

The MND Charter is a statement of the respect, care and support that people living with motor neurone disease (MND) and their carers deserve, and should expect.

We believe that everyone with a connection to MND, either personally or professionally, should recognise and respect the rights of people with MND as set out in the Charter, and work towards the Charter's vision of the right care, in the right place at the right time.

About MND:

- **MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.**
- **It can leave people locked in a failing body, unable to move, talk and eventually breathe.**
- **A person's lifetime risk of developing MND is up to one in 300.**
- **It kills around 30% of people within 12 months of diagnosis, more than 50% within two years.**
- **It affects people from all communities.**
- **It has no cure.**

Therefore, what matters most is that people with MND receive a rapid response to their needs and good quality care and support, ensuring the highest quality of life as possible and the ability to die with dignity. The MND Charter serves as a tool to help make this happen.

MND is a devastating, complex disease and particularly difficult to manage. We believe that if we get care right for MND we can get it right for other neurological conditions, and save public services money in the long run. But more importantly, we can make a positive difference to the lives of people with MND, their carers and their loved ones.

1

People with MND have the right to an early diagnosis and information

- THIS MEANS:**
- An early referral to a neurologist.
 - An accurate and early diagnosis, given sensitively.
 - Timely and appropriate access to information at all stages of their condition.

There is no diagnostic test for MND – it can only be diagnosed by ruling out other neurological conditions. People with MND can be halfway through their illness before they receive a firm diagnosis.

GPs need to be able to identify the symptoms and signs of a neurological problem and refer directly to a neurologist in order to speed up diagnosis times for MND.

Appropriate tests must be carried out as soon as possible to confirm MND. The diagnosis should be given by a consultant neurologist with knowledge

and experience of treating people with MND¹. The diagnosis should be given sensitively, in private, with the person with MND accompanied by a family member/friend and with time to ask questions. A follow-up appointment with the neurologist should be arranged soon after diagnosis.

At diagnosis people with MND should be offered access to appropriate information and should be informed about the MND Association. Appropriate information should be available at all stages of the person's condition in a language of their choice.

2

People with MND have the right to high quality care and treatments

- THIS MEANS:**
- Access to co-ordinated multidisciplinary care managed by a specialist key worker with experience of MND.
 - Early access to specialist palliative care in a setting of their choice, including equitable access to hospices.
 - Access to appropriate respiratory and nutritional management and support, as close to home as possible.
 - Access to the drug riluzole.
 - Timely access to NHS continuing healthcare when needed.
 - Early referral to social care services.
 - Referral for cognitive assessment, where appropriate.

People with MND may need care provided by health and social care professionals from up to 20 disciplines. This clearly needs co-ordination to work effectively. Co-ordinated care can improve the quality of life of people with MND and provide value for money for the NHS by preventing crises and emergency hospital admissions. The care should be co-ordinated by a specialist key worker with experience of MND who can anticipate needs and ensure they are met on time. Ongoing education for health and social

care professionals is important to reflect advances in healthcare techniques and changes in best practice.

A third of people with MND die within 12 months of diagnosis. Early access to specialist palliative care² soon after diagnosis is therefore vital and should be available in a setting of the person's choice. Some hospices give preferential access to people with a cancer diagnosis. It is important that access is based on need, not diagnosis, so that people with MND have equitable access to hospice care. Hospices can

provide high-quality respite care, which can benefit both the person with MND and their carer.

As MND progresses, the respiratory muscles and muscles of the mouth and throat may be affected. People with MND may therefore need respiratory and nutritional support. It is important that these services are available as close to the person's home as possible so that travelling is minimised and support is available quickly.

In 2001 the National Institute for Health and Care Excellence (NICE) recommended riluzole as a cost-effective drug for people with MND. GPs can be reluctant to prescribe riluzole on cost grounds, despite its NICE-approved status, or to monitor for

side effects during its use. However, it is vital that people with MND have ongoing access to this important treatment.

As the disease progresses, people with MND may need more intensive health care. It is important that people with MND have timely access to NHS continuing healthcare when they need it.

