Irish
Motor
Neurone
Disease
Association

CONNECT

ISSUE 25 | AUTUMN 2022

Climb with Charlie

The Latest news, views and
information from IMNDA

CONTENTS

NEWS & RESEARCH

LIVING WITH MND

FUNDRAISING

EDITORS DESK

IMNDA DIARY DATES

7TH – 8TH OCTOBER:

IMNDA AGM Conference & Weekend

20TH OCTOBER:

Art Exhibition in The Richmond Centre Dublin 7

NOVEMBER – DECEMBER:

Light up a Star on our Christmas Memory Tree

CHRISTMAS:

IMNDA Christmas Cards & Decorations for sale

FEBRUARY:

Voice4MND – Lose your voice so others can be heard

FOR MORE SEE IMNDA.IE

A NOTE FROM OUR CEO

Welcome to the Autumn edition of our Newsletter – Connect and I hope that everyone has enjoyed what has turned out to be a lovely summer with plenty of sunshine and heat.

We have had a very busy number of months here at IMNDA. I hope you enjoy reading our Newsletter which gives you an overview of our activities and developments as we grow and develop as an organisation in ensuring that we provide better and improved services for our clients, their carers and families as they navigate a very difficult period of their lives.

We started the year with Charlie Bird's very honest and moving account on TV of his diagnosis of MND. Determined to make a difference and "reach out the hand of friendship" to those facing extreme difficulty in their lives as a result of physical and mental challenges, he decided to climb Croagh Patrick on April 2nd as a means of raising funds for IMNDA and Pieta. What started out as a personal ambition grew to such proportions that saw thousands of men, women and children do their climb all over the country and beyond. To those who took part in this initiative we are eternally grateful. We were simply overwhelmed at the level of support shown by individuals, families, schools, colleges, workplace groups – all efforts which culminated in a staggering €1.6million for IMNDA with a similar amount shared with Pieta, our partner with the initiative.

On behalf of our clients and their families we want to thank Charlie for all his efforts over the last six months. His efforts will be reflected in an increased public awareness of MND for a long time. In keeping with Charlie and Claire's strong desire to leave a lasting legacy we have begun the process of consultation with our clients and their families in assessing how best to use these funds in a meaningful way. The results of a recent survey will be shared with all our clients over the coming weeks.

Following a review of our Association in 2021 and mindful of the need to provide the highest level of support to our regional nurses we made a significant appointment in June last. We welcome Naomi Fitzgibbon to the role of Director of Nursing and Patient Services and Naomi's role will be to provide that level of leadership and support to our nurses who largely work independently across the country supporting our clients and families. Naomi's first task is to look how effective our coverage of nursing support is and look at ways of enhancing our services nationally. With the support of an extremely generous donation from the J P McManus Foundation, we are in a position to appoint an additional nurse working in the regions and increasing our compliment of nurses to five regionally.

We had the privilege of meeting with many of you over the last few months. Our memorial service held at the O'Reilly Hall in April was so very well attended and we hope provided an opportunity for family members to remember their loved ones in a collective way. We met many of our families again at the launch of our "Living with MND" book launch which was edited by Dr Marie Murray and we hope will be a guide to families and healthcare professionals working in the area of MND with patients.

In good IMNDA style we "lit" Dublin city up in green for Global Awareness Day on June 21st last and welcomed many clients and researchers to our Global Awareness event at the Davenport Hotel. This day marks the summer solstice and is seen by many as a turning point in the year and a season hope. We welcomed speakers from Trinity College, Dublin, who shared updates and news on the research front as we all look to the future with hope and optimism for a cure and improved treatments for our MND community.

Throughout the year, we have been so appreciative to all those who undertook fundraising events on our behalf at community level. We have simply been "bowled over" by both the level of support and indeed, the success of all of these events. All monies raised go directly to support our clients through our services and it is a testament to these local fundraisers who have simply excelled with their achievements this year. Well done one and all!!!

As we move to the last quarter of 2022, we look forward to meeting many of you in person at our Annual Conference to be held at the Charleville Hotel, Cork on October 7th next. The first in-person event since 2019 we have an interesting agenda for you for the day and we will be introducing you to our newest Board and staff members who are looking forward to being part of this event. Sadly, we will be saying goodbye to our Chairman, Dr Declan MacDaid who is resigning from IMNDA after nine years at the helm as Chairman.

I'm sure we will have the chance to congratulate Declan on his long tenure as he hands the "baton" over to the new incoming Chair, Jonathan Healy for the next number of years.

I look forward to meeting you in Cork in October and to those can't attend my very best wishes to you.

Lillian McGovern
Chief Executive Officer

ANNUAL CONFERENCE 2022

We are holding our Annual Conference 2022 on Friday 7th October at the Charleville Park Hotel, Charleville, Co. Cork at 11am and we have a variety of speakers so far;

- Dr Sile Carney - How will MND affect my family (supporting young people when there is a diagnosis in the family.)
- Chef Niamh Condon, Dining with Dignity (making modified diet appetising)
- Nick Goldup, Director of Care Improvement at MND Association and Richard Cave, Senior Speech and Language Therapist, MND Association, will do a virtual presentation on "I will always be me" project

We are delighted to be back having an in-person event. Although, if you are unable to be with us in person you can join us virtually for the AGM and conference. We will have further details on joining the virtual meeting closer to the time. If you would like to get in touch and express your interest, please drop us an email at info@imnda.ie

MND RESEARCH UPDATES, ACADEMIC UNIT OF NEUROLOGY, TCD: SEPTEMBER 2022

PRECISION ALS

The Irish Motor Neuron Disease Research Group, based at Trinity College Dublin and Beaumont Hospital, is leading on a new initiative called PRECISION-ALS. This is an academic /industry research collaboration between the European ALS Consortium TRICALS (Treatment Initiative to Cure ALS (www.Tricals.org) and two Science Foundation Ireland Research Centres, FutureNeuro and ADAPT.

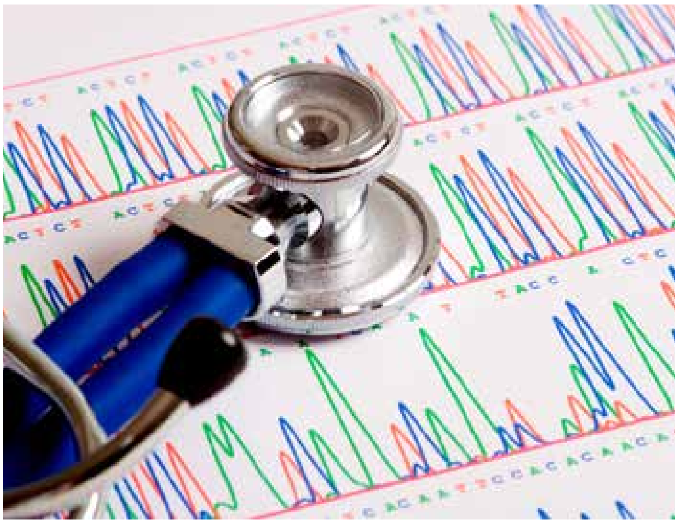
The leader of the project is Prof.Hardiman, Consultant Neurologist and lead clinician at the MND Centre at Beaumont Hospital and Professor of Neurology at Trinity College Dublin. Prof. Hardiman is also Co-Chair of TRICALS along with Prof.van den Berg from University Medical Centre, Utrecht. TRICALS is the world's largest network of specialist Clinical ALS Centres and the largest European research initiative focused on finding a cure for MND.

The TRICALS members have worked collaboratively over the past 15 years to collect and share multimodal data, (i.e., lots of different types of data), pertaining to patients, their treatment, and their care. Prof. Hardiman and her colleagues in Beaumont Hospital and Trinity College Dublin, along with other TRICALS members also manage the treatment and care of ALS patients in Europe and have developed Registers for ALS/MND. The Irish population-based Register for ALS/MND in Ireland has been in continuous operation since 1995 and has helped to pave the way towards new and better treatments.

However, to effect a true precision medicine approach towards ALS, TRICALS recognizes the need to prospectively collect assimilate and analyse multi-modal data from everybody with ALS/MND. This forms a core aspect of the TRICALS Roadmap to better treatments. Indeed, finding new treatments for ALS/MND is the key objective for clinicians, researchers, patients and families alike. Despite a lot of success in laboratory studies, new therapies that work in animal often fail to work as patient treatments due to the complexity of the human neurological system, and the heterogeneity of human disease. Heterogeneity refers to the diversity of different presentations of the same disease in different people.

To find better treatments, we first need to find better ways to understand how to subcategorize ALS/MND into meaningful patient subgroups, so that new treatments can be targeted to specific forms of the condition. As this is a rare disease, researchers will work cooperatively to better understand the disease and develop treatments. To achieve this, PRECISION ALS will develop a new and customised European patient data platform that will collect and analyse data from everybody with ALS/MND across 9 European centres. PRECISON ALS will also allow us to understand the impact of ALS/MND on the person's family, and to explore the overall impact of the illness from the person's perspective. This will enable TRICALS researchers and partner companies in PRECISION ALS to develop a precision medicine approach towards new treatments, such that the right drug is developed and provided for the right patient at the right time. It will also allow us to develop a better understanding of the overall impact of the condition on day to day living.

The Precision ALS project kicked off in December 2021 and is due to run for a period of four years to meet its initial objectives. However, the legacy of this project will be a lasting one with much future work building on that of the initial term and further developing the platform to meet the essential needs of the precision medicine approach at the heart of cutting-edge ALS/MND research.



