Motor neurone disease: assessment and management

NICE quality standard

Draft for consultation

February 2016

Introduction

This quality standard covers the assessment and management of motor neurone disease. For more information see the motor neurone disease topic overview. This quality standard does not cover issues that are applicable to end of life care in general. This is covered by End of life care for adults (NICE quality standard 13).

Why this quality standard is needed

Motor neurone disease (MND) is a neurodegenerative condition affecting the brain and spinal cord. MND is characterised by the degeneration of primarily motor neurones, leading to muscle weakness.

Presentation of the condition varies. It can be as muscle weakness, wasting, cramps and stiffness of arms or legs; problems with speech or swallowing or, more rarely, with breathing. As the disease progresses, the pattern of symptoms and signs becomes similar, with increasing muscle weakness in the person’s arms and legs, problems swallowing and communicating, and weakness of the muscles used for breathing, which ultimately leads to death. Most people die within 2–3 years of developing symptoms, but 25% are alive at 5 years and 10% at 10 years. The most common type of MND is amyotrophic lateral sclerosis (ALS). There are rarer forms such as progressive muscular atrophy or primary lateral sclerosis, which may have a slower rate of progression.

Every person with MND has an individual progression of the disease. About 10–15% of people with MND will show signs of frontotemporal dementia, which causes cognitive dysfunction and issues in decision-making. People with MND can also show signs of mild cognitive change, which may affect their ability to make decisions and plan ahead.

MND can affect adults of any age, but mainly affects people aged 50 to 65 years. There are approximately 5,000 people with MND in England and Wales at any one time. The cause is unknown. About 5–10% of people with MND have a family history of the disease and several abnormal genes have been identified.

The quality standard is expected to contribute to improvements in the following outcomes:

- patient- and carer-reported outcomes; for example, symptoms, quality of life and pain
- hospital admissions (including unplanned admissions)
- survival.

How this quality standard supports delivery of outcome frameworks

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – patient safety, patient experience and clinical effectiveness – for a particular area of health or care. They are derived from high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following 3 outcomes frameworks published by the Department of Health:

- Adult Social Care Outcomes Framework 2015–16
- NHS Outcomes Framework 2015–16
- Public Health Outcomes Framework 2013–16.

Tables 1-3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 The Adult Social Care Outcomes Framework 2015–16

Domain	**Overarching and outcome measures**
1 Enhancing quality of life for people with care and support needs	***Overarching measure*** 1A Social care-related quality of life** ***Outcome measures*** **People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs** 1B Proportion of people who use services who have control over their daily life **Carers can balance their caring roles and maintain their desired quality of life** 1D Carer-reported quality of life**
3 Ensuring that people have a positive experience of care and support	***Overarching measure*** **People who use social care and their carers are satisfied with their experience of care and support services** 3A Overall satisfaction of people who use services with their care and support 3B Overall satisfaction of carers with social services *Placeholder 3E The effectiveness of integrated care* ***Outcome measures*** **Carers feel that they are respected as equal partners throughout the care process** 3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for **People know what choices are available to them locally, what they are entitled to, and who to contact when they need help** 3D The proportion of people who use services and carers who find it easy to find information about support **People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual** This information can be taken from the Adult Social Care Survey and used for analysis at the local level.

4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm	***Overarching measure*** 4A The proportion of people who use services who feel safe** ***Outcome measures*** **Everyone enjoys physical safety and feels secure** **People are free from physical and emotional abuse, harassment, neglect and self-harm** **People are protected as far as possible from avoidable harm, disease and injuries** **People are supported to plan ahead and have the freedom to manage risks the way that they wish** 4B The proportion of people who use services who say that those services have made them feel safe and secure
Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 2 NHS Outcomes Framework 2015–16

Domain	Overarching indicators and improvement areas
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** ***Improvement areas*** **Ensuring people feel supported to manage their condition** 2.1 Proportion of people feeling supported to manage their condition **Improving functional ability in people with long-term conditions** 2.2 Employment of people with long-term conditions*, ** **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers** **Enhancing quality of life for people with dementia** 2.6 i Estimated diagnosis rate for people with dementia* *ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life*,***

4 Ensuring that people have a positive experience of care	***Overarching indicators*** 4b Patient experience of hospital care 4c *Friends and family test* *4d Patient experience characterised as poor or worse* *i Primary care* *ii Hospital care* ***Improvement areas*** **Improving hospitals' responsiveness to personal needs** 4.2 Responsiveness to inpatients' personal needs **Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers' views on the quality of care in the last 3 months of life **Improving people's experience of integrated care** *4.9 People's experience of integrated care***
Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Table 3 Public health outcomes framework for England, 2013–16

Domain	Objectives and indicators
1 Improving the wider determinants of health	***Objective*** Improvements against wider factors that affect health and wellbeing and health inequalities ***Indicators*** 1.8 Employment for those with long-term health conditions including adults with a learning disability or who are in contact with secondary mental health services*,**
Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework * Indicator is shared ** Indicator is complementary Indicators in italics in development	

Patient experience and safety issues

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to motor neurone disease.

