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](http://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
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
PO Box 246, Northampton NN1 2PR

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

MND Connect is accredited by the Helplines Standard.

“I was in contact with you and your advisers during a very difficult time, and was always given help and time to talk, something I found really invaluable…We were able to gain knowledge about the condition, and were prepared (as much as you can be) for each stage of the illness and the options available.”

“How do I get further help? / Help from the MND Association

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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.

“ My Association visitor has been really, really helpful. She’s been prepared to help and support whenever I’ve asked and has been very good at keeping one eye on the future.”

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.

If you would like to be supported by an AV, please contact your local regional care development adviser (RCDATA). If an AV is not available in your area, we can offer ongoing support and help through regular contact with the MND Connect helpline, or your local branch or group. Please see other listed services in this section for details.

Our work with volunteers is accredited by the Investing in Volunteers standard.

Regional care development advisers (RCDAs)
Our regional care development advisers either have a professional health or social care background or they have significant experience that will support them in the role. They have expert knowledge of the management and care of people with MND and work closely with local service providers to ensure care and support is available at the right time.

A key part of their role is to influence statutory services and to advise in complex situations, including how end of life care is managed. They also manage our regional teams of Association visitors (AVs).

“The regional care development adviser has been excellent in helping when equipment I needed has taken months to arrive. Also when there was a problem with no support for my wife as my carer managing this disease.”

Our regional care development advisers are listed on our website, or you can contact our helpline (see previous MND Connect helpline heading).

Local branches and support groups
We have a network of around 90 branches and groups, run by volunteers, throughout England, Wales and Northern Ireland. They provide a warm welcome, friendship and the opportunity to meet others affected by MND.

“ Friendships have been formed with like-minded individuals who all have differing levels of MND and are at different stages of the disease… the camaraderie between survivors and carers is so important to us all in our support group. We are there for each other through thick and thin.”
Our branches and groups offer guidance and support, including newsletters and regular meetings, including get togethers and group meetings specifically for carers. Our branches are listed on our website with contact details, or contact MND Connect to help you find the nearest location (see previous MND Connect Helpline heading).

MND Care Centres / Networks

MND Care Centres and Networks can offer the specialist help you may need, to cope with the complexity of the disease.

All of the centres and networks use specialist doctors and nurses to coordinate the care of people with MND.

The MND Association has established and part-funds more than 20 MND Care Centres and Networks across the UK. The Care Centres are based in large hospitals and the three networks operate with outreach teams.

If you cannot access one of these centres or networks easily, you can still receive coordinated support through regional neurological services and local specialist palliative care services.

“ The Care Centre staff are all brilliant. It’s a great place to go to solve medical problems and it’s good meeting other people with MND as well.”

MND Care Centres:

• are the location for clinical drug trials and undertake clinical research.

The networks work in a similar way, but do not have a fixed location, in order to provide a service across a wide geographical area.

You may need to ask your GP for a referral to access MND Care Centres and Networks.

The MND Care Centres and Networks are also listed on our website with contact details, or contact MND Connect to find out about the nearest location (see previous MND Connect Helpline heading).

“ I receive excellent care at the MND Care Centre. Help is just a phone call away, plus there are once-a-month support meetings run by the hospital and separate monthly support meetings by the MND Association branch.”

Equipment loan and MND support grants

Following a diagnosis of MND, our Support Services team may be able to provide certain items of equipment and communication aids on loan, or consider financial support requests for a variety of needs, such as respite care, home adaptations or equipment rental.

We provide support grants for people with MND and carers, and children or young people close to someone with MND.

“ I’ve had excellent advice about preparing well in advance for the ‘disasters and indignities’ ahead, I’ve had financial support to alleviate the costs of the move downstairs… I’ve also been provided with a recliner seat.”
All statutory funding and services should be explored first, but loaned items can be provided while you wait for services to arrange equipment or where an item cannot be supplied this way. In most cases, initial requests must be made to us by a health and social care professional, following assessment of your needs. If you have any queries, contact:

Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org
MND Association
PO Box 246, Northampton NN1 2PR

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

Wheelchair Support Service
If you need information on wheelchairs, experience delays in assessment or provision, or require top-up features, our wheelchair service may be able to help.