LIGHTHOUSE 2: TRIUMEQ STUDY

While the cause of ALS/MND is unknown in most cases, there is now evidence that in some patients, a virus called human endogenous retrovirus (HERV-K), may become activated and contribute to disease onset. A small study in Australia (LIGHTHOUSE) used an anti-HIV drug with a good safety record (Triumeq) to determine whether it might work in ALS/MND. The study had very promising results that have paved the way for a bigger study (LIGHTHOUSE 2) that is taking place in Europe and Australia. Because Triumeq is already available for HIV, the study is being funded from grants and support from voluntary organizations like the IMNDA, and not by the pharmaceutical industry.

In Ireland, we plan to add LIGHTHOUSE 2 to the range clinical trials that we are currently undertaking at the Clinical Research Centres at Beaumont and St. James Hospitals. Subject to approval from the HPRA and National Research Ethics Committee, we will identify 10-20 patients who are eligible and willing to participate in this exciting study. Consenting patients will be randomized to the treatment vs control groups in a 2:1 ratio and will be followed up for a minimum of two years, with monitoring that limits burden to a minimum. We will explore whether biomarkers (blood, urine and new technologies using EEG) are effective for monitoring disease progression, and we will measure the effect of treatment on quality of life of people with ALS/MND. A treatment benefit from LIGHTHOUSE 2 will revolutionize therapeutic strategies in ALS/MND.

Qualitative Assessment of Patient Journey

To date there has been little worldwide interest in fully mapping, defining, and addressing the impact of disease diagnosis and progression on the patient and caregiver in the context of their social environments, and taking into account interactions with the overall healthcare system in its widest iteration, and with society at large. The personal experiences and the culture in which an illness is experienced are often ignored, although we know that some aspects of illness that could be of great importance to the patient and caregiver experience are sometimes lost, either because they are difficult to measure, or because they are devalued by not falling within the description of what constitutes the "true" disease state. Moreover, impact of the illness on caregivers is rarely assessed as an outcome, notwithstanding the fact that informal caregivers are key elements in health care systems and often are sole support providers when formal services are limited.

While there remains an unmet need for effective therapeutics for ALS and related conditions, it is equally important to understand how best to preserve the wellbeing of patients and caregivers, and there is a shortage of research in this area. As a "spin off" part of PRECISION ALS we will explore the patient journeys we have already collected from the patient and caregiver perspectives, exploring the interaction of patients and their caregivers, and characterizing the impact of disease through a variety of pathways that illustrate how individuals engage with their illness and the health services. The data are configured to enable exploration differing measures of caregiver burden, and user perspectives on the utilization of services within the healthcare system. This in turn will help us to understand the lifestyle and attitudinal factors that are important to people with MND and their families.

GLOBAL DAY

Every year the International Alliance of ALS/MND Associations marks 21st June as the global day of recognition of ALS/MND – a disease that affects people in every country of the globe.

ALS/MND is a global problem. It does not discriminate on the basis of race, ethnicity, socioeconomic status or region. There are people living with ALS/MND all over the world. For every person diagnosed, the impact of the disease will be forever felt by their loved ones.

Alliance members across the world use the hashtag #ALSMNDWithoutBorders on 21st June to raise awareness and funds on Global Day.

The IMNDA supports the international alliance on 21st June every year by promoting the day on social media, on our website as well as mentioning it in our monthly bulletin to our supporters. This year, we also approached the Office of Public Works (OPW) and asked if several historical buildings and monuments could be lit up green on 21st June to mark this day and show recognition to the MND community in our country. Some of these monuments included:

Farmleigh Water Tower Phoenix Park

The Phoenix Monument, Phoenix Park

The Casino at Marino

The Wolfe Tone Monument St. Stephens Green

The Rock of Cashel

This was a small token to raise awareness of MND. If you would like to get involved and help us to make 2023 an even bigger event, please get in touch with the communications team by emailing pr@imnda.ie

PATIENTS ARE WAITING LONGER, DELAYING DIAGNOSIS AND TREATMENT, THEY DESERVE BETTER

Over thirty TDs and Senators attended a briefing on the Patients Deserve Better Campaign organised by the Neurological Alliance of Ireland on Wednesday 15th June.

Oireachtas members heard that there is a shortage of 100 nurse specialists across adult neurology services. The Patients Deserve Better campaign is calling for investment over 5 years to tackle this shortage, starting with funding for up to 20 nurses in the upcoming Budget.

Oireachtas members heard directly from specialist nurses Sinead Jordan and Martina McKenna who highlighted the critical importance of specialist nurses in patient care, as well as the challenges posed by the shortage of 100 nurses leading to a "postcode lottery" and lack of access to a specialist nurse. For example only 21% of people with Parkinson's disease in Ireland have any access to a nurse specialist.

Aoife Kelly, a young Galway student living with epilepsy, spoke of the challenges involved in living day to day with epilepsy and the importance of having access to the information and reassurance provided by a nurse specialist.

Tony Wilkinson, a Parkinson's patient from West Cork, highlighted his experience of accessing a specialist nurse in the UK, a service that was not available when he moved to Ireland.

Professor Orla Hardiman, National Clinical Lead for Neurology, highlighted the ask for specialist nurses as a sensible and cost effective approach which has already been shown to be effective in improving patient outcomes, reducing waiting lists and A & E attendances.

NAI will be following up with individual elected representatives to call for further support for the campaign ask for up to 20 nurses in the upcoming Budget.

The Patients Deserve Better campaign is supported by 15 NAI member organisations. For further information visit www.patientsdeservebetter.ie

30 YEARS OF INTERNATIONAL ALLIANCE

30

INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

This year marks the 30th year of the International Alliance of ALS/MND Associations working towards its vision of A World Free of ALS/MND.

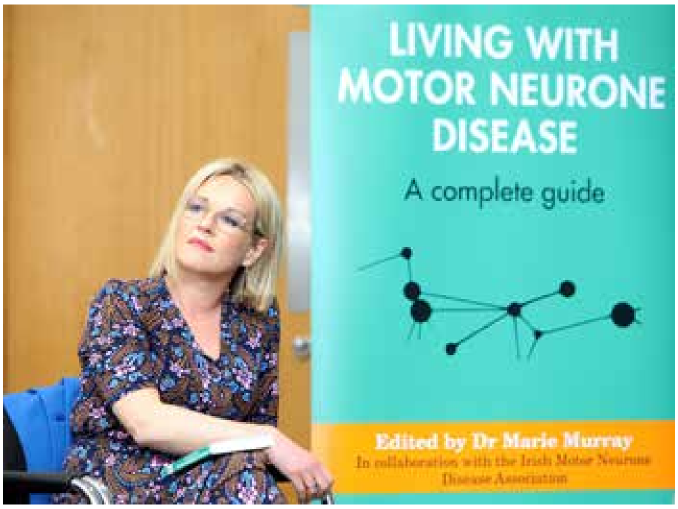
November 4th to 6th, 1992 was the first International Alliance Meeting in Solihull, England. The MND Association's Thumbprint Magazine immediately wrote, "In drawing associations together, the International Alliance of MND/ALS Associations should bring them closer to their ultimate goal: the conquest of MND." That is still our goal today!

The representatives noted in the minutes for this meeting were from "New Zealand, France, Italy, USA, Ireland, Scotland, South Africa, Sweden, Canada, Japan, Switzerland, Denmark, Spain, Uruguay, Croatia, United Kingdom, and Australia." Proudly, all of those associations are still involved with the Alliance today!

We would be remiss if we did not acknowledge the army of volunteers that has helped the Alliance over the past 30 years. THANK YOU to all of the board members, committee members, advisory council members, speakers, donors, and industry partners for your time, effort, and relentless support. A great big THANK YOU also goes to all the people living with ALS/MND who have given their time and resources. We stand today on the foundation all of you have given us.

THE LAUNCH OF LIVING WITH MOTOR NEURONE DISEASE – A COMPLETE GUIDE.

Living with Motor Neurone Disease is the fourth book in the Cork University Press ***MindYourSelf*** book series edited by Clinical Psychologist Dr Marie Murray. The book was formally launched in UCD in April of this year by RTE presenter Claire Byrne.



Speaking at the launch in **University College Dublin, RTE's Claire Byrne** said, "Navigating the path following a life changing diagnosis can be bewildering and exhausting. This wonderful book shines a guiding light on the road ahead with the experts who have walked it- the medics, the caregivers and, perhaps most importantly, those who are living with Motor Neurone Disease. I know this guide will provide some comfort to those who are starting on this road and their families, whose burden will only be eased if we all commit to supporting them."

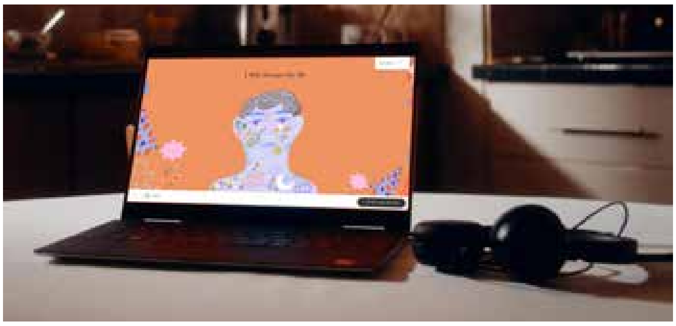
The family of the late Andy Minogue who made a contribution to the book also attended the launch. Andy's family are pictured here with Claire Byrne.