NICE has developed guidance and an associated quality standard on patient experience in adult NHS services (see the NICE pathway on patient experience in adult NHS services), which should be considered alongside this quality standard. It specifies that people receiving care should be treated with dignity, have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. It also covers providing information to patients and people who use services. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect patient experience and are specific to the topic are considered during quality statement development.

Coordinated services

The quality standard for motor neurone disease specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole motor neurone disease care pathway. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to people with motor neurone disease.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality. Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing a high-quality motor neurone disease service are listed in Related NICE quality standards.

Training and competencies

The quality standard should be read in the context of national and local guidelines on training and competencies. All health, public health and social care practitioners involved in assessing, caring for and treating people with motor neurone disease should have sufficient and appropriate training and competencies to deliver the actions and interventions described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

Role of families and carers

Quality standards recognise the important role families and carers have in supporting people with motor neurone disease. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

List of quality statements

Statement 1 Adults diagnosed with motor neurone disease (MND) are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Statement 2 Adults newly diagnosed with motor neurone disease (MND) are assessed to identify any cognitive or behavioural changes.

Statement 3 Adults with motor neurone disease (MND) have their respiratory function and symptoms assessed at diagnosis and then monitored in multidisciplinary team assessments.

Statement 4 Adults with motor neurone disease (MND) who have respiratory impairment are offered non-invasive ventilation.

Statement 5 Adults with motor neurone disease (MND) have regular, coordinated assessments by a specialist multidisciplinary team.

Statement 6 Adults with motor neurone disease (MND) have their mobility and daily living needs monitored in multidisciplinary team assessments.

Statement 7 Adults with motor neurone disease (MND) have personal care and support carried out by workers known to them and their family members and carers.

Statement 8 Adults with motor neurone disease (MND) are offered opportunities to discuss their preferences and concerns about end of life care.

Questions for consultation

Questions about the quality standard

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 Are local systems and structures in place to collect the data for the proposed quality measures? If not, how feasible would it be for these system and structures to be put in place?

Question 3 Do you have an example from practice of implementing the care described in this draft quality standard? If so, please submit your example to the NICE local practice collection on the NICE website.

Question 4 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources required to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Questions about the individual quality statements

Question 5 For draft quality statement 2: To support measurement of this draft quality standard statement, within what timeframe from diagnosis should the person be assessed for any behavioural or cognitive changes?

Question 6 For draft quality statement 3: Within what timeframe after diagnosis should respiratory function and symptoms be assessed?

Question 7 For draft quality statements 3, 5, and 6: There is some overlap between draft quality statements 3, 5, and 6. Statement 5 covers regular assessments of symptoms and needs of people with motor neurone disease including respiratory function, respiratory symptoms and non-invasive ventilation; and physical function, including mobility and activities of daily living. Statements 3 and 6 also cover regular assessment of respiratory function and symptoms and mobility and daily living needs respectively. What is the key area for quality improvement: Is it that comprehensive regular assessments are not taking place (the focus of draft statement 5), or that regular assessments do take place but that respiratory function (draft statement 3) or mobility (draft statement 6) are not well-covered?

Question 8 For draft quality statement 8: Are there clearly defined points at which offers to discuss end of life care should be made?

Quality statement 1: Information and support at diagnosis

Quality statement

Adults diagnosed with motor neurone disease (MND) are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Rationale

MND is rare and most healthcare professionals will have little experience and knowledge of it. Receiving a diagnosis of MND can be distressing for a person and they (and also their family members and/or carers, as appropriate) are likely to have a variety of questions and concerns. A consultant neurologist with expertise in treating people with MND can deliver the diagnosis with understanding and provide accurate and up-to-date information on the prognosis and management of MND. In some situations, such as if a person presents with breathing problems that need urgent treatment, diagnosis may have to be given by a different healthcare professional.

Quality measures

Structure

Evidence of local arrangements to ensure that people can be referred to consultant neurologists with expertise in MND for diagnosis; that these consultants are able to keep their knowledge of MND up to date; and that information about the diagnosis, prognosis and management of MND is delivered by these consultants.

Data source: Local data collection.

Process

Proportion of people who are diagnosed with MND who are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Numerator – the number in the denominator who are given information about the diagnosis, prognosis and management of MND by a consultant neurologist with expertise in treating people with MND.

