

**Irish Motor Neurone
Disease Association**



**Strategic Plan
2021 - 2026**

FOREWORD BY THE CHIEF EXECUTIVE

I am delighted to introduce our new Strategic Plan for the period 2021 – 2026. This plan was informed following an extensive consultation process amongst a range of key stakeholders and experts, including people living with MND, their families and caregivers, healthcare professionals, the board and staff of IMNDA, the MND research community, and our loyal donors and supporters.

Navigating your way through a complex condition such as Motor Neurone Disease can be stressful at the best of times and debilitating at worst. Throw a complex, under pressure and bureaucratic healthcare system into the mix and it becomes a minefield.

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. Increased demand on our services means we are constantly faced with new challenges in terms of how we plan, develop, deliver and fund our core services. With this in mind, we have identified the following **four strategic priorities** which together form the framework for this plan.

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.

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 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 affected by MND.

I would like would like to take this opportunity to thank everyone involved in this process for their time, their honesty and their constructive observations and feedback. I would also like to thank the staff and board of the IMNDA, whose commitment to our MND community goes above and beyond every minute of every day.

We look forward to keeping you up to date on all future developments as the years and months go by.

Warm Wishes.

Roisin Duffy
Chief Executive

“The IMNDA worked with our family every step of the way, nothing was left undone. They worked with us at a pace that was right for us. I will never forget the conversations we had with our IMNDA nurse.”

INTRODUCTION

Welcome to the publication of IMNDA's Strategic Plan 2021-2026.



The past year has been a difficult year for us all in many different ways, bringing many challenges and changes throughout which our services to our clients and families have remained steadfast.

Two of the major challenges for IMNDA has been communications and fundraising, both of which are essential to keep the services which our clients and families deserve. These will remain our focus as we implement our Strategic Plan.

I want to thank all of our participants who contributed to the development of the Strategic Plan 2021-2026 which provides a roadmap for IMNDA for the next five years.

It is with great professional and personal pleasure that I introduce, on behalf of the Board of IMNDA, our Strategic Plan 2021-2026.

Dr Declan Mac Daid,
Chair,
IMNDA.

INTRODUCTION

About the Irish Motor Neurone Disease Association

The Irish Motor Neurone Disease Association (IMNDA) is the only organisation of its kind in the country. We are dedicated to working on behalf of people living with MND and their families and carers. Our key services include home visits by our four MND outreach nurses, financial assistance towards home help and the supply of specialised equipment and communication aids on loan. We also fund and promote research into the causes and treatments of MND.

The aim of IMNDA is:

- To encourage and promote the best methods of care, education, research, and treatment for people with Motor Neurone Disease throughout Ireland, contributing to worldwide efforts in research and development of treatment.
- To establish and promote models of good practice in the delivery of specialised services to our patients, their families and carers, setting standards of excellence.
- To communicate widely, knowledge of Motor Neurone Disease and related disorders in order to raise awareness in the wider community.

Our Vision

A World Free of MND.

Our Mission

To support people living with motor neurone disease (MND), their families and carers through advocacy, home, and professional support.

Our Values

- To enable people with MND to live as active independent citizens.
- To empower people with MND to make informed decisions.
- To put people with MND at the heart of our focus.
- To ensure that people with MND have a voice by advocating on their behalf.
- To value everyone who contributes to our association.
- To value everyone who works for our association.



Our MND Community

We aim to meet the needs of all those with an interest in the condition of Motor Neurone Disease.



Patients with Motor Neurone Disease

- One to one support services
- Information materials and helpline
- Home visits from MND outreach nurse
- Specialist equipment and communication aids
- Funding towards counselling
- Co-ordination of medical services
- Advocacy on the patient's behalf
- Social media interaction

Carers of those with Motor Neurone Disease

- Information materials
- One to one support services
- Advice from MND outreach nurse
- Helpline
- Social media interaction
- Provision of services and equipment
- Funding towards counselling

Working with the Medical Community

- Working with clinical teams
- Nursing support and engagement
- Providing information regarding research programmes
- Acting as a co-ordinator for patient care within and between different care organisations

In the Broader Community

- Fundraising
- Education and awareness raising with different stakeholders about MND
- Educating the public through multiple communications channels
- Advocacy and empathy

“Based on the experience my uncle has had with IMNDA, I have full belief their services will meet his needs and benefit him in the future.”

