis. I was in shock. I was too young.

Within a week, I saw a neurologist in Dublin, and he confirmed it was multiple sclerosis. I asked him if there was anything I could do to prevent the disease from worsening. He said 'No.'. I asked would a healthy lifestyle affect the course of the disease. His opinion was I could eat, drink and smoke, and it would have no effect on the outcome. He recommended starting treatment with disease-modifying therapy. My husband and I wanted three children. We decided to delay starting treatment to try for another child. We said we would give it six months

Luckily I got pregnant, and during my pregnancy, I scoured the internet to read as much on MS and the prognosis of MS. Unfortunately, there was little realistic prognosis as there were four courses of the disease, from benign to primary to progressive, and it was a wait and see approach. I researched MS and diet & lifestyle, from meditation to exercise. I ordered books and read articles on various diets, even on the water diet! I had always eaten healthily, and I swam regularly. I thought no matter what disease or condition a person has, if you are in your best of health, you have a better chance of getting better or just living with the illness. There are plenty of snake oil treatments on the internet. But one thing was eating unprocessed food and sugar free. I never smoked, and our social life was non-existent due to the children. So we had a quiet life except for the demands of motherhood.

After our third child - our millennium baby, I saw a different neurologist in Dublin that I was more comfortable with and began treatment. I started on an injectable medication before the auto-injector. Before I administered my first injection, the nurse told me to practice and plunge a ¼ inch needle into an orange!

After the birth of my son, I suffered extreme fatigue, and again, my vision was affected. My balance was affected, and luckily I found a physiotherapist who had worked in a neurology department when she was training. My muscles were weak, and I found it difficult to walk in a straight line. With lots of physio and time, the strength came back. I was a swimmer, and this helped.

I taught part-time but became a stay-at-home mum after the birth of our third child. Fatigue was a huge problem. My speech would become laboured, and I found myself slurring words when I became tired. I felt that I couldn't have coped with the demands of motherhood and working outside the home.

Over the years, I had a few attacks, but luckily, I recovered in time from each relapse. When my sudden father passed away in 2012, I was struck by shock and grief, and I had a relapse. My left side became weakened, and again my speech was affected. Again I called on the physio services, so after time I gained back most of my strength.

The following month after my father passed away, my only daughter Ciara was diagnosed with SVT –



a heart arrhythmia manifesting in a fast heartbeat. Ciara was twelve years old. Thankfully It wasn't life-threatening.

In 2013 Ciara told me to do something other than drinking coffee with my friends. I saw an ad in our local paper for a creative writing course and signed up for it. I hadn't written fiction before, believing I didn't have the skill, let alone the imagination. However, from the first day of the course, I couldn't believe I hadn't found the joy of writing sooner. I wrote a short story tentatively based on my great aunts working for Eamon De Valera and Michael Collins in their Sinn Fein offices in Harcourt St during the 1918 elections. She was involved in the anti-treaty side in the subsequent War of Independence. After the course, I thought this would be a good book, so I created a fictional character inspired by my great aunt.

On July 9th 2016, tragedy struck our house. Ciara passed away at a Kodaline concert in Dublin. She was just seventeen years old. The post-mortem showed she had an undiagnosed condition called ARVC, a heart condition. My world fell apart. Grief consumed the family and me. My sister-in-law is a GP and reminded me to take my medication, eat, and sleep. We were aware of my father's death's stress on my health and how it brought on an MS attack. She really looked after me, but I had to look after the boys. Luckily, my MS did not suffer.

The band Kodaline wrote a song called Angel for Ciara, which is on their third album, ***The Politics of Living***.

My grief counsellor suggested writing. So, I wrote my pain, and this developed in a Dear Ciara diary. After about two years, with my head still consumed by grief, I looked at my manuscript with the character based on my great-aunt. I sent it to an agent in the UK, and she signed me up. She loved the story and the history of Ireland's fight for Independence. British publisher signed me, and this was a part of history very little British knew about. Last January, *Dublin's Girl* was published in Ireland and the UK.

Now, there are very few outward signs of my MS. However, I can't cope with long car drives, and if I talk for too long. I have a very small twitch in my hands, and I experience a lot of paresthesia, which isn't painful, just a little uncomfortable. These minor symptoms seem to be hormonal-related, and there was a slight increase when menopause started.

I don't know if my diet and lifestyle have affected my disease course or genetics. But I know stress definitely does, so I had had to be very careful when Ciara passed away.



The symptoms of MS can vary greatly from one person living with the condition to another. Fatigue is a very common symptom of MS, impacting between 75-90% of people living with MS, on some level. Fatigue can create feelings of exhaustion, tiredness, weariness or lack of energy. It is different to the fatigue experienced by those who do not live with MS. MS-related fatigue can be very difficult to diagnose, understand and communicate. But what exactly causes fatigue? What effective techniques or strategies can be used to manage fatigue?

## What causes fatigue?

There are two different types of fatigue, primary fatigue and secondary fatigue.

Primary fatigue is the direct result of damage to the central nervous system (brain and spinal cord). It can be caused by hormones, demyelination, inflammation and even how we use our brain. MRI's have indicated that people living with MS sometimes use more of their brain in order to carry out a task than people that do not live with the condition. Demyelination in MS results in damage to the nerves in the brain that conduct signals, enabling us to use our bodies. This damage can result in our brains having to find a new route to send a signal. More of the brain is used, resulting in fatigue.

Secondary fatigue is caused by factors that may be related to MS but is not directly caused by MS. It can relate to MS symptoms such as muscle weakness, tremor or pain. Infections, a rise in temperature and medication can also lead to secondary fatigue. Factors associated with living with MS such as lack of sleep, lower levels of mobility and cognitive or emotional impacts can also lead to secondary fatigue.

## What does fatigue look like?

There are various forms of fatigue including:

**Physical fatigue** - The body is working harder to function which can result in physical fatigue. This can result in muscle weakness.

**Psychosocial fatigue** - You may experience difficulty in getting motivated, you may feel low or worn out. Being in a group or conversing with people may feel overwhelming. Psychosocial fatigue is related to low mood, anxiety and struggling with social environments.

**Cognitive/Mental fatigue** – Difficulty with concentrating, focusing, processing and recalling information.

## How can fatigue be managed?

Everyone's experience with fatigue is unique. What helps one person to manage fatigue may be different to what helps another. It is important to find the strategies that work for you. Here is a selection of strategies that can be used to help manage fatigue.