Denominator – the number of people who are diagnosed with MND (and for whom it has not been necessary to give the diagnosis in an urgent situation).

Data source: Local data collection.

Outcome

Confidence in care and reduced uncertainty for people with MND.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers (neurology services) ensure that adults who are diagnosed with MND are given information about the diagnosis, prognosis and management, by a consultant neurologist with up-to-date knowledge and experience of treating people with MND, unless it is necessary to give the diagnosis in an urgent situation.

Healthcare professionals (consultant neurologists with expertise in treating people with MND) ensure that they provide information about the diagnosis, prognosis and management to adults at diagnosis. Because not everyone will want to receive a great deal of information when MND is diagnosed, information should be given according to the person's needs.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services in which adults who are diagnosed with MND are given information about the diagnosis, prognosis and management by a neurologist with up-to-date knowledge and experience of treating people with MND.

What the quality statement means for patients, service users and carers

Adults who are diagnosed with MND receive information about the diagnosis, how MND is likely to progress and what will happen next, from a consultant neurologist with expertise in treating people with MND. A neurologist is a hospital doctor who specialises in disorders of the nervous system, including the brain, spinal cord and nerves.

Source guidance

- Motor neurone disease recommendation 1.2.1.

Definitions of terms used in this quality statement

Consultant neurologist with expertise in treating people with MND

A consultant neurologist with up-to-date knowledge and experience of treating people with MND. They should have knowledge and expertise in the following:

- Symptoms.
- Types and possible causes.
- Treatment options.
- How it may progress (including cognitive and behavioural changes) and how progression may affect the treatments offered.
- Crisis prevention (for example, if there is an acute hospital admission or a breakdown in care arrangements).
- Opportunities for people with MND to be involved in research.
- Likely needs and concerns of people with MND and their family members and/or carers (as appropriate).
- Advance care planning.

[Adapted from Motor neurone disease recommendation 1.2.1.]

Urgent situation

These include situations such as a person whose condition is rapidly deteriorating or who presents with breathing problems that need urgent treatment, when it would not be possible for a neurologist to give the diagnosis. In these circumstances the diagnosis may have to be given by a different healthcare professional.

[Adapted from Motor neurone disease]

Equality and diversity considerations

Cognitive problems are a common symptom of MND. People can experience a wide range of difficulties, ranging from minimal cognitive impairment to frontotemporal dementia. All information should be accessible, as much as possible, to people with cognitive problems. People receiving information about MND should have access to an interpreter or advocate if needed.

Quality statement 2: Cognitive assessment

Quality statement

Adults newly diagnosed with motor neurone disease (MND) are assessed to identify any cognitive or behavioural changes.

Rationale

Many people with MND have changes in cognitive function, ranging from minimal cognitive impairment to frontotemporal dementia. It is important to identify significant cognitive changes as early as possible because this has implications for communication, decision-making and the type and amount of care people may need.

Quality measures

Structure

Evidence of local arrangements and written protocols to ensure that people newly diagnosed with MND are assessed to identify any cognitive or behavioural changes.

Data source: Local data collection.

Process

Proportion of people diagnosed with MND who are assessed to identify any cognitive or behavioural changes.

Numerator – the number in the denominator who are assessed to identify any cognitive or behavioural changes

Denominator – the number of people diagnosed with MND

Data source: Local data collection.

Outcome

Health-related quality of life.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and commissioners

Service providers (specialist MND multidisciplinary teams) ensure that psychologists are available to help identify and support any cognitive or behavioural changes in adults who have been diagnosed with MND.

Healthcare professionals (neurologists and specialist MND multidisciplinary teams) ensure that people who are diagnosed with MND are assessed to identify any cognitive or behavioural changes.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that assess adults who have been diagnosed with MND to identify any cognitive or behavioural changes, and that have psychologists to help in this identification and support.

What the quality statement means for patients, service users and carers

Adults diagnosed with MND are assessed to find out whether they have any cognitive changes (problems with thinking, language, behaviour and personality) as soon as they are comfortable to do so. This will allow healthcare professionals to provide extra help and support in appointments and when planning and providing care.

Source guidance

- Motor neurone disease recommendation 1.3.2.

Question for consultation

To support measurement of this draft quality standard statement, within what timeframe from diagnosis should the person be assessed for any behavioural or cognitive changes?

Quality statement 3: Assessment for respiratory impairment

Quality statement

Adults with motor neurone disease (MND) have their respiratory function and symptoms assessed at diagnosis and then monitored in multidisciplinary team assessments.

