MS news
Winter 2025

Issue
115

YOUNG PERSONS NETWORK
YOUR SPACE, YOUR PACE, YOUR PEOPLE

‘MS News’ is the magazine of MS Ireland. It exists to foster informed debate and comment about all issues relating to MS. The views 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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IS THERE SOMETHING You’d like to share?

We would love to hear from you!

A key aim of MS News is to share things that matter to our community.

If you’d like to write a piece for the magazine or share your story, please contact aoifek@ms-society.ie

You might even win a beanie hat!

AVA'S WELCOME

Dear Friends,

As we come to the close of another year, I want to begin by saying thank you. Thank you to everyone living with MS, to families and carers, to our volunteers, branches, donors, fundraisers, clinicians and supporters nationwide. Every conversation, every event, every act of care and solidarity is what makes MS Ireland what it is.

This December issue of MS News captures something I'm proud we see again and again across our community: resilience, connection, and a determination to keep moving forward together. Whether it's your local branch sharing a milestone moment, a volunteer giving years of service, or someone living with MS telling their story with honesty and hope, you remind us that no one should face MS alone.

This year has brought real momentum in our advocacy work. We have met with the Minister for Health, the Minister for Disability and other senior decision-makers to keep MS firmly on the national agenda, focusing on fair access to community supports and neuro-rehabilitation. Importantly, Budget 2025 included a €3 million investment in community neuro-rehabilitation teams, a meaningful step in the right direction and a testament to your voices through our campaigning.

We also marked big strides in regional development, including a community preview of our future Limerick Hub. When completed, this centre will provide vital services for people across the Mid-West, including Limerick's first fully accessible gym and dedicated spaces for peer support, education and connection. Read more on these on **pages 4-7**.

Reliable information is power, especially when navigating a complex condition like MS. I'm delighted that we've launched a new HSCT (stem cell) resource on our website, giving clear information to anyone exploring this option. On **page 10**, you can read Sorcha's story of accessing HSCT.

In this issue, we also highlight why trustworthy, personalised advice matters more than ever in the age of AI. You can read more about this on **page 8**.

Our services continue to grow because of your engagement. Our physiotherapy programmes show clear benefits for strength, balance, endurance, fatigue and mental wellbeing and just as importantly, they offer something many people tell us they value deeply: being in a room (or on a screen) with others who truly understand. Read more about what you can expect if taking part in one of our physiotherapy programmes on **page 23**.

That sense of shared understanding is also at the heart of our Young Persons Network. If you're aged 18–35 and living with MS, this peer-led space is there for you. Find out more about this group on **page 21**.

This issue carries powerful reflections on living with MS not just medically, but emotionally and socially. Michelle's story of rediscovering joy and belonging through Gaelic 4 Mothers and Others (and taking that community all the way to New York!) is a beautiful reminder that everyday wins matter. You can read more about Michelle's story on **page 22**.

On **page 18** you will find a piece by Ronan Carbery on chronic illness in academia which speaks to something many of you have shared: how MS reshapes relationships, identity and the way we ask for and offer support.

Across the country, our branches and volunteers continue to be the heartbeat of MS Ireland: from celebrating carers, to honouring long-serving volunteers, to gathering people together through friendship weeks, runs, readathons and more. Thank you for keeping connection alive locally. You can read about our National Awards on page 16 and Community News on **page 14**.

Finally, to everyone who fundraised, donated, took part in events, or encouraged others to support MS Ireland this year: you've made a real difference. Your generosity strengthens our regional services, fuels advocacy, and allows us to keep showing up for people and families across Ireland. As we head into 2026, our new MS Ireland Lotto and other fundraising initiatives will be vital in sustaining and expanding this work. If you can get involved, please do and if you already have, thank you. Find out more about our fundraising updates on **pages 24-27**.

I hope this Christmas season brings you moments of peace, comfort, and connection. I want you to know that MS Ireland will continue to stand with you in the year ahead, pushing for better services, sharing trustworthy information, and building community across every county.

From all of us here, thank you for being part of MS Ireland.

Warm regards,

Ava Battles
Chief Executive, *MS Ireland*

MS Ireland Launches New HSCT Stem Cell Treatment Information Hub

MS and Stem Cell

MS Ireland has launched a new online resource to support people living with MS who are exploring stem cell treatment options.

In November, MS Ireland published **"HSCT (Stem Cell) Treatment for Multiple Sclerosis (MS) in Ireland"**, a dedicated information hub focusing on haematopoietic stem cell transplantation (HSCT).

The resource explains what HSCT involves, outlines potential benefits and risks, and provides clear information on who may be eligible and how the current treatment pathway works for people in Ireland.

The new online guide aims to help people with MS, their families and health professionals navigate a complex and often confusing topic. It brings together evidence-based information, links to further reading, and practical considerations for anyone thinking about HSCT, including the importance of discussing treatment options with a neurologist and understanding issues such as safety, recovery and life after treatment.

MS Ireland hopes this will be a living resource, updated regularly as new research emerges, services develop and Irish pathways evolve. Visitors will be able to access refreshed content over time, reflecting advances in HSCT, clinical trials and policy or service changes relevant to people living with MS in Ireland.

Speaking about the resource, Aoife Kirwan, MS Ireland's Information Officer said:

"We know that some people living with MS in Ireland are actively seeking information on stem cell therapy, but until now that information has often been fragmented and hard to navigate. By bringing together clear, reliable details on the current route to HSCT and the different aspects people need to consider, this resource aims to support people with MS to make informed choices about their treatment and care."

The resource also features a case study, offering personal insight into the HSCT journey, this piece has been included in MS News and can be found on **page 10.**

The resource is now available on the MS Ireland website at: **ms-society.ie/hsct-stem-cell-treatment-multiple-sclerosis-ms-ireland.**

Research Together 2025: Strengthening Academic–Charity Partnerships

MS Ireland participated in **Research Together 2025**, held as part of Maynooth University's Research Week and the national PPI Festival. Co-designed by Health Research Charities Ireland (HRCI) and The Wheel, the event brought together researchers, charities and support professionals to explore how collaborative partnerships drive meaningful impact.

Speaking on a panel, Alison Cotter, MS Ireland's Advocacy & Research Officer highlighted that successful collaboration depends on shared purpose, mutual respect and a commitment to using evidence for positive change. The event underscored that impact is not a single moment but a sustained process rooted in strong relationships and collective responsibility.

Advancing Supports for Young People with Neuroinflammatory Conditions

MS Ireland met with Dr Hugh Kearney and Dr Susan Byrne, to discuss advocacy priorities, service development and transition pathways for children and young people with neuroinflammatory conditions, including paediatric-onset MS.

MS Ireland extended a heartfelt 'thank you' to the many individuals with lived-experience who contributed insights ahead of the meeting. Their perspectives played a central role in shaping the agenda and ensuring that young people's needs remain at the forefront of future service improvements.

A Milestone for the Mid-West: Preview of MS Ireland's Future Limerick Hub

MS Ireland celebrated an important moment in Limerick with a community preview of the organisation's future Limerick Hub on Singland Road. Staff, volunteers, community members and elected representatives came together to see first-hand the transformative potential of this new centre.

The Hub will provide much-needed services and supports for people living with MS and other neurological conditions across the Mid-West. Once complete, the facility will include Limerick's first fully accessible gym, alongside dedicated spaces for education, peer support, and community programming, filling a longstanding gap in regional neurological services.

The strong attendance of cross-party representatives underlined the importance of community collaboration, political will, and sustained advocacy in bringing this project to life.

MS Ireland Contributes Lived Experience Insights to Trinity College Neuropsychology Programme

MS Ireland was pleased to support a special teaching session for Master's students in Applied Clinical Neuropsychology at Trinity College Dublin, facilitated by Professors Orla Hardiman and David Mothersill.

