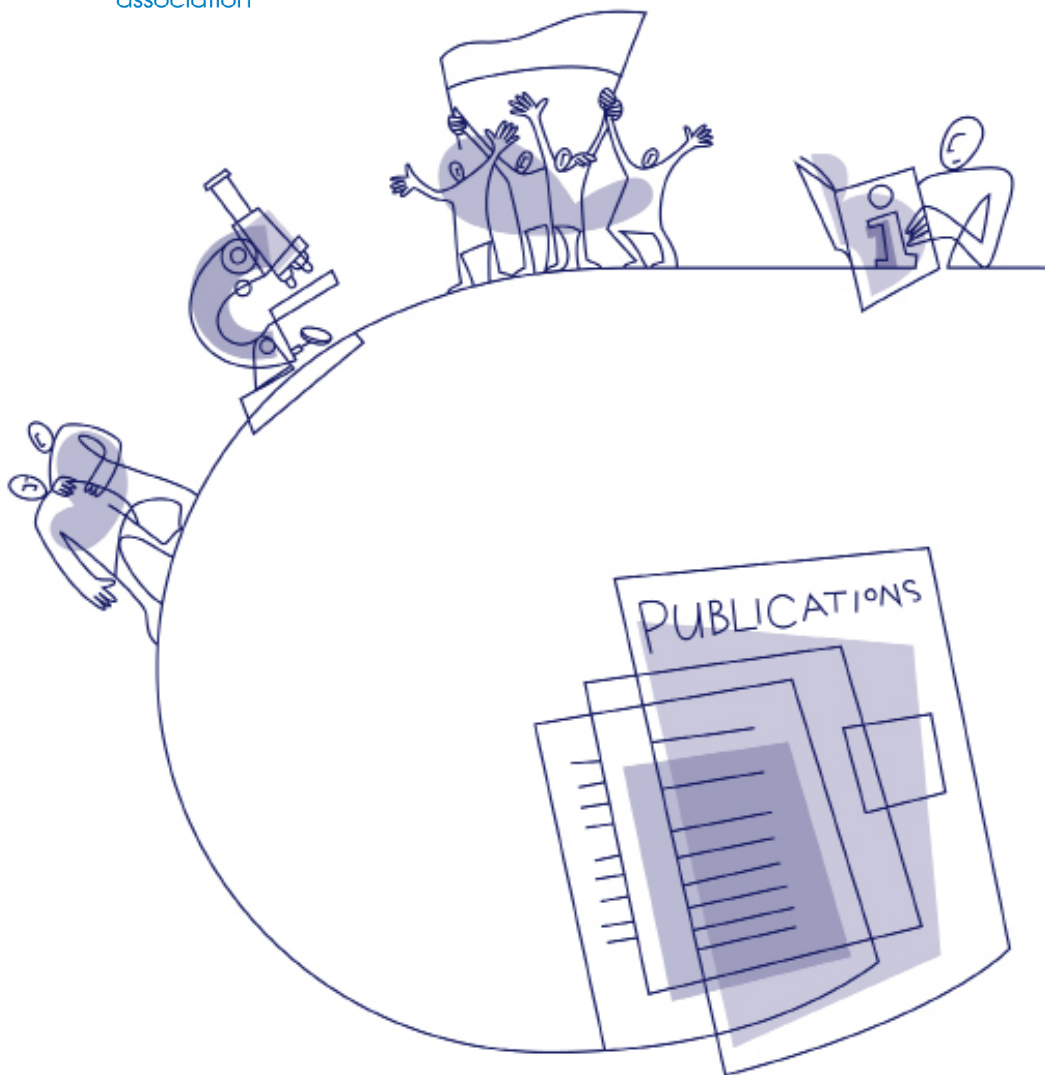


**mnda**

motor neurone disease  
association



# **MND Association 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 for themselves or 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 Industrial Estate, 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 £2.00 post and packing per copy. see page 18 for more information.*

You can also order through our helpline, MND Connect.

