Irish
Motor
Neurone
Disease
Association

CONNECT

ISSUE 23 | SPRING 2021

The latest news, views and
information from IMNDA.

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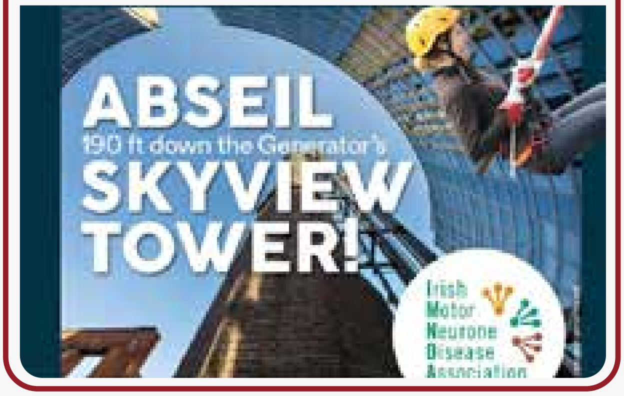

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A NOTE FROM OUR CEO

Welcome to the spring edition of Connect Magazine. I feel a sense of hope as the days get brighter and more and more of our community have had a least one dose of the vaccine. The last 12 months have been particularly tough on everyone so I know we would all welcome some semblance of normality to return – and it will. I would like to take this opportunity to send my heartfelt condolences to anyone who lost a loved one during the pandemic. Our thoughts are with you.

Here in the IMNDA we are looking to the future with optimism. You may remember, we began a body of research work just before Covid-19. This valuable research was undertaken to shape our 2021 – 2026 Strategic Plan and the future direction of the Association. We conducted a series of one on one interviews with clients, caregivers and healthcare professionals, as well as surveying our wider MND community to find out what we do best, what needs improvement and where we need to focus our efforts. We also consulted our staff and the Board of IMNDA. From this work, four key strategic priorities have been identified.

1. Provide practical client and caregiver-centred support on both a national and local level to ensure people affected by MND receive the best possible standard of care.
2. Strengthen communications with all key stakeholder groups, especially families directly affected by MND, and enhance public awareness of the impact of MND through advocacy.
3. Support, fund and communicate research into causes, management and treatment of MND amongst all key stakeholders including families affected by MND and the wider healthcare community.
4. Invest in long term sustainable income streams in order to continue to operate a stable, transparent and accountable organisation, meeting best practice standards amongst the charity sector in Ireland.

It is our hope that this new strategic plan will form a clear roadmap for the Association to follow over the next five years, ensuring our core supports are fit for purpose and aligned with what our MND community urgently need. I would like to say a big thank you to everyone who took the time to feed into this plan, we really do value your input and your insights. You can read more about our 2021 – 2026 Strategic Plan on page 25.

Knowing this body of work is now complete, it makes it easier for me to step down as Chief Executive and take on new challenges. Words cannot express how rewarding this past three years have been for me. It has been an absolute honour to lead the Association and work on your behalf. The highlight for me has always been getting to know you, our MND community. Please know you have made an impact on me and everyone in the Association. Whether you are directly affected by MND or you are one of our fundraisers and supporters, you really have made a mammoth difference and helped us raise awareness and funds, which in turn has allowed us to do a better job.

So for now, I will leave you in the very capable hands of Team IMNDA. I could not have asked for a more supportive, hardworking and dedicated team. They really do have your back. I would also like to say a huge thank you to the Board of IMNDA for their unwavering support and guidance over the years. Together, we have been able to develop and advance our care and support services and achieve great things.

Mind yourself.

Roisin Duffy
Chief Executive

Until there's a CURE, there is CARE.

TRICALS

Finding new treatments for MND has been disappointing, despite a lot of success in laboratory models. Part of the problem is that human MND disease is complex, and we need to invest in ways to better understand this human complexity. In Ireland, our research Team is leading a new European collaboration as part of the TRICALS group.

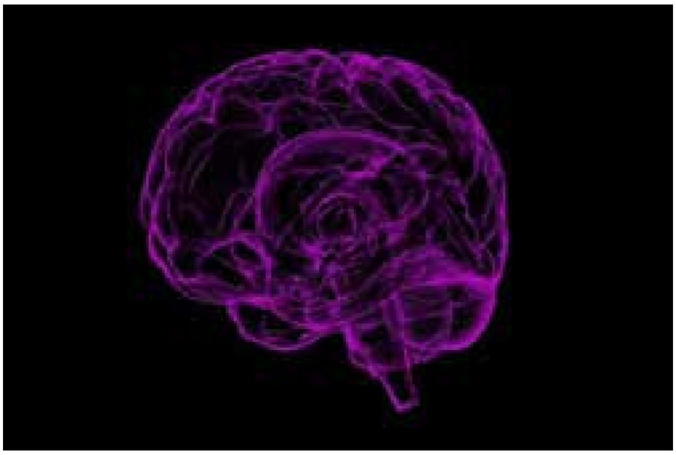
TRICALS (Treatment Initiative to Cure ALS www.tricals.org) has been formed by the leading centres in MND research in Europe. The purpose of TRICALS is to speed up new drug treatments so that we can provide the right drug for the right patient at the right time. To do this we need to take a "precision medicine" approach as we need a much better understanding of the disease than we have at present.

The Irish MND Research Group, along with partners in TRICALS, have begun an ambitious collaboration between Clinicians, Computer Scientists, Information Engineers, Technologists, and Data Scientists that will help to address the key clinical, computational, data science and technology associated research questions needed to better understand MND, and to find new and better drugs. And as new drugs come to the fore, the TRICALS group will engage in clinical trials to identify those drugs that are most likely to slow down the progression of MND.

There are many such drugs in development and over the coming year, we anticipate many new clinical trials. Beaumont Hospital and Trinity College Dublin are leading on the research in Ireland. Each trial has different criteria for inclusion, and not everybody will be suitable for every drug.

Starting in late spring, as we obtain approval from the HPRA and our research ethics committee, we will begin to discuss these clinical trials with those with MND and their families, to identify those people who might be interested in participating.

Within the Academic Unit of Neurology at Trinity, the main research focus is on **Amyotrophic Lateral Sclerosis (ALS)**, also known as Motor Neurone Disease (MND). There is now strong evidence that ALS has many different causes, and that there are considerable differences in how the disease behaves.



Professor Orla Hardiman and her team's world class research strengths are in clinical evaluation, epidemiology, neuropsychology, genetics, brain imaging and neural engineering. They work closely with the **Trinity Clinical Research Facility, St James Hospital** and at **Beaumont Hospital** in Dublin. The team's research will help to fast track and reduce the cost of clinical trials by making sure that the right drug is given to the right patient at the right time, in the right dose, using a precision medicine approach. Precision medicine recognizes that the factors leading to disease are likely to differ between patients, and that a much better understanding of the basis for these differences is required.

Professor Orla Hardiman

To achieve this, Professor Hardiman and her team are developing research tools that will allow them to reliably identify distinct subgroups of patients with well-defined characteristics. Some of these characteristics can be identified by detailed clinical examination or neuropsychological assessment, or by genetic analysis. But other characteristics will require new innovations in brain wave mapping and imaging.

Recent research successes at the Academic Unit of Neurology

In the past year, the team have had some notable successes in their research. They have participated in the first gene-based therapy trial for ALS and have two similar trials planned for this year (2021).

Their epidemiology research has shown that genetic factors contribute to half of the risk of developing ALS, and they are working with the International **Project MinE Consortium** (**www.projectmine.com**), and colleagues in South America to identify which combinations of genes increase or reduce the risk. Interestingly, they are also studying whether different ancestral populations have different manifestations of ALS.

EEG studies undertaken by the team have shown that different subgroups of patients have different and distinct patterns of brain network disruption. These patterns also predict how fast or slow the disease progresses, and these patterns are also reflected in changes in the brain that we can detect on MRI.

The work with those with the disease has been instructive in teaching the research team that how people experience illness often differs from how doctors define disease progression. As a result, they are now developing better measures that incorporate with greater clarity the perspectives of those with the condition and their families.

Professor Hardiman's clinical and research team at Beaumont Hospital and Trinity College Dublin recognised the impact that the COVID pandemic was having on patients with MND and the difficulties it presented in terms of the provision of medical care and support. The need for remote monitoring and delivery of highly specialised care, away from a hospital setting, became vital to protect vulnerable MND patients. Using their collaborator Sheffield Teaching Hospital's system TiM, and working with the UK company, Advanced Digital Innovation (ADI) to produce the specialised **TiM MyPathway app** has enabled Professor Hardiman's team to manage their patients digitally.

MND Patients and caregivers often find travelling long distances to their appointments arduous, not only that but when they arrive at the clinic the waiting time is considerable. The team's data indicated that a large proportion of the patient's time in the clinic (70%) is spent waiting for review by members of the multidisciplinary team, with only 30% of time spent in meaningful engagement with clinical professionals.