Contributions from individuals with lived experience, including MS Ireland's Aoife Kirwan and NAI Vice Chair and MS Ireland Advocacy & Research Officer Alison Cotter, helped illuminate the importance of listening, communication, and co-production in clinical practice.

Student feedback demonstrated the profound impact of hearing directly from those who navigate neurological conditions in their daily lives.

MS Ireland Engages with Minister Norma Foley as Part of The Home Care Coalition

As a member of The Home Care Coalition, MS Ireland joined a delegation of 23 charities and advocacy organisations in a meeting with Minister Norma Foley and her team to highlight ongoing challenges in the home care sector.

The discussion centred on the need to deliver the commitments outlined in Budget 2025 and to ensure that people can access high-quality supports in their own homes. MS Ireland looks forward to continued engagement with the Minister and her Department as efforts progress to strengthen community-based care nationwide.

MS Ireland Meets Minister Hildegarde Naughton to Discuss Budget Priorities

MS Ireland met with Minister Hildegarde Naughton in Galway to outline key budget priorities for the MS community and to highlight the urgency of advancing supports for people living with neurological conditions.

During the meeting, Alison Cotter, MS Ireland's Advocacy & Research Officer presented evidence-informed budget asks focused on improving access to community services, strengthening neuro-rehabilitation pathways, and addressing ongoing gaps in regional supports. The discussion provided a valuable opportunity to reinforce the organisation's commitment to ensuring equitable service provision across the country.

MS Ireland Delivers Workshop at RCSI

MS Ireland delivered an interactive educational workshop to second-year Immunology students at RCSI. The workshop introduced students to the fundamentals of Multiple Sclerosis, including its clinical characteristics, impact on daily life, and the broader context of neurological conditions in Ireland. Students also received an overview of MS Ireland's national services, community supports, and advocacy work.

A key component of the session was an experiential learning session, designed to help students understand the lived reality of MS. This was complemented by a powerful contribution from a lived-experience representative, whose personal insights deepened students' understanding of the challenges and resilience within the MS community.

Feedback from attendees highlighted the value of integrating lived experience and patient perspective into early clinical education, an approach MS Ireland remains committed to expanding.

MS in the Workplace: Training Continues Nationwide

MS Ireland has continued to roll out its *MS in the Workplace* training across the country this year, supporting employers, HR teams and colleagues to better understand and support staff living with multiple sclerosis.

The training provides an overview of MS, including common symptoms, how it can impact people differently, and the kinds of challenges that may arise in the workplace. It also covers employee rights, employer obligations, reasonable accommodations, and practical examples of supports that can help people with MS to stay in work and thrive in their roles.

Sessions are designed to encourage open discussion, address stigma and misconceptions, and build confidence among managers and colleagues in having supportive conversations and creating inclusive workplace cultures. Participants are also signposted to further resources and supports available through MS Ireland.

If you know of a workplace that would be interested in MS in the Workplace training, please contact **melaniec@ms-society.ie** for more information.

Call for Full-Time Community Worker in Sligo-Leitrim Gains Strong Political Support

MS Ireland hosted a powerful and emotional gathering at the Radisson Blu in Sligo to highlight the urgent need for a full-time MS Ireland community worker for Sligo and Leitrim, the only counties in Ireland currently without this essential support.

The event featured moving testimonies from people with lived experience, contributions from the MS Ireland Leitrim Branch, and strong cross-party backing from local Oireachtas members and councillors.

Representatives including Martin Kenny TD, Frank Feighan TD, Senator Nessa Cosgrove, and councillors Brendan Barry, Gary Prior, Paddy O'Rourke, and Paddy Farrell all committed to progressing the issue.

A single post, costing €72,997.56, would provide life-changing support for the region. The message from the day was clear: this is about equity, ensuring that people with MS in Sligo and Leitrim receive the same level of service available across the rest of the country.

Budget 2025: €3m Investment in Community Neuro-Rehabilitation Teams Welcomed

MS Ireland warmly welcomed the Government's announcement of a €3 million investment in community neuro-rehabilitation teams, a direct response to the issues raised through the **#MyNeuroRehabTeam campaign**.

The campaign, delivered in partnership with the Neurological Alliance of Ireland (NAI), was strengthened by powerful lived-experience testimonies and the tireless commitment of campaign spokespersons, MS Ireland staff, member organisations, and supporters played a central role in shaping and driving this advocacy effort.

This investment represents a significant step towards ensuring that people living with neurological conditions have access to the coordinated, community-based supports they need.

MS Ireland Meets Minister for Health to Advance Priority Issues for the MS Community

MS Ireland engaged in a constructive and forward-looking discussion with the Minister for Health, Jennifer Carroll MacNeill, senior officials from the Department of Health, and representatives from the Department of Children, Disability and Equality.

These conversations remain essential to ensuring that the needs of people living with Multiple Sclerosis are recognised across Government and that services continue to evolve in line with national priorities.
MS Ireland welcomed the opportunity to reaffirm its key advocacy aims, emphasising equitable access to services, appropriate community supports, and strengthened pathways of care.

Launch of New TFI Supports

Transport for Ireland (TFI) has launched new accessibility resources to better support people with disabilities, including hidden conditions. The new "Please Offer Me a Seat" badge and card provide a simple, discreet way for passengers to signal that they may need a seat due to fatigue, pain, balance issues or other symptoms that aren't immediately visible.

Developed with Invisible Disability Ireland, the badge aims to make everyday travel more comfortable and reduce the stress of having to verbally ask for help, something many people living with MS find challenging on busy buses, trains or trams.

Resources are free and available across the TFI network. Find out more or request a badge or card at: https://www.transportforireland.ie/accessibility/

MS Information in the age of Artificial Intelligence (AI)

MS can be overwhelming and seeking information can sometimes be challenging. It can seem as though you're drowning in the vastness of the sheer amount of information that is available at our fingertips and it can be tempting to turn to AI tools like for quick answers. These tools can seem helpful, especially when you're worried or trying to understand test results like MRIs, but while AI can be useful in some ways, there are real dangers in relying on it for medical advice, especially when it comes to something as complex as MS.

Today, even a simple Google search about MS can generate an AI summary at the top of your results. While this might look convenient, it's important to remember that these summaries are automatically generated and can sometimes include inaccurate, incomplete, or outdated information.

AI answers questions by analysing patterns in data and using information from existing online sources to form a response to the question you ask, but that information may not always be reliable or current.

AI Is Not a Doctor

First and foremost, no matter how smart or realistic it seems, AI is not a trained medical professional. AI doesn't know your personal medical history, your treatment plan or the specifics of how MS is affecting you. MS is different for everyone and a chatbot can't replace the advice of your neurologist, MS nurse or GP. AI can't do physical exams or read the full picture of your MRI in the context of your full medical history.

Dangers of Feeding AI Your MRI or Health Reports

You might be tempted to copy and paste parts of your MRI report or other test results into an AI chat to ask, "What does this mean?" But this can be risky for a few reasons:

1. Misunderstanding medical language: AI might give a confident-sounding answer that's completely wrong or based on outdated information.
2. Privacy concerns: Even when AI tools assure users that data isn't stored, it's still wise to be cautious about sharing sensitive health information online, as it can be challenging to remove once posted.
3. Stress and confusion: AI might suggest serious conditions or outcomes that don't actually apply to you. Being given information, that may or may not be accurate with no context or support can cause unnecessary stress or confusion.

That said, not all use of AI is bad. An example of how you can use it to help is with something like preparing for your neurology visit by asking it to help you organise questions you may have.

If you're using AI, you may wish to use it as a support tool and not a source of truth.