Who do we assist?

For those who have been diagnosed with MND or who know someone who has, our information services can make a real difference in the weeks, months and years following diagnosis. MND is a life-changing illness and the Association is dedicated to making each life-altering change as smooth as possible for everyone involved.

“They are present in that moment of need and have empathy and understanding when it comes to the impact of MND.”



We are known for:

- Our understanding of MND and the changing nature of the condition
- Being the only organisation in Ireland providing free access to dedicated care and support to people affected by MND
- Providing vital services, including nursing support, equipment provision, financial assistance towards home help, counselling and funding towards research
- Creating awareness about MND
- Advocating on behalf of, and representing those affected by MND in Ireland
- Providing support and information to health care professionals
- Reliability and integrity
- Maintaining close and strong working relationships with National MND clinics/ Neurologists/ multidisciplinary teams and researchers

“IMNDA provided us with equipment as and when we needed it”

STRATEGIC PLAN 2017 – 2020

KEY ACHIEVEMENTS

Before we lay out our future plans for the Association, it is imperative that we reflect on our last strategic plan and all that we achieved. Our 2017 – 2020 priorities were as follows:

- **STRATEGIC PRIORITY ONE**
Support People living with MND
- **STRATEGIC PRIORITY TWO**
Connect and Communicate about MND
- **STRATEGIC PRIORITY THREE**
Strengthen our Organisational Presence and Capacity

Strategic Priority One – key milestones achieved

- Employed a new dedicated Information & Support Officer to advise families regarding rights and entitlements and to act as a conduit between the nursing team and the wider MND community.
- Invested more than €1.7 million in the provision of crucial new equipment.
- Spent more than €1.6 million on home care grants.
- Introduced a once-off yearlong Family Caregiver Support Programme in 2019
- to provide extra respite and support for family carers – this was made possible thanks to the success of Drink Tea for MND.
- Employed a 4th MND Outreach Nurse thanks to the fundraising efforts of Fr. Tony Coote's Walk While You Can campaign.
- Introduced a Bereavement Counselling Grant to enable us to continue to support families to the very end of their difficult MND journey.

Strategic Priority Two – key milestones achieved

- Greater collaboration and knowledge sharing with other disability services to ensure our MND community have access to all relevant information and services.
- New website with enhanced functionality.
- Greater collaboration with our MND community to enhance awareness of MND in the media.
- More information sharing with families as a result of new Information and Support Officer post.
- New booklet produced for newly diagnosed people.
- Greater sharing of research initiatives and findings with MND community thanks to strengthened links between IMNDA and Research Motor Neurone in Trinity College.

Strategic Priority Three – key milestones achieved

- Recruitment of two new service delivery posts (nursing and information and support) and two new board members with the added skillsets needed for strategic growth.
- Enhanced finance and budgeting systems were implemented to maximise efficiency and strengthen governance. A new financial controller was also recruited in this period.
- Increased strategic investment in fundraising and marketing to raise IMNDA's profile and generate more funds –steady income growth year on year with the exception of 2020 which dipped slightly due to Covid-19.
- Greater organisational presence at international MND meetings such as International Alliance for ALS/MND and other important stakeholder meetings regarding research projects.
- Enhanced internal structures across all departments.
- Moved to larger more suitable offices to facilitate organisational growth.
- Partnered with Healthcare 21 in order to deliver a more streamlined service for all equipment deliveries, collections, decontamination and testing.
- The IMNDA also achieved full compliance with the Voluntary Governance Code for Voluntary Organisations in this period.



DEVELOPING THE STRATEGIC PLAN

The IMNDA made significant progress over the period of the last plan in terms of how it develops, implements and funds its core services. The efforts of individuals such as Fr. Tony Coote raised the profile of the condition and highlighted the impact of the disease on all those affected. With the exception of 2020 and Covid-19, the Association has seen a steady increase in funds raised year on year. This success was achieved as a result of the work of multiple stakeholders including:

- The general public and the philanthropic business community.
- The inspiring efforts of those who shared their journey with MND.
- The work of carers and supporters.
- The work of our teams within the organisations.
- The valued support and strategic input from our voluntary Board of Directors.