Rationale

Respiratory muscle weakness resulting in respiratory impairment is a major feature of MND. The onset of respiratory muscle weakness can be sudden and unexpected, leading to emergency ventilation or death. Regular monitoring of respiratory function allows respiratory muscle weakness to be identified earlier (rather than after symptoms of respiratory impairment appear) and means that strategies such as non-invasive ventilation (NIV) can be considered and started before an emergency situation occurs.

Quality measures

Structure

a) Evidence of local arrangements and written protocols to ensure that adults diagnosed with MND have their respiratory function and symptoms assessed as part of the initial assessment to diagnose MND, or soon after diagnosis.

Data source: Local data collection.

b) Evidence of local arrangements and written protocols to ensure that adults with MND have their respiratory function and symptoms assessed at least every 2-3 months (unless less frequent assessment has been agreed).

Data source: Local data collection.

Process

a) Proportion of adults diagnosed with MND who have their respiratory function and symptoms assessed as part of the initial assessment to diagnose MND, or soon after diagnosis.

Numerator – the number in the denominator who have their respiratory function and symptoms assessed as part of the initial assessment to diagnose MND, or soon after diagnosis.

Denominator – the number of adults diagnosed with MND.

Data source: Local data collection.

b) Proportion of adults with MND who have had their respiratory function and symptoms assessed within the past 3 months (unless less frequent assessment has been agreed).

Numerator – the number in the denominator who have their respiratory function and symptoms assessed within the past 3 months (excluding those for whom an assessment frequency of less than every 3 months has been agreed).

Denominator – the number of adults diagnosed with MND at least 3 months ago (excluding those for whom an assessment frequency of less than every 3 months has been agreed).

Data source: Local data collection.

Outcome

Rate of unplanned hospital admissions for issues related to respiratory impairment.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals, and commissioners

Service providers (specialist MND multidisciplinary teams) ensure that adults with MND have their respiratory function and symptoms assessed as part of the initial assessment to diagnose MND, or soon after diagnosis, and then every 2–3 months by the multidisciplinary team unless it has been agreed that this assessment should occur more or less frequently.

Healthcare professionals (members of the MND multidisciplinary team, such as respiratory physiologists or healthcare professionals who can assess respiratory function) ensure that they monitor signs and symptoms of potential respiratory impairment and perform respiratory function tests as part of the initial assessment to diagnose MND, or soon after diagnosis, and then every 2–3 months by the multidisciplinary team unless it has been agreed to carry out these assessments more or less frequently.

Commissioners (NHS England) ensure that services they commission have healthcare professionals with appropriate competencies to perform respiratory function tests and monitor signs and symptoms of potential respiratory impairment.

What the quality statement means for patients, service users and carers

Adults with MND are regularly checked to see if they are having any problems with their breathing. These checks should happen when they are diagnosed with MND (or shortly afterwards) and then in appointments with the multidisciplinary team (usually every 2–3 months).

Source guidance

- Motor neurone disease recommendations 1.5.3, 1.12.1, 1.14.8 and 1.14.10.

Definitions of terms used in this quality statement

Respiratory function assessment

Motor neurone disease includes details of respiratory function tests in section 1.14.

Regularly assessed

A healthcare professional with appropriate competencies should perform the respiratory function tests every 2–3 months, although tests may be performed more or less often depending on:

- whether there are any symptoms and signs of respiratory impairment (see box 1 in recommendation 1.14.7 in motor neurone disease)
- the rate of progression of MND
- the person's preference and circumstances.

[Motor neurone disease recommendation 1.14.10]

Symptoms and signs of potential respiratory impairment

Box 1 in motor neurone disease recommendation 1.14.7 gives details of symptoms and signs of potential respiratory impairment.

Assessment for potential respiratory impairment includes monitoring cough effectiveness (weak cough being a sign of potential respiratory impairment) potentially by measuring cough peak flow. [Motor neurone disease recommendation 1.14.7; expert opinion] NICE Motor neurone disease section 1.13 includes guidance on what to do if problems with cough effectiveness are identified.

Questions for consultation

Within what timeframe after diagnosis should respiratory function and symptoms be assessed?

There is some overlap between draft quality statements 3, 5, and 6. Statement 5 covers regular assessments of symptoms and needs of people with motor neurone disease including respiratory function, respiratory symptoms and non-invasive ventilation; and physical function, including mobility and activities of daily living. Statements 3 and 6 also cover regular assessment of respiratory function and symptoms and mobility and daily living needs respectively. What is the key area for quality improvement: Is it that comprehensive regular assessments are not taking place (the focus of draft statement 5), or that regular assessments do take place but that respiratory function (draft statement 3) or mobility (draft statement 6) are not well-covered?