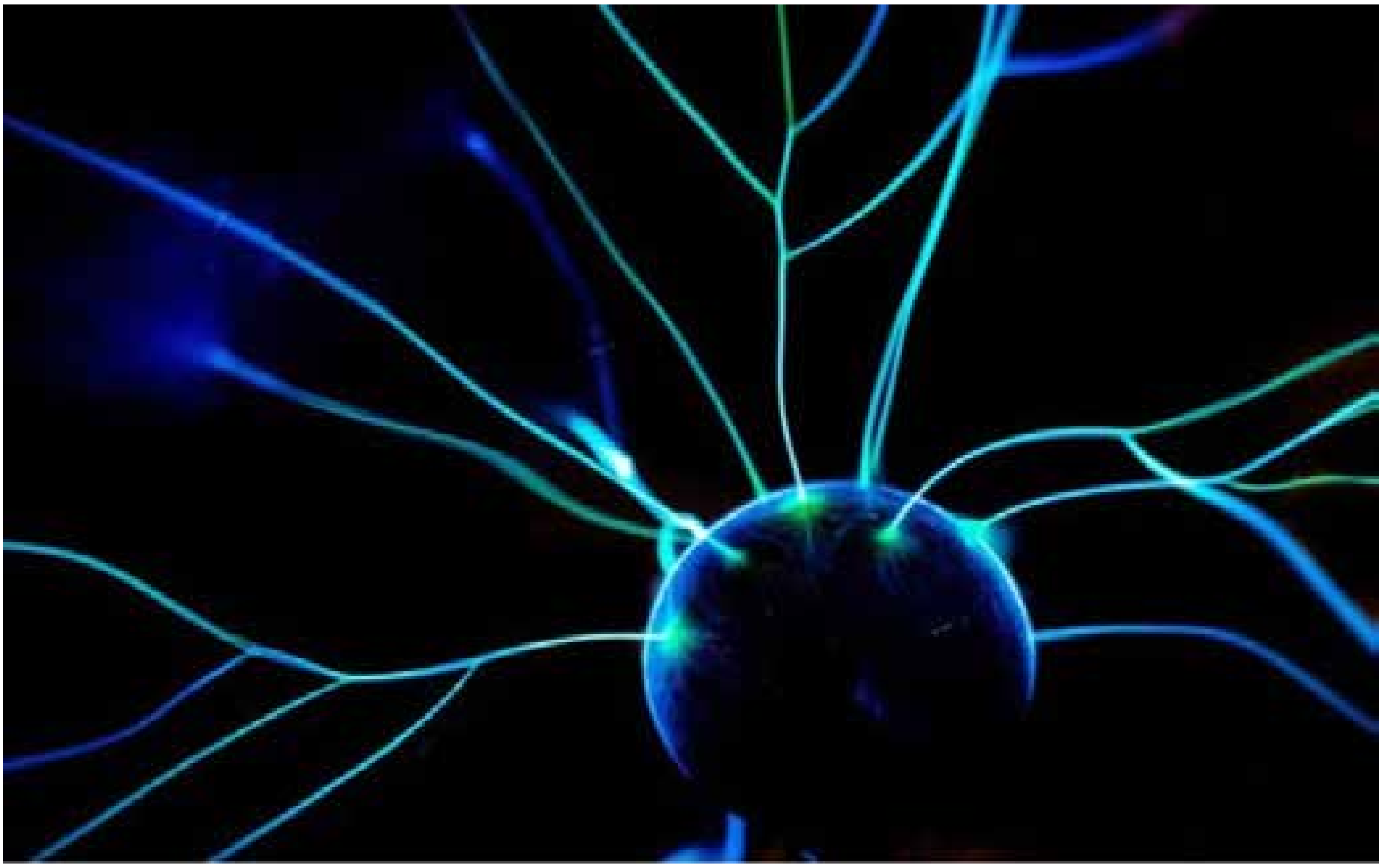
The research team's patient journey data also indicates that community based clinical professionals have limited experience of MND, therefore patients and caregivers may struggle to access the expertise required between clinic visits and may receive advice that is not in keeping with best practice. All these problems have been considerably magnified by the recent COVID-19 pandemic.

The new system aims to address the issues of long waiting times in clinic, relatively short consultation times, and the need to communicate with services locally to ensure a standardized quality of care. The platform allows patients and their caregivers to report their progress and symptoms from their homes using a remote digital application. Clinicians can remotely monitor their patient and are alerted to any concerns or changes in their condition. Information leaflets and resources developed by the Irish Motor Neurone Disease Association (IMNDA) are linked to the TiM system ensuring patients access reliable and useful information.

Professor Orla Hardiman, Professor of Neurology, Trinity College Dublin, said:

This important telehealth project will meet the needs of vulnerable patients and families with progressive neurologic disease whose care is compromised as a direct consequence of the disruption imposed by the COVID-19 pandemic. In the longer term, the work will help to address the considerable fragmentation of care in Ireland. We will have a sophisticated communication system between patient/caregivers and their health care professionals in hospital and community settings.

This virtual support is currently only open to patients that are attending the MND clinic at Beaumont Hospital. The team hopes that in time, the support may be offered to patients nationally.



The ADAPT Centre is the Science Foundation Ireland Research centre for AI-Driven Digital Content Technology, based at Trinity College. The ADAPT Centre sees the possibility of interoperability between TiM on MyPathway and the Patient Data Display Platform by building an API that allows the ingestion of data from the TiM on MyPathway app. This data could be used to further enrich the knowledge graph and Patient Data Display Platform outputs and is something the ADAPT Centre would hope to pursue.

The ADAPT team have been working with Professor Hardiman's team to develop an ontology and schema to accommodate data from a variety of different sources that can be uplifted to a knowledge graph. This data interrogation will be output through a variety of visualisations via a patient data display platform. These outputs will allow the clinicians to view and assess a particular patient's data or group of patients' data utilising a range of data points and timelines.

ONLINE MND SUPPORT

The IMNDA are delighted to announce a new online community hub. Our Community Hub is a safe and supportive online discussion site for people affected by MND, their caregivers and families.

- **Looking to discuss your experiences with other people?**
- **Interested in finding, receiving and providing support?**
- **Want to connect with others at a time convenient for you?**

Our community page allows you to post questions, share tips or advice, and interact with people with MND and their loved ones from around the country.

Knowledge is power and we want this to be safe and interactive environment where people can freely ask questions and receive answers and support from other people affected by MND.

Registration is free and your contact details are kept confidential. You will find our online community hub here at http://community.imnda.ie/

Once registered, you will have access to the following services:

Forums

Our forums can be read by anyone, but in order to interact with others and post messages of your own, you will need to register with this site.

Blogs

A blog is a shared online journal where people can post diary entries about their personal experiences. We will also share entries by health professionals and those involved with research.

Connect

Reach out to people living with MND. Registered members can connect to freely discuss topics in a private and safe area.

The online community is open to people affected by Motor Neurone Disease and provides a place to connect, and find support in a safe space. For more information please visit: http://community.imnda.ie/

COPING WITH STRESS AS A PERSON WITH MND

by Dr. Ailín O'Dea

Introduction

"To say my world was turned upside-down that day in clinic is an understatement. I was expecting bad news, but the diagnosis came as a terrible shock. Some days, even now, I stop and ask myself has this actually happened." Person with MND

A diagnosis of motor neurone disease is life changing. For many people, it comes as a devastating blow, both to the person diagnosed and their loved ones. It is normal to feel very distressed around the time of diagnosis. It brings shock and often profound sadness. For many, it comes at a time in life when they were preparing to enjoy retirement. Grief at the loss of the future you thought was ahead can hit like a tidal wave.

The shock of the initial diagnosis usually settles with time, and thankfully, most people adjust such that they can focus on living as well as possible with the condition. MND is a moving target however, and the reality of dealing with change and new challenges can bring ongoing stress and pressure to adapt. In this piece, I cover three areas

1. I name some of the **challenges** that can cause stress for people living with MND.
2. I list some **supports** that are available to help with these challenges.
3. I also discuss **coping strategies** that can be useful at difficult times.

1. Sources of Stress

"There are so many things to deal with as a person with MND. Sometimes it gets too much; I just want to bury my head in the sand and pretend this is not happening." Person with MND

Stress looks different for different people. It can show up as anxiety, causing physical symptoms such as increased heart rate, sweating, and upset stomach. It can be difficult to think clearly and solve problems when you're under stress. Stress can also show up as low mood, with symptoms such as disturbed sleep and withdrawing from loved ones.

There are many different worries that can trigger stress for people with MND. Typical sources of stress include

- Worry about the **future**
- **Financial** worries
- Fear about how **family** will cope as the condition progresses
- **Grief** at the losses brought by MND
- Anxiety due to **shortness of breath**
- Fears of **choking**
- Worries about changes to **mood and memory**
- Fears around **death and dying**

2. Sources of Support

"You matter because you're you, and you matter to the end of your life. We will do all we can not only to help you to die peacefully, but also to live until you die."
(founder of hospice movement Dame Cicely Saunders)

There are, of course, no easy solutions to these worries. They are valid and understandable concerns for anyone dealing with a condition as difficult as MND. There are, however, many supports available that can help you through. I tend to think of getting support as putting legs under a table; the more you access, the steadier you tend to feel. Supports such as the following can help

- **Talking to your MND team, your neurologist or nurse specialist;** they may not be able to solve every problem but talking openly with your team will help clarify your concerns. Chances are they will have experience dealing with the difficulty you describe. There may be options and supports they can suggest that you hadn't thought about.
- **Linking with the IMNDA**; the IMNDA will do everything possible to support you with information on financial and legal matters, specialist equipment, care hours and counselling for you and your family. Do pick up the phone and call. If they can't help, they may be able to link you with someone who can.
- **Talking to specialists on the MND team about specific worries**
  - The **speech and language therapist** can talk though worries about choking, suggesting ways of coping and if necessary, changes such as a modified diet.
  - The **physiotherapist** can suggest ways of staying active and can assess your breathing. She can offer information and support, as well as assistive devices if necessary.
  - The **occupational therapist** can talk about supports to help you stay as independent as possible for as long as possible, including specialist equipment and modifications to your home.
- **Linking with palliative care**; many people worry that a referral to palliative care means the end is near, but palliative care can be an important support from quite early on with MND, to help manage symptoms. The hospice and palliative care team can also talk through any worries you have around end of life.

