

## MND Just in Case Kit - Carers

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

### About the MND Just in Case kit

The MND Just in Case kit is designed to help you plan for emergencies, even though they may never happen. Your GP will have provided this kit with medication that can be given immediately in case of severe breathlessness, choking or problems clearing saliva, mucus or phlegm.

There are separate medications for an appropriate professional to give. By having the kit nearby, you will know that medication is on hand if a doctor is called out of hours.

This kit has been provided in case of emergency. If these events continue, speak to your specialist MND or palliative care team. When no longer needed, please take this box and its contents to your local pharmacist. Please do not return the box to the MND Association.

### When you receive the medications:

- please read this information
- check which medications have been included and mark them on the enclosed medication sheet
- the prescriber should explain how to use the 'medication for carer use'
- include copies of any documents about future care/wishes
- keep the box in a safe but accessible place in the home
- ensure, with the GP, that the kit is kept up to date.

**As a carer, you will be the best judge of when to call for professional medical help. You can give the 'medication for carer use' to the person with MND while waiting for medical help to arrive.**

### If you decide to call for professional medical help:

- call someone to be with you until the help arrives
- tell the professional which medication you have used
- show the professional that there is other medication available
- paramedics/ambulance crew may not be able to use these medications, but will have equivalent drugs that they can administer.

### For people using assisted ventilation

Some people with MND will use assisted ventilation, known as non-invasive ventilation (NIV). As MND symptoms progress, a person may become more dependent on using the machine for symptom relief.

An open discussion with the doctor or respiratory team should help to form a plan of action for use in the event of a crisis.

If someone is using ventilation through a tracheostomy, they are unlikely to feel breathless. If problems occur, seek expert help immediately.

## Documents to include with this kit

If you haven't already, you may wish to speak to your GP about the following records of future wishes, which may be included in or alongside the MND Just in Case kit.

### **Advance Decision to Refuse Treatment (ADRT) and Do Not Attempt CPR (DNACPR)**

If an ADRT and/or a DNACPR has been recorded, keep copies with this box to make an attending professional aware of these decisions. In some areas, a standard form such as ReSPECT form may be used. For more information about ADRT or DNACPR, contact MND Connect on 0808 802 6262 or [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### **MedicAlert**

Any ADRT, DNACPR or other advance decisions may also be registered with MedicAlert. A necklet or bracelet will alert any professional called in an emergency, who can access the MedicAlert database for further information.

To find out more, contact MedicAlert on 0800 581 420, email [info@medicalert.org.uk](mailto:info@medicalert.org.uk) or visit [www.medicalert.org.uk](http://www.medicalert.org.uk)

## IN AN EMERGENCY

- **try to stay calm:** this will help everyone to stay calm
- reassure the person and encourage them to stay calm
- call for help: is there anyone nearby who can assist you (may not be a professional)?
- check the problem and possible causes
- would a change of body position help?
- if needed, give appropriate medication for carer use.

Carers would not normally be asked to give an injection.

## Medication for carer use

Both are used for restlessness, agitation, fear and anxiety.

### **Lorazepam**

**How to give it:** as a tablet by mouth, or dissolve under the tongue (depending on type prescribed).

### **Midazolam**

(may not be prescribed for carer use in some areas)

**How to give it:** squirt into the mouth between the cheek and gums as advised by your doctor or nurse. Refer to personal care plan for usage and doses.

## Choking

- try to stay calm
- would a change of position help?

### Mild or partial choking

This is where the airway is only partially blocked. The person should be able to:

- answer a question or make a sound (where speech is unaffected by MND)
- cough and breathe.

In mild or partial choking, do not slap the person on the back. They may breathe in, forcing the obstruction further down the airway.

### Severe choking

If choking is severe, the person will be unable to:

- speak or make a sound (where speech is usually unaffected by MND)
- respond by nodding, shaking their head or by gesture (where this is a usual response)
- to make sounds apart from small wheezing noises.

Attempts to cough will be silent due to inability to breathe in or out.

### In case of severe choking:

1. call 999 for professional help
2. stand slightly behind and to one side of the person
3. lean the person forward and support their chest with one hand
4. provide up to five sharp blows between the person's shoulder blades with the heel of your hand
5. stop after each blow to see if the blockage has been dislodged.

### If five back blows fail to clear the obstruction, then provide up to five abdominal thrusts:

1. stand behind the person (if they are in a chair/wheelchair, position yourself behind it or stand alongside, and follow the procedure as closely as you can)
2. place your arms around their waist and bend them forward
3. clench your fist and place it above the person's belly button
4. place your other hand on top and thrust both hands backwards into their stomach with a hard, upward movement
5. repeat this five times until the blockage is removed
6. stop after each thrust to check if the blockage has cleared
7. if the obstruction is still stuck, continue alternating back blows with abdominal thrusts.

## Acute breathlessness

Medication for carer use: lorazepam or midazolam

- try to stay calm
- call for help
- try a change of position: 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
- open a window or use a fan to improve the flow of air in the room.

## Clearing saliva

- tilt the body and head to one side and support the head with pillows
- if there is no solid object in the airway, any feeling of choking will be due to saliva or fluids going 'down the wrong way'
- do not pat on the back - may cause a sharp intake of breath.

Ask an occupational therapist/physio about positioning.

## Spasms in throat muscles

Some people have spasms in their throat muscles, which prevent them from breathing or speaking. It may look as if they are choking.

**Action:** use lorazepam or midazolam.