Quality statement 4: Non-invasive ventilation

Quality statement

Adults with motor neurone disease (MND) who have respiratory impairment are offered non-invasive ventilation.

Rationale

Progressive respiratory muscle weakness resulting in respiratory impairment is a major feature of MND. Non-invasive ventilation can improve symptoms and signs related to respiratory impairment, and hence survival.

Quality measures

Structure

Evidence of local arrangements to provide non-invasive ventilation for adults with MND who have respiratory impairment.

Data source: Local data collection.

Process

Proportion of adults with MND who have respiratory impairment who are offered non-invasive ventilation.

Numerator – the number in the denominator who have been offered non-invasive ventilation.

Denominator – the number of adults with MND who have respiratory impairment.

Data source: Local data collection.

Outcome

Number of adults with MND established on non-invasive ventilation.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals, and commissioners

Service providers (specialist MND multidisciplinary teams) ensure that there are local arrangements for providing non-invasive ventilation and agreed local protocols for referral to these services, and that healthcare professionals are aware of these protocols.

Healthcare professionals (members of specialist MND multidisciplinary teams and respiratory ventilation services) offer non-invasive ventilation to adults with MND who have respiratory impairment. Decisions to offer non-invasive ventilation should be made by the multidisciplinary team in conjunction with the respiratory ventilation service, and the person with MND.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission non-invasive ventilation services and that there are agreed pathways for referral to these services.

What the quality statement means for patients, service users and carers

Adults with MND who are having difficulty breathing are offered non-invasive ventilation using a portable ventilator – a machine that supports the person's breathing.

Source guidance

- Motor neurone disease recommendation 1.12.2.

Definitions of terms used in this quality statement

Non-invasive ventilation

Non-invasive ventilation refers to methods of providing ventilatory support to a patient without placing an artificial airway in the main windpipe (trachea). This is usually achieved by fitting a mask covering the nose or mouth and nose, or using nasal tubes or a mouthpiece, which is connected to a ventilator by tubing. The ventilator detects when the patient tries to take a breath in and delivers an extra flow of air to increase the volume of air inhaled. [Motor neurone disease glossary]

Quality statement 5: Multidisciplinary care

Quality statement

Adults with motor neurone disease (MND) have regular, coordinated assessments by a specialist multidisciplinary team.

Rationale

People with MND have a complex and diverse range of needs that will change with the progression of the disease. Responding to these needs effectively requires input from a variety of different specialists and services working together as a specialist MND multidisciplinary team. The main tasks of the multidisciplinary team are to carry out regular, coordinated assessments with the person, and to establish effective communication and coordination between everyone who is involved in their care.

Quality measures

Structure

Evidence of local arrangements to ensure that people with MND have regular, coordinated assessments by a specialist multidisciplinary team.

Data source: Local data collection.

Process

Proportion of adults with MND who have coordinated assessments by a specialist multidisciplinary team at least every 3 months (unless less frequent assessments have been agreed).

Numerator – the number in the denominator who have had a coordinated assessment by a specialist multidisciplinary team within the past 3 months (excluding those for whom an assessment frequency of less than every 3 months has been agreed).

Denominator – the number of adults diagnosed with MND at least 3 months ago (excluding those for whom an assessment frequency of less than every 3 months has been agreed).

Data source: Local data collection.

Outcome

Unplanned hospital admissions and health-related quality of life for people with MND.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and social care practitioners, and commissioners

Service providers (neurology services) ensure provision of coordinated care for people with MND using a specialist MND multidisciplinary team approach.

Healthcare professionals and social care practitioners (specialist MND multidisciplinary teams) ensure that there is effective communication and coordination between all healthcare professionals and social care practitioners involved in the person's care. They should ensure that people with MND have regular, coordinated assessments (usually every 2–3 months) by the multidisciplinary team to assess their symptoms and needs.

Commissioners (NHS England) ensure that they commission services that provide coordinated care for people with MND, using a specialist MND multidisciplinary team approach.

What the quality statement means for patients, service users and carers

Adults with MND have their care provided and coordinated by a team of specialists called a MND multidisciplinary team, who work together to provide care wherever the person is – in hospital, clinic or GP surgery, and also in the person's own home. Adults with MND have an appointment with the multidisciplinary team usually every 2–3 months, depending on their symptoms and needs.

Source guidance

- Motor neurone disease recommendations 1.5.1, 1.5.2, 1.5.3, 1.5.4 and 1.5.6.

Definitions of terms used in this quality statement

Coordinated assessment by a multidisciplinary team

Recommendation 1.5.3 in NICE's guideline on motor neurone disease includes details of what a multidisciplinary team should assess, manage and review, including muscle problems, physical function, pain, respiratory function, cognition and behaviour, and social care needs.

