

# Publications order form



## Section A

### How to order our publications

Our publications are free of charge to people living with or affected by motor neurone disease (MND), or Kennedy's disease. Health and social care professionals can also order items free on behalf of someone with or affected by MND or Kennedy's disease.

As a registered charity, our resources are limited. Please help reduce our information costs by downloading items whenever possible and only requesting print items that you need.

1. If possible, download them free from our website for instant access, at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**
2. Alternatively, add the quantity you need against the required items shown on this order form and send the whole booklet to us.
3. Complete the details on the final page of this form to ensure delivery.
4. Return **all of the pages** of this order form to:  
MND Association, Francis Crick House, 6 Summerhouse Rd, Moulton Park,  
Northampton NN3 6BJ

*All resources are free, unless health and social care professionals wish to order multiple copies of our larger guides, or to support people living with other health conditions. In this case guides will cost £5 each, plus postage and packing. See page 18 for more information.*

To order a new publications order form	Quantity
<b>Publications order form</b> Also provided with our Living with MND, Caring and MND, and End of life guides	

You can also order through our helpline,

#### **MND Connect**

Telephone: 0808 802 6262

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

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Section B

### Information for people with MND or Kennedy's disease, their families and carers



Our care information resources are evidence based, user tested and expertly reviewed.

Introductory information	Quantity
<b>Motor neurone disease (MND) - How to find out more</b> Basic facts about the disease. <i>A5 leaflet</i>	
<b>An introduction to motor neurone disease (MND)</b> A short guide to help at diagnosis. <i>A5 booklet</i>	
<b>An easy read guide to motor neurone disease</b> For people with learning difficulties. <i>A4 booklet</i>	
<b>Caring and MND: quick guide</b> To help identify available support as a carer. <i>Included with our Living with motor neurone disease guide. A5 booklet</i>	

Guides and booklets	Quantity
<b>Living with motor neurone disease</b> An overview of MND. To view the guide or individual sections online, download at <a href="http://www.mndassociation.org/lwmnd">www.mndassociation.org/lwmnd</a> or order from MND Connect. <i>A4 guide</i>	
<b>Caring and MND: support for you</b> Practical and emotional support for unpaid carers. To view the guide or individual sections, download at <a href="http://www.mndassociation.org/carerguide">www.mndassociation.org/carerguide</a> or order from MND Connect. <i>A4 guide</i>	
<b>Types of care</b> An overview of the range of care available to help you if you have MND or Kennedy's disease, from primary care through to specialist.	
<b>Personal care with MND</b> Information about equipment and services that could support you to prolong independence with everyday tasks and how to access them.	
<b>Sex and relationships</b> Guidance on intimacy for anyone affected by MND.	
<b>Eating and drinking with motor neurone disease (MND)</b> Guidance and easy swallow recipes. <i>Wiro bound colour A4 book</i>	
<b>Making the most of life with MND</b> Ways to continue doing the things you enjoy. <i>A5 booklet</i>	
<b>Getting around with MND</b> Driving, transport, and holiday guidance focusing on different ways to get out and about with reduced mobility.	

<b>Emotional and psychological support</b> For people affected by MND. <i>A5 booklet</i>	
<b>Changes to thinking and behaviour with MND</b> For people with MND, including guidance for carers. <i>A5 booklet</i>	
<b>Inherited MND and genetic testing</b> Guidance on genetic counselling and testing, for people with MND or a family history of the condition. <i>A5 booklet</i>	

<b>Decision making and planning ahead</b>	<b>Quantity</b>
<b>MND Checklist</b> A write on A4 form to help you manage your condition and think ahead.	
<b>Understanding My Needs</b> A4 write on form to help you guide hospital staff and care workers about the care you want and need. <i>Also included with our Living with MND and End of life guides</i>	
<b>What you should expect from your care</b> Short notes to help at appointments. Endorsed by the National Institute for Health and Care Excellence (NICE). <i>Included in our Living with MND, Caring and MND and End of life guides. A7 pocket sized booklet</i>	
<b>End of life: a guide for people with motor neurone disease</b> Candid information about planning ahead and end of life decisions. To view the guide or individual sections, download at <a href="http://www.mndassociation.org/EOLguide">www.mndassociation.org/EOLguide</a> or order from MND Connect. <i>A4 guide</i>	
<b>Finding your way with bereavement</b> To help you identify emotions and support with practical guidance. <i>A5 booklet</i>	

