

Irish Motor Neurone  
Disease Association



**Strategic Plan 2026–2030**  
A Five-Year Plan: By Your Side



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# CHAIRPERSON FORWARD

Welcome to the publication of IMNDA's Strategic Plan 2026-2030. As many of you will be aware, I joined the Board of the IMNDA in 2018 after our family benefited from the fantastic care and support given to my brother Karl throughout his MND journey - we got to experience first-hand what a difference the IMNDA made.

It was an absolute honour to step into the role of Chairperson of the Board at the AGM & Conference in October 2025.

Since my brother was diagnosed with MND in 2010, IMNDA has seen growing demand for its services and supports, reflecting both the complexity of the disease and the vital role the Association plays for families across Ireland.

Advocating for greater support will form part of our new strategy as we strive to not only sustain the vital services IMNDA currently provides but also evolve and strengthen our work in areas where people living with MND and their families have told us more is needed.

I want to thank all of our participants who contributed to the development of the Strategic Plan 2026 - 2030, which provides a roadmap for the IMNDA for the next five years.

On behalf of the Board of the IMNDA, I introduce our Strategic Plan 2026 - 2030: By Your Side.

**Norman Hughes**  
Chairperson  
Irish Motor Neurone Disease Association



# CEO MESSAGE



I am both proud and deeply honoured to present IMNDA's Strategy 2026-2030: By Your Side.

This plan represents an important moment for our organisation and, most importantly, for the MND community across Ireland. The strategic planning process has been about listening - listening to people living with MND, to families and caregivers, to those who have been bereaved, and to the clinicians, staff and volunteers who support them every day. What we have heard has been both affirming and challenging: affirming in the amount of trust placed in IMNDA, and the positive feedback on our current services, and challenging in the clear need to do more, reach further, and influence change at a systems level.

I am incredibly excited about what this strategy sets out to achieve over the next five years. At its heart is a simple but powerful ambition: that no person or family affected by Motor Neurone Disease feels alone. We know that an MND diagnosis changes everything and often very quickly. Our role is to stand beside people at every stage of that journey, providing not only expert, person-centred care, but also reassurance, clarity, and compassion when it is needed most.

Over the lifetime of this strategy, we aim to strengthen and expand the supports that matter most to people. This includes continuing to deliver excellent nursing and practical supports, while also creating a more co-ordinated and seamless experience from diagnosis through to bereavement. We will place a stronger focus on supporting families and caregivers, recognising their vital and often demanding role. We will work to ensure greater equity of access across all regions, so that where you live does not determine the level of support you receive.

But we also recognise that IMNDA's role extends beyond direct service delivery. As the national organisation for MND, we have both an opportunity and a responsibility to influence the wider system. Over the next five years, we will strengthen our voice, advocating for timely access to services, raising awareness of MND, supporting

education for healthcare professionals, and working to shape a more co-ordinated and responsive health and social care system. We will ensure that the lived experiences of people with MND and their families are at the centre of everything we do.

Delivering on these ambitions will require a strong and resilient organisation. This strategy sets out how we will continue to invest in our people, our systems, and our partnerships, while building a more sustainable funding model that allows us to meet growing demand and plan confidently for the future.

None of this work would be possible without the extraordinary commitment of our staff, volunteers, Board, supporters, and partners. Nor would it be possible without the courage, honesty, and generosity of the MND community, who continue to inspire and guide everything we do.

As CEO, I am both optimistic and determined. This strategy provides a clear and purposeful roadmap for the years ahead. It builds on our strengths while challenging us to go further and improve the experience of care, to strengthen connections, and to drive meaningful change.

Together, we will continue to ensure that IMNDA is not just a service provider, but a constant, trusted presence-by your side-throughout the MND journey.




**Kevin Burn**

Chief Executive Officer

Irish Motor Neurone Disease Association

# OUR VISION, MISSION & VALUES

 Our vision, mission and values provide the foundation for this strategy and guide how IMNDA will continue to support people living with MND, families and caregivers over the next five years.

## Our Vision:

A future where everyone affected by MND can live with dignity, choice, and the best possible quality of life.

