

MND Just in Case kit Information for GPs



What is the MND Just in Case kit?

Motor neurone disease (MND) is a progressive and terminal disease that results in degeneration of the motor neurones in the brain and spinal cord.¹

The MND Just in Case kit is designed to hold medication that may be needed if a person with MND experiences a sudden change in their symptoms. This may include:

- choking
- breathlessness
- related anxiety/panic.

This kit was developed with GPs, community nurses, palliative care teams and other healthcare professionals. The principle is the same as other Just in Case kits that are widely used in palliative care settings.²

You may be providing similar medication for all palliative care patients: this kit helps refine medication choice for MND and to indicate medication for carer use.

Anticipatory prescribing

Most people with MND die peacefully if symptoms are well managed.³ However, some people with MND may need medication to relieve distress during a crisis or towards the end of life.⁴

A period of distress will be remembered by families and can greatly affect their bereavement, so it is essential that symptoms are managed effectively.

The aim of the medication within this kit is to manage distressing symptoms, and not to shorten life. Opioid analgesics are commonly used in palliative care and with careful titration, respiratory depression and excessive drowsiness can be avoided.⁵

Why provide the MND Just in Case kit?

Although not everyone will need to use an MND Just in Case kit, its presence in the home will reassure the person with MND and their carer that practical help is ready at hand, just in case.

The MND Just in Case kit is a box supplied free of charge to a GP or specialist palliative care team for a named patient. It is designed to hold medication for the management of symptoms in an emergency: this may include times of breathlessness, choking and/or associated anxiety or panic.

The kit includes practical tips and information for carers and health and social care professionals on how to handle these situations.

Should an emergency occur, the carer can offer immediate relief by giving the appropriate medication for carer use. A doctor or nurse called to the home can take immediate and appropriate action, using the medications for healthcare professional use.

How to order an MND Just in Case kit

- 1 The supply of an MND Just in Case kit is agreed between the person with MND, their carer and GP.
- 2 The GP requests a kit for the named patient by calling MND Connect on **0808 802 6262**.
- 3 The MND Association sends the kit to the GP, free of charge.
- 4 The GP prescribes medication for the kit (appropriate for the person).
- 5 The GP, or community or district nurse, gives the kit to the person with MND and ensures the carer knows how it can be used.
- 6 The kit should be kept up to date, with medication prescribed, dosages and any other changes.

The MND Just in Case kit includes:

- separate compartments to hold medication for carer use and medication for healthcare professional use
- a space to list emergency contact details on the lid of the box
- a record of the contents on the inside of the lid
- stickers that can be used in the home to let professionals know where the MND Just in Case kit can be found
- a leaflet about our *End of life guide*, which can support any discussions you have with your patient about planning ahead.

Leaflet for carers: tips for dealing with a range of issues, and the medications that can be given.

Leaflet for healthcare professionals: information on how to manage emergencies in MND and which medications to give.

The GP should:

- prescribe medications to be included within the MND Just in Case kit that are appropriate to the individual and their circumstances (see pages 5-7)
- discuss the purpose and provision of the kit with the district or community nurse involved in the care of the person with MND
- involve the district or community nurse in advising/training the carer in how to give the medication for carer use and supporting the carer in the use of the kit
- give the filled MND Just in Case kit to the person with MND and their carer, or arrange for a community nurse to do so
- advise that the box should be kept in a safe but accessible place in the home.

The contents of this box and use of the kit should be regularly reviewed. Early medical review is recommended when any of the contents have been used.⁶

Medication to prescribe

The following medication is suggested for the management of situations where there is a distressing symptom or a crisis has occurred.^{7,8} For dosages, refer to the current edition of the Palliative Care Formulary or guidance from local palliative care specialists.

The prescribed medications that can be given by carers and those for administration by a doctor/nurse must be kept separately. They should be placed in the relevant side of the MND Just in Case kit.

As the person approaches end of life, the medications included within the MND Just in Case kit should be reviewed. Other options may be prescribed in addition to, or instead of, those within this kit.

Medication for carer use

The use and administration of each drug should be fully explained to the carer.

Midazolam

sedative medication, available in buccal form as Buccolam

Use: restlessness, agitation, fear, anxiety and muscle spasm

Administration: to be given buccally – the medication should be drawn up in a syringe and the contents then squirted into the mouth, inside the cheek. Pre-filled syringes are also available.

Note: The carer must be given training in administration of midazolam. Midazolam may not be prescribed for use by carers in some areas due to local policy on anticipatory prescribing.

Lorazepam

Use: same effect as midazolam

Administration: sublingually or orally in tablet form.

Medication for healthcare professional use

Morphine sulphate: opioid analgesic

Use: pain relief, relief of breathlessness

Administration: subcutaneous injection as single doses

Possible alternatives: if higher doses of opioids are required, diamorphine may be used. It is more soluble and can be given in a smaller volume. Oxycodone may be used where morphine is not tolerated.

Glycopyrronium bromide: antimuscarinic

Use: excessive and/or noisy respiratory secretions, excessive drooling

Administration: orally, or by subcutaneous injection in divided doses, or by continuous subcutaneous infusion using a syringe driver.

Hyoscine hydrobromide: antimuscarinic

Use: excessive and/or noisy respiratory secretions, excessive drooling

Administration: by subcutaneous injection in divided doses, or by continuous subcutaneous infusion using a syringe driver. Transdermal patches are available, but are not suitable in an emergency.

Cyclizine: antiemetic

Use: can be useful for nausea and vomiting that may occur with the use of opioids

Administration: orally, or by subcutaneous injection in divided doses, or by continuous subcutaneous infusion using a syringe driver. Subcutaneous infusion can precipitate at concentration above 10mg/ml or in the presence of saline.

Haloperidol: antiemetic with sedative properties

Use: nausea, agitation, restlessness and intractable hiccup

Administration: by subcutaneous injection in divided doses, or by continuous subcutaneous infusion using a syringe driver.

Levomepromazine: antiemetic with sedative and analgesic properties

Use: nausea and vomiting, restlessness

Administration: orally, or by subcutaneous injection in divided doses, or by continuous subcutaneous infusion using a syringe driver.

Midazolam: sedative

Use: restlessness, agitation, fear, anxiety and muscle spasm

Administration: by subcutaneous injection, or by continuous subcutaneous infusion using a syringe driver.

The section for healthcare professionals will also need:

- water for injections
- syringes
- needles
- at least 5 to 10 ampoules of the prescribed medication should be prescribed.

If the person is very distressed it may be appropriate to give an opioid and a benzodiazepine at the same time and not wait to assess effectiveness of each medication.

If it is anticipated that the patient will need further doses or is very symptomatic, then commencing a syringe pump with a combination of medications that can be reviewed daily will be appropriate.⁹

If possible, stay with the person with MND and their family until the situation is more settled.

If after 30 minutes the person with MND is still distressed, repeat the injection. This injection can be repeated every four hours thereafter.

NB For those who cannot have or are unable to tolerate morphine, alternatives such as oxycodone may be used.

Palliative care and advance care planning

The MND Just in Case Kit should be seen as part of a framework of holistic care for the person with MND.

While this kit is appropriate for emergency use, further thought may be needed to providing medication on a more continuous basis. Establishing links at an early stage with specialist palliative care services may provide a useful source of advice and support.

The terminal stage of MND

For some people, death can be very sudden, before an obvious end stage is reached. Others experience a protracted final stage, which can last many weeks. The most usual clinical picture is of rapid deterioration over a few days, often following an upper respiratory tract infection.¹⁰ It is very important to reassure people with MND and carers that while someone with MND may experience choking episodes, people with MND very rarely die from choking.³

Advance care planning

People will have concerns about the progression of MND and time is needed for the person to feel comfortable enough to talk about this. It is important that concerns are taken seriously and solutions, where possible, are made available. Discussions around options for care and preferences for end of life should be held before the need is urgent or the capacity to communicate is limited and tiring. Having time to think things through and to know wishes have been recorded can give peace of mind. If discussions are held and decisions are made, they should be documented and communicated to relevant professionals.

This may be in the form of an Advance Statement – which explains the person's views but is not binding – or an Advance Decision to Refuse Treatment – which is legally binding if completed correctly.

Advance Decision to Refuse Treatment (ADRT)

An ADRT allows people to make decisions to refuse specific treatments or have treatment withdrawn in specific circumstances in the future. This may include withdrawal of treatments that sustain life, such as assisted ventilation. An ADRT may be discussed as part of advance care planning.

Do Not Attempt CPR (DNACPR)

Someone with MND may choose to have a DNACPR. This will be respected in most instances, but is not legally binding. In England and Wales, refusal of CPR may be included on an ADRT form, which is legally binding, with clear instructions about when this should be applied. In some areas, a standard form such as ReSPECT form may be used.

Reviewing choices

Any decisions made about advance care should be regularly reviewed. If changes are made, new copies should be signed and dated and distributed to those who hold the existing paperwork.

Assisted ventilation

Assisted ventilation – usually non-invasive ventilation (NIV), or sometimes tracheostomy ventilation – may be provided to relieve symptoms of respiratory muscle weakness. While someone may not use ventilation all the time at first, they may start to use the machine more frequently, leading to continual use as the respiratory muscles weaken. If a mask is not fitting properly and therefore not working as effectively, it should be changed or refitted by the specialist respiratory team.

As physical symptoms progress, people will have increasing care needs and dependency on others, and difficult decisions on when to stop ventilation may need to be made. Careful discussion early in the disease progression may help people with MND make decisions so that any actions that have to be taken are in line with their priorities.

Use caution with oxygen

People with respiratory failure due to chronic neuromuscular weakness (seen in MND) are at risk of rapid carbon dioxide retention. Supplementary oxygen therapy can have a serious detrimental effect in people with MND, reducing respiratory drive and worsening their condition. Oxygen therapy (unless as a palliative measure, which may be appropriate) should be used with great caution in patients with MND-related respiratory problems and monitored by arterial blood gas analysis.¹¹

Advance care planning checklist

- Is someone helping the person with MND to develop an advance care plan?
- Does a palliative care clinician or team need to be involved?
- Have you discussed end of life with the person and their family, so they are prepared for what may happen?
- Has the person with MND and their family been reassured that death by choking is not the norm?
- Is there adequate physical and emotional support for the family if the person wishes to die at home?
- Has an ADRT or DNACPR been recorded? If so, copies should be placed with this box. In some areas, a standard form such as ReSPECT form may be used.
- Has any existing advance care plan/DNACPR/ADRT been reviewed?
- Is the ambulance service aware of any signed DNACPR or ADRT?
- Have you informed your local primary care out-of-hours service of any DNACPR or ADRT?
- Does the district or community nurse know that there is someone with MND in their area?
- Do you have contact details of the local specialist MND team?
- Is the person included in the surgery's Gold Standards Framework/palliative care meetings?

Information for you

- Information sheet P6 – *Evaluation and management of respiratory symptoms in motor neurone disease (MND)*

Information you can share

Our resources for people affected by MND include information sheets 8A-8D, which cover breathing problems and ventilation. Our *End of life guide* may support you in conversations about advance care planning. Order from MND Connect or download from our website at www.mndassociation.org/publications

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About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Our mission

We improve care and support for people with MND, their families and carers.

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

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

MND Association

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About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.

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