

Just in case kit for motor neurone disease

Motor neurone disease (MND) is a progressive and terminal disease that results in degeneration of the motor neurones, or nerves, 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.

The MND Just in Case kit is a box supplied free of charge to a GP for a named patient. The GP should prescribe medications to be included in the kit that are appropriate to the individual.

The box is split into two sections. In an emergency:

- the **carer** can offer immediate relief by giving the person with MND the **medication for carer use**
- a **healthcare professional called to the home** can take immediate and appropriate action, using the **medication for healthcare professional use**.

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

The principle is the same as other Just in Case kits that are widely used in palliative care settings and similar medication may be provided for all palliative care patients.² This kit is not designed to replace existing systems but, where needed, to refine medication choice for people with MND and to indicate medication for carer use. The main difference to other palliative or end of life kits is the suggestion of lorazepam and/or buccal midazolam for the carer to administer.

Although some people will never need to use the MND Just in Case kit, its presence in the home will bring confidence and reassurance to many people with MND and their carers.

The MND Just in Case kit includes:

- separate compartments to hold medication for carer use and for healthcare professional use
- a space to list emergency contact details on the lid of the box
- a chart on the inside of the lid that can be used to record the medication contained
- stickers that can be used around the home to let professionals know where the 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 about planning ahead.

For the GP: information about the box and medications to prescribe.

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.

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, 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.

The GP should then:

- prescribe medication for the MND Just in Case kit (appropriate for the individual)
- 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
- review the contents and use of the kit as required.

References

- 1 Bäumer D, Talbot K and Turner MR. *Advances in motor neurone disease*. Journal of the Royal Society of Medicine. 2014; 107:14.
- 2 Wowchuk SM et al. *The palliative medication kit: an effective way of extending care in the home for patients nearing death*. J Palliat Med. 2009; 12(9):797-803.

Acknowledgements

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The MND Association would like to acknowledge the Ken Hopkins Tribute Group, and in particular Professor David Oliver, for the development of the original kit in 1990, and for providing advice on the updated Kit.

How we can support you and your team

MND Connect

Our helpline offers help, information and support, and signposting 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

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. Opportunities include online modules and face-to-face training.

www.mndassociation.org/education

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 treatment and brings us closer to a cure.

www.mndassociation.org/research

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan the care and discover more about the cause of the disease.

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 multidisciplinary care for people with MND.

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. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

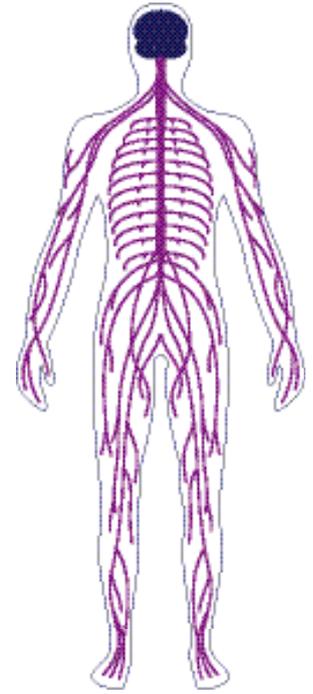
We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit www.smartsurvey.co.uk/s/mndprofessionals or email your comments to infofeedback@mndassociation.org

If you would like to help us by reviewing future versions of our information resources, please email us at infofeedback@mndassociation.org

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 sight, hearing or sensation.
- 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 some 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.



Would you like to find out more?

Contact our helpline if you have any questions about MND or want more information about anything in this publication.

mndconnect
0808 8026262
mndconnect@mndassociation.org

www.mndassociation.org/professionals

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