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National Conference



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Extraordinary Fundraiser

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World MS Day



EXPLORING MS

MS Ireland were thrilled to launch *Exploring MS*, an engaging activity booklet designed to help children learn about MS in a friendly and accessible way. Through a combination of stories, activities, and exercises, this resource offers young readers a chance to explore what MS is, how it feels, and how it impacts daily life for those living with the condition.

The booklet aims to build empathy and understanding, helping children connect with friends, family members, or others in their community who may live with MS. With simple explanations and interactive activities, *Exploring MS* clarifies misconceptions about the condition while encouraging thoughtful discussions. Children are also introduced to emotional support tools and affirmations, empowering them to process their feelings and express care for others.

By making complex topics relatable and easy to understand, *Exploring MS* nurtures compassion and encourages inclusivity. Whether used at home or in other

settings, this booklet provides a supportive space for children to learn how they can help and empathise with loved ones who have MS.

Speaking to the value of the resource, Orla Marron, a mother living with MS says “I would have loved to have had a resource like this when I was diagnosed. It would have been a great conversation starter and helped me to navigate a challenging topic with my children. Going through the booklet together, since its creation, has been wonderful—the activities are engaging, the explanations are simple yet thorough, and it’s made talking about MS so much easier.”

The booklet is available on our website as well as a letter containing answer keys to the various activities.

We hope this resource inspires a greater understanding of MS and fosters a world where kindness and awareness grow hand in hand.

EXPLORING MS

A children's activity book
about multiple sclerosis



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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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Dear Friends,

Welcome to the latest edition of MS News! In this issue, we bring you a wealth of insights, stories, and updates that reflect the resilience and unity of our MS community.



Throughout this edition, you will find heartfelt letters from our *Many Stories* campaign, offering powerful perspectives from those living with MS. This campaign was part of our World MS Day 2024 activities.

We are particularly excited to highlight the extraordinary efforts of Ciaran Coakley, a remarkable teenager who took on an incredible challenge to raise awareness and funds for MS Ireland. This can be found on **page 10**.

MS Ireland recently held our National Conference and Annual Awards in Monaghan! You can read all about it on **pages 8 & 9**.

We're particularly honoured to share a personal account from a husband supporting his wife with MS, providing a touching glimpse into life with the condition. You will find this piece on **page 18**.

Additionally, we delve into the importance of sleep hygiene on **page 24**, offering practical tips for those seeking to improve their rest and overall well-being.

On **page 26**, you'll also find a summary of the recent budget and how it may impact you, along with updates on our new MS Awareness in the Workplace project on **page 28**

You will find updates on our fundraising efforts from **pages 29-31**.

Your involvement and support make a significant difference in our mission, and we are grateful for your continued engagement.

We hope you enjoy this edition of MS News and find the stories and information meaningful. As always, we welcome your feedback and contributions - our Editor, Aoife Kirwan, is always happy to hear from you.

Warm regards,
Ava Battles.

Ava Battles
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Advocacy for Neurological Conditions at Leinster House



As Vice Chair of the Neurological Alliance of Ireland, Alison Cotter, MS Ireland's Advocacy and Research Officer joined Minister Colm Burke and Senator Martin Conway at Leinster House for a crucial briefing on neurological conditions. The session gathered clinical healthcare leaders and patient advocates to address the challenges faced by individuals with neurological disorders. The World Health Organisation highlights that these conditions are the leading cause of disability globally. Discussions focused on the progress made in healthcare strategies and the ongoing need for resources to support over 50,000 new diagnoses annually in Ireland.

Health Insurance Talks

MS Ireland were delighted to engage with the Health Insurance Society of Ireland recently to discuss the realities of living with MS. This opportunity provided us with a chance speak directly to personnel working in various health insurance companies to show the human impact MS can have and some of the challenges that exist in relation to health insurance. As a follow on to this, MS Ireland are working on a guide to MS and Health insurance which will be available in the coming months.



Addressing the Oireachtas Committee on Health

MS Ireland's Advocacy and Research Officer had the honour of addressing the Oireachtas Committee on Health as Vice Chair of the Neurological Alliance of Ireland. The focus was on the essential role of voluntary sector providers in delivering neurorehabilitation services beyond the standard 12-week window provided by Community Neurorehabilitation Teams (CNRTs). The call for increased investment in long-term rehabilitation services emphasised the need to help individuals maintain independence and quality of life.

World MS Day 2024



On May 30th, 2024, MS Ireland marked World MS Day with a range of nationwide events and awareness initiatives, centring around this year's theme of *Diagnosis*. Aimed at raising understanding and reducing stigma around multiple sclerosis, the day created a space for those living with MS to share their experiences.

Some of the activities included the *Many Stories* campaign, where members of the MS community wrote letters about their diagnosis, addressed to themselves, family, healthcare providers, or decision-makers. This powerful initiative allowed individuals to express the complex emotions of their unique paths and share insights into the realities of their experiences of MS. To kick off this campaign and to highlight this, 6 individuals wrote letters that were used online and as part of a display in St Stephen's Green Shopping Centre. These letters are included in this edition of MS News. Our many thanks to those who took part in this campaign. A special thanks to Novartis who supported us with this.

With the support of the HSE, Irish Pharmacy Union, community pharmacies and our wonderful community,

MS Ireland circulated fact sheets that shared crucial information about MS, reaching beyond the MS community to raise general awareness.

Nationwide, a range of Regional events took place which included coffee mornings, meet ups for younger people living with MS, Branch fundraisers, information seminars and radio interviews.

Across Ireland, *Dip for Diagnosis* encouraged participants to take a refreshing plunge—whether in their favourite swimming spot, local pool, or even a bathtub—in solidarity with people affected by MS and to help raise funds to support MS Ireland.

A coffee morning was held at the MS Care Centre, where supporters enjoyed coffee, entertainment, a plant sale, and a raffle.

In Leinster House, a Briefing and Panel Discussion was held launching the findings of the *My MS My Needs Survey*. This survey revealed significant gaps in care of individuals living with MS in Ireland, including lengthy wait times for neurologist appointments and inadequate access to neurorehabilitation services. The event aimed to empower policymakers with evidence-based insights while highlighting MS Ireland’s role in advocacy and support.

An Information event addressing the uncertainty that often accompanies an MS diagnosis was held. Featuring insights from Dr. Hugh Kearney, Dr. Sarah Casey, and MS community member, Jamie Crawford, speakers explored how MS can impact life decisions and the challenges of navigating unpredictability. This event provided guidance and support to help those affected by MS manage the emotional and practical aspects of living with uncertainty.

Across the country, heritage sites, landmarks and buildings were illuminated in red, symbolising unity and raising awareness.

A massive thanks to everyone who got involved, attended an event or supported World MS Day 2024.

Development of the National Disability Strategy

Our Advocacy and Research Officer participated in a pivotal event regarding the National Disability Strategy’s development, focusing on inclusive learning, employment, independent living, and health. The collaborative discussions engaged various stakeholders in shaping a more inclusive future for individuals with disabilities in Ireland.

Engagement with HSE Leadership



The Advocacy Officer met with HSE CEO Bernard Gloster and key stakeholders to discuss critical issues in neurology and neurorehabilitation services, reaffirming the importance of voluntary sector providers in delivering necessary care.

Call for Budgetary Support for Neurological Conditions



As Vice Chair of the Neurological Alliance of Ireland, Alison Cotter, MS Ireland’s Advocacy and Research Officer emphasised the urgent need for funding in the upcoming budget to support community neurorehabilitation teams and access to neurologists in various regions.



Opening of the National MS Respite Centre



MS Ireland celebrated the successful launch of the National MS Respite Centre, made possible by additional funding in Budget 2024. This successful advocacy initiative represents a significant step forward in supporting individuals with MS and other neurological conditions.

Advocacy for Long-Term Neurorehabilitation Services



The Advocacy and Research Officer addressed the Oireachtas Committee on Disability Matters, advocating for the expansion of long-term neurorehabilitation services and the critical role of voluntary providers in supporting individuals with neurological conditions. The presentation highlighted the need for sustainable funding to address geographic disparities in service provision.

Young Persons Network

Following on from the European Multiple Sclerosis Platform (EMSP) and MS Ireland event which took place in January 2024, a Young Persons Network has been active throughout the year. This group meets online to discuss various topics, support with the co-creation of resources and provide feedback on a number of MS Ireland projects. If you are aged 18 to 35 years, living with MS and would be interested in joining the young person network, please email Aoife Kirwan – aoifek@ms-society.ie



Stem Cell Webinar

In July, MS Ireland hosted a webinar exploring the use of stem cell therapy in MS. MS Ireland's Information Officer was joined by Dr. Maria Gaughan and James Flanagan to discuss MS and stem cell therapy. Dr. Gaughan shared expert insights on stem cell treatments, explaining their potential and challenges in managing MS. James Flanagan, who lives with MS, recounts his personal experience with stem cell therapy, offering a firsthand perspective on its impact. The recording is available on our website and YouTube Channel.