Telephone: 0808 802 6262

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

Mon-Fri 9am to 5pm and 7pm to 10.30pm

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

# 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:

**Introduction to motor neurone disease**

**Information sheet 1B - Health information in other languages or formats**

**Information sheet 7A - Swallowing difficulties**

**Information sheet 7B - Tube feeding**

**Information sheet 8A - Support for beathing problems**

**Information sheet 8B - Ventilation for motor neurone disease**

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.

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

# 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 and general information	Quantity
<p><b>Motor neurone disease (MND) - How to find out more</b> Basic facts about the disease. <i>A5 leaflet.</i></p>	
<p><b>An introduction to motor neurone disease (MND)</b> A short guide to help at diagnosis. <i>A5 booklet</i></p>	
<p><b>Living with motor neurone disease</b> An overview of MND. Download the guide and its sections at <a href="http://www.mndassociation.org/lwmnd">www.mndassociation.org/lwmnd</a> or order from MND Connect. <i>A4 guide</i></p>	
<p><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></p>	
<p><b>Caring and MND: support for you</b> Practical and emotional support for unpaid carers. Download the guide and its sections at <a href="http://www.mndassociation.org/lwmnd">www.mndassociation.org/lwmnd</a> or order from MND Connect. <i>A4 guide</i></p>	
<p><b>Making the most of life with MND</b> Ways to continue doing the things you enjoy. <i>A5 booklet</i></p>	
<p><b>An easy read guide to motor neurone disease</b> For people with learning disabilities. <i>A4 booklet</i></p>	
<p><b>What you should expect from your care</b> 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></p>	

Introductory and general information	Quantity
<p><b>Eating and drinking with motor neurone disease (MND)</b> Guidance and easy swallow recipes. <i>Wiro bound colour A4 book</i></p>	
<p><b>MND Checklist</b> A write on A4 form to help you manage your condition and think ahead.</p>	
<p><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.</p>	
<p><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 <i>MND Buddies</i> at: <a href="http://www.mndbuddies.org">www.mndbuddies.org</a> <i>A4 storybook</i></p>	
<p><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></p>	
<p><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></p>	
<p><b>End of life: a guide for people with MND</b> Candid information about planning ahead and end of life decisions. Download the guide and its sections at <a href="http://www.mndassociation.org/lwmnd">www.mndassociation.org/lwmnd</a> or order from <i>MND Connect</i>. <i>A4 guide</i></p>	
<p><b>Finding your way with bereavement</b> To help you identify emotions and support with practical guidance. <i>A5 booklet</i></p>	
<p><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></p>	
<p><b>Emotional and psychological support</b> Ways to find emotional support after an MND diagnosis <i>5 booklet</i></p>	
<p><b>Changes to thinking and behaviour</b> For people with MND, including guidance for carers. <i>A5 booklet</i></p>	

Information sheets (all A4)	Quantity
<b>1A - About the NICE guideline on motor neurone disease</b> Endorsed by the National Institute for Health and Care Excellence (NICE).	
<b>1B - Health information in other languages or formats</b>	
<b>1C - Where can I find the information I need?</b>	
<b>1D - How we use your information</b>	
Disease types	
<b>2B - Kennedy's disease</b>	
<b>2C - Primary lateral sclerosis (PLS)</b>	
<b>2D - Progressive muscular atrophy (PMA)</b>	
Types of care	
<b>3A - MND care centres and networks</b>	
<b>3D - Hospice and palliative care</b>	
Telling people about MND	
<b>4A - Communicating about MND with children and young people</b> has been replaced by our guide: <b>Telling people about MND</b> <i>See section B</i>	
Medication	
<b>5A - Riluzole</b> Information about the only licensed drug for MND in the UK.	
Physical therapies	
<b>6A - Physiotherapy</b>	
<b>6B - Complementary therapies</b>	
<b>6C - Managing pain</b>	
Mouth and throat (bulbar) symptoms	
<b>7A - Swallowing difficulties</b>	
<b>7B - Tube feeding</b>	
<b>7C - Speech and communication support</b>	
<b>7D - Voice banking</b>	

