Motor neurone disease: non-invasive ventilation

Clinical guideline
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Introduction

Motor neurone disease (MND) is a fatal neurodegenerative disease. It is characterised by the onset of symptoms and signs of degeneration of primarily the upper and lower motor neurones. This leads to progressive weakness of the bulbar, limb, thoracic and abdominal muscles. Respiratory muscle weakness resulting in respiratory impairment is a major feature of MND, and is a strong predictor of quality of life and survival. Non-invasive ventilation can improve symptoms and signs related to respiratory impairment and hence survival.

There is currently no evidence-based guideline for use in England, Wales and Northern Ireland that addresses the use of non-invasive ventilation in patients with MND. This guideline considers the signs and symptoms that can be used for predicting respiratory impairment in patients with MND, the diagnostic accuracy of investigations for detecting and monitoring respiratory impairment, the clinical and cost effectiveness of non-invasive ventilation for treating respiratory impairment and the information and support needs of patients and their families and carers relating to the use of non-invasive ventilation.
Patient-centred care

This guideline offers best practice advice on the use of non-invasive ventilation in the care of adults (aged 18 and over) with a diagnosis of motor neurone disease (MND).

Treatment and care should take into account patients' needs and preferences. People with MND should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent and the code of practice that accompanies the Mental Capacity Act. In Wales, healthcare professionals should follow advice on consent from the Welsh Government.

Good communication between healthcare professionals and patients is essential. It should be supported by evidence-based written information tailored to the patient's needs. Treatment and care, and the information patients are 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.

If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care.

Families and carers should also be given the information and support they need.
1 Guidance

The following guidance is based on the best available evidence. The full guideline gives details of the methods and the evidence used to develop the guidance.

1.1 List of all recommendations

Multidisciplinary team

1.1.1 A multidisciplinary team should coordinate and provide ongoing management and treatment for a patient with MND, including regular respiratory assessment and provision of non-invasive ventilation.

- The team should be led by a healthcare professional with a specific interest in MND. The leader should ensure that the patient's multidisciplinary care plan (see recommendation 1.1.19) is coordinated and is communicated to relevant healthcare and social care professionals, including the patient's primary care team, as well as to the patient and (where appropriate) their family and carers.

- The team should include a neurologist, a respiratory physician, an MND specialist nurse, a respiratory specialist nurse, a specialist respiratory physiotherapist, a respiratory physiologist, a specialist in palliative care and a speech and language therapist (team members do not have to be at the same location).

- Access to other healthcare professionals should be provided as needed.

- Team members who provide non-invasive ventilation should have appropriate competencies.

Information and support needs of patients with MND and their families and carers

1.1.2 Offer to discuss the possible use of non-invasive ventilation with the patient and (if the patient agrees) their family and carers, at an appropriate time and in a sensitive manner. This may be at one or more of the following times:

- soon after MND is first diagnosed
- when monitoring respiratory function
- when respiratory function deteriorates
• if the patient asks for information.

1.1.3 Discussions should be appropriate to the stage of the patient’s illness, carried out in a sensitive manner and include information on:

• the possible symptoms and signs of respiratory impairment (see table 1 in recommendation 1.1.7)

• the natural progression of MND and what to expect in the future

• the purpose, nature and timing of respiratory function tests, and explanations of the test results

• available interventions for managing respiratory impairment, including the benefits and limitations of each intervention

• accessing and using respiratory equipment, including that for non-invasive ventilation

• how non-invasive ventilation (as a treatment option) can improve symptoms associated with respiratory impairment and can be life prolonging, but does not stop progression of the underlying disease

• how non-invasive ventilation can be withdrawn

• palliative strategies as an alternative to non-invasive ventilation.

1.1.4 Inform all relevant healthcare professionals about key decisions reached with the patient and their family and carers.

