MND Scotland
Making time count

There's no time to lose

Our manifesto for the 2026 Scottish Parliament Election

Time isn't on our side

MND is a rapidly progressing terminal illness which causes a person to lose the ability to do things like walk, talk, eat or breathe unaided. In Scotland right now, 481 people are living with MND, and over 200 people are diagnosed each year. As a progressive, neurodegenerative condition, MND affects every part of a person's life. The average life expectancy of someone diagnosed with MND is just 18 months from diagnosis.

Receiving a diagnosis of MND is devasting for the individual, and the people around them. No one with a terminal illness should be spending the precious time they have left fighting to get the support they need to live safely and with dignity. But this is the situation facing many with MND, as statutory services fail to keep up with the rapidly progressing nature of the disease. We hear reports of people washing loved ones on garden decking; of people trapped in a single room; of family lifesavings and pensions being drained or taking on debt to pay for what should be a statutory provision; and of care assessments and packages which are so delayed that someone has died by the time they are started.

MND Scotland's vision is for a Scotland where no one with MND is left without the support they are entitled to. We want people to be able to focus on making memories with loved ones, and what matters to them, rather than waiting for statutory services and support which might never arrive in time.

To achieve this, the next Scottish Government must legislate and recognise the urgent statutory rights and needs of those with terminal illnesses like MND, to deliver timely, fast-tracked support for everyone with MND.

We are therefore calling on the next government to deliver:

1. Invested in, and fast-tracked, housing and adaptations

2. Fast- tracked social care

3. Increased, targeted funding for neuro-progressive conditions.

There is no time to lose.

The current situation

The cost of MND is enormous…

From quality of life, through to the financial costs which those affected bear, the impact of MND on an individual and their family is enormous. Recent data tells us that families spend an average of **£12,000** on medical equipment and adaptations following diagnosis, with many forced to rely on savings, releasing equity, or falling into debt.

Yet statutory services have waiting lists longer than average life expectancies in some local authorities[1]…

15.5 months
for a ramp

4 years
for alternative
accessible housing

9 months
for a wetroom

And people are struggling to get the support they need…

The most common problems people tell us about are housing adaptations, accessible housing and social care. Along with lengthy delays for accessible and adapted housing, many people find themselves waiting weeks for care packages to be put in place, and unpaid carers are often left to plug gaps without sufficient support. **60%** of people with MND, **65%** of family members, and **85%** of bereaved family members told us that they faced delays in accessing care packages[2].

60%

of people with MND
faced delays

65%

of current family
members/carers
faced delays

85%

of bereaved family
members/carers
faced delays

We need systems that keep pace with MND to make life better for those affected now. This must go hand in hand with investment in research, so that the future of MND looks different. MND is not uncurable. But it is underfunded.

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[1] - ' No time to lose: Addressing the housing needs of people with MND', MND Scotland (2022)

[2] - Research conducted by MND Scotland, 2023

Our Priorities for the 2026 Scottish Parliament election

1. Invested in, and fast-tracked, housing and adaptations

We need a housing system that: receives proper investment, with increased percentage building targets for wheelchair accessible housing; clear and consistent definitions; and greater funding consistency across tenure types.

2. Fast-tracked social care

We need fast-tracked assessments, an invested in social care workforce, respite for family members, and proactive support that can cope with progressing needs.

3. Increased, targeted funding for rare, neuro-progressive conditions

The next Scottish Government must devise a long-term roadmap to help unlock this, and enable investment in rare, neuro-progressive research and development.

1. Invested in, and fast-tracked, housing and adaptations

The current situation:

For people living with MND, having somewhere safe and accessible to live is a time critical necessity.

- Waiting lists for adaptations such as ramps and wetrooms are extensive. A lack of proactive policies means that people with terminal and progressive conditions risk never receiving the support they need. We reported that the average wait time for a ramp in one local authority was 15 months. In addition, budgets for adaptations are being spent rapidly, meaning individuals are having to wait for the next financial year for support – a wait which is untenable in the context of terminal illness.
- Not all homes can be adapted. In these cases, alternative housing may be necessary. There is a widespread lack of accessible housing stock, meaning that waiting lists for alternative wheelchair accessible properties are longer than the prognosis for someone living with a terminal illness. Our 2022 report charted a four-year wait in one local authority and a similar picture across many others.
- Different local authorities use different definitions of accessible and wheelchair accessible homes. One local authority has a definition for wheelchair accessible which includes 'fewer than four steps up to the front door'.
- A lack of accessible housing and delays in adaptations processes also increases costs to social care, NHS, and contributes to delayed discharge.

Our ask: A properly invested in housing system with clear and consistent targets and definitions ensuring people with MND are not left waiting and at increased risk of harm.