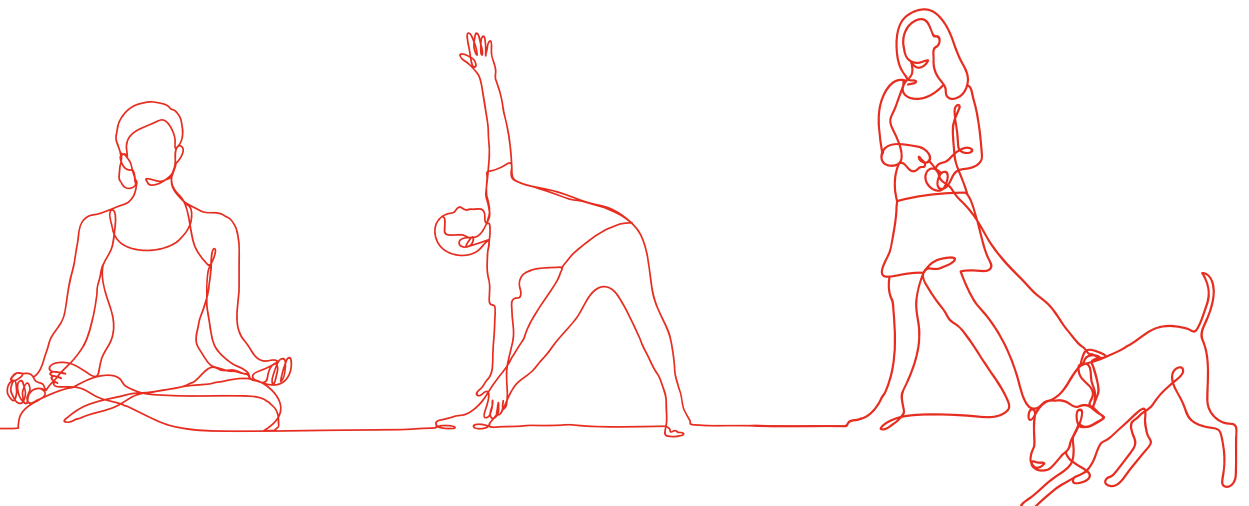
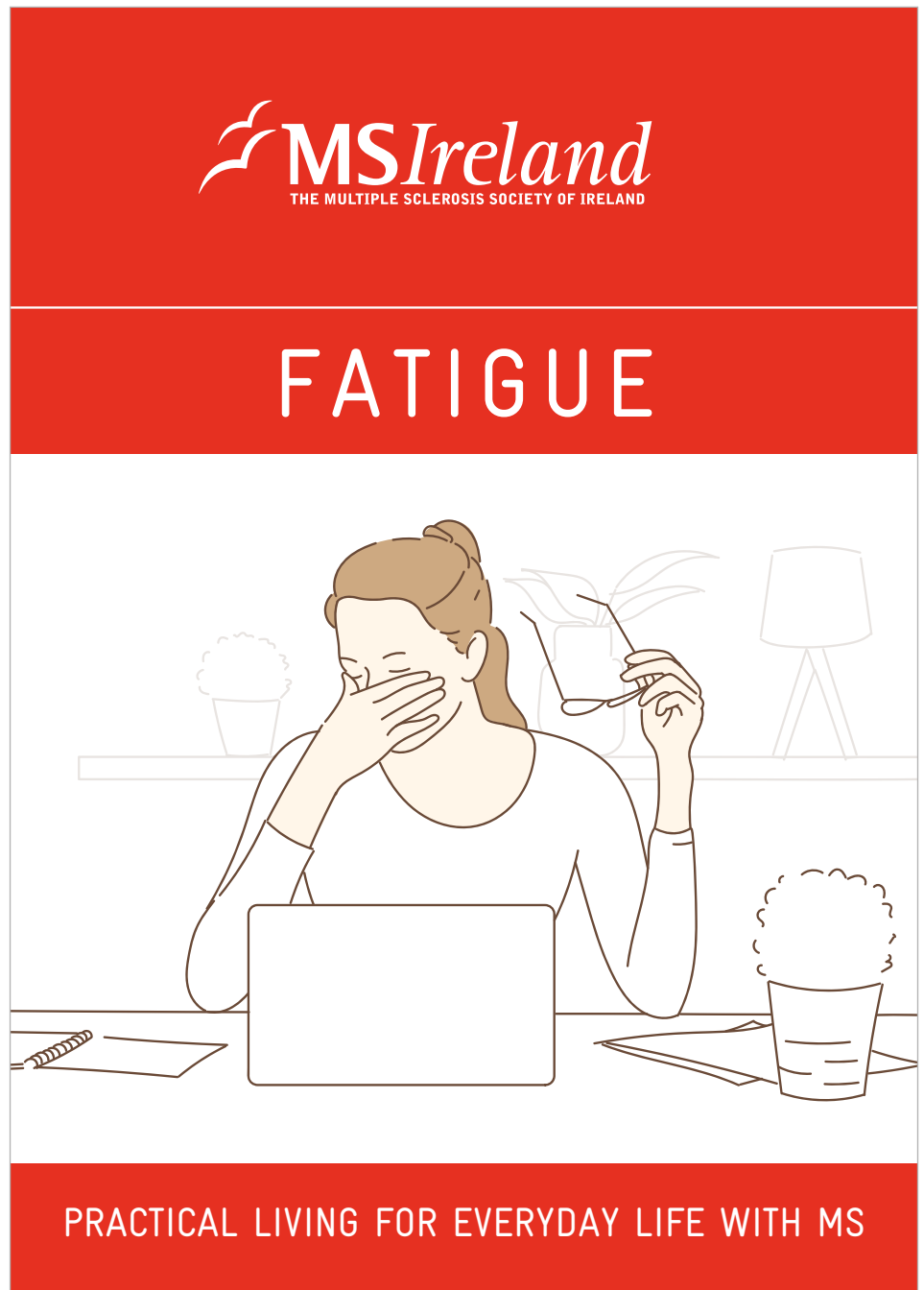
Launch of Fatigue Booklet

MS Ireland was thrilled to announce the launch of our newly updated fatigue management booklet. This is the first in a series of revised symptom management resources aimed at equipping our community with practical, evidence-based information to navigate the challenges of living with MS.

Fatigue is one of the most common and debilitating symptoms of MS, affecting individuals in diverse ways. The updated booklet provides comprehensive insights into the causes of MS fatigue and offers actionable strategies to help manage it effectively. It includes sections on tracking fatigue patterns, self-management techniques, and advice on balancing activity and rest.

This updated resource would not have been possible without the dedicated efforts of key contributors, including MS Ireland staff members as well as our Online Participant Forum and the Young Persons Network.

The Fatigue Management Booklet is available now from MS Ireland, in print and online.



MS Ireland National Conference 2024

The MS Ireland National Conference 2024 was a two-day event held at the Hillgrove Hotel, Monaghan, on November 6th and 7th. The conference brought together individuals living with MS, their families, caregivers and professionals to explore some of the latest developments in MS, share personal stories and celebrate contributions to the MS community.

Day 1

The conference began with a gala dinner and an evening of entertainment on November 6th. This elegant gathering set the tone for the conference, creating an atmosphere of camaraderie, connection and celebration. Attendees enjoyed live music and the captivating performances of an illusionist.



A highlight of the night was the announcement of the **MS Ireland Annual Awards 2024**, which recognised outstanding contributions to the MS community.

MS Person of the Year 2024: Kathryn Moroney

Kathryn's decade-long commitment as a Branch Committee member has been nothing short of inspirational. Despite enduring severe MS-related pain, she has led the Financial Assistance Committee with integrity, wisdom and kindness - always protecting the

dignity and privacy of those she supports. She balances her duties with caring for her family and raising awareness and funds for MS Ireland.



MS Carer of the Year 2024: Patsy Fagan

Patsy's lifelong devotion to his wife Liz, who has lived with MS for 44 years, moved all in attendance. Married for 45 years, Patsy has been her steadfast support, raising significant funds for MS initiatives and spreading awareness about the condition.



MS Volunteer of the Year 2024: Paul Ferguson

Paul's quiet yet dependable contributions over 12 years, from fundraising events to personal care for his brother-in-law, highlight the vital role volunteers play in the MS community.



Special Recognition Award 2024: Trevis Gleason and Emma Rogan

Trevis and Emma have been pillars of support and advocacy through initiatives like the *MS and Me Blog*, marking its 10th anniversary in 2023. Their co-authored book, *Living Well with Multiple Sclerosis*, provides invaluable guidance for those navigating life with MS. Their dedication has left a lasting impact, and MS Ireland deeply appreciates their invaluable contributions.