## Our Mission

To support people and families affected by MND with compassion, practical care, and a strong collective voice.

## Our Values

### Person-Centred

We place people living with MND and their families at the heart of everything we do.

### Compassion

We provide compassionate, respectful, and high-quality support throughout the MND journey.

### Empowerment

We support informed decision-making, independence, and choice.

### Voice

We champion the needs, experiences, and rights of people affected by MND.

### Integrity

We act with transparency, accountability, and strong governance.

# STRATEGIC CONTEXT

**M**otor Neurone Disease (MND) presents profound and rapidly changing challenges for individuals and families. Its impact extends far beyond the person diagnosed, affecting every aspect of life: physical, emotional, social, and practical. There are close to 500 people living with MND in Ireland at any given time, with approximately 150 new diagnoses each year.

IMNDA is a national organisation, supporting people living with MND, their families and caregivers across all regions of the Republic of Ireland. For more than 40 years, IMNDA has been recognised as a vital and compassionate source of support, often acting as a trusted anchor for individuals and families navigating the realities of MND.

Through extensive consultation with people living with MND, caregivers, bereaved family members, clinical stakeholders, staff, volunteers, and Board members, a clear and consistent message emerged: while IMNDA is deeply valued and trusted, the wider health and social care system can often feel disjointed and difficult to navigate.

The responsiveness of the organisation, the expertise and experience of its dedicated employees, and the practical and emotional supports provided were consistently described as making a meaningful difference at some of the most difficult times in people's lives.



At the same time, the consultation highlighted important opportunities and responsibilities for the future. People spoke about the need for earlier access to information and supports, more co-

ordinated services, stronger emotional and psychological supports, greater regional consistency, and continuity of support beyond bereavement. Caregivers described the intensity and isolation of their role, while clinical stakeholders highlighted gaps in awareness, integration, education, and system capacity.

This strategy responds directly to those insights. It sets out a clear ambition to strengthen IMNDA's core role in delivering high-quality, person-centred support while also helping to improve how people and families experience support throughout the full MND journey.

Central to this strategy is a commitment that no person or family should feel alone in navigating MND. This means delivering excellent direct supports while also strengthening co-ordination across services, improving navigation and advocacy, supporting families and caregivers, and ensuring continuity throughout the full journey from diagnosis through to bereavement.

The strategy also recognises IMNDA's role beyond direct service delivery. As a trusted national voice, the organisation is uniquely positioned to influence policy, improve awareness, strengthen partnerships, support education, and shape how services are designed and delivered nationally.

IMNDA's impact is also hugely dependent on the strength of the organisational functions that fund, co-ordinate, communicate, govern and sustain its frontline services. Delivering on this strategy will require ongoing organisational and financial resilience.

Strengthening all parts of the organisation is fundamental to sustaining and improving patient and family support throughout the full MND journey. Investment in people, systems, governance, cyber security, digital capability, partnerships, and sustainable funding will be critical to ensuring IMNDA can continue to meet growing demand while maintaining the compassion and quality that define its work.

# LOOKING BACK: PROGRESS SINCE 2020

Over the lifetime of the previous strategy, IMNDA made significant progress in strengthening services, expanding reach, and deepening impact for people living with MND and their families. Despite a challenging external environment, including the COVID-19 pandemic and increasing pressure on health and social care services, the organisation continued to grow and adapt in response to increasing demand and evolving needs.

There was substantial growth in frontline support and service delivery. The number of people supported increased significantly, alongside major increases in nursing contacts, home visits, equipment provision, and practical supports.

IMNDA also strengthened its ability to respond quickly and effectively to individual needs. This included the development of rapid-response equipment supports and the introduction of specialist technologies such as eye-gaze systems and voice banking, helping to maintain communication, independence, and quality of life.

Support for families and caregivers also evolved, with increased investment in counselling, caregiver programmes, night nursing, and targeted financial supports.

At an organisational level, IMNDA significantly strengthened its foundations. Fundraising income increased markedly, driven in large part by the extraordinary public response to the 'Climb with Charlie' campaign, which transformed awareness of MND and demonstrated unprecedented

national solidarity with the MND community.