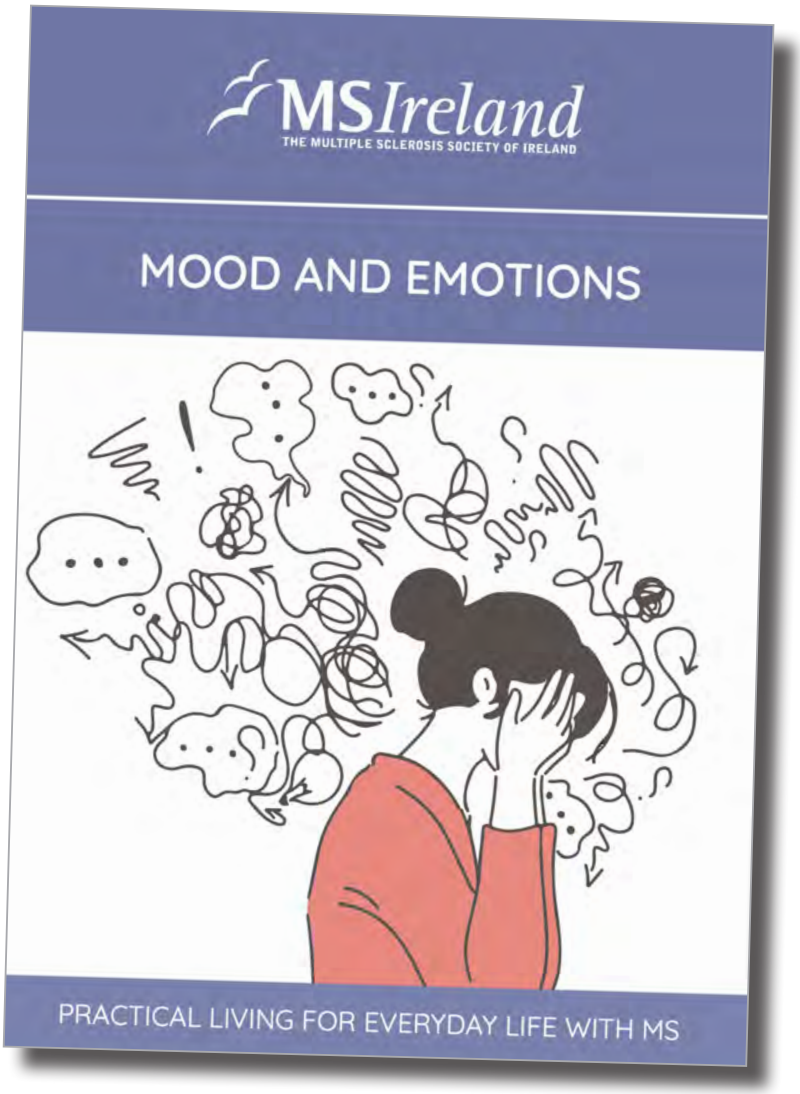
Practical Tips for Staying Safe

- Don't share personal medical info: Never upload your MRI scans, test results, or personal health history into an AI tool.
- Stick to trusted sources: For accurate, Ireland-specific MS info, use websites like the MS Ireland website (www.ms-society.ie), HSE (www.hse.ie) or ask your healthcare team directly.
- Use AI to prepare for appointments: You can ask AI to help you form questions for your neurologist, but never let it answer those questions for your doctor.
- Check the date of the info: AI can sometimes give outdated advice. Always cross-check any health advice with a real medical professional. It can also give incorrect advice.

AI might seem like a quick fix when you're looking for answers about your MS. But when it comes to your health, shortcuts can lead to confusion, stress and even danger. You deserve personalised, professional care and your healthcare provider is best placed to provide this to you.

Launch of Mood and Emotions: Practical Living for Everyday Life with MS

MS Ireland is delighted to announce the launch of “Mood and Emotions: Practical Living for Everyday Life with MS.”



Unveiled at MS Ireland’s National Conference 2025 by Information Officer Aoife Kirwan, this publication focuses on one of the most important and sometimes least talked about aspects of living with multiple sclerosis, how MS can affect mood, emotions and overall psychological wellbeing.

Living with MS doesn’t just affect the body, it can have a powerful impact on how people feel, think and relate to others. Mood changes may be:

- A direct result of MS and its effect on the brain
- A natural emotional response to diagnosis, uncertainty, and change
- Linked to the side effects of medications, or to other life stressors

This booklet aims to explain these different influences in clear, accessible language and reassure readers that emotional reactions such as shock, fear, denial, anxiety, anger, grief, guilt and frustration are common and understandable responses to life with MS.

The publication is designed as a practical, everyday guide, whether you’re newly diagnosed or living with MS for many years. It includes:

- **Understanding the impact of MS on emotions**
- **Emotional and psychological reactions to MS**
- **Managing your emotions**
- **When and how to seek professional help**
- **Emotional and psychological symptoms in MS**
- **Other mood and emotional disorders & behavioural symptoms**
- **Case studies with real-life experience**
- **Useful organisations and further information**

We extend our sincere thanks to everyone who contributed, whether by sharing their expertise or generously offering their lived experience of MS and mental health.

Special thanks to Dr Fiadhnait O’Keeffe for her support and input throughout the development of this publication. Her expertise has helped ensure the information is accurate, practical and sensitive to the realities of life with MS.

How to access the publication

The booklet is available digitally via MS Ireland’s website and can be downloaded and shared with family members, friends or professionals involved in your care. Printed copies may also be available through MS Ireland’s regional offices or through the Information Service.

If you would like to learn more, request a copy, or talk about any of the issues raised, you can contact MS Ireland’s Information Line or speak to your local MS Ireland Regional Community Worker.

Caring for emotional health is every bit as important as managing the physical aspects of MS. With this new publication, MS Ireland hopes to make that journey a little more understood, more supported and less lonely for everyone affected by MS.

Sorcha's MS and Stem Cell Story

In April 2014, at 33 years old, Sorcha Boyle was diagnosed with MS. Her diagnosis came through a private consultation, though she later moved back into the public health system. Looking back, she recalls how symptoms had already been troubling her for a year before that, but early consultations had left her feeling dismissed. By the time she finally received clarity, there had already been significant delays, and her MS had quickly begun to show an aggressive course.

From the beginning, treatment was difficult. Her first medications caused severe reactions or simply did not work, and within a short space of time she had already cycled through three DMTs. Each attempt was followed by new activity, new relapses and fresh complications. One of the most devastating relapse led to a ten-week hospital stay followed by a further eight weeks as an inpatient in rehabilitation. Even when higher-efficacy medications were trialled, the disease activity did not relent, and in the midst of this she also developed thyroid problems that required surgery.

MS can be overwhelming and affect your mood in different ways. These emotions can influence how you feel physically, impact fatigue, sleep, your ability to concentrate, how you see yourself, your relationships and your overall wellbeing.

The COVID-19 pandemic only made things more complicated. Her treatment was paused during this period, and when it resumed, she tried yet another DMT. But still the pattern continued: every four months she relapsed, with new symptoms each time. By 2021, it had become painfully clear to her that her MS was unresponsive and highly aggressive.

In August of that year, her neurologist suggested her case should be put before a committee determining access to stem cell treatment in London. To her surprise, by September she was told she met the NHS criteria and had been approved for HSCT.

> *"I was sick of constant relapses,"* she recalled. *"We're all looking for the silver bullet when it comes to treatment for MS. When HSCT was suggested, I didn't expect anything, but it felt like a chance. Life had become punctuated by relapses. So when I was accepted, it was good news. What did I have to lose?"*

Fertility was an important part of the discussions at this stage. While she already had a child and did not intend to have more, she understood that for many others this is a crucial consideration, and she encourages women to explore options such as egg freezing before beginning treatment. At the same time, she was forced to step back from her work, another reminder of how MS was stealing parts of her life.