Day 2

The second day focused on learning, connecting and addressing some of the challenges faced by those living with MS. With 208 attendees attending in-person, as well as some joining the livestreams online, the conference proved to be a vibrant hub for knowledge-sharing and connection under the theme *Making Connections*.



The day commenced with Maurice O'Connor, MS Ireland Board Member and MC, welcoming attendees. Prof. Chris McGuigan from St. Vincent's University Hospital delivered the keynote address, "Current and Emerging Treatments in MS." Prof. McGuigan outlined existing treatment options and introduced some new therapies on the horizon, empowering attendees by providing them with information they can take forward to enable meaningful conversations with their healthcare team and to make informed choices.



Moderated by Dr. Michelle Murphy, the *Living with Uncertainty* panel discussion explored the emotional and practical realities of living with MS. Claire Lyons and Naomi Hunter shared

their personal journeys, while Mike Stapleton offered insights from his perspective as a caregiver to his

wife, Kathleen. The session provided a rich tapestry of experiences, strategies, and support mechanisms for managing the unpredictability of MS. Many attendees found this session deeply moving and relatable.

Afternoon Parallel Sessions

The afternoon featured diverse breakout sessions designed to address specific aspects of living with MS:

1. Understanding Entitlements for People with MS

This session demystified the complex financial and social support systems available to those living with MS, helping attendees navigate entitlements with greater confidence.

2. The Importance of Peer Connections

Participants explored how forming relationships with others in the MS community can alleviate feelings of isolation and foster mutual support.

3. Fatigue Management

Fatigue is one of the most challenging symptoms of MS, and this session provided practical tools and strategies to manage energy levels effectively and maintain an active lifestyle.

4. Assistive Technology

This session showcased innovative technologies designed to assist people with MS in their daily lives, offering solutions that enhance independence and improve quality of life.

Sophie Pratt, a registered dietitian, closed the conference with her talk on *Diet, Nutrition & MS*. She provided evidence-based insights into how dietary choices can influence MS symptoms and overall well-being, equipping attendees with actionable advice for managing their health.

Throughout the day, an information fair featured 18 exhibitors, offering attendees the opportunity to connect with service providers and organisations. Stands ranged from Community Policing to providers of aids and appliances, giving participants access to a wealth of resources.

MS Ireland would like to express our deepest thanks to everyone who attended the conference, both physically and virtually. The sense of community and support was palpable throughout the event, reflecting the shared commitment to improving the lives of those living with MS.



MS Ireland would like to thank Viatrix, Novartis, Merck and Roche for supporting our National Conference.

Extraordinary Fundraiser



Ciaran Coakley, a remarkable teenager from Clonakilty, has become a real source of inspiration in his community. After his mother was diagnosed with MS three years ago, Ciaran decided to take on a big challenge to raise money and awareness for MS Ireland. He ran an incredible 250km over 25 days between April and May, doing 10km every day.

What makes this even more impressive is that he managed to fit all this running around his schoolwork, sports, and other activities, running both in the early mornings before school and in the evenings.

Ciaran's reason for doing this is very personal. He was diagnosed with a rare mitochondrial disorder at birth, so he's faced his own health challenges from a young age. But Ciaran hasn't let this hold him back. He's become a talented footballer and hurler, and he's also doing great in school! He's clearly determined not only to succeed but also to help others.

Ciaran wasn't alone in his challenge. His friends from school and teammates from Ahamilla Clonakilty GAA club came out to support him, running alongside him every day so he always had company. On his final run, 58 members of his GAA club joined him for the last 5km, showing just how much everyone respects and admires him.

Ciaran's original goal was to raise €1,000 for MS Ireland to help the 10,000 people in Ireland living with MS, including his mother, who deals with pain and other symptoms every day. But thanks to his hard work and the generosity of his community, he ended up raising an amazing €14,408!

The Coakley family is well-known for their charity work, often raising funds for local causes. Ciaran's parents and siblings are incredibly proud of what he's achieved with this challenge. While Ciaran might be following in his parents' footsteps when it comes to helping others, it's clear he's carving out his own special path.

MS Ireland was delighted to have our Board member, Maurice O'Connor, accept the cheque on our behalf. Maurice was thrilled to meet the wonderful Ciaran and his family, and he shared our deep gratitude for their incredible efforts.

Ciaran's story is one of courage, kindness, and determination. Despite his own health issues, he's focused on helping others, especially those like his mother who are living with MS. The success of his 250km challenge is a powerful reminder that even when times are tough, we can still make a big difference in the lives of others.



#WorldMSDay

Hi Clare,

I know you are ill. How beautiful you look though – the image of me. Pardon my modesty!

B.D. – Before Diagnosis

I'm right, am I not? That's how you see it. **Your life fragmented into the before's and the after's.** Your baby finger, left hand waved at everyone continuously. Your right eye blinked and winked yet nobody chatted you up. When you lined up for a free throw at basketball, you missed, though you used to score. The numbness and pins and needles lasted for hours, not minutes. Your mouth could neither control your tongue nor the speech that emanated from it. Your difficult gait, problematic eyesight and incoherent speech would hospitalise you.

B.D. – Why would you want to go back there?

D for Diagnosis

Pins, prods, pokes, needles, no food, nudity – part of the process. Wobbles, wonders, weariness, welcome sleep – part of the process. No diagnosis, no prognosis, what the hell's osmosis? – Part of the process. Lost, lousy, alone, bereft – Part of the process. M.R.I scan and lumbar puncture – uncomfortable part of the process.

"You have MS" the specialist said, from the end of the bed, then walked away. SHOULD NOT HAVE BEEN PART OF THE PROCESS!

A.D. – After Diagnosis

You look up the web. Would I be better off dead, if I lose my walk and lose my talk? **Dependency, despair, stuck in a chair. Who in their right mind would want to 'go there'?**

Now

You live, love, mourn, cry, treasuring the knowledge you ain't gonna die. Life just moved sideways, in a different direction. Giving you valuable time for introspection.

**You recognise your disability, interspersed with pain,
But empathise your possibilities, a myriad to gain.**

Clare, I wish you well in all that you do.

You have MS – It doesn't have you.

Sláinte,
Do Chara dílis,

Clare

#ManyStories

Delphi Teens Peer Support Event By John McDonald

In 2004, MS Ireland Western Regional Office recognised a peer support need for teenagers that have a family member living with MS. The reasoning behind this was that we recognised that many children and teens living in a family where a parent or other family members has MS may have little or no access to talk with others of their own age in a similar situation. Our objective was to create an environment that was fun, stress-free and relaxing.

Delphi provides fun and exciting activities for teens in spectacular surroundings and is an extremely well-equipped facility where the safety and enjoyment of the participants is paramount. Each year there is 24-hour supervision of the children by Delphi staff, as well as three MS Ireland Regional Community Workers available in case of emergencies or for any of the young people to come to if they have any concerns or questions.

We estimate that over 200 young people have attended the programme since 2004 and we generally have between 20-26 participants every year. To date, the trip has been largely funded by the HSE National Lottery Fund with a nominal donation ask from participants to help cover travel and other costs.

Since 2004, every August for two nights, the participants have had the chance to go kayaking, surfing, zip wiring, high ropes climbing, archery, orienteering, campfires and a big favourite in recent years, the very messy bog walk obstacle course! All activities are run under professional supervision and tuition by the amazing staff at Delphi Adventure Centre.

Many young people return each year, which is an indication of value they place on the activity. The age range of participants is 11-16 years old. Brothers and sisters from the same families have had the chance to experience this event over different

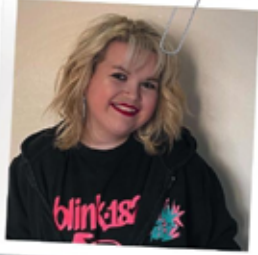
years. It also gives many parents with MS the chance to offer their children an adventure break which may have been a challenge otherwise.

The Community Work team have witnessed meaningful friendships develop and many of the participants look forward to meeting up each year. Many of the young people stay in contact and see their friendship develop into adulthood.

We are very proud to offer this opportunity to young people. Over the years, it has provided a platform for children and young people living in a family where MS is present, the opportunity to talk to others of the same age and share similar experiences where they may not normally have the opportunity to do so.



KAYAKING



#WorldMSDay

Dear Katie of April 6th 2016,

Today was a tough day for you, I should know. Today was the day that you were officially diagnosed with relapsing remitting MS.

Saying the diagnosis was a shock was an understatement. I know you never thought it could be something like that at your age. I know that it took a long time to get the label put on the symptoms that you have been having. I know that it took over a year of never-ending visits to different doctors and specialists, a year of scans, tests, x-rays, MRI's and countless pokes of needles for blood tests.