Speaking at the launch **Lillian McGovern CEO, IMNDA** said "We are delighted to have this book available for the families and carers of those with MND. The book provides practical information on managing MND and provides an insight into the many varying and challenging aspects of the illness. We hope that it will also inform healthcare professionals working with families in supporting them through their MND journey."

Speaking at the Launch, **Dr Marie Murray** said "We hope that what emerges from reading this ***MindYourSelf*** book is not how grim MND is but how astonishingly people cope with it; how great the love of families for each other; how concerned are friends, how expert the professionals; how determined the researchers to crack the code, find the cure and blitz it into history. The book is dedicated to all who are living with MND and everyone it has bereaved. Having collaborated with the IMNDA for the past two years on this book there are insufficient superlatives to describe what the IMNDA provides in compassionate practical care - all based on its maxim 'until there is a cure, there is care."

Living with Motor Neurone Disease: A complete guide is available from Cork University Press €14.95 at www.corkuniversitypress.com or from www.imnda.ie Royalties to IMNDA.

NEW DEVELOPMENTS IN VOICE BANKING



We are hugely excited to watch developments taking place in the UK in the area of voice banking. MND UK, along with expert partners, Dell, Intel and Rolls Royce have introduced a method of voice banking using an eBook and which heralds the start of a new chapter in this area. A REVOLUTIONARY new eBook, which has been developed to allow people living with MND to bank their voice as they read the story aloud, has been launched in the UK.

I Will Always Be Me is a short story written by New York Times bestselling author, Jill Twiss, and is written from the perspective of someone living with MND as they explain the condition to their loved ones.

The book, created by these companies involved in the (UK's) MND Association's Next Generation Think Tank, takes less than half an hour to read and is designed to be a shared experience between somebody who is living with MND and their family and friends.

Once the story has been read, the recording is uploaded and transformed into a digital voice by voice banking specialists SpeakUnique, which can then be used with communication devices when it is needed.

The (UK) MND Association will provide funding for people living with MND in England, Wales and Northern Ireland to use the book, thanks to donations from Dell Technologies and Intel. This free service extends to people living with MND in Scotland, with funding provided by MND Scotland.

Yvonne Johnson, who is living with MND, said: "The story in the book was so detailed but in a simplified way. So, by just reading the story my voice was banked immediately.

The story has a beautiful way of explaining the changes that may happen to my mobility while living with this condition, in a way that if I tried to explain it without the book, I would probably break down. Especially with my close loved ones.

The book is an amazing tool which can be used to explain in the most simplified way to both children and adults. Even someone who has never heard of MND, would definitely have a greater understanding of it rather than hearing an explanation from a medical professional."

Michael, who is living with MND, was among a small group of people living with MND who were able to trial the book, and provide feedback.

He said: "When I was diagnosed with MND I decided I can sit back and feel sorry for myself, or I can do something positive to help others. Being involved in I Will Always Be Me was absolutely brilliant – my family was there to support me, and we all had a fun day. I'm hoping this project will lead to a much better understanding and awareness of MND, not just for families and friends, but for the general public as well."

I Will Always Be Me is dedicated to the memory of Brian Moss, who died of MND in 2014. His son Stuart, Head of IT Innovation at Rolls Royce, was compelled to help improve the lives of other people affected by MND and joined forces with the MND Association to help create the Next Generation Think Tank in 2019. Dell Technologies and Intel were among the first to join the Think Tank and have been heavily involved in the development of the book.

The (UK's) MND Association's Director of Care Improvement, Nick Goldup, said: "Voice banking is incredibly important for someone diagnosed with MND, but traditionally it could be extremely time-consuming, laborious and often a very lonely process for the person taking part. We wanted to change that, and so we are incredibly proud that I Will Always Be Me is a completely different experience. People with MND have been at the heart of this project from the very start so it was important for us to develop something that was easy to use, engaging, and offer the opportunity to become a long-lasting, treasured resource. I Will Always Be Me is a brilliant example of how bringing together the Think Tank's expertise and resources can improve the quality of life for people with MND and we can't wait to find other ways to make a real difference."

Lillian McGovern CEO of Irish Motor Neurone Disease Association said "voice banking is so important for our clients with MND. Awareness of this has been heightened over the last number of months with developments in technology here in Ireland and demonstrated by Charie Bird throughout his "Climb with Charlie" campaign. All initiatives in this area are to be hugely welcomed and we will be working to ensure that everyone who needs and wants a voice banking service will have full access to it"

You can find out more about I Will Always Be Me by visiting the website https://iwillalwaysbeme.com/.

NATIONAL MND AWARENESS MONTH OF JUNE & DRINK TEA FOR MND!

June is National Awareness, and this is an opportunity for us to highlight MND and how it effects people. We do this by approaching those who have MND or a family member and ask them if they would be interested in sharing their story to highlight the condition. We started this a number of years ago in response to people telling us that there is not enough awareness out there about the condition.

As well as an awareness campaign it is also a fundraising drive, Drink Tea for MND is the national event that is held in June to raise the necessary funds to provide supports to our people with MND. This year we were delighted to see actual 'in person' tea parties being held. After the last couple of years, the possibilities were endless. And every kettle boiled, and tea made supported someone with MND in Ireland this year!!

Helping us out were our fantastic Drink Tea Ambassadors. They agreed to share their stories on radio on newspaper and on social media to help spread awareness of MND during the month of June, and to encourage people to get involved. These people were Mark Dignam, Margaret Mulvany, Todd Nugent, Andy McGovern, Roy Taylor, and Denis Cagney. A very special thank you to them for sharing their stories and pictures across all the media channels this year.

Here are some of the IMNDA Drink Tea Ambassadors Stories, first up we have Mark Dignam from Offaly.

Mark Dignam – My Journey with MND

It all started so simply. A European city break, good food, long walks and beautiful scenery. On the second day I developed a slight limp in my left leg and cursed the cheap shoes I choose to bring with me. I thought nothing of it and only complained at the end of each day. If I could only have known what was in store for me, I might have done things differently; but such is life and such is the impatient nature of our modern human existence. Over the next two years I fought a losing battle with my left leg, cursing it ever more frequently and wondering why it wasn't getting any better despite elasticated supports and shoe insoles, amongst other things.

In April 2019 something changed. I was boarding an early morning flight to the UK; one of those many occasions where able-bodied people dash across the concrete apron and climb the cold slippery steps. My limp was so pronounced that I was easily the last person to reach the aircraft steps and as I started the climb, I felt the weight of the small suitcase dragging me backwards. Something was wrong. I made it to the cabin and had barely enough strength to lift the suitcase to the overhead bin. I crashed into my seat exhausted, my mind racing ahead with foreboding thoughts; what the hell was happening? That evening, in another anonymous business hotel, I phoned my wife and recounted what had happened. 'Had I had breakfast?', 'No'. 'Was I very tired?', 'Yes, I left the house at 4:30am'. 'When are you going to slow down?'; 'I don't know'. But I was worried.

Looking back now, before my diagnosis in April 2020, I abused my body and never listened to what it was trying to tell me. Between those two April dates, roughly twelve months apart, I was tested and scanned a number of times with no obvious conclusion until finally, on the 4th of April 2020, Professor Hardiman in the Beaumont MND Clinic confirmed the diagnosis. One month after an unprecedented pandemic lockdown, the hospital was almost empty, I was on my own and alone with my thoughts. Mostly, I was flooded with a sense of relief; it had a name; it could be managed; the experts were here, and the back-up and information were available. My parents and grandparents had given me the gift of resilience, a determination that others found unbeatable – this mountain would be climbed one step at a time. My Granny Susan Dignam would say "Never let anything best you".

And so, in the depths of a worldwide crisis, I faced my own personal challenge. A new challenge – perhaps the biggest of my life to date. The enormity of what I faced was too big to contemplate – it could only be bitten off in pieces. But how to tell loved ones and friends when a 2km circle from your house was the known world for months on end? How to explain to friends and colleagues over the phone, when the world was troubled enough, and people were losing their jobs every day? Initially, I chose to tell a very small group of immediate family and sought out a therapist to start to put order on what was happening. The IMNDA paid for the therapy and laid out a network of immediate support that all of my fellow sufferers rely on every single day.

When people ask me what the disease is like, I say it's intrusive – it intrudes on almost every aspect of your life. And just when you think you have managed a symptom or restriction, it intrudes again. Even though the symptoms of MND are very individual, it's this intrusion that is common, very personal and debilitating. I have learned to be so grateful for the independence I have retained and the parts of me yet untouched by the disease; my mind, my voice and my sense of humour.

Slowly but surely the mountain will be climbed, one foot in front of the other. An ankle splint and walking stick have been replaced by a walker and more recently, a powered wheelchair for longer distances. Through working from home, I proved myself to be just as effective in my job as before and have never missed more than a day or two of work here and there. In fact, the new perspective granted by this awful condition, I believe has made me a better father, husband, manager and colleague. And each time I reached a barrier, or this disease punches me again, I find a solution, a friend who knows, a gadget to buy or an expert who knows why. Two years after my diagnosis, the fact that I have made it this far, that life goes on and continues to be so worthwhile, gives me all the strength and determination I need.

Next, we have Margaret Mulvany…

Margaret Mulvany is from Galway and lives with her husband Liam. She was diagnosed with MND in January 2022, this is her story…

My journey to Motor Neurone diagnosis. All my life I walked everywhere. I loved to walk and walked in excess of 5 miles a day. I have always kept fit, with a healthy diet.