- First, you need to identify **what your triggers are** as they will be important in determining appropriate strategies to manage fatigue. A way to do this is to develop a fatigue diary in which you log your daily activities, your rest and your fatigue levels. This may help you to identify behaviours that might be contributing to fatigue. It is important to complete this on good and bad days to help identify patterns.
- Next, you **develop strategies based on the triggers and patterns** of behaviour you have identified. For example, if you identify that your cognitive function is better in the evening than in the morning, you could move some of the more cognitively demanding tasks to the evening.
- **A to-do list and prioritising activities** can save energy and ensure important tasks get done at a time that is suitable for you.
- You may also find it useful to **break activities down into a series of smaller tasks**.
- **Be realistic** with how much you can get done in a day. You need to consider that fatigue may feature.
- **Ask for help** with certain tasks. Be aware of your limitations and what might be very



demanding of your energy and ask for help. For example, if you are planning to do the grocery shopping, it may be helpful to have someone pack the groceries or help put them away when you get home. These little energy savings can make a difference! Remember that asking for help is a sign of strength, organisation. It shows that you are motivated to stay well.

- **Minimise distractions.** For example, if you are reading the newspaper and the radio is on in the background, your attention may be switching from one to the other. Switching off the radio may help you to focus on reading the newspaper and reduce cognitive demand.
- **Focus on one task at a time**, if and where you can.
- **Repetition** can be helpful in creating a routine so your brain doesn't need to think about certain things all of the time.
- **Creating associations** between things you might need to remember can help. An example is having a basket by the door that you put your keys in so your brain knows the keys go in the basket every time. Having certain things in certain places can help your brain to build 'muscle memory' so it doesn't have to overthink.
- **Visual or verbal cues** Finding different ways to perform tasks. There may often be tasks you have to complete regardless of whether or not you are experiencing fatigue. So finding ways to complete those tasks in a way that is less demanding of your energy could help. Perhaps that looks like sitting down to fold laundry instead of standing to do it.
- **Visual or verbal cues** or reminders can be of great use.
- **Prioritising the information**, you want to focus on may be beneficial. When receiving information, focus on the parts that matter most.
- It may be useful to **adopt memory/attention aids** such as checklists, a notebook, wall planner/calendar, alarms/timers or a Dictaphone.

**Rest is essential in managing fatigue. Pace yourself, take regular rests and allow your brain to decompress.**

**Developing a good sleep routine is also a very important element in fatigue management.**

## What can I do to help with cognitive fatigue?

- **Some activities** can help with cognitive fatigue. These include jigsaws, cards, listening to music, meditation, word searches or even engaging with memory matching or attention test apps.
- **Assess your environment.** You want to create an environment that is easy to move around. Storing heavy items at a low level. Keep items you regularly use within reach. If there are items you use together, you could store them together. Try to keep clutter to a minimum and keep items in the same place, if you can.
- **Medication** can sometimes impact fatigue. Someone could feel immediately better or worse after taking their medicine. Plan activities around those times. If your fatigue is persistent on your medication, it may be worth flagging this with your healthcare provider in case any tweaks or changes are required.
- **Try to maintain a healthy lifestyle** with a well-balanced diet and exercise at a level that is suitable for you. It is also important to try to avoid or minimise stress. Stress can cause fatigue as our bodies can become tense or tight and we are in a state of 'fight or flight'.



**If you need support with fatigue management, please speak to your healthcare provider who may be able to provide individualised support, advice or information for you.**

# What do Community Workers Do?

By Katie Hourigan, Regional Community Worker and South East Co-ordinator

Hi there, do you know what community workers do? People often ask, 'what is it you do?' So, I've put a few key points together as to the agreement with our funders, key needs of people with MS in the South East and Community Work Service in the South East Region. Regional Community Workers in the South East Region are funded by a Disability Service Level Agreement to provide two core pieces of work:

- Case Work to adults with MS and
- To support client's data to be registered on NASS

Health services are mainly provided through the HSE and Community & Voluntary Sector via key pillars. Community Work is funded under Social Care which includes Disability and Older Person Services. The purpose of Social Care is "to support and maintain people to live at home, in their own community and to promote independence and lifestyle choice in as far as possible." Services vary within available resources.

Other Pillars include:

- Primary Care services
- Health and Wellbeing services
- Mental Health services
- Hospital/ Acute services

## Case Work

Case work is one to one, confidential support to people living with MS and their families. The focus of case work is on providing an opportunity for people living with MS (PwMS) to explore their experience, their options, and make choices that encourage independence.

It involves providing information and support around the time of diagnosis. It is very important that people access correct and accurate information in the early stages of diagnosis so as to best inform themselves in the management of their MS.

Over the course of their journey with MS people may require supports such as Home support, Personal Assistants, Public Health Nurse, Physiotherapist, O.T and a range of additional Health Professionals. The services offered by these professionals can greatly enhance the quality of life of those concerned. The Community Worker is ideally placed to help the person and/or their family link in with whatever supports are deemed necessary.

People with MS may also require advice regarding benefits, allowances, and grants available. The Community Worker (CW) will, in these instances, encourage the person to contact appropriate services such as government agencies, Citizens Information Centres, MABS or other agencies.

People living with MS requiring care in their homes may wish to avail of respite breaks. This can be for the benefit of both the person with MS and their family/carers. Respite at a specialised centre such as the MS Care Centre in Dublin means the persons care needs, regardless of how complex, can usually be catered for. The Community Worker may suggest respite and help identify a suitable respite facility. The CW can also help with the application process and explore transport options if necessary. People with MS may also avail of day services in their locality.

- Sometimes people with MS may need the assistance of technical aids or appliances to help manage in their daily lives. In such cases the CW can request an assessment by an OT and/physiotherapist, to advise on the most appropriate appliances for the persons needs.
- People with MS may also benefit from neuro-rehabilitation/therapeutic intervention. The community worker can assist with links to Royal Hospital Donnybrook neuro-rehab unit or local supports if available. The CW works together other Disability Voluntary agencies to help identify a suitable therapeutic and intervention and rehabilitative service.
- People with MS may also require residential care. The Community Worker may help identify a suitable residential facility. The CW can also help with the application process and explore options if necessary. Services vary from region to region depending on available resources.

## Supporting clients' data to be registered on National Ability Supports System (NASS)

Community workers also support clients' data to be registered on NASS so that service can be planned appropriately in their community. If your needs are not captured or you have not informed your service provider of your need, how will the planners know that there is an identified need? The better we know the needs of people with disabilities the better we can plan interventions to support people living well in their community.

Data is a key resource for planning future services and evaluating service use. The data is used to inform decisions such as budget allocations and policy considerations. Therefore, it is essential that everyone who is eligible for inclusion on the NASS database is encouraged to participate so that their individual needs are reflected. It is a form of self-advocacy. A recent report showed that neuro-rehabilitation service, physiotherapy, occupational therapy, personal assistant, supports for daily living, respite, technical aids and appliances, joining in community activities are people with MS priorities. Make sure your needs are registered. Contact your regional community worker.