Her HSCT treatment began in January 2022 in London. The first phase involved a series of outpatient assessments, scans, and a priming dose of chemotherapy. At home, she gave herself twice-daily injections to stimulate stem cell production in her bloodstream, ultimately harvesting between eight and nine million cells, well above the three million required.

Two weeks after her first chemotherapy, she began losing her hair and decided to shave her head before returning to London. During this period, she also had to be vigilant about avoiding infections such as COVID-19 or chickenpox, which could have proved devastating.

In March 2022, she was admitted for the second phase: a more intensive course of chemotherapy followed by reinfusion of her stem cells. Recovery was closely monitored, involving daily blood tests, antibiotics, and antivirals. Sorcha recalls that on St. Patrick's Day her neutrophil count, a type of white blood cell that fights infection, had returned to a safe level. This signalled the first signs that her new immune system was taking hold. She remained in hospital for a further week and a half before being discharged, returning home to follow-up care with a haematologist in Beaumont and eventually resuming the care of her neurologist.

Since undergoing HSCT, her MS has been stable. Sorcha describes it now as "in hibernation." While she was told not to expect improvements, she has noticed changes and sees those as a bonus. "The goal is to stop MS in its tracks," she said. Looking back, she sometimes struggles to reconcile the fact that she is the same person who went through so many hospitalisations and relapses. “That feels like someone else’s story.”

Her experience has not been without challenges. She was the first patient from her hospital to undergo HSCT for MS through the NHS, which meant there was no peer support to draw on. A dedicated stem cell nurse became an invaluable source of guidance.

Financially, the process was extremely difficult. Although her treatment was approved under the Treatment Abroad scheme, reimbursement for flights and other expenses never materialised, and she had to rely on fundraising to cover the costs. Returning to Ireland also brought hurdles. Some healthcare professionals were unfamiliar with HSCT for MS and questioned why she would undergo such a procedure, leaving her feeling she had to defend her choices.

Reflecting on the transformation, she describes an important shift in identity. “Instead of being the girl with MS who can’t do this or that, I am just Sorcha again.” While her career had been taken from her by the relentlessness of relapses, she now feels as though her condition is asleep and hopes it will remain that way.

For others considering HSCT, she is honest: it is a serious undertaking with risks attached, and it demands self-advocacy, especially in countries like Ireland where it is not yet available. Everyone responds differently to chemotherapy, and while her side effects were manageable, that will not be the case for all. Fertility, family planning, aftercare and long-term supports all need to be thought through carefully.

Despite the financial strain, the gaps in understanding within the Irish system and the uncertainty of what the future holds, Sorcha believes HSCT has been life-changing for her. Above all, she feels it has given her hope, more presence in her daughter’s life, and the chance to reclaim her identity. As she puts it “My MS is asleep now, and long may it stay asleep.”

An Taoiseach Micheál Martin attends MS Ireland’s National Conference 2025

MS Ireland was honoured to welcome An Taoiseach Micheál Martin to our National Conference 2025, a visit coordinated through the organisation’s ongoing advocacy efforts.

The Taoiseach met directly with individuals and families affected by MS, hearing about their experiences accessing care, the importance of community supports, and the day-to-day reality of life with MS. His presence signalled a strong recognition of the challenges facing the MS community and the importance of national leadership in addressing them.

Attendees described the conference as an energising and meaningful weekend focused on connection, care, and mental health.

Highlights from the Annual MS National Conference

By: Louise Power - MS Ireland's Readathon Ambassador for 2025

On Saturday 15th November, MS Ireland held their annual conference in Cork International Hotel. This year's theme was **Living with MS: Conversations on Care, Connection & Mental Health.**

This was my 6th conference, (I think) and it didn't disappoint. Before I went to my first MS Ireland conference, I felt apprehensive, nervous and doubted whether I should/needed to go. Now, when I look back, it was the best decision ever to go. I meet so many people every year from all parts of the country and hear from fantastic speakers from a variety of expertise.

Yes, Mayo to Cork was a fair 'oul trek but worth every minute. Mingling and catching up with people at the drinks reception the night before the conference, sitting at a table with strangers at the start of the night but friends by the end and listening to a choir and the band.

The next morning, the conference kicked off with a welcome from MS Ireland's Chief Executive, Ava Battles and then the MC for the day was Morris O'Connor, who previously volunteered in one of the Regional Offices and who is now the Company Secretary.

Now onto the speakers

First up was **Professor Rhona Moss- Morris** with **"Living with MS; Psychological adjustments in a changing body".** During her talk she spoke about adjustment, therapeutic approaches to facilitate adjustment to MS and our digital future.

Second up was **Judith Spring with "Think it, plan it, do it: The power of goal setting"** and a panel discussion. I did happen to miss some of this one as I was recording a podcast but that night, I was able to catch up on MS Ireland's YouTube channel.

Just before we broke up for lunch, we heard from **Dr Rebecca Maguire** about the launch of the **Promise Project – Improving mental health supports for people with MS in Ireland.**

Then, we heard briefly about **Cognitive Occupation Based Programme for people with MS. (COB-MS)** with **Dr Sinead Hynes.** I was very fortunate to be one of the first people to take part in the research stage of COB-MS, in the trial stage and I have to say, it was fantastic. If you get the chance, check it out. There is another phase of the research, and they are looking for participants to take part. You can find out more about it here:

While at lunch I got to chat to even more new people and hear their stories. After lunch the afternoon sessions got slightly delayed due to a surprise visitor. Our very own Taoiseach Michael Martin. He greeted us, chatted to us and listened to our various stories. There was no rush or panic and he took time with lots of people. Here's hoping he will support MS Ireland's business cases.

Parallel sessions ran for the first hour of the afternoon. Everybody got to choose which one they would like to attend. I chose "**A holistic Approach to managing MS fatigue, Mental Health and Thinking Skills"** with **Dr Fiadhnait O'Keefe.** I would highly recommend watching this on MS Ireland's YouTube channel.

The other sessions that people choose to attend were,

- *Sexuality and MS Changing Perspectives with Mary Leonard*
- *The Resilient Carer; An Interactive Workshop for Carers with Jackie Keogh*
- *Moving Minds; the Mental Health Benefits of Physical Activity in MS with Dr Susan Coote*

Following the parallel sessions, Aoife Kirwan, MS Ireland's Information Officer, launched the Mood and Emotions publication which was truly amazing to read through. There is such a wide range covered in the booklet that I just wish it was around when I was diagnosed. I feel it would have helped to know what I could do when I was anxious or feeling down and when I was grieving the old me. I actually think it will still help now, 10 years later, and I will also be armed and ready if I was to chat to someone who may be in need of the booklet.

Finally, the day finished with **"Understanding MS Treatment"** with **Professor Simon Cronin**. Here we heard about existing treatments and up-and-coming treatments which are currently at different stages of trials. Understanding the updated diagnostic tools that neurologists use to diagnose MS and to treat those already diagnosed.

Did I learn anything from the conference? Yes, I will spend the next week or two processing everything and starting to put some of it into practice.

Will I be going next year? Oh yes, without a doubt. I am looking forward to meeting familiar faces and even more new faces. We are all in it together.

Thank you, MS Ireland, for holding these conferences. Over the years I have gotten so much from them, been reassured in one way or another and have had doubts put to bed.

You can watch sessions from the conference on the MS Ireland YouTube channel here:

Meath Branch

In November 2024, Patsy Fagan from the Meath Branch was awarded the Multiple Sclerosis Carer of the Year. His wife Elizabeth was diagnosed with MS forty-four years ago and Patsy and his family has lovingly cared for her since.

On the 25th of August *Nationwide* paid a visit to their home. Filming and interviews were carried out there. At one o'clock on the day, friends and neighbours gathered at their local hostelry to honour the Fagen family. The *Nationwide* team spent time filming there too.

