



P4A

## MND Just in Case kit

### Information for health and social care professionals

**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.<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.

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 **doctor or nurse 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.<sup>2</sup> 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 absence of oxygen and the suggestion of lorazepam and/or buccal midazolam for carer use.

Although most 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.

## How the MND Association can support you and your team

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

### MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

Please contact MND Connect if you have any questions about the information in this publication.

### Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND.

Downloads of all our information sheets and most of our publications are available from our website at **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**. You can also order our publications directly from the MND Connect team.

### MND Association website

Access information for health and social care professionals on our website at **[www.mndassociation.org/professionals](http://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, such as conferences and masterclasses. Find out more at **[www.mndassociation.org/education](http://www.mndassociation.org/education)**

## MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan.

Our support grant service consists of providing care and quality of life grants for people with MND. This service is supported by MND Association branch and group funds, and by the Association's central fund.

Our equipment loan service is focused on three core items of equipment to help people with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on **01604 611802**, email **support.services@mndassociation.org** or visit **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. Contact the Research Development team on **01604 611880** or **research@mndassociation.org**. Alternatively, visit **www.mndassociation.org/research** for more information. For the latest research news, visit our research blog at **www.mndresearch.wordpress.com**

## MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email **membership@mndassociation.org**

## Local support

### Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

### MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

### Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

### Association visitors (AVs)

Association visitors provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals. You may be in contact with Association visitors following up on queries from the families they support.

## Acknowledgements

Thank you to the following people for their valuable contributions to the MND Just in Case Kit:

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**Professor Mark Rickenbach, Visiting Professor Healthcare and Education Quality, Winchester University, GP and lead for Research and Training, Park and St Francis Surgery, Chandlers Ford**

**Victoria Walley, Pharmacy Manager/Responsible Pharmacist, Dialchemist Ltd**

**The original version of this kit was created by Dr David Oliver, Honorary Reader, Centre for Professional Practice, University of Kent, UK and Locum Consultant in Palliative Medicine, Wisdom Hospice, Rochester, UK**

**Thank you to the people affected by MND and other professionals who provided feedback on the MND Just in Case kit.**

## 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.

## 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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## MND Association

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[www.mndassociation.org](http://www.mndassociation.org)



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