3. Coping Strategies: Having your feeling without your feeling having you

Name it to tame it	Research has shown that simply naming your experience e.g. **"I'm anxious and feeling tense", "I'm feeling sad because so much has changed"**, is often enough to give relief and shift your brain from panic mode into a more helpful frame of mind.
Stay moving	Exercise is a great stress buster but staying active can be a real challenge as your condition progresses. Ask your physiotherapist for advice and try **creative approaches** to movement such as using music to help motivate you.
Breath based relaxation	Take **three slow, deep breaths**. That can be enough to help relieve stress. When we're stressed we often forget to fully breathe. It's the simplest support of all and it's always there for us, if we can only remember to use it.
Sensory anchors	For some people, the **senses** are easier than the breath to help connect them to the present moment. List out what you can see, hear, smell, taste right now. Use **comforts** that work for you such as warm drinks, massage, music, a soft scarf around your neck.
Self-soothing	Self-compassion is easy to talk about but hard to do, especially when you're stressed. Try placing a **hand over your heart** and deliberately offering words of kindness to yourself; **"I'm here for you. You're doing your best in this. This is a difficult time."**
Beat the negativity bias	Research has shown that we're hard-wired to notice the negative, such as mistakes we feel we've made. This bias helped our ancestors to survive, but nowadays it adds to our stress. Beat this bias by **paying attention to what you've done well, listing the things you're grateful for**, actively remembering the good times in your life.
Catch the storytelling mind	Thinking and telling stories is what minds do best. When we're stressed however, the thoughts we have and stories we tell are often focussed on worst case scenarios and really r**amp up the stress response**. Try catching those thoughts and gently redirecting or challenging them. **Talk about how you're feeling with someone you trust**. Consider linking with a counsellor or psychologist.
Think Ahead	Discuss your concerns about the **future** with your family and care team; **sort out the practical and legal issues and document your care preferences**. These are very difficult conversations to have but having them can really take a weight off your mind. Documents such as **Think Ahead** can support you to do this (see links below).
Make lasting memories	Reflect on **what matters** to you. Seek out experiences with family and friends that will provide lasting memories. Record them in some way. Put them in a **"hope box"** or a folder on your phone that you can pull out at difficult times.

I tend to think of stress, anxiety and depression as different places along the same road. Any of the coping strategies I've described can help with all three. It's important to talk to your doctor, however, if you feel you're suffering from depression or need help with anxiety.

This is especially important if you're feeling overwhelmed a lot of the time or are having thoughts that life is not worth living. Consider linking with a counsellor or psychologist. Working with difficult thoughts and feelings is often too much to manage on your own. Your doctor or a trusted health professional can assist you to get the help you need. The IMNDA can offer financial support with the cost. Don't suffer in silence.

Finally, I want to wish you well in your path, may you stay connected to what sustains you. There are links below that offer ideas and support if you wish to look further.

Dr. Ailín O'Dea is a Senior Clinical Psychologist at Beaumont Hospital. She is a member of Professor Orla Hardiman's Team. Ailín works on a study looking at online groups for families and caregivers of people with MND. She is interested in what helps people with MND and their families live as well as possible with the condition. She is contactable at aiodea@tcd.ie

Links to Support Coping, Mental Health and Memory

- One practice that can be useful to help connect with inner stillness and strength, even if you can't move about, is the mountain meditation. Here's a link to one I like, but there are lots of different ones available online **https://soundcloud.com/ucsdmindfulness/15-min-mountain-meditation-by-lois-howland?in=ucsdmindfulness/sets/short-meditation-sessions**
- The excellent stress control programme offers great tips and ideas; the booklets are always free and the sessions with Jim White are regularly offered by the HSE ; keep an eye on the website for upcoming live stream dates and free downloads **https://stresscontrol.ie/**
- Beaumont Mindfulness and Relaxation Centre; lots of free exercises and sound advice **beaumont.ie/marc**
- San Diego Mindfulness Center; lots of great exercises based on the Mindfulness Based Stress Reduction Programme. I particularly like Marta Patterson's guidance. **https://medschool.ucsd.edu/som/fmph/research/mindfulness/programs/mindfulness-programs/MBSR-programs/Pages/audio.aspx**
- The Alzheimer's society have a very useful booklet on technology that can help for anyone with memory difficulties **https://alzheimer.ie/wp-content/uploads/2018/11/ASI-Assistive-Technologies-Brochure-Nov-2019-website.pdf**
- You might prefer to use a folder on your phone, but there's an app Virtual Hope Box **https://play.google.com/store/apps/details?id=com.t2.vhb&hl=en_IE&gl=US** that includes distraction and support for difficult times and you can add your own media under Distract Me- Photo Puzzle.
- Pieta house provide 24 hour support for people in acute distress or at risk of self-harm **https://www.pieta.ie/**

End of Life Care and Planning Information

- Information on palliative and hospice care **https://hospicefoundation.ie/i-need-help/i-am-seriously-ill/about-palliative-care/**
- The Think Ahead form, for anyone who wishes to record their end of life care preferences **https://hospicefoundation.ie/i-need-help/i-want-to-plan-ahead/think-ahead/**
- Information on advance care planning in Ireland **https://www.citizensinformation.ie/en/health/legal_matters_and_health/advance_care_directives.html#**
- Information on legal arrangements for incapacity in Ireland **https://www.citizensinformation.ie/en/health/legal_matters_and_health/legal_arrangements_for_incapacity.html**

End of life guide for people with MND from UK: lots of very useful information in here but bear in mind the legal issues apply to the UK, ask locally for Irish information **www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/end-of-life-a-guide-for-people-with-motor-neurone-disease/**

THE SIMPLE POWER OF A WHEELCHAIR

In the past ten years, the IMNDA has purchased, customised and delivered more than 160 wheelchairs all across Ireland. Wheelchairs that have changed people lives and given them back their freedom and their independence. There are many different makes, models and even styles, but they all have one thing in common – and that's the life-changing impact they have on someone's everyday life. The power of a wheelchair can never be and should never be underestimated.

However, like all specialised medical equipment they are not cheap. But we can safely say that their value far outweighs the price tag. A standard manual wheelchair can cost anywhere from €250 - €2,500, while a more high spec powered (electric) wheelchair can be anywhere from €10,000 - €15,000 depending on customisation. This is why is so important that we can continue to raise much – needed funds year on year. We need to ensure that we can provide our community with the equipment they need, when they need it. Your continued support allows us to meet those needs.

Mobility and energy - quality of life issues

- The ability to walk can be limited or inefficient for 90% of people diagnosed with MND/ALS. A wheelchair allows people to conserve their precious supplies of energy.
- A wheelchair is a tool that allows people to move from place to place. The human need for movement is a very basic one.
- Increased mobility produces a virtuous circle of activity, socialisation and better mental and physical health.

Wheelchairs – users' perspective

Wheelchair users describe the impact of wheelchairs – provided by the IMNDA - on their lives. Contributors' names have been changed to protect privacy. In addition, **Tracy Hutchin**, IMNDA Services Manager, explains the Association's policy regarding wheelchairs

Independence and freedom come in many forms:

• "My best friend"

The powered wheelchair gives people independence in the house. **Eddie**, who lives in Co. Donegal, explains the series of small activities that – in his wheelchair - are now possible. He says, ***"It's my best friend. It is doing everything I need. I can wheel about the house; make myself a cup of tea. I am independent"***.

• Outside

The wheelchair allows people to live their lives and continue doing what they always did, such as shopping, with ease.

Colm, who lives in Co. Cork, writes, ***"We always bring my wheelchair when we go shopping in the city. Without the wheelchair, I would be very restricted in what I could do outside of our house. It has allowed me to get to places where, otherwise, I would have struggled to get to"***. Tracy notes, ***"It's about people using carefully whatever energy they have. Walking requires a lot of energy and becomes exhausting"***.

• Excursions

A wheelchair brings a whole range of outings within reach. Colm writes, ***"I use my wheelchair to get everywhere – restaurants, matches, museums. If we are going somewhere on holidays or to a hotel we always bring my wheelchair"***.

Wheelchairs make longer excursions and family day-outs possible. **Sean**, who lives in Co. Waterford, explains, ***"It has given me great freedom to do the things I enjoy doing. Last summer, my family and I spent three wonderful hours on the Waterford Greenway. It was glorious"***.

• Interaction

Out and about, people can meet with friends and maintain a social life. It facilitates interaction in all settings.

Sean says, ***"The promenade is only a short distance from the house. I go in my wheelchair and spend time there chatting to people. It allows me to meet up with friends from when I played golf or bridge"***.

Colm writes, ***"Because of the wheelchair I can be involved in so many things. I am able to meet people in comfort"***.

Eddie notes, ***"When I am in company and in my wheelchair, I can move independently through the group"***.

• Best medicine

A wheelchair allows people to enjoy the lasting health benefits of fresh air.

Sean says, ***"I am out every day of the year except when the rain prevents it. I get loads of fresh air which is good for the spirit and much better for you than any pills"***.

Colm writes, ***"I have the freedom to be able to get out with my partner when she is going for a walk"***.

- ## Personal trainer

Everyone - both users and their companions - benefit from the speed settings. Speed can be adjusted to suit different requirements.

Sean explains, ***"The speed really doesn't matter to me. I vary it according to what my companion wants. For some it's too fast and for others it's too slow. My son sometimes accompanies me and he prefers a faster pace. I joke that I will develop a personal training programme especially for him"***.

- ## Kilometres

Some get an exceptional amount of use from their wheelchairs, clocking up an impressive number of kilometres. Sean estimates that he does around seven kms a day – weather permitting.

Colm writes, ***"On a typical weekend I would probably travel anywhere between five and 10 kms"***.

Heavy usage leads to tyres and batteries needing replacement. Sean admits that he goes through a set of tyres every two years. The IMNDA is happy to oblige with replacements.

Tracy notes, ***"We are delighted to send new tyres and batteries. It's great, it means people are doing their own thing and being independent. This helps create a happier home life"***.

Elevating/tilting

The powered wheelchair provides a raft of other health-related benefits. It reduces immobility and its associated risk factors – such as pressure injuries. The powered wheelchair can be tilted. This distributes weight to the back and reduces pressure on the 'sit bones'. Legs can also be elevated to reduce swelling caused by fluid retention.

Sean notes, ***"I usually tilt the chair coming back from my daily walk. Pressure sores are not a problem but I am aware that they could be"***.

Eddie explains, ***"I use the leg elevation function at times. My legs can get swollen so that helps"***.

Tracy points out, ***"The chair itself is as important as the wheels. The wheelchair is about more than going from A to B. It's also about independence. The powered wheelchair allows users who cannot move their own legs to elevate them. This is important as they do not have to depend on someone else to come and lift their legs for them"***.