Patsy is a great musician and singer and he and his musician friends entertained all present with lovely music and songs.

Ava Battles attended the event and thanked Eva, Patsy's daughter for highlighting MS. It was not a fundraising event, yet people present donated €410 to the Meath Branch.

Patsy and his wife Elizabeth represented the Meath Branch at the National Conference in Cork on the 14th of November.

South Wexford Branch

Full hearts and full throttle, thank you Bree Vintage Club!!

We were delighted to gather in Byrnes of Bree recently to receive a very generous cheque for €8,156.27 from the wonderful Bree Vintage Club, raised through their very successful Annual Road Run

This fantastic contribution will go a long way in supporting the work of the South Wexford Branch. We extend our heartfelt thanks to everyone who helped organise, participated in, and supported this event. Your community spirit and generosity are deeply appreciated

Honouring 13 Years of Service: Patrick McCarthy

Donegal Branch

Honouring 13 Years of Service: Patrick McCarthy

MS Ireland is delighted to share that long-time volunteer Patrick McCarthy, who lives with multiple sclerosis and epilepsy, has been recognised for his remarkable contribution to community life in Donegal.

Recently, Donegal Volunteer Centre celebrated Patrick as one of their longest-serving and most dedicated volunteers. Patrick has been a much-loved part of the centre for the past 13 years, bringing warmth, humour and a deep commitment to helping others.

After many years working in social work at Letterkenny General Hospital (now LUH), Patrick found himself with more time, but the same strong desire to support people in his community. In August 2012, he registered with Donegal Volunteer Centre, a decision he describes as "One of the best steps I've ever taken."

His first volunteering role was with Letterkenny Men's Shed, helping to organise a woodwork display. That experience opened the door to a wide range of community work. Since then, Patrick has given his time in many different ways, including teaching English, supporting a Ukrainian exhibition, and assisting at the North West 10K. "You never know where volunteering might lead," Patrick says. "Each opportunity opens a new door, a new person, a new place, a new skill."

A particularly meaningful chapter for Patrick was his time with Rehab Donegal, under the guidance of Katja Schwenkerr, whom he describes as "a wonderful manager who really believed in people." He also has very fond memories of working with Letterkenny Tidy Towns saying "There's something special about helping your own town shine."

During the COVID-19 pandemic, Patrick took part in a storytelling initiative called *Uncover Rediscover in Your Locality*. He contributed a heartfelt piece titled *Memories of Oatfield Sweets*, celebrating the much-loved Letterkenny company. "Oatfield sweets were part of my childhood, and they followed me across the ocean," he recalls, remembering conversations in GAA clubhouses in New York, "where a sweet from Donegal could bring us all home for a moment."

Patrick's voice has also helped shape important research. In 2021, he took part in a cross-border polypharmacy research project led by Queen's University Belfast, contributing as a client voice to research on the impact of medication on older and vulnerable adults. Both he and Donegal Volunteer Centre were acknowledged in the final paper, which is now listed in the National Library of Medicine.

"It meant a lot to know that my voice could help shape something so important. Volunteering isn't just about giving, it's about being heard, being valued."

In 2022, Patrick welcomed a delegation of European volunteer centre managers to Donegal, guiding them on visits to Cornwall Flax Mill, Gweedore, and the wild west of the county. That same year, he received a Volunteer Recognition Award from Rehab Care.

Throughout all of this, Patrick has continued to balance life with multiple sclerosis and epilepsy. He has always chosen volunteering roles that match his interests and energy levels. "The team at Donegal Volunteer Centre never pressured me. They always asked, 'What would you enjoy?' and that made all the difference."

Over the past 13 years, Patrick has found purpose, joy and belonging through volunteering. His message to others is simple, "If you're thinking about volunteering, just try it. There's something for everyone, and you'll get far more out of it than you ever expected."

Our many congratulations to Patrick!

Fermoy Branch

The Fermoy Branch of MS Ireland which covers the area of North & East Cork continues to hold its monthly committee meetings on Zoom on the second Monday of the month.

A good attendance is always assured. With a committee of twelve, we plan fundraising events such as church gate collections and flag days right throughout our large Branch area.

Our Annual Walk, as always, is held on the third Sunday of June (Father's Day). This year's walk, the 44th, was held in Glansheskin Forest Recreation Area (Kilworth Wood), which is a Coillte facility. We are thankful to them for granting us permission to hold the event.

We recently met with the Mallow section of our Branch in The Arches Bar for a much anticipated catch up over a coffee & refreshments. This was a particularly joyful occasion as we hadn't met for some time. We have a similar get together planned for our Midleton/Youghal area. The hope is that we will do something similar with the Fermoy/ Mitchelstown section.

Some of our committee & friends are taking part in this year's Readathon, enjoying the pleasure of reading while raising much needed funds for MS Ireland and at the same time encouraging reading in all age groups to support good mental health & wellbeing.

In mid-November we attended the National MS Conference which was held this year in the Cork International Hotel.

Cork North & East Community Work Department of HSE marking 50 years of supporting local groups across Cork City & county. Held during Fermoy Friendship week on World Kindness Day acknowledging the contribution of community groups supported through the HSE Southwest funding.

South Mayo Branch

Newport Pickleball Club recently ran a Round Robin Tournament fundraiser for the South Mayo Branch. A number of members of the South Mayo Branch attended a cheque presentation.

Many thanks to the club for their generous support!

Celebrating our MS Ireland National Awards

MS Ireland is delighted to share and celebrate the exceptional individuals recognised at this year's MS Ireland National Awards. Each of them embodies the strength, community spirit and compassion that define our MS Ireland family.

MS Person of the Year

Patrice Brady Carton

Nominated by Laura Lockwood, South West Dublin

"Patrice is the driving force behind the MS Sing for Fun choir, a group she created and continues to lead with incredible dedication. She recognised the deep therapeutic and social value of music for people living with MS, and transformed that insight into a lifeline for so many. The choir offers connection, joy, and an "ever-going network" that combats isolation and strengthens wellbeing. Patrice uses her own lived experience to lift others, and her impact reaches far beyond the music".

Carer/Helper of the Year

Joe & Breda Flood

Nominated by the South Dublin Branch

"For more than 11 years, Joe and Breda have supported the South Dublin Branch with unwavering kindness and commitment. They are a shining example of mutual care, dignity and respect in the face of MS. Joe is the official nominee, but both Joe and Breda embody teamwork, compassion and dedication. Their quiet, steadfast support has made a meaningful difference to so many in their community".

Volunteer of the Year

Goolam Bhamjee

Nominated by the South Dublin Branch

"Goolam has been an incredible volunteer and fundraiser for the South Dublin Branch since 2014. Along with his wife Anne, he has devoted time, energy, and creativity to strengthening our work. His consistent support — from donating Specsavers vouchers for raffles and quizzes to helping at collections — has boosted our fundraising and visibility for more than a decade. His advocacy within Specsavers, including securing us as "Charity of the Month" multiple times, has been invaluable".

My name is Michelle. In 2004, at the age of 21 and not long after the birth of my first child, I received the life-changing diagnosis of multiple sclerosis.

At first, it was extremely difficult to accept. I experienced frequent relapses, steroid treatments and hospital visits. My future felt uncertain and overwhelming. There were moments of denial and frustration as I tried to look after myself and a new baby with my coordination gone, numbness on my right side and vertigo. I questioned my daily life, worrying that I might never feel "normal" again.

But through it all, I was surrounded by an incredible network of support. My family and friends became my anchors, and the guidance of my MS nurse and hospital team was invaluable. They helped me navigate treatments, manage relapses and reminded me that I was not alone on this journey.