Governance, systems, communications, fundraising capability, operational processes, and organisational infrastructure were further strengthened and professionalised, positioning the organisation to pursue sustainable, multi-year funding with greater confidence.

However, these advances were achieved in the continued absence of secure statutory funding, underscoring IMNDA's ongoing reliance on voluntary income to meet growing need. Despite this challenge, the organisation is now better equipped to advocate nationally for people living with MND and for the long-term public investment required to support them.

This progress provides a strong foundation for the next phase of IMNDA's work. However, demand is increasing, needs are becoming more complex, and expectations of services continue to grow. The next strategy must build on these achievements while responding to new challenges and opportunities.

### Impact of Strategic Plan 2021-2026

- +16% increase in people supported
- +69% increase in nursing contacts
- +40% increase in home visits
- Nursing team expanded 4 → 7
- Equipment investment nearly tripled

### ORGANISATIONAL STRENGTH

- Income growth to €4m+
- Enhanced governance and board capability
- Stronger advocacy at government level

### SERVICE & SUPPORT IMPROVEMENTS

- 19,500+ home care hours annually
- Increased night nursing provision
- Cost of living supports introduced
- Rapid-response equipment service and specialist technology (eye-gaze, voice banking)
- Counselling investment doubled



# LOOKING AHEAD: A CHANGING LANDSCAPE

Building on a strong foundation, IMNDA is now operating in an increasingly complex and demanding environment. Demand for services continues to grow with increasing complexity in care and support needs. People living with MND can often experience isolation due to limited community supports and the unpredictable progression of the disease, which can lead to more intensive support requirements and additional pressure on families and services.

At the same time, the broader health and social care system is under sustained pressure. Variability in community services, geographic inconsistency, capacity constraints, delays in access, and gaps in co-ordination mean that individuals and families often rely on IMNDA to bridge systemic gaps.

Expectations of support are also evolving. People living with MND and their families are seeking faster responses, more co-ordinated care, improved regional equity, better access to specialist equipment, and stronger emotional and practical supports throughout the full journey, including bereavement.

There is also a growing opportunity for IMNDA to play a stronger role in influencing education, clinical pathways, research participation, and service design as Ireland becomes increasingly connected to international research and innovation in MND care.

These trends present both challenges and opportunities. They require IMNDA to think differently about how it delivers services, supports families, builds partnerships, and influences the wider health and social care system.

In response, this strategy is shaped by several key strategic imperatives:

- Plan for sustained growth in demand and complexity
- Strengthen co-ordination and continuity of support throughout the full MND journey
- Expand support for families and caregivers
- Increase regional consistency and accessibility
- Strengthen partnerships and system collaboration
- Increase influence on policy, services, education, and awareness
- Build a financially and organisationally resilient organisation

# WHAT WE HEARD

As part of the development of this Strategic Plan, we undertook a comprehensive consultation process with those at the heart of IMNDA's work. This included patients, caregivers, bereaved family members, clinical stakeholders, staff and board members.

Consultations took place between October 2025 and May 2026.

The consultation combined:

- Quantitative survey data (185 responses across four groups)
- In-depth qualitative interviews with patients, caregivers, bereaved family members and clinicians across all regions.
- Staff Team Meetings
- Senior Management Team Meetings
- Board Meetings
- Combined Board & Staff Team Strategic Planning Day
- Fundraising Research

This mixed-method approach enabled us to capture both the breadth of experience across the community and the depth of individual lived experience.

The findings are both affirming and challenging, highlighting the strength of IMNDA's current model while pointing clearly to where the organisation must evolve.

Across consultations several consistent themes emerged but there was one very consistent and powerful message:

**IMNDA is highly valued and deeply trusted.**

Respondents described the organisation as compassionate, responsive and a vital source of reassurance:

*“Only for them...”*

*“I don't know how we would have managed without the support - it made an unbearable situation more manageable.”*

*“You're not just another case. They actually know you and what you're dealing with.”*

Patients, caregivers and clinicians consistently emphasised:

- Quality of nursing support
- Timely information and advice
- Access to equipment
- Responsiveness as needs change

There was a clear sense that IMNDA's person-centred, relationship-based model is a core strategic asset that must be protected. However, stakeholders were equally clear on where change is required.

