

Motor Neurone Disease Association Vision

A world free from MND

The MND Charter

We want to ensure all people with MND receive the right care, in the right place, at the right time. The MND Charter sets out the key priorities for local services to help get it right for MND. We believe that if we get it right for MND we can get it right for other neurological conditions.

Our 5 point charter is:

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

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

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

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

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

Background to the Outcomes Standards

Three outcomes frameworks were introduced in England in 2010: public health; adult social care and NHS; with the aim to provide a focus for action and improvement across the health and care system. They represent a move from measuring processes to monitoring and measuring meaningful outcomes for people. We are expressing our aims and objectives for the health and care of people with MND in a similar way. We will be producing equivalent documents to fit with the structures in Wales and Northern Ireland.

Objectives of the Outcomes Standards

The MND Association mission states that 'We improve care and support for people with MND and their families'. The outcome standards will be one way of achieving our mission. They represent what good care looks like for people living with MND. The NHS and adult social care outcome frameworks are used as a basis for them. We want our Outcomes Standards to be of clear use to professionals working with people living with MND, and to commissioners. We will monitor change using indicators which will illustrate progress made towards realising the outcomes.

The Association has used the domain headings from the NHS Outcomes Framework. Each of the 5 domains is considered essential for the delivery of high quality health and care. The domains are listed below in bold with the outcomes considered important for people with MND numbered and grouped underneath. The complete Association Outcomes Standards can be found on the next page.

Domain 1 – Preventing people from dying prematurely

- 1.1 Quick and accurate diagnosis
- 1.2 People living with MND receive appropriate effective treatments

Domain 2 – Enhancing quality of life for people with long term conditions

- 2.1 Prompt and equitable access to specialists and treatment
- 2.2 Access to high quality information
- 2.3 Supported management of the condition
- 2.4 Co-ordinated health and social care

Domain 3 – Helping people to recover from episodes of ill health or following injury

- 3.1 Remaining functional ability maintained through effective therapy and rehabilitation

Domain 4 – Ensuring that people have a positive experience of care

- 4.1 People living with MND are able to make informed decisions about their care
- 4.2 People living with MND are confident in arranging their own care
- 4.3 Prompt access to effective palliative care
- 4.4 Good quality of life for carers

Domain 5 – Treating and caring for people in a safe environment; and protecting them from harm

- 5.1 People living with MND have access to appropriate equipment and accommodation adaptations
 - 5.2 The nature of rapidly progressing long-term diseases is recognised, understood and reflected in practice for people living with MND
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Domain One – Preventing people from dying prematurely

Outcomes

- 1.1 Quick and accurate diagnosis
- 1.2 People living with MND receive appropriate effective treatments

Indicators

- Time taken from presentation of symptoms to a referral to neurology
- Referrals from general neurology to a specialist neurologist within a month
- Time to accurate diagnosis of MND
- CCGs in which a riluzole shared care protocol is in place
- People with MND in receipt of the respiratory assessments stipulated in the NICE guideline
- People with MND who have access to assisted ventilation services and respiratory specialists eg. respiratory physiotherapist or nurse
- People with MND in receipt of NIV
- People known to the Association living with MND that have had contact with a specialist NHS neurology centre

Domain Two – Enhancing quality of life for people with long term conditions

Outcomes

- 2.1 Prompt and equitable access to specialists and treatment
- 2.2 Access to high quality information
- 2.3 Supported management of the condition
- 2.4 Co-ordinated health and social care

Indicators

- Patients waiting between 0-3 months for a first appointment with a neurologist
- People with MND who have contact with a specialist who understands their condition within 24 hours of admission to hospital
- People with MND supported to maintain safe nutrition and hydration
- People with MND in receipt of support to maintain their breathing
- People with MND supported to maintain effective communication
- MND Association membership numbers
- GPs supported to understand MND following a referral and confirmed diagnosis of MND in their patients
- Follow-up appointments, post diagnosis, within 2 weeks
- People with MND told about the Association at point of diagnosis
- Expressed levels of carer quality of life
- CCGs in which referral to an effective MDT or equivalent system is available
- People with MND with access to a clinical specialist coordinator
- People with MND with a personalised care plan/support plan
- Early facilitated discharge to good, co-ordinated care
- Emergency hospital admissions and readmission for people with MND

All indicators given in terms of patients, carers or people with MND will be assessed with reference to the number or proportion that are in receipt of, or able to access, this level of service whenever it applies to them. We will continue to identify sources and develop the ways in which we measure these indicators.

Domain Three – Helping people to recover from episodes of ill health or following injury

Outcomes

- 3.1 Remaining functional ability maintained through effective therapy and rehabilitation and compensatory techniques

Indicators

- Emergency hospital admissions and readmissions for people with MND
- Hospital bed days for people with MND following emergency and elective admissions
- Referral to neuro-rehabilitation services for people with MND

Domain Four – Ensuring that people have a positive experience of care

Outcomes

- 4.1 People living with MND are able to make informed decisions about their care
- 4.2 People living with MND are confident in arranging their own care
- 4.3 Prompt access to effective palliative care
- 4.4 Good quality of life for carers

Indicators

- People with MND that hold or have been offered an advance care plan
- People with MND and their carers satisfied with Association care information resources
- People living with MND with access to volunteer support
- People with MND dying in their place of preference
- People with MND listed on an end of life register
- People with MND receiving their diagnosis in an empathic way
- People living with MND with access to personal health budgets
- People with MND that feel their autonomy and independence is respected when in receipt of health and social care services
- People with MND that feel they make the key decisions to determine health and social care services
- People with MND with access to palliative care from diagnosis
- Access to hospices with expertise to admit and support people with MND and their carers
- Non-professional/unpaid carers that have had a carer's assessment

Domain Five – Treating and caring for people in a safe environment; and protecting them from avoidable harm

Outcomes

- 5.1 People living with MND have access to appropriate equipment and accommodation adaptations
- 5.2 The nature of rapidly progressing long-term diseases is recognised, understood and reflected in practice and timely intervention for people living with MND

Indicators

- Assessments carried out in a timely manner
- People with MND receiving necessary adaptations and aids as defined by assessment, with funding or loan as appropriate.
- AAC, environmental controls and wheelchairs provided and maintained in accordance with national standards and guidelines
- People with MND affected by avoidable complications