In November 2019, I tripped while out walking and just scraped my hands and my knees. I thought that I had tripped over something but didn't see anything. There was nothing obvious to concern me.

Then in February 2020, I started to trip over my left foot. It was as if my foot did not bend to lift. I was dragging my foot and really had to concentrate to lift it.

I booked an appointment with the GP and he referred me for a lower back scan. Nothing showed up on the scan and all appeared normal.

I began to think it was footwear causing the problem and began searching for the perfect pair of shoes or trainers to stop the foot tripping. However, nothing worked. I went back to my GP after a number of months and he examined the foot and could not see what was wrong. He referred me to a podiatrist. The Podiatrist immediately noticed it was not the foot and suggested a neurologist should look.

I carried on trying to walk although I became very unsteady on my legs. I used a stick and often walked holding onto garden walls along the street. I was determined to keep walking to my beloved abbey each day where I like to sit in the peaceful grotto. I did not want to let go of my independence.

Once the pandemic lockdown came into force in 2020, there was no opportunity to see any specialist. Unfortunately, at the same time, my second eldest daughter Elizabeth, age 41 years old was diagnosed with terminal cancer, completely unexpectedly. I was devastated but determined to be there as a support for my daughter as she battled through her last months at home with her four young children.

My condition got progressively worse quickly, but I wanted to focus all my attention on Elizabeth. Over the months leading to her death, I became less able to walk.

After Liz died, I was encouraged by my family to go back to the doctor. On this occasion, I was referred to a spinal surgeon. I had some decompression on the spine due to an old injury and my arms were affected. The surgeon could not identify if the decompression was the cause of the leg dragging.

He also sent me to a neurologist that did every test he could to see if there was a neurological issue but both my reflexes and strength were good. My symptoms baffled the neurologist.

In March 2021, I underwent a major spinal surgery. Although the surgery did rectify the issues with my neck, and arms, my legs continued to get worse. I also noticed my breathing sometimes was difficult. By now, both my legs were dragging and I could no longer stand unaided. Very fine motors skills such as closing a button or an earring became impossible.

Every week I had sessions with the physio who was also baffled by my condition as she could see that I had good strength and normal reflexes but could not explain why my legs were dragging.

I had physio for 5 weeks and, but the physio could see that although I did, my exercises religiously, I was in fact deteriorating. She suggested that I go back to the consultant.

I carried on with a private physio but after 4 sessions, she urged me to go back to the doctor. I went back to my GP who again referred me to the neurologist.

On 12th December 2021, the doctor decided to admit me for a series of tests that took five days, and he was able to establish in January 2022 that it was indeed Motor Neurone Disease.

All told, it took 3 years to reach my diagnosis. I was so relieved to finally have a diagnosis as I had been pushing myself so hard, thinking if I could keep walking that my ability to walk would somehow return. I felt I was losing my mind and my faith was the only thing that kept me going.

The relief to know what was actually going on was profound and I was able to accept my diagnosis and, in the acceptance, found some peace.

I have been adjusting and adapting well to a new way of living. The support I have received from Irish Motor Neurone Disease Association has been overwhelming and helped me greatly. Only for them, I felt trapped. Johanna was my first port of call on the phone and was able to reassure immediately. Fidelma, MND nurse specialist, came to the house to reassure us that there was support available. She also was able to explain so much about the condition and to reassure me that I was not doing anything wrong.

Community Nurse Dolores, Community Occupational Therapists Colm and Esther have all been remarkable in their support.

Alana my carer understood how difficult it was for me to hand over my independence and in particular helping with personal hygiene was very difficult but she made it easy and I am grateful such services are available to me.

My husband Liam has been an amazing support and really stepped into the breach. He is doing most of the day-to-day chores including all the cooking, keeps the house tidy and helps me to bed. I appreciate everything he does for me. I want to take this opportunity to especially thank Liam for all that he is doing for me.

My children have been a huge support and my neighbours too, especially my neighbour Ann. Everyone has rallied round.

Because this disease is so rare it is often misdiagnosed, or GPs simply have never come across it. I urge anyone that has concerns about their limbs not working how they used to but not experiencing pain should request to be referred to a neurologist and to keep going back until you have a diagnosis.

"The relief to know what was actually going on was profound and I was able to accept my diagnosis and, in the acceptance, found some peace."

Now we have Denis Cagney from Dublin, and this is his story of Motor Neurone Disease.

"I was diagnosed with MND in April 2020. I was 67 and living a very active life, running, golfing, cycling, and doing some part-time consultancy. My wife Margaret and I were retired, and life was great. But I had a little weakness in my left thumb, and I'd had a few falls when running so I went to get checked out.

The diagnosis floored me. I had to walk around the hospital grounds before going home to break the news to the family. You can imagine the impact on us all.

Three days later I had my first emotional meltdown. I was listening to Brendan O'Connor in the car when he played Mary Hopkin singing "Those were the Days my Friend" for some reason the tears welled up and I had to pull in immediately. For fifteen minutes I cried. Then I pulled myself together and got on with my day.

That has been the general pattern ever since. Most of the time I am strong and resilient but every so often I get very emotional. Margaret is a great help when this happens.

Mercifully my speech, breathing, interest in life and sense of humour are fine. I still enjoy life very much.

At a physical level the MND is more in the nature of frustration and restriction rather than pain. Two factors help me enormously, firstly the love and support from Margaret and the children Donagh, Neil and Anna and the active support of my two brothers and close friends. The impact on the family helps me keep a sense of balance. I'm not the only show in town!

Secondly the support services from IMNDA, the Beaumont hospital team, the HSE district staff (alias the Three Graces) and the stalwart carers have all been wonderful especially in easing me through the various milestones for example from walking stick to rollator to wheelchair. I'm very proud of all the professionals who work so hard to help.

Professor Hardiman urged me at my first consultation to try to take each day as it comes. Then she smiled and said this was harder to do in practice than in theory but was still worth doing. How right she was on both counts.

I still actively enjoy life. My brothers and I take frequent jaunts to the beach and nearby parks to enjoy nature. My long-time buddies call regularly to shoot the breeze, slag each other and resolve the world's problems! I'm still playing Bridge with Margaret. This can be a bigger challenge to a marriage than MND! My family come home frequently and I'm looking forward to seeing them all especially my little granddaughter Sienna."

Thanks to our ambassadors who shared their story of MND for June National Awareness and also for Drink Tea for MND campaign and thanks to all of you who raised funds for the Association.

ALAN JOHNSON'S STORY OF MND

During the year Alan Johnson who was diagnosed with MND approached us and told us he would like to tell the MND community about his story. He lives with his wife Mary in Glasnevin. He is 59 years old and works as a civil servant. In November 2019, after experiencing some issues with his swallow and voice, Alan was diagnosed with MND. These are his words.....

"I am slow to do things these days and everything takes so much longer to do now. My voice has been deteriorating for a long time now. Last year, when holidaying in Kerry, I went to a takeaway in Killarney. It was the time when restrictions had just eased and there were lots of people around, a lot were drinking. There was a man sitting on the floor drunk in the takeaway. I ordered a 44 with rice, the man taking my order did not understand me, all I had to say was the number of the dish with rice, I think he thought I was drunk and would not take my order, worse yet he gestured for me to leave the premises, it was a very unpleasant event for me. I went back again with my wife, she explained my circumstances, the man did not say sorry.

My next story is of the Good Samaritan. When I go to Beaumont Hospital for appointments I always park outside the hospital, I have a ten-minute walk to the hospital. On one occasion this year, it was very stormy, the wind was very strong, I can be a bit unsteady on my feet, especially after sitting down for a while. A man coming out of his house observed me and asked where I was going, I told him, he insisted on giving me a lift, he would not take "No" for an answer, he drove me to the hospital. When I got out of the car, he held on to me and called an orderly to bring me in to the hospital. I was put into a wheelchair and wheeled into the lobby, only then was I released from the chair. I felt as though I have been abducted, I had no choice but to go along, I was powerless to do otherwise. The gentleman was very good to do what he did, he even came out to me when I went to get back in my car 2/3 hours later, he had a chat with me, it was one sided as he found it difficult to understand me. I had to go from one building to another that day for two different appointments. I was blown against a wall when going to my second appointment. I don't know what might have happened to me in the open area on the walk to the hospital, if the kind man had not driven me to the hospital, I would probably have been blown away, lucky for me he could not understand me.

Sometimes when people don't understand me, they say nothing in response, other times they guess what I said or talk about something else altogether. I find this very annoying; I know they cannot understand me, but they will not admit same. I much prefer it when someone says they can't understand me, it is the right thing to do, but I guess people do not want to offend me by saying they don't understand a word I am saying. When my voice is bad, I can repeat myself over and over again and still not be understood. It is very, very frustrating.

When diagnosed with MND I purposely did no research on it, I did not want to know what was ahead for me, I would just let it take its course. There is no cure, so I decided to change nothing in my life, I would carry on as normal. Bit by bit things deteriorated. I still go to work, train 6 days a week, run and do pretty much everything I did as a man. I recently tried to enter a kickboxing tournament run by friends of mine on the NGB of Kickboxing Ireland for which I was the National Treasurer for many years up to a couple of years ago. I was refused entry, instead they let me spar a friend at the competition. I received an email from a coach at the event, I was happy reading it in the knowledge that me fighting MND in my way inspired a fighter on that day. Whether it was my speech or my sorry display on the floor. Maybe it might give others with this disease a push in the right direction, if I can do things approaching my 1,000th day, there is no reason why others like me can't do things that someone might feel inappropriate. If anyone is interested in taking up kickboxing, if only for the different exercises we do, my club is based in Chanel College in Coolock Village. I can give further details if required.

