

How do I get further help?

15: Help from the MND Association

16: Useful organisations

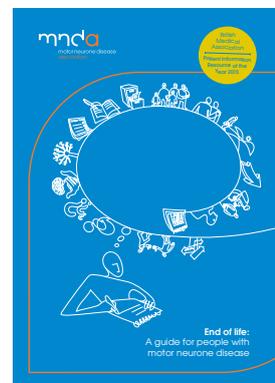
The following sections are extracted from our full guide *End of life: A guide for people with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/eolguide

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



End of life:
A guide for people with
motor neurone disease

15: Help from the MND Association

This section will help you access services and support from the MND Association.

At times, you may feel very isolated, but you are not alone.

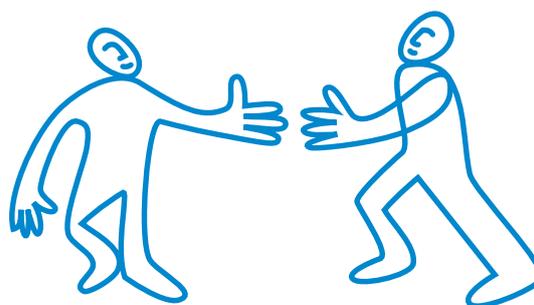
We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland.

The following explains how you can access our support, as and when needed, including guidance about information and services relating to end of life.

Our ultimate vision is a world free from MND.

Our mission is to:

- improve care and support for people with MND, their families and carers
- fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND
- campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.



MND Connect helpline

The MND Connect helpline is our support and information service for people living with MND, their families, carers, our volunteers and health and social care professionals.

If you are concerned about end of life, or any aspect of MND, the team will be happy to listen and advise in any way they can.

They will also be able to help direct you to appropriate external services for further support or guidance.

The service is available Monday to Friday, from 9am to 5pm and 7pm to 10.30pm.

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org
MND Association

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

Health and social care professionals can also contact the helpline for guidance and information about MND.

“ Letting things out is so important. Just tell someone if it gets bad and why you’re feeling that way. Don’t struggle with everything in silence.”

Association visitors (AVs)

AVs are volunteers who provide free and confidential personal support to people living with MND, their carers, their family and close friends.

An AV can help you identify problems as they arise and discuss your choices for how these might be managed. AVs can make contact with you by phone, email or home visit.

All AVs are carefully selected, undergo a thorough training programme and a Disclosure and Barring Service (DBS) check. This was formerly known as a Criminal Records Bureau (CRB) check.

Find out more about AVs and local support on our website at: www.mndassociation.org/support-and-information/our-services

If an AV is not available in your area, we can offer ongoing support and help through our MND Connect helpline, regional staff or your local branch or group, as explained in this section.

Local branches and support groups

We have a network of more than 85 branches and groups, throughout England, Wales and Northern Ireland. These are run by volunteers and provide a warm welcome and the opportunity to meet others affected by MND.

Our branches and groups offer guidance, information and get-togethers where people can share experience and support. These meetings often include gatherings specifically for carers. Our branches are listed on our website at:

www.mndassociation.org/branchesandgroups or contact our MND Connect helpline for help, as shown in this list.

Regional staff for local support

Our regional staff for local support have knowledge about the management and care of people with MND. They work with volunteers and affected families, or help to influence local service providers. Their aim is to help ensure care and support is made available at the right time.

Find out more about our services and local support on our website at: www.mndassociation.org/support-and-information

or contact our MND Connect helpline, as shown in this list.

MND care centres and networks

We part-fund MND care centres and networks across the UK. These offer specialist help to support people with MND, their carers and families.

MND care centres and networks bring together a range of health and social care professionals to provide co-ordinated care. They are usually referred to as a multidisciplinary team (MDT).

If you cannot get to a care centre or network easily, you can still receive co-ordinated care through regional neurological services and local specialist palliative care services.

MND care centres are not 'buildings', but usually take place in an established clinic in one place, such as a hospital.

MND networks provide similar services, but do not have a fixed location, as they cover a wide geographical area.