'Turns on a sixpence'

Users highlight a number of key features that facilitate mobility:

- ## Manoeuvrability

Wheelchairs are easy to move and direct in just about any space, giving confidence and increasing independence.

Sean notes, ***"It's a fantastic piece of equipment. It fits nicely through doors. You could turn this wheelchair on a sixpence. It is so neat and versatile. It has a brilliant turning circle for tight spaces. Even the narrowest of hallways is easily manoeuvred"***.

Eddie explains, ***"I consider this wheelchair to be top of the range. I have a small bathroom, but I turn the chair in the smallest of spaces. Just have to mind my toes, though"***.

Colm adds, ***"It is ideal for lifts in various premises and also moving in tight spaces"***.

- ## Joystick

The joystick, which controls both speed and direction, is simple and easy to use. Speed control is perfect, giving people confidence to move around in crowds, tackle door ramps and even hilly inclines.

Colm writes, ***"In a crowded area you can slow it right down with a simple joystick movement"***.

Sean notes, ***"I must slow down for the ramp at the back of the house, of course"***.

- ## Comfort

Comfort is a key criterion. A comfortable chair is more enjoyable to sit in – especially for extended periods of time. Comfort also encourages mobility and activity.

Eddie explains, ***"I'm sitting in the chair from when I get up until when I go to bed – around 12 hours every day. I use it everywhere - at the kitchen table or at the counter"***.

"Horses for courses"

There is no one-size-fits-all when it comes to wheelchairs. Tracy explains, ***"We provide anything from five to 26 wheelchairs to users per year. Each wheelchair must be customised to a certain degree to suit people's changing needs, conditions and lifestyles"***.

Users describe their experiences:

Colm

Colm uses a Saoirse manual wheelchair, which a Benoit Light Assist attachment transforms into a powered wheelchair.

Colm writes, "It suits my needs perfectly I love the freedom that it gives me. I feel very independent. The Saoirse wheelchair is lightweight and fits easily and tidily into the boot of the car. It only takes 30 seconds to assemble and disassemble".

"It is easy for my partner to manage. It is far more comfortable than a small mobility scooter and far less conspicuous than a powered wheelchair".

Previously Colm had used mobility scooters. He writes, "Initially, I had a mobility scooter which came apart in six pieces and fitted into the boot of the car. That scooter was too heavy for my partner to lift into the boot and would not go up a steep incline. I then bought a heavy duty mobility scooter, which could go up hills, but would not fit in the car".

"I don't use my wheelchair in the house. I am still able to walk around with my two sticks. I try to walk as much as possible every day to retain my mobility for as long as possible".

Sean

Sean uses a powered wheelchair, with a folding table in front of him. He only needs the wheelchair when he leaves the house.

He explains, "This model is similar to my previous wheelchair which had the joystick on the right side. As my right hand lost strength, I could no longer control the joystick. I just need someone to open and fold the table for me. The original joystick which came with this wheelchair was too small so my son made me a larger joystick from wood".

"My son-in-law built a ramp at the backdoor for me. I go round the side of the house and off down the road. I need someone to accompany me as there are two pedestrian crossings on the way and I cannot reach the push button from my chair".

Eddie

Eddie has been using a powered wheelchair for approximately six months. He previously relied on crutches and a walking frame. He was reluctant to use a wheelchair. He explains, "I tried to avoid the wheelchair for as long as possible. But I had a few falls. I was losing confidence and didn't want to leave the house. The wheelchair was parked in the sitting room for months. But this is the way to go. It is now my best friend".

"I was a bus driver so I consider that I still have good enough driving skills. Until I gained experience in the wheelchair. I had a few accidents brushing against the walls and banging my toes. At the moment I am independent. I just need help to dress".

Re-use, re-cycle

The IMNDA, as with all equipment and devices, re-uses and re-cycles wheelchairs as much as possible. Tracy explains, ***"We aim for three users per chair. Each wheelchair is fully de-contaminated and serviced before it is given to someone else"***.

Besides the obvious cost savings, reusing brings other benefits. Tracy notes, ***"It allows us to reduce wait times and makes for a more responsive service. Wheelchairs are customised to suit users' specific needs. It only takes a week for a chair that we hold in stock to be adjusted. This compares to an eight week delay when we order a new top specification wheelchair"***.

IMNDA

All users and carers express their gratitude to the IMNDA for its help and practical support.

Eddie explains, ***"IMNDA is fantastic, brilliant. The IMNDA provided me with my wheelchair. The HSE occupational therapist had measured me for the wheelchair but the HSE would not then fund one. My nurse, Eithne, is just a phone call away. She always responds with advice"***.

Sean adds, ***"The IMNDA is fantastic, brilliant. My nurse will always respond quickly"***.

Colm writes, ***"They are so friendly and supportive every time we need to contact them"***.

The IMNDA are here, whatever your needs or questions – we have a dedicated Services Team that are on hand to assist you with all your concerns. Please do not hesitate to contact us to find out more on our services on how we can support you and your family. Please Freephone 1800403403 or email services@imnda.ie

MND AND COMMUNICATION

by Lesley Doyle, Clinical Specialist Speech and Language Therapist

MND can affect the muscles used for speech, causing them to become weak or tight. Some people find that their speech sounds become less clearly pronounced or their voice becomes strained or maybe very quiet. This problem can become worse over time but if speech becomes very difficult to understand, alternative ways to communicate can be used alongside or instead of speech. Speech and Language Therapists (SLTs) give advice on communication tools. Alternative ways to get a message across include writing or pointing to letters on a printed alphabet chart.

Many people also use an electronic communication aid such as a touch screen tablet or a computer that can be controlled by a mouse, joystick or eye-gaze reader if hand movement is difficult. These devices have software with built-in computer-generated voices that speak out words or sentences as they are typed on a keypad; this is referred to as a 'text-to-speech' function. It is also possible to save some frequently used phrases referred to as 'pre-stored phrases' which can make communication faster for these messages because they do not need to be re-typed each time.

Banking speech can be considered as a 'vocal insurance'. It is a way of planning ahead to preserve a part of personality that is captured by a person's unique speaking voice. Banking speech involves making recordings for potential use in the future on an electronic communication aid should speech become difficult to understand. There are two ways to record speech for such a use: message banking (which can be used to read out 'pre-stored phrases' when selected on a device) or voice banking (which can be used to read out anything typed using a 'text-to-speech' function). These are explained below. If a person completes one or both of these, it might never be necessary for them to consider using an electronic communication aid, but if they do, they will have created the option of incorporating their recorded phrases into their communication system.

For anyone with MND who chooses to bank their speech, an SLT can help and a technician from an assistive technology service can set up a communication system for you incorporating your recordings.

Message banking involves thinking of personally meaningful phrases and making voice recordings of those phrases, usually on a dictaphone-style recorder. The type of phrases that people tend to record are terms of endearment, sarcastic comments, phrases used mostly with close family or friends or catchphrases that others would associate with them. When played on an electronic communication device, they would sound exactly the same as the person's voice when the recording was made.

Voice banking involves using a commercial service to create a personal computerised voice that is representative of the person's own voice. It usually involves recording a large inventory of speech by reading aloud set lines of text that capture different speech sounds in different parts of words. Speech clarity therefore needs to be very strong for a successful outcome. The quality and likeness can vary between people. This type of computerised voice will sound more robotic with less intonation than natural speech because it is electronic.

New Information Animation

A fantastic new animation has been developed as part of the 'Irish Message Banking Project', which aims to develop resources for use in the Irish context by professional Speech and Language Therapists and people who may experience speech changes. The project group involved the SLT services in Beaumont Hospital and the Assistive Technology and Specialised Seating department of the Central Remedial Clinic – both of these organisations work regularly with people with a diagnosis of MND. It also involved research expertise from the Clinical Speech and Language Studies centre in Trinity College Dublin and was funded by Research Motor Neurone. This animation is available on our **imnda.ie** website under Voice & Message banking or you can view it on **rmn.ie** – it is a really great resource to have and you can share with loved ones as well from your mobile phones and devices.

For more information on the process of message banking, voice banking and recommended recording or communication equipment speak to your hospital SLT, community-based SLT or discuss it at an appointment with an Assistive Technology service. You should seek advice before making any recordings to ensure this is the right option for you and that you are using the right equipment.

LIVING WITH MOTOR NEURONE DISEASE:

Sometimes Silence Can Speak Volumes

Imagine an hour…a day….a week without speech. Unfortunately, that is the fate met by most people living with Motor Neurone Disease (MND). Over 80% of people living with MND will experience some loss of speech during their illness.

This February we held our sponsored silence campaign #Voice4MND to highlight the impact that speech loss has on the lives of people living with MND and of their carers, families and friends. Madeline O'Connor, Patricia Yarrow and Valerie Hurley were the campaign ambassadors and they all spoke honestly and bravely on how MND had affected their lives.

Patricia Yarrow

Patricia Yarrow lives in Blackrock in Cork with her husband Leigh. She is 70 years old and is the proud mother of one son and beautiful granddaughter. She was diagnosed in September 2020 with Motor Neurone Disease. This is her story:

I looked at a Christmas card passing by the table and looked at it again, it was a card from the IMNDA. It gave me a jolt as it dawned on me that this time last year I knew absolutely nothing about MND. After 10 months of exhaustive tests and investigations around the cause of my slowing and sometimes slurring speech (naively thinking it was great they had found nothing ominous), I received my diagnosis of MND in early September 2020. I cannot find the words that adequately describe the range of feelings that followed, but overwhelming grief is certainly one of them. I was healthy, working, enjoying my life to the full, looking forward to becoming a grandmother for the first time, surely they cannot be talking about me?

By the end of September I made the decision to close my practice as a psychotherapist which broke my heart as I loved my work, but my voice was deteriorating to the stage where it was not really an option to try and continue. If it's true that one's work contributes to a sense of one's identity, I wondered who am I now, Trish with MND? I hated that.