<b>Information to help support children and young people</b>	<b>Quantity</b>
<b>Telling people about MND</b> To help open conversations with family, children, friends, colleagues and health and social care professionals. <i>A5 booklet</i>	
<b>When someone close has MND: A workbook for children aged 4-10</b> An activity workbook to help children close to someone with MND. Includes guidance for a trusted adult.	
<b>Why are things changing?</b> Storybook to help young children start to adjust to the changes that MND brings to family life. Can also be read online with our MND Buddies at: <a href="http://www.mndbuddies.org">www.mndbuddies.org</a> <i>A4 storybook</i>	
<b>So what is MND anyway?</b> Support for young people and young carers up to age 18, who are close to someone with MND. Also available as a web app at <a href="http://www.mndassociation.org/ypinfo">www.mndassociation.org/ypinfo</a> <i>A4 guide</i>	
See also our online resources on the MND Buddies website at <a href="http://www.mndbuddies.org">www.mndbuddies.org</a>	

## Information sheets (all A4)

General information	Quantity
<b>1A – About the NICE guideline on motor neurone disease (MND)</b> Endorsed by the National Institute for Health and Care Excellence (NICE).	
<b>1B – Health information in other languages and formats</b>	
<b>1C – Where can I find the information I need?</b>	
<b>1D – How we use your information?</b>	

Disease types	Quantity
<b>2B – Kennedy’s disease</b>	
<b>2C – Primary lateral sclerosis (PLS)</b>	
<b>2D – Progressive muscular atrophy (PMA)</b>	

Types of care	Quantity
<b>3A – MND care centres and networks</b>	
<b>3D – Hospice and palliative care</b>	

Medication	Quantity
<b>5A – Riluzole</b> Information about this drug, to help with the treatment of MND	

Physical therapies	Quantity
<b>6A - Physiotherapy</b>	
<b>6B – Complementary therapies</b>	
<b>6C – Managing pain</b>	

Mouth and throat (bulbar) symptoms	Quantity
<b>7A – Swallowing difficulties</b>	
<b>7B – Tube feeding</b>	
<b>7C – Speech and communication support</b>	
<b>7D – Voice banking</b>	

<b>Breathing and ventilation</b>	<b>Quantity</b>
8A – Support for breathing problems	
8B – Ventilation for motor neurone disease	
8C – Withdrawal of ventilation with MND	
8D – Air travel and ventilation for motor neurone disease	

<b>Benefits, financial support, and social care</b>	<b>Quantity</b>
10A – Benefits and entitlements	
10B – What is social care?	
10C – Disabled Facilities Grants and home accessibility	
10D – NHS continuing healthcare	
10E – Work and motor neurone disease	
10F – Personal health budgets	
10G – Support for families with children	

<b>Daily living</b>	<b>Quantity</b>
11C – Equipment and wheelchairs	
11E – Environmental controls	

<b>Planning ahead</b>	<b>Quantity</b>
14A – Advanced Decision to Refuse Treatment (ADRT) and advance care planning	

*All resources are free, unless health and social care professionals wish to order multiple copies of our larger guides, or to support people living with other health conditions. In this case guides will cost £5 each, plus postage and packing. See page 18 for more information or contact MND Connect.*

***We cannot provide bulk or standing orders for professional use, so please 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.***

Other items		Quantity
<p><b>Notepad for people with speech difficulties</b> <i>Small notepad</i>  Each page is headed with:  'I can understand you but have difficulty speaking please read on.'</p>		
<p><b>Speech card for people with speech difficulties</b>  Display card, showing the words:  'I have a physical problem which affects my speech, but I can hear and understand you. Your help and patience would be appreciated. Thank you.'  <i>Pocket sized card</i></p>		
<p><b>MND Alert card</b>  A card that states you have MND and provides details of your emergency contacts. <i>Pocket sized card</i>  <i>Also provided with our Living with MND and End of life guides</i></p>		
<p><b>MND alert wristband</b></p> <p>Lets emergency and hospital staff know you have MND and may be at risk with oxygen therapy.</p> <p><i>Medium sized band provided with our Living with MND and End of life guides.</i></p>	<p><b>Small</b> (180mm)</p>	
	<p><b>Medium</b> (202mm)</p>	
	<p><b>Large</b> (210mm)</p>	
<p><b>Online forum card</b>  Card with details of our online forum.  <i>Pocket sized card</i>  <i>Also provided with our Living with MND and Caring and MND: support for you guides.</i></p>		
<p><b>Information flyer</b>  Details about our information resources. <i>A5 flyer</i></p>		