But then they finally said the term MS to you. I know that you are in shock, I know that you are petrified of what's to come, fearing the unknown. I know that you are so angry at the world. I am so aware that there are a thousand different emotions going through your head at the moment. **I know that the main thought you are having at the moment is that this isn't fair, and I'll agree with you on that. The way in life that everything happens for a reason, well sometimes it's hard to find the reason why.**

The reason why I have chosen to write this letter to you, is to let you know that things will be okay, and that I am so proud of you. I'm not going to lie, it's an incredibly tough and scary road that you are about to embark on. The journey will be full of twists, turns and mountains to climb.

You will be faced with days that you are so sick that you will not be able to get out of bed. Where you have pain so severe that all you want to do is curl up and forget about the world.

There will be days that you will face judgement and comments by people who don't think you are sick just because you happen to be having a good day.

There will be moments in your life that will be hard to face, watching people around you achieve life goals that you thought you would have reached.

Unfortunately, living with MS does not make you immune to life's other challenges. There are some incredible heartbreaks to come. Some that most people will never face but you will at such a young age. **Some that will make you wish the world would stop spinning because you feel you just can't do it anymore. But Katie I want to tell you that you can and will.**

MS will also give you some awesome opportunities and bring some of the most incredible people into your life.

Before closing this letter, I wish to thank you. **Thank you for becoming one of the strongest people I know.** It can be hard but you can do this! It will be okay. I promise.

Lots of love,

Katie 2024

#ManyStories

PHYSIOTHERAPY AND EXERCISE



MoveSmart MS is MS Ireland's online, nationally recruited, symptom-focused physiotherapy program. It offers specialised, tailored, education and exercise programmes for participants living with Multiple Sclerosis, grouped by age and stage in their MS journey.





Active Neuro is a specialist physiotherapist and physio assistant led exercise programme for people with MS nationally and for people with other neurological conditions in the West and Mid-West.



Getting the Balance Right is MS Ireland's regional Exercise and Physiotherapy service. We offer online and in person exercise classes, such as physiotherapy and yoga, in all 10 regions across the country. The classes are stratified by ability so that exercises can be tailored to meet the needs of the participant.

Physio West offers physiotherapy and physiotherapy-led individual programmes for people with MS living in the West.

Taking part in MS Ireland designed physiotherapy programmes has been shown to result in:

-  Reduction in usage of healthcare services by **43.1%**
-  A&E and inpatient services utilisation reduced by **33%** and **57.4%** reduction in bed days
-  Significant improvements in quality of life (**20.2%**), fatigue (**16%**) and mental health (**20%**)
-  Our data suggests that we can **reduce the number of people falling***, and the number of falls they have through our programmes by **49%**

*People with MS, Stroke and Parkinsons (PD) fall at a similar rate to the over 85's (50% in a three month period).

**TO FIND OUT MORE,
VISIT OUR WEBSITE OR
SCAN HERE**





#WorldMSDay

To Ppal

I may be a stranger to you, but I understand what you might be going through. It has been quite a journey since our introduction, and I have a few things I need to address with you. From the very beginning, you made it clear that you are here to stay, a constant presence in my life. Initially, I was confused, anxious, and fearful, especially about how you would impact my independence and the lives of my loved ones. Knowing your true nature as Primary Progressive MS was a strange relief—at least you were not the brain tumor I had feared, the same illness that took my father.

You have asked me to call you Ppal (Primary Progressive and Loyal). I think you do see yourself as some kind of twisted friend. Nearly as though you're a gift in my life. Your presence has been anything but a gift, despite your insistence on calling your symptoms "gifts." Losing my balance and having to rely on two sticks for mobility was just the beginning. Your presence in my life has meant the introduction of a wheelchair, impacted my ability to speak easily, and altered my appearance and independence. **Your persistence is beyond anything I could have imagined, and the speed at which you have progressed has been noted by all the neurologists I have seen.**

Despite your relentless nature, I have found ways to cope and even thrive. You may have taken some of my physical independence, but you have not touched my spirit. I've found immense strength in the love and support of my friends and family. This journey has shown me the true meaning of friendship and loyalty. I've met strangers who have become dear friends and have been surrounded by personal assistants who have opened up a new world for me. Their support and kindness go far beyond their job descriptions, offering me genuine care and companionship.

I sometimes think about how I used to light up a room with my smile and laughter, and you seem to take some satisfaction in diminishing that light. **However, even in the face of your cruellest attempts, my laughter has not disappeared. It has become a source of strength, a reminder of the positive moments in my life.** The laughter that filled my home during my father's illness, shared between my parents and their friends, has taught me that joy can exist even in the darkest times. This remains true. Despite the challenges you have brought my way, there is always light.

Your lack of understanding about emotions like love and laughter is clear. These are concepts beyond your grasp, but they are central to my existence. Love has been my greatest ally, helping me navigate the challenges you present. It is deeper than appearances and physical abilities. Love is a bond - something you can never touch.

Besides the constants of love, friendship, and laughter in my life, nature remains my solace. It is a constant, unyielding presence that provides me with perspective and peace. The sights, sounds, and smells of the natural world are etched in my mind and spirit. Nature's indomitable spirit mirrors my own.

So, Ppal, while you may remain a part of my life, understand this: I will continue to live with love, laughter, friendship, and the healing power of nature. You have taken much, but you have not, and will not, break my spirit. **My life with MS will be defined by my resilience and the strength of the bonds I cherish.**

Sincerely,

Shona

#ManyStories

Taking Care of Your Mental Health During Winter Months

The winter months, especially Christmas, can challenge routines and strain our mental health. Balancing expectations, dealing with emotional challenges, and adapting to shorter days often leave us feeling drained. Here are practical, evidence-based strategies—adapted from Mental Health Ireland—to support your mental health during this time.

Spend Time Outdoors

Despite the chilly weather, if you can, try to spend at least 15 minutes outdoors daily. Fresh air and daylight can significantly improve your mood and help regulate your sleep cycle. A short walk or a few moments in your garden can help you feel refreshed.

Plan Nourishing Meals

Nutritious meals support your physical and mental wellbeing. Create a simple plan for meals and snacks, and prepare some ahead of time, like soups or salads. Having healthy options readily available reduces the temptation to reach for less nutritious choices.

Stay Connected

Human connection is a cornerstone of mental health. Reach out to friends or family members each day, even if it's just a quick text or phone call. Planning a to go for a coffee or a walk with someone close can provide meaningful social interaction.

Stick to a Routine

At this time of year, our usual routines can be disrupted, but keeping two or three core habits, like regular meal times or a bedtime, can help you feel grounded and in control.



Enjoy Your Passions

Set aside daily time to engage in activities you love, such as reading, crafting, or listening to music. These moments of joy can be powerful stress relievers.

Managing Gatherings

Family gatherings often come with high expectations and potential stressors. Here are some strategies to navigate these situations with care:

- **Set Boundaries:** Decide in advance how long you'll stay at gatherings and communicate this to your host.
- **Plan Ahead:** Let family members know about topics you'd prefer to avoid and be clear about your needs.
- **Take Breaks:** Step away if needed. Use mindfulness techniques like deep breathing to regain calm.
- **De-stress Afterwards:** Plan a relaxing activity, such as watching a favourite show or taking a warm bath, to help you unwind.

Coping with Loneliness or Grief

For many, winter and particularly Christmas, can highlight feelings of loneliness or the loss of loved ones. Honour their memory through meaningful rituals, like lighting a candle or cooking a favourite dish. Remember to be kind to yourself—embrace calming moments like a warm cup of tea or gentle exercise without pressuring yourself to feel festive.

Cultivate Gratitude and Mindfulness

Starting or ending your day with mindfulness or journaling can help you focus on the positives. Write down what you're grateful for or reflect on the small joys in your day.

Set Realistic Expectations

Shift your focus to what feels manageable and peaceful. Make to-do lists to help you prioritise tasks and ensure you include self-care. Say "no" when necessary to protect your time and energy.

Winter and Christmas can be a mixed bag of joy and challenges. By planning, setting boundaries, and prioritising self-care, you can navigate this time with greater ease. Remember, small, consistent efforts to nurture your wellbeing can make a big difference. For more tips, visit Mental Health Ireland and explore their resources to maintain balance and mental health - www.mentalhealthireland.ie

New Hope and Advancements for MS

For people living with multiple sclerosis (MS), 2024 has brought a wave of exciting breakthroughs in diagnosis, treatment, and even the possibility of a cure. These advances not only make life with MS more manageable but also offer hope for the future. Here's a look at some of the biggest developments this year.

A Step Forward in Diagnosing MS

One of the most important changes for people living with MS is the revision of the McDonald Diagnostic Criteria, announced at theECTRIMS Congress in Copenhagen. These updates are designed to improve early detection and help doctors avoid misdiagnosing MS, which is believed to occur in approximately 20% of cases. With the addition of new MRI techniques and biomarkers, such as the “central vein sign” and neurofilament light chain, doctors can now make a more accurate diagnosis. This is a game-changer as accurate diagnosis can lead to earlier treatment and prevent further disease progression.

