



Motor neurone disease (MND)
in acute, urgent and emergency care

As most people with MND are cared for at home, if an acute incident occurs, they will need to access crisis intervention services.¹

Whatever your role in acute, urgent or emergency care, this information is designed to give succinct guidance on actions you need to take and things you need to consider when treating someone with the condition.

For more information about MND, contact MND Connect:

0808 802 6262

mndconnect@mndassociation.org

The helpline is open to professionals 9am to 5pm Monday to Friday.

On hospital admission of a person with MND, an MND specialist (nurse, neurologist or care centre coordinator) should be alerted within 24 hours.

MND Paramedic's Card for JRCALC

We have produced an information card on MND which slots inside the JRCALC. See page 16 for how to order resources.

Please use the space below to record local contacts who may provide support in MND emergencies.

Service	Contact number/extension
MND specialist nurse, care centre or network	
Respiratory support for people with MND	
Hospital speech and language therapy support	
Hospital dietetics support	
Hospital physiotherapy support	
Hospital occupational therapy support	
Hospital palliative care team	
Community palliative care team	
Local hospice (for out-of-hours advice)	

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For drug dosages please refer to the British National Formulary (BNF) or Palliative Care Formulary (PCF), or liaise directly with pharmacy and/or palliative care/local hospice.

People with MND may need emergency care for a number of reasons, related or unrelated to their condition. Particular issues related to MND may include:

Chest infection

The leading cause of hospital admission in MND²
– see page 6 for Respiratory symptoms.

Acute respiratory distress

See page 6 for Respiratory symptoms.

Choking caused by mucus build-up or problems swallowing food, water or saliva

See page 8 for Dysphagia/choking/enteral feeding tube problems.

Problems with a blockage in feeding tube

See page 8 for Dysphagia/choking/enteral feeding tube problems.

Dehydration due to swallowing difficulties

See page 8 for Dysphagia/choking/enteral feeding tube problems.

Collapse of social care package/carer illness

See page 9 for Social care breakdown/carer illness.

End of life

See page 14.

Key points when you have a patient with MND

In all acute settings

Oxygen

See caution on oxygen therapy (opposite) before considering this course of action.

Does the patient have a record of these documents?

- Emergency healthcare plan
- ReSPECT – a summary of recommendations to help make immediate decisions about a person's care and treatment
- Advance care plan – this includes preferences for care, including place of care and end of life decisions.
- Advance Decision to Refuse Treatment (ADRT) . If so, this must be considered.
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) – if so, this must be considered. Sometimes also known as an Allow Natural Death order (AND).
- MND Alert Card or Understanding My Needs – These include key contacts and information about their care team and the specialist help they may need.

Communication - this can take great effort in MND. The person may use communication aids.

Does the patient use a non-invasive ventilator? If so, use it to manage symptoms of dyspnoea and help prevent or treat worsening hypercapnia.

Does the patient have capacity to make key decisions for themselves? See page 13.

In emergency medicine

• Is the patient pyrexial and taking riluzole?

Check full blood count (FBC) for signs of neutropenia and liver function tests (LFTs) for sign of disturbance, especially alanine transaminase (ALT).

• **The patient may not be able to lie flat for x-rays/ scans** – due to decline of respiratory function in MND. Propping the patient at a 30-45° angle or using NIV if they already have it will help. Additional tubing may be required to facilitate MRI scanning.

• **Locate the next of kin and Lasting Power of Attorney (if appropriate)** – Once located, take account of their insight into the person's condition and care needs.

• **Does the patient have an enteral feeding tube?** This will affect decisions around administration of medication (including route and type) and fluids.

• **Consider the administration route of any drug you choose to prescribe** – especially if the patient has swallowing difficulties and no enteral feeding tube.

• **Contact your local MND care centre/network for specialist advice and support**

• **If the patient has been admitted with Covid**, ensure Riluzole is stopped until all bloods back to within normal limits.

Communicating with someone with MND

It may take great effort for a person with MND to communicate and, in the case of an emergency admission, this may be even more difficult, if not impossible.

Where it is possible to communicate with the person with MND, it is vital to make the effort to do this in order to understand their individual needs.

Do:

- find out how the person with MND prefers to communicate and any equipment they like to use
- find out whether the person uses a simple code for “yes” and “no”. This can be a movement of any part of the body that can be carried out reliably, such as eye blinking
- remember that unspoken communication is important
- ensure the person with MND is the focus of communication
- check back with the person on what you think has been said and admit when you don’t understand.

Try not to:

- alter the rate or sound of your speech, unless the person with MND has asked you to
- finish the sentences of the person with MND, unless they ask you to, and avoid interrupting them
- use a family member or carer as a translator for the person with MND, unless it is clear that this is what the person with MND wants
- ask complex questions that require long or difficult answers and take up unwelcome time and energy
- use multiple choice questions. Simple questions that can be answered with yes, no, or a single word are easier when speech is difficult.

