

MND Just in Case Kit - Professionals

This leaflet is for attending health professionals. See separate guidance for carers.

This kit contains medication, prescribed by a GP, that may be required if there is a sudden change in a person with motor neurone disease (MND), eg:

- choking
- breathlessness
- related anxiety.

Although most people with MND will never need to use an MND Just in Case kit, its presence in the home will bring confidence and reassurance to many people with MND and their carers – practical help, readily at hand, just in case.

In an emergency

Careful positioning of the person with MND is vital to:

- maintain the airway
- reduce pressure on the thorax and abdomen.

If possible, **sit the person upright or slightly reclined** to allow the fullest expansion of the lungs. Keep the airway as clear as possible with the chin clear of the chest and neck supported.

Someone with MND may not be able to lie flat due to compromised respiratory function.

CAUTION: Oxygen usage

People with respiratory failure due to chronic neuromuscular weakness (seen in MND) will rapidly retain CO₂. Supplementary O₂ therapy can have a serious detrimental effect, depressing respiratory drive and worsening breathing.

O₂ therapy (unless a palliative measure, which may be appropriate) should be used with great caution in people with MND-related respiratory problems and monitored by arterial blood gas analysis.

Does the person use assisted ventilation?

Use of non-invasive ventilation may help to palliate breathlessness.

Note: some people with MND will use invasive ventilation by tracheostomy.

Consider alternative drug administration routes. This is essential if the person has swallowing problems and no feeding tube.

Is there an ADRT or DNACPR?

A copy may be included in this kit or registered with MedicAlert. In some areas, a standard form such as ReSPECT form may be used for advance care planning.

Medication for healthcare professional use

The following may be given together in one syringe to relieve distress:

- morphine sulphate
- midazolam
- glycopyrronium bromide.

If possible, stay with the person with MND and their family until the situation is more settled. After 30 minutes, if the person is still distressed, repeat the injection. It can be repeated every four hours.

□ Midazolam – sedative

(may not be prescribed on an anticipatory basis in some areas)

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

Administration: subcutaneous injection or buccally.

□ Morphine sulphate – strong opioid analgesia

Use: pain, dyspnoea and cough

Administration: subcutaneous injection as single doses.

If higher doses of opioids are required, diamorphine may be used. It is more soluble and can be given in a smaller volume. Alternatives such as oxycodone may be used for those who cannot have morphine.

□ Glycopyrronium bromide – antimuscarinic

Use: excessive saliva or excessive/noisy respiratory secretions

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

□ Haloperidol – antiemetic with sedative properties

Use: nausea, vomiting, agitation, restlessness and intractable hiccup

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

Possible alternatives include levomepromazine for agitation where other medications do not help.

□ Hyoscine hydrobromide – antimuscarinic

Use: excessive saliva or excessive/noisy respiratory secretions

Administration: transdermal patch on the scalp behind the earlobe and changed every third day (72 hours), or subcutaneously in divided doses, or as a continuous subcutaneous infusion using a syringe driver.

□ Cyclizine – antiemetic

Use: nausea and vomiting – useful for that which may occur with the use of opioids

Administration: orally, or subcutaneous injection in divided doses, or by continuous subcutaneous infusion. In subcutaneous infusions, can precipitate at concentration above 10mg/ml or in the presence of saline.

□ **Levomepromazine – antiemetic with sedative & analgesic properties**

Use: nausea and vomiting – useful for that which may occur with the use of opioids

Administration: orally, or subcutaneous injection or continuous infusion.