One of my greatest sources of inspiration is my daughter. Watching her passion for Gaelic football, playing since she was 6 years old, gave me the push to join a team and get more active. I joined Gaelic 4 Mothers and Others with Wanderers GAA Club Ballyboden, a non-competitive sport that focuses on fun and fitness. What began as a way to stay active turned into a source of friendship, laughter and support. The social connections with the girls and our shared experiences lifted me up in ways I never expected.

We often hear incredible stories of people with MS running marathons or climbing mountains. Those achievements are amazing and inspiring. But I've learned that sometimes the real victories are also found in the everyday, showing up to training on a wet Thursday night, sharing a laugh while putting our boots on pitch-side, feeling part of a local team. For me, the win is in being included, being active and being surrounded by women who cheer each other on, on and off the pitch.

Through this team, many opportunities have presented themselves. Ones I never imagined I'd be able for when I first received my diagnosis. One of the most unforgettable of these was travelling to New York to participate in the New York Gaelic 4 Mothers and Others Festival of Football tournament.

A local team from Ballyboden suddenly found ourselves on a truly unique adventure that included a 5K walk/run in Central Park, the main football festival in Rockland, and our closing party in Stout NYC.

It wasn't about competition, it was a celebration of community and inclusion, with teams from all over coming together to make the best memories. Standing on a pitch in America, surrounded by friends I'd met through Gaelic 4 Mothers and Others, I realised that this was my version of climbing a mountain. Our ordinary training sessions had led us somewhere extraordinary. The warmth, encouragement and pure craic from the group made it an experience I will never forget.

I have learned that the power of connection and community is just as important as the physical activity. Even on tough days, friendships and support keep me going. My journey with MS has been one of highs and lows, challenges and triumphs. It has shaped me, strengthened me and led me to experiences I might never have had otherwise, including lacing up my boots in New York City with my team by my side.

I share my story in the hope that it encourages others facing their own battles to find strength in acceptance, to value the everyday wins, to embrace opportunities for connection and to remember to have faith. Even when life feels uncertain, there is always room to rediscover joy, purpose and resilience, sometimes starting with something as simple as joining your local team!

Living with Chronic Illness in Academia:

How MS Transformed My Understanding of Relationships and Support

By Ronan Carbery

This article was first published by Voices in Academia on November 7th, 2025 and has been shared with permission from the author.

Multiple sclerosis (MS) entered my life in 2013 with my wife's diagnosis. We spent time learning to manage the condition and moved to another city to be able to draw on family support while understanding the nature of the disease. This learning curve steepened dramatically when cancer complicated her condition in 2015, leading to two years of treatment that pushed MS management into the background. When she achieved remission, we thought we'd found our new normal.

In 2023, ten years after her diagnosis, I learned I had MS too. I went from being a supportive partner to someone living with the condition myself. The medical reality was compounded by the psychological weight of uncertainty about career sustainability and whether I could maintain the professional identity I had spent years building. The persistent worry was whether disclosing this would mark me as damaged goods, potentially derailing any chance of promotion or career advancement. This has prompted two years of reflection on my part on how chronic illness changes not just what we do as academics, but how we relate to the colleagues who make that work possible.

In his book *Metamorphosis: A Life in Pieces* (2023), academic Robert Douglas-Fairhurst uses Kafka's The *Metamorphosis* (1915) as a lens for understanding a diagnosis of MS. Like Kafka's protagonist Gregor Samsa, we don't simply acquire a medical condition; we undergo a transformation that reshapes how we move through professional spaces and how others perceive us.

Yet unlike Samsa, whose transformation leads to isolation, living with MS offers possibilities for adaptation and continued contribution. The key difference lies in the quality of relationships we maintain and cultivate throughout our academic careers.

The Embodied Reality of Academic Work

Academia often presents itself as a purely intellectual pursuit, conveniently forgetting its embodied nature. MS makes this physical reality impossible to ignore. On one occasion shortly after my diagnosis, I fell over myself whilst teaching; a sudden, involuntary reminder that my scholarly identity is inseparable from my physical being. More distressingly, on a small number of occasions, I have forgotten a word mid-lecture, standing before students as cognitive fatigue suddenly erased the expertise I was there to share.

I now tell my students at the beginning of each semester that I have MS in order to mitigate any potential misunderstandings. Students generally respond with empathy rather than concern about my teaching ability, and a number of them have said my openness helps them feel more comfortable approaching me about their own challenges.

These moments reveal the fundamental contradiction in how I once conceptualised academic work: we celebrate the life of the mind whilst pretending it doesn't require a functioning body to support it.

The cognitive symptoms of MS create particular challenges in a profession that values mental acuity above almost all else. Fatigue-induced brain fog doesn't align with intensive 8-hour teaching blocks on an Executive MBA programme. Cognitive processing delays don't accommodate publication deadlines. I have had to teach myself to become better at saying no to non-essential service commitments, recognising that energy management requires prioritisation of core responsibilities. In addition, scheduling PhD supervision meetings in the early morning has meant less likelihood of cognitive fatigue.

In my teaching, I look at how professional identities develop through consistent performance and peer recognition. MS disrupts this process by introducing unpredictability into professional performance—raising complicated questions about how academic identity persists when one's capacity fluctuates from day to day.

Research Friendships: The Antidote to Academic Isolation

What has sustained me through my experience with chronic illness isn't institutional support or formal accommodations—it is the genuine friendships I've developed with collaborators over my career. Those with whom I research and write are those whom I would call friends, and their understanding of the ebb and flow of MS has allowed me to maintain a healthy approach to work.

These aren't merely professional relationships enhanced by personal warmth. For me, they represent a fundamental reorientation of how academic work gets done. My colleagues have intuitively grasped what Douglas-Fairhurst describes as the need to 'live with uncertainty' that MS brings.

When cognitive symptoms flare, these colleagues adapt our collaborative processes without making me feel diminished. When energy levels fluctuate, they adjust timelines and expectations with the same ease they might accommodate a colleague's sabbatical or family commitments. Most importantly, they see past the symptoms to the intellectual contribution that (I hope) remains consistent even when delivery mechanisms vary. For academics seeking to build such relationships, I think that authenticity matters more than timing. The colleagues who became genuine supporters weren't necessarily those I'd known longest, but those who responded to professional vulnerability with curiosity rather than discomfort. Seek out colleagues who already demonstrate flexibility in their working styles, who speak about work-life integration rather than just productivity, and who show interest in diverse perspectives. These individuals are more likely to understand that accommodating chronic illness represents adaptation, not compromise.

These relationships have also prompted reflection on how we define academic success. Conventional metrics — citations, funding, teaching evaluations — assume consistency of capacity that chronic illness directly challenges. My colleagues have shown that meaningful academic careers can accommodate health-imposed limitations whilst recognising that lived experience with illness can enrich research in ways that purely theoretical approaches cannot.

This form of friendship-based collaboration operates according to different rules than traditional academic partnerships. There's an implicit understanding that some days I'll contribute more, some days less, but that the overall relationship remains equitable.

Strategic Disclosure in a Competitive Environment

The decision to disclose chronic illness in academic settings involves complex calculations of risk and benefit. Unlike many workplace environments, academia maintains particularly blurry boundaries between personal and professional life.

I initially shared my diagnosis with a carefully selected group of colleagues—those with whom I'd already established mutually supportive relationships. Their responses provided insight about how the broader academic community might react, allowing me to refine my disclosure strategy over time.

This approach revealed significant variation in how academics respond to chronic illness in their midst. Most colleagues demonstrated remarkable flexibility, adapting collaborative workflows without drawing attention to these adjustments. Some seemed cognitively accepting but emotionally uncomfortable, creating technically accessible but interpersonally strained working relationships.

The research friends who responded most effectively shared a crucial characteristic: they understood that accommodating MS isn't about lowering standards but about recognising that good work can emerge through diverse pathways.