I have never met anyone with MND, presumably people at the clinic in Beaumont have it, but I never spoke to anyone who has it. Charlie Bird is the only person I know of who has it. I climbed Croagh Patrick on Sunday 31st July with my two brothers, sister and 3 of their sons. My family thought Croagh Patrick was a great success, they never thought I would get as far as I did, I wanted to get to the top or at the very least to the steps at the summit, that was my goal but I didn't manage to achieve it, I won't dwell on it, I got to spend the weekend with the family and we all worked hard to get me as far as I went up the mountain, so all in all it was a good weekend.

Life is for living, I believe people like me should try to live their life as they did before MND, people should not tell us what we should or should not do. Sitting at home waiting to die is not for me. If pushing myself all the time cuts my life short, happy days, I will be living for as long as I am around, not hiding at home feeling sorry for myself."

> **"I still go to work, train 6 days a week, run and do pretty much everything I did as a man. I recently tried to enter a kickboxing tournament run by friends of mine on the NGB of Kickboxing Ireland for which I was the National Treasurer for many years…"**

Living Well

BUILDING BETTER CAREGIVERS

Are you a caregiver?

Building Better Caregivers: classes are highly participatory, where mutual support and success build the participants' confidence in their ability to manage their caregiving tasks and maintain a fulfilling life.


Building Better Caregivers

What is the Living Well Building Better Caregivers programme?

Living Well is a free online group programme, delivered over seven workshops via WebEx (1.5hrs x 1 introduction & 2.5hrs x 6). This is a self-management programme is for caregivers with the aim of improving your quality of life to better manage your daily health. Living Well can help you develop the skills and confidence to manage your health condition(s). It is delivered by two trained leaders, one or both of whom are peers who are or have been family caregivers.

Workshop Topics

Skills that may lead to stress reduction for caregiver and their care partner.

Topics include:

- Self-care methods to improve caregiver's health
- Dealing with difficult emotions
- Managing difficult care partner behaviours
- Planning for the future
- Finding resources
- Improving communication skills with family and friends
- Family meetings
- Communicating with health professionals and health care system
- Action-planning, problem-solving, decision-making and much more

Why join the Living Well programme?

People who are supported in this way increase their knowledge, skills and confidence to better manage their health in partnership with their health care provider.

How: For more information or to register, contact the Living Well Coordinator Leah Harrington: **0873654392** or Email: **leah.harrington@hse.ie**

When:

Starting on Thursday October 27th – December 8th from 7.00pm – 9.30pm for 7 weeks

Self-management Support

hi Healthy Ireland

SMRC Self-Management Resource Center

Sláintecare.

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

This is an SMRC Evidence Based Self-Management Programme originally developed at Stanford University. This project has received funding from the Government of Ireland's Slaintecare Integration Fund 2019 under grant agreements numbers 38, 78,185, 219, 413, 418.

PSYCHOLOGICAL SUPPORT AND MND

Dr Annette Lloyd is a Senior Clinical Psychologist in Beaumont Hospital working with Motor Neurone Disease patients. She has specialist training in Cognitive Behavioural Therapy, Compassion Focussed Therapy, Dialectical Behavioural Therapy, Acceptance and Commitment Therapy and Eye Movement Desensitization Reprocessing Therapy. Annette works as part of a multi-disciplinary team across in-patients and out-patients and explains the support available to individuals and their families.

A diagnosis of Motor Neuron Disease is life altering for the individual, their family and loved ones. It brings with it a huge amount of change both physically, emotionally and psychologically that individuals and their families are faced with managing. Working within the MND team in Beaumont Hospital over the last year, I have learnt a significant amount from individuals with MND and their family members about their experiences of how they navigate this journey. Everyone's experience is individual and there is no one way to adapt or cope to this diagnosis. There is a wide range of normal emotions that people experience before and after diagnosis including uncertainty, grief/sadness, anxiety, stress, guilt and anger amongst others. I have also been humbled by individuals' experiences of how they cope, their incredible resilience and the love, hope, compassion, positivity, and flexibility they demonstrate in a time of significant change and uncertainty.

For many the immediate focus for individuals will be supporting their physical needs and ensuring the appropriate supports are in place. Several individuals and families I have worked with speak of how busy the initial few weeks post diagnosis are and often they do not have much time to process what has occurred. Once this period has settled it is important to also prioritise our psychological well-being, which has a key role in helping individuals to adjust and manage MND. For many this will be naturally supported through the people and activities/interests in your life.

Within the MND clinic in Beaumont we also have a range of psychological supports available through clinical psychology, for those who feel they may require additional support. The main interventions offered are talking therapies which provide a confidential space to talk about your experience of MND, make sense of this and learn coping strategies to manage the impact of this on your life. This may include having a space to discuss changes in your sense of self, reduced independence, guilt and shame and concerns about death and the future. It is a flexible space offered to meet the needs of a wide range of people across the country and can be provided face to face in Beaumont Hospital or from home virtually through our online platform.

Some of the therapies offered include Cognitive and Behavioural Therapy, Acceptance and Commitment Therapy and Mindfulness, amongst others. These therapies have been shown to be beneficial for individuals experiencing anxiety, depression, stress and high levels of distress. A primary focus of psychological support is to help individuals continue to connect to their values and interests in life and maintain a good quality of life.

In addition, clinical psychology offers support to individuals and their families who are experiencing changes to their thinking and behaviour. We offer neuropsychological testing to assess individuals' cognition if there are concerns that this may be affected. Within our team psychology and medical social work run a monthly cognitive behavioural clinic which offers support for loved ones and family members who are supporting individuals with MND experiencing cognitive and/or behavioural changes. The aim of this clinic is to provide psychoeducation about the types of cognitive/behavioural changes that individuals with MND may experience and suggestions for any management strategies that may help. In addition, we aim to link/signpost caregivers and families to supports in the community to help them care for their loved ones and access practical and emotional supports.

If you feel that you may require psychological support or are interested in learning more about the supports available, please discuss this with a member of our MND team including myself or your IMNDA nurse, who will be able to make a referral to psychology on your behalf.

For anyone struggling- know that you are not alone and that often your experiences are shared by others going through this journey. I look forward to working with more individuals with MND and their families and developing further psychological supports to offer in the near future!

DINING WITH DIGNITY – HELP FROM THE DYSPHAGIA CHEF

Niamh Condon is a Dysphagia Chef since 2018, she set up Dining with Dignity in 2019 to provide catering & consultancy training in the healthcare sector. 'Dining with Dignity' has taken its name from witnessing the dining experience and seeing the need for change. She is here to provide tips and advice on regular food and how it can be modified safely…

Have you been told that you can't have regular food? Do you understand why? Do you understand the level that you have been told to follow for food & drinks? Do you know how to safely modify your food?

Some of these questions are very familiar to some and can be very frustrating when you don't know how to achieve the correct & nutritious food consistency for a safe swallow.

So what is Dysphagia?

Dysphagia is a medical term used to describe a swallowing disorder! It impacts on how safely a person can eat or drink It is categorized by having a difficulty in chewing and moistening foods in the mouth, or in moving food from the mouth to the stomach. Weakness of the mouth and the throat muscles can occur in dysphagia and may result in food or drinks going down the wrong way. This means that the food or drinks go into the lungs instead of the stomach this can cause chest infections and pneumonia.

What is IDDSI?

IDDSI is an international collaboration of professionals who developed a standardized framework for labelling texture-modified foods and thickened liquids. The framework is designed to avoid the confusion created by variable terminology and definitions to describe modified diets around the world. So, no matter where you are in the world the same descriptor will be used to label your modified diet and it will avoid confusion and make dysphagia foods safer for those who need them.

https://www.iddsi.org/

© The International Dysphagia Diet Standardisation Initiative 2019 @ https://iddsi.org/framework/
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Why do we need to thicken drinks?

Thickened liquids may be recommended to compensate for reduced safety of efficiency of swallow.

Thickened liquids may:

- Slow down the rate at which the liquid moves in the mouth
- Allow the person to be able to control the liquid in their mouth
- Prevent the liquid from entering the lungs

Food

When it comes to preparing food for somebody with a swallowing difficulty, the first point of reference is the IDDSI level that was recommended by the Speech & Language therapist. Once we know this, we know our limitations.

There are 5 levels within the food descriptors and each of these levels have different requirements.

Level 7 ~ regular which means most of the everyday foods like steak, crisps, bread cakes etc with no restrictions

Level 7 ~ Easy to Chew which simply means anything that you can easily break with the side of a fork. For example, a piece of fish, most vegetables & potatoes but not foods that are fibrous, tough, or chewy.

Level 6 Soft & Bite sized ~ is size restricted! 15mm for an adult and 8mm for a child. It is also texture dependant where the food should be easily broken with a fork when pressed and not return to its original shape. This level is not permitted bread or cakes unless a speech & language therapist signs off, in a swallow care plan.

Level 5 Minced & Moist ~ is also size restricted! 4mm for an adult and 2mm for a child. The most universal tool to measure this is a standard dinner fork. The gaps between the prongs of the fork are 4mm apart and each particle must pass through the prongs of the fork to meet the IDDSI requirements. This is called the fork test.

It must also pass another test where the food that is minced must fall off the spoon in one lump and not leave a sticky residue. It must not flow off the spoon or sprinkle from the spoon.