This update is also significant for understanding “radiologically isolated syndrome,” a condition that may signal the onset of MS but hasn't always been clear-cut. Getting a clearer diagnosis means fewer uncertainties and better outcomes for those affected (Medscape).

Hopeful New Therapies

On the treatment front, researchers are making great strides. One new therapy that is at a very early stage of development combines immune system modifications to help restore balance in the body's defences. By targeting the dendritic cells, which play a key role in immune response, this therapy has shown promise in early trials. For people with MS, this could offer a more personalised treatment option, possibly slowing the disease or preventing new relapses.

This kind of progress is exciting because it opens the door to more tailored therapies that could offer better results and fewer side effects (ScienceDaily).

Striving for a cure

While finding a cure for MS has always seemed like a distant dream, researchers are becoming increasingly optimistic that it may be within our lifetime. Advances in understanding how the immune system damages myelin—the protective covering of nerves in our brains—have already led to groundbreaking treatments that have transformed how MS is managed. Medications that target B cells, for example, have significantly reduced relapses and slowed disease progression.

Experts are now hopeful that a cure may be possible, with some even suggesting it may not be too far off. The idea that future generations might live without MS is a powerful source of hope for everyone affected by it (University of California, San Francisco).

Tackling the Root Cause: Epstein-Barr Virus

Another major area of research is focused on the Epstein-Barr Virus (EBV, also known as glandular fever), which has been strongly linked to the development of MS. Scientists are now exploring vaccines and other preventive treatments that target EBV, which could significantly reduce the number of new cases of MS. This could change the way we approach the disease entirely—focusing on prevention rather than just treatment (ScienceDaily).

What Does This All Mean for You?

All of these advancements show just how far MS research has come—and how much closer we are to transforming lives. For people living with MS, these developments bring hope that better diagnostics, more treatment options and the possibility of a cure are all within reach. While the journey isn't over, these breakthroughs are a step in the right direction.



The 'Gift' that Keeps on Taking

By John Burke

This article was originally published by Mary O'Connor in the Galway Advertiser in April 2024 and is reprinted here with permission from the author. Names have been changed to protect the privacy of individuals.

Before John Burke got married in September 1992, a number of people asked him if his wedding was still going ahead and if he realised what he might be "taking on"?

John, and his then fiancée, Mary, who live in the city, were in their thirties and were looking forward to spending their lives together. They had a wide circle of friends, an active social life, and successful careers. They were very happy and did not envisage any black clouds on the horizon.

Mary, a former second-level teacher, had been diagnosed with multiple sclerosis earlier that year but even that did not cast a shadow on their happiness. However, others in their life were worried about her diagnosis and voiced their concerns.

"We were in our early thirties and invincible," said John. "We were no different to any other couple, full of dreams and imaginings as to what the future would hold. Everything was positive and exciting. We were oblivious to anything that was not positive affecting us and, sure what if it did, we were invincible and committed to each other and to the idea of any unknowns that might visit us would be taken in their stride"

"MS was something that was in the knowledge bank, but on the face of it, was something that was having no effect and as Mary's mother used to tell her friends: 'Mary had a 'touch of MS'. I remember laughing at the thought of 'a touch of MS', it was even then like describing a woman as being a 'little bit pregnant!'"

It is 32 years since those halcyon days. In the intervening years, the Burkes had two sons, now aged 29 years and 25 years, who have brought them great joy. The couple's love for each other has been unfaltering down through the years. Sadly, one of the other constants in their lives has been multiple sclerosis and the insidious nature of what he describes as this often, cruel disease.

"I guess hindsight has been our greatest teacher. Amazing, how looking back on the past can make sense of the present. I know every family has individual experiences, but for us, MS was definitely the 'gift' that kept on taking."

John grew up in Dublin and met Salthill woman, Mary, while he was working in Galway. He later began working with people with progressive illnesses. This was a blessing in many ways, he said, because it taught him a lot about MS, a progressive degenerative condition of the central nervous system.

Collective experiences

"It helped our sons realise that Mary's fatigue and cognitive difficulties are not a life choice and are as a result of our unwelcome guest, [MS], and not how she feels about them. This has been a difficult path for them I think, in that we live in a world where perfection is valued over reality - the perfect family, the perfect Christmas, the perfect mother Oftentimes, we lose sight of the 'good enough', for we are all imperfect and mostly endeavour to do the best we can with the skills and collective experiences that formed us."

Mary's MS journey began early in 1992 before she and John got married. Her symptoms began with numbness in her big toe which was not improving. She was working in Sligo then and attended the local hospital for tests. These ruled out several conditions but a question mark still hung over her symptoms. She was referred to Dublin for an MRI scan.

"She was called back for a follow up appointment where the consultant met her and unceremoniously said to her: 'Well, it looks like you have the real thing....multiple sclerosis and there is not much we can do'. Remember, this was 1992 when there was nothing like the level of knowledge and treatments for MS as there is now. Not knowing at the time what MS was, Mary was subsequently referred to a neurologist (the deliverer of the diagnosis was not a neurologist). That was all in May 1992 and the wedding was planned for September of that year. I think that what we did was parked this information in the back of our heads as there was nothing to think about in the now, just possibilities and statistical probabilities.

"I would never have regarded Mary as being 'sick or suffering from some illness'. I have always tried to approach life from the perspective of language creates reality and sick, suffering, and illness was not part of our reality or maybe we chose it not to be." However, as the years progressed, the Mary he knew was gradually but inexorably disappearing,

he says. “With us, MS has been an unwelcome guest in our lives that has never gone away. Like all unwelcome guests, its presence has felt, at times, intense, impossible, and at other times, insidiously smouldering away, but always there.

“Life is sometimes too busy [for us] to recognise that the bits and pieces of life are changing constantly and to ‘survive’ progressive illness and loss you have to adapt. In reality, the goalposts are changing and you need to adapt. In our case, Mary is redefining herself as insidious changes manifest themselves but the rest of the family is also redefining ourselves in relation to her. So much of this is instinctive but some of it is about making definite decisions.

“Adapting the bathroom, ramping the front of the house, getting a scooter, knowing where is accessible before you set off, purchasing continence pads, all of this curbing spontaneity..... In the early days, there were the delights of two beautiful sons and all that that journey brings - their dreams, becoming the best versions of themselves, and blossoming into creative young men formed by the collection of experiences of our family unit as all children are formed by their collective experiences.”

John believes there are themes within experiences such as loneliness, aloneness, lack of intimacy, and the need to reframe one’s dreams, which link us to others who are coping with life’s challenges. “I know that our family experience is not uncommon. But I think what connects us to many is the lonely road that can be the result, especially for Mary.”

The stolen child

In her heyday, this once vibrant woman was “the centre of things”, according to John. An accomplished English teacher with a love for Gerard Manley Hopkins and WB Yeats (she would recite the Sligo man’s earlier poem, *The Stolen Child* “and Hopkins’ *The Windhover* at the drop of a hat”.)

“Ironically she is now the ‘stolen child’, stolen from us as a family but also stolen from many of her friends who no longer know how to be with here or relate to her and she is now a member of what I call the ‘forgotten people’. There are so many forgotten in our midst and maybe it is time to welcome them back from the shadows. I think we need to learn how to ‘be’ with people, our families, our friends, truly understand difference of what it is to be human being and human doing.

“I remember chatting to one of the carers that come into Mary who was telling me that she found it very difficult to be with her because she, (the carer), was a

doer. Her idea of success was caught up in what she accomplished and because Mary was not ‘doing’, she, (the carer), believed she was failing in some way. But as I listened to her, I suggested that ‘being present’ to someone was equally, if not more, important than ‘doing’. For when we are present to someone, we ‘see’ them....”

John stopped working last December, not so much to become a full-time carer for his wife, but more an active supporter for her, he said.

“I have, for as long as I can remember, lived with the maxim that ‘language creates reality’ and, so for me, the language of ‘supporter to’ and ‘carer of’ mean such different things, even though to the outside world the tasks may appear the same. But, I am not ready to become a carer in the truest sense of the word. In truth, for all our life together we have been carers, we have cared for each other and our children but to become the carer of one’s wife who now requires assistance for nearly all daily activities, throws such a different light on everything.

“I worked in the area of progressive illness for 29 years and met many people on their journey and also their family members. I am very conscious that the world is very much divided into the perspective of the inside looking out (the person with MS, in our case) and the outside looking in (family members, friends, medical teams). From the outside looking we are all ‘experts’ on everyone else’s’ life but from the inside looking out the vista is very different. Perhaps our challenge is to become more familiar with the perspective of the inside looking out!

“I met many who had a similar journey to the one that we were on and was also very conscious that working in the area of progressive illness was a real privilege in that it gave me an understanding of the nature of conditions like MS and how they played out, especially in regard to the invisible symptoms like fatigue and cognitive decline.”