## REGIONAL COMMUNITY WORK ALSO PROVIDE ADDITIONAL SERVICES:

### Professional Information & Advice Workshops, Seminars, Webinars, Programmes

Community workers also organise Professional and Information Advice workshops on symptoms of MS (fatigue, continence, mobility etc), chronic disease Self-Management courses and webinars for newly diagnosed people with MS (assistive technology etc), Mindfulness-Based Stress Reduction (MBSR).

### Networks/links: a large part of our work involves collaboration with other regional service providers.

Community workers collaborate with the local health care team; GP's Public health nurses, physiotherapists, occupational therapists, continence advisors, neuro-rehabilitation teams and home care support teams. We work closely with Cheshire, IWA, Enable, CRC, SAGE, Family Resource Centres, Sports Partnerships, mental health supports, Citizen's information, MABS etc.

## Regional Physical Activity Programme

The Community Work team organises regional physical activity programmes (yoga and physiotherapy led classes). Keeping active is good for everyone. Participating in exercise increases mobility and helps combat fatigue, improves physical and mental health and cognitive abilities. Exercise helps walking ability, balance, strength, mood and thinking, quality of life and falls prevention. If you are already involved in physical activity in your everyday life such as gardening, walking for leisure, swimming for good health, continue these activities as they help you to stay active and enjoy the benefits of a healthier lifestyle.

If you have a specific query or need specific advice, ask your GP to refer you to a HSE chartered physiotherapist. You are entitled to be assessed by a physiotherapist who may set an individualised home programme for you.

If you want to join MS Ireland online classes – see [www.ms-society.ie](http://www.ms-society.ie). The classes run throughout the year. The terms generally coincide with school terms with breaks for easter, summer, Halloween etc.

Various classes are organised throughout the year. Details can be obtained by contacting your Community Worker.

## THE IMPORTANT THING IS TO BE ACTIVE:

### Voluntary Branch Network:

MS Ireland also has a network of Voluntary Branches nationally. Branches provide an opportunity for people with MS and their families and friends to meet informally themselves. They organise informal socials, family outings and meetings throughout the year. Some local Branches provide limited financial assistance. For current Branch details contact national website: [www.ms-society.ie/what-we-do/branches](http://www.ms-society.ie/what-we-do/branches) or your regional office/community worker for details.

Community Workers provide a variety of supports in the region. Our key role is to offer individual case work and support people's data to be registered on NASS. People do not have to be a member on the organisation to avail of community work service. You are welcome to contact us any time and we will do our best to get back to you as soon as possible.



## E-BIKE REVIEW

By James Flanagan

I used to cycle a racing bicycle for many years but when I began to lose some strength in my leg, I felt as though cycling may not be for me anymore. When my friend Ben, from Derby UK, suggested getting an e-bike it seemed there may be an alternative way to keep doing what I love.

Physical exercise is the most obvious benefit from cycling, but for me I found many other more enjoyable reasons to cycle. The beautiful views, peacefulness and scents of the Irish countryside are a few better reasons, I think! My e-bike has enabled me to continue to enjoy cycling while helping me to stay motivated to keep active. I often found that other types of exercise could be somewhat labour intensive and boring for me but cycling just suited me.

The e-bike offers power assistance to my own effort. It does not power without my physical input. The effort I put in to pedaling the bike is multiplied by the bikes electric motor. I was amazed at how much it can help it even on short cycles. My bike has 5 power assistance settings that I can adjust at the touch of a button to support me to a level I'm comfortable with. Usually when powering up a hill I'll ask for maximum support while on a flat level road I'll reduce assistance. It's completely up to me and how I feel on the day. I charge the battery once it is low, and it takes about 4 hours to charge up fully.



For safety, before I cycle, I plan my route carefully. I usually go cycling with my brother or my Dad. I use the Strava app to track my cycle routes and record my progress. I find the safest cycle routes are the Greenways. Especially from Kilmacthomas to Dungarvan, Co. Waterford. It is breathtaking! Recently my girlfriend Laura and I brought our bikes to the largest of the Aran Islands, Inismór. Here we toured the whole island on bike. It was stunning, the fresh salty air off the Atlantic and beautiful landscape was just unbelievable to experience. It felt like we had the whole island to ourselves as we were able to get off the beaten track and go our own way. This was greatly helped by use of my e-bike.

When I first started using the e-bike 1 year ago, I started taking short cycles of 10-15 km.

Now I often go for cycles 30 km+.

My longest cycle so far was 92 km on the Athlone to Mullingar greenway. We

enjoyed it but I will admit that it was tough going!

In total, my e-bike's odometer shows how I've cycled over 1200 km since I bought it.

I want to give a heartfelt thank you to the MS Ireland – South Tipperary Branch who helped me to purchase the e-bike. Their support combined with the Cycle To Work Scheme helped me to purchase the e-bike.

The e-bike has changed my outlook on how people with MS can remain physically active. It has made so much of the countryside much more accessible to me and helps me to continue to live a normal life. I would highly recommend anyone, with MS or not, that would like to increase their physical activity level in an enjoyable way to consider using an e-bike.

**I will always want to cycle and stay as active as possible. Thanks to my e-bike I will for many years to come.**

# Feedback From You

## By Mary McCusker

Since programmes and services have been offered to the MS community across the country, MS Ireland has asked participants about their experience. This was conducted from January to June 2021 using an online questionnaire. Feedback about online programmes has been really interesting and will likely have a big impact on how MS Ireland delivers programmes and services in the future.

In total, **239** people with MS submitted responses once they had completed some form of online group activity. These included physiotherapist-led exercise programmes, yoga groups, meditation, time to chat groups and webinars. **194** (81%) of respondents to the questionnaire were **female** and **45** (19%) of these were **male**. The average age of respondents was 54.2 years. The demographic breakdown of respondents is shown below.

