

Youth and Philanthropy Initiative (YPI) Scotland Further Information Booklet



What is MND?

Motor neuron disease (MND) is a rapidly progressing terminal illness which stops signals from the brain reaching the muscles. This may cause someone to lose the ability to walk, talk, eat, drink, or breathe. The average life expectancy of someone with MND is just 18 months from diagnosis.

There is no cure or meaningful treatments.

MND not only causes physical health issues for individuals, but may also have a significant impact on their mental health, social issues, and the financial situation of them and their loved ones. For both someone with MND and their family, a diagnosis is incredibly challenging with people often having to deal with issues such as depression, anxiety, apathy and anticipatory grief, alongside MND.

After a diagnosis, a person may have to give up work and often a loved one must also stop working to become a full-time unpaid carer. This can change the dynamic in a relationship, make people feel isolated or change how they see themselves. In addition, as the disease progresses, people often require home adjustments, such as wet rooms, ramps, and expensive equipment to live as independently as possible.

Unfortunately, there is currently no cure or meaningful treatment for MND available in the UK. The current treatment offered, Riluzole, extends a person's life by around three months, but does not stop or slow disease progression.

It's important that we continue to fund research and learn more about the disease to help us improve diagnosis, care and treatment options for people with MND in the future.

MND Scotland is here to make time count for people in Scotland living with MND and their loved ones.



Our Services

MND Scotland is the only charity that provides direct support to people affected by MND and their loved ones in Scotland, while also funding vital MND research. Our dedicated support team provide the following support:

Benefits advice and income maximisation

Our Welfare & Benefits Service provides professional guidance to help people claim all the benefits they're entitled to in order to maximise their income.

Last year, **234** people received a benefits review, generating over **£1.4 million** in additional income for people with MND and their carers.



Counselling service

Our Counselling Service provides free, confidential support to people living with MND and their loved ones. We also offer specialised bereavement counselling for those who have lost a loved one to MND.

Each person can receive **8** free sessions and last year we provided **1,560** hours of counselling.



Advice and support service

Our Advice and Support Service offers specialist guidance on care, housing, and home adaptations, helping people live safely and independently at home as well as advocating on social and housing issues.



Voice banking funding

We work in partnership with [SpeakUnique](#) to help fund Voice Banking, enabling people with MND to preserve their voices and maintain independence in communication.

Thanks to us, **66** people were able to bank their voice for free.



Accessible holiday lodges

For families looking for a break, we provide free accessible holiday accommodation.

Our lodges are fully accessible and equipped to meet our clients' needs, allowing them to spend more time making lasting memories with their loved ones. Last year, we welcomed **370** guests to our lodges in St Andrews and Oban.



Policy and campaigning

Through Policy and Campaigning, our team represents the voices of people with MND.

We work closely with the Scottish Government and MSPs to address key issues such as housing and social care.



(please note all statistics relate to the 24/25 financial year)



Our organisation also funds vital MND research that looks to help us better understand what causes MND, what goes wrong in MND, and ways that we may be able to try and treat it. Adding to our growing knowledge of MND will help us to improve diagnosis, care, and treatment for those affected by MND in the future.

At MND Scotland we fund:

- Clinical trials such as the UK's largest MND clinical trial MND SMART, which tests potential treatments for MND.
- Research aiming to help better understand the causes of MND and identify new treatments or targets for treatments.
- Research to help us improve how MND is diagnosed to help speed up the time consuming and stressful diagnostic process.
- Social science research to help understand some of the behavioural changes that can be seen in MND and how an MND diagnosis impacts a person, or their families, quality of life.
- Projects which aim to improve the care services available for people affected by MND.

We have been investing in research since the late 1980's. You can find information on the research we currently fund on our website.

Our Research Team also runs engagement events for people with MND across the country to meet with local MND researchers and learn about the MND research going on in their area. These **Lived Experience and Researcher Network** (LEARN) events bring local MND communities together to share knowledge and experience as well as build connections.

Who does MND Scotland help?

We are committed to making time count for everyone with and affected by MND in Scotland by providing direct support to them and investing in research to help those affected by MND in the future.

In 2024/2025 our organisation was able to provide support to 94% of people living with MND in the country and we continue to offer our support to all.

Stuart's story

Stuart Mactaggart, from the Scottish Borders, was a carer for his wife, Claire, following a motor neuron disease diagnosis.

Claire was diagnosed with MND on 5th July 2024 and sadly passed away in August 2025.

The couple were able to access support from MND Scotland and holiday at the St Andrew's Lodge after Claire was diagnosed.

"MND Scotland has been brilliant. When we were told about Claire's MND diagnosis, we didn't know what to do or where to go for support. MND Scotland stepped in and did everything for me – from helping with accessing benefits to providing support on how to set up Power of Attorney, and support in writing a Will – they were fantastic. Without them, it would have been a minefield, and I wouldn't know what I would have done. I sincerely can't speak any more highly of them".

