

A rapid  
response  
to a rapidly  
degenerative  
disease

**The case for a  
National Strategy  
for MND**



# Why is the MND Association calling for a National Strategy for MND?

Urgent national action is required to improve the quality of life and achieve dignity in death which people with MND need and have a right to expect, no matter where they live in this country.

Urgent national action is required to realise efficiency gains and value for money of spend on care for people with MND and research into the causes and cure of this disease.

**A National Strategy for MND** will provide a road map and set standards for the co-ordinated, holistic care of people with MND, from diagnosis to death. It

will lend weight to efforts to address bureaucratic and regulatory burdens that currently delay much needed research. A National Strategy for MND will support effective resource planning and allocation, thereby realising value for money.

**Imagine a healthy and alert mind trapped inside a body that can't move, but can still think and feel. That's the devastating reality of motor neurone disease. By joining our call for a National Strategy for MND, you can help make a real difference to the lives of people with MND.**

## About motor neurone disease

Motor neurone disease (MND) is a fatal, rapidly progressing disease of the brain and central nervous system. It leaves people locked into a failing body, unable to move, walk and talk. The mind is usually unaffected. There is no effective treatment. And there is no cure.

In the UK in 2007, 1,884 people died from MND – equivalent to five people each day and one death in every 305. The number of people dying from MND is increasing year on year. In 2001, MND accounted for 1,595 deaths (one in 378 deaths). Whilst MND can and does affect younger people, most people dying of the disease are over 40. Given that there is currently no reliable diagnostic test, people can live with lengthy uncertainty – the average time from onset of symptoms to diagnosis is 17 months. Once diagnosed, half of people with MND die within 14 months.

### About the Motor Neurone Disease Association

The Motor Neurone Disease (MND) Association is the only national organisation in England, Wales and Northern Ireland dedicated to the support of people with MND and those who care for them.

Our mission is to fund and promote research to bring about an end to MND. Until then we will do all that we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible, and die with dignity. We will also do all that we can to support the families and carers of people with MND.

**Our vision is of a world free of MND.**

# What challenges do we face?

## Unacceptable delays and inequities in care for people with MND

MND may be a disease of low prevalence but it is one of high need. The rapid progression and wide range of symptoms means that people with MND have complex and demanding care and support requirements.

The NHS and social services can find it challenging to meet the care and support needs of people with MND in a timely and equitable way. The experiences of people with MND demonstrate that rapid and significant improvements are required to drive-up national and local standards in the provision of health and social care services, and in the care provided by clinicians and health and social care professionals.

The quality of care provided by the NHS and social services is fragmented and of variable quality; primary care trusts and local authorities lack the road map of services (and their associated costs) that people with MND need from diagnosis to death. Clinicians and health and social care professionals outside areas and centres of expertise in MND rarely have occasion to care for people with MND. Even for those regularly working with people with MND, providing high-quality care can be complex and challenging. These professionals are without national guidance or direction on acceptable standards of care.

## Research is hampered by bureaucratic and regulatory burdens

The economic burden of MND alone provides a sound basis for increased investment in MND research. It is estimated that the maximum direct costs of the health and social services for a person with MND is £198,459 annually, representing a maximum cost to health and social services in UK of £373 million a year, in addition to indirect costs to the economy of approximately £1.1 billion. There has never been a better opportunity to realise the benefits of medical research for people with MND. The UK is uniquely positioned to realise such benefits including morbidity reduction and efficiency gains in care of people with MND. Yet, the national situation is one of missed opportunity.

Whilst interest by the medical research community is rapidly increasing, thanks to recent major advances in understanding the causes of the disease, research remains poorly funded with clinical research in particular hampered by bureaucracy and regulatory burdens.



### CHALLENGE 1

## Onset of symptoms to diagnosis

**Length of time taken for diagnosis and from diagnosis to death:** The average time from the onset of symptoms to diagnosis is 17 months and from diagnosis to death is 14 months.

**Low awareness of MND and neurological conditions amongst GPs:** When a patient visits their GP, they are generally being dealt with by a medical professional who may only see one or two cases of MND in their career. It can take GPs many months to recognise a neurological condition as the cause of symptoms and make a referral to a neurologist.

**Neurologists:** There is often a lengthy wait between a referral by a GP and an appointment with a neurologist. Even then the current absence of a diagnostic test for MND means that it is a case of diagnosis by elimination, further prolonging the time to a firm diagnosis.

Awareness of MND and of advances in care and support amongst neurologists, particularly those outside areas of MND expertise, needs to be significantly improved to ensure that diagnoses are made appropriately and that follow-up care and support by neurologists is provided and is of a high standard.

The low number of neurologists in the UK compounds delays to a diagnosis: one for every 170,000 people, compared with one for every 18,000 – 35,000 people in other European countries.

### RESPONSE

## Faster, better diagnosis

#### **GP awareness programmes:**

- A multi-agency approach is needed to ensure GPs are supported to develop a greater awareness of neurological conditions.