**Table 1:** Characteristics of the people that responded

	Male	Female	Total
	19% (n=45)	81% (n=194)	100% (n=239)
Type of MS			
Relapse Re-mitting MS	9.2 (22)	51 (122)	60.3 (144)
Secondary Progressive MS	4.6 (11)	10 (24)	14.6 (35)
Primary Progressive MS	10.8 (12)	18 (43)	23 (55)
Other	0	2.1 (5)	2.1 (5)
<b>Service or group type</b>			
Physiotherapist-led exercise programme	10.5 (25)	50 (117)	59.4 (142)
Information session/webinar	2.5 (6)	13.3 (32)	15.9 (38)
Yoga	4.6 (11)	12.6 (30)	14.2 (41)
Other Group programmes	0.8 (2)	6.2 (15)	7.1 (17)

When asked about attending online physiotherapist-led exercise and yoga programmes well over 90% of respondents said that they were satisfied with the online programme that they attended. Around 90% of respondents also said that they would recommend the programme that they attended to others. When asked ‘What difference (if any) has your participation in online exercise made to you?’ responses focused on areas such as motivation and self-efficacy, social isolation and peer interaction, improvement in symptoms, mental and emotional well-being and convenience. Some examples of feedback are highlighted below:

**‘I find it much easier to get up out of a chair, the spasticity I used to experience has severely reduced/gone. I can walk better, far better balance.’**

**‘My balance was terrible before I started to participate in the classes and I have a lot more ability and confidence now.’**

**‘A massive difference as it’s important to do exercise as I’m sure I would not have done the exercises on my own.’**

**‘By having the commitment of a physio led class it motivates me. I definitely would not do a 45 min session on my own.’**

**‘I love being online as no traveling to venue and lifting my Rolator in and out of the car particularly on those wet days that we get plenty of!’**

**‘Definitely felt better for doing some exercise. Also, it got me out walking too and I enjoyed chatting to my fellow classmates.’**

**‘[I am] [m]ore independent physically and socially, mentally more alert. In better form.’**

In a separate survey, we asked people what their preferences were for attending programmes in the future. In total 497 people responded across the country. When asked about preferences for exercise programmes 54% of respondents want a mix of in-person and online, 20% would like to restart on online only and 22% would like in person only. Responses for other types of programmes such as meditation and peers support groups was very similar.

These results are significant and will likely affect the planning and development of future programmes. Thanks to everyone who took part.

## The Importance of Exercise



Exercise can directly impact your quality of life. Research has shown that physical activity can be beneficial for a wide range of typical MS symptoms. Exercise can improve your balance, it can reduce your fatigue, it can increase your overall fitness which in turn means more strength and stamina for the activities you enjoy. Exercise has also been shown to have a beneficial effect for the mental health of people living with MS as it can lead to a reduction in the frequency and severity of low moods and depression. It is our goal to make people who are newly diagnosed with MS aware of the impact exercise can have upon their own quality of life and to support those living longer with MS to use exercise as part of their living well toolkit.

**“I attended the Move Smart Better Balance classes online for 8 weeks under the leadership of Susan Coote & Mary Davis. I have only good to report on the whole experience. We were put with other people who had the same challenges to face from all over the country and it always felt comfortable and easy to share with them, from the comfort and convenience of home.**

**The social aspect was an important part of the course as well as the obvious benefits of the physical activity, under the expert guidance of Susan and Mary. I have thankfully not had a fall since the start of the classes thanks to following the advice given and I’m trying to integrate movement more into my everyday life, as the importance of movement and exercise was clearly demonstrated in combatting our daily struggles with MS.**

**I would encourage everybody to attend such a course.”**

**Eibhlín, Living with MS,  
Galway**

## The Move Online

While the pandemic has been a trying time for everyone, in forcing MS Ireland’s exercise programmes online, it has been a blessing in disguise. Our feedback from participants has been fantastic - by hosting classes online there is no longer any commute to worry about, there’s no travel time, no fatigue-related to travelling to consider nor any accessibility issues to be concerned with. Additionally, Move Smart MS can recruit on a national scale. Our classes are full, with people from around the country, all participating in specialised, symptom-focused programmes.

**“I didn’t think that a physio class would work so well on zoom. In fact, I think it worked better as we were grouped together by ability rather than location. Also less stressful not having to travel to a location to attend class. With Covid I would not have attended this class to a location.”**

## What does Symptom-Focused mean?

Our exercise programmes are led by physiotherapists specialising in MS. They take place over an 8-10 week period, just the same as many MS Ireland regional exercise programmes. However, where Move Smart MS differs is that our programmes specifically tackle a certain goal or MS symptom. For example, we offer programmes that aim to reduce dizziness, improve balance to reduce falls or focus on bladder and bowel management. We even have a programme dedicated to those newly diagnosed and imparting all the beneficial information and exercises they might need at the start of their MS journey. By specialising our programmes, Move Smart MS takes a targeted approach to managing your MS symptoms.

**“Physio is so important when you have MS. The session was most enjoyable and fun. The balance of 30 minutes discussing a topic related to MS, followed by a very robust 30 full on physio class was excellent. I cannot recommend it highly enough.”**

**Mark Mitchell, 65**



## The Importance of Education

While we do want to get you moving at Move Smart MS, we also want to get you thinking. As mentioned, exercise can directly impact your quality of life, but it must be bolstered by the knowledge of how to exercise and why you are performing specific actions. Each of our programmes offers an educational component wherein the physiotherapist leading your class will talk to you about the specific focus of your programme, and why you are concentrating on particular movements and exercises. We aim to help you find motivation, to overcome any barriers you might face and leverage any advantages you might find. By increasing your own understanding of exercise's role in your MS journey, you increase its impact upon your quality of life. As our programmes conclude, our goal is to give you both the tools and skills to keep going without us.

**“[Move Smart MS Physio] made me feel very comfortable asking questions. She was happy to detour on occasion to suggest possible variations that may work best for individuals. I found it very help to be able to ask questions in a supportive environment.”**

## Stronger Together



Lockdown has obviously been an isolating time. Even now, for many of us around the country, the reality of meeting up indoors and in-person is still a way off. Our feedback to date has shown that regular Move Smart MS exercise classes can also be a much-needed social event for many of our participants. Though hosted online, Move Smart MS represents a regular opportunity to socialise with people around the country, at a similar stage through their MS journey. In addition to the educational component of our classes, in which participants are encouraged to voice their thoughts,

there is a sense of community and teamwork that comes with participating in one of our specialised online exercise classes.

**“[I] think the approach of having a wider suite of tailored programmes to cater for differing needs of people with MS was great. Having the classes led by physiotherapists with a knowledge of & interest in MS gives people with MS a sense of security & encouragement that the exercises will be manageable for them & that their particular concerns will be taken into account.”**

## Who foots the bill?

Move Smart MS is funded by the Innovate Together Fund from Rethink Ireland in 2021. Rethink Ireland supports non-profit organisations working in communities across the country. Essentially, as Move Smart MS is directly funded by Rethink Ireland, we can offer our programmes free of charge. This removes yet another barrier to participation for some people - a financial one.

We are currently exploring avenues for making Move Smart MS a sustainable programme and are investigating funding options for 2022.

