

May 2026

First Minister
Holyrood
Edinburgh
EH99 1SP
Scotland

Dear First Minister,

In Scotland right now, 481 people are living with Motor Neuron Disease (MND). Between now and 2031, we estimate another 1,000 more people will be diagnosed across the country. There is no cure. The average life expectancy is just 18 months from the point of being diagnosed.

The cost of MND is enormous. Yet statutory services have waiting lists longer than life expectancies in some local authorities, and people are struggling to get the support they need. No one with a terminal illness should be spending the precious time they have left fighting to live safely and with dignity. This is the situation facing many with MND, as statutory services fail to keep up with the rapidly progressing nature of the disease.

Our top priorities for this Scottish Government

We need to make things better for people now and in the future. To do this, we must achieve:

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. No one should be trapped in their homes, unable to access washing facilities.

2. Fast-tracked social care

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



Fast-tracked assessments for those with terminal illness were committed to in the Care Reform Act. But people are still waiting with no change almost a year on. People with MND need fast-tracked assessments and interim measures to enable fast-tracking now, 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

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

In your role as First Minister, you have the power to make a difference for people with MND. We need you to make our vision of a Scotland where no one with MND is left without the support they are entitled to a reality. 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. There is no time to lose.

Yours sincerely,

MND Scotland

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