Circle of support

Fatigue, which can be an issue for many people with MS, as well as their partners and children, can be much misunderstood, he said. Sometimes, it is wrongfully interpreted as not being bothered.

“This can lead to much unintentional distancing, resulting in a very narrowing of that circle of support. Cognitive decline, in our case, was the most profound change, where at this point Mary is there but no longer there. The only way of describing this is present absence. The closest experience [to this] is

the dementia space but it is also very different to that. In reality, it is what it is and drawing comparisons to other diseases can be helpful and also unhelpful as once you liken it to something else the expectations of how it may play out into the future may also change so we have become a day-to-day family!"

What does he miss most? "My companion", is his answer. "It is so strange to miss somebody who has physically not gone, who looks the same, sounds the same. There are vignettes of clarity which in the moment are remembrances of presence but they are fleeting and the impact of these fleeting glimpses can be both beautiful and frustrating at the same time.

"I miss 'imagining' with my companion in life and sentences that start with 'let's....' the other aspect I miss so much is intimacy. The intimacy I speak of is not necessarily physical but it is that touch, that glance, that sense of connection, being seen, warts and all, and that feeling of being loved and connected."

Sometimes John feels jealous when he hears couples chatting in restaurants, or at parties, or discussing their holidays or future plans. He experiences waves of "tremendous loneliness" because of this loss of intimacy and adult companionship.

"There is no-one to talk to about issues past, present, or future. This may sound odd but I always thought that the worst thing that could happen would be to lose a loved one to death. I now realise that as painful as that must be, there is an end, and, to some degree, life can go on. For me, watching Mary deteriorate slowly over several years seems so much worse. Death seems to be occurring in an incremental way."

Anyone interested in speaking to John can telephone him at 087 250 0726



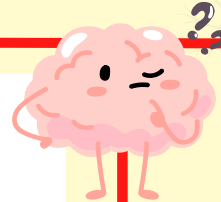
Activity Time



This section is all about taking a few minutes to engage in fun, easy activities that are not only enjoyable but also great for your brain health.

Whether you're looking to challenge your mind or simply relax and unwind, these activities are designed to give your brain a boost while offering a little break from your day.

- Advocacy
- Awards
- Awareness
- Community
- Connection
- Empower
- Fatigue
- Health
- Information
- Resources
- Sharing
- Support
- Technology
- Uncertainty
- Volunteer



Sudoku

3		9	8	1	7	4		
8	7	2	3		4	9		5
6	4	1				3	8	
2		7	5				3	8
						5		
			6	8	3	7	9	
7	9		1			8	4	
	8		7	9	6			1
1	2		4			6	7	9

C L S F H U D G O I V U R G E S R N M C
 H P N C A G L I T O E A N M R H E P O O
 C M T O R T U E W E O N P Y S A E A Y M
 E I L V I T I O N H C O U Z M R T I T M
 V D N E T T S G L O W H A F C I N T N U
 S S B L A M A Y U E I H N A E N U U I N
 E N R D Q O H M R E T T W O E G L D A I
 C A C O G Y N T R C M A C I L O O A T T
 R A D V O C A C Y O R R H E C O V L R Y
 U G U H N E R S I E F T L T N A G G E N
 O E M O U T C R N I O N M L L N D Y C R
 S P A C S D E E L T O X I G P A O I N Y
 E N R E V S S U P P O R T Y M I E C U A
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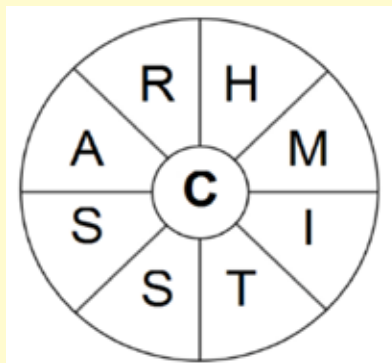
Riddles

- A.** What has keys but can't open locks?
- B.** I have cities, but no houses. I have forests, but no trees. I have rivers, but no water. What am I?
- C.** What can travel around the world while staying in the corner?
- D.** I'm tall when I'm young and short when I'm old. What am I?
- E.** What can be cracked, made, told, and played?
- F.** What has many teeth but can't bite?
- G.** What is so fragile that saying its name breaks it?

Word Wheel

See how many words you can make from our word wheel.

You can only use each letter once and you have to use the centre letter in every word!



Answers to our activities (excluding the Word Wheel) can be found on page 31.

The 40th Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) held in Copenhagen from September 18-20, 2024, showcased a range of significant advancements in multiple sclerosis (MS) research. Below are just some of the key topics discussed at the conference.

Blood Biomarkers: Predicting Disease Progression

An observational study presented by Dr. Enric Monreal from Hospital Universitario Ramón y Cajal in Madrid revealed promising insights into using blood biomarkers to predict disease progression in early MS. The study indicated that higher levels of neurofilament light (NfL), a biomarker associated with nerve damage, were correlated with both relapse-related worsening and progression independent of relapse (PIRA).

The research involved blood samples from 725 MS patients across Spain and Italy, primarily women averaging 34 years old. Findings showed that elevated NfL levels increased the risk of relapse-related worsening and PIRA by approximately 45%. Interestingly, glial fibrillary acidic protein (GFAP), associated with astrocytes in the brain, also indicated a risk for PIRA, particularly in patients with low NfL levels.

Dr. Monreal noted that identifying these biomarkers early could enable healthcare providers to tailor treatment strategies according to individual risk profiles. Patients with low levels of both biomarkers might benefit from less aggressive treatments, while those with high NfL levels may require more robust therapies to prevent long-term disability.

Early Treatment: Reducing Long-Term Disability in Children

Dr. Sifat Sharmin from the University of Melbourne presented registry data suggesting that early access to highly effective monoclonal antibody treatments can significantly reduce long-term disability in children with MS. Among 282 children studied, 39% began treatment between the ages of 12 and 17, while 61% started later, between 20 and 22 years old.

Results indicated that those who started treatment early exhibited less disability by ages 23-27, with a smaller increase in their disability scores compared to late starters. Dr. Sharmin explained that children typically experience more frequent relapses than adults, making early treatment crucial during the disease's most active phase.

While only fingolimod (Gilenya) is currently approved for children, off-label use of stronger therapies is becoming more common. The findings suggest that initiating treatment during adolescence can significantly enhance long-term outcomes, although the long-term safety of these treatments remains under investigation.

Tolebrutinib Slows Disability in Non-Relapsing SPMS

Tolebrutinib, a Bruton tyrosine kinase (BTK) inhibitor, is showing promise in tackling smouldering inflammation in multiple sclerosis. Presented at ECTRIMS 2024, the treatment significantly delayed disability progression in non-relapsing secondary progressive MS, reducing progression risk by 31% compared to placebo. This targeted approach addresses microglial activity and B-cell function which are key contributors to neuroinflammation.

Tolebrutinib is being tested in four global Phase 3 trials, covering relapsing MS and progressive forms. Its potential to improve outcomes, combined with advances in digital biomarkers, provides real-time insights into disease activity and treatment effects. These findings support its promise as a next-generation MS therapy.

Updated MS Diagnosis Guidelines

The McDonald criteria for diagnosing MS have received their third update in 15 years, reflecting advancements in the field. These updated guidelines, presented by experts at ECTRIMS, aim to assist neurologists in distinguishing MS from other similar conditions, potentially allowing for earlier diagnosis and treatment.

Key revisions include the incorporation of new MRI techniques and biomarkers, such as NfL and the central vein sign, along with updated protocols for assessing changes in the optic nerve and identifying radiologically isolated syndrome (RIS) - which can now be diagnosed as MS if there are abnormalities present in the spinal fluid. Dr. Peter Calabresi, co-director of the Precision Medicine MS Center at Johns Hopkins University, chaired the session discussing these changes.

While the 2024 revisions are complex and pending peer review, they represent a significant opportunity to improve MS diagnosis, which has faced a historical misdiagnosis rate of around 20%. Dr. Calabresi emphasized the importance of clear communication within the MS community regarding these updates.

For more information on these and other topics, visit [ECTRIMS](#). MS Ireland was also grateful to have community member [Trevis Gleason](#) attend ECTRIMS and provide updates from the conference. His videos are available on MS Ireland's [YouTube account](#) - www.youtube.com/@MSSocietyIRELAND



#WorldMSDay

Dear letter reader,

I may be a stranger to you, but I understand what you might be going through.

The physical challenges, the mental fog, the battery of tests, the looming uncertainty. It's a lot to grapple with. Trying to maintain your routine, focusing on college assignments, pursuing your career goals—all while hoping for negative test results. Until that day, that final clinic appointment, hearing the words "Yes, you do have Multiple Sclerosis."