The following section, 'Building on Strengths', highlights feedback pointing to areas where support can be strengthened over the next five years.

# BUILDING ON STRENGTHS: WHERE MORE IS NEEDED

Although IMNDA is highly responsive and a trusted source, individuals and families often experience difficulty navigating the wider health and social care system. Gaps, delays and inconsistencies across services mean that many are left to co-ordinate care themselves. They describe complicated systems and processes which take time to complete.

IMNDA is frequently seen as the central point of guidance, creating a clear opportunity to strengthen its role as a navigator and co-ordinator within a complex health and social care system.

*“You’re constantly trying to figure out who to call for what.”*

*“The system is very fragmented - you’re joining the dots yourself.”*

*“Without IMNDA, we wouldn’t have known where to start.”*

There is a strong desire for more joined-up, seamless support from diagnosis through to bereavement. This points to an opportunity to develop a more pro-active, staged and journey-based model of care, where supports are clearly mapped and introduced at the right time.

Participants described uncertainty at key transition points:

*“We didn’t know what was coming next - you’re always reacting instead of planning.”*

*“It would have helped to know earlier what supports were available down the line.”*

*“You only find things out when you’re already in crisis.”*

## Recognising and Supporting Caregivers as a Distinct Client Group

Caregivers consistently described significant emotional and practical strain, often feeling that their own needs were secondary to those of the person with MND.

*“Everything is focused on the patient, but you’re the one holding everything together.”*

***There's no switch off - it's constant, and you're exhausted.***

***You don't even realise how much you need support yourself until you're overwhelmed.***

There is a clear need to recognise caregivers as a distinct client group, with tailored supports that address their wellbeing, resilience and practical needs throughout the MND journey.

### **Strengthening Continuity into Bereavement**

Bereaved family members expressed deep appreciation for the support received during illness. However, many described a sense of disconnection following the death of their loved one.

***After everything stops, it's very quiet - that's when it really hits.***

***A follow-up call meant a lot, but I would have liked something a bit later too.***

***You go from constant contact to nothing, and that's very hard.***

This highlights the need for more structured and sustained bereavement support, recognising that grief evolves over time.

Bereaved families also spoke of the lasting impact of navigating the healthcare system and expressed a strong desire to contribute their insights to improve services for others. Their lived experience represents a valuable resource in shaping future service design and advocacy.



### **Strengthening Advocacy and System Influence**

Across all consultations, there was a strong call for IMNDA to further strengthen its role as a national voice for people living with MND and their families. This includes raising awareness, engaging in research, influencing policy, and advocating for equitable access to services and supports.

Participants highlighted significant challenges in accessing services at times, often requiring individuals and families to advocate for themselves during an already difficult time.

***More needs to be done at a national level - people don't understand MND.***

*“There should be more awareness among healthcare professionals.”*

*“It shouldn’t be this hard to access basic supports.”*

Geographic inequity was a consistent concern:

*“It really depends on where you live what you can access.”*

*“Services feel very Dublin-based.”*

*“People in rural areas are at a disadvantage.”*

There is a clear mandate for IMNDA to play a stronger role in addressing these systemic challenges and influencing more consistent, equitable service provision nationally.



## Protecting the Wellbeing of Staff

IMNDA staff are deeply committed and take great pride in their work, consistently describing it as meaningful and purposeful. Their dedication is reflected in the extraordinary efforts made to support individuals and families.

*“Mountains are moved to get things done.”*

*“The nurse was the one constant in a very uncertain situation.”*

However, the emotional intensity of working in this context, combined with cumulative exposure to loss, requires a more structured and proactive organisational response. Supporting staff wellbeing is essential to sustaining high-quality services and ensuring long-term organisational resilience.

## Growing Demand and the Need for Sustainable Funding

Demand for services continues to increase, placing sustained pressure on IMNDA’s resources and reinforcing the need for a resilient and diversified funding model. To meet future demand, the organisation must strengthen both its financial sustainability and operational capacity.