## Publications in other languages

To download our translated resources, see:  
[www.mndassociation.org/languages](http://www.mndassociation.org/languages)

We provide the following publications in a range of languages:



Other languages	Quantity
<b>Introduction to motor neurone disease</b>	
<b>Information sheet 1B – Health information in other languages or formats</b>	
<b>Information sheet 7A – Swallowing difficulties</b>	
<b>Information sheet 7B – Tube feeding</b>	
<b>Information sheet 8A – Support for breathing problems</b>	
<b>Information sheet 8B – Ventilation for motor neurone disease</b>	

To help you make an important decision about treatment and care, we may also be able to translate an additional information sheet or a section from our larger guides. Other formats such as Braille may be available. Contact the MND Connect helpline to discuss your needs and order.

As a charity, we support people with or affected by MND, or Kennedy’s disease, in England, Wales and Northern Ireland. Unfortunately, we are not able to provide or post printed publications outside of these three nations, except in exceptional circumstances.



## Section C

### Information for health and social care professionals



Resources for professionals can be ordered free of charge (unless otherwise indicated). Our care information is also free when you order on behalf of someone with or affected by MND or Kennedy's disease, but you may be charged if ordering in multiples, or for other conditions. For example, our *Living with motor neurone disease* guide would cost £5 per copy, plus p&p.

General publications	Quantity
<p><b>Motor neurone disease – a guide for GPs and primary care teams</b>            For professionals who have a role in the management of MND. Endorsed by the Royal College of General Practitioners (RCGP)  <i>A5 booklet</i></p>	
<p><b>MND: A guide for social care services</b>            Helping social care professionals, including social workers, to offer the best possible support to people with MND, their carers and family.  <i>A5 booklet</i></p>	
<p><b>Occupational therapy for motor neurone disease</b>            How to help people adapt with MND. Endorsed by the Royal College of Occupational Therapists (RCOT)  <i>A5 booklet</i></p>	
<p><b>Multidisciplinary team working for MND</b>            To help establish, develop, and maintain an effective multidisciplinary team (MDT). <i>A5 booklet</i></p>	
<p><b>Cognitive change, frontotemporal dementia and MND</b>            Information and practical tips on management  <i>A5 booklet</i></p>	
<p><b>Motor neurone disease: Communication, speech, and language support</b>  <i>A5 booklet</i></p>	

General publications	Quantity
<p><b>MND Association support for health and social care professionals</b>  Details of the support and services the MND Association offers professionals  <i>A5 booklet</i></p>	
<p><b>Caring for someone with motor neurone disease: information for care workers</b>  Practical advice on care for a person with MND.  <i>A5 booklet</i></p>	
<p><b>Supporting children and young people close to someone with MND</b>  For professionals working with children or young people close to someone with MND, including teachers, school nurses, youth workers and social workers. <i>A5 booklet</i></p>	
<p><b>Motor neurone disease (MND) in acute, urgent, and emergency care</b>  Succinct guidance on actions that may be taken and those that require caution when treating someone with MND in an emergency. Endorsed by the College of Paramedics and the Royal College of Emergency Medicine  <i>A5 booklet</i></p> <p><i>You may also wish to order our Respiratory Checklist card and MND First Contact Card on page 13 to carry in your wallet.</i></p>	
<p><b>A professional's guide to end of life care in motor neurone disease (MND)</b>  To help health and social care professionals discuss death, assist advance care planning, and support the process of dying with MND  <i>A4 booklet</i></p>	
<p><b>Advanced care planning</b>  Information and practical strategies to support professionals to effectively facilitate advance care planning for people with MND.  <i>A5 booklet</i></p>	
<p><b>Red Flag diagnosis tool</b>  A tool created in partnership with the Royal College of General Practitioners (RCGP) to help GPs recognise the signs of MND.  <i>A4 document</i></p>	