I am writing this letter specifically for you - the twenty something year old student. The thirty year old young professional. The person looking to buy your first home, settle down to plan out your family and future. **Your dreams and aspirations may feel like they're slipping away, as though someone has snatched your future with those few damning words, "Yes, you do have Multiple Sclerosis."** I recall it vividly: the breath escaping your body, the dread of what lies ahead.

I'm writing to restore your hope, to alleviate some of your fears. Yes, multiple sclerosis can be a life-altering diagnosis, but it need not dictate your life entirely. I am lucky to lead a largely normal life despite MS. Initially, I grappled with sensory and physical challenges, but over the past four years, I've remained symptom-free.

Since my diagnosis, with the support of my loved ones and a therapist, I've come to terms with my MS. I decided not to let it define or control me. For the sake of my family and my child, I committed to self-care. This determination led me to embrace more physical activity, prioritise gym sessions, adopt healthier eating habits, and carve out time for self-care.

When I heard that I had MS, my first thought was, my life is over and I would one day end up in a wheelchair. Looking back on it now, it seems so ludicrous to me but at the time that's all my irrational mind could imagine. **But here I am thirty six and fitter than before my diagnosis.**

If I could give anyone currently going through a diagnosis or newly diagnosed a piece of advice it would be this: **Don't jump to conclusions. Wait and see what happens. Reach out to people, speak to people, engage in therapy if you are open to it and engage with reliable information to learn more about MS.**

Most people are unaware of my MS, and that's how I envision your experience—a condition that lingers in the background, present but not dominant. The road to diagnosis can be difficult one. The start is hard. It's emotional and can sometimes cause tensions between loved ones. **One day, in the future, I hope you will realise it's not actually as bad as you feared, and some days, MS slips from memory entirely.**

So best of luck with your college course, aim high to achieve the goals you want in your career, and you will have a bright future living with MS.

Warm Regards,

Stephen

#ManyStories

Sleeping Well with MS

For those living with MS, quality sleep is vital for health and well-being. Sleep aids physical recovery and plays a crucial role in mood regulation, memory consolidation, and cognitive function. However, many individuals with MS face specific challenges that disrupt their ability to sleep soundly. Here are strategies to enhance your sleep quality and manage MS symptoms effectively.

The Importance of Sleep

Sleep is essential for maintaining optimal health. During sleep, critical processes occur in the body, ensuring we function well while awake. Most adults require 7 to 9 hours of sleep each night, though individual needs can vary. It's crucial to listen to your body and recognise signs of inadequate rest. Healthcare professionals can assist in identifying these signs and addressing sleep-related concerns.

How MS Affects Sleep

MS can lead to sleep disturbances due to a combination of symptoms and lifestyle factors:

MS Symptoms:

- Muscle Spasms and Pain: These can hinder your ability to find a comfortable sleeping position.
- Bladder Problems: Frequent nighttime urination, known as nocturia, interrupts sleep cycles.

Living with MS:

- Psychological Factors: Stress, anxiety, and depression can worsen sleep challenges.
- Reduced Activity: A sedentary lifestyle may negatively affect sleep quality.
- Fatigue: Persistent daytime fatigue can impact nighttime sleep.

Other Conditions:

- Restless Legs Syndrome (RLS): This common condition causes uncomfortable sensations in the legs, leading to an urge to move them, especially at night.
- Sleep Apnoea: A disorder that disrupts breathing during sleep, resulting in frequent awakenings.
- REM Sleep Behaviour Disorder: This condition causes individuals to act out their dreams, disrupting sleep.

Lifestyle Factors:

- Noise, irregular sleep patterns, excessive caffeine intake, and insufficient time for rest can all contribute to poor sleep.

Why Poor Sleep Matters

Inadequate sleep can exacerbate MS symptoms such as fatigue, pain, and cognitive issues, leading to increased irritability and concentration difficulties. Over time, chronic sleep deprivation may heighten the risk of cognitive decline, impacting memory and thinking abilities in both those with and without MS.

Sleep Hygiene

Establishing a good 'sleep hygiene' routine can have a positive effect on sleep quality. Some tips for creating good habits include:

- Stay physically active.
- Get daily exposure to sunlight.
- Allow plenty of time to wind-down before bedtime.
- Try to avoid getting overtired as this can make it difficult to get to sleep.
- Avoid large meals and stimulants (caffeine, chocolate, alcohol) before bedtime.
- Try to manage stress, especially before bedtime.
- Establish a bedtime routine. This can include going to bed at the same time every night, using relaxation techniques or taking a warm bath.
- Avoid using screens in bed. This includes televisions and phones.
- It may also be useful to limit the use of screens before bedtime.

If sleeping problems persist it is important to seek advice from a health care professional.



#WorldMSDay

Dear Darling,

I'm writing this letter not for you to read now, but perhaps one day when it might hold meaning. Putting my thoughts down helps me process them, and maybe it will help you understand someday.

Twelve years ago, I was diagnosed with relapsing-remitting MS. Initially, I was terrified. It felt like a dark cloud over our future, bringing immense fear of the unknown—**what would this mean for our family, for me, for you?**

Thankfully, I've been fortunate. My symptoms have been mild and have always receded. MS has been a quiet passenger in my life rather than a disruptive driver. It's something I've had to accept, but it hasn't stopped me from living fully.

I've shared my diagnosis only with a few close family members and friends. It's not a secret, but it doesn't define me. MS has been a small part of our journey together. The moments that truly matter—watching you grow, sharing laughter and tears, navigating life's ups and downs—define us.

My days are filled with the joyful chaos of parenthood, the satisfaction of work, and the warmth of family life. MS is there, but it's in the back seat, and I hope it always will be. Yes, there are moments of anxiety about the future, but they are fleeting. What remains constant is my determination to enjoy and cherish each day.

A fantastic support system helps me maintain this positive outlook. We are surrounded by loving family and friends, and I have excellent healthcare professionals. I am also grateful for advances in MS research. Living with MS today is very different from what it would have been 20 or 30 years ago. While there's still progress to be made, it's a hopeful time for me, and I'm thankful for where we are now.

Life's unpredictability can be daunting but also beautiful. It has taught me to appreciate the present and cherish the simple pleasures and love around us. I hope you carry that with you as you grow.

I want you to understand that while MS is part of my life, it doesn't define me. I am your parent, your confidant, your biggest supporter, and someone who loves you more than words can express. That is my true identity.

So, even though there's a shadow of uncertainty, it's just a shadow. The light, the joy, the laughter—that's what fills our days. That's what I want you to remember. If you ever read this letter, I hope you see that despite any fears or uncertainties, life is about living to the fullest, embracing every moment, and finding happiness in the journey.

With all my love,

Mam

#ManyStories

BUDGET 2025

What Budget 2025 means for people affected by MS so far

- An additional €336million for disability services as a whole.
- €12 increase in the maximum personal rate of weekly disability payments from January 2025.
- October 2024 cost of living bonus will be paid on the same basis as the Christmas bonus
- The amount not taken into account when you sell your home to move into care will increase to €337,500 from January 2025 for those who get State Pension (Non-contributory) , or Disability Allowance or Blind Pension
- €400 cost of living lump sum payment for people in receipt of Disability Allowance, Invalidity Pension and Blind Pension* to be paid in November 2024
- €12 increase in the maximum rate of the Carer's Allowance and Carer's Benefit from January 2025.
- Carer's Benefit to be extended to people who are self-employed from January 2025
- €150 increase in the Carer's Support Grant paid annually in June
- Carer's Allowance will become a qualifying payment for Fuel Allowance from January 2025, subject to meeting all criteria of the Fuel Allowance scheme.
- €20 increase a month in Domiciliary Care Allowance from January 2025
- Increase of 20,000 Personal Assistant (PA) hours and 40,000 home help hours in Budget 2025
- Most long-term weekly social welfare payment recipients will receive a cost of living bonus.
- 5 additional consultant neurologists have been funded at hospitals in Kerry, Portlaoise, Wexford, Mayo, and Letterkenny, as well as further investment in Bantry Hospital, and the expansion of Community Neuro-Rehabilitation Teams with funding for 25 new Whole-Time Equivalents (WTEs).



#WorldMSDay

Dear Cousins & Friends,

For many years you have supported me through my Ulcerative Colitis and its complications which saw me hospitalised several times, not least during the PanProctoColectomy with End-Ileostomy surgery, which I underwent in 2016 to resolve it. **During these tricky years you may have heard me mention the odd neurological symptom,** which doctors & I put down as probable extra-intestinal manifestations that are part of inflammatory bowel disease.