Level 4 Puree ~ The food must be blended in a mechanical blender to achieve this consistency. The test associated with this level is the fork & spoon test. The fork test is where the food will sit on a mound above the fork and a tail will drip below the fork. The spoon test is also used to determine whether the food is sticky or not. Both tests need to be passed in order to be a safe level 4 food item.

Level 3 Liquidised ~ Food is blended in a mechanical blender with liquid and cannot be eaten with a fork. It will flow from a spoon and can also be eaten with a wide bored straw.

While preparing any food for somebody with dysphagia a point to note would be the quality of the ingredients that are used. Certain cuts of meats will pass the IDDSI testing methods better than others, for example the cheaper cuts like Chuck, shin & brisket. Fish will also be easier to pass these tests.

Cooking foods slow and low will achieve the perfect texture for the IDDSI levels. From level 7 easy to chew to Level 3 liquidised. From my experience, cutting the meats up into small pieces in a raw state and cooking slowly in a braising liquid will achieve better results faster.

Roasting foods will dry them out and risk creating a crusty exterior that is not safe for swallowing difficulties. However, keeping the juices from a roasting tin to add to a blender if you need to puree or liquidise a meal is the perfect solution to intensify the flavour.

For level 6, yes, it is size dependant but, it is difficult to understand the importance of the correct texture. Think about cooking a carrot. If you cook the carrot so that it is soft enough to mash with a fork with minimal effort, this is the texture that we are looking for across the full meal. From meat/fish to vegetables to potatoes. My advice is to cut all the food in its raw state to the correct size (15mm) and slowly cook the meats in advance, then cook the vegetables ensuring that all items pass the texture test (fork test), where they break easily with a fork and not return to its original shape. Because most people that have a swallowing difficulty have issues with dry mouth, it is a good idea to serve the meal with a thick sauce or puree. This will achieve two things; it will help with the chewing process and move the food easier in the mouth and it will also help keep the food hot

Vegetable pasta with Chickpeas

Quinoa, butternut squash beetroot and feta salad

Both Meals are level 6

For level 5 meals you can take the individual elements of a meal and place them in a food processor and pulse it until you achieve a minced consistency. This is not the same as purchasing minced meat from the butcher. If you purchase minced meat from the butcher, you will still need to pulse it in a blender to achieve the size particle to meet the IDDSI guidelines. So, for the meat, place it in the blender without the sauce or liquid and pulse it until the required size is achieved (4mm adult 2mm child). Once this is complete you can then stir the sauce into the minced meat to create the moist element of the food. If you were to add the sauce at the start with the meat in the blender, then you will get a more pureed food.

Level 5 Fish pie

The vegetables will be the same where you can pulse them first and then decide if they need more moisture. Bear in mind that every vegetable will be different and may or may not need something added to achieve the moisture element of the food.

Shakshuka Eggs

Level 5 Guinness & Beef Stew

To achieve level 4 puree, one must keep in mind that when blending foods the nutritional components of the meal. We do not want to dilute the nutritional value of the meals.

Place the items separately into the blender and turn it on full power, add stock or sauce to achieve the correct consistency. Check the consistency each time you add some liquid by testing with the fork and spoon.

Level 4 carrot

Spoon test

Level 4 fork test
Mound above the fork and a tail below the fork

Samples of piping different vegetables

Avoid blending sweetcorn and celery as you will find it difficult to achieve a smooth consistency. Once blended and tested with the fork and spoon, pass the puree through a sieve to ensure that there are no lumps or fibrous pieces left as this can pose a choking hazard.

Level 4 beef casserole

Always blend the food at the temperature that you intend the person to eat it. So if it is a hot dinner then the food will need to be blended hot and if it is a salad then the food will need to be cold prior to blending. This is because food behaves differently at cooler temperatures. For example, picture lovely hot fluffy mashed potatoes and then let them cool, they become very stiff and solid, so what is perfect at hotter temperatures needs to be altered again if left cool.

Do not try to blend potatoes as they will become sticky and inedible.

Best method for mashed potatoes:

- Slice potatoes 1cm (do not ¼ them as the corners will cook first and leave you with a soggy mess)
- Place into a pot with some cold water and boil
- Cover and simmer for approx. 10 min

Place sieve over a bowl and get a slotted spoon to remove the cooked slices of potatoes and put directly into the sieve. The now soft potatoes will pass through the sieve quite easily without effort and you will have smooth potatoes without lumps. To achieve the correct consistency, add hot milk/cream and butter to the sieved potatoes and stir through. The less work that you do with potatoes the better.

When cooking for level 3 meals, it can be a one pot wonder. If using meats in these meals, they can be cooked first in the pot and then add the vegetables to finish off the cooking. Try not to add too much stock/liquid in the cooking as again this will water down the nutrients. Try to incorporate as much protein and calories as you can as this is somebody's meal. Using lentils, chickpeas, beans, peas, meats & skimmed milk powder can help you achieve a good quality meal.

These meals will flow from a spoon and cannot be eaten with a fork.

Using cream or coconut milk to thin the meal can add some extra calories where needed.

It is imperative that these meals are sieved to avoid any fibrous pieces that can be left after blending.

Think layering flavours as we cannot pipe this level.

Top tips:

- Chose the right cut of meat
- Have a high-speed blender
- Handheld stick blender
- Sieve
- Think Temperature
- Think food safety
- Taste everything that you cook
- Be mindful of presentation
- Fork & Spoon
- www.iddsi.org
- Speak to Speech & Language therapist
- Speak with a dietitian
- Be patient

CLIMB WITH CHARLIE…

It all began on the Late Late Show in October 2021 when Charlie Bird announced that he had Motor Neurone Disease (MND) … an idea was put out there about climbing Croagh Patrick as Charlie loves hill walking and he walks quite regularly with his wife Claire and his friends. It was decided on this evening that plans would be put in place to do an event to raise funds and awareness for 2 charities.

After Christmas Charlie appeared again on The Late Late Show with the grand plan of #ClimbwithCharlie and so began the campaign, a challenge to climb Croagh Patrick on 2nd April 2022. Charlie announced he would climb the reek with family and friends, and he encouraged people from all over Ireland to climb their own mountain locally for people with a terminal illnesses and mental health issues.

Charlie said he wanted to do it for 2 charities close to his heart, The Irish Motor Neurone Disease Association (IMNDA) and Pieta House. He chose MND as he himself had been diagnosed with it and Pieta House as this was a charity he had supported for many years.

Lots of well-known people joined the campaign, from Daniel O'Donnell, Imelda May, Dermot Bannon, Bas Ashmawy, Damien Dempsey, Paddy Moloney, Carl Henry and Johanna Donnelly to name but a few. Bono and U2 donated a song to the campaign and Michael English penned another beautiful song along with a family member from the MND community. Dunnes Stores also got involved with the campaign and dedicated the whole weekend of donations at the till by their customers to the Climb with Charlie campaign.

Exclusive new track from Bono in support of #climbwithcharlie tune into @instatubridy in the morning

With the on-going press about the event from January to April, the whole country was brought along on the journey with Charlie, his wife Claire & Tiger the dog! They visited schools up and down the country and songs were sang, dances were danced, instruments were played and Charlie, Claire & Tiger were met with a warm welcome from everyone.


CROAGH PATRIC
IRELAND'S HOLY MOUNTAIN
CRUACH PHÁDR
SLIABH NAOFA NA hÉIREANN


In memory of Brian
2nd April 2022
In memory of Brian
2nd April 2022

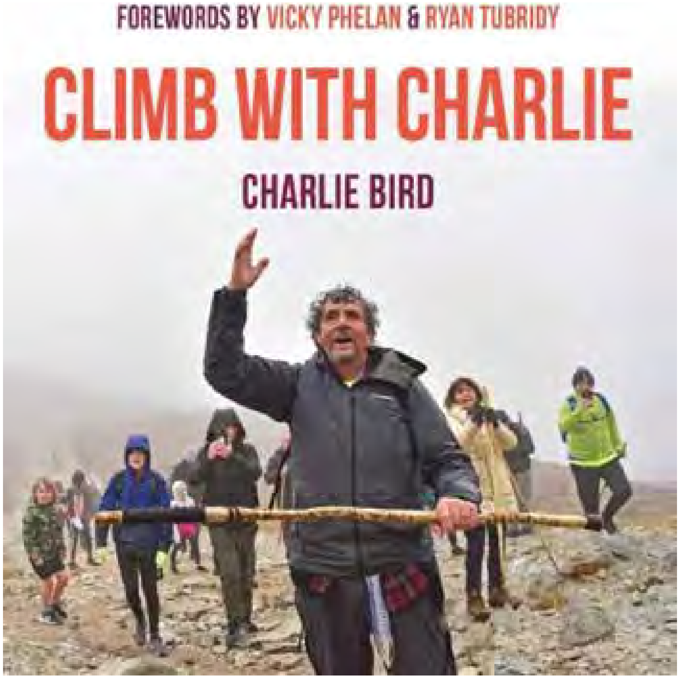
On 2nd April Charlie climbed Croagh Patrick with family friend and the wider community and the rest of the country climb mountains around the country! It was truly an emotional journey for Charlie and his family and everyone who climbed their own mountain…Lots images were captured of all the climbs that took place. Charlie asked people to send in their images and he made a beautiful book with all the images and what happened on that day on Croagh Patrick and all around the country.

Over €3.3million was raised from the event overall and in July a cheque presentation was made to both Irish Motor Neurone Disease Association and Pieta House.