Specialist MND multidisciplinary team

The core multidisciplinary team should consist of healthcare professionals and other professionals with expertise in MND, and should include the following:

- Neurologist.
- Specialist nurse.
- Dietitian.
- Physiotherapist.
- Occupational therapist.
- Respiratory physiologist or a healthcare professional who can assess respiratory function.
- Speech and language therapist.
- A healthcare professional with expertise in palliative care (MND palliative care expertise may be provided by the neurologist or nurse in the multidisciplinary team, or by a specialist palliative care professional).

The multidisciplinary team should have established relationships with, and prompt access to, the following:

- Clinical psychology and neuropsychology.
- Social care.
- Counselling.
- Respiratory ventilation services.
- Specialist palliative care.
- Gastroenterology.
- Orthotics.
- Wheelchair services.

- Assistive technology services.
- Alternative and augmentative communication (AAC) services.
- Community neurological care teams.

[Motor neurone disease recommendations 1.5.4 and 1.5.5.]

The multidisciplinary team should:

- include healthcare professionals and social care practitioners with expertise in MND, and staff who see people in their home
- ensure effective communication and coordination between all healthcare professionals and social care practitioners involved in the person's care and their family members and/or carers (as appropriate)
- provide coordinated care for people who cannot attend a clinic, according to the person's needs.

[Adapted from Motor neurone disease recommendation 1.5.2.]

Question for consultation

There is some overlap between draft quality statements 3, 5, and 6. Statement 5 covers regular assessments of symptoms and needs of people with motor neurone disease including respiratory function, respiratory symptoms and non-invasive ventilation; and physical function, including mobility and activities of daily living. Statements 3 and 6 also cover regular assessment of respiratory function and symptoms and mobility and daily living needs respectively. What is the key area for quality improvement: Is it that comprehensive regular assessments are not taking place (the focus of draft statement 5), or that regular assessments do take place but that respiratory function (draft statement 3) or mobility (draft statement 6) are not well-covered?

Quality statement 6: Assessment of mobility and daily living needs

Quality statement

Adults with motor neurone disease (MND) have their mobility and daily living needs monitored in multidisciplinary team assessments.

Rationale

People with MND can have multiple functional problems and may therefore have complex equipment needs. In addition, MND is a progressive disorder so these needs will change over time. Regular monitoring of a person's daily living needs will help to assess and anticipate any changes, allowing equipment to be provided or adapted appropriately.

Quality measures

Structure

a) Evidence of local arrangements to ensure that adults with MND have regular monitoring of their mobility and daily living needs.

Data source: Local data collection.

b) Evidence of local arrangements to ensure that equipment is provided, or adapted, to meet any changes in mobility and daily life needs identified for adults with MND.

Data source: Local data collection.

Process

Proportion of adults with MND who have had an assessment of their mobility and daily living needs within the past 3 months (unless less frequent monitoring has been agreed).

Numerator – the number in the denominator who have had an assessment of their mobility and daily living needs within the past 3 months (excluding those for whom less frequent monitoring has been agreed).

Denominator – the number of adults diagnosed with MND at least 3 months ago (excluding those for whom less frequent monitoring has been agreed).

Outcome

Patient satisfaction that equipment provided meets their needs.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and social care practitioners, and commissioners

Service providers (multidisciplinary MND teams) ensure that people's mobility and daily living needs and abilities are monitored every 2-3 months in multidisciplinary team assessments, and that there are locally agreed pathways to ensure that people who have needs, or changes to their needs, identified are referred to appropriate services without delay.

Healthcare professionals and social care practitioners (members of the MND multidisciplinary team, such as physiotherapists and occupational therapists) ensure that they monitor and anticipate changes in the person's mobility and daily living needs and abilities.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission MND services in which people's mobility and daily life needs and abilities are monitored every 2–3 months in multidisciplinary team assessments.

What the quality statement means for patients, service users and carers

Adults with MND have regular checks to make sure that any equipment they have been given to help them manage their condition, for example, a wheelchair, is still meeting their needs. These checks also help to anticipate any future changes in their needs, or if any changes to existing equipment or new equipment will be needed. The checks should happen in appointments with the multidisciplinary team (usually every 2–3 months).

Source guidance

- Motor neurone disease recommendations 1.5.3, 1.9.1 and 1.9.6.

Definitions of terms used in this quality statement

Monitoring of mobility and daily life needs and abilities

Assessing and anticipating changes in the person's daily living needs should take into account the following:

- Activities of daily living, including personal care, dressing and bathing, housework, shopping, food preparation, eating and drinking, and ability to continue with current work and usual activities.
- Mobility and avoiding falls and problems from loss of dexterity.
- The home environment and the need for adaptations.
- The need for assistive technology, such as environmental control systems.