Care centres and networks sometimes run clinical drug trials and undertake clinical research about MND. They also help to educate colleagues in the community and share good practice to improve MND care and support.

To find your nearest MND care centre or network, contact our MND Connect helpline, as shown in this list.

Equipment loan and grants

We may be able to provide certain items of equipment and communication aids on loan, or consider requests for financial support through grants.

All statutory funding and services should be explored first. However, loaned items can be provided if you have to wait for health and social care services to arrange equipment or if they are unable to provide an item.

The following types of grant are available:

MND support (care) grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided.

Application: by a health or social care professional following assessment of need, where this need cannot be met through the services they link to, or where provision will be delayed.

Can be used for: a variety of purposes, such as home adaptations, equipment or respite care.

MND quality of life grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided, up to £500 in any one grant.

Application: by any family member, Association visitor, health or social care professional or a regional care staff contact.

Can be used for: improving quality of life for the person diagnosed, or for equipment that does not require a health or social care assessment.

MND carer's and young carer's grant

Provided to: family or non-professional carers, who are 16 or older.

Amount provided: up to £500 is available in any one year.

Application: by the carer, or on their behalf by one of our Association visitors or a health and social care professional.

Can be used for: a break from caring, as with a pamper day, a short break or to support a hobby.

Young person's grant

Provided to: a child or young person aged 18 or under, who has a parent with MND or Kennedy's disease, or who lives in the same household with someone who has been diagnosed.

Amount provided: up to £250 is available in any one year.

Application: by a family member for the young person, or on their behalf by one of our Association visitors, a regional care staff contact or a health or social care professional.

Can be used for: a variety of purposes, such as decorating their room at home, a family day out or for equipment to help the young person, such as a laptop.

If you have any queries about grants or equipment loans, please contact our MND Connect helpline, as shown in this list.

“ MND has a gradual drip-drip effect, but it's life changing. Things like a stairlift or lift going in, rails and handles, and a seat in the shower.”

Benefits Advice Service

The MND Association Benefits Advice Service provides free, confidential and impartial advice on any benefits you may be entitled to.

Telephone: **0808 801 0620** (England & Wales)
0808 802 0020 (Northern Ireland)
Email: Through the website contact page, at:
www.mndassociation.org/benefitsadvice

Communication Aids Service

Help with queries about communication aids, for people with or affected by MND, and health and social care professionals.

A limited amount of financial support can be provided, and some items on loan (if unavailable or delayed through health and social care services).

Telephone: **0808 802 6262**
Email:
communicationaids@mndassociation.org

Our website

The MND Association makes every effort to ensure it provides trustworthy information (see *Care information and publications* heading). Please visit the MND Association website to find out more about MND, our services and the Association at: www.mndassociation.org including news about our research, volunteering, fundraising and campaigning activities.

Our online forum

A safe place to share experiences and tips with others affected by MND.

Access the forum on our website, or at:
<https://forum.mndassociation.org>

Care information and publications

We provide a wide range of information, developed and revised under the PIF Tick kitemark scheme:

<https://pifonline.org.uk/pif-tick>

This means our content is considered trustworthy. Look for the following kitemark:



Patient Information Forum

You can download the majority of our care information from our website, including our publications list, using the following address:
www.mndassociation.org/publications

Or contact MND Connect to order printed copies (see previous *MND Connect helpline* heading).

“ If I had to go through it again, I’d want to know the background about the disease and the how and why. Also, what happens next?”

Membership

Membership of the MND Association is free for people living with MND, their spouses, partners and carers. It enables you to join a community of people who share the same vision of a world free of MND. This creates a powerful voice to support campaigns on behalf of all those affected, demonstrating that we represent a significant number of people living with or affected by the disease.

As a valued member you will enjoy a number of unique benefits:

- a welcome pack, including a personal membership card.
- our quarterly membership magazine, *Thumb Print*
- an optional link to your nearest branch or group
- attendance and voting at our annual meeting (AGM)
- invitations to our exclusive conferences and events.

To find out more, see:

www.mndassociation.org/membership.

