



# Making time count for people living with motor neuron disease

2022-25 Strategy

# A bold new chapter

At MND Scotland we strive to be flexible and adaptable to changing circumstances, growing, and **building on** everything we have learned over the last **forty years** and through the COVID19 pandemic.

We must not lose that learning and our new 3-year strategy seeks to build on our experience and expertise, harnessing our unique position at the heart of the motor neuron disease (MND) community, to guide us forwards to become a more robust, resilient, and engaging organisation. A bold new chapter.

Whilst this is a 3-year strategy, it will not sit on a shelf and gather dust – our strategy is a living, breathing document which will flex and grow, benefitting from our ethos of **continuous improvement** and firm commitment to being **founded in the voice of lived experience**.

**MND Scotland is unique.** We are the **only MND charity in Scotland** to be privileged to offer direct support to those of you living with MND and your friends and families. We know you. We laugh with you, and we cry with you. We are your voice in a system

where it can feel you have none. We are here to support you **every step of the way**.

We would not be where we are without our supporters, and we give you our **continued commitment** that we will make every penny you raise work hard, being **efficient** in our processes and **innovative** in our outlook to ensure we can significantly but **sustainably** increase the amount we spend on providing services for people living with MND and their loved ones. Over the coming months we will grow as an organisation but not for the sake of it – I give you my assurance of that – rather because there is so much more to be done to support everyone affected by MND in Scotland.

We will be **proactive** in our approach, continuing to invest in ground-breaking **research**, making your voice heard through our tireless **campaigning** and ensuring that people with MND have the **best possible**



**outcomes** in life and dignity in death. We will forge new and robust partnerships across and within sectors, learning and sharing knowledge and collaborating wherever possible.

Reaching new audiences with our message, we aim to ensure every person in Scotland knows MND Scotland and how we can help. So they know we are here for them should they need us.

Every one of us at MND Scotland is committed to our cause and to you.

Together, we will make time count.

*Rachel*

**Rachel Maitland**  
CEO, MND Scotland

# The helping hand of support

Our vision is a world without MND. Until that day comes, our mission is to make time count for everyone affected by MND in Scotland.

Since our charity was founded forty years ago, we have been at the front line against MND in Scotland. We fund ground-breaking MND research and world-class clinical trials. We campaign to fix a broken system and to secure lasting change.

But much of our day-to-day work is in **making time count** for people with MND and the loved ones supporting them.

Whether that's helping families make memories through accessible holidays, grants to improve quality of life, or an Advocate to fight their corner and secure essential home adaptations faster, we are here to help.

Our new logo and refreshed visual identity encapsulates why we are here.

When time matters most, we're a helping hand of support, so you can make precious time count with the ones you love.



## A word from Co-founder Peigi Macleod



Forty years ago, the Scottish MND Association was founded in the front room of Peigi and John Macleod, after police officer John was diagnosed with MND and could find little support.

Since 1981 our name has changed, and our logo has changed and evolved too. But the one thing that hasn't changed, nor will it, is our commitment to the people we serve.

*"John's determination from the outset was to support individuals and families with this devastating disease and to find a cure for MND."*

*"The new branding and logo are part of the evolution of the charity and will help grow fundraising for those needing support and the researchers working to find a cure."*

*"John would be delighted to know where the charity is today. However, I can hear him saying: 'Don't stop now, get on with it!'"*