## Moving into the Future

Move Smart MS currently offers 12 different specialist programmes for coping with specific MS symptoms or outright improving strength and fitness. In September, Move Smart MS has a new batch of classes commencing and 90 people living with MS from around the country will participate in our programmes. If you would like to register your interest for programmes in 2022, please email [MoveSmart@ms-society.ie](mailto:MoveSmart@ms-society.ie) or call **086-074 9628**.

Ultimately, it is our aim for Move Smart MS to be regarded as the natural first step towards achieving your fitness or symptom-focused goals.

**“I am now walking at least 5000 steps a day, and one day I reached 12000 using my rollator!... This is an excellent class. For the first time since my diagnosis I feel I've got this!”**

## DAVID LAYDE'S NETFLIX STORY

*In the summer of 2020, MS Ireland received an email from the production company of Netflix's smash hit comedy series 'Sex Education' starring Asa Butterfield and Gillian Anderson. The production team were looking for someone to play the role of Roland Matthews, a father, living with MS who is warm, cheeky, sharp and witty.*

*MS Ireland put out the call on our social and email channels, which caught the eye of David Layde. David is an actor from Dublin and is living with MS the past 11 years, he applied for the role and the rest is history! Recently we caught up with David about his experience starring in one of Netflix's biggest series.*



I was born raised and still living in the big smoke of Dublin! I got into acting through my mom and dad, both my parents were actors. My father was a well-known actor back in his day, Pat Layde. He was in the likes of Philadelphia here I come, and he had a small part in "Ryan's Daughter" as well as being a regular at the Abbey. My mother, Joyce Layde, was an actress too so you could say that acting was in the blood.

Last year, a good friend of mine, Pauline Good, who is living with MS saw the ad looking for a role on MS Ireland's Facebook page, she tagged me in the comments as she knows I am into the acting. I had a look at the post and thought that it looked interesting, and said to myself, "I am going to give this a go", and that was it.

MS Ireland was my first contact, I reached out to Tom at MS Ireland and he put me in touch with Eleven films (the shows production company), there was a small bit of back and forth, some screening questions about my MS and how I was doing. I sent them over a C.V. of my work and they seemed pretty pleased with everything I told them about my career and my life with MS.

They invited me to make a self-tape, which is usually the first stage of an audition process. Most of the time this is just a simple selfie video of someone's face and a white background, but my girlfriend and I decided to give it a real go and re-enacted the full scene. My girlfriend was great, she is not an actress but took part in the full scene for me, she made me wear a leopard skin dressing gown for the tape which she claims swung it for me!

I sent the audition tape to my agent, and she mailed back saying it was great and she sent it off to Netflix. Within a day they got back saying they loved it and they will get back to me. This all took place in July in the Summer of 2020 and one day I got a mail saying that I had the part. Before I knew it, I was booked in for filming on the 4th of November.

I flew over on the first week of November, I didn't meet anyone until I went on to set and I was put up in a hotel. First, I had to travel to London to get my wardrobe sorted and what I was going to wear on set and the next day I was driven to Wales put up in a hotel and the following morning I was on set. It was all a bit surreal, walking on to set and

filming with two big stars like Asa Butterfield and Mimi Keene. They were both absolutely amazing and friendly with me, they really helped me with my nerves by playing some word games in the dressing room beforehand. We shot the scenes all in sequence and it took almost one day to complete the scenes in full. The director was a real pro and went into everything into great detail. Joe Wilkinson who was also in the scene, playing Jeff, is someone that I am a huge fan of so it was bit of a dream to work with him.

I was playing a character called Roland Matthews, who was the father of Ruby Matthews, who revealed in the second season that her father was living with MS. It was interesting because usually I must imagine the world the role is in, but I was diagnosed with MS and have been living with it the last 11 years, so I kind of knew how it might affect the world and people around you. I used my own experiences and learnings to show how that would affect Ruby, and his wife – so it was unique in terms of my preparation for it.

I think Roland had more physical ailments, with restricted movements, which I don't, so there is a bit of research into the different types of MS, it can be so different to different people. A friend of mine is a physio in Galway so I spoke to him about lack of spasticity in the muscles and how that might impact my movement. Roland obviously has challenges, and he is a warm character at heart and someone who loves his daughter dearly.

In terms of my own MS story, it all started about 12 years ago, I was diagnosed with optic neuritis completely out of the blue. I had some strange vision going on in my eyes and I decided to get some tests in the Eye and Ear. Initially they couldn't really find what was wrong, and I thought nothing off it. Later, a doctor called me and encouraged me to go back for another scan and that was when I was diagnosed with Optic Neuritis. It was at the Eye and Ear Hospital that they mentioned that it might be MS and referred me to St Vincent's.

I can remember it clearly being told it might be MS. I left in complete shock. I walked up Dame Street, in my head I

was thinking this was Motor Neuron Disease. I was in a state of absolute shock it felt like the bottom has fallen out of things.

The team at St Vincent's were amazing. Once I was diagnosed, they referred to a neurologist who helped me get my head around the diagnosis. The MS nurse I had at the time was wonderful about speaking sense to me and keeping me grounded. She would tell me facts and would tell them to me very straight but in a nice way. She told me that many people can live a very happy life with MS.

Although it came as a shock and has impacted my life, there has been some positives to my diagnosis. I gave up smoking after 16 years and I started to make some positive life changes. I got fitter and became committed to leading a healthier life. Looking back at my diagnosis now, what seemed at the time was a scary thing, there were a lot of positive outcomes as a reaction and my choices.

I have challenges. My life has changed but making positive changes in my life, I find that I can help me manage the difficult times. My advice would be to anyone who has been diagnosed is to keep at it and keep going. I could have taken the news worse. If you told me two years ago, I would be in a Netflix hit doing scenes with A-list celebrities, I wouldn't have believed you! I was thinking of giving up acting prior to the role but was so happy I didn't. My message might be clichéd, but it is simple, **NEVER GIVE UP!**





## MS IRELAND ANNUAL AWARD WINNERS



Our Annual Awards are the Society's way of recognising the contribution many of our members make within their families, local communities and MS Ireland. We are delighted to celebrate this year's winners.

### MS PERSON OF THE YEAR MAIRIN HARRIS

**Nominated by Mark Mitchell MS Ireland's East Wicklow Branch.**

Mairin has been the most dedicated branch member of MS Ireland's East Wicklow Branch and was a member of the original Bray branch. Mairin attends every flag day from Bray to Greystones to Wicklow and Arklow, without fail she always attends our coffee mornings, AGM's, annual lunch's, Summer BBQ's, and all our branch outings. She even attended the Aras and met Michael D himself! She always supports our MS calendar and Christmas cards faithfully. Mairin tends to hide from the highlights and does not participate in committees.