1.1.5 Provide the patient and their family and carers with support and assistance to manage non-invasive ventilation. This should include:

• training on using non-invasive ventilation and ventilator interfaces, for example:
  - emergency procedures
  - night-time assistance if the patient is unable to use the equipment independently (for example, emergency removal or replacement of interfaces)
  - how to use the equipment with a wheelchair or other mobility aids if required
  - what to do if the equipment fails
- assistance with secretion management
- information on general palliative strategies
- an offer of ongoing emotional and psychological support\(^1\) for the patient and their family and carers.

1.1.6 Ensure that families and carers:

- have an initial assessment if the patient they care for decides to use non-invasive ventilation, which should include:
  - their ability and willingness to assist in providing non-invasive ventilation
  - their training needs
- have the opportunity to discuss any concerns they may have with members of the multidisciplinary team and/or other healthcare professionals.

Identification and assessment of respiratory impairment in patients with MND

*Symptoms and signs*

1.1.7 Monitor the symptoms and signs listed in table 1 routinely to detect potential respiratory impairment.

Table 1 Symptoms and signs of potential respiratory impairment

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Signs</th>
</tr>
</thead>
</table>

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Breathlessness  
Orthopnoea  
Recurrent chest infections  
Disturbed sleep  
Non-refreshing sleep  
Nightmares  
Daytime sleepiness  
Poor concentration and/or memory  
Confusion  
Hallucinations  
Morning headaches  
Fatigue  
Poor appetite

Increased respiratory rate  
Shallow breathing  
Weak cough\(^1\)  
Weak sniff  
Abdominal paradox (inward movement of the abdomen during inspiration)  
Use of accessory muscles of respiration  
Reduced chest expansion on maximal inspiration

\(^{1}\) Weak cough could be assessed by measuring cough peak flow.

**Respiratory function tests**

1.1.8 As part of the initial assessment to diagnose MND, or soon after diagnosis, a healthcare professional from the multidisciplinary team who has appropriate competencies should perform the following tests (or arrange for them to be performed) to establish the patient’s baseline respiratory function:

- oxygen saturation measured by pulse oximetry (SpO\(_2\)):
  - this should be a single measurement of SpO\(_2\) with the patient at rest and breathing room air
  - if it is not possible to perform pulse oximetry locally, refer the patient to a specialist respiratory service
then one or both of the following:

- forced vital capacity (FVC) or vital capacity (VC)\[^1\]
- sniff nasal inspiratory pressure (SNIP) and/or maximal inspiratory pressure (MIP).

1.1.9 If the patient has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment:

- ensure that $\text{SpO}_2$ is measured (at rest and breathing room air)
- do not perform the other respiratory function tests (FVC, VC, SNIP and MIP) if interfaces are not suitable for the patient.

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

- whether there are any symptoms and signs of respiratory impairment (see recommendation 1.1.7)
- the rate of progression of MND
- the patient's preference and circumstances.

1.1.11 Perform arterial or capillary blood gas analysis if the patient's $\text{SpO}_2$ (measured at rest and breathing room air):

- is less than or equal to 92% if they have known lung disease
- is less than or equal to 94% if they do not have lung disease.

If it is not possible to perform arterial or capillary blood gas analysis locally, refer the patient to a specialist respiratory service.

1.1.12 If the patient's $\text{SpO}_2$ (measured at rest and breathing room air) is greater than 94%, or 92% for those with lung disease, but they have sleep-related respiratory symptoms:

- consider referring them to a specialist respiratory service for nocturnal (overnight) oximetry and/or a limited sleep study **and**
• discuss both the impact of respiratory impairment and treatment options with the patient and (if the patient agrees) their family and carers.

1.1.13 If the patient's arterial partial pressure of carbon dioxide (PaCO₂) is greater than 6 kPa:

• refer them urgently to a specialist respiratory service (to be seen within 1 week) and

• explain the reasons for and implications of the urgent referral to the patient and (if the patient agrees) their family and carers.

