



# themndcharter

Achieving quality of life, dignity and respect for people with MND and their carers



“Many people with MND die without having the right care, not having a suitable wheelchair, not having the support to communicate.

We have got to set a standard so that people like us are listened to and treated with the respect and dignity we deserve.

We have got to stop the ignorance surrounding this disease and have to make sure that when a patient is first diagnosed with MND, they must have access to good, co-ordinated care and services.

One week waiting for an assessment or a piece of equipment is like a year in most people’s lives, because they are an everyday essential to help us live as normal a life as possible and die with dignity”

*Liam Dwyer, who is living with MND*

The MND Charter aims to gain support from individuals and organisations with a personal or professional connection to MND, in working towards the vision of the right care, in the right place, at the right time for people with MND and their carers.

Anyone can sign up to the MND charter. By doing so, you are showing that you have listened to the voice of people with MND and their carers, and pledge to understand and support the principles and priorities set out in the charter.

Show your support and sign the MND Charter:

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**Online:** [www.mndassociation.org/mndcharter](http://www.mndassociation.org/mndcharter)

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**Email:** [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)

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**Telephone:** 01604 611684

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## **MND Association**

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[www.mndassociation.org](http://www.mndassociation.org)

Registered charity no 294354

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## 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 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 at 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 access quality care and treatments

#### THIS MEANS:

- access to high-quality co-ordinated services 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 and appropriate access to NHS continuing healthcare when needed

People with MND may need as many as 18 health and social care professionals providing care at any one time. 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. On-going education

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

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 Clinical 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 monitoring 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.

Half of people with MND die within 14 months of diagnosis. Early access to specialist palliative care<sup>1</sup> from 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.

### 3

## People with MND have the right to be treated as an individual 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**
- **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 plan<sup>2</sup> to specify what care and support they need. The plan should be regularly reviewed as the disease progresses and the person's needs change.

As the disease progresses, some people with MND will lose their ability to communicate due to severe speech and physical impairments. 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)<sup>3</sup>. 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.

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.

Many people with MND value the opportunity to be involved in research as it provides hope that one

<sup>1</sup> **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

<sup>2</sup> **Personal care plan** – a plan which sets out the care and treatment necessary to meet a person's needs, preferences and goals of care.

<sup>3</sup> **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

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.

People with MND should be offered the opportunity to develop an Advance Care Plan<sup>4</sup>

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.

## 4

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

#### **THIS MEANS:**

- **timely and appropriate access to equipment, home adaptations, wheelchairs and suitable housing**
- **timely and appropriate access to disability benefits**

In order to maximise their quality of life, people with MND may need 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**
- **having their needs assessed as carers and individuals, 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.

<sup>4</sup> **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



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Achieving quality of life, dignity and respect for people with MND and their carers

The MND Charter embraces the natural rights of people with MND and their carers and sets out the respect, care and support they deserve and should expect.

We urge all individuals with a connection to MND, either personally or professionally, and organisations working with people with MND to endorse and sign up to the charter.

By signing the charter, you are pledging your understanding and support for the charter statements to help ensure people with MND and their carers have their rights respected and are given the very best opportunity to access the care they need to live the highest quality of life possible and achieve dignity in death.

Motor neurone disease (MND) is a fatal, rapidly progressive disease. It can leave people locked into a failing body, unable to move, walk, talk and eventually breathe. Life expectancy from diagnosis is two to five years, and around half of those die within 14 months. The rapid progression of MND means rapidly changing needs. 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 – and it will save the Government money in the long run.

The MND Charter sets out the key priorities for local services to help get it right for MND. This disease is particularly difficult to manage. We believe that if we get it right for MND we can get it right for other neurological conditions.

**We all have a responsibility to make it work for MND – show your support by signing the five point charter**