Well, five months on, the meltdowns, of which there were many, have reduced in number but my voice has deteriorated further and I find it embarrassing when I cannot be understood easily. Sometimes it is assumed I am drunk or have an intellectual disability, but whatever the assumption, the word I find that fits the experience for me is "diminishing". I feel 'less than' compared to how I used to be and vulnerable, not being able to express/explain myself, in a way that is new to me. With people I am close to, I can put my hand up and say 'wait for me' or 'please don't leave me out' because the flow of normal conversation is faster than I had realised and, yes, we joke about it too!

We are all on parallel journeys in life, but there is a loneliness around this journey, being afraid to make plans for the future with confidence, the absence of the lovely taken for granted aspect of life. Family and friends have been loving and supportive and I am blessed beyond words, I cannot imagine getting through this without them, but this is a solo trip necessarily. No one can stop the inevitable decline this disease brings, a stripping away of taken for granted activities and functions and a robber of hope because there is no cure, there is no treatment plan to "fix" it. That's why awareness of MND is so important and fund raising for further research is so vital. The support the IMNDA offers is truly sanity saving. They swooped in within two days of me contacting them, a visit from Katie, one of four IMNDA nurses who cover the country, within a week, advice, supports, reassurance and a sense of not being on our own were all invaluable in the midst of shock and grief and this support continues.

My biggest fear around this disease and losing my voice is that people will lose sight of me, Trish. My favourite thing in the world has always been the enjoyment of good company and I love the banter and fun, I still do, even though I cannot participate as before, I still enjoy a gin and tonic or a glass of red, have not lost my sense of humour and never want to be the person whom it's someone's turn to 'look after'. I am still 'me' and will be, as this disease progresses, so please don't assume, just ask me! I'm still here though silenced!

Madeline O'Connor

Madeline O'Connor is a proud Mum of one daughter, living in the Kingdom of Kerry. She is 65 years old and last April she received the devastating diagnosis of Motor Neurone Disease. The diagnosis was a massive blow to Madeline and she was forced to retire from her work in the Eir Call Centre as her voice had deteriorated so much.

This is Madeline's Story:

I had a stammer as a child and it returned in August 2019. Someone close to me was very sick at the time, I presumed it was stress. My voice got weaker and weaker and by the time I was diagnosed with MND in April 2020, my words were slurring. I would be on the phone at work and people would ask me, "Are you ok?" Or get frustrated that they couldn't understand me.

When I speak, it sounds perfect in my head. But now nobody can understand me.

I use an app on my iPad and I would be lost without it. I resisted it at first. I did everything I could to get my voice back. I still pray it will come back. But I can communicate well with the help of the app.

What I miss most about losing my voice is being able to have chats with my daughter, Mari and conversations with friends. Everything needs to be written down or typed out.

The MND sponsored silence is a wonderful way to raise awareness of the difficulties facing someone who has lost their voice. It is difficult to go out into the community when people don't understand that I require a little more patience. If we could raise awareness of the needs of MND patients then it would be a wonderful confidence boost for us to go out into the community and enjoy life as normal.

Valerie Hurley

In October 2017, Valerie Hurley's life inextricably changed forever. Her husband Michael was diagnosed with MND. Valerie and Michael faced MND head on and together they battled the disease for over 3 years. In October 2020, Michael sadly passed away. This is their story:

Michael and I met eighteen years ago. I had three sons at the time and Michael just took to them like they took to him. We married in 2007, a year after Calum was born. We shared many wonderful moments shared so many memories, but like any relationship we also dealt with the hardships.

Before Michael's diagnosis was a particular Rollercoaster in our marriage, which still sticks with me today, had I only seen his arm!! Had I forgiven and let go faster, then I would have seen the extent of the problem, something we thought was a trapped nerve was in fact the start of MND.

On the 13th October 2017 Michael was diagnosed within three weeks of seeing our GP by a neurologist in Bantry. He was then referred onto CUH to the MND clinic and Beaumont Hospital. Now we were faced with MND and what seemed like a Rollercoaster turned into a ride that didn't stop. The past became the past, it became more important to deal with this awful disease together as hard as it may be. I knew wholeheartedly that this was a battle and Michael needed us now more than ever. After all we were made to be there for each other.

Michael battled hard for three years and eight days, he fought with such courage and bravery. He never complained but often got upset, he just wanted to stay was all. Sadly Michael lost his battle on the 25th of October 2020.

Michael's MND started in his upper body starting with the right arm, moving then to the left. I truly urge anyone diagnosed with upper bulbar palsy, which starts in the upper body to avail of the iPad tablet smart box. It's such a wonderful device and will certainly give you independence. It will help you to communicate in the case you lose your voice like Michael.

The IMNDA and all the other services were truly amazing. From the equipment provided to many appointments between Bantry and Marymount palliative care services. Our local health providers were always here to help at any time. There are just no words to thank you all, you provided such wonderful care and support.

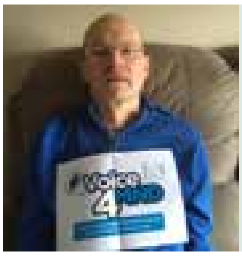
In the final days, a night nurse was provided for me to rest, an angel is all I can say. I never thought we would but we did, we forgave and loved. That was far more important than anything we had ever faced and we as a whole family made decisions together. Some very hard discussions were had, but love, loyalty and family prevailed over everything.

Michael and the boys along with many others, climbed Ireland's tallest mountain Carrauntoohil in the Kingdom of Kerry just last year raising €11,000 for the IMNDA. It was such an amazing accomplishment and achievement for Michael and just a month before he passed was awarded a silver pin award from the IMNDA because of his efforts. I also received one but due to spinal damage unfortunately was unable to climb. Although it was so heart-warming to be named The Dream Team, by Róisín Duffy CEO of the IMNDA, because in the end we really were. We spent nearly every moment together.

Times were extremely difficult but we as a family made all Michael's wishes come true. I just hope and pray daily that he could hear us all and will watch over us forever. Forever loved and missed. Michael will be in our thoughts and heart always. To home carers, just believe in your strength and you are capable of anything. Take time breathe and talk always.

From all at the IMNDA, we just want to say a massive heartfelt thank you to Patricia, Madeline and Valerie. Their courage and spirit throughout the campaign was amazing. They had the entire country buttoning their lips for MND.

But they were not alone in championing the silence. People living with MND took part right across the country!!! And here is what they had to say about it!!!



"MND has taken away my voice but it doesn't define me nor can it take away my fighting spirit," said Andy Minogue, 53, living in Clare with Motor Neurone Disease.

"Communications is key to everything we do. I am fighting every day to keep my voice," said Valerie O'Carroll, 59, living in Dublin with MND.

"I have noticed a slight difference in my voice these past few months. Thanks to the equipment out there I will still be able to communicate," Jason Corrigan, aged 29, living with MND in Mayo.

"This challenge is such an effective way of supporting people who have lost their voice to this awful disease," Jer Spillane, 38, living with MND in Mitchelstown, Co Cork.

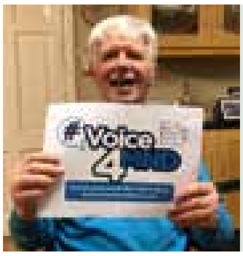
"So, if you are too tired to speak, sit next to me, because I, too, am fluent in silence," said Gerard Tracey, living with Motor Neurone Disease in Co. Offaly.

"Sometimes words can mean a lot. For February your silence can mean so much more!" said Roy Taylor, 63, living with MND in Dundalk.

"I am fundraising for IMNDA for the day I will need their help as I know I can rely on them for the help I will need,"

said Michael (MK) Clancy, a Clare man living with MND in Limerick.

"This is my Dad and I. I am taking on the sponsored silence challenge for 24 hours in support of him and all others who have MND. Dad always loved music and had a beautiful singing voice which he said has been the hardest thing for him to accept and lose. We wanted to send a message to say how thankful we are to the IMNDA and the nurses who have supported Dad on his journey so far," said Claire Sheerin, daughter of Gerry Sheerin who has MND.



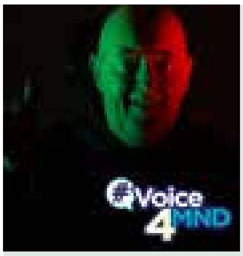
"I find I take longer to say something because of the way my voice is",

said Paddy Swarbrigg living with Motor Neurone Disease in Mullingar, Co Westmeath.

"My husband Des, was diagnosed with Motor Neurone Disease on 14th February 2020. In just one year, his speech has gone completely. None of us will ever hear his voice again and it is a dreadful loss, not just for him, but for all of us. He has other problems too, but the loss of his ability to converse is worst of all. It's so sad. The IMNDA relies on donations from the public to provide electronic and other devices, along with highly trained personnel, to sufferers of speech loss due to MND.

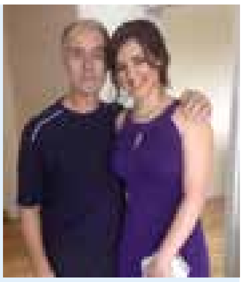
I asked the 5 older of our 8 grandchildren to draw a picture of how they remember their Grandad Des. These are the drawings done by Tara, Ronan, Ewan, Gwen and Fionn,"

said Valerie Collins.



"Losing my voice has been the toughest symptom of MND for me personally. Seeing family and friends struggle to decipher my mumblings now is soul destroying, and is a heartbreaker. On a lighter note, I miss not being able to cheer on the mighty MAYO football teams over the last number of years. We both live in the hope for redemption. Aaaah the curse the curse be gone,"

said Andy McNicholas, living with MND in Mayo.



Megan Moriarty took on a 24 hour Sponsored Silence as her father sadly passed away from Motor Neurone Disease in 2017. When her Dad was sick, she was only 20 years old and starting college. No one was able to relate to what she or her family were going through.

Her Dad was a very strong man, built her family home in Kerry and was really a family man. MND completely changed him but he fought it until the end. The one thing he really struggled with was talking, which is why Megan chose to do this campaign. She felt this fundraiser has highlighted to people of her age what her family went through.