The Research Programme Undertaken

In seeking to chart the direction for the organisation and its services, we conducted a year-long consultation exercise with our stakeholders. We engaged Amárach Research, the leading research-based consultancy company to design and implement a qualitative and quantitative stakeholder engagement programme. The implementation was impacted by the Covid pandemic. This restricted the opportunity for Amárach to engage with some stakeholders because they were vulnerable (patients and carers) or fully engaged in fighting the pandemic through their work on the front line within the health services.

The stakeholder engagement process was made up of both qualitative and quantitative research components.

Qualitative Research Component

- Discussion with the Board and its members on the organisation's purpose and direction.
- Focus groups with the office team based in IMNDA's office and also the outreach nursing team.
- Interviews at home with selected patients and their carers.
- Interviews with those involved in the medical diagnosis and treatment of patients with MND.

The qualitative research provided key findings in two ways:

- The findings themselves were fed back to the Chief Executive and the team.
- The findings helped in the design of the quantitative research programme.

“IMNDA is an incredible organisation, we could not have navigated our journey with MND without them.”

Quantitative Research

IMNDA invited all those on its active membership database (circa 3,000) to participate in the survey programme. The wider audience were invited to engage and complete the survey online. People living with MND and registered with the Association (and their next of kin) received an online link and were also sent the survey via post. All survey data went back to Amarach Research directly. The IMNDA database contains people who have engaged with the organisation in a variety of different ways in the present and in the past. It includes:

- People living with MND.
- People caring for those who are living with MND.
- People who previously cared for people with MND.
- Fundraisers and supporters.

In total 326 people completed the survey. Given the nature of the database, the response rate was very satisfactory.

“The IMNDA were very efficient. They provided me with a wheelchair. The HSE occupational therapist measured me for one but they couldn’t fund it then. My nurse, Eithne, is great. She’s just a phone call away and always responds with advice.”



Findings

We know that our work is valued by people living with MND. We know this from our research asking people for their views and experiences of IMNDA supports. Nevertheless, we know that there is always work to be done on improving and expanding what we do and how we do it. We need to ensure we continue to develop and grow to facilitate our MND community's needs, particularly during the current climate.

From the research we can glean that there is a wide recognition of the critical role played by continuous support from IMNDA, an ongoing flow of information and an understanding. The IMNDA is seen to understand MND and its impact on those affected, and it is this personal factor, which is so important to our community.

However, it is very clear from our findings that there is no one size fits all when it comes to MND. 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.

Undoubtedly, due to the nature of MND, there are challenges in providing information to patients and carers. Anticipating future needs on behalf of those affected by MND, and sharing more information on the services and support available and relevant at particular points may assist in easing some concerns clients and carers have about dealing with what the future holds.

The research findings provided a valuable contribution to the development of our strategic plan. Based on the reality of the lives and opinions of our key stakeholder groups, they have served to sharpen our focus as we plan the organisation's direction for the next five years. The research outcomes have been particularly useful in the planning process as we formulated specific aims, objectives and deliverable goals.



IMNDA STRATEGIC PLAN 2021 – 2026

Over the next five years, we aim to protect and maintain existing services and activities, while also expanding and developing in new directions to ensure people living with MND and their families continue to benefit from our work. They remain at the core of our purpose.

We have identified four strategic priorities which together form the framework for this plan.

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.



“Our support has been excellent. It’s true nothing can cure it right now but there are lots of things to help make life that bit easier along the journey. IMNDA has been outstanding in our experience”

Built into the four Strategic Priorities are Strategic Outcomes that we will endeavour to meet during the five-year period of the plan, subject to adequate funding being available.

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.

Outcome #1: People with MND, their carers and families receive the best medical, practical and emotional support available from IMNDA regardless of where they live.

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.

Outcome #2: People affected by MND are well informed about the condition, how it affects them and what range of supports are available through the IMNDA and other state bodies locally and nationally. The general public and broader groups have a stronger understanding of MND, its affects and how society as a whole should respond.