To become a member, you can contact us on **01604 611860**, or if preferred by email: membership@mndassociation.org

Getting involved

Many people with or affected by MND or Kennedy's disease ask how they can get involved with our activities. If you would like to know more, see the following web pages:

Volunteering:

www.mndassociation.org/volunteering

Fundraising:

www.mndassociation.org/fundraising

Campaigning:

www.mndassociation.org/campaigning

Research:

www.mndassociation.org/research

Or contact enquiries:

Telephone: **01604 250505**

Email: enquiries@mndassociation.org

Support for minority and ethnic groups

We are here for everyone living with or affected by MND.

We are aware that not everyone will have the same needs, as everyone's experience of MND will be unique. Culture and religion may also influence the way care and support should be provided and the MND Association supports diversity and equality in all of its services.

Please ask the service you are dealing with if you have any particular preferences or needs that you wish to be taken into consideration.

We offer a limited translation service for our health and social care information, other formats and telephone interpreters. Contact our MND Connect helpline for details (see previous heading *MND Connect Helpline*).

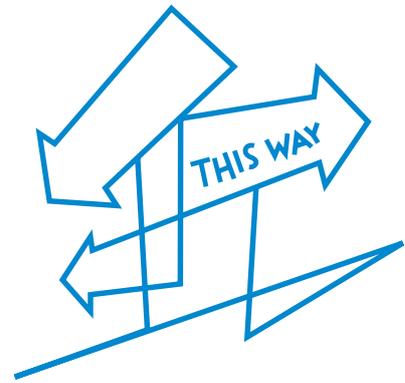
Key points

- Our MND Connect helpline is not just here to provide information, the team can also offer a listening ear if you need support. MND Connect supports people living with MND, their families, carers and health and social care professionals.
- Before contacting us about equipment loan or financial support, try to gain an independent assessment of your needs by an appropriate health and social care professional.

[See Section 16: Useful organisations for further contacts.](#)

16: Useful organisations

This section identifies some of the services and organisations you may need.



You can access a wider list of useful organisations on our website at: www.mndassociation.org/usefulorgs. We also list relevant organisations at the end of all our information sheets.

You may also wish to contact your local branch or group, an Association visitor or our helpline MND Connect, to ask about external services and advice about local support.

[See Further information at the end of this section for contact details.](#)

Your local authority or council will also have lists of regional providers and may offer a directory of services on their website.

Organisations

Please note, we do not necessarily endorse the organisations listed here and cannot be held responsible for anything stated on their website or supplied as a service or product.

Organisation details may change between revisions. Contact our MND Connect helpline if you need assistance.

[See Section 15: Help from the MND Association for our service details.](#)

Age UK

Advice and information for people in later life, including support on benefits.

Age UK, Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: **0800 678 1174** (England)

08000 223 444 (Wales)

0808 808 7575 (Northern Ireland)

Email: through the website contact page

Website: www.ageuk.org.uk

arrangingafuneral.co.uk

Guidance and support about arranging a funeral.

Arranging a Funeral, First Floor, 41 Clifford Road, Blackpool FY1 2PU

Telephone: **0800 0198 451**

Email: through the website contact page

Website: www.arrangingafuneral.co.uk

Aura

For storing information to share with loved ones after your death and a safe space to engage with others about death.

Aura, Studio One, Bunkers Hill Farm, Unstead, Godalming, Surrey GU7 1UP

Email: hello@aura.life

Website: www.aura.life

BACP (British Association for Counselling and Psychotherapy)

Advice on how to seek counselling and psychotherapy support, with directions to trained practitioners.

BACP, BACP House, 15 St John's Business Park, Lutterworth LE17 4HB
 Telephone: **01455 883300**
 Email: bacp@bacp.co.uk
 Website: www.bacp.co.uk

Bereavement Advice Centre

This organisation has produced an A5 booklet called *What to do when someone dies, A practical guide*, which helps advise on the legal and practical steps to take after someone's death.

Bereavement Advice Centre,
 Heron House, Timothy's Bridge Road,
 Stratford Upon Avon CV37 9BX
 Telephone: **0800 634 9494**
 Website: www.bereavementadvice.org

Carers Trust

Information and support for all those who find themselves in a caring role.