Stephanie took on the challenge of losing her voice in support of her Dad and others all around Ireland. She wanted to thank everyone who has helped them this far, especially our MND nurse Katie and his wife Frances. Well done Stephanie and Patrick!

"I am living with MND, I need support and I have it. Thankfully, I have support from family, friends, carers, doctors, HSE and the IMNDA who supplied this wheelchair - my new best friend!" said Charlie Boyle in Donegal.

"I sound like I've had a few drinks", said Paul Lannon. Sandra, his wife gave Paul the gift of silence for Valentine's Day. Sandra wanted to highlight to her friends and family the full extent of Paul's needs and what their daily lives entail. This dynamic duo recorded several videos for social media and raised over €7,000. Guys, we can't thank you enough for all the awareness raised.

No two journeys of MND are the same, it affects people so differently and by communicating our experiences – it can help others understand. Thanks to everyone across the country championing the campaign, it was a tremendous success. It was the biggest Sponsored Silence to date. Thank you to everyone who shared their stories. Thanks to you all, over €150,000 was raised!

More people took on the challenge. More people quit speaking and stayed quiet for MND. People took on the challenge at home, in work and in their communities. We had a great response from families and friends coming together to take on our silent challenge. The length people stayed quiet for ranged from 30 minutes right up to 24hours!

Thank you, thank you, thank you to absolutely everyone who took part - the word is now out, our silence shouts!

THANK YOU FOR YOUR SUPPORT!

We would like to take this opportunity to say a huge big thank you to everyone for your continuing support. It has truly been a year that none of us will ever forget.

Over 12 months ago, we didn't know what to expect or how we would cope. Ensuring that our critical services continued to our MND families was paramount and our wonderful nurses and dedicated team really stepped it up a notch, but the worry and uncertainty still remains.

However, there was a constant light in the darkness. A beacon that helped us to stay on course and that never wavered. This light was you. This year more than most, your efforts, encouragement and endorsement has enabled us to steer through one of the toughest fifteen months that we have ever faced.

We are beyond grateful for the outpouring of support we have received. Thank you for all coming together, while staying apart. Thank you for being there when we needed you the most. Thank you!

NATIONAL MND AWARENESS MONTH OF JUNE

DRINK TEA FOR MND!

There is no doubt that the global pandemic has changed our everyday lives. With so many of us, working and staying at home, our kettles have been in full demand. One thing certainly has not changed during this time and that is enjoying a well-deserved cup of tea.

We are so used to telling our friends and loved ones we have to make 'a cuppa' before we jump on our video chats. So this year we are asking people to join their loved ones for a virtual cup of tea and all for MND.

Helping us out are our fantastic Drink Tea Ambassadors. They have agreed to share their stories to help spread awareness of MND during this month to encourage people to get involved and brew the most valuable cup of tea that they will make this year.

IMNDA Drink Tea Ambassadors:

Ger Tracey

Ger Tracy is 55 years old and lives in Clara in Co. Offaly. Ger was diagnosed with MND last year. This is his story.

I have always had a love for the gym, I was well built and I lifted very heavy weights, so I suppose this is where I first noticed change in myself. I noticed over a three-year period I was losing strength and size in my chest and arms. I didn't over think it at the time, I just put it down to getting older.

Then last year I noticed changes in my breathing. I would be out of breath for the least thing. I also noticed little changes in my hands, I thought it was just arthritis as there is a family history of it. I lost my mam in June of last year and it was then I decided to change my GP. When she examined me, she noticed my muscles twitching as well and she became concerned.

I was sent to Tullamore hospital the following week for three days of tests including an MRI and a nerve conduction test. On the third day, I was told to bring my partner with me and it was then I was delivered the bad news that I had Motor Neurone Disease and it was terminal.

Obviously, we were devastated as we had just got engaged at the end of summer and had great plans for the future. I was then referred to Professor Hardiman in Beaumont who advised me life wasn't over and all my plans and life should go ahead as normal and to try and live as normal as possible.

Yes, there are changes to what I can do and what I can't do but I have learned to adapt to each circumstance. Things like sometimes not being able to zip up my jacket, close my buttons or even tie my laces don't frustrate me anymore. I've learned its ok to ask for help.

I don't work now, which was very hard to get used to after working the last 40 years of my life but again I have accepted not been able to lift things and getting used to not over doing things that would get me out of breath. I continue to live as normal a life as possible and we are busy now planning our wedding for August hopefully depending on government guidelines.

I try in every way not to let MND change my life, Instead I try to adapt to new challenges. I am also blessed to have a wonderful partner, three brilliant kids, grandchildren, extended family and friends who are always there to help if I need them, So I thank god every day for all I have.

Denis Fitzgerald

Denis Fitzgerald is 67 years old and lives in Kinsale, Co Cork with his partner Helen. Denis has two sons, one daughter and six grandchildren. Helen has one daughter. This is his story:

I was first diagnosed with MND in December 2005, but had symptoms for the best part of two years before that. I have had Melanoma Cancer since 1989 and had a reoccurrence in 2001. When I first developed a limp in my right leg, my oncologist referred me to a neurologist who sent me for several tests MRI, CT Scans etc. They noticed something in the thoracic area of my spine and so in consultation with the oncologist decided to *operate on my back and removed one of my discs to see if this would cure my limping issue. They were concerned that the cancer had returned.*

However, the operation did not cure the limp and so they continued to carry out nerve conduction studies in the Mercy Hospital in Cork before referring me to a Professor Findlay. He did several scans and nerve conduction studies over the course of a week in October 2005. On 1st December I was given the diagnosis of Motor Neurone Disease.

Neither Helen nor I had a clue as to what this disease was and so he went on to explain it. He said my prognosis was not good and at best, my life expectancy was 5 years. We were both in terrible shock. How could this be happening to me?

I was a very fit and active man. I continued to work in Lilly where I was Procurement Manager with a number of people reporting to me, a job I loved. Gradually my right arm became quite stiff and I found it difficult to play my guitar, a passion of mine. Within months, both of my legs and arms were impacted. I was no longer able to do the gardening, wash the cars and general odd jobs around the house all of which I found very therapeutic. Helen was now doing these jobs and I felt useless.

By early 2007, my speech, swallow and breathing became affected, at which point I became very down in myself and despondent. I could no longer sing and play my guitar and I hated the sound of my speech. I had become very tired during the day and needed to take rest breaks. I felt my life was over.

I attended Professor Orla Hardiman in Beaumont hospital and she recommended that I attend Dr Aisling Ryan's MND clinic in Cork rather than making the trips to Dublin. Dr Aisling Ryan really gave Helen and me great hope in that "my disease could be managed". These were the words that we needed to hear rather than all of the doom and gloom which had really brought me to a very low place. I was very depressed.

I did not feel like speaking and my voice had become very weak, however Aideen O'Riordan Speech Therapist on Dr Ryan's team did tremendous work with me over a number of months and I slowly regained my confidence to speak again. She gave me several exercises to strengthen my voice and control my breathing skills. Likewise, I was attending Liz O'Sullivan Physiotherapist on the team and she too built up my confidence to walk as much as I could each day and equipped me with two sticks for support. I hated those sticks at first but gradually I accepted the tremendous help and independence they gave me. I had to take early retirement from my work in Lilly in July 2008 after 28 years' service and a job which I adored.

Helen has been my rock throughout this entire journey. She has been so positive and gives me tremendous support and love on a daily basis. My children too are a great support to me as is Helen's daughter and I absolutely adore my six grandchildren. My two sisters are also a wonderful support and live close by.

I am still enjoying my life every single day and "today is my best day" is my motto now. Helen and I don't do negative anymore we try and look for the positive, we continue to laugh every day about something. Now I go on the phone regularly to negotiate our insurance bills, utility bills etc. I have regained my confidence to speak up and I begin my external phone conversations by saying "I have a speech difficulty so can you please bear with me."

Now I focus on the things that I can still do every day and not on what I can no longer do. I feel positivity is very important no matter what illness you have, a positive outlook helps me to keep going and enjoy every day.

The IMNDA have been wonderful in their support providing me with a Shower Toilet, which continues to allow me to hold onto my dignity. They funded a Benoit Light Drive System for my manual wheelchair, which affords me great independence and freedom to get to places with Helen. It is lightweight and Helen can easily disassemble it and put it in the car boot.

The IMNDA have also funded a Home Buddy program for physio type stretching exercises, which have been invaluable in keeping me mobile. I really feel the benefit of this program. I try to keep mobile and positive every single day. Yes, there are days when I struggle somewhat with pains and stiffness, but I do my best not to let it drag me down. I use a BiPap breathing machine every night and without it, I would not survive. It is excellent although it did take months for me to adjust to it. Without this machine, I would not have the same energy each day. It is keeping me alive for sure..

The message I would like to give to newly diagnosed people with MND, is a one of hope which is why I have shared so much about my journey. I was initially told that I had ALS then years later was told actually maybe you have PLS. My initial neurologist said that it did not matter which type I had because my outcome would be the same. He gave me no hope at all. MND is a very tough diagnosis for sure but there is hope, I am proof that there is hope and I continue to have hope for the future.

Róisín Clarke

Róisín Clarke provides a caregivers perspective for our Drink Tea campaign. She looked after her husband Alan every step of the way. This is her story:

My name is Róisín Clarke, I turn 50 years old in July and I am from Carrickmacross in

Co Monaghan. I was raised on a small farm and I am the eldest of eight siblings, four boys and four girls. I am so blessed to have a really fantastic family and to still have both my parents.

I work with the Irish Blood Transfusion Service, a job I love. I have been working there since 2001. My work colleagues are like my extended family and I would have truly been lost without their support over the past few years.

I met Alan 27 years ago and we got married on the 6th May 2000. We built a beautiful bungalow and had two beautiful boys Raymond (19) and James (17). Alan was a self-employed electrician. He also had an obsession with cars and machinery. He was always buying and selling them and spent countless hours going to trade shows and auctions. He loved diggers and machinery and he was forever coming home with different parts and scrap material.