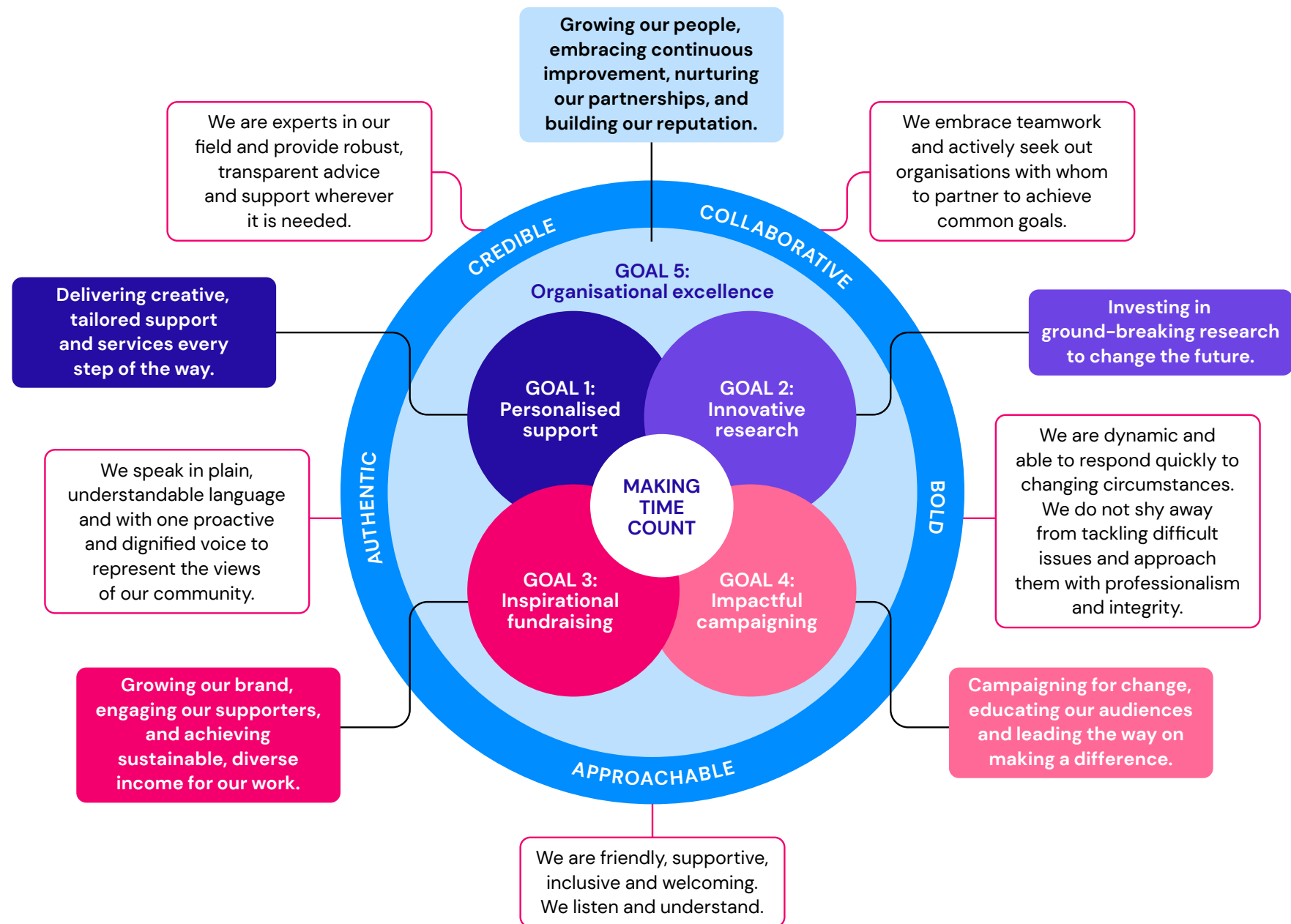


“Making time count is a principle that runs to the very heart of our organisation. Everything we do, and the way in which we do it, puts the MND Community at our core. Our values and goals define us. We are proud that they do.”

Rachel Maitland,  
MND Scotland CEO



# How we will make time count





# Goal 1: We will provide personalised support



We will provide a tailored, consistent support offering to each person affected by MND across Scotland.

## We already:

Provide hands-on practical, emotional and financial support to anyone affected by MND across the country through our:

- Advocacy service
- Welfare & Benefits support
- Equipment provision
- Grants
- Peer group support
- Counselling
- Physiotherapy
- Accessible holiday accommodation
- Information and advice

## Over the next three years we also commit to:

- Introducing tailored respite and bereavement support services
- Celebrating carers and ensuring we offer a dedicated suite of services to support their specific needs
- Providing a dedicated support line for anyone affected by MND
- Providing further holiday accommodation to enable more people affected by MND to spend precious time with their loved ones
- Developing our support for children and young people
- Integrating smart technology across our support services



# Goal 2: We will invest in innovative research



We will adopt a collaborative approach to funding MND research, avoiding duplication and with the aim of discovering effective treatments, improving quality of life, and finding a cure.

