

Motor Neurone Disease Association: General Election Manifesto 2019

We call on all political parties to pledge to:

- **Urgently reform the definition of a terminal illness for the purpose of accessing benefits by removing the 6-month restriction**
- **Develop a sustainable and fair funding solution for social care, which must include both older people and working-age adults**
- **Provide more funding for home adaptations and build more accessible homes**
- **Prioritise and improve support for unpaid carers**
- **Develop a funded MND research strategy to accelerate progress towards a world free from MND.**

1) Supporting people living with a terminal illness to access welfare benefits

The problem: The benefits system has a special pathway for people living with a terminal illness. It fast-tracks a benefits application and removes the need to complete long forms, attend an assessment and carry out work-related activities. Although MND is terminal in all cases, many cannot access this fast-track because in law there must be a reasonable expectation of their death within 6 months. This 6-month restriction unfairly excludes many people with MND simply because they have a complex and unpredictable terminal condition. In addition, an award under the special rules only lasts for three years, which makes no sense as the person's condition will only worsen during that time.

The solution: The next government must remove the 6-month restriction from the definition of a terminal illness under the Welfare Reform Act (2012). This change was recently made by the Scottish Government, and they also removed the three-year award duration. The next government must urgently enact a similar law change for the rest of the UK.

2) A sustainable funding settlement for social care

The problem: The urgent funding crisis affecting adult social care services needs immediate and decisive action. The system struggles to meet the current levels of social care need and is not equipped to deal with future pressures as the population changes. This is an issue keenly felt by people living with MND. As a severely disabling and progressive condition, most people are likely to have significant care and support needs. Our latest survey of people living with MND found only 27% of respondents received social care.

The solution: The next government must address significant funding shortfalls in the social care system in the short-term and deliver a sustainable funding solution for the long-term. Importantly, these solutions must cover both older people and working age adults.

3) Funds for more accessible homes for disabled people

The problem: Finding an accessible home or adapting an existing home for someone living with MND is time critical as the condition usually progresses rapidly. Yet there is a chronic shortage of homes built to accessible standards. People with MND and their families also

experience problems with accessing housing adaptations. The cost, time taken, and a lack of information are some of the greatest barriers. To find out more, read our [Act to Adapt](#) report.

The solution: The next government must build more accessible homes for disabled people, including to fully wheelchair accessible standards. It must also provide more funding for Disabled Facilities Grants (DFGs) as part of the Better Care Fund beyond 2020/21.

4) Support for unpaid carers

The problem: Unpaid carers make an enormous contribution to the lives of those they care for as well as to the UK's economy and society. Too often this contribution is overlooked by government. For example, at £66.15 per week, Carer's Allowance does not provide adequate support to carers, many of whom do the equivalent of a full-time job and more, whilst collectively providing unpaid social care estimated to be worth at least £57 billion.

The solution: The next government must fully identify and address the needs of unpaid carers. As a start, the next government must immediately raise the level of Carer's Allowance to that of Jobseekers Allowance.

5) Support for MND research

The problem: There is still no cure for MND, and treatment options are very limited. Only one drug is available to treat MND progression through the NHS, and it has only a small (though proven) impact on disease progression. Consequently, MND remains a terminal and progressive condition in all cases. In addition, the causes of MND are not yet understood, and no biological indicators have been identified to enable faster diagnosis and improved understanding of disease progression. The MND Association funds and supports research as a top priority, but the government must do more to speed up the search for a cure.

The solution: The next government must develop and implement a funded MND research strategy to accelerate progress towards a world free from MND.

About motor neurone disease (MND):

- MND is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure
- While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe
- MND kills a third of people within a year and more than half within two years of diagnosis
- A person's lifetime risk of developing MND is up to 1 in 300. There are about 5,000 people living with MND in the UK.

Who we are: The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland. Our vision is of a world free from MND. Until that time, we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

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