

We are calling for:-

FULL IMPLEMENTATION OF QIS STANDARDS FOR MND

The NHS QIS standards for Neurological Health Services were introduced in October 2009. As well as generic standards which apply to all neurological conditions, 13 standards that relate specifically to MND were also introduced. Full implementation of these standards would represent a significant step forward in the delivery of care for people with MND and would allow care to be delivered equitably across Scotland and would significantly improve on the standards of care currently being received

SUPPORT FOR MND RESEARCH

Clinical research in the UK can be intensely bureaucratic, with significant time and resources spent on administration. The burden falls disproportionately on rarer diseases like MND which require multi-centre participation in clinical research because of their low prevalence.

The opportunity to take part in clinical trials is known to be psychologically beneficial to people with MND, irrespective of whether the trial provides them with any improved clinical treatment; this opportunity should be made available to all people with MND who wish to make use of it.

IMPROVED ACCESS TO EQUIPMENT AND ADAPTATIONS

A significant improvement in the way statutory services respond to rapidly progressive diseases like MND is needed to ensure that people with MND receive appropriate equipment in a timely way.

A national 'fast track' procedure needs to be instituted and a person diagnosed with MND should automatically be dealt with under this procedure.

IMPROVED ACCESS TO BENEFITS

People with MND and their carers are typically entitled to two key benefits: one of either Disability Living Allowance (DLA, for those under 65) or Attendance Allowance (AA, for those over 65); and Carers' Allowance (CA). All are prone to slow payments and difficulty of access which causes anxiety and places undue stress on people with MND and their carers.

A diagnosis of MND should automatically result in the application being considered under the special rules procedure and allow it to be fast tracked.



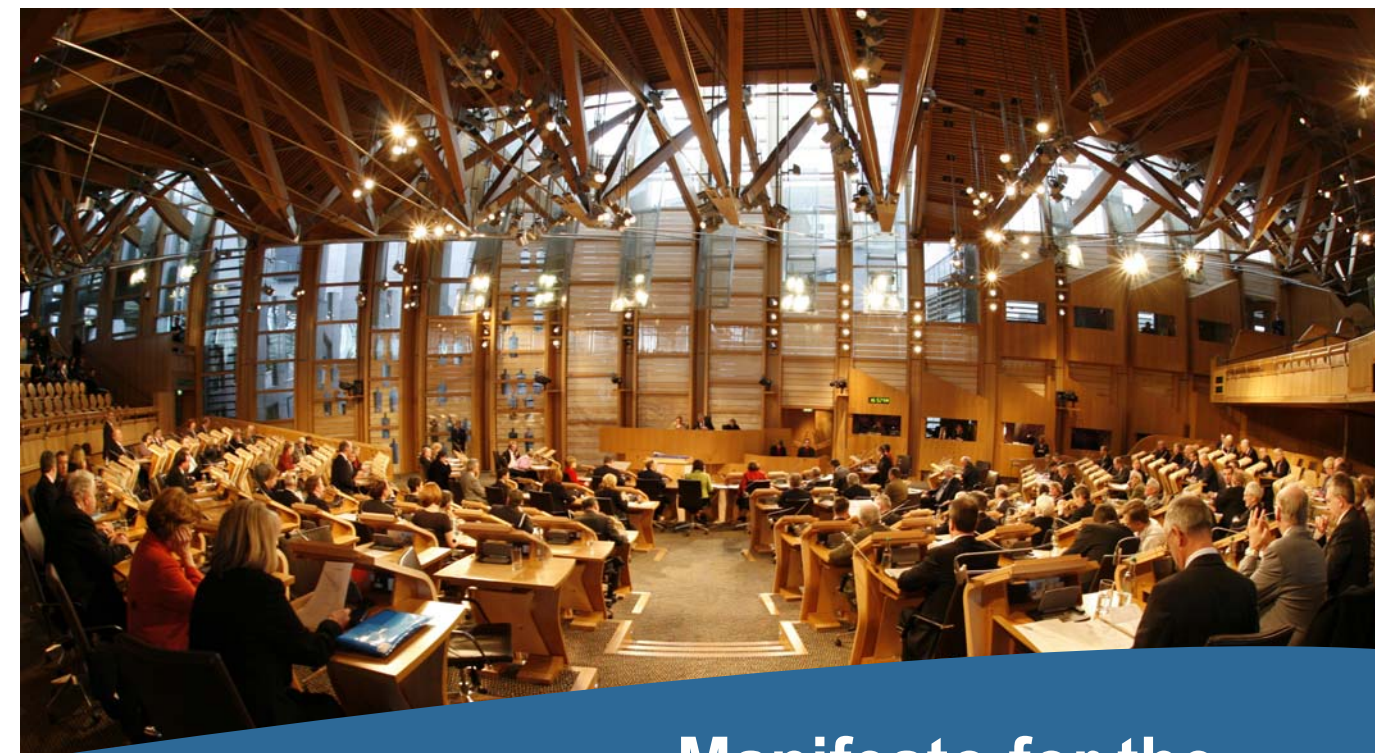
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MND Scotland is the only charity funding research and providing care and information for people affected by Motor Neurone Disease in Scotland. Scottish charity no. SC002662. Company limited by guarantee, registered in Scotland no. SC217735.