Information sheets (all A4)	Quantity
Breathing and ventilation	
<b>8A - Support for breathing problems</b>	
<b>8B - Ventilation for motor neurone disease</b>	
<b>8C - Withdrawal of ventilation with MND</b>	
<b>8D - Air travel and ventilation for MND</b>	
Emotions, thinking and behaviour	
<b>Information sheets 9A-9C</b> about thinking, behaviour and emotions, have been replaced by our guides: <b>Changes to thinking and behaviour with MND</b> and <b>Emotional and psychological support</b> <i>See section B</i>	
Benefits, financial support and social care	
<b>10A - Benefits and entitlements</b>	
<b>10B - What is social care?</b>	
<b>10C - Disabled Facilities Grants</b>	
<b>10D - NHS Continuing Healthcare (CHC)</b>	
<b>10E - Work and motor neurone disease</b>	
<b>10F - Personal health budgets</b>	
<b>10G - Support for families with children (financial support)</b>	
Daily living	
<b>11A - Clothing</b>	
<b>11B - Mouth care</b>	
<b>11C - Equipment and wheelchairs</b>	
<b>11D - Managing fatigue</b>	
<b>11E - Environmental controls</b>	

Information sheets (all A4)	Quantity
Getting around	
<b>12A - Driving</b>	
<b>12B - Choosing the right vehicle</b>	
<b>12C - Travel and transport</b>	
<b>12D - Planning a holiday</b>	
Intimacy	
<b>13A - Sex and relationships for people with MND</b>	
<b>13B - Sex and relationships for partners of people with MND</b>	
Planning ahead	
<b>14A - Advance Decision to Refuse Treatment (ADRT) and advance care planning</b> Includes a sample completed form and a blank form.	

*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 £2.00 post and packing per copy. See page 18 for more information or contact MND Connect.*

**mndconnect**  
**0808 802 6262**  
 mndconnect@mndassociation.org



Other items	Quantity						
<p><b>Notepad for people with speech difficulties</b> <i>Small notepad</i>  Each page is headed with:  <i>'I can understand you but have difficulty speaking, please read on.'</i></p>							
<p><b>Speech card for people with speech difficulties</b>  Display card, showing the words:  <i>'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> <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>	<table border="1"> <tr> <td data-bbox="360 568 909 715" style="text-align: center;"><b>Small</b> (180mm)</td> <td data-bbox="909 568 1044 715"></td> </tr> <tr> <td data-bbox="360 715 909 836" style="text-align: center;"><b>Medium</b> (202mm)</td> <td data-bbox="909 715 1044 836"></td> </tr> <tr> <td data-bbox="360 836 909 999" style="text-align: center;"><b>Large</b> (210mm)</td> <td data-bbox="909 836 1044 999"></td> </tr> </table>	<b>Small</b> (180mm)		<b>Medium</b> (202mm)		<b>Large</b> (210mm)	
<b>Small</b> (180mm)							
<b>Medium</b> (202mm)							
<b>Large</b> (210mm)							
<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 for people with or affected by MND. <i>A5 flyer</i></p>							

## 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 £2.00 p&p.

Please visit [www.mndassociation.org/professionals](http://www.mndassociation.org/professionals) to see our online information for health and social care professionals.

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>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 <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>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>	

General publications	Quantity
<p><b>Caring for someone with motor neurone disease: information for care workers</b> <i>A5 booklet</i>            Practical advice on care for a person with MND.</p>	
<p><b>Supporting children and young people close to someone with MND</b> <i>A5 booklet</i>            For professionals working with children or young people close to someone with MND, including teachers, school nurses, youth workers and social workers.</p>	
<p><b>Motor neurone disease (MND) in acute, urgent and emergency care</b> <i>A5 booklet</i>            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</p>	
<p><b>A professional's guide to end of life care in motor neurone disease (MND)</b> <i>A4 booklet</i>            To help health and social care professionals discuss death, assist advance care planning and support the process of dying with MND</p>	
<p><b>Red Flag diagnosis tool</b> <i>A4 document</i>            A tool created in partnership with the Royal College of General Practitioners (RCGP) to help GPs recognise the signs of MND.</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>	
<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. Contact MND Connect to order the Just in Case Kit.	
<b>P5 - Providing medical evidence for benefit applications made by people with MND.</b>	
<b>P6 - Evaluation and management of respiratory symptoms in MND.</b>	
<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>P-12 - Information for dental teams.</b>	
<b>PG015 - Augmentative and Alternative Communication (AAC) Pathway for MND: full guidance notes.</b>	
<b>PG015A - Augmentative and Alternative Communication (AAC) Pathway for MND: summary guidance notes.</b>	

Other items	Quantity
<b>MND Connect poster</b> <i>A4 colour display poster</i> For display at surgeries, clinics and events, to raise awareness of our helpline team MND Connect.	
<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>Professional reply cards</b> <i>Pre-paid postcards</i> Designed for distribution at educational events and conferences. Professionals can complete this card with their details in order to receive more information about MND.	