People with MND are likely to need help with getting up, washing, dressing and preparing food as the disease progresses. Access to social care services is therefore important to maintain quality of life. People with MND may also need access to cognitive assessment, as up to half of people with the disease experience changes in cognition.

3

People with MND have the right to be treated as individuals and with dignity and respect

- THIS MEANS:**
- Being offered a personal care plan to specify what care and support they need.
 - Being offered the opportunity to develop an Advance Care Plan to ensure their wishes are met, and appropriate end-of-life care is provided in their chosen setting.
 - Getting support to help them make the right choices to meet their needs when using personalised care options.
 - Prompt access to appropriate communication support and aids.
 - Opportunities to be involved in research if they so wish.

Everyone with MND should be offered a personal care plan³ to specify what care and support they need. The plan should be regularly reviewed as the disease progresses and the person's needs change.

People with MND should be offered the opportunity to develop an Advance Care Plan⁴ to make clear their wishes for future care and support, including any care they do not wish to receive. The plan should be developed with support from a professional with specialist experience and may include preferences for end-of-life care.

Some people with MND will need support to help them make the right choices to meet their needs when using personalised care options, such as personal budgets.

As the disease progresses, some people with MND will experience difficulty speaking. It is important

that people with MND can access speech and language therapy to help them maintain their voice for as long as possible. However, as the disease progresses, people with MND may need access to communication aids including augmentative and alternative communication (AAC)⁵. The ability to communicate is a basic human right. For people with MND, communication support and equipment are vital in order to remain socially active and to communicate their wishes about their care, especially during hospital stays and other medical environments.

Many people with MND value the opportunity to be involved in research as it provides hope that one day an effective treatment will be developed. Everyone with MND who wishes to should be able to participate in research as far as is practicable.

4

People with MND have the right to maximise their quality of life

- THIS MEANS:**
- Timely and appropriate access to equipment, home adaptations, environmental controls, wheelchairs, orthotics and suitable housing.
 - Timely and appropriate access to disability benefits.

People with MND may find their needs change quickly and in order to maximise their quality of life, they may need rapid access to equipment, home adaptations, wheelchairs and suitable housing. These needs should be anticipated so that they are met in a timely way. This is particularly true of wheelchairs which are important for maximising independence and quality of life.

People with MND need timely and appropriate access to disability benefits to help meet the extra costs of living with a disability. Information on appropriate benefits needs to be readily accessible in one place and easily understandable.

5

Carers of people with MND have the right to be valued, respected, listened to and well supported

- THIS MEANS:**
- Timely and appropriate access to respite care, information, counselling and bereavement services.
 - Advising carers that they have a legal right to a Carer's Assessment of their needs¹, ensuring their health and emotional well being is recognised and appropriate support is provided.
 - Timely and appropriate access to benefits and entitlements for carers.

Caring for someone with MND is physically and emotionally demanding. Carers need to be supported in order to maintain their caring role. Every carer should have their needs assessed and given timely and appropriate access to respite care, information, counselling and bereavement services. It is important to support the emotional and physical needs of the

carer in a timely way so that they can continue their caring role.

Carers should also have timely and appropriate access to benefits and entitlements to help manage the financial impact of their caring role.

¹ Recommendation in the NICE guideline on MND.

² Specialist palliative care – palliative care is the active holistic care of patients with progressive illness, including the provision of psychological, social and spiritual support. The aim is to provide the highest quality of life possible for patients and their families. Specialist palliative care is care provided by a specialist multidisciplinary palliative care team.

³ Personal care plan – a plan which sets out the care and treatment necessary to meet a person's needs, preferences and goals of care.

⁴ Advance care plan – a plan which anticipates how a person's condition may affect them in the future and, if they wish, set on record choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide or communicate their decision when their condition progresses.

⁵ Augmentative and Alternative Communication (AAC) – is used to describe the different methods that can be used to help people with speech difficulties communicate with others. These methods can be used as an alternative to speech or to supplement it. AAC may include unaided systems such as signing and gesture as well as aided systems such as low tech picture or letter charts through to complex computer technology.