Respiratory symptoms

Signs and symptoms of respiratory compromise may include:

- shortness of breath
- orthopnoea
- acute panic
- signs of CO₂ retention, including drowsiness, anxiety, confusion, bounding pulse
- increased phlegm production or phlegm which is mucopurulent.
- falling oxygen saturations
- increased respiratory rate
- inability to clear bronchial secretions.

Rarely, patients may experience respiratory distress without other symptoms and MND may not yet have been diagnosed.²

Investigations:

- full physical examination
- temperature
- O₂ saturation
- bloods: FBC, U&Es, LFTs, ABG
- chest x-ray.

Check if the person has an ADRT or Lasting Power of Attorney, as this might impact on any treatment you give.

CAUTION: Inappropriate ventilation/against patient wishes

- Ideally, discussions around ventilation will have taken place between the patient and respiratory specialist and recorded on an advance care plan.³
- Where appropriate, a respiratory specialist should explore options for assisted ventilation. In an acute situation, an appropriate professional should decide whether to introduce NIV, then seek advice about long-term management.
- In case of intubation, extubation may be problematic: seek advice from the home ventilation team. The course of action may be to wean on to NIV, unless there is significant bulbar weakness. Ventilation via tracheostomy has implications for future care and is rarely the first choice of action.²
- Where ventilation is not used, medication (including titrated opioid analgesics) may be used to palliate breathlessness.

CAUTION: Oxygen therapy in MND

MND causes respiratory muscle weakness, as a result oxygen saturations may be lower than expected. Oxygen saturations in a patient with MND of between 88 and 92% are acceptable. Oxygen does not help breathlessness. **Supplemental oxygen should only be used with extreme caution in MND as excessive oxygen can lead to acidaemic respiratory failure and death.** Respiratory problems should be monitored by arterial blood gas analysis.

See our video on oxygen use at <https://bit.ly/MND-Oxygen>

Seek guidance from the specialist palliative care team or a respiratory consultant with links to neurology.

Actions/reminders for all acute settings

Signs of respiratory failure

- Does the patient have an ADRT or DNACPR?
- If the patient uses non-invasive ventilation, this may help to palliate breathlessness.

Panic/acute distress

- This may be a physiological response to breathing problems. It is vital to treat the symptom.
- Lorazepam and morphine salts (Oramorph) may help. In acute situations, buccal midazolam may be indicated.⁵
- Reassure that death from choking is rare.

Signs of infection

- Does the patient have an ADRT?
- Discuss with patient whether they wish to have antibiotic treatment.
- Treat symptoms of infection: pyrexia, discomfort, shortness of breath.
- Morphine salts may help ease the sensation of breathlessness.⁶

If the patient is 24-hour dependent on NIV and presents with breathlessness

- Treatment may involve changes to NIV settings.
- Liaise with the home ventilation team.

Actions/reminders in emergency medicine

Signs of respiratory failure

- Contact the on-call respiratory specialist for urgent review.
- Is non-invasive ventilation an option? The respiratory specialist will explore this, if appropriate, with the patient. People may not want this option as it may prolong life.³

Difficulty clearing thick bronchial secretions

- Ensure the person is hydrated.
- Consider carbocisteine (liquid preparation for those with swallowing problems. Contraindicated in those with gastric ulceration).⁷
- Humidification or a saline nebuliser (driven by pressurised air, not O₂) can moisten secretions.⁸
- Contact the on-call physiotherapist for techniques to clear secretions. Ongoing support may be needed from the respiratory team to improve cough through breath stacking, manual assisted cough or mechanical insufflation-exsufflation.²
- Liaise with respiratory specialist around referral to specialist teams.

Is the patient known to the local specialist MND respiratory service?

- If so, liaise with this team.

Dysphagia/choking/enteral feeding tube problems

- loss of swallow
- acute choking episodes due to build-up of mucus/food/liquids, which may lead to aspiration pneumonia
- blockage of enteral feeding tube
- excessive saliva
- dehydration.

Investigations:

- full examination and bloods: FBC, U&Es
- abnormal levels of electrolytes need to be corrected, eg with calcium gluconate or phosphate
- swallow function assessed by SLT
- check patency of enteral feeding tube.

Acute choking

Actions/reminders for all acute settings

- Clear the blockage (saliva, food or fluids).
- Palliation may be required in case of distress (see suggestions for panic/acute distress).

Actions/reminders in emergency medicine

- Intensive chest physiotherapy may be needed.
- SLT will assess whether swallow is safe and if it is not, will advise food texture to minimise risk.