Community fundraising, corporate partnerships and the ongoing generosity of supporters across Ireland remain central to the organisation’s work.

Building on this strong foundation, there has been work undertaken to further develop a more strategic fundraising approach by deepening corporate engagement, strengthening long-term supporter relationships, and enhancing income stability. IMNDA will explore further opportunities to build relationships with philanthropic funders and major donors whose priorities align with the needs of people living with MND and their families, with a view to supporting sustainable, multi-annual investment in services, advocacy, research and organisational capacity.

However, voluntary income alone cannot sustainably underpin essential services.

There is a clear need to secure predictable, multi-year statutory funding that reflects IMNDA's role as a key provider within the health and social care system.

Over the lifetime of this strategy, IMNDA will pursue a balanced funding model, combining strong voluntary income with secured statutory funding to ensure that services are sustained and able to grow in line with need.



# OUR STRATEGIC APPROACH

The 2026-2030 strategy is built around two core principles:

- Strengthening what IMNDA does best: delivering high-quality, person-centred support
- Expanding IMNDA's impact: enabling a more connected system of care and influencing change nationally

At the heart of this strategy is the recognition that people living with MND and their families require co-ordinated, compassionate, and continuous support that evolves alongside changing needs throughout the full MND journey.

This reflects the strong consultation feedback that people affected by MND should not feel alone in navigating complex systems, changing needs, or difficult transitions.

The strategy therefore focuses not only on direct services, but also on how IMNDA connects services, supports families, builds partnerships, strengthens awareness, and influences systems nationally.

Delivering this strategy will require a whole-organisation effort. While frontline nursing and support services remain

central to IMNDA's impact, the strategy recognises the critical contribution of fundraising, community, communications & advocacy, finance, governance, operations, administration in enabling high-quality services and sustainable growth.

Fundraising and public support will continue to play a particularly important role in sustaining and expanding services over the lifetime of this strategy. The extraordinary generosity of communities, supporters, corporate partners, donors, volunteers, and campaign advocates across Ireland has enabled IMNDA to significantly strengthen supports for people and families affected by MND.

Over the next five years, IMNDA will continue to invest in building strong supporter relationships, increasing public awareness, strengthening community and major donor partnerships, and enhancing organisational capability to ensure services remain sustainable into the future.

This strategy therefore reflects the contribution of the entire organisation - recognising that every role across IMNDA contributes to supporting people and families throughout the full MND journey.

# 2026-2030

# STRATEGIC PILLARS

## **Pillar 1 Person-Centred Excellence**

Delivering high-quality, responsive, and compassionate supports that place people with MND and their families at the centre of everything we do.

## **Pillar 2 Support Throughout the full MND Journey**

Ensuring people and families experience co-ordinated, compassionate, and continuous support throughout the full MND journey.

## **Pillar 3 Advocacy, Evidence & Influence**

Strengthening IMNDA's role as a trusted national voice by influencing policy, raising awareness, building evidence, supporting research engagement, and shaping system change.

## **Pillar 4 Sustainable Growth & Capability**

Building a resilient, sustainable, and well-supported organisation with the people, systems, partnerships, and capability required to meet future demand.



# PILLAR 1: PERSON-CENTRED EXCELLENCE

Delivering high-quality, responsive, and compassionate supports that place people with MND and their families at the centre of everything we do.

Consultation feedback consistently highlighted the strength, responsiveness, and compassion of IMNDA services. The expertise and experience of nurses and staff, practical supports, and responsiveness to changing needs were repeatedly identified as core strengths.

This pillar focuses on protecting and strengthening this core capability while ensuring services continue to evolve in response to changing needs, increasing demand, and expectations around quality, equity, and accessibility.

## Strategic Commitments

### **1. Deliver excellent person-centred and individualised support**

We will continue to provide high-quality, compassionate and responsive support that reflects the individual needs, choices and circumstances of each person living with MND.

### **2. Improve access and responsiveness of support**

We will strengthen how people access IMNDA supports, with a continued focus on timely response, clear information and appropriate support as needs change.