However, she makes up for this by her total dedication to the branch. Living in Arklow, Mairin

was instrumental in setting up the Friday coffee morning meet-ups which has been running very successfully for the past few years and over twenty PwMS in Arklow attend faithfully.

Mairin is incredibly supportive to everyone in the community at the coffee mornings and on Zoom due to COVID. Mairin likes to get involved and is a great listener offering support by being there and giving people the space to feel comfortable to talk about their MS.

Mairin never misses the support groups and her contribution stands out a long way. Mairin has a positive attitude and has touched the lives of so many people by showing she cares.

A very worthy candidate for the MS Person of the Year Award.

As already mentioned Mairin is a lovely woman who always supports coffee mornings, branch meet ups flag days, AGM, lunches, and always with a smile and caring way. Shows great interest to newcomers advising people of different ways to cope with any worries they may have with their ailment her dry sense of humour takes me by surprise all the time she well deserves this honour of MS Person of the Year

### CARER / HELPER OF THE YEAR HELEN BINIONS

Helen cares for Her husband Clinton Binions. Clinton was a dairy farmer in Ballyhad in Co. Wicklow. Two years post-diagnosis, Clinton had to use a wheelchair and it was a significant adjustment adapting to life as a wheelchair user.

He introduced me (Mark Mitchell) to the ECDL course by distance learning c/o National Learning Network in Bray. I asked Clinton was it tough going, his reply was, "Well, I was a farmer and I managed, so if I can do it, anyone can."

Helen oversaw her entire house being adopted for Clinton and drove him to every branch committee meeting, every coffee morning, AGM, annual lunch, all our branch outings and every flag day etc. Helen cared for him single-handedly all of the time though there is wonderful family support. Over the years Clinton has had health issues and Helen always stood by Clinton bring him to all his hospital appointments.

Clinton played badminton on winning teams with Helen until his MS. Helen has always been a great carer - worked with Riding for the Disabled for over 30 years. Clinton drove for as long as he could and said giving up driving was one of the hardest things. Then Helen brought him everywhere for his beloved bluegrass/country and gospel bands playing all over Ireland all year round as well as all the Wheelchair Association and MS meetings and functions.

She cared for 5 grandchildren on and off during this time - always cheerful and loving no matter how tough times were. She kept Clinton swimming for as long as possible in Ireland and abroad. During COVID she has kept him in touch with his family through Zoom. Always imaginative and finding new ways of making life more interesting for Clinton. Married 51 years this year.

**From Martina O'Sullivan, EWB Treasurer:**



I met Helen years ago when attending yoga in Shankill she used to bring Clinton to and back from the classes and we go for a cuppa afterwards she was always in good form and she would join in the conversation, comes up with some good fundraising ideas like wear your wedding dress for MS and even when she had a significant birthday she asked people to give donations to MS society.

Helen deserves this award as she is always thinking of others rather than herself, love the way herself and Clinton enjoy. Always doing things together they go on trips away to country music festivals which is brilliant.

## VOLUNTEER OF THE YEAR WILLIE DOHERTY

**Nominated by Jackie Browne, Chairperson of the Donegal Branch**

Involvement with MS Society – Willie has been involved with the Donegal Branch for over 40 years as fundraiser extraordinaire and has served on the Welfare Committee for many years helping those in need with MS.

Willie has dedicated his life to helping those with MS raising tens of thousands of euro to support those with MS. Willie turned 90 years young this year and is as dedicated as ever.

Willie organises church gate collections in 12 parishes, gathers many thousands worth of sponsorship for greens and prizes in the golf classics, sold hundreds of boxes of MS Christmas cards and got prizes sponsored for the MS Christmas dinner. Willie is well known for sitting outside Tesco selling tickets etc. He went to Lourdes as a carer on 3 occasions. It gives me great pride to nominate Willie to be considered for the volunteer awards – he is one of life's genuine, caring people and a true champion in helping those with MS all across Donegal and further afield. Willie also won an award from the ME4U Volunteer awards in Donegal.





Kathleen and Mike Stapleton live in Ballyragget, Co Kilkenny, and they have gone through a lot in the last 21 years. From a point where they were told that Kathleen's illness was 'all in her head' to today, where she is part of a ground-breaking project using robotic technology to help people walk. It's been a rollercoaster journey, but

one where they have learned many lessons and cherished the positive experiences.

Teenage sweethearts, Kathleen and Mike started to notice what turned out to be symptoms of Multiple Sclerosis when Kathleen was just 18. She started getting numbness in her leg, which got worse as time went on. But then the symptoms went away for a long time.

Some time later Kathleen began to get a pain in her arm and shoulder. It was a severe pain, Mike described those first signs. This went on for a while. Mike was worried but Kathleen was a young mother and very active, loved walking with her friends. One day a friend rang Mike, after she'd been for a walk with Kathleen. She was worried. Kathleen seemed 'wobbly,' was she drinking at home? She wasn't, but the symptoms were now becoming more obvious and Mike was really worried.

"We went to the doctor, we went to St Luke's, but we were brushed off. Kathleen was told she needed physiotherapy, but there was no one more active than Kathleen," Mike said. It came to a head when Kathleen went to a funeral in Paulstown, one day, and had a fall. Mike was working in Dublin in those days, and immediately got the train back to Kilkenny. Again, they went to a doctor, and to St Luke's. This time Kathleen was admitted.

More than 20 years ago a lot less was known about MS and how to diagnose it. Even with all her symptoms, advice from doctors differed. Mike said they met one young doctor who did a lot of tests and he was not happy with what he saw. He arranged for Kathleen to undergo an MRI. But another doctor told Mike that it was all in Kathleen's mind. The next day, before Kathleen was taken to Limerick for the MRI a doctor told Kathleen she was wasting the time of the ambulance crew and ambulance.

Kathleen stood up for herself, Mike said, and went to Limerick for the scan. That evening he got a call from the hospital to be with Kathleen the next day for those results.

They knew something was wrong when a doctor hovered around the ward door and couldn't speak to them until joined by a nurse. 'The news is bad,' the doctor said when she eventually joined them. "We had four young children. In my head the game was up," Mike described his dreadful fear in that moment that his wife would be diagnosed with a terminal tumour.

'You have multiple sclerosis,' the doctor told Kathleen. Mike's response was to exclaim 'oh Jesus, thank God,' because, he said, he knew people with MS and he knew they were living with it.

After five or six years of symptoms and looking for a diagnosis they finally had one.

Multiple Sclerosis is a life-changing condition. It's an autoimmune condition that affects the brain and spinal cord.

21 years ago it was so hard to get a diagnosis, Mike explained. For Kathleen the diagnosis was a 'pure relief.' The first thing she said to Mike was that she wasn't mad.

Life went on after that, he said.