First and foremost, Alan was a family man. Sundays were our days. We would go to mass then I would cook a roast or we would go out for dinner. Then there would be a match or away off on a spin somewhere, up the mountains, to the beach for a picnic. Sunday was the only day I saw him in good clothes! Life was a dream.

In March 2016, our world came crashing down. Alan had a strange feeling, a tingling in his arms and legs and he couldn't warm up his hands. We decided that he needed to see the GP. She reffered him straight away to a neurologist in Beaumont and within a week he was diagnosed with MND. Alan didn't realise what Motor Neurone Disease was. When he left the neurologist in Beaumont, he rang me from the car on his way home. I was getting ready for work. When he told me, my heart sank and I had shivers down my spine. Alan pulled in off the road and googled it, he was on his own. We were not expecting to receive news like this.

I was waiting for him in the kitchen with the kettle on, we sat at the table and cried. He just said. "Why not me? Families get different news every day of the week". Over his 4 years with MND, his outlook never changed.

That was the first day of grieving for me. However, we decided there and then that we would have a plan to tackle this. We would pretend that nothing was wrong; we would keep ourselves in a little bubble. Once a month we came out of the bubble for his check-ups in Beaumont Hospital.

Alan was a very practical man. He went to the undertaker and told him his wishes, he visited the solicitor and got his affairs in order. He didn't want to cause his family any extra stress or worry. He folded up his business. This was heart-breaking for us. Absolutely horrendous. The day he sold his work van, he shuck the man's hand and wished him the best of luck. Alan was very strong mentally and physically but that was a hard day for him.

From that day on we did as much as we could with the two boys. We went on a Mediterranean cruise while Alan could still walk. We went on weekends away, had picnics, went out for meals and to the movies. We had 2 very good years creating special memories. Then came our old friend the wheelchair. But this didn't stop us. We bought a wee van and had some great laughs in the middle of pure turmoil.

We had a fantastic MND nurse Eithne. She lightened the mental load for me. I honestly do not know what we would have done without her and the support of the IMNDA. The IMNDA are a fantastic team, they work with the family every step of the way. Nothing is left undone. They work with you at whatever pace you are at. I will never ever forget the conversations with Eithne. The funding for all the equipment and how fast it could be in our home was just unbelievable.

Alan was the love of my life. The love we had, some people don't experience a week of it. Alan died on our 20th wedding anniversary at 8.20pm in my arms surrounded by his boys, fantastic mother, his two sisters, his extended family and work colleagues. I whispered in his ear that at this time 20 years ago we were having our first dance as Mr and Mrs. A tear rolled down his cheek and he took his last breath. I just said, "Alan, I will see you on the other side".

Todd Nugent

Todd Nugent is 69 years old and was diagnosed with MND in June 2010. This is his story:

I live in Mullingar with my wife, Patricia. We have one son, Conor. I have been an insulin dependent diabetic for the past forty-five years. In December 2003, I contracted a bacterial strain of meningitis, known as listeria. This left me with peripheral neuropathy and resulted in significant nerve damage to my feet. I was out of work for eighteen months and after returning for a short period, was forced to retire on the grounds of ill health.

In January 2009, I began to notice a periodic drag in my right leg. A subsequent MRI scan showed nothing unusual. In March the following year, nerve conduction studies revealed possible signs of MND. I was referred to Professor Orla Hardiman. After a number of consultations, multiple sclerosis and Parkinson's were ruled out. MND was later diagnosed. Professor Hardiman explained the exact strain of the illness could not be determined for a number of years. I was hopeful I could avoid the worst outcome. In 2014, a diagnosis of Primary Lateral Sclerosis was confirmed. This meant the most common symptoms of MND could develop gradually, over a number of years.

MND has primarily impacted my mobility. I use a walking stick around the house and a rollator for trips outside. The IMNDA installed a stair lift, which has significantly improved my quality of life. I am still able to use a car, as the vehicle has been adapted to operate with my hands.

What does the future hold? Well, who knows? I have three guiding principles - take things one day at a time, focus on what I can do as opposed to what I can't and remember that the glass is always half full, not half empty.

I would like to thank all the people who have helped me throughout this journey. My wife, Patricia, my son, Conor, my family and friends and of course, Professor Hardiman and the team in Beaumont Hospital. I am particularly grateful to the IMNDA, for their constant help and support over the years.

Patrick Hurley

Pat is 68 years old and grew up in North County Dublin. He has lived in the beautiful town of Skerries for the past 30 years. This is his story:

I have been married to Justine for 42 years and we have four children, three boys and one girl, ranging in age from 29 to 39, all living in Dublin. I have always had a great interest in sport, music, travel and DIY. I played Gaelic football at a high level, then squash, golf, and hill walking. In 2006, I walked the Dublin City Marathon in less than 6 hours. In 2016, I climbed Ben Nevis in Scotland with two of my sons and we climbed Mount Snowden in Wales in 2018. I have been in choirs for many years. Our travels have taken us to the US, Canada, Hawaii, South Africa, Vietnam, Cambodia, Cuba, Sweden and many other European countries. I have always been very fit and I was taking no medication until 2020.

On a number of occasions in 2018/19, friends and family remarked that I was losing condition on my shoulders and they advised me to do some weight training (which I ignored). Late in 2019 I began to experience pain in my joints, particularly to my right shoulder and ankle. I attended a rheumatologist and she ordered a series of tests including bloods, x-rays, and MRI scans. While having these tests, in mid-January 2020, I became aware of a loss of power in my right hand and arm. Further tests failed to identify the cause and I was eventually referred to Prof Hardiman in Beaumont Hospital. In late March she diagnosed Motor Neurone Disease. This diagnosis was devastating, not only to me, but to Justine, our children and the wider family. It took some months to come to terms with the news and gradually there came acceptance.

Since then I have continued to live a totally normal life and I have experienced very little deterioration in my condition. I have noticed a slight build-up of saliva in my mouth and my balance is no longer perfect and, at times, my voice becomes weak. Muscle waste is continuing to my right arm and leg. My wife, family and friends have been very supportive without dwelling on the subject. Clearly, I frequently think of the future and what it holds but I quickly move on with the attitude to "not cross bridges until I come to them".

I still walk about 10 km every day and I only wish that Covid was in the past and I would be able to resume travel at home and abroad. I only retired two years ago and I am still looking forward to, and planning for, several years of enjoyment and positive living. I am taking Rilutex medication for the MND and I am also on medication for osteoarthritis. I'm participating in a MND drug trial called TUDCA-ALS since December and this will continue for 18 months. The researchers hope that this drug will delay the progression of the disease.

Life is for living and that's what I am doing.

To help support the MND community and spread MND Awareness this month we want you to Drink Tea for MND this June! So put the kettle on and have a cuppa to help provide essential services to more than 400 families right across Ireland affected by this disease.

We are asking people to support the 21st of June by Drinking Tea for MND event in or around this day. You can also ask friends to support you by 'purchasing' tea, coffee or some delicious goodies from our Thoughtful Treat Cafe!

To organise your very own Drink Tea for MND event in or around June 21st, all you have to do is visit **imnda.ie** and register your Virtual tea event. For more information just email **fundraising@imnda.ie**

If you can't host a tea event, why not make a tea donation – go to imnda.ie to find out how or just text MND to 50300 and donate €2. Text cost €2. IMNDA will receive a minimum of €1.80. SP: LikeCharity. Helpline: 0766 805 278.

DRINK
JUNE 21
TEA
FOR MND
Helping others.
It's everyone's cup of tea.

WALK WHILE YOU CAN FOR MND IN YOUR AREA

Four years ago, the remarkable Fr. Tony Coote undertook an extraordinary walk from Donegal to Cork – some 550 kilometres – for Motor Neurone Disease. It took a month on the road travelling from town to town in all weather conditions but in the end a remarkable €700,000 was raised for the IMNDA and MND Research.

From these miraculous funds, IMNDA were able to hire a much needed fourth outreach nurse to care and support people living with Motor Neurone Disease in Ireland. The IMNDA's nursing service helps over 400 people and families spread across 26 counties. This is the only service of its kind in the country and it is funded entirely from public donations. We will never forget what Fr Tony Coote did for Motor Neurone Disease.

Sadly, on the 28th August 2019 Fr Tony passed away at just 55 years old. This year, as things remain uncertain, we will not be able to hold our annual 5K event in the Phoenix Park in September. However, that is not going to stop us!

We are encouraging people to be part of something special by taking part in their own Walk While You Can, Where You Can for MND this September. You can register online by simply visiting www.imnda.ie

WALK WHILE YOU 5K CAN

Hope starts with one step. Change happens with many.

Please help us honour Fr. Tony's incredible achievement and in turn help hundreds of people nationwide who are affected by this cruel and debilitating disease.

Roisin Duffy, CEO of IMNDA says

'Like all charities we are facing a very worrying and challenging time. We aim to be there every step of the way for someone who is diagnosed with MND. Without events like Walk While You Can, we wouldn't be able to continue providing support."

It's now up to all of us to ensure that Walk While You Can continues to raise urgently needed funds for people living with MND. Together we can keep Fr Tony's legacy going. He himself found hope in times of adversity so we must do the same.

All the information you need can be found on www.imnda.ie

Remember hope starts with one step, change happens with many

STRATEGIC PLAN

2021 - 2026

As many of you know, in seeking to chart the direction for the Association and the vital services it provides, we conducted a year-long consultation exercise with all major stakeholders, led by Amarach Research.

We held face to face interviews, prior to Covid-19, with many clients, carers and healthcare professionals and then quickly switched to telephone interviews as the pandemic unfolded. Focus groups were also held with the staff and Board of IMNDA.

Whilst the arrival of Covid-19 certainly presented new challenges (many of our stakeholders were engaged in fighting the pandemic) we are glad to say we were still able to complete this body of work and capture the views of our MND community through an online and postal survey. In total, more than 326 people completed our survey (83% online and 17% via post) which was a good representation of our client base (more than 50% of all feedback came from current clients and carers, our key stakeholder groups).