Carers Trust, Unit 101, 164-180 Union Street,
 London SE1 0LH
 Telephone: **0300 772 9600** (England)
0300 772 9702 (Wales)
 Email: info@carers.org
 Website: www.carers.org

Carers UK

Information and support for all those who find themselves in a caring role.

Carers UK, 20 Great Dover Street,
 London SE1 4LX
 Telephone: **0808 808 7777**
 (England and Wales)
028 9043 9843 (Northern Ireland)
 Email: through the website contact page
 Website: www.carersuk.org

Childhood Bereavement Network

Information and support for bereaved children, with directions to other national and local services.

National Children's Bureau,
 23 Mentmore Terrace, London E8 3PN
 Email: cbn@ncb.org.uk
 Website:
www.childhoodbereavementnetwork.org.uk

Childline

A counselling service for children and young people, with a free 24 hour helpline for children in distress or danger.

Childline, Via NSPCC, Weston House, 42
 Curtain Road, London EC2A 3NH
 Telephone: **0800 1111**
 Email: through website and confidential login
 Website: www.childline.org.uk

The Cinnamon Trust

An organisation dedicated to helping people in later years, or with life-shortening conditions, to find foster care or alternative homes for their pets.

The Cinnamon Trust, 10 Market Square,
 Hayle, Cornwall TR27 4HE
 Telephone: **01736 757 900**
 Email: through website contact page
 Website: www.cinnamon.org.uk

Citizens Advice

Free guidance to resolve legal, money and other problems.

Telephone: **0800 144 8848** (England)
0800 702 2020 (Wales)
See website for local numbers
in Northern Ireland
Website: www.citizensadvice.org.uk

Community Law Service

Independent advice and representation, including help on welfare benefits, debt and housing. Find local service details online.

Conversations for Life

Help for families, professionals and communities to start discussions about end of life care.

Conversations for Life, 2 The Mill Yard,
Staveley, Cumbria LA8 9LR
Telephone: **01539 234108**
Email: info@conversationsforlife.co.uk
Website: www.conversationsforlife.co.uk

Cruse Bereavement Care

Cruse is a leading bereavement charity in the UK, offering information, advice and support.

Cruse Bereavement Care, PO Box 800,
Richmond, Surrey, TW9 1RG
Helpline: **0808 808 1677**
Email: helpline@cruse.org.uk
Website: www.cruse.org.uk

Disability Law Service

Assistance on disability law.

Disability Law Service, The Foundry,
17 Oval Way, London SE11 5RR
Telephone: **0207 791 9800**
Email: advice@dls.org.uk
Website: <https://dls.org.uk>

The Disabled Living Foundation

Following a website name change, see the entry for *Living Made Easy* for a wide range of support and advice for people with disabilities.

Dying Matters

Run by Hospice UK, the aim of Dying Matters is to open conversations about death and dying to improve support.

Email: through the website contact page
Website: www.dyingmatters.org

Funeral Planning Authority (FPA)

The FPA is an independent regulatory organisation working to protect consumer rights within the funeral planning sector.

Funeral Planning Authority, Barham Court,
Teston, Maidstone, Kent ME18 5BZ
Telephone: **0345 601 9619**
Email: info@funeralplanningauthority.co.uk
Website: www.funeralplanningauthority.co.uk

GOV.UK

Online government advice, including information on benefits and related entitlements. You can access associated claim forms through the website.

Email: all email addresses can be found on the website, related to the type of enquiry
 Website: www.gov.uk
www.nidirect.gov.uk (Northern Ireland)

Health and Care Professions Council (HCPC)

Check their register of qualified health professionals, to find psychologists, physiotherapists, occupational therapists, speech and language therapists, and more, who meet standards of practice.

Health Professions Council, Park House 184
 Kennington Park Road, London SE11 4BU
 Telephone: **0300 500 6184**
 Website: www.hcpc-uk.org

Healthtalk.org

A website database of personal and patient experiences, including a series of interviews with people affected by or living with MND.

Email: info@healthtalk.org
 Website: www.healthtalk.org (search for *motor neurone disease*)

Hospice UK

An organisation offering information about hospice care, what services are available, who provides them, who can receive hospice care and how to get referred.