1.1.14 If the patient's PaCO₂ is less than or equal to 6 kPa but they have any symptoms or signs of respiratory impairment, particularly orthopnoea (see recommendation 1.1.7):

• refer them to a specialist respiratory service for nocturnal (overnight) oximetry and/or a limited sleep study and

• discuss both the impact of respiratory impairment and treatment options with the patient and (if the patient agrees) their family and carers.

1.1.15 If any of the results listed in table 2 is obtained, discuss with the patient and (if the patient agrees) their family and carers:

• the impact of respiratory impairment

• treatment options

• possible referral to a specialist respiratory service for further assessment.

Table 2 Results of respiratory function tests

<table>
<thead>
<tr>
<th>Forced vital capacity (FVC) or vital capacity (VC)</th>
<th>Sniff nasal inspiratory pressure (SNIP) and/or maximal inspiratory pressure (MIP)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(if both tests are performed, base the assessment on the better respiratory function reading)</td>
</tr>
</tbody>
</table>
Patients with a diagnosis of dementia

1.1.16 Base decisions on respiratory function tests for a patient with a diagnosis of dementia on considerations specific to their needs and circumstances, such as:

- their ability to give consent\(^1\)
- their understanding of the tests
- their tolerance of the tests and willingness to undertake them
- the impact on their family and carers
- whether they are capable of receiving non-invasive ventilation.

Non-invasive ventilation for treatment of respiratory impairment in patients with MND

1.1.17 Offer a trial of non-invasive ventilation if the patient’s symptoms and signs and the results of the respiratory function tests indicate that the patient is likely to benefit from the treatment.

- Discuss both the benefits and limitations of the intervention with the patient and their family and carers.

- Only consider a trial of non-invasive ventilation for a patient who has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment if they may benefit from an improvement in sleep-related symptoms or correction of hypoventilation.
Before starting non-invasive ventilation, the multidisciplinary team should carry out and coordinate a patient-centred risk assessment, after discussion with the patient and their family and carers. This should consider:

- the most appropriate type of non-invasive ventilator and interfaces, based on the patient's needs and lifestyle factors
- the patient's tolerance of the treatment
- the risk, and possible consequences, of ventilator failure
- the power supply required, including battery back-up
- how easily the patient can get to hospital
- risks associated with travelling away from home (especially abroad)
- whether a humidifier is required
- issues relating to secretion management
- the availability of carers.

Before starting non-invasive ventilation, the multidisciplinary team should prepare a comprehensive care plan, after discussion with the patient and their family and carers (who should be offered a copy of the plan). This should cover:

- long-term support provided by the multidisciplinary team
- the initial frequency of respiratory function tests and monitoring of respiratory impairment
- the frequency of clinical reviews of symptomatic and physiological changes
- the provision of carers
- arrangements for device maintenance and 24-hour emergency clinical and technical support
- secretion management and respiratory physiotherapy assessment, including cough-assist therapy (if required)
• training in and support for the use of non-invasive ventilation for the patient and their family and carers

• regular opportunities to discuss the patient’s wishes in relation to continuing or withdrawing non-invasive ventilation, and other end-of-life considerations (see also recommendations 1.1.24 and 1.1.25).

1.1.20 When starting non-invasive ventilation:

• perform initial acclimatisation during the day when the patient is awake

• usually start regular treatment at night, before and during sleep

• gradually build up the patient’s hours of use as necessary.

1.1.21 Continue non-invasive ventilation if the clinical reviews show:

• symptomatic and/or physiological improvements for a patient without severe bulbar impairment and without severe cognitive problems

• an improvement in sleep-related symptoms for a patient with severe bulbar impairment or with severe cognitive problems that may be related to respiratory impairment.

1.1.22 Discuss all decisions to continue or withdraw non-invasive ventilation with the patient and (if the patient agrees) their family and carers.