#### **Improved diagnosis delivery:**

- A multi-agency approach is needed to ensure diagnoses are made sensitively with support and appropriate information. Referrals to designated key workers who specialise in co-ordinating care for MND and to the MND Association should also be made.
- A multi-agency approach is needed to increase awareness of MND amongst neurologists, especially those working outside areas of MND expertise.

#### **Increased neurological resources:**

- A national target is needed to ensure that patients are seen by a neurologist within four weeks of being referred by a GP.
- Multi-agency led, proactive measures are needed to increase the number of neurologists practising in the UK.

### CHALLENGE 2

## Care and support after diagnosis

**Equipment and adaptations:** People with MND experience unacceptable delays and inequities when seeking access to equipment and home adaptations from health and social services. The timely provision of appropriate equipment and home adaptations is essential to enable people with MND to maximise their independence and quality of life. The MND Association has identified over 25 areas of concern across England with regard to wheelchair provision.

The MND Association routinely supplies key pieces of vital equipment for people with MND including riser/recliner chairs, light-writers and suction units, profiling beds and washer/dryer toilets, where the statutory service response is simply too slow to meet their needs. The Association believes it is unacceptable that statutory services deliberately allow the financial burden of vital equipment and adaptation provision to fall on a charitable organisation.

**Respiratory management:**

Respiratory insufficiency is one of the most severe and distressing symptoms of MND. There are wide fluctuations in the availability of respiratory support, with perhaps as few as 5% of people with MND having access to non-invasive ventilation which significantly improves quality of life and can extend

survival by up to seven months. In England the MND Association has identified 44 areas where respiratory support for people with MND is of serious concern.

**Palliative care and end-of-life care:**

The provision of appropriate palliative care for people with MND enables them to secure as high a quality of life as possible, for as long as possible. However, people with MND experience unacceptable inequities in access to specialist palliative care across the country. In 2005 only a quarter of palliative care services were providing care to people with MND within six months of diagnosis, and only a third of palliative care services were providing care in the 'terminal' phase of the disease. Overall only 39% of people with MND had been referred to specialist palliative care services.

**Inconsistent support for carers:**

MND is a rapidly degenerative condition. A person with MND will typically begin to require assistance with even the smallest tasks from an early stage and will become totally dependent on others before they die. Appropriate and timely respite care is vital for carers as is high quality and consistently available formal care. Both respite and formal care remain unacceptably inconsistent and of varying quality across England.

### RESPONSE

## Care and support for quality of life and dignity in death

**Prompt supply of appropriate equipment:**

• 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.

**Responsive wheelchair provision:**

• The MND Association has developed a partnership model with Wheelchair Services in eight areas to ensure people with MND can have timely access to a wheelchair that meets their needs. A national Government and MND Association partnership should be established to ensure that this solution can be effectively implemented across the country.

**Fast track for home adaptations:**

• A national fast track procedure needs to be instituted for the Disabled Facilities Grant and a person diagnosed with MND should automatically be dealt with under this procedure.

**Consistent and co-ordinated approach to respiratory management:**

• A comprehensive multi-faceted, respiratory management service must be established or made available to people with MND. It should reflect the person's journey from diagnosis to death, with specialist support in the community and at end of life.

**High quality palliative care:**

• People with MND must be offered the opportunity to access specialist palliative care

services as soon as possible after diagnosis. Effective palliative care provision needs to be responsive and adapted as the condition progresses and the needs of the person with MND change.

- Palliative care for people with MND must be co-ordinated by professionals with a good knowledge of MND and delivered by professionals with a range of specialist skills.
- Hospices must be supported to offer places to people with MND and other neurological conditions.

**Integrated approach to end-of-life issues:**

- Care professionals should support people with MND, their families and their carers to help them understand the options available at end of life and to assess which might be right for them. This should happen before the person with MND loses the ability to communicate effectively. Systems such as Advanced Care Planning must be put in place to ensure that these decisions are known to all professionals involved in caring for a person with MND, even in an emergency scenario such as admission to hospital by ambulance.

**Formal recognition and support for carers:**

- Local arrangements for formal care, respite care and counselling and bereavement services need to cater appropriately for people with MND and their carers. These services must be accessible, appropriate and available in a timely manner. The carer's 'annual health check' must be made appropriate for a carer of a person with MND.

### CHALLENGE 3

## Systemic issues

**Lack of designated key workers, specialist nurses and multi-disciplinary teams (MDT):** The complexity of the symptoms presented by MND mean a large number of health and social care professionals may be involved in the care of someone with MND.

A designated key worker often achieves the best results by bringing together and co-ordinating a multi-disciplinary team to care for a person with MND. Many people with MND, and their carers, face intense difficulties and often slip through the various provider groups without a designated key worker. Research has shown that access to a multi-disciplinary team increases survival by an average of 7.5 months for people with MND.