## We already:

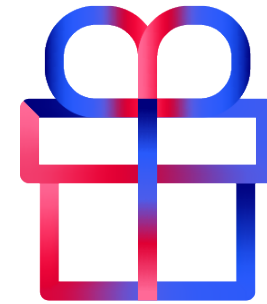
- Are the majority funder of MND-SMART, a pioneering MND clinical trial which allows hundreds of people across the UK to take part in testing potential treatments
- Co-fund the Gordon Aikman Scholarships to understand better ways of supporting people living with MND
- Fund the collection of brain and spinal cord tissue for use in medical advances in the understanding of MND
- Fund early career researchers to ensure the MND research community continues to thrive in the future

## Over the next three years we also commit to:

- Extending our investment in innovative clinical trials and bioresources to speed up routes to new treatments
- Ensuring our research funding decisions are informed by the priorities of people affected by MND, MND research scientists, and the clinical community
- Identifying new funding strategies to better understand MND, build future research capacity, and lead to genuine impact for people affected by MND
- Promoting engagement, raising awareness, and campaigning to ensure the importance of MND research to people affected by MND is understood
- Embedding partnership working in our ethos to enable transformation in MND research



# Goal 3: We will be inspirational in our fundraising



We will inspire, excite, and delight new and existing supporters, ensuring that we are providing superb supporter care in order to raise the funds needed to continue our vital work.

## **We already:**

- Deliver a programme of well-loved events to an established base of incredible supporters

## **Over the next three years we also commit to:**

- Identifying, capturing, and sharing extraordinary stories about our work to raise awareness of MND amongst a wider audience
- Inspiring, engaging, retaining and attracting new supporters by being clearer and more vocal about how their support helps people living with MND
- Diversifying our income streams and events programme to ensure a robust future for the charity
- Developing new ways to demonstrate our impact, ensuring that supporters can see the value we create with their money
- Develop a 'living' impact assessment, allowing our supporters to access up to date information about how we are spending their money





# Goal 4: We will be impactful in our campaigning



We will proactively influence key decision makers to bring about meaningful and long-lasting change to benefit people affected by MND.

## **We already:**

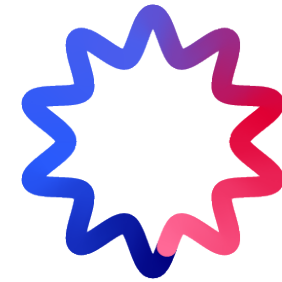
- Actively work to improve how people with MND are treated by the system

## **Over the next three years we also commit to:**

- Further educating and engaging policy makers and legislators to ensure that their decisions are informed by the needs, diversity, challenges and urgency faced by people affected by MND
- Proactive lobbying to ensure greater consistency in approach across local authorities in all areas affecting people with MND
- Campaigning with one voice to deliver the changes needed to make life fairer for people affected by MND
- Working collaboratively with like-minded organisations to change the narrative about disabilities in Scotland



# Goal 5: We will embody organisational excellence



We will be our best in everything that we do.

## We already:

- Put teamwork, communication and staff well-being at the core of what we do

## Over the next three years we also commit to:

- Extending our reach across Scotland to ensure we are on everyone's radar should they, or a loved one, need us
- Ensuring that the views of people affected by MND are central to the development, implementation, and ongoing evolution of all activities across the charity
- Educating our audiences to raise awareness of MND
- Attracting, developing, and motivating the very best team, ensuring everyone has the appropriate knowledge and understanding of what we do and how we do it whilst ensuring staff well-being is paramount
- Developing strong influencing, communication, collaboration, and fundraising skills across the organisation to ensure we are cohesive in approach and able to fully engage with our supporters
- Being efficient, ethical and transparent in our processes
- Working towards becoming a carbon neutral organisation







“The support of my family, friends and MND Scotland during Liz’s illness was absolutely vital to me every day. I’m looking forward to seeing MND Scotland grow and do even more for those living with MND today.”

Alan Ogg



# Key questions

To ensure we meet our strategic goals, whilst remaining true to our values, every decision we make will be assessed against 6 key questions:

1

Will it make things easier for people with MND and friends and family, foster hope and be founded in lived experience?

2

Will it increase our reach to ensure a wider understanding of MND and engagement with our purpose and commitment to making time count?

3

Can the work be undertaken within the existing governance, risk, and compliance framework of the organisation?

4

Does it support our commitment to investing in team growth and development?

5

Will it improve the diversity, sustainability and strength of our funding base?

6

Does it build on our existing strengths and skills and allow for sustainable, organic growth?



# With **special** thanks to:

Peigi Macleod, our founder, and her sons Donald, Iain and Gordon for their ongoing support and involvement

MND Clinical Nurse Specialists

MND Consultants

Our supporters

Our corporate partners

Our friends at MND Association, Irish MND Association and My Name's Doddie Foundation

## **Our Trustees:**

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Founders: John and Peigi Macleod Royal Patron: HRH Princess Royal

MND Scotland, 6th Floor, Merchant Exchange, 20 Bell Street, Glasgow, G1 1LG. Company limited by guarantee, registered in Scotland. Company number SC217735. Scottish Charity number SC002662. VAT number 195 0616 96.