

Department of Health response to the MND Association's correspondence campaign for a national strategy for motor neurone disease (MND)

The Department recognises the strength of feeling behind the call for a national strategy for MND and shares a desire for people with the condition to have timely and equitable access to services that will help them achieve the highest possible quality of life.

The Department recognises that, in many areas, people with MND do not yet receive the high quality care and support that they require. The Department recently published the White Paper *Liberating the NHS*, which sets out plans for NHS reform and a commitment to deliver excellence and to tackle inequalities. The Department's vision for health and social care will necessitate a fresh approach to developing clinical strategies, which will focus on improving outcomes whilst giving maximum freedom to local services to innovate and improve.

At present, the *National Service Framework (NSF) for Long-Term Conditions* sets standards of care for people with a range of conditions, including MND.

The NSF was published in 2005 as a ten-year strategy for improving health and social care services for people with a long-term neurological condition in England. The NSF covers all aspects of care from assessment, through diagnosis, information/education, treatment and support, to end-of-life decisions and palliative care. Throughout the NSF, the emphasis is on patient involvement and choice, to support people to:

- live as independently as possible;
- continue to live their chosen lifestyle;
- make informed choices; and
- implement those choices.

The NSF's quality requirements include a separate section on addressing the needs of people with rapidly progressing conditions, such as MND, where services need to respond quickly.

It is for local health bodies to arrange and commission suitable services to meet the needs of those living with MND. The Department has worked with a range of partners, including the Neurological Alliance, to identify and develop support and practical tools that can help local services and organisations to deliver the NSF.

The Department has also asked the Neurological Alliance to establish a group of key stakeholders to provide direction and take a strategic long-term view of priorities for the final five years of the NSF implementation.

Evidence from the Research Initiative for Long-Term Neurological Conditions will also help to measure the impact the NSF has made on the way neurological services are designed and delivered, as well as adding to the understanding of the nature, experience and management of long-term neurological conditions. One study in particular has been looking at the need for, and experiences of, services for people with progressive neurological conditions, including MND. This benchmarking study will provide a clear quantitative and qualitative evidence base for MND, giving a picture of current patterns of health, quality of life, access and experience of services for patients and their carers so that progress in developing services can be measured. The research initiative will finish in 2011 and produce a summary report of its findings.

Finally, the National Institute for Health and Clinical Excellence recently consulted on and published a short clinical guideline on the use of non-invasive ventilation in the management of MND. Respiratory problems are the main cause of death in people with MND, and the guideline aims to provide evidence-based recommendations to improve the care and quality of life of people with MND.