We want to see the next government commit to:

- Increased targeted investments in adaptations, and urgent delivery the already committed to adaptations review.
- Greater funding consistency across tenure type for adaptations.
- Establishing a consistent national standard for accessible housing, informed by and with disabled people, housing associations, local authorities, and other key partners.
- Commitments to increased new build accessible housing targets to at least 10%.
- Recognising the budgetary links between health and housing, including the benefit spend-to-save of investing in housing to save health and social care costs.

2. Fast-tracked social care

The current situation:

- A diagnosis of MND means a person might need support with day-to-day activities, especially as the condition progresses. This can include support getting out of bed, with personal care, with feeding, and with assistive equipment.
- Issues such as delays with getting assessments, a shortage of care staff, a lack of training, and a postcode lottery of care means that many people are not receiving high-quality, equitable or consistent social care. This has detrimental impacts on both the person diagnosed with MND, as well as family members who are left to provide exhausting, relentless 24/7 care.
- Only 20% of current carers feel able to take time away from caring, with poor awareness of respite and inadequate provision of regular breaks, overnight care, or occasional time off.

Our ask: A social care sector that works for people living with a terminal illness like MND, and recognises the importance of getting support in quickly

We want to see the next government commit to:

- Prioritisation of secondary legislation relating to fast-tracking care assessments under the Care Reform (Scotland) Act, including interim measures to enable people to access fast support now.
- Fair pay for the workforce, to ensure that social care workers are valued and paid a wage which matches the skilled, compassionate work these professionals provide.
- Clear, proactive and accessible respite provision breaks for Carers.

Increased, targeted research funding for neuro-progressive conditions

The current situation:

- For many living with complex, rare, and currently incurable neurological conditions, advances in medical research can be lifesaving and life changing, but they continue to be underfunded.
- Despite being a hotbed for scientific research, most recent data from 2022 suggests that the Scottish Government invests more than a third less per head of the population on medical research than the UK government does in England[5].
- Charities are a major funder of medical research and development in Scotland, investing an estimated £122m; every £1 million spent on medical research supports 31 jobs which is almost double the Scotland average of 17[6].
- Despite the Scottish Government's desire to grow and strengthen a 'more inclusive and innovative Scotland'[7], and clear financial and scientific benefits, universities are making substantial staffing cuts, affecting research. In addition, the nature of short-term research funding means many are leaving the research sector entirely, being attracted to offers in other countries, or being forced to move to work on conditions with greater funding attached.

Our ask: Increased targeted funding for research, infrastructure and career development for researchers working on rare and neuro-progressive conditions.

We want to see the next government commit to:

- Developing a long-term strategy and accompanying roadmap to enable investment in rare, neuro-progressive research and development.
- Greater targeted and increased funding and investment in research specific to rare and neuro-progressive conditions such as MND.
- Making neurological research more accessible through opportunities, multi-year funding, and schemes which attract and retain a diversity of researchers at all career stages.

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5 - Medical research in Scotland - BHF - https://www.bhf.org.uk/what-we-do/in-your-area/scotland/medical-research-in-scotland/

6 - fraserofallander.org/wp-content/uploads/2022/03/FAI-The-contribution-of-medical-funding-by-charities-to-the-Scottish-economy.pdf

7 - Science and research - gov.scot - https://www.gov.scot/policies/science-and-research/

Conclusion

We need a Scotland where no one with MND is left without the support they are entitled to. We want people to be able to focus on making memories with loved ones and what matters to them, making time count rather than waiting for statutory services and support which might never arrive in time. We want a world where research into neuro-progressive conditions is invested in, so that we no longer need to say that MND has a devastating prognosis or a lack of treatment.

We must act now.

About MND

Motor neuron disease (MND) is a rapidly progressing terminal neurological illness, which stops signals from the brain reaching the muscles. This causes muscle weakness and wasting. MND can rob someone of the ability to walk, talk, swallow and breathe. The average life expectancy of someone with MND is just 18 months from diagnosis. There is no cure or meaningful treatments.

Key stats

- Someone's lifetime risk of getting MND is 1 in 300
- There are around 480 people in Scotland currently living with MND
- On average almost 200 people are diagnosed each year in Scotland
- 30% of people with MND die within 12 months
- Average life expectancy is just 18 months from diagnosis.

About MND Scotland

MND Scotland is the only charity in Scotland dedicated to directly supporting people with MND, their families and friends. Since being founded over forty years ago, MND Scotland has provided practical, financial and emotional support to anyone affected by MND whilst also funding essential research into finding effective treatments and a cure. MND Scotland is funded entirely by donations and grants. The charity's patron is Her Royal Highness, the Princess Royal.

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Royal Patron: HRH Princess Royal

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