A person's ability to use equipment should also be regularly reviewed and adaptions made to equipment as necessary. Equipment provided should, if possible, be adaptable to cope with future changes.

[Adapted from expert opinion and Motor neurone disease recommendations 1.9.1 and 1.9.6].

Question for consultation

There is some overlap between draft quality statements 3, 5, and 6. Statement 5 covers regular assessments of symptoms and needs of people with motor neurone disease including respiratory function, respiratory symptoms and non-invasive ventilation; and physical function, including mobility and activities of daily living. Statements 3 and 6 also cover regular assessment of respiratory function and symptoms and mobility and daily living needs respectively. What is the key area for quality improvement: Is it that comprehensive regular assessments are not taking place (the focus of draft statement 5), or that regular assessments do take place but that respiratory function (draft statement 3) or mobility (draft statement 6) are not well-covered?

Quality statement 7: Continuity of care

Quality statement

Adults with motor neurone disease (MND) have personal care and support carried out by workers known to them and their family members and carers.

Rationale

Continuity of care provided by workers who are aware of the specific needs of a person with MND ensures that care needs do not need to be repeatedly explained to new workers. Such explanation may be difficult for people with MND who may have reduced communication abilities and need a family member or carer to be present to explain what care they need.

Quality measures

Structure

Evidence of local arrangements to ensure that, wherever possible, adults with MND have their personal care and support carried out by workers known to the person and their family members or carers.

Data source: Local data collection.

Process

Proportion of home care visits to adults with MND in which the home care worker is known to the person and their family members.

Numerator – the number in the denominator in which the home care worker is known to the person and their family members.

Denominator – the number of home care visits made to adults with MND.

Data source: Local data collection.

Outcome

People with MND and their families or carers' experience of social care support.

Data source: Local data collection.

What the quality statement means for service providers, social care practitioners, and commissioners

Service providers (multidisciplinary MND teams) ensure that wherever possible, personal care and support is carried out by workers known to the person and their family members and/or carers (as appropriate).

Social care practitioners (specialist MND multidisciplinary team members and practitioners with knowledge of MND or rapidly progressive complex disabilities) ensure that there is continuity of care with familiar workers so that wherever possible, personal care and support is carried out by workers known to the person and their family members and/or carers (as appropriate).

Commissioners (local authorities) ensure that services they commission are able to ensure that wherever possible, personal care is carried out by workers known to the person and their family members and/or carers (as appropriate).

What the quality statement means for patients, service users and carers

Adults with MND have their personal care and support provided by someone who they know and who is familiar with their needs.

Source guidance

- Motor neurone disease recommendations 1.5.10 and 1.6.5.

Quality statement 8: Planning for end of life care

Quality statement

Adults with motor neurone disease (MND) are offered opportunities to discuss their preferences and concerns about end of life care.

Rationale

MND can present in different ways and the prognosis may be variable, but the majority of people with MND die within 2–3 years of diagnosis. Discussions about end of life will be difficult, but sensitive discussions about patient concerns and the support available may be helpful to the person and their families and carers. Earlier planning for care at the end of life also ensures that families and professionals can be made aware of a person’s wishes for end of life care before communication or cognitive changes make this difficult or impossible.

Quality measures

Structure

Evidence of local arrangements to ensure that adults with MND are offered opportunities to discuss their preferences and concerns about end of life care.

Data source: Local data collection.

Process

Proportion of adults with MND who are offered opportunities to discuss their preferences and concerns about end of life care.

Numerator – the number in the denominator who have been offered opportunities to discuss their preferences and concerns about end of life care.

Denominator – the number of adults diagnosed with MND.

Data source: Local data collection.

Outcome

Support, choice and control at the end of life for people with MND.

Data source: Local data collection.

What the quality statement means for service providers, healthcare professionals and social care practitioners, and commissioners

Service providers (such as neurology services and MND multidisciplinary teams) ensure that healthcare professionals and social care practitioners are able to provide support and advice on advance care planning for end of life to people with MND and their family members and carers, and that they offer people with MND the opportunity to discuss their preferences and concerns about care at the end of their life.

Healthcare professionals and social care practitioners (members of the MND multidisciplinary team) ensure that they offer people with MND the opportunity to discuss their preferences and concerns about care at the end of their life at trigger points such as diagnosis, a significant change in respiratory function, or when interventions such as gastrostomy or non-invasive ventilation are needed. Healthcare professionals and social care practitioners should ensure that they are sensitive about the timing of discussions and take into account the person’s current communication ability, cognitive status and mental capacity.

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services that have staff who are able to provide support and advice on advance care planning for end of life to people with MND and their family members and carers.