### **3. Strengthen consistency and regional equity**

We will work to improve consistency of support across regions, recognising that people affected by MND should have access to high-quality support regardless of where they live.

### **4. Embed service quality, learning and improvement**

We will use feedback, service data, quality standards and reflective learning to continuously improve the quality and impact of IMNDA services.

Strategic KPI	5-Year Target
Overall service user satisfaction	Maintain or improve from Year 1 baseline, with an ambition to achieve ≥85-90% positive rating
Support reflects individual needs	≥85% of service users report that IMNDA support reflects their individual needs
Timely access to support	Year-on-year improvement in response times from Year 1 baseline
Regional equity of access	All regions demonstrate progress against an agreed minimum service standard by Year 5
Service quality and consistency	Service quality framework developed, implemented and reviewed annually by Year 5



## Operational Metrics

- Response time to referrals
- Number of home visits or contacts per client
- Equipment delivery timeframes
- Caseload ratios per nurse
- Number of service improvement initiatives delivered annually
- Service quality audit scores.

# PILLAR 2: SUPPORT THROUGHOUT THE FULL MND JOURNEY

Ensuring people and families experience co-ordinated, compassionate, and continuous support throughout the full MND journey.

Consultation findings highlighted the challenges many people experience navigating health and social care systems and in co-ordinating supports during periods of significant emotional and practical stress.

Caregivers described exhaustion, isolation, and the feeling that their own needs were often secondary. Bereaved family members also described the difficulty of the transition after the death of a loved one and the value of continued connection and support.

This pillar focuses on strengthening the experience around the person - ensuring that care is co-ordinated and there is continuity from diagnosis through to bereavement. The grief of loss to MND can be complex and there is a role for IMNDA to offer flexible supports to people “all the way” through the journey.

## Strategic Commitments

### 1. Develop a co-ordinated model of support

We will develop a clearer model of support that helps people and families understand what support is available at each stage of the MND journey and how IMNDA works alongside clinical and community services.

### 2. Strengthen family and caregiver supports

We will expand structured supports for families and caregivers, recognising the emotional, practical and ongoing demands of the caregiving role.

### 3. Provide support at key transition points

We will strengthen support at diagnosis, disease progression, end of life and post-bereavement, helping people and families feel better prepared, informed and supported.

#### 4. Strengthen bereavement as part of the wider journey

We will explore ways to support bereaved families through appropriate follow-up, signposting and practical guidance, recognising that the impact of MND continues beyond the death of the individual.

#### 5. Build partnerships that support navigation and continuity

We will strengthen relationships with healthcare, community and support organisations to improve navigation, signposting and continuity of support.

Strategic KPI	5-Year Target
Ease of navigating supports	≥80% of clients report that IMNDA helps them navigate supports effectively
Caregiver support	≥80% of caregivers report feeling supported by IMNDA
Planned support across the journey	Increased % of service users with a documented care/support plan, with target set following Year 1 baseline
Preparedness for next stage of journey	Improved “prepared for next stage” score across the journey
Bereavement Support	Increased proportion of bereaved families report feeling supported post-bereavement

### Operational Metrics

- Number of clients with full care plans
- Number of caregiver supports delivered (e.g. groups, counselling uptake)
- Percentage receiving bereavement follow-up
- Participation in peer supports/programmes
- Information resource usage.

# PILLAR 3: ADVOCACY, EVIDENCE & SYSTEM INFLUENCE

Consultation findings highlight significant challenges within the wider health and social care system, including variability in access, and limited awareness of MND among both the public and some healthcare professionals. Individuals and families often experience delays, gaps in community services, and difficulty navigating complex systems, reinforcing the need for stronger advocacy and system-level change.

This pillar marks a shift from IMNDA primarily responding to system gaps towards proactively shaping a more co-ordinated and equitable system of health care and social care. It reflects a commitment to ensuring that the needs of people with MND are understood, prioritised, and addressed at a national level.

Through targeted advocacy, strategic partnerships, education, awareness, research engagement and the use of evidence and lived experience, IMNDA will work to drive tangible improvements in access to services, resource allocation, and policy development. A stronger focus on awareness and education will also support earlier intervention, improved care, and more consistent understanding of MND across the health and social care system.