Hospice UK, 34-44 Britannia Street,
 London WC1X 9JG
 Telephone: **020 7520 8200**
 Email: info@hospiceuk.org
 Website: www.hospiceuk.org

Humanists UK

An organisation that can provide guidance and support for funerals where no religious content is wanted.

Humanist UK Association, 39 Moreland Street, London EC1V 8BB
 Telephone: **020 7324 3060**
 Email: ceremonies@humanism.org.uk
 Website: <https://humanism.org.uk>

Institute of Civil Funerals

An organisation that can advise on civil funerals, with a search facility to locate civil celebrants.

Lytchett House, 13 Freeland Park,
 Wareham Road, Poole, Dorset BH16 6FA
 Telephone: **01480 861411**
 Email: admin@iocf.org.uk
 Website: www.iocf.org.uk

Living Made Easy

Hosted by the Disabled Living Foundation. See this site for a wide range of support and advice for people with disabilities, including information on daily living equipment.

Telephone: **0300 999 0004**
 Email: info@dlf.org.uk
 Website: <https://livingmadeeasy.org.uk>

Marie Curie

Marie Curie is a UK charity dedicated to the care of people with terminal illnesses, including non-cancer patients.

Marie Curie, 89 Albert Embankment,
 London SE1 7TP
 Telephone: **0800 090 2309**
 Email: online chat available through website
 Website: www.mariecurie.org.uk

Macmillan Cancer Support

Macmillan focuses mainly on people affected by cancer but they do provide some support for non-cancer patients. Ask your health and social care team for advice about Macmillan nurses and services in your area.

Macmillan Cancer Support, 89 Albert Embankment, London, SE1 7UQ
Telephone: **0808 808 00 00**
Email: through the website contact page
Website: **www.macmillan.org.uk**

Medic Alert

A registered charity providing an identification system for individuals with medical conditions and allergies, usually in the form of bracelets or necklets, and supported by a 24 hour emergency telephone service.

The MedicAlert Foundation, Suite 1, Liscombe South, Liscombe Park, Soulbury LU7 0JL
Telephone: **01908 951045**
Email: **info@medicalert.org.uk**
Website: **www.medicalert.org.uk**

Motability

For details about vehicle leasing or hire purchase through the Motability scheme.

Telephone: **0300 456 4566**
Email: through the website contact page
Website: **www.motability.co.uk**

MND Scotland

Formerly the Scottish Motor Neurone Disease Association, providing care, information and research funding for people affected by MND in Scotland.

MND Scotland, Unit 8, 76 Firhill Road, Glasgow G20 7BA
Telephone: **0141 332 3903**
Email: **info@mndscotland.org.uk**
Website: **www.mndscotland.org.uk**

My Living Will

Help to create an Advance Decision to Refuse Treatment (ADRT) or an Advance Statement, when planning ahead for future care.

My Living Will, 32 Laurier Road, London NW5 1SJ
Email: **hello@mylivingwill.org.uk**
Website: **www.mylivingwill.org.uk**

National Association of Funeral Directors (NAFD)

Advice on funeral arrangements and location of registered funeral directors. Members must comply with its Code of Practice.

National Association of Funeral Directors, 618 Warwick Road, Solihull, West Midlands B91 1AA
Telephone: **0121 711 1343**
Email: **info@nafd.org.uk** or use contact page
Website: **https://nafd.org.uk**

The National Society of Allied and Independent Funeral Directors (SAIF)

An organisation providing advice on funeral arrangements and location of registered funeral directors. The National Society of Allied and Independent Funeral Directors has a code of practice for its members.

The National Society of Allied and Independent Funeral Directors, 3 Bullfields, Sawbridgeworth, Hertfordshire CM21 9DB
Telephone: **0345 230 6777**
Email: **info@saif.org.uk** or use contact page
Website: **https://saif.org.uk**

NHS UK

Online health information from the NHS.

Telephone: **111**
Email: through the website contact page
Website: **www.nhs.uk**

NHS 111

The NHS online/telephone help and support for urgent (but not emergency) health advice and information, 24-hours a day, 365 days a year.