[Read more of Stuart's story here](#)



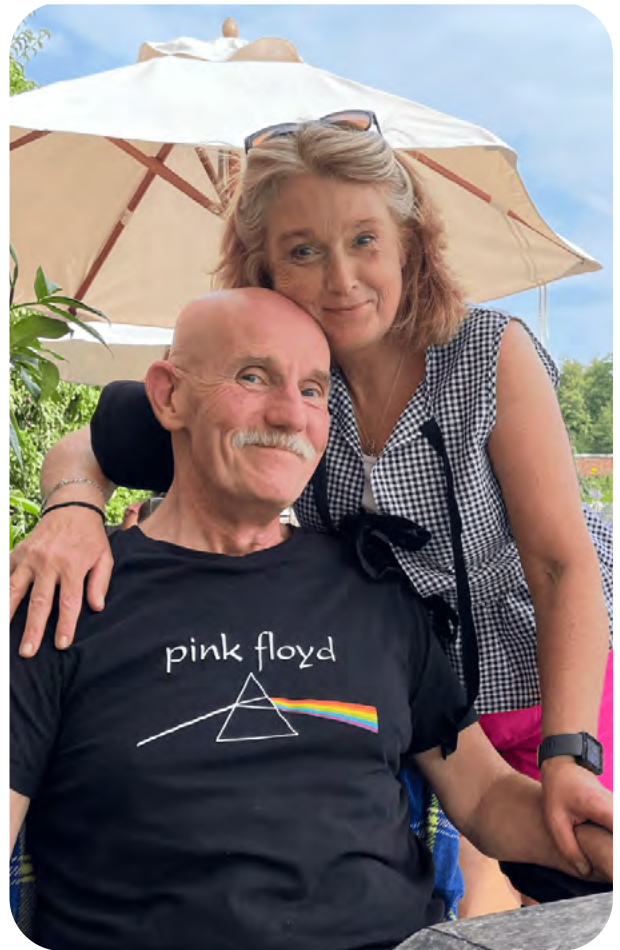
Lynda and Bill's story

Lynda Gilroy, from Darnick near Melrose, cares full-time for her husband Bill, 66, who was diagnosed with MND in October 2024.

Lynda has been campaigning alongside MND Scotland's Policy Team for change to Scotland's home adaptations system after being forced to wait more than a year for essential work – despite the average life expectancy following a diagnosis of motor neuron disease (MND) being just 18 months.

Lynda is determined to use her voice to prevent others from facing what she and Bill have endured, *"I want the process to be changed because I don't want other people to go through what we have experienced. Nothing will change in time to help Bill. But if telling our story helps save one other family from going through this, then it's worth it".*

[Read more of Lynda's story here](#)



Lucy's story

Lucy Lintott-Smith was a teenager when she received the devastating news that she had motor neuron disease (MND). Now, twelve years later, she continues to navigate her journey with MND, whilst being a loving mother to three beautiful children and a devoted wife to her husband, Tommy.

Speaking about MND Scotland's research projects including, LEARN, Lucy said,

"Events like these matter to me because living with MND can feel isolating, even when you have amazing family and friends. Being able to meet others who truly understand, to share experiences, and to learn from each other is invaluable. Hearing directly from researchers gives me hope that progress is being made towards finding a cure. For me, it's about knowledge, connection, and leave remembering that we're not alone, and about the hope, support, and practical tools to face the future".

[Read more of Lucy's story here](#)

What could MND Scotland do with £3,000?

£3,000 could help support MND Scotland make time count for people affected by MND by:



Providing 60 hours of counselling for people living with MND and their loved ones.



Allowing 6 families to spend 3 nights each at one of our accessible holiday lodges.



Paying for between 5 and 12 people to have their Wills or Power of Attorney arranged..



Paying for 12 people to have their voice banked through SpeakUnique.



Covering running costs for up to 6 local support coffee afternoons.



Covering the running costs for up to 6 LEARN local events.



Contribute towards our currently funded research portfolio.

Our community

MND Scotland offers support to people affected by MND.

Our support team works with local authorities and health boards to help make sure people with MND, no matter where they are in Scotland, get the care and support they need and deserve. We work closely with the MND Specialist Nurses across all health boards to make sure that every person diagnosed with MND is aware of our organisation and the support we can provide to them.

Our local events, like our support coffee afternoons and research LEARN events, bring people together to build relationships for support and advice from others who have a lived experience of the condition.

We have funded research at Universities in St Andrews, Dundee, Aberdeen, Edinburgh, Glasgow, as well as locations within NHS Fife, NHS Tayside, NHS Greater Glasgow & Clyde, NHS Highlands, NHS Lothian and NHS Ayrshire & Arran. This not only has helped ensure research thrives in areas across Scotland but also helped create jobs and pay salaries in local communities.



Resources

To support your presentation please find below a selection of resources that you might find helpful.

Powerpoint template

Video 1

Video 2

Video 3

Video 4

Video 5

Photo 1

Photo 2

Photo 3

Photo 4

Photo 5

Photo 6

Photo 7

Photo 8

Photo 9

Photo 10



Making time count for people with
motor neuron disease (MND)
mndscotland.org.uk



mndscotland



@MNDScotland

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