From all in the IMNDA we are blown away by the support and generosity of absolutely everyone who got involved with Climb with Charlie. We cannot thank everyone enough – there are simply no words to describe the gratitude, love and appreciation we have for the thousands of people in this great country and around the world that extended the hand of friendship and supported this extraordinary climb.

To Charlie, Claire and Tiger – what you have achieved, in such a short period is momentous. We thank you from the bottom of our hearts for your courage, spirit and friendship. To raise that kind of money is almost unfathomable.

CLIMB WITH CHARLIE BOOK LAUNCH



Following the Climb with Charlie campaign on the 2nd April, the former RTÉ broadcaster Charlie Bird gathered with friends, family and colleagues at Hodges Figgis in Dublin for the launch of a book commemorating 'Climb With Charlie' event!

The book contains photos of the day thousands of people climbed Croagh Patrick to raise funds for Pieta and the Irish Motor Neurone Disease Association.

In autumn 2021, the journalist and broadcaster publicly announced that he had motor neurone disease. Despite this devastating diagnosis, Charlie decided to organise a charity climb of Croagh Patrick. Climb with Charlie turned into a national event and raise over €3.3 million for the Irish Motor Neurone Disease Association and Pieta House.

CEO of the IMNDA Lillian McGovern attended the book launch of Climb with Charlie along with Board Members Katie Hallissey & Norman Hughes.

"We are delighted to be part of this great initiative. The book captures all the climbs – the memories made and emotions felt so beautifully. Our thanks to Charlie and Claire." CEO, Lillian McGovern

THANK YOU!!!!

It is hard to know where to begin when trying to sum up 2022 so far, it really has been a year like no other as we appreciate more than ever what can be achieved when we come together after 2 years of staying apart.

It's been a busy year in the Fundraising Department, as well as the hundreds of people who climbed mountains in April we have been truly inspired as always by the wonderful individuals, community groups and companies across Ireland and beyond who chose to take the time and effort to raise funds for families living with Motor Neurone Disease. It is impossible to mention and thank each of you individually but please know how much it means to our MND Community.

A special mention to the **West of Ireland** who not only hosted Charlie's Croagh Patrick climb but also organised Hurling for Hope which took place in March. A group of friends, players mentors and teammates from Ballyhaunis GAA Club took on a 100km solo run with a hurling ball from Castlebar to Roscommon. This phenomenal event raised more than €210k split between the IMNDA and Mayo Roscommon Hospice! Thank you, Frank Browne, the Higgins family and all involved.

We must also give a shout out to Ricki Wynne who broke the world record for the most vertical metres ascended and descended in a 24-hour period by running up and down Croagh Patrick 15 times in June and raising over €35k for the IMNDA!

Our families living with Motor Neurone Disease have blown us away this year with some of the events they have organised. John Considine's fundraising events took place (after a long wait due to Covid) across Ennis in June raising over €17k.

Over to Cavan.. when our own Thomas Doonan asked the people of Bawnboy to 'Move in March' they surely did and they didn't stop until they raised €43k!

Also well done to Cavan man Shane Maguire for cycling ACROSS CANADA!!!

Down in **Munster** we had incredible support in Tipp for Mairead Gill's 'Motor with Mairead' which was another real community effort. 5k walks raising over €70k!! Just wow!

Another Tipp native Emma Daly took on a mega challenge and cycled from Malin to Mizen in memory of her dad raising over 50k! Well done Emma and all who took part and thanks to DBFL Consulting Engineers for supporting their colleague!

We can't mention cycling without mentioning Malcolm McGrath who continues to keep the wheels pedalling in memory of his wife Sinead, we don't know how you do it Malcolm!

Let's not forget Paul Kennelly who took on an immense challenge in Kerry over Easter completing a 44-minute workout every 4 hours for 44 hours to the tune of €21k!

Thanks as always to Christy Lehane and Friends of Motor Neurone who continue to fly the IMNDA flag across the Kingdom through several fundraising endeavours.

Well done to Mark Cummins for completing the Cork City Marathon in June and raising a huge €16k from that and his coffee morning!

Long time IMNDA supporter Jerry Twomey from Limerick decided to run the 32 counties in memory of his father in July, what a feat to take on raising over €22k!

The **Midlands** was well represented with a fantastic vintage car event in Laois organised by Johnny Talbot. Also in Laois, a stunning photo book called 'Healing Whispers' was produced by Lisa Doyle, Liz Phelan and Niamh Ryan in memory of their dear friend Aine Purcell.

Laois man Ciaran Doyle took on 4 5k's in June in memory of his wife Eilish – this lovely gesture raised €6k!

Mullingar man Eamon Dunne, who has MND raised some serious cash from his fundraising night and the Women's Mini Marathon with the help of family and his local community. €58k, just wow!!

We of course remember Ireland's 'forgotten' county and must mention one event in particular - **Donegal's** Manus Boyle and all involved in the Agri Tractor Run which raised a phenomenal €27k!

In the **capital** we were delighted to see The Good Run return to Saint Anne's Park, Raheny as well as the VHI Women's MINI Marathon back on the streets of South Dublin! Thanks to everyone who joined in.

A huge well done to Orlagh Reynolds for rallying the troops in her quest to run 100km in August and that she did raising over €37k in the process! Watch out for Orlagh's upcoming event -Black & White Art Exhibition which will be taking place on 20th October in The Richmond, Dublin 7, all information will be on IMNDA'S website and social media channels.

In his **Greystones** gym – Ignite Fitness - Adam Brennan took on a Spinathon in June and handed over a whopping €17k to the IMNDA!

There have been hundreds of wonderful fundraising initiatives already this year…It's been great to see so many golf events, tractor runs and vintage car rallies back with a bang throughout our communities. Along with family fun days, table quizzes, auctions, bridge nights, music nights, art exhibitions, bake sales, head shaves and football and rugby tournaments… the list goes on!

To all our cyclists, walkers, skydivers, trekkers, climbers and all-round fitness fanatics and adrenalin junkies… we take our hats off to you for the challenges you have taken on in support of those who face the toughest of challenges every day.

THANK YOU so very much.

As ever our wonderful community got behind **Drink Tea for MND** in June and organised tea parties in their homes, gardens, community centres and at work. A special thanks to our Ambassador Mark Dignam and his employer Nicholas O'Dwyer Consulting Engineers for their incredible support as well as Mark's family and friends.

To everyone who got behind Drink Tea 2022 including SuperValu, THANK YOU!!

Corporate Support

It has been a great year for corporate support also! We were absolutely delighted to be chosen by the O'Callaghan Collection hotel group as their charity partner for 2022. We have already worked together on a competition, Drink Tea for MND, Community Hero Programme, Global Awareness Day, Walk While You Can and Climb with Charlie. We look forward to working with you for the rest of the year.

Another exciting partnership that kicked off in 2022 was the TU Dublin Students' Union RAG Charity of the Year, we are super excited about working with you over the next academic year!

We were also delighted to be chosen by the Dublin Motorcycle Touring Club (Shankill) as their charity of the year!

If your company offers a CSR or Charity of the Year programme and would like to discuss ways in which we can work together, please email fundraising@imnda.ie

Voice for MND will take place in February 2023. We will be looking for people to share their stories to help raise awareness of this campaign. This will mean sharing your story of MND with us and giving us permission to share it across all media channels. If you or a family member is interested in getting involved, please contact pr@imnda.ie

We would like to take this opportunity to thank everyone who got involved in #Voice4MND in 2022. A special thank you to Barry Jennings from Mayo who helped us to promote this event and allowed us to share his story across the media.

We would also like to take the opportunity to mention Michael Harte's involvement in the campaign too, sadly Michael passed away, our thoughts are with his wife and family.

And finally, thank you to all of you who gave us images and quotes to use on our social media pages and helped spread the word about the campaign. Not forgetting those of you that took part and did a sponsored silence and gave up your voice earlier in the year as without your wonderful support we would not be able to continue the work that we do… so thank you all.

THE ASSOCIATION WELCOMES NEW BOARD MEMBERS

Lisa Doherty

Lisa Doherty is a public servant with over 25 years' experience in the Education Sector. She completed her Bachelor of Arts Degree in Human Resource Management with the National College of Ireland. Lisa is an Administrative Officer in the Human Resources Department , City of Dublin Education and Training Board.

Gillian Lynch

Gillian is a solicitor with more than 20 years' experience. Gillian is currently Knowledge Director in a top-tier law firm where she leads a team of knowledge lawyers and legal librarians. She is responsible for developing and implementing the firm's knowledge strategy.

Before her current role, Gillian worked as a senior associate in another leading law firm and as senior legal advisor at Bank of Ireland.

In her role as Knowledge Director, Gillian works across the firm to develop best practice, to achieve efficiencies and to manage risk. She also delivers legal training, and designs and implements projects.

Gillian holds degrees in law, political science, and Japanese studies. She has a diploma in Compliance and a certificate in Professional Education. Gillian also completed the professional certificate in Charity Law, Trusteeship and Governance in 2015. In her personal time, Gillian enjoys reading, occasional golf and is an active member of the Terenure Cricket Club.

Joseph Ritchie

Admitted to the role of Solicitors in 1998 I have run my own legal Practice as a sole practitioner since 2005 under the name of Donal M Gahan Ritchie & Company with expertise in the area of property, probate / estate planning and litigation.

Joseph is married with 4 daughters living in County Dublin and is currently a Board member with the Carmichael Centre, training organization supporting the voluntary sector. We look forward to meeting all our new board members at the AGM in October.