Today, getting a diagnosis is a very different situation and people are checked for it a lot. Once Kathleen got into the system, 'people were brilliant.' She got to see a neurologist and a pain specialist. Mike had seen his wife at times in severe pain. It was explained to them that it was nerve pain and one day it would just stop. Painkillers did nothing to ease the pain when Kathleen was struck with it, but then one day the pain did ease and, over a few months, seemed to go.



“I found once we were in the system they were brilliant. The equipment we have in this house for Kathleen is second to none,” Mike said. She was able to avail of occupational therapy, physiotherapy and speech therapy. “Anything we needed. They are brilliant, I can’t fault them,” Mike said of the HSE.

He also has great praise for Castlecomer District Hospital where Kathleen goes for respite care. “The care she gets there, I can’t say enough good about the hospital in Castlecomer,” Mike said.

The family are also supported by homecare hours and Mike said the Irish Wheelchair Association ladies “are brilliant, kind, nice people. As good as you can get.” He paid tribute to Carers Ireland and Sage for helping them get those support hours. Mike had special praise for Katie Hourigan, the regional community worker with MS Ireland in Kilkenny, and South East co-ordinator. The organisation doesn’t just support people with an MS diagnosis, but also their families.

“When I hit a wall, I rang her,” Mike said. He had been caring for Kathleen and at the time she had worrying health difficulties. He was tired and stressed. “Kathleen’s health is brilliant at the minute, but there were times when I didn’t know where to turn,” he said. “Five or six years ago Kathleen’s health was really bad. I didn’t know what to do or where to turn. I said ‘I can’t give up’ but I thought I’d have to. I rang Katie at 3pm one day. She was here the next day.”

Katie, and all who help in MS Ireland, understand what’s happening and are able to answer questions. They can put those with MS and their families in touch with organisations who can help and other supports.

When Mike wanted to get Kathleen walking again Katie put him in touch with Dr Paul Carroll at the National Rehabilitation Hospital in Dun Laoghaire. Dr Carroll enrolled Kathleen in a six-week programme at the Royal HOspital in Donnybrook to see if he could help her.

At the time Kathleen’s health wasn’t great. She had been back in St Luke’s and there wasn’t any more they could do for her. It was a low point but Dr Carroll said it was exactly the way he wanted her. Kathleen never looked back. The new treatments ‘turned her life around,’ Mike said and

recommended anyone with MS to look into the treatment provided there. “It was a miracle,” he said. These days Kathleen is confined to a wheelchair, but she is full of life. Science is giving her amazing hope.

A chance viewing of the Late Late Show, one Friday night, has led Kathleen to her next adventure. She and Mike were watching as guest Ronan Langan from Dublin City University (DCU) Exoskeleton Programme showcased how it is helping people to walk. Kathleen was in tears just watching. Their daughter was also watching and that very night sent an email to DCU. The next Monday they made contact with Kathleen and soon she was part of the programme.

The exoskeleton programme “has changed Kathleen’s world,” Mike said. The first day Ronan Langan fitted her to the robotics and she stood up Mike could see pure joy on his wife’s face. “The next thing she was off walking around the gym!” “It’s a game changer. We go to DCU once a week and I’m being trained to use the robot myself,” Mike said. In the future they hope the robotic equipment can be used outside the university setting.

The DCU programme is designed to deliver an array of benefits that regular walking in an exoskeleton provides for persons with spinal cord injury, stroke, multiple sclerosis and other neurological conditions. “Everything now is so positive, so good. Over the years it was tough for Kathleen and me, and very tough on our children. They are amazing, so good to us.”

Mark and Kathleen want people to know that while a diagnosis of MS is a serious one, there are a lot of reasons to be hopeful. They also want people to know there is wonderful support available to them from MS Ireland. The support and human kindness Mike and Kathleen have experienced has made a huge difference to their lives.

*This piece originally appeared in **Kilkenny People**. It has been slightly edited in order to reduce the word count to fit our publication. Our many thanks to **Kilkenny People** and the author Sian Moloughey for their permission to share.*



# MS INFORMATION LINE

We've changed our  
number to

**0818 233 233**

**CONNECT WITH US ON SOCIAL MEDIA**



**VISIT OUR WEBSITE**

**WWW.MS-SOCIETY.IE**



## My Abseil Experience

### By Eoghan Brophy

The annual abseil fundraiser in Croke Park took place this year on the 30th of June. An overcast, drizzly morning greeted a group of intrepid fundraisers for MS Ireland into Croke Park. Previous years had seen us all gather in the Hogan Stand, but this year was unusual. Croke Park has been doing double duty in recent months as a venue for both the Courts Service and as a COVID-19 vaccination centre. Luckily the Cusack Stand was not in use.

The rain eased off as the first group of abseilers ascended the stairs, suitably attired in their red MS Ireland t-shirts and wearing their climbing harnesses. Nerves were minimal. Apart from a pair of disposable nitrile gloves and the customary facemasks worn these days, it was business as usual. I myself had done the abseil twice before,

The practice session was most instructive. The instructors were experienced and explained how the various pieces of climbing equipment worked including the carabineers and ladder-feed. It actually is impossible to fall at an unsafe speed. No reason to be apprehensive then, unless you have a fear of heights.

The abseil in Croke Park isn't complicated. You strap on a climbing harness, a pair of gloves and a helmet, do the practise session with the excellent instructors and then walk to the top of the stadium around the skyway until you get through the bones of the building to the top of the scoreboard. It's about 80 metres above the stand below. Actually, the trickiest part for me was getting down the ladders onto the scoreboard without bruising my knees.

The most difficult part of the experience is getting to the 'going down' part. Someone was looking after my safety rope, ensuring I would be gently eased to the ground. It's an odd feeling hearing someone tell you that can "swing your legs over there and step off the gantry whenever you're ready".

Being a former member of the UCD climbing club, I understood how the equipment worked and so knew how to trust it. It would be unusual not to be nervous

of course, so I checked my knots and fixture before I took my short step into thin air.

I am glad I went. I always meet lovely people at MS events and fundraisers. I was even able to help another abseiler with a wayward GoPro. My own descent footage was less spectacular. I'll surely get better results next year.

As the various groups began to trickle back to the assembly area under the Cusack Stand, their smiles and sense of accomplishment were self-evident. A small step in the right direction is always welcome. Numbers were down this year due to the pandemic affecting corporate groups. We hope to see them next year as things improve.





# FUNDRAISING COMPILATION

## UPCOMING EVENTS

### New Year – New Challenge



Check out our website for ideas of challenges that you can take up to support MS Ireland. Join our Spring Facebook Challenge 3,000 Crunches in March 2022 – this online event was a huge success in 2021 with

over 1,000 participants completing over 3 million crunches and raising €135,000.