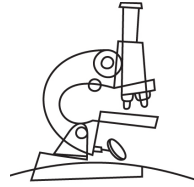
Audio visual	Quantity	Unit	Total
<b>Understanding MND training DVD.</b> Introduces MND. Alternatively, view online for free, at: <b><a href="http://www.mndassociation.org/understandingmnd">www.mndassociation.org/understandingmnd</a></b>	DVD	£5 plus	
	USB stick		

*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 £2.00 post and packing per copy. see page 18 for more information.*

# 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](mailto: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> Facts about the rare inherited form of MND.</p>	
<p><b>B2 - Inherited MND: genetic testing and insurance</b> Guidance on testing and insurance for those who have the rare inherited form of MND.</p>	
<p><b>B3 - Inherited MND: options when starting a family</b> Guidance for those affected by inherited MND when thinking about starting a family.</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>DA - MIROCALS clinical trial</b> Information about the MIROCALS clinical trial and who can take part.</p>	
<p><b>DB - TUDCA-ALS clinical trial</b> Information about the TUDCA-ALS clinical trial and who can take part.</p>	
<p><b>E - Research we fund</b> A brief overview of the portfolio of research grants awarded by the MND Association.</p>	

Research information sheets	Quantity
<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>	
<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>Fundraising pack</b> <i>A4 folder/various items</i> Our events diary, guide to fundraising, materials order form and additional MND Association information.</p>	
<p><b>Legacy information</b> <i>A5 booklet</i> A gift in your will could help achieve a world free from MND</p>	
<p><b>A tribute to someone special</b> <i>A5 leaflet</i> A Tribute Fund celebrates the life of someone special while supporting our vital work.</p>	
<p><b>Fightback Funds</b> <i>A5 leaflet</i> Helping people with MND fight back through fundraising.</p>	
<p><b>Membership form</b> <i>A5 membership leaflet</i> To apply for membership of the MND Association - free for people with MND, their spouses, partners and carers.</p>	
<p><b>Direct Debit form</b> <i>A4 single page form</i> To set up a regular donation by Direct Debit.</p>	
<p><b>Bakeit!</b> <i>A4 folder/various items</i> Details of how to get involved in this fundraising campaign.</p>	
<p><b>Walk to d'feet MND</b> <i>A4 folder/various items</i> Pack to help organise a fundraising walk at any time of year.</p>	

Volunteering publications	Quantity
<p><b>Could you help support someone with MND?</b> <i>A5 leaflet</i> How to become an Association visitor (AV).</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>	

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?

- |  |  |
|--|--|
| <input type="checkbox"/> someone living with MND or<br>Kennedy's disease | <input type="checkbox"/> an agency, other charity<br>or organisation |
| <input type="checkbox"/> a carer/family member<br>or friend              | <input type="checkbox"/> a student                                   |
| <input type="checkbox"/> a health or social care<br>professional         | <input type="checkbox"/> 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 £2.00 post and packing per copy. 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](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:**

Increase your donation at no extra cost

*giftaid it*

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 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.

We focus on improving access to care, research and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

## 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.

## We welcome your views

We welcome feedback on our publications to help us improve. Feedback forms or links to surveys are either provided with each item or can be found through our website:

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

You can also email suggestions to: **[info.feedback@mndassociation.org](mailto:info.feedback@mndassociation.org)**  
Or you can write to us at:

**Information feedback, The MND Association, Francis Crick House,  
6 Summerhouse Road, Moulton Park, Northampton. NN3 6BJ.**

### 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

Last updated: November 2020

Registered Charity No. 294354 © MND Association 2020

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

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