The Emotional Labour of Managing Perceptions

Chronic illness in visible professional settings necessitates a distinctive form of emotional labour by managing others' perceptions and reactions to illness alongside managing the illness itself.

When I stumble over words during a lecture, I try to simultaneously:

1. Recover my train of thought
2. Briefly explain to students why my brain has misfired
3. Redirect attention back to the course content

This multidimensional management occurs against the backdrop of physical and cognitive symptoms demanding their own attention. Douglas-Fairhurst captures this exhausting duality when he describes the constant self-monitoring that MS requires—not just of symptoms, but of how those symptoms might be perceived by others. The academic with MS becomes a performer managing multiple audiences: students who expect competence, colleagues who may question capability, and institutions who need assurance of continued productivity. My colleagues have largely relieved this particular burden. With them, I can acknowledge a difficult symptom day without it becoming a commentary on my professional worth. This freedom from performative competence creates space for authentic collaboration.

Building Resilience Through Connected Autonomy

The academic profession offers a paradoxical combination of isolation and interconnection. We work independently on specialised research whilst participating in deeply collaborative knowledge communities. At a broad level, this creates both vulnerabilities and opportunities for academics managing chronic illness.

The autonomy of academic work can accommodate the unpredictable nature of MS symptoms, allowing for flexible work scheduling and location. Simultaneously, the interconnected nature of scholarly communities provides pathways for support and adaptation.

What I like to think of as *connected autonomy* emerges as a particularly effective approach for academics with chronic illnesses. This allows us to maintain independence in work design whilst establishing supportive interdependence in professional relationships.

This balance requires intentional cultivation of collegial networks that understand and value your contribution enough to create space for fluctuating capacity. It means focusing available energy on meaningful work rather than peripheral obligations. Most importantly, it demands selective collaboration with colleagues who enhance rather than deplete limited resources.

My colleagues embody this connected autonomy perfectly. They facilitate independence whilst offering support that feels genuine rather than patronising. They understand that some collaborations must be structured differently without seeing this as inferior to traditional academic partnerships.

What Colleagues and Institutions Can Do

These personal strategies work within existing academic structures, but systemic change requires institutional awareness. My positive experiences suggest several approaches that colleagues and institutions might consider. Colleagues can normalise flexible working arrangements by offering multiple collaboration options rather than assuming traditional models suit everyone. Simple phrases like ‘Would it work better to meet virtually or in person?’ or ‘Would you prefer to tackle this over several shorter sessions?’ create space for accommodation without requiring disclosure.

Institutions might consider how promotion criteria could recognise diverse contribution patterns, thereby valuing sustained intellectual engagement even when productivity metrics fluctuate.

Conclusion

Part of my reason for writing this piece is that I have never met another academic with MS, nor could I find any literature on how universities support academics with ongoing health issues. For those navigating chronic illness in academic settings, hopefully my perspective offers hope. Most importantly, I hope readers, whether they live with chronic conditions themselves or work alongside those who do, recognise that academic excellence can emerge through diverse pathways, and that our scholarly communities become stronger when we embrace rather than merely accommodate human variation. The challenge lies in building communities of scholarship that accommodate human variation whilst advancing our collective understanding.

Where Douglas-Fairhurst’s use of Kafka’s Metamorphosis as a metaphor for MS proves most instructive is in highlighting what need not be inevitable. Gregor Samsa’s transformation leads to alienation, shame, and eventual death because he cannot find ways to maintain meaningful connections despite his changed circumstances.

When receiving my MS diagnosis two years ago, I feared a similar risk of professional isolation and impact on my chances of career progression because of potential cognitive and physical limitations. Yet I have found that transformation need not lead to isolation by cultivating relationships that value the whole person rather than just productive output.

Main Character Energy: How to own your Appointments

A resource co-created with MS Ireland's Young Persons Network

For a lot of young people living with MS, a healthcare appointment isn't "just another visit." You psych yourself up, write down symptoms, maybe rehearse questions in your head on the way there… and sometimes still walk out thinking:

- Did they actually hear me?
- Did I explain that badly?
- Should I have pushed harder?

If that sounds familiar you're not alone. People in MS Ireland's Young Person's Network have shared that, at times, they've felt rushed, dismissed, or reduced to their MRI scans instead of being seen as whole people juggling work, study, friendships, relationships, and a very real condition.

This resource was co-created with them, for you.

It's not about bashing healthcare professionals (HCPs). We know that HCPs care deeply, and they're often working in a system under serious time pressure. But two things can be true at once:

1. Your HCP is doing their best.
2. You can still feel unheard, sidelined, or brushed off.

So what can you do in those moments without feeling like you're causing conflict, shutting down or walking away frustrated? One powerful tool is language. Having a few calm, confident phrases ready to go so you can bring the focus back to you and your lived experience.

Below are some examples of what you might feel like saying in the heat of the moment and a more clinic-friendly version you could say instead.

When you don't feel listened to

What you might feel like saying:
"Are you even listening to me?"

What you could say instead:
"I'm not feeling fully heard right now. Can we pause and go back to my main concern for a moment?"

You're naming the problem, but in a way that invites your healthcare provider to lean in, not shut down.

When your lived experience feels minimised

What you might feel like saying:
"You don't get it, you're not the one living with this."

What you could say instead:
"I know you have medical expertise, and I have lived experience in this body. Both perspectives are important here."

That line says: I'm not against you. I'm beside you.

When a symptom feels brushed off

What you might feel like saying:
"You're acting like this isn't a big deal, but it's ruining my life."

What you could say instead:
"This symptom is having a big impact on my daily life. I'd really appreciate if we could spend a bit more time on it."

You're anchoring the conversation in impact, not accusation.

When the conversation feels rushed or overwhelming

What you might feel like saying:
"Slow down, I have no idea what you're talking about."

What you could say instead:
"I'm feeling a bit overwhelmed. Could you slow down and explain that again in simpler terms?"

Most clinicians genuinely want you to understand, sometimes they just need a gentle nudge to shift gears.

When you want more say in your care

What you might feel like saying:
"You don't get to decide everything for me."

What you could say instead:
"I'd like to be more involved in decisions about my treatment. Can we go through the options together?"

You're claiming your seat at the table. You're not a bystander in your own care.

When your age feels like a barrier

Young people in the MS Ireland network have said they sometimes feel underestimated because of their age.

What you might feel like saying:
"Just because I'm young doesn't mean I don't know anything/know what I want."

continued on next page

What you could say instead:
“I know I may be younger than many of your patients, but my symptoms are very real for me. I’d like them to be considered with that in mind.”

It’s just a little reminder that youth doesn’t cancel out seriousness.

When you’re wondering about a second opinion

Sometimes, even with good intentions on both sides, the fit just isn’t there.

What you might feel like saying:
“I want a different doctor.”

What you could say instead:
“I want to feel confident in my care. If we can’t address my concerns, I may need to consider a second opinion.”

It’s honest, clear, and still respectful.

You deserve to be part of the conversation

Living with MS is already a lot. You shouldn’t have to fight to be heard on top of that. It’s okay to:

- Bring notes or a symptom diary
- Ask for things to be repeated
- Say, “I’m not comfortable moving on yet”
- Bring someone you trust into the appointment

Speaking up for yourself doesn’t make you “difficult”; it makes you an active, informed partner in your own care. Your voice, your story, and your experience are not extras in the room, they’re central to it.

Potential titles:

Got a question for our Young Persons Network that you’d like to see featured in the next MS News? Send it to aoifek@ms-society.ie and if selected, we’ll share it anonymously with the YPN for their thoughts! Don’t worry, we’ll send you the group’s response first so you can approve it before your question appears in the magazine!

You’re young. You’ve got MS. You’re not alone.

Join MS Ireland’s Young Persons’ Network!

Living with MS can feel like …a lot! From education, work, relationships, future plans, plus symptoms, appointments and everything in between, it can be difficult to navigate and sometimes you just need to chat with others who just get it.