Telephone: **111**
Email: through the website contact page
Website: search for NHS 111 at: **www.nhs.uk**

NHS 111 Wales

Similar to NHS 111, but for medical advice in Wales.

Telephone: **111 (0845 46 47 in some areas)**
Website: **https://111.wales.nhs.uk/**

NHS Northern Ireland

Online information for the NHS in Northern Ireland.

Email: through the website contact page
Website: **http://online.hscni.net**

NI Direct

Online government information for Northern Ireland, including benefits.

Email: through the website contact page
Website: **www.nidirect.gov.uk**

The Office of Care and Protection

The organisation that handles applications for Enduring Power of Attorney (EPA) in Northern Ireland.

Office of Care and Protection, Room 2.2A, Second Floor, Royal Courts of Justice, Chichester Street, Belfast BT1 3JF
Telephone: **0300 200 7812**
Email: **OCP@courtsni.gov.uk**
Website: search for *enduring power of attorney* at: **www.nidirect.gov.uk**

Office of the Public Guardian

The organisation that handles applications for Lasting Power of Attorney (LPA) in England and Wales.

Office of the Public Guardian, PO Box 16185, Birmingham B2 2WH
Telephone: **0300 456 0300**
Email: **customerservices@publicguardian.gsi.gov.uk**
Website: search for *office of the public guardian* at: **www.gov.uk**

Record Me Now

A downloadable free app to leave video messages for family and children, so you can provide love and guidance after death.

Email: through the website contact page

Website: www.recordmenow.org

Samaritans

Confidential non-judgemental emotional support, 24 hours a day, for people experiencing feelings of distress or despair. Their service is available by telephone, email, letter or face-to-face in most of their branches. Contact your local branch or:

Samaritans, Freepost RSRB-KKBY-CYJK,
PO Box 9090, Stirling FK8 2SA

Telephone: **116 123**

Email: jo@samaritans.org

Website: www.samaritans.org

Sue Ryder Care

A charity providing a range of services for people who are terminally ill, in their own homes, day centres, Sue Ryder hospices and care centres. They also provide neurological centres for people with long term neurological conditions.

Sue Ryder, 183 Eversholt Street,
London NW1 1BU

Telephone: **0808 164 4572**

Email: through the website contact page

Website: www.sueryder.org

Tell Us Once

A service through GOV.UK that enables someone to inform government departments that a person has died in order to stop benefits and related support, without having to make repeated contact. The service is available in England, Wales and Scotland. It does not apply to Northern Ireland. Access the service through your local register office or online:

Website: www.gov.uk/tell-us-once

Winston's Wish

A bereavement charity to help children after the death of someone close. The website has a section for parents and an interactive area for children and young people.

Winston's Wish Head Office,
17 Royal Crescent, Cheltenham GL50 3DA

Telephone: **08088 020 021** (helpline)

Email: ask@winstonswish.org

Website: www.winstonswish.org

Key points

- Always try to obtain an independent assessment of your needs before approaching commercial companies for products or services. For example, see an occupational therapist before purchasing any costly equipment or aids. You need to be aware of what will be suitable for you and whether your needs are likely to change. Some equipment may be available free or on loan through health or social care services.

Further information:

We produce a wide range of publications to help you gather information about MND and its management. Our resources include a numbered range of information sheets and larger guides.

How to access publications and further information:

Most of our publications can be downloaded from our website:

www.mndassociation.org/publications or

you can order them from the

MND Connect Helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional staff.

See Section 17: Help from the MND Association, for details about our services.

Online forum:

Hosted by the MND Association at:

<https://forum.mndassociation.org> for you to share information and experiences with other people affected by MND.

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Version: 1 in this revision period

MND Association
Francis Crick House (2nd Floor)
6 Summerhouse Road, Moulton Park
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Tel: 01604 250505

Website: www.mndassociation.org

Registered Charity No. 294354

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For references and acknowledgements please
refer to the full guide, *End of life: A guide for
people with motor neurone disease*.

The full guide can be ordered in hardcopy
from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



This resource has been evidenced,
user tested and reviewed by experts.