Patients with a diagnosis of dementia

1.1.23 Before a decision is made on the use of non-invasive ventilation for a patient with a diagnosis of dementia, the neurologist from the multidisciplinary team should carry out an assessment that includes:

• the patient’s capacity to make decisions and to give consent[^a]

• the severity of dementia and cognitive problems

• whether the patient is likely to accept treatment

• whether the patient is likely to achieve improvements in sleep-related symptoms and/or behavioural improvements
• a discussion with the patient's family and/or carers (with the patient's consent if they have the capacity to give it).

Planning end-of-life care

1.1.24 Offer to discuss end-of-life care with the patient and (if the patient agrees) their family and carers, at an appropriate time and in a sensitive manner. This may be at one or more of the following times:

• around the time that MND is first diagnosed (but only if requested by the patient explicitly, or if the patient's clinical condition indicates that ventilator support will be needed in the immediate future)

• when non-invasive ventilation is accepted or declined

• when the patient is becoming increasingly dependent on non-invasive ventilation

• if the patient asks for information.

1.1.25 Discussions about end-of-life care should include:

• planning of end-of-life care

• considering advance decisions to refuse treatment

• considering what to do if non-invasive ventilation fails because of either:
  
  – an acute, but potentially reversible, deterioration in health or

  – irreversible disease progression

• strategies to withdraw non-invasive ventilation if the patient wishes

• the involvement of family and carers in decision making (with the patient's consent if they have the capacity to give it).


[2] The difference between the measurement of vital capacity and forced vital capacity is very subtle and so either can be used.
See 'Dementia'. NICE clinical guideline 42 (2006).
2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover. The scope of this guideline is available from our website – click on 'How this guidance was developed'.
3 Implementation

NICE has developed tools to help organisations implement this guidance.
4 Research recommendations

We have made the following recommendations for research, based on our review of evidence, to improve NICE guidance and patient care in the future.

4.1 Cost effectiveness of non-invasive ventilation for patients with MND

Is non-invasive ventilation or standard care more cost effective for improving survival and quality of life for patients with MND?

Why this is important

More than half of patients with MND have respiratory symptoms and need some form of respiratory management. There is evidence to suggest that non-invasive ventilation improves the quality of life of patients with MND. However, there is a lack of evidence relating to the costs associated with non-invasive ventilation. Despite this lack of robust evidence with regard to cost analyses, the use of non-invasive ventilation by patients with MND is perceived to be cost effective compared with standard care. A prospective study enrolling only patients with MND receiving non-invasive ventilation is required to assess the costs associated with this intervention. The primary outcome measures should be: (i) a thorough cost record at each visit or assessment; and (ii) the duration of overall survival. Secondary outcome measures should include any adverse events and related costs.

4.2 Withdrawing non-invasive ventilation at the end of life

What is the most effective and acceptable method of treatment withdrawal for patients with MND who wish to stop using non-invasive ventilation as their disease progresses, and how should this be facilitated and managed?

Why this is important

As more patients receive non-invasive ventilation, there will be a corresponding increase in the numbers of patients who wish to withdraw from this treatment when they become more disabled and dependent. This is a very difficult decision for patients and their families and carers, and can also cause distress, conflict and difficulty for members of professional teams. A mixed-design longitudinal qualitative and quantitative study is an appropriate research design to address this question. Such a study should enrol patients with MND who are receiving non-invasive ventilation (and who have the cognitive ability to participate in interviews and complete structured questionnaires), their families and carers, and healthcare professionals. The outcome measures...
should be: (i) the experiences of patients, their family and carers and healthcare professionals on how withdrawal was managed (through case notes reviews and interviews); and (ii) assessment of quality of life, locus of control and mood (through structured questionnaires and analysed by structural equation modelling).

4.3 Communication with patients, families and carers

What communication should take place when discussing the use of non-invasive ventilation – in particular, what information do patients and their families and carers want to be included in these discussions?