Information sheets (all A4)	Quantity
<b>P1 – Head supports for people with motor neurone disease</b>	
<b>P2 – Wheelchairs for people with motor neurone disease</b>	
<b>P3 – Managing saliva problems in motor neurone disease</b>	
<p><b>P4A – MND Just in Case Kit</b> (information)            Enables a GP to prescribe medications for a person with MND to keep close at hand, in case of sudden breathlessness, feelings of panic or choking.</p> <p>Contact MND Connect to order the Just in Case Kit.            If ordering for training purposes and not for a GPs named patient there will be a cost of £23 per kit.</p>	
<b>P5 – Providing medical evidence for benefit applications made by people with MND</b>	
<p><b>P6 – Evaluation and management of respiratory symptoms in MND</b>  <i>You may also wish to order our Respiratory Checklist card and MND First Contact Card on page 13 to carry in your wallet.</i></p>	
<b>P7 – NHS Continuing Healthcare for MND</b>	
<b>P8 – Dysphagia in MND</b>	
<b>P9 – Oral suction</b>	
<b>P10 – Voice banking for people with MND</b>	
<b>P11 – Pain in motor neurone disease</b>	
<b>P12 – Information for dental teams</b>	
<b>P13 – Using our care information to help you support people with or affected by MND or Kennedy’s disease</b>	
<b>PG015 – Augmentative and Alternative Communication (AAC) Pathway for MND</b>	

Other items	Quantity
<b>Paramedics card (printed card to fit JRCALC)</b> Information card highlighting key points on MND for emergency care, which slots inside a paramedic's JRCALC.	
<b>Respiratory checklist</b> <i>Credit card size</i> A summary of respiratory symptoms and signs related to MND, for respiratory monitoring and management.	
<b>(PX025) First contact card</b> includes prompts to consider respiratory function during first contact with someone with MND.	

Audio visual	Quantity	Unit	Total
<b>Understand MND training DVD</b> Introduces MND. Alternatively, view online for free, at: <b><a href="http://www.mndassociation.org/understandingmnd">www.mndassociation.org/understandingmnd</a></b>	DVD	£5 plus	
	USB stick		

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## Section D

### Research information

If you have any questions or would like to discuss MND research, contact our Research Development team on **01604 611880** or **research@mndassociation.org**



Research information sheets	Quantity
<p><b>A – Introduction to MND research</b> What happens in motor neurones and ways to find out more about MND research.</p>	
<p><b>B1 – Inherited MND: Introduction</b> <b>B2 – Inherited MND: Genetic testing and insurance</b> <b>B3 – Inherited MND: Options when starting a family</b></p> <p>Are no longer available. Information on <i>Inherited MND and genetic testing</i> can found in our new booklet – see Section B.</p>	
<p><b>C – Unproven treatments in MND</b> Facts and issues to consider when making an informed decision about alternative or unproven treatments.</p>	
<p><b>D – Clinical trials</b> An explanation of how clinical trials work and what to think about when taking part.</p>	
<p><b>E – Research we fund 2022</b> A brief overview of the portfolio of research grants awarded by the MND Association.</p>	
<p><b>F – Stem cells and MND</b> An explanation of stem cells and how they are used in MND research.</p>	
<p><b>G – Biomarkers</b> What biomarkers are, why they are useful and which ones have been identified for MND.</p>	

Research information sheets (continued)	Quantity
<p><b>H – Accessing unapproved drugs</b> The process behind approving drugs, and access options to drugs not yet approved.</p>	
<p><b>I – Tissue donation</b> Explains how donated tissue may be used and how to arrange a donation.</p>	
<p><b>J – What happened to my UK MND Collections sample?</b> About samples deposited with the MND Association’s DNA Bank.</p>	
<p><b>K – Statins</b> An overview of the use of statins in MND research.</p>	
<p><b>L – Research involving animals</b> The MND Association’s position on research involving animals.</p>	