What the quality statement means for patients, service users and carers

Adults with MND are asked if they would like to talk about any concerns they have about dying and what they would prefer to happen (or not happen) at the end of their life.

Source guidance

- Motor neurone disease recommendation 1.7.1.

Definitions of terms used in this quality statement

Discussion of preferences and concerns about end of life care

Discussions should involve providing support and advice on advance care planning for end of life to the person with MND and their family members and/or carers (as appropriate). The discussion should include:

- What could happen at end of life, for example how death may occur.
- Providing anticipatory medicines in the home.
- Advance care planning, including Advance Decisions to Refuse Treatment and Do Not Attempt Resuscitation orders, and Lasting Power of Attorney.
- Areas that people might wish to plan for, such as:
  - what they want to happen (for example preferred place of death)
  - what they do not want to happen (for example being admitted to hospital)
  - who will represent their decisions, if necessary
  - what should happen if they develop an intercurrent illness.

Be sensitive about the timing of discussions and take into account the person's current communication ability, cognitive status and mental capacity.

[Adapted from Motor neurone disease recommendations 1.7.1 and 1.7.3]

Equality and diversity considerations

Cognitive problems are a common symptom of MND. People can experience a wide range of difficulties, ranging from minimal cognitive impairment to frontotemporal dementia. Cognitive or behavioural change does not mean that a person with MND will no longer be able to make decisions but rather that care should be provided in a way that accommodates the cognitive or behavioural changes. This could include allowing more time for decision making and an understanding of behaviour change. All information provided should be accessible, as far as possible, to people with cognitive problems. People receiving information about MND should have access to an interpreter or advocate if needed.

People should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If someone does not have capacity to make decisions, healthcare professionals should follow the code of practice that accompanies the Mental Capacity Act and the supplementary code of practice on deprivation of liberty safeguards.

Question for consultation

Are there clearly defined points at which offers to discuss end of life care should be made?

Status of this quality standard

This is the draft quality standard released for consultation from 25 February to 24 March 2016. It is not NICE's final quality standard on motor neurone disease. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 24 March 2016. All eligible comments received during consultation will be reviewed by the Quality Standards Advisory Committee and the quality statements and measures will be refined in line with the Quality Standards Advisory Committee's considerations. The final quality standard will be available on the NICE website from July 2016.

Using the quality standard

Quality measures

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. These include indicators developed by the Health and Social Care Information Centre through its Indicators for Quality Improvement Programme. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See NICE's What makes up a NICE quality standard? for further information, including advice on using quality measures.

Levels of achievement

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of

100% should be aspired to (or 0% if the quality statement states that something should not be done). However, NICE recognises that this may not always be appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

NICE's quality standard service improvement template helps providers to make an initial assessment of their service compared with a selection of quality statements. It includes assessing current practice, recording an action plan and monitoring quality improvement.

Using other national guidance and policy documents

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in Development sources.

Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments are available.

Good communication between health, public health and social care practitioners and people with MND is essential. Treatment, care and support, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with MND should have access to an interpreter or advocate if needed.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

Development sources

Further explanation of the methodology used can be found in the quality standards process guide.

Evidence sources

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the Quality Standards Advisory Committee to develop the quality standard statements and measures.

- Motor neurone disease (2016) NICE guideline NG42

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- National Audit Office (2015) Services for people with neurological conditions: progress review
- Health and Social Care Information Centre (2014) Compendium of neurology data, England – 2012–13
- Welsh Government (2014) Neurological conditions
- NHS England (2013) Complex disability equipment alternative and augmentative communication/communication aids (all ages)
- NHS England (2013) Complex disability equipment specialised wheelchair and seating services (all ages)
- NHS England (2013) Neurosciences: specialised neurology (adult)
- NHS England (2013) Respiratory: complex home ventilation (adult)
- Royal College of Physicians and Association of British Neurologists (2011) Local adult neurology services for the next decade

Definitions and data sources for the quality measures

- Motor neurone disease (2016) NICE guideline NG42

Related NICE quality standards

Published

- End of life care for adults (2011) NICE quality standard 13

In development

- Home care. Publication expected June 2016.

Future quality standards

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- Neurological problems (relatively uncommon neurological problems such as muscular dystrophy)
- Service user and carer experience: services user and carer experience of social care

The full list of quality standard topics referred to NICE is available from the quality standards topic library on the NICE website.

Quality Standards Advisory Committee and NICE project team

Quality Standards Advisory Committee

This quality standard has been developed by Quality Standards Advisory Committee 4. Membership of this committee is as follows:

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About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The methods and processes for developing NICE quality standards are described in the quality standards process guide.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

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