

Publications order form



Where to find the information you need

You may be searching for information resources about motor neurone disease (MND) or Kennedy's disease.

We offer a wide range of resources, but you may not need them all immediately. If you have either condition or support a person who has been diagnosed, we recommend starting with:

- *An introduction to motor neurone disease* for a first overview.
- *Living with motor neurone disease (MND)* for more detail on daily routines.
- *Caring and MND: quick guide* for those new to the caring role.
- *Caring and MND: support for you* for wellbeing support in a caring role.
- *Kennedy's disease* for facts and support. As this condition shares similar symptoms with MND, much of our wider information will also be helpful.

See the following page to order in print or find our resources at:

Our website

www.mndassociation.org

Our Care Information Finder

To help you search and share our information resources by need.

www.mndassociation.org/careinfofinder

Our Professional Information Finder

To help health and social care professionals find and share resources.

www.mndassociation.org/pro-info-finder

Section A

How to order our printed 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 using the *Care Information Finder* on the previous page.
2. Or order through our MND Connect helpline, call at 0808 802 6262 or email at **mndconnect@mndassociation.org**
3. Alternatively, add the quantity you need against the required items shown on this order form and send the whole booklet to us.
4. Complete the details on the final page of this form to ensure delivery.
5. 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 19 for more information or contact MND Connect.

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 elsewhere, other than in exceptional circumstances.

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

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.

Find these resources online at www.mndassociation.org/careinfo

Introductory information	Quantity
Motor neurone disease (MND) - How to find out more Basic facts about the disease. <i>A5 leaflet</i>	
An introduction to motor neurone disease (MND) A short guide to help at diagnosis. <i>A5 booklet</i>	
An easy read guide to motor neurone disease For people with learning difficulties. <i>A4 booklet</i>	
Caring and MND: quick guide 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
Living with motor neurone disease An overview of MND. To view the guide or individual sections online, download at www.mndassociation.org/lwmnd or order from MND Connect. <i>A4 guide</i>	
Living alone with motor neurone disease This guide explores the likely challenges when living alone with either condition and offers information resources that can help. <i>A5 booklet</i>	
Kennedy's disease An overview of Kennedy's disease, a separate, but similar condition to MND that is supported by the MND Association, download at www.mndassociation.org/kennedys or order from MND Connect. <i>A5 booklet</i>	
Inherited MND and genetic testing Guidance on genetic counselling and testing, for people with MND or a family history of the condition. <i>A5 booklet</i>	
Caring and MND: support for you Practical and emotional support for unpaid carers. To view the guide or individual sections, download at www.mndassociation.org/carerguide or order from MND Connect. <i>A4 guide</i>	
Types of care 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.	

Personal care with MND Information about equipment and services that could support you to prolong independence with everyday tasks and how to access them.	
Sex and relationships Guidance on intimacy for anyone affected by MND.	
Eating and drinking with motor neurone disease (MND) Guidance and easy swallow recipes. <i>Wiro bound colour A4 book</i>	
Making the most of life with MND Ways to continue doing the things you enjoy. <i>A5 booklet</i>	
Getting around with MND Driving, transport, and holiday guidance focusing on different ways to get out and about with reduced mobility.	
Emotional and psychological support For people affected by MND. <i>A5 booklet</i>	
Changes to thinking and behaviour with MND For people with MND, including guidance for carers. <i>A5 booklet</i>	

Decision making and planning ahead	Quantity
MND Checklist A write on A4 form to help you manage your condition and think ahead.	
Understanding My Needs 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>	
What you should expect from your care 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>	
End of life: a guide for people with motor neurone disease Candid information about planning ahead and end of life decisions. To view the guide or individual sections, download at www.mndassociation.org/EOLguide or order from MND Connect. <i>A4 guide</i>	
Finding your way with bereavement To help you identify emotions and support with practical guidance. <i>A5 booklet</i>	

Information to help support children and young people	Quantity
Telling people about MND To help open conversations with family, children, friends, colleagues and health and social care professionals. <i>A5 booklet</i>	
When someone close has MND: A workbook for children aged 4-10 An activity workbook to help children close to someone with MND. Includes guidance for a trusted adult.	
Why are things changing? 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: www.mndbuddies.org <i>A4 storybook</i>	

So what is MND anyway?