Actions/reminders in emergency medicine

Saliva control problems

- Ask the patient whether saliva has been thick, thin or a mixture of secretion types.
- Antimuscarinic medication can be used to dry up saliva. Consider glycopyrrolate for people with cognitive impairment.³
- Treatment of this symptom may be difficult to address. Dosage must be monitored, as treatment can dry the saliva too much so it sticks in the throat.

Loss of swallow

- This will have been developing for some time and is unlikely to be a sudden change.
- Does the advance care plan include a decision about enteral feeding? The patient may have discussed this with their MND team, but may have delayed the decision or may change their mind when swallow is lost.
- Ask the patient if they want to have enteral feeding. If they agree and a respiratory function assessment makes them suitable, contact the enteral feed dietitian/nutrition team/upper GI specialist on call.
- Consider short term nasogastric tube feeding until enteral feeding tube can be inserted.

Actions/reminders in emergency medicine**If the patient does not want enteral feeding**

- Contact the hospital palliative care team for ongoing support during office hours or speak to the local hospice out of hours.

Enteral feeding tube blockage

- Call the nutrition team/upper GI specialist to address.

Dehydration

- This can be a problem for people who do not want enteral feeding or fluids.
- Any decision to treat this with IV fluids, in line with the wishes of the patient, must only be considered a short-term treatment, particularly to allow the patient to get home for end of life care.⁹
- The patient needs to be aware of this and be able to give informed consent.

MND Association professional information

- *Dysphagia* information sheet
- *Managing saliva problems* information sheet

See page 16 for how to order resources.

Social care breakdown/carer illness

People with MND living at home may have or need large packages of care and a lot of on-going support. Because MND is progressive, the care package needs to be regularly reviewed and upgraded when needed.

Unfortunately, packages of care can break down, or family members become unwell or cease to cope. Sudden change can lead to acute admission.

- Let the MND care coordinator know about the admission: see inside front cover for contact details.
- Determine the patient's care needs, home situation, current care package and family/carer situation.
- Find out what the patient and carer would need for discharge to be facilitated.
- Does the patient have social care funding or continuing healthcare funding?
- What short-term care placements are available? For example: hospital admission (if there is medical need), local GP hospital unit/cottage hospital, nursing home, residential care, hospice, care in a family member or friend's home etc. The hospital discharge team may be able to increase the care package or arrange a placement. The person's palliative care team may be able to arrange hospice or nursing care cover.

Pain

Pain may be caused by:	Medication options:
Muscle cramps	<ul style="list-style-type: none"> • Consider quinine as first-line treatment. Quinine sulphate is not associated with the problems of sedation seen with benzodiazepines.³ • If quinine is not effective, not tolerated or contraindicated, consider baclofen instead as a second-line treatment.³ • If baclofen is not effective, not tolerated or contraindicated, consider tizanidine, dantrolene or gabapentin.³ <p>Warning: dosage of muscle relaxants should be carefully adjusted to avoid increased weakness, and decreased mobility.¹²</p>
Muscle stiffness, spasticity or increased tone	<p>Consider baclofen, tizanidine, dantrolene or gabapentin.³</p> <p>If these treatments are not effective, not tolerated or contraindicated, consider referral to a specialist service for the treatment of severe spasticity.³</p>
Mechanical stress on joints from muscle weakness	<p>For joint pain: simple analgesia, eg long-acting non-steroidal anti-inflammatory drugs (NSAIDs).¹²</p>
Occasionally, neuropathic pain	<ul style="list-style-type: none"> • tricyclic antidepressants • gabapentin/pregabalin.¹⁶
<p>Other potential causes:</p> <ul style="list-style-type: none"> • skin sensitivity – good skin pressure care is vital • immobility – care should be taken when positioning, handling and lifting. Passive limb exercises should be carried out to avoid pain from immobility. Contact physiotherapy for advice managing this. • oedema – diuretics are rarely helpful, as they can promote urinary urgency and electrolyte disturbance • constipation - avoid laxatives that need large volumes of water eg Laxido/Movecol, as person with end stage MND is unlikely to be able to tolerate it and may feel more nauseous. 	



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Cognitive change and decision-making

There is now increased awareness of cognitive and behavioural changes in MND, and people with MND may fall into one of four groups:

- around 50% are unaffected by cognitive change
- around 35% experience mild cognitive and/or behavioural change, with specific deficits in executive functions, language and/or social cognition^{17, 18, 19}
- up to 15% develop frontotemporal dementia (FTD), either at the same time or after diagnosis of MND²⁰.

Mild cognitive impairment and/or behavioural change tends to include subtle changes that may have little impact on daily life.²¹

Those with MND and frontotemporal dementia (MND-FTD) will show marked cognitive change. Some will exhibit challenging behaviour.²¹

Cognitive change can have implications for decision-making.²³ Ideally, advance care planning will have taken place and documentation will exist of the patient's wishes for care and treatment.