Why this is important

As guidelines on non-invasive ventilation are implemented across services, there will be an increased need to discuss with patients and their families and carers the positive and negative aspects of non-invasive ventilation in the management of MND. There is very little evidence about what occurs in these discussions or about what patients, family members and carers want to be included. This research would enable clearer ideas to be developed about the best methods of communication. A mixed-design longitudinal qualitative and quantitative study is an appropriate research design to address this question. Such a study should enrol patients with MND who are about to start or who are already receiving non-invasive ventilation (and who have the cognitive ability to participate in interviews and complete structured questionnaires), and their families and carers. The outcome measures should be: (i) experiences of the discussions; (ii) how decisions are reached; (iii) what patients and their families and carers want to discuss; and (iv) patient and carer views on how to undertake these discussions.

4.4 Non-invasive ventilation for patients with MND with severe bulbar impairment

What is the impact of non-invasive ventilation on quality of life and survival in patients with MND with severe bulbar impairment?

Why this is important

One randomised controlled trial (RCT) suggests that non-invasive ventilation does not improve survival in patients with MND with severe bulbar impairment, but can improve some aspects of their quality of life. This is low-grade evidence based on subgroup analysis of a secondary endpoint. Further research is a priority, as the current practice of treating patients with bulbar impairment may not be based on secure evidence. An RCT with a long follow-up period should enrol patients
with MND with severe bulbar impairment who have respiratory impairment. The patients should be randomised to one of two arms: severe bulbar receiving non-invasive ventilation, and severe bulbar without non-invasive ventilation. Outcome measures should include survival, quality of life, respiratory function, cognitive function and other sleep-related symptoms.

4.5 **Training and education needs**

What are the training and education needs and the requirements for ongoing support of carers and healthcare professionals in managing the care of patients with MND who are using non-invasive ventilation?

**Why this is important**

Many patients with MND become dependent on a family member to manage their care and equipment. Patients entering another care setting (for example, respite care or in an emergency) feel very vulnerable, particularly because staff may not be familiar with MND or non-invasive ventilation. A mixed-design longitudinal qualitative and quantitative study should enrol family members and carers, healthcare professionals and social care professionals who are involved in delivering treatment and care to patients with MND (for example, in care homes and respite care, as well as home carers). Outcome measures should be: (i) current level of knowledge of MND; (ii) training received and current skills in providing non-invasive ventilation; and (iii) the types of training, education and support that participants think they need in order to deliver non-invasive ventilation.
5 Other versions of this guideline

5.1 Full guideline

The full guideline, 'Motor neurone disease: The use of non-invasive ventilation in the management of motor neurone disease', contains details of the methods and evidence used to develop the guideline.

5.2 Information for the public

NICE has produced information for the public explaining this guideline.

We encourage NHS and voluntary sector organisations to use text from this information in their own materials about motor neurone disease.
6  Related NICE guidance

Published

- Dementia. NICE clinical guideline 42 (2006).
- Improving supportive and palliative care for adults with cancer. NICE guidance on cancer services (2004).
7 Updating the guideline

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. Please see our website for information about updating the guideline.
Appendix A: The Guideline Development Group, the Short Clinical Guidelines Technical Team, the Short Clinical Guidelines Team and the Centre for Clinical Practice

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Appendix B: The Guideline Review Panel

The Guideline Review Panel is an independent panel that oversees the development of the guideline and takes responsibility for monitoring adherence to NICE guideline development processes. In particular, the panel ensures that stakeholder comments have been adequately considered and responded to. The panel includes members from the following perspectives: primary care, secondary care, lay, public health and industry.

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About this guideline

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

The guideline was developed by the Short Clinical Guidelines Technical Team. The team worked with a group of healthcare professionals (including consultants, GPs and nurses), patients and carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

The methods and processes for developing NICE clinical guidelines are described in The guidelines manual. This guideline was developed using the short clinical guideline process.

We have produced information for the public explaining this guideline. Tools to help you put the guideline into practice and information about the evidence it is based on are also available.

Changes after publication

December 2011: Layout changed to match other NICE guidelines.

May 2013: Minor maintenance

Your responsibility

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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Motor neurone disease (CG105)

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