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

www.mndassociation.org/ypinfo *A4 guide*

See also our online resources on the MND Buddies website at www.mndbuddies.org

Information sheets (all A4)

General information	Quantity
1A – About the NICE guideline on motor neurone disease (MND) Endorsed by the National Institute for Health and Care Excellence (NICE).	
1B – Health information in other languages and formats	
1D – How we use your information?	

Disease types	Quantity
2C – Primary lateral sclerosis (PLS)	
2D – Progressive muscular atrophy (PMA)	

Types of care	Quantity
3A – MND care centres and networks	
3D – Hospice and palliative care	

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

Physical therapies	Quantity
6A – Physiotherapy	
6B – Complementary therapies	
6C – Managing pain	

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

Breathing and ventilation	Quantity
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	

Benefits, financial support, and social care	Quantity
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	

Daily living	Quantity
11C – Equipment and wheelchairs	
11E – Environmental controls	

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

Other items		Quantity
Notepad for people with speech difficulties <i>Small notepad</i> Each page is headed with: 'I can understand you but have difficulty speaking please read on.'		
Speech card for people with speech difficulties 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>		
MND Alert card 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>		
MND alert wristband Tells emergency and hospital staff that you have MND and may be at risk with oxygen therapy. <i>Medium sized band provided with our Living with MND and End of life guides.</i>	Small (180mm)	
	Medium (202mm)	
	Large (210mm)	
Online forum card 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>		
Information flyer Details about our information resources. <i>A5 flyer</i>		

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 19 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.

Publications in other languages

Other languages	Quantity
Introduction to motor neurone disease	
Information sheet 1B – Health information in other languages or formats How to get help with accessible information from health and social care services, and from the MND Association.	
Information sheet 7A – Swallowing difficulties	
Information sheet 7B – Tube feeding	
Information sheet 8A – Support for breathing problems	
Information sheet 8B – Ventilation for motor neurone disease	

We may have more resources currently available in other languages. We also offer a limited translation service and alternative formats such as Braille and audio.

Contact the MND Connect helpline for help. Find our guidelines for translation in a range of languages and download language resources at:

www.mndassociation.org/languages

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.

Find our professional information on our website at www.mndassociation.org/forprofessionals

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

General publications	Quantity
<p>MND Association support for health and social care professionals Details of the support and services the MND Association offers professionals. <i>A5 booklet</i></p>	
<p>Caring for a person with motor neurone disease: A guide for care workers Practical advice on care for a person with MND. <i>A5 booklet</i></p>	
<p>Supporting children and young people close to someone with MND For professionals working with children or young people close to someone with MND, including teachers, school nurses, youth worker and social workers. <i>A5 booklet</i></p>	
<p>Motor neurone disease (MND) in acute, urgent, and emergency care 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>A professional's guide to end-of-life care in motor neurone disease (MND) 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>Advanced care planning Information and practical strategies to support professionals to effectively facilitate advance care planning for people with MND. <i>A5 booklet</i></p>	
<p>An introduction to Kennedy's disease This booklet introduces health and social care professionals to Kennedy's disease, and highlights support and treatment options. <i>A5 booklet</i></p>	
<p>Red Flag diagnosis tool 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
P1 – Head supports for people with motor neurone disease	
P2 – Wheelchairs for people with motor neurone disease	
P3 – Managing saliva problems in motor neurone disease	
<p>P4A – MND Just in Case Kit (information)</p> <p>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>	
P5 – Providing medical evidence for benefit applications made by people with MND	
<p>P6 – Evaluation and management of respiratory symptoms in MND</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>	
P7 – NHS Continuing Healthcare for MND	
P8 – Dysphagia in MND	
P9 – Oral suction	
P10 – Voice banking for people with MND	
P11 – Pain in motor neurone disease	
P12 – Information for dental teams	
P13 – Using our care information to help you support people with or affected by MND or Kennedy’s disease	
PG015 – Augmentative and Alternative Communication (AAC) Pathway for MND	