Supporting people affected by Motor Neurone Disease



Manifesto for the Scottish Parliament 2011



What is Motor Neurone Disease (MND)?

Motor Neurone Disease (MND) is a progressive disabling and fatal muscle wasting disease that can affect any adult. As MND progresses, the motor neurones degenerate and the signals from the brain no longer reach the muscles. The result - weakening and

wasting of muscle until movement, speech, eating and breathing can no longer be possible without aid.

Medical science has yet to discover the cause or cure. MND Scotland aims to improve the quality of life for people affected by MND.



We are calling for:-

FULL IMPLEMENTATION OF QIS STANDARDS FOR MND

The NHS QIS standards represent a significant step forward in the delivery of care for people with MND. Full implementation of the standards specific to MND will see care being delivered equitably across Scotland and significantly improve on the standards of care currently being



IMPROVED ACCESS TO EQUIPMENT AND ADAPTATIONS

People with MND experience unacceptable delays and inequalities when seeking to access equipment and home adaptations. These services, if delivered in a timely way, are essential to enable people with MND to maximize their independence and quality of life.



SUPPORT FOR MND RESEARCH

Government support to encourage research into MND is called for together with the need for regulation of multi-centre research to be reduced to encourage full participation and access by patients and promote the development of clinical trials within Scotland



IMPROVED ACCESS TO BENEFITS

Given the progressive and often rapid nature of MND, a diagnosis of MND should automatically result in applications for benefits to be considered under the 'special rules' provisions.

The Key Facts

- In Scotland there are on average 130 new cases of MND diagnosed each year.
- Currently within Scotland there are over 400 people living with MND.
- 48% of those newly diagnosed will die within the first year.
- Less than 7% will live for more than 5 years.
- The average life expectancy of someone diagnosed with MND in Scotland is 14 months from diagnosis.
- Over the last two years the number of people living with MND has risen by 25%

MND Scotland

Supporting people affected by Motor Neurone Disease

Specialist Care and Equipment Loan

We have Specialist Care Team who visit people affected by MND at home to provide information, assess their needs and coordinate their care.

Our equipment loan service has specialist items to help people cope with a variety of challenges as their symptoms progress.

Information

Our information officer manages a collection of pamphlets, books, journals and DVDs about MND and related issues. These are available for anyone to borrow, particularly patients, their families and health and social care professionals.

Research Funding

MND Scotland provides funding to improve the lives of people with MND and support well conceived research projects.

Education

We run Family Information Evenings across the country to help family and friends find out more about MND. We also organise in-service education days for allied health professionals and study days for professionals who aim to develop specialist knowledge of MND to provide the best possible care.

Counselling

We train and coordinate a special team of volunteer counsellors covering the whole of Scotland. The aim is to help people come to terms with the emotional stress and pressure of living with a terminal condition and its aftermath.

Welfare and Benefits

Welfare and Benefits service is available to offer advice and information about a range of financial and practical entitlements to help and support those affected by MND..

Small Grants

We provide small grants of up to £500 per year to help defray exceptional costs that can come when living with MND.

Local Branches and Support Groups

Offer support, raise awareness and provide a place for people affected by MND to come together and share experiences.

Other Services

We also offer other limited services, such as Befriending (Tayside and North Fife only) and some Complementary Therapies in areas where volunteers are available .