A FAREWELL TO DECLAN WHO DEDICATED 10 YEARS TO IMNDA

Derry native, Dr Declan Mac Daid, was educated at St Columb's College, Derry and spent 22 years as a Headmaster in Dublin. He holds several degrees including a Masters in Leadership & Management and a Doctorate in Education specialising in Teaching and Ethics.

He was approached to become a member of the IMNDA Board in 2012 during what was a challenging time for all charities. The financial situation in Ireland was still very fragile after the Celtic Tiger crash. As a small charity, the IMNDA did not share the same high profile as larger charities. Declan was asked to become Chair of the Board in 2014.

The Board began the task of achieving and acquiring sufficient funds to support clients and their carers both in equipment and in ongoing services. They knew that the profile of IMNDA would have to be raised so that the charity could acquire sufficient funds and monies to provide enhanced nursing services, more sophisticated technology and better communications. The number of clients diagnosed with MND rose over these years however the level of funding from the HSE remained the same.

Declan said, *"I have had the benefit of a superb board of directors and a very committed staff. We enhanced IMNDA with additional nurses, a more focused organisation in-house, thus bringing IMNDA to the forefront as a leading Irish charity. Opportunities came our way and we grasped them fully, such as the Ice Bucket Challenge, the Father Tony Coote walk and recently the climb with Charlie sensation. However I cannot forget the local communities and families around the entire country and their fund-raising constantly throughout the year. It has been a pleasure and privilege to meet many of them over the years."*

During that time, the Board successfully updated its governance, constitution and articles of association and remains fully compliant with financial, charity and legal requirements. This includes succession planning in board membership, ensuring the charity has a professional set of Board members with appropriate skill-sets for a leading charity. Declan would like to see the creation of a Clinical Governance Advisory Group and an Investment Advisory Group to advise the Board on these two key areas of development.

Declan added, *"As I step down from the chair of the Board of IMNDA and reflect on the work achieved and barriers surmounted. I know that the foundations on which IMNDA functions are very sound and new challenges will be met with the same professional and caring commitment to clients and their families and carers. I have enjoyed my roles with IMNDA and will miss it hugely, along with all the people I have met and worked with enroute."*

Jonathan Healy, Deputy Chairman of IMNDA, added, *"Declan has been an outstanding leader for the entire organisation, and has ensured its continued success through his diligence and commitment. His selfless efforts have helped thousands of people whose lives have been impacted by motor neuron disease in Ireland, and that community is in his debt. As a board, we will continue to build the organisation using the strong foundations he has laid, and we wish him well in whatever direction his career takes him next."*

Lillian McGovern, CEO, added, *"On behalf of our team at IMNDA I would like to thank Declan for his enormous contribution to the Association over the last 10 years. We would not have been able to accomplish the growth of the organisation without his wise counsel and patient advice. As we look back on difficult and challenging times that we have lived through in recent years we know that our achievements would not have been possible without Declan at the helm."*

A NEW DIRECTOR OF NURSING & PATIENT SERVICES

The IMNDA is delighted to announce that we have appointed a new Director of Nursing and Patient Services. Naomi Fitzgibbon comes with a wealth of experience and will provide the strategic and operational delivery of all nursing care and patient support services across IMNDA in partnership with statutory and non-statutory agencies.

Naomi graduated from Beaumont Hospital Dublin as a Registered General Nurse after which, she spent 10 years working in London. As Senior Ward Manager in King Edward VII Hospital she deputised for the Director of Nursing in the management of the Hospital. She completed her MSc in Clinical Leadership in UCD and achieved her Fellowship with the Faculty of the School of Nursing and Midwifery RCSI and is an Honorary Teaching Associate. She was awarded a Scholarship at National Cancer Institute Curriculum in Cancer Prevention, Washington where she gained a global perspective of health behaviour.

Naomi has also worked at senior level in the charity sector, developing evidence-based service in collaboration with universities and industry. She is an expert patient advocate, representing the voice of clients and family. She is a committee member of the National Healthcare Quality Reporting System (NHQRS), which gives an overview of quality in our health service.

This is an exciting time to join our Association as we transform the way we deliver care and support services regionally. This role will be integral in leading on the development of new regional service offerings that support the delivery of the Association's strategic aims.

A NEW FUNDRAISING ADMINISTRATOR

We would also like to welcome Linda Foy to the IMNDA team. She joined the association in February 2022. She comes with a wealth of experience, with a background of over 15 years in healthcare. Linda works within the Fundraising Department and assists with accounts.

GOODBYE TO KATIE

We are very sad to say a fond farewell to our colleague and nurse of seven years, Katie Kinsella. Katie was a valued and considerate team member who went above and beyond for all her MND families. We will all miss her so much. We will be forever grateful for her knowledge, experience, and compassion.

She made so many connections and helped countless families in her time. We will miss her greatly and wish her nothing but the best for the future. From all the team in the IMNDA – thank you and good luck!

CHRISTMAS MEMORY TREE

We miss our loved ones all year round but at Christmas we miss them that little bit more. It's a time to keep their memories shining brightly even though they are no longer with us.

Lighting up a star on our online Memory Tree is a small way of remembering someone special during the festive period.

The stars that light up the darkest night are the lights that guide us.

From the 1st November our Memory Tree will be ready to be lit up, please visit imnda.ie for more.

LEAVE A LEGACY AND MAKE LIFE MORE MANAGEABLE FOR SOMEONE WITH MOTOR NEURONE DISEASE.

A will is a very important life document that everyone should have and is an act of love for those you leave behind. Without a Will to give your final instructions, those decisions will be made for you by others.

Legacies are about changing lives in the future. Remembering a charity in your will – once your loved ones are taken care of - is a great gesture of kindness that continues your support of the IMNDA.

Helping us to continue to provide vital services will make a difference to the lives of those who may need it in the future.

Until there is a cure, there is care.

You don't need to be wealthy to give a significant gift to people affected by MND and you can make a substantial contribution that costs nothing during your lifetime.

If you would like to find out more information about leaving a legacy to IMNDA, please visit here: imnda.ie/get-involved/donate/legacies/

However, much you choose to leave is up to you but please be assured that every legacy counts, no matter how large or small.

To get in touch email fundraising@imnda.ie or call 01 670 5942.

The IMNDA is a member of My Legacy – to find out more – visit www.mylegacy.ie

HAPPINESS AND LOVE

When Motor Neuron took my reins,
I bedded myself into happiness and love
and promised myself a life of joy and
I focussed on my calm successes.

These emotions pulled me into a world
of happiness and love and filled my heart,
and filled every room I entered and
calmed and stimulated my night-times.

A consonance of joy illuminated my future,
as pleasure filled my daytimes and nights
and an authenticity of friendship encased
in love moved me to moments of bliss.

When love dressed me in the colours of unity,
an overwhelmed beauty drove me into a world
of pleasure I could not be rescued from and
embroidered every minute of my days with happiness.

Undressing is the pleasure I truly love,
as my lover kissed and hugged me and
expressed how much she loved me, which
etched itself deep into my waiting marrow.

Each day I dress myself in the colours of unity,
and allow into my mind how much I am loved.
Motor Neuron is but a hamstring to take you away
from the reality, I do not want to escape from.

©Gene Barry

CHRISTMAS SHOP

Decorations

This brand-new beautiful Christmas decoration will look lovely sparkling in your home over the festive season or even all year long. This durable ornament can be personalised with a favourite photo of family or friends and would be a perfect Christmas gift for someone special. The decorations have a green ribbon for hanging up and come safely packaged in a white box with the IMNDA logo on the lid.

Each decoration is €20 including postage and packaging.

Christmas Cards

Our charming traditional Christmas cards are €10 per pack of 12 cards (postage will be added on at checkout) and each pack has 6 different designs (2 of each design) which are brand new for 2022!

Buying a pack and sending our cards is a simple and effective way for you to help us raise awareness and also show your family and friends who are thinking about them over the festive season.

Both decorations and cards are available to purchase at imnda.ie or by calling the Fundraising Team on 01 670 5942.

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

Irish
Motor
Neurone
Disease
Association

To Contact Us:
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Unit 3, Ground Floor
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DIRECTORS: Declan Mac Daid (Chair Person), Alison Gray (Hon Treasurer), Katie Hallissey, Bernie Conolly, Jonathan Healy, Norman Hughes, Lisa Doherty, Gillian Lynch, Joseph Ritchie.

CHY 8510 R.C.N: 20021009

CHRISTMAS IS COMING...


Irish
Motor
Neurone
Disease
Association

This pack contains 6 designs (2 of each)

IMNDA
Unit 3, Ground Floor, Marshalsea Court, 22/23 Merchant's
Quay, Dublin 8, D08 N8VC
Ph: 01 670 5942 **Web:** www.imnda.ie
Email: fundraising@imnda.ie **R.C.N:** 20021009
CHY: 8510

Send a Card

Spread a little bit of IMNDA festive spirit this Christmas by purchasing a pack of our charming Christmas cards. BRAND NEW DESIGN FOR 2022!! The cards are €10 per pack of 12 cards and each pack has 6 different designs (2 of each design in each pack) and postage will be added at time of order. Buying a pack and sending our cards is a simple and effective way for you to help us raise awareness.

Christmas Cards are available to purchase from our online shop: www.imnda.ie or by calling the Fundraising Team on 01 670 5942. Please note postage fees will vary depending on quantity ordered.

FREEFONE 1800 403 403
EMAIL info@imnda.ie
www.imnda.ie

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