That’s where the Young Persons’ Network comes in.

We’re a peer-led online group for young people living with MS in Ireland (aged 18-35). In 2026, we’ll be meeting monthly online to hang out, swap experiences and talk about the stuff that actually matters to you.

The real-life, unfiltered version of living with MS.

In 2025 we’ve already chatted about things like:
- Studying, working and managing fatigue
- Dating, friendships and telling people about MS
- Mental health, boundaries and burnout
- Staying active, gaming, hobbies and having a life beyond MS

YOUNG PERSONS NETWORK

YOUR SPACE, YOUR PACE, YOUR PEOPLE

No need to “have it all figured out”.
This is just a chilled, supportive space where people get it.

Want in?

If you’re interested in joining the Young Persons’ Network or would like to find out more about it, contact aoifek@ms-society.ie

We can’t wait to hear from you!

What could I expect if I took part in MS Ireland's physiotherapy programmes?

MS Ireland offer a range of physiotherapy programmes, both locally and nationally. You can find more information about our programmes by scanning the QR code opposite. We hold a participant forum each year, and this summer they told us that they really enjoyed hearing about the benefits of the programmes and the aim of this article is to share that information with the readers of MS News.

Our participants complete surveys and tests before and after each 10-week programme and we also give participants the opportunity to feedback on their experience.

So, what does all this data tell us?

In short, from both a statistical analysis point of view and from a clinical perspective, our programmes provide a range of benefits for both physical and mental health, and this is reinforced by what people tell us the programmes have meant for them.

Let's look at the data first and then see what the participants told us. The surveys are considered to be patient-reported outcome measures, and we used them to evaluate Move Smart MS. The answers told us that statistically significant improvements were seen and that there was large % changes meaning that it was clinically impactful. This was for:

MS Impact	**29%**
Fatigue	**21%**
Perceived Walking Ability	**13%**
Mental Health	**28%**

This confirms what we know from other research, that being physically active has a positive impact on many of the so-called hidden symptoms of MS.

The second part of our evaluation is the objective measures, or the tests that involve doing. Taking part in our programmes led to big improvements in:

Strength	**16.2%**
Balance	**7.9% right leg, 10% left leg**
Walking Endurance	**22m**

that were both statistically and clinically significant. Again, this reinforces what we see from research, which is that taking part in exercise leads to improvements in these symptoms.

What did people tell us about what the programmes meant to them?

When we looked at all the quotes, we could see strong themes arising, these were that the programmes were beneficial in terms of physical and mental health, that people appreciated the specialist knowledge of the physiotherapists, and that being in a group with others "in the same boat" was beneficial for both peer learning and social support. When we asked participants to rate their experiences, the average response was 9.4 out of 10 and 92% rated it as a score of 9 or 10 out of 10.

> "It's invaluable! So important in developing a clearer understanding of symptoms and how to identify and manage them. And most importantly, the importance and relevance of exercise"

> " As always, I find these programmes hugely beneficial, both mentally and physically. A very important tool to have at our disposal. I love these programmes!"

> "Thoroughly enjoy each session, the 10 weeks went by so quickly. I was apprehensive at first thinking I would not be able to do the exercises but week by week I got more confident and attempted them all"

> "My overall fitness has improved. I am more informed about the benefits of exercises for MS patients. I am more motivated to continue exercising"

If you'd like to take part in any of our physio programmes, you, a family member or a healthcare professional can complete an expression of interest. You will then be screened by a physiotherapist and allocated to the class that best suits your needs – either a weekly exercise class (Getting the Balance Right)

or an exercise and education class that addresses a specific symptom with others at a similar age and stage of MS (Move Smart MS).

MS Ireland

THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

LOTTO

With a Jackpot starting at €500, and a guaranteed €50 winner each week!

Play

Pick 4 numbers
The same numbers will be played for you each week

Pay

1 line for €3.00, 2 lines for €5.00 or 3 lines for €6.00
Maximum 3 lines per person

Win

Match 4 numbers to win the Jackpot

Join now

Scan the QR code or go to our website

https://www.ourfundraiser.ie/org/msireland

Powered by Our Fundraiser For more information email fundraising@ms-society.ie

MS Ireland is thrilled to announce we are launching a new campaign —

The MS Ireland Lotto

MS Ireland's charity lotto is a fundraising initiative that will help support the wonderful work our regional services provide. This fundraising enables us to continue our support in local areas and help people with multiple sclerosis access services.

How it works:

- **€3 for 1 line, €5 for 2 lines, €6 for 3 lines** (maximum of 3 lines per person)
- The **jackpot rolls over** until there is a winner, and it will rise to **a maximum of €3,000**
- **Every Thursday** there is a draw for a prize of €50, plus the chance to win the Jackpot

We hope you and your friends and family will consider joining our lotto to support our regional services. The funds will go towards providing a wide range of group support through Physiotherapy programmes, events, workshops and activities. We have nearly 7,200 people with MS who are registered with regional services. Last year, 2655 individuals received a 1:1 casework, over 1000 received physiotherapy, along with many other programmes.
We hope to continue this work by raising funds through the lotto.

You can learn more here www.ourfundraiser.ie/org/msireland

CHRISTMAS CARDS

BE ORGANISED FOR CHRISTMAS BY ORDERING YOUR CARDS IN PLENTY OF TIME WITH OUR GREAT SELECTION OF CARDS.
WE HAVE 2 PACKS OF DESIGNS- 10 CARDS IN EACH PACK.
PRICED AT ONLY €10 PER PACK.

Contact fundraising@ms-society.ie to order today!

Dublin Marathon

Our wonderful fundraisers did not let us down as they raised in excess of €75,000.

UPCOMING EVENTS

Advent challenge

Join us in December for our exciting Advent Challenge when you will get your daily challenge alert every morning with different challenges each day. Keep an eye on our socials to register and get your pack including a t-shirt and tracker sheet.

Abseil

We had a wonderful day at the exciting new Abseil location in the Burren where our intrepid fundraisers scaled the craggy cliff down to the sea. If you would like to join us in the Burren or in Dalkey contact **melaniec@ms-society.ie** for more details & dates.

Skydive

Our wonderful skydivers have been jumping out of planes not only in Ireland, but also in Spain! To register to skydive in Ireland 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.

Charity Golf Day

Luttrellstown Golf Club Captains both decided to support MS Ireland with their charity day.

Many thanks to all the participants and sponsors for their very generous support. If you are 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**

THANK YOU

We have had several marathon and half-marathon runners in the New York, the new Dublin half-marathon, Belfast, Omagh and Cork. If you would like to run the Paris marathon in 2026 contact **melaniec@ms-society.ie** for more information.

EXCEPTIONAL FUNDRAISERS

Women's Mini Marathon

This was a wonderful day with Team MS Ireland well represented as always.

For 2026 we have got a limited number of entries – contact melaniec@ms-society.ie for information.

EXCEPTIONAL FUNDRAISERS

Great Erris Run

The 2nd Great Erris 10K, in memory of Pauline Sweeney. “She was a dear friend and a much-loved member of the Erris community, and we wanted to honour Mikie’s dear mother by bringing people together for a meaningful cause.”

They raised over €11,000!

Community Fundraisers

Weddings

Bridge clubs

Ann & Tim Gardiner did a musical event in Galway – great fun and very successful

Corporate Partners

Kirby Group – cycling event topping €100,000 for a wide variety of charities, local, national and international.

Musgraves Gives Back – staff fundraising initiative raised funds for various charities including MS Ireland – we received €33,000 from the committee.

MS Information Line

0818 233 233

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

Our Information Line will close for Christmas on December 19th and will reopen January 5th

CHY No: 05365
CRA: 20007867
CRN: 296573
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