### Skydive

Register for a skydive via our website [www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland](http://www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland) and contact [melanie@ms-society.ie](mailto:melanie@ms-society.ie) for dates that suit you



### Virtual Golf

If your club is hosting a Charity Day, you could put MS Ireland forward as the beneficiary. Golf Charity days are great fun events and a huge support to charities.



### Bridge

Do you play bridge? Would you nominate MS Ireland to be a beneficiary of your charity events? Please contact [melanie@ms-society.ie](mailto:melanie@ms-society.ie) for more information.

## Challenge yourself

Join Team MS Ireland and try something different - why not register for one of the many challenges or come up with your own. Contact [melanie@ms-society.ie](mailto:melanie@ms-society.ie) for ideas.

## Thank you

### Abseil

At the end of July we were able to have our first in person event in 2 years – where 30 intrepid fundraisers Abseiled down from the top of Croke Park. It was fantastic to finally be able to hold this event which has originally been scheduled for October 2020. This challenge raised nearly €20,000

### 10,000 steps a day in August

An enormous thank you to all those who participated in our 2nd Facebook Challenge – it was a huge success! Our intrepid walkers took on the challenge of walking 10,000 steps every day in August. Over the month of August they sent us wonderful photos from all the locations they were walking reminding us of the beautiful country we live in. This challenge raised €50,000.

### Mini Marathon

This year's Mini Marathon was a virtual event again over a weekend in late September instead of its usual date of the Bank Holiday June weekend. Despite the continuing changes we had a wonderful group of ladies join Team MS Ireland who raised approximately €11,000



## Challenges



Clarice

Conor

Ken

Thank you to the many Amazing people who have undertaken challenges for MS Ireland this year including - Ciara Griffin, Clarice Tighe, Tammy Feeney, Conor Heaphy, Noirin Flynn, Keith Kavanagh, Michelle Holland, Ben Hunt, Sean O'Shea, Emma Flood, Julien Jully, Danny Murphy and Micheal Mooney, who all took on extraordinary challenges and raised much need funds for MS Ireland. There are many others who took on wonderful challenges, too many to mention.

**THANK YOU!!**

## Sunrise for Brain Conditions

This voluntary group raises funds for 4 charities including MS Ireland with various challenges during the year – the main event being the Croke Patrick walk held on the last weekend of June.

## Henley Mermaids

The intrepid Henley Mermaids have taken on a variety of challenges including an attempt to be the first all-female team to swim the Bristol Channel (they swam 60 of the 65 miles before they were caught by the tide) We are very grateful to them for all they have done this year.



## Marathon des Sables



This is a 6-day marathon over 250Kms in the Moroccan desert, a real endurance test to even attempt the race, never mind complete it and raise funds. But this is exactly what Andrew Lynch did. He completed the 250kms and raised a staggering €35,000!

**Andrew Lynch took on an incredible challenge**

## Shave or Dye



Many thanks to James Flanagan who raised over €22,000 on behalf of the South Tipperary branch with the 'Shave or Dye!' event'.

**James Flanagan presented the cheque to MS Ireland's Maurice O'Connor**

## Public Service Credit Union

Thank you to the Public Service Credit Union for their incredibly generous donation of €25,000 towards MS exercise related activity.



**The team presented the cheque to MS Ireland's Mary McKeon and CEO Ava Battles at our National MS Care Centre**



## RTE Does Comic Relief

MS Ireland was delighted to have received a very generous grant of €50,000 from “RTE does Comic Relief”, to update IT infrastructure within the organisation. Thank you for the support!



## Information Line

MS Ireland would like to extend our many thanks to Alkermes for their support of the MS Information Line over the past two years. From January to October 2021 alone, there were 615 calls to the Information Line, 229 emails, 9 letters, 16 Facebook contacts and 20 contacts from other sources. What an impact!

## MS Care Centre

A massive thank you to our friends at Perrigo for their incredibly generous donation of €40,000 to carry out essential works to the National MS Care Centre. The ongoing support of Perrigo to the MS Care Centre is hugely appreciated by our residents and staff.



Paul Hatton from Perrigo handing over the cheque to MS Ireland CEO Ava Battles

## Maynooth Students Union



MS Ireland's Sally Spearman paid the college a visit for the cheque presentation

A huge thank you to all the brilliant students and the team from Maynooth Students Union, who over 20/21 put on several fantastic virtual events in aid of MS Ireland raising €10,000!! Our Senior Fundraiser, Sally Spearman, recently paid the college a visit for the cheque presentation.

## The May 50K


A huge thank you to everyone who participated in The May 50K this year! It was an amazing month: the MS Community in Ireland raised over €252,000 - 50% of the funds raised will go to MS Ireland projects and 50% will fund life-changing MS research and access to treatment projects around the world.





## MS News Feedback

During the COVID-19 pandemic, there has been disruption to our usual MS News schedule and format. We have taken time to consider the relevance of this publication to our community but would love to hear from you to best understand the level of importance of this publication to our community and to establish if the content we are providing is interesting and relevant to our readership. We would greatly appreciate if you could take a few minutes to complete a very short questionnaire to help us understand your views and thoughts on MS News.

If you have a smart phone and would like to complete the survey online, please scan this code which will bring you to a Survey Monkey link. 



If you would prefer to respond on this page, please complete it and return to **Aoife Kirwan, MS Ireland, 80 Northumberland Road, Dublin 4.**

All responses are entirely anonymous and the information gathered will only be used inform our planning for information provision. Taking part is entirely voluntary.

### How do you receive MS News?

- Via post
- Via email

- Feature pieces from professionals
- Fundraising updates
- Branch News

### Would you still be able to receive MS News if it was only distributed by email?

- Yes
- No

### How frequently do you feel MS News should be distributed?

- Every 3 months
- Every 6 months
- Every year

### Do you feel MS News is of benefit to you?

- Yes
- No
- Not Sure

### Did you find the option of using QR codes useful in this edition of MS News?

- Yes
- No
- Unsure

Please rate the following elements of the publication in terms of their importance to you. (With one being of no importance and 5 being very important)

- News
- Advocacy updates
- Information on how to get involved in advocacy activities
- Stories from people living with MS

### Would it be useful to you if you could access MS News articles as audio files which you could listen to?

- Yes
- No
- Unsure

### What kind of content would you like to see in MS News?

### Are there any other thoughts you would like to share with us regarding MS News or suggestions for improvements?





*Charity  
Research*

# *Ball*

*Saturday 28th May 2022*

*McBrisson Hotel Dublin*

*7pm till Late*

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 **MSIreland**  
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND