

## 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.<sup>1</sup>**

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.<sup>2</sup> 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.<sup>3</sup> However, some people with MND may need medication to relieve distress during a crisis or towards the end of life.<sup>4</sup> 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.<sup>5</sup>

## **Why provide the MND Just in Case kit?**

Although most people will never 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 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
- stickers that can be applied to each medication to indicate expiry date, and the person responsible for issuing a replacement
- 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 4-6)
- complete and sign the administration permissions on pages 7-8
- 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
- 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.<sup>6</sup>**

# Medication to prescribe

The following medication is suggested for the management of symptoms in an emergency situation.<sup>7,8</sup>

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 appropriate 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.

**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:** orally in tablet form.

## Medication for healthcare professional use

**Morphine sulphate:** opioid analgesia

**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:** transdermal patch behind the earlobe, changed every 72 hours, or by subcutaneous injection in divided doses, or by continuous subcutaneous infusion using a syringe driver.

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

**Possible alternative:** levomepromazine for agitation where other medications do not help.

**Midazolam:** sedative

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

**Administration:** buccally or by subcutaneous injection.

**The section for healthcare professionals will also need:**

- water for injections
- syringes
- needles.

**A subcutaneous injection of the following can be given in one syringe (by an appropriate professional) to relieve distress:**

- **morphine sulphate** injection (or a dose in proportion to the oral dose, ie 50% of the four-hourly oral dose of morphine) – to relieve pain, dyspnoea and reduce cough
- **midazolam** (injectable form) – to ease anxiety and reduce muscle spasm
- **glycopyrronium bromide** – to reduce respiratory secretions.

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.

If the continuation of parenteral medication is necessary, a continuous subcutaneous infusion of medication, using a syringe driver, should be considered.<sup>9</sup>

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

# Administration permissions

To allow medication to be administered, a prescription should be completed and updated every three months. Original prescriptions will be required by pharmacy services.

Patient name \_\_\_\_\_

DOB \_\_\_\_\_ NHS number \_\_\_\_\_

In case of emergency I authorise the following medication to be given:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signed: \_\_\_\_\_

Name: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Patient name \_\_\_\_\_

DOB \_\_\_\_\_ NHS number \_\_\_\_\_

In case of emergency I authorise the following medication to be given:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signed: \_\_\_\_\_

Name: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Patient name \_\_\_\_\_  
DOB \_\_\_\_\_ NHS number \_\_\_\_\_  
In case of emergency I authorise the following medication to be given:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Signed: \_\_\_\_\_  
Name: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Patient name \_\_\_\_\_  
DOB \_\_\_\_\_ NHS number \_\_\_\_\_  
In case of emergency I authorise the following medication to be given:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Signed: \_\_\_\_\_  
Name: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Patient name \_\_\_\_\_  
DOB \_\_\_\_\_ NHS number \_\_\_\_\_  
In case of emergency I authorise the following medication to be given:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Signed: \_\_\_\_\_  
Name: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

# 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.<sup>10</sup> 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.<sup>3</sup>

Ensure you discuss with the person with MND and their carer what their wishes would be in the event that the person suddenly deteriorates or stops breathing.

## **Advance care planning**

People will have many concerns about the progression of MND and time is needed for the person to feel comfortable enough to talk about their worries. 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 clearly documented and communicated to relevant professionals.

## **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, which is legally binding, with clear instructions about when this should be applied.

## **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) but sometimes invasive ventilation via tracheostomy – may be provided to relieve symptoms of respiratory muscle weakness. While someone may not use NIV 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, someone 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 choices.

## **Oxygen**

People with respiratory failure due to chronic neuromuscular weakness (seen in MND) will rapidly retain carbon dioxide. Supplementary oxygen therapy can have a serious detrimental effect in people with MND, causing reduced 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.<sup>11</sup>

## 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.
- 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-8E, 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](http://www.mndassociation.org/publications)

The MND Just in Case kit is a box supplied free of charge to a GP 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.
- 5 The kit should be kept up to date, with medication prescribed, dosages and any other changes.

### References

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- 10 Rafiq MK et al. Respiratory management of motor neurone disease: a review of current practice and new developments. *Pract Neurol*. 2012;12(3):166-76.
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