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.

Outcome #3: IMNDA works practically to contribute to research projects, both nationally and internationally, and this research is effectively communicated to all key stakeholders.

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

Outcome #4: The organisation has adequate resources in place to raise the necessary funds from both state funding and the general public in order to deliver on its long-term vision and mission. The organisation demonstrates best practice in the areas of governance, administration, human resources and financial management.

STRATEGIC PRIORITY 1

Ensuring Quality Care & Support

Our first priority is to continue to 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.

Navigating your way through a rare and complex condition such as Motor Neurone Disease places a huge amount of stress not only on the person living with the disease, but on the family as a whole. It's an overwhelming journey that comes with many practical questions, concerns and challenges.

Looking to the future the IMNDA will continue to enhance its core supports, as well as develop new services, to ensure that every person affected by MND receives the best practical and emotional support available.

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.

We will do this by focusing our efforts in the following ways:

- Work with healthcare professionals and regional and local organisations to streamline how care and support is coordinated in the community.
- Ensure clear pathways are devised for all aspects of IMNDA's core supports to ease service navigation and deliver an enhanced service user experience.
- Provide practical at home support by way of equipment on loan into homes.
- Provide emotional support through counselling and holistic therapies for both clients, families and family carers and revisit this service with them at various times throughout their journey.
- Provide regular at home support and proactive contact with both clients and carers via IMNDA's services team and nursing team - taking on board a family's needs and wishes.
- Continue to provide additional homecare respite funding to bridge the gap in HSE resources. Advocate for additional home care hours when needed.
- Provide practical and administrative advocacy support to families and carers.
- Forge stronger strategic connections with other regional agencies in order to explore more localised client and carer support.



STRATEGIC PRIORITY 2

Creating Connections & Raising Awareness



Our second priority is to strengthen communications with all key stakeholder groups, especially families directly affected by MND, and enhance public awareness of the impact of MND through advocacy.

Communication is key when it comes to understanding a rare condition such as MND. For many families, a diagnosis is their first introduction to the disease.

We want to ensure that no person feels isolated or kept in the dark when it comes to living with MND so we will endeavour to better communicate and educate not only the families we serve but society at large. It is so important that the general public, state bodies and community healthcare professionals have a strong understanding of MND so they can better support and respond to their needs on a local and national level.

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.

Over the next five years we will:

- Connect families affected by MND by developing an online community platform where they can engage with each other in a meaningful way.
- Ensure people affected by MND have access to high quality, comprehensive and up to date information through a series of quarterly 'Ask the Expert' sessions online.
- Share more personal stories about the various types of MND to highlight and inform what one can expect at different stages of living with the disease.
- Ensure IMNDA website is fit for purpose with clear, concise and easy to understand information.
- Continue to communicate regularly with our clients, carers and the wider MND community.
- Ensure regular information sessions/ evenings are held.
- Enhance, expand and develop a range of new booklets and information sheets in consultation with our medical colleagues and our MND community.

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 contact them”



STRATEGIC PRIORITY 4

Governance, Compliance & Strengthening Sustainability

We will continue to collaborate and build beneficial partnerships with other organisations so that we can achieve more for our MND community. We are fully committed to working and using our resources even more effectively.

Our intention is to continue to be a well-governed, well administered charity that is guided by and meets good governance standards. Our focus remains on building capacity in order to advance our work. Supporting the needs of people living by MND and all who love and care for them is, as always, our main priority.

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.

Over the next five years we will:

- Continue to grow our income to ensure increased/adequate funding is available to meet the demands of our clients and families.
- Continue to update and refine all internal operations and policies to ensure compliance and best practices are being adhered to.
- Ensure our team in IMNDA has all the necessary skills to deliver on IMNDA's mission and vision.
- Continue to support staff to excel in their work.
- Cultivate new strategic relationships to further enhance our work.



“The IMNDA is really good at giving you tools, advice and equipment to help you cope with the disease. Electric wheelchairs, hoists and even eye gaze technology. These all help to improve your quality of life and to keep you as independent as possible for as long as possible.”





The Irish Motor Neurone Disease Association

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