Consenting to treatment in an emergency

In an emergency situation, it's not always possible to find out a patient's wishes in terms of treatment. As with any emergency, treatment can be carried out without consent if it is immediately necessary to save their life or prevent a serious deterioration of their condition.²²

However:

- someone with MND may have expressed a wish to refuse treatment that could potentially prolong life - check for ADRT
- interventions such as invasive ventilation via tracheostomy, for example, have serious implications for future care and survival for people with MND.²

Where possible, it is essential to support and encourage patients to be involved, as far as possible, in decisions about their care.

MND Association professional information

- *Cognitive change, frontotemporal dementia and MND* booklet

We also have three information sheets for people affected by MND on cognitive change and managing emotions. See page 16 for how to order.

End of life

Even if someone with MND has recorded a wish to die elsewhere, for example at home, they may be seen in emergency medicine as end of life approaches.

- The aim in this situation is to facilitate where the person's preferred place of care is. They may feel, once no more can be done, that they want to get home as soon as possible.
- The patient may be scared and think there is something more that can be done to prolong their life.
- The carer may feel unable to cope.
- They may wish to be an in-patient, or be transferred to a hospice.
- Some patients with MND may die in an acute setting. In those cases, the aim is to ensure the best possible care is achieved.

Assess all symptoms:	Medication to consider
Pain – patients may experience severe discomfort and/or distress, particularly in the later stages.	<ul style="list-style-type: none"> • analgesics to manage pain, including carefully titrated opiates (morphine salts, diamorphine)^{10, 11, 12} • sedatives to manage distress (lorazepam, midazolam)¹³
Nausea – may be due to enteral feeding, or some medications.	<ul style="list-style-type: none"> • anti-emetics (levomepromazine)¹⁴
Salivation	<ul style="list-style-type: none"> • antimuscarinics (glycopyrronium bromide/hyoscine hydrobromide) for excessive respiratory secretions¹⁴
Anxiety/depression	<ul style="list-style-type: none"> • sedatives such as diazepam, midazolam and lorazepam to reduce anxiety.¹³ Use with some caution, as they may adversely affect respiratory drive. However, this should not be the sole reason to avoid treating symptoms in end of life care.
Dyspnoea/orthopnoea	<ul style="list-style-type: none"> • opioid analgesics (morphine salts, diamorphine) to reduce cough reflex, control pain, relieve dyspnoea (breathlessness), and therefore fear and anxiety¹²

Also assess for:

- pressure area care
- dysphagia
- insomnia
- restlessness/agitation (consider urine retention and constipation as causes)
- effective elimination of bowels and bladder
- reassessment of emotional/spiritual and practical needs of patient, carer and family.

Delivery of suitable medications via a syringe driver may maximise symptom control.²

Oxygen should only be given to people with MND in specific circumstances (see page 6) but may be given along with sedatives at end of life.²

Death in MND

The most common cause of death in MND is respiratory failure, often with additional chest infection.²

Death in the majority of cases is peaceful, following lengthening periods of sleepiness, gradually resulting in unconsciousness and death. Very occasionally, this process may occur suddenly.

Palliative care services should be involved as early as possible to support people nearing end of life.

Communicating with the person with MND

This may become extremely difficult as the patient with MND reaches end of life, but even if they are unresponsive, every attempt should be made to maintain communication (see page 5).¹⁵

Withdrawal of non-invasive ventilation (NIV)

As respiratory muscle weakness progresses, there will be a point when NIV is no longer effective. Some people may continue to use NIV for palliation of symptoms of breathlessness.

Some may have specified within their advance care plan when they would want the treatment to be withdrawn. This may be when symptoms reach a particular point. In some cases, NIV will be withdrawn by the medical team due to its ineffectiveness.

If the time comes for NIV to be withdrawn, it should be done with supervision from a palliative care doctor, pre-medication and support for the person with MND and their family.²

Seek advice from the respiratory team on call.

The MND Association's End of life guide

This booklet for people with MND may answer some of your questions. See page 16 for how to order resources.

How the MND Association can support you and your team

MND Connect

Our helpline offers help, information and support to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

To order hard copies, please contact MND Connect using the details above.

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND.

www.mndassociation.org/education

Professionals' Community of Practice

A peer led group of health and social care professionals encouraging and supporting the development of good care for people with MND.

www.mndassociation.org/cop

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

www.mndassociation.org/research

MND Register

The MND Register aims to collect information about every person with MND to help researchers focus on the right areas.

www.mndregister.ac.uk

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist MND care.

www.mndassociation.org/care-centres

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND.

www.mndassociation.org/associationvisitors

We value your feedback

We would greatly appreciate your feedback on this guide.

Please complete our survey at www.smartsurvey.co.uk/s/mndprofessionals or email your comments to infofeedback@mndassociation.org

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Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

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