



# P13

## Using our care information resources

**Motor Neurone Disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.<sup>1</sup>**

We understand that effective health and social care information is a vital part of your communication with people living with MND or Kennedy's disease, and our resources can help you provide that support. This sheet explains how to find and order our resources, with guidance on what to provide at diagnosis.



Our award-winning care information is evidenced, user tested and reviewed by independent experts, and accredited through the national PIF Tick quality mark. See more at [piftick.org.uk](http://piftick.org.uk).

- 1. Printed publications**
- 2. Where to start**
- 3. Our resources for professionals**



## Useful links:

Find our patient information at: [mndassociation.org/careinfo](http://mndassociation.org/careinfo)

Use our digital Care Information Finder to help your patients search our care resources by need: [mndassociation.org/careinfofinder](http://mndassociation.org/careinfofinder)

Find information for professionals at: [mndassociation.org/professionals](http://mndassociation.org/professionals)

Use our Professional Information finder to find all our resources, for you and for your patients. Search for information specific to your profession or on a specific topic: [mndassociation.org/pro-info-finder](http://mndassociation.org/pro-info-finder)

## 1. Printed publications

Our printed publications are available free of charge in England, Wales and Northern Ireland, for people with or affected by MND or Kennedy's disease. We only charge at cost (plus postage and packing) for use with other conditions. Unfortunately, we are unable to ship hard copies worldwide, outside of the three countries, except in exceptional circumstances. See next page for order details.

### How to order printed publications

We cannot provide bulk or standing orders, so please always order in small quantities at point of need for your patients.

As a charity that works on donations only, this helps avoid unnecessary print runs and wastage after revisions. All outdated versions need to be recycled. Thank you.

To order, contact our Care Admin team by emailing [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org) or call the team on 01604 611868 / 611812.

People affected by MND or Kennedy's disease can also order direct, through our MND Connect helpline. Email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) call 0808 8026262.

## 2. Where to start?

Some people want detail at diagnosis – others just an overview. We recommend the following from our wide range, to guide people to the level of content they prefer.

### MND

- How to find out more – our basic facts leaflet for display in surgeries or clinics.
- An introduction to MND – ideal for use at first diagnosis.
- Living with MND – for further reading if people want detail.

- An easy read guide to MND – for people with reading difficulties.
- [mndassociation.org/about-mnd](https://mndassociation.org/about-mnd) – our introductory web pages.
- [mndassociation.org/support-and-information](https://mndassociation.org/support-and-information) – our services and information.
- [mndassociation.org/publications](https://mndassociation.org/publications) – access to all of our published resources.

## Kennedy's disease

Kennedy's disease - Our main booklet for people living with Kennedy's disease, also known as spinal bulbar muscular atrophy (SBMA), which is a separate, but similar condition to MND and is supported by the MND Association.

- [mndassociation.org/kennedys](https://mndassociation.org/kennedys) – our web pages for Kennedy's disease.

## Carers

- Caring and MND: quick guide – to help people adjust if new to a caring role.
- Caring and MND: support for you – comprehensive support on carer wellbeing.
- [mndassociation.org/carers](https://mndassociation.org/carers) – our web pages for carers and family members.
- [mndassociation.org/cyp](https://mndassociation.org/cyp) – our web pages for children, young people and parents.

## Animations

- [mndassociation.org/animations](https://mndassociation.org/animations) – short overviews for both conditions.

## 3. Our resources for professionals

In addition to the resources we provide for people with or affected by MND or Kennedy's disease, we offer a range of information and educational opportunities for health and social care professionals:

- [mndassociation.org/professionals](https://mndassociation.org/professionals) – our main hub for professionals
- [mndassociation.org/professionals/publications](https://mndassociation.org/professionals/publications) – our publications for professionals
- [mndassociation.org/education](https://mndassociation.org/education) – our education hub, including our events calendar.

## Stay connected

- Sign up to our monthly education newsletter for professionals:  
[mndassociation.org/educationupdate](https://mndassociation.org/educationupdate)
- Follow us on X: [x.com/mndeducation](https://x.com/mndeducation)
- Join our Community of Practice, a peer led group with a shared passion to improve MND care: [mndassociation.org/cop](https://mndassociation.org/cop)

# How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.

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

Tel: **0808 8026262**

## MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.  
[mndassociation.org/professionals](http://mndassociation.org/professionals)

Stay updated on events, publications and opportunities for professionals.  
[mndassociation.org/educationupdate](http://mndassociation.org/educationupdate)  
X: [mndeducation](https://twitter.com/mndeducation)  
Bluesky: [mndeducation.bsky.social](https://bluesky.mndeducation.bsky.social)

## Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.

[mndassociation.org/pro-info-finder](http://mndassociation.org/pro-info-finder)  
[mndassociation.org/careinfofinder](http://mndassociation.org/careinfofinder)

## Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.

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

## MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.

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

## Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.  
[mndassociation.org/local-support](http://mndassociation.org/local-support)

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.  
[mndassociation.org/care-centres](http://mndassociation.org/care-centres)

## Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.

[mndassociation.org/getting-support](http://mndassociation.org/getting-support)

## MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.

[mndregister.ac.uk](http://mndregister.ac.uk)

## Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.  
[mndassociation.org/research](http://mndassociation.org/research)

## 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 [smartsurvey.co.uk/s/mndprofessionals](https://smartsurvey.co.uk/s/mndprofessionals) or email your comments to [education@mndassociation.org](mailto:education@mndassociation.org).

If you would like to help us by reviewing future versions of our information resources, please email us at [education@mndassociation.org](mailto:education@mndassociation.org).

## How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from [mndassociation.org/publications](https://mndassociation.org/publications) or contact MND Connect to order hard copies. Call 0808 8026262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

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**Every day we support people affected  
by Motor Neurone Disease.  
Because with MND, every day matters.**