By amplifying the voices of people with MND and their families, IMNDA will continue to play a leadership role in shaping a system that is more responsive, informed, and compassionate.

## Strategic Commitments

### 1. Drive national advocacy for equitable access to services and supports

We will lead a focused programme of national advocacy to address inequalities in access to MND services, equipment and supports. This will include clear policy priorities, sustained engagement with decision-makers and a strong emphasis on securing appropriate funding and resources for MND services.

### 2. Strengthen education and awareness among healthcare professionals

We will increase understanding of MND among healthcare professionals and frontline staff through targeted education, information and engagement. This will support earlier intervention, more consistent care and improved experiences for people living with MND and their families.

### 3. Build evidence to influence policy, practice and service design

We will strengthen the use of data, lived experience, service insight and evaluation to inform advocacy, service development and national policy engagement. This will include more systematic capture of patient and caregiver experience, stronger use of internal service data and clearer evidence of the needs of people affected by MND.

#### 4. Strengthen research, innovation and evidence partnerships

We will define IMNDA’s role as a trusted connector between people living with MND, families, clinicians, researchers and national and international research networks. This will include improving access to clear information on research developments and participation opportunities, supporting patient and caregiver involvement in research and service design, and exploring opportunities to contribute to registries, data and evidence initiatives that support better understanding of MND and future care planning in Ireland.

#### 5. Build IMNDA’s national voice, profile and public awareness

We will strengthen IMNDA’s role as the leading national voice for MND in Ireland by increasing public understanding, improving the visibility of MND, and ensuring that the experiences of people living with MND and their families are central to advocacy, awareness and system change.

Strategic KPI	5-Year Target
IMNDA recognised as a trusted national voice on MND	Stakeholder perception feedback / survey
Policy and system engagement	Consistent increased year-on-year engagement through policy submissions and formal engagements/forums
Healthcare professional engagement	Year on year growth in healthcare professionals reached through education, information or awareness initiatives
Public awareness of MND and IMNDA	Baseline-to-trend improvement through campaign reach, media and public engagement
Research and academic partnerships	Growth in active partnerships with clinical, academic, research or evidence bodies
Lived experience involvement in advocacy and service design	Evidence that patient, caregivers and/or bereaved families have informed advocacy, research, awareness or service design initiatives annually

### Operational Metrics



- No. of policy submissions
  - No. of formal engagements with government and key stakeholders
  - Participation in advisory groups, forums and taskforces
- No. of healthcare professionals reached
- No. of research partnerships established
- No. of research opportunities communicated to service users
- No. of research updates/accessible resources produced
- Campaign reach and engagement; media coverage
- Social media engagement; no. of advocacy, awareness, research or service design initiatives informed by patients, caregivers or bereaved family members.

# PILLAR 4: SUSTAINABLE GROWTH & ORGANISATIONAL CAPABILITY

It is clear that in recent years, there have been increasing demands placed on the organisation. IMNDA's impact for people living with MND and their families is made possible not only through its frontline nursing, equipment, information and support services, but also through the wider organisational infrastructure that enables these services to be delivered, funded and sustained.

Over the next five years, IMNDA will place greater strategic emphasis on the support functions that underpin its work. Sustainable growth will depend on the whole organisation working together around a clear case for support, strong impact evidence, effective communications, robust financial reporting, good data, clear governance and a shared understanding of IMNDA's future funding needs.

IMNDA is currently highly dependent on public fundraising, with fundraising contributing an average of 85% of total income in recent years. While the fundraising team has delivered strong results and excellent donor care, the strategy also identifies the need to diversify income, strengthen supporter stewardship, invest in fundraising capacity, and improve data and CRM systems.

For this reason, IMNDA will continue to strengthen the organisational systems, roles and capabilities that sit behind direct service delivery. This will include investment in fundraising and supporter development, finance and reporting, communications and advocacy, CRM and data quality, internal processes, governance, compliance, staff development and cross-functional working. These supports are essential to ensuring that IMNDA can respond quickly to people affected by MND today, while also building the resilience, sustainability and capability required for the future.