Since my mid twenties I've had episodes when my right foot did not lift willingly off the ground and would trip over it, and I felt "heavy", with the thumb & forefinger of my left hand taking on a life of their own. My balance was always a bit off, and as the years went on I dreaded coming down steps as I'd find myself having to cling tightly on to the rail. I used to make excuses as to why I wouldn't go up the stairway of a historic building and I'd be sneaking a look around to see if there was a ramp to come down. **I sometimes wondered if others were experiencing similar or if it was just my own idiosyncrasy.** MS did cross my mind, but the very idea seemed to be dismissed when I'd raise any concern, so I gave up mentioning any such symptoms. "Your colitis can act up in many ways" I was told, "it is likely your electrolytes".

At a hospital appointment I mentioned about a sore blurred eye, and was told my "optic disc is grey". Another time I had an MRI for Trigeminal Neuralgia & was told I had "some hyper-intensities, cant tell you of their significance." I mentioned neurological symptoms again, & my short term memory, when tested, was poor. I was diagnosed with "mild cognitive decline". **I ended up being lost to follow-up.**

Only in summer of 2023, aged 62, did a Neurologist diagnose me with MS, when my symptoms were florid. I'd endured several bad falls, ended up unconscious at home, unable to summon help or move for hours. **Most of the feeling had left my lower legs, I experienced "electric shock" sensations, arm weakness, poor hand dexterity, muscular spasms,** & fainting due to rapid blood pressure drop. The decline was quite abrupt, as I had managed to do a skydive in Gran Canaria a few months before.

Cousins and friends, you were as puzzled at my diagnosis, just as the Neurologist was at how late in the day I came to present to him. "Are you sure the doctor said that, it's a dreadful disease!" I wanted you all to simply take in the diagnosis, and you did when it sank in, and you have been great even when I bombard you with updates good and bad! **Being told what I had, proved to be a huge relief and validation for my largely unexpressed concerns.** I was at long last able to "wear the t-shirt" that was waiting long in my metaphorical wardrobe!

Martine

#ManyStories

MS Awareness in the Workplace



MS Ireland has launched an innovative training program, *MS Awareness in the Workplace*, designed to educate employers and employees about MS and foster a more inclusive work environment. This comprehensive training provides an invaluable opportunity for workplaces to deepen their understanding of the symptoms and challenges faced by individuals living with MS.

The training aims to demystify MS, explaining its varied symptoms and their potential impact on daily work life. Participants will learn how they can effectively support colleagues living with the condition, ensuring that all employees feel valued and empowered. The program covers essential topics such as reasonable accommodations, equipping workplaces with practical strategies to help employees manage their MS while maintaining productivity.

One of the standout features of the MS in the Workplace training is its experiential aspect. Participants engage in an interactive session that simulates the challenges faced by those living with MS. This

hands-on approach fosters empathy and understanding, enabling attendees to appreciate the daily obstacles that their colleagues may encounter. By experiencing these challenges firsthand, employers and co-workers are better equipped to implement supportive measures and create an accommodating work environment.

This initiative aligns with MS Ireland's commitment to raising awareness and promoting inclusivity for individuals affected by MS. Workplaces interested in this training are encouraged to reach out for more information. By investing in this training, employers not only enhance their understanding of MS but also contribute to a more supportive and inclusive workplace culture.

For further details and to schedule a training session, please contact Melanie at melaniec@ms-society.ie



UPCOMING EVENTS

Dublin City Marathon

If you have a place in the Dublin City Marathon and you would like to join Team MS Ireland – please contact **melaniec@ms-society.ie** for a fundraising pack.



Charity Golf Day

Are you a member of a Golf Club – would you nominate MS Ireland as the charity of the year? These events are fantastic fundraisers, and we can support your event with banners, items for goodie bags etc. Please contact **melaniec@ms-society.ie**



Advent Challenge

This month, many of our supporters have taken part in our fun Christmas fundraising challenge where they get a different daily challenge and their friends and family sponsor them to complete each challenge!

Thanks to all for taking part.

Bridge

Do you play bridge? Would you nominate MS Ireland to be a beneficiary of your charity event? Please contact **melaniec@ms-society.ie** for more information.



Skydive

Register via our website **https://www.ms-society.ie/get-involved/fundraise-us/skydive-ms-ireland** or contact **melanie@ms-society.ie** for dates that suit you.



THANK YOU

We were delighted to have had corporate volunteers from a variety of companies who came to the Care Centre to help keep our lovely garden looking perfect for our residents – this initiative was a huge success - thank you to Chubb Insurance, The Central Bank, The Culinary Food Company and A&L Goodbody for their help.

We had a variety corporate partners who chose to support MS Ireland through different fundraising events such as pub quizzes, corporate sponsorship of events such as *Hell and Back*, *Christmas Jumper Day* and

Skydives – Thank you to PWC, Morgan McKinley, Glasbury Management and Tesco for their support

We ran 2 challenges in May for World MS Day including *Dip a Day* in May and *Dip for Diagnosis* on World MS Day – both of which were very successful. Thank you to everyone who participates in our challenges as these are amazing fundraisers for MS Ireland. To join our next challenge please check out our website - <https://www.ms-society.ie/get-involved/fundraise-us>

Exceptional Fundraisers

Our exceptional fundraiser is Ciaran Coakley – please see article on page 10. Other amazing support came from Sally & Lucy Hanrahan, Ciaran Delaney and family, Chloe Leo, Ciara Beecham, Niamh Devlin & team in Sydney, Aoife Bradley, Cillian McCabe and not forgetting our CE Ava Battles, along with many wonderful fundraisers who took on challenges of all sorts and raised much need funds to help us to continue providing vital services to the MS community.

Fortune Family Raises €2,631.04 for MS Research



MS Ireland is delighted to announce the remarkable fundraising efforts of Bernadette Fortune and her family, who have raised an impressive €2,631.04 for MS research. Their hard work and commitment to supporting this cause have made a significant impact on the entire MS community.

Pictured alongside Bernadette are Adam and Dylan O’Toole from the Hardy Bucks Music, who joined in celebrating this incredible fundraising.

We extend our heartfelt gratitude to Bernadette and Jenny for their generosity and tireless support. Their contribution is helping to advance MS research and improve the lives of those living with multiple sclerosis.



3	5	9	8	1	7	4	2	6
8	7	2	3	6	4	9	1	5
6	4	1	9	5	2	3	8	7
2	6	7	5	4	9	1	3	8
9	3	8	2	7	1	5	6	4
5	1	4	6	8	3	7	9	2
7	9	6	1	2	5	8	4	3
4	8	3	7	9	6	2	5	1
1	2	5	4	3	8	6	7	9

Riddles:

- A: Piano
- B: A map
- C: A Stamp
- D: A candle
- E: A joke
- F: A comb
- G: Silence

RENEW MS IRELAND

In 2025, MS Ireland is embarking on two major renovation and refit projects as part of our commitment to renewing our services and ensuring we continue to provide the highest quality of care for people living with Multiple Sclerosis (MS) in Ireland. These projects will remodel our existing facilities and enable us to expand our services to meet the growing needs of the MS community.

The Care Centre at Bushy Park Road, Dublin

Since the late 1980s, MS Ireland has operated a Care Centre for individuals with MS at 65 Bushy Park Road, Dublin. Since then, the 12-bed facility has become a cornerstone of our services, offering respite and rehabilitation for thousands of people living with MS and other neurological conditions across Ireland. To this day, it remains the only Care Centre dedicated to people living with Multiple Sclerosis in Ireland.

However, as we look to the future, large-scale renovations and refits are necessary to ensure the Care Centre remains fit for purpose and can serve as a National Services Hub for MS Ireland.

Our vision for 2025 is to convert the Care Centre into the MS Ireland National Services Hub. This transformation will allow us to centralise our services, enhancing our ability to provide high-quality care and support to the MS community nationwide. However, these ambitious renovations require substantial financial support, which is why we are calling on our community and network of supporters to help us make this vision a reality.



The MS Resource Centre in Limerick

The new MS Ireland Resource Centre in Limerick will be a welcoming and supportive space dedicated to enhancing the well-being of people living with Multiple Sclerosis (MS). The centre will proudly feature Limerick's first and only fully accessible gym, ensuring that everyone, regardless of mobility, can participate in tailored fitness programs. Here, individuals will also benefit from physiotherapist-led group exercise sessions designed to improve mobility, strength, and overall physical health.

Additionally, symptom management programs (such as fatigue management programmes), will help attendees better navigate the challenges of MS. The centre will also host informative seminars that provide valuable insights into living with MS and managing symptoms.

Most importantly, this resource centre will serve as a vital community hub where people with MS can come together, share experiences, and support one another in a nurturing environment.

MS Ireland has launched the official website for our transformative Renew MS Ireland project. This dedicated platform provides updates, insights, and details about our ambitious renovation and refit projects scheduled for 2024 and 2025.

Visit renewmsireland.ie today to explore this exciting journey and see how we are building a brighter future for the MS community in Ireland.





MS Information Line

0818 233 233

Open Monday-Friday from 9:30-5pm (excluding public holidays)

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