## Section E

### General publications, fundraising and volunteering



Fundraising publications	Quantity
<p><b>Events diary</b> Information about upcoming events and challenges you can join. <i>A5 booklet</i></p>	
<p><b>Guide to fundraising</b> Your complete guide to fundraising, whether you are organising your own event or taking part in a fundraising challenge. <i>A5 booklet</i></p>	
<p><b>Legacy information</b> A gift in your will could help achieve a world free from MND <i>A5 booklet</i></p>	
<p><b>A tribute to someone special</b> A Tribute Fund celebrates the life of someone special while supporting our vital work. <i>A5 leaflet</i></p>	
<p><b>Fightback funds</b> Helping people with MND fight back through fundraising. <i>A5 leaflet</i></p>	
<p><b>Direct debit form</b> To set up a regular donation by Direct Debit. <i>A4 single page form</i></p>	

General reading	Quantity
<p><b>Impact report</b> Annual report of the difference we all make.</p>	
<p><b>Trustees' Annual Report</b> Annual Report and Financial Statements.</p>	
<p><b>What is an MND Association visitor?</b> Explains what an Association visitor (AV) is and how they can support you if you are affected by MND.</p>	



## Payment details

Send your order with payment, if relevant, to:

**The MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park, Northampton NN3 6BJ**

Delivery details: (Please complete in **BLOCK CAPITALS**)

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Postcode: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

Are you?

someone living with MND  
or Kennedy's disease

an agency, other charity  
or organisation

a carer/family member  
or friend

a student

a health or social care  
professional

a general enquirer

All resources are free, unless health and social care professionals wish to order multiple copies of our larger guides, or to support people living with other health conditions.

In this case guides will cost £5 each, plus postage and packing.

Contact MND Connect, **0808 802 6262**, for more information or email:

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

Total cost of order, including p&p (if applicable):	
Donation to MND Association:	
£5.00	
£10.00	
Other	
Total amount:	

Please see our privacy policy for further details on how we use your information:

**[www.mndassociation.org/privacy-policy](http://www.mndassociation.org/privacy-policy)**

## Payment method

**Please only complete when ordering chargeable items or making a donation.**

I enclose a cheque for £\_\_\_\_\_ made out to MND Association, or

I authorise you to debit my payment/credit card with the total amount:

Card number:

Expiry date:

Billing details for card account (UK card holders only):

House number/name:

Postcode:

Signature:

Date:

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### **Increase your donation at no extra cost**

Thanks to the Gift Aid scheme, the MND Association can reclaim 25p for each £1 you give, increasing its value to £1.25.

If you have made a donation, please tick one of the following boxes:

I am a UK taxpayer and would like the MND Association to treat all donations I have made in the past four years, or I make in future as Gift Aid donations. I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

I am not a UK tax payer.

Name:

House number/name:

Postcode:

Signature:

Date:

**Data protection:** We greatly value your support and would like to keep you up to date with our work and how you, your family and friends can support us in the future. This could be by volunteering, campaigning or financially, through fundraising events and appeals. If you consent to receiving these communications, please indicate below.

Yes, I consent to further communications by:

Post

Email

## About us

The MND Association was founded in 1979 by a group of volunteers, all with their own personal experience of MND. Over the years, the Association has grown into the vibrant community we know today, made up of members, volunteers, campaigners, supporters and staff from across England, Wales, and Northern Ireland.

As well as being the biggest charitable funder of MND research in the UK, the Association focuses on improving access to care, providing support and campaigning for those people living with or affected by MND in England, Wales, and Northern Ireland.

Our community is united behind one clear vision – **a world free from MND.**

# We welcome your views

We welcome feedback on our publications to help us improve the content.

Find feedback links about information for people with or affected by MND, or Kennedy's disease, in the option for *Feedback forms, revision dates and corrections* at:

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

You can also email suggestions to: **[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)** or return by post to *Information Feedback* at the address below.

## MND Association

Francis Crick House, 6 Summerhouse Rd, Moulton Park, Northampton NN3 6BJ

Tel: 01604 250505

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

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



@mndassoc



/mndassociation



@mndassoc

If you need any further information or support, please contact our helpline:

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

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