**Difficulty accessing continuing NHS healthcare:** Continuing NHS healthcare is the system that provides funding for patients who need constant 24-hour medical care. Timely access to continuing NHS healthcare is vital for a person with MND to maintain as high a quality of life as possible once the disease is at an advanced stage. However people with MND often struggle to obtain continuing NHS healthcare because assessment panels have no knowledge of, or are ill informed about, MND.

**Barriers in the benefits system:** 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 causing anxiety and placing undue stress on people with MND and their carers.

**Commissioning:** As evidenced by the wide variations in care provision across the country, local and regional commissioning often does not take into account the needs of people with a neurological condition or the particular needs of people with MND.

**Personalisation:** Personalisation could offer greater choice and control for patients by enabling them to choose the services they receive, and when and where they receive them. However, arranging your own care can be time-consuming and complex and it is important that people can choose to opt-out of personal health budgets and access their care in the traditional way. There must be equity between delivery models.

**Clinical research:** There has been a historical failure of investment in research to find the causes and cure of rarer diseases like MND; published data demonstrates that spend on MND research is disproportionately low in comparison to other diseases. A critical barrier to bringing about the end of MND is lack of funding for investment in MND research. In addition, 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 low prevalence. Addressing these challenges in the UK will ultimately support the establishment of an international research programme leading to a world free of MND.

### RESPONSE

## Put people with MND at the heart of the system

### **Designated key workers and MDTs:**

- To ensure that people with MND can have the highest quality of life possible and die with dignity, a single point of contact, i.e. a key worker, is needed. A key worker should always be a clinician with specialist knowledge of MND.
- MDTs, ideally located within communities, need to be embedded into practice and become a routine part of care delivery for people with MND.

### **Automatic fast-tracking to continuing NHS healthcare:**

- There is a Fast Track Pathway within the continuing NHS healthcare national framework for people with terminal or rapidly deteriorating conditions. MND is both of these things. The system needs to be amended so that when a person with MND is judged to need continuing healthcare, the diagnosis of MND means that they are automatically placed on the Fast Track Pathway.

### **A flexible and responsive benefits system:**

- The existing six-month life expectancy threshold for access to the fast track special rules needs to be more flexible. A diagnosis of MND should automatically result in placement within the special rules system.

### **Needs-led commissioning:**

- Quality standards and mechanisms governing and auditing commissioning must ensure that services procured meet the needs of those with neurological and rapidly degenerative conditions such as MND.

### **MND Year of Care Pathway:**

- To support commissioners to meet the needs of people with MND, the MND Association has produced the MND Year of Care Pathway.

The pathway is an invaluable commissioning tool that supports anticipatory and efficient commissioning for people with MND. It provides, in an accessible format, the disease milestones and the health and social services required as well as detailing the associated costs of each service per person.

### **Making personalisation work for people with MND:**

- The MND Association wants to ensure that the introduction of personal health budgets does not disadvantage people with rapidly progressing and unpredictable conditions like MND where a flexible and rapid response is necessary to meet the needs of patients.
- It is important that budgets are flexible and can react to a sudden change in circumstances. Personalisation should endeavour to meet needs and achieve value for money; it should not be used as a mechanism through which to make cost savings.

### **Investing in MND research:**

- Funding needs to be increased to accelerate advances in finding the causes of MND.
- Increased funding is also needed to pursue the translational opportunities arising from advances in basic research.

### **Streamlined bureaucracy and increased funding for clinical research:**

- Measures need to be put into place to relieve the bureaucratic burden and ensure that the UK remains at the forefront of research into MND.
- The regulation of multi-centre clinical research needs to be streamlined so that rarer conditions do not bear a disproportionate bureaucratic burden.

# What difference will a National Strategy for MND make?

Everyone with MND in this country will have equitable and timely opportunity of access to the range of care and support services, enabling them to achieve the highest quality of life possible and to die with dignity. Health and social care services will be delivered with value for money.

Increased investment and reduction in bureaucracy will enable the UK to lead the world in MND research so that MND will be beaten. Therefore investment in MND research will also realise significant financial savings both to the health and social care budget and to wider society.

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## What you can do to help

- Write to the Prime Minister and Secretary of State for Health highlighting the need for a National Strategy for MND.
- Encourage your party to endorse the call for a National Strategy for MND.
- Sign our Early Day Motion supporting a National Strategy for MND.
- Speak to the social service and healthcare providers, and commissioners in your constituency to ensure that they are aware of, and addressing the everyday care issues facing people with MND.
- If you are a councillor, raise these issues within your local authority structures and investigate the services provided to people with MND against those outlined in this manifesto – if you need support and advice on how to improve local services, please contact us.
- To find out more about services for people with MND in your constituency or ward, please contact the MND Association at [mndstrategy@mndassociation.org](mailto:mndstrategy@mndassociation.org) or telephone the Public Affairs team on 01604 611842.