This pillar focuses on strengthening the organisation's foundations to ensure long-term sustainability, resilience and impact. It recognises that delivering high-quality, person-centred services depends on a supported workforce, strong governance, effective systems, and a stable financial base.

## Strategic Commitments

### 1. Build a sustainable and diversified funding model

We will strengthen financial resilience by diversifying income, increasing predictable funding and aligning financial planning with strategic priorities.

## 2. Invest in workforce capacity, wellbeing and retention

We will support, develop and retain IMNDA's staff, recognising the emotional and operational demands of the work and the importance of a sustainable working environment.

## 3. Strengthen systems, data and digital infrastructure

We will invest in systems, data quality, digital capability and reporting processes that improve decision-making, service co-ordination and the ability to demonstrate impact.

## 4. Enhance governance, leadership and organisational effectiveness

We will continue to strengthen governance, leadership, accountability, planning and cross-organisational collaboration.

## 5. Build capacity to respond to future demand

We will ensure the organisation is positioned to adapt and respond to increasing demand, changing needs and wider system pressures.

Strategic KPI	5-Year Target
Diversified income mix	Reduced reliance on any single income source by Year 5
Predictable and recurring income	Year-on-year growth in recurring, multi-annual or predictable income streams
Financial resilience	Reserves maintained in line with Board-approved policy throughout the strategy period
Workforce retention and wellbeing	Improved staff retention and wellbeing
Systems, data and digital capability	Successful implementation of core systems (CRM, data infrastructure)

## Operational Metrics

- Fundraising income by stream
- Donor retention rates
- Grant applications
- Staff turnover rates (annual)
- Training participation rates
- CRM implementation milestones
- Data completeness rates
- Board reporting timeliness
- Internal engagement scores
- Cyber security and compliance actions.

# IMPLEMENTATION

This strategy will be delivered through phased implementation over five years, supported by annual operational plans and regular review. Progress will be tracked at two levels. Strategic KPIs will be monitored at Board level over the lifetime of the strategy and will focus on the outcomes and indicators most closely linked to IMNDA's strategic impact. Operational metrics will be tracked through annual operational and departmental plans and may evolve over time to reflect changing priorities, capacity and implementation progress.

Year 1 of the strategy will establish or confirm baseline data for key indicators. Where no reliable baseline currently exists, targets will be expressed as improvement trends over the five-year period, with specific numerical targets confirmed once baseline data is available. This will ensure that the strategy remains ambitious, realistic and capable of being meaningfully reported.

Implementation will focus on:

- Clear prioritisation of actions
- Alignment of resources to strategic priorities
- Ongoing stakeholder engagement
- Partnership development
- Continuous improvement and learning
- Regular monitoring and reporting

A balanced scorecard approach will be used to track progress across four areas:

- Service quality and impact
- Experience of individuals and families
- Advocacy and System Influence
- Organisational sustainability and resilience

## Impact Outcomes

- People with MND experience consistent, high-quality support
- Families feel supported, informed, and less isolated
- There is improved co-ordination and continuity of care for people living with MND
- There is stronger national recognition and support for MND
- IMNDA is a sustainable organisation capable of meeting future demand

# CONCLUSION

This strategy reflects the voices, experiences, and priorities shared throughout the consultation process.

It builds on IMNDA's considerable strengths while recognising the increasing complexity of the environment in which people living with MND and their families are navigating.

Over the next five years, IMNDA will continue to strengthen high-quality supports, improve co-ordination and continuity of care, advocate for system change, and build a resilient organisation capable of meeting future need. Most importantly, this strategy is grounded in IMNDA's commitment:

**No person or family affected by MND should feel alone.**

Through compassionate support, strong partnerships, national advocacy, and co-ordinated services, IMNDA will continue to stand beside people and families throughout the full MND journey.





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Joseph Ritchie, Board Member  
Lisa Doherty, Board Member  
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Orlagh Reynolds, Board Member  
Aisling Moore, Board Member  
Paul Ryan, Board Member