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

Audio visual	Quantity		Unit	Total
Understand MND training DVD Introduces MND. Alternatively, view online for free, at: www.mndassociation.org/understandingmnd	DVD		£5 plus	
	USB stick			

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.

Section D

Research information

You can find all our information on research at
www.mndassociation.org/research

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
A – Introduction to MND research What happens in motor neurones and ways to find out more about MND research.	
C – Unproven treatments in MND Facts and issues to consider when making an informed decision about alternative or unproven treatments.	
D – Clinical trials An explanation of how clinical trials work and what to think about when taking part.	
E – Research we fund 2022 A brief overview of the portfolio of research grants awarded by the MND Association.	
F – Stem cells and MND An explanation of stem cells and how they are used in MND research.	
G – Biomarkers What biomarkers are, why they are useful, and which ones have been identified for MND.	

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

Section E

General publications, fundraising and volunteering



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

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

Further information support from the MND Association

How we can help

Our range of services, including MND Connect, regional support and financial support.

Website: **www.mndassociation.org/our-services**

Finding other organisations

We don't endorse organisations, but many provide support and information.

Website: **www.mndassociation.org/usefulorgs**

Animations

Provide short overviews to help explain each disease or a type of support.

Website: **www.mndassociation.org/animations**

What do all the words and initials mean?

Health and social care services terms and initials are explained in lists on our website.

Website: **www.mndassociation.org/words**

Low-cost apps

A list of free or low-cost apps to make life with a disability a little easier:

Website: **www.mndassociation.org/apps**

MND Association Benefits Advice Service

Providing free, impartial advice and information on benefits you may be entitled to.

Website: **www.mndassociation.org/benefitsadvice** or MND Connect

Getting the right care

Find out how to check if your treatment and care are appropriate, or make a complaint at:

www.mndassociation.org/mycare

Keeping up to date with our information

Find news about our resources at:

MND Education



@mndeducation.bsky.social



@mndeducation

MND Association



@mndassoc.bsky.social



/mndassociation



@mndassoc



@mndassoc

If you are a health and social professional, you can also sign up for our education update newsletter: www.mndassociation.org/educationupdate

Other information support

Adult Social Care Services

Contact your local authority or council in England, Wales or Scotland, or your health and social care trust in Northern Ireland, for access to needs assessment and services.

Website: www.gov.uk (England and Wales)

www.nidirect.gov.uk (Northern Ireland)

www.gov.scot (Scotland)

Benefits, finance and work

Find information about benefits, financial support and work at:

England and Wales: www.gov.uk

Northern Ireland: www.nidirect.gov.uk

Scotland: www.gov.scot

NHS and UK healthcare

Information about NHS services and healthcare across the UK

Website: www.nhs.uk

For England

Telephone: 111 (for urgent medical advice, available 24/7)

Website: <https://111.nhs.uk>

For Wales

Telephone: 111 (for urgent medical advice, available 24/7)

Website: **<https://111.wales.nhs.uk>**

For Northern Ireland

Telephone: through each Trust's website contact page

Website: **www.hscni.net**

For Scotland

Telephone: 111 (for urgent medical advice, available 24/7)

Website: **www.nhs24.scot**

NICE Guideline on motor neurone disease (MND)

The National Institute for Health and Care Excellence (NICE) guideline on MND.

Website: **www.nice.org.uk/guidance/ng42**

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.

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

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

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

MND Association

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

Tel: 01604 250505

Email: enquiries@mndassociation.org

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

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