One thing that became very clear from our findings is that there is no one size fits all when it comes to MND. This is a challenge the Association has always faced in terms of service delivery. Everyone is unique, as are their circumstances in terms of who cares for them on a daily basis, and what support they have access to in the community. This is why it's so important that the IMNDA continues to work closely with each and every person on an individual bespoke basis. Everyone is different physically, emotionally and practically and their needs will differ greatly as a result. This applies to both clients, carers and the family unit as a whole.

Based on this reality, the research findings provided invaluable insights which helped us shape and develop our 2021 – 2026 Strategic Plan.

Here's a sample of what you had to say….

STRATEGIC PLAN
2017 – 2020
KEY ACHIEVEMENTS

Before we lay out our future plans
that we reflect on our last strateg
Our 2017 – 2020 priorities were

- STRATEGIC PRIORITY ONE
  Support People living with MND
- STRATEGIC PRIORITY TWO
  Connect and Communicate abou
- STRATEGIC PRIORITY THR
  Strengthen our Organisational

Strategic Priority One – key milestones achieved

- Employed a new dedicated Information & Support Office advise families regarding rig entitlements and to act as a between the nursing team wider MND community.
- Invested more than €1.7 provision of crucial new
- Spent more than €1.6 m care grants.
- Introduced a once-off Caregiver Support Pr

STRATEGIC PRIORITY 3

Continue Research Funding & Support

Our third priority is to support, fund and communicate research into causes, management and treatment of MND amongst all key stakeholders including families affected by MND and the wider healthcare community.

Understanding that today's research could be tomorrow's treatments and a cure, the IMNDA will continue to invest in key research projects, both nationally and internationally. We dream of a world free of MND and we understand the only way this vision can be realised is through continuous progress in research. The Association will continue to work closely with our research colleagues on a local level in Trinity College and also on a global scale and we will ensure all opportunities regarding research projects and clinical trials are communicated to our community.

Priority #3: Support, fund and communicate research into causes, management and treatment of MND amongst all key stakeholders including families affected by MND and the wider healthcare community.

We will do this by:

- Communicating the latest news and information on research projects and clinical trials to our MND Community.
- Working closely with our research colleagues in Trinity College and through collaboration with other European, UK and international research groups.
- Continuing to fund projects both nationally and internationally funds permitting.

"They are so friendly and supportive every time we need to

What We Do Best

Most people said they approached IMNDA in the first instance for general information on living with MND and/or caring for someone with MND, followed by equipment provision. Specific services subsequently deemed useful and rated highly, such as equipment provision, nursing services and counselling support were often not known about when first contacting the organisation.

We asked people to rank our services in terms of what one was most important. Both the nursing service (48%) and the provision of equipment (28%) were noted as our top two, followed closely by our counselling grant (15%). Many people commented they couldn't pick a particular service as being more important than another as they relied heavily on all our services.
We asked people what service IMNDA does best. Two thirds of those surveyed said IMNDA does 'general support' best and it is this general 'go-to' nature of the IMNDA, along with the human nature of the staff and helpline service that stand out most strongly for people.

We asked you how each service performed in terms of poor to excellent and 69% said our equipment service was excellent and delivered exactly what was needed. A further 29% said it was good and worked well.

When it came to our nursing service 92% ranked it in the good to excellent range with some saying they wished there was a larger nursing team to allow for more regular contact.

Our homecare grant saw 48% of people rank it as excellent, with a further 42% saying it was good and worked well.

- On a scale of (1 – 10) 74% of people rated IMNDA between 8 and 10 in terms of meeting their current needs.
- On a scale of (1 -10) 67% of people rated IMNDA between 8 and 10 in terms of their needs being met during Covid – 19, with 50% giving a 10 rating.
- On a scale of (1 – 10) 78% of people ranked IMNDA between 8 and 10 when it came to anticipating their future needs and were confident the Association will deliver.

While the overarching results of the research were extremely positive the IMNDA is aware there is always room for improvement. This was a very worthwhile and much needed body of work which has helped us to understand that anticipating future needs on behalf of those affected by MND, and sharing more information on the services and support available, especially at particular points, will go a long way to ease concerns for both clients and carers.

Suggested Areas for Improvement

Communication, communication and more communication. This was the number one suggestion put forward by clients and carers across all areas. More proactive and frequent contact would be welcome but all said they understood that this isn't always possible given resources and the size of the organisation. Most said they would like more personal stories to be shared about the various stages of the disease so they could plan and future proof all aspects of their day to day life. More practical information and advice would also be welcome at various stages of the disease for the same reason. Many noted they would welcome more information on research projects and clinical trials.

Based on all research findings, it is our hope that this new strategic plan will form a clear roadmap for the Association to follow over the next five years, ensuring our core supports are fit for purpose and aligned with what our MND community urgently need.

Delivering person-centred care has always been, and will continue to be, the IMNDA's number one priority. With this in mind, we have identified the following four strategic priorities to concentrate our efforts on over the next five years.

Priority 1: Provide practical client and caregiver-centred support on both a national and local level to ensure people affected by MND receive the best possible standard of care.

Priority 2: Strengthen communications with all key stakeholder groups, especially families directly affected by MND, and enhance public awareness of the impact of MND through advocacy.

Priority 3: Support, fund and communicate research into causes, management and treatment of MND amongst all key stakeholders including families affected by MND and the wider healthcare community.

Priority 4: Invest in long term sustainable income streams in order to continue to operate a stable, transparent and accountable organisation, meeting best practice standards amongst the charity sector in Ireland.

To read IMNDA's full 2021 – 2026 Strategic Plan please visit www.imnda.ie

We are confident this new plan will guide us from where we are today and ensure we stay focused on the areas we need to expand and develop in order to better serve you, our MND community, in future years.

We as an organisation look forward to working in partnership with all the remarkable people in our MND community – clients, caregivers, families, neurologists, clinicians, researchers, policy makers and all our wonderful donors and supporters to deliver better outcomes for everyone impacted by MND.

We would like would like to take this opportunity to thank everyone who fed into this process. We value your time, honesty and constructive observations and feedback. We look forward to keeping you up to date on all future developments as the years and months go by.

Irish Motor Neurone
Disease Association

Strategic Plan
2021 - 2026

IMNDA STAFF UPDATES

As Róisín mentioned, it is with a heavy heart that we bid her farewell. Róisín was a wonderful support to all the team and we will miss her leadership and direction. She was our committed captain who steadied the boat upon many a storm. We will miss you Róisín and wish you nothing but the best for the future. We know that whatever you decide to turn your hand to, you will bring the same amount of dedication, enthusiasm and creativity that we were so lucky to have benefitted from. Thank you and good luck!

But it is not all sad goodbyes, we also have two fantastic new arrivals! It is with open arms that we welcome back a face that maybe familiar to a lot of you. To replace Maeve Leahy on her Maternity Leave, Derbhla Wynne will be taking back over the role of PR & Communications Executive. Derbhla brings more than 17 years experience in communications and MND. Welcome back Derbhla! You can contact Derbhla on **dwynne@imnda.ie** or Freephone 1800403403.

Another new addition to the team is our new Services Administrator Lisa McNally. This position is funded through the Loretto Dempsey Placement Initiative, kindly supported by Arthur Cox. Lisa will be a point of contact for those with MND and their families. She will also be liaising with our MND Nurses & community healthcare professionals concerning direct service provision. Delighted to have you on board Lisa!

Coronavirus COVID-19

COVID-19 UPDATES

The IMNDA are closely following developments in relation to Covid-19. We are aware that the situation surrounding the spread of coronavirus may be causing people affected by motor neurone disease (MND) concern. We are also aware of the continuous fluctuations in the vaccine rollout. We are monitoring the situation closely and we will continue to update our services users as and when necessary. For all information in relation to Covid-19 & MND, please see the new section on our website: **https://imnda.ie/coronavirus-covid-19-and-mnd/**

Rialtas na hÉireann
Government of Ireland

MONTHLY GIVING

Regular gifts are so important to the IMNDA, it's secure fundraising that we can rely on. If you can spare a little each month to help families living with Motor Neurone Disease, please read on….

We are delighted to launch our brand-new monthly giving function – **fundraise.imnda.ie/donate**.

There is no minimum amount – every Euro makes a real and lasting impact so choose a monthly amount that works for you. You can cancel your monthly donation at any time, just drop us a line at fundraising@imnda.ie.

So just visit **fundraise.imnda.ie/donate** choose your preferred amount and select 'Monthly', fill in the very brief contact details form, enter your payment details and you're good to go!

And remember by donating €21 or more a month the IMNDA will benefit from tax relief from the Irish Government. This makes the value of your donation considerably greater than your original contribution.

Registering your Fundraising Event

Please register all fundraising events with the IMNDA before they take place and ensure all your details (name/address & event) are on the lodgement slip when lodging proceeds into the bank.

To register and receive promo items / lodgement slip etc:

Email: fundraising@imnda.ie
Freefone: 1800 403 403

Thank you for your support and co-operation.

IMNDA Bank Account details:
'Motor Neurone Disease Association'
AIB, Capel Street
Sort Code: 93-13-14 **Acc No.** 07725002
IBAN: IE32 AIBK 9313 1407 7250 02
BIC/SWIFT: AIBKIE2D

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Motor
Neurone
Disease
Association

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Freefone: 1800 403 403
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DRINK TEA FOR MND
JUNE 21

Helping others.
It's everyone's cup of tea.

IRISH MOTOR NEURONE DISEASE ASSOCIATION

This June Join us for Tea and help people with MND.

> You can help people and families living with Motor Neurone Disease, simply by putting the kettle on!

Ger Tracey, living with MND

See imnda.ie for how you can get involved!

It will be the most valuable cup of tea you will make this year

Irish
Motor
Neurone
Disease
Association

Freefone **1800 403 403**
Email **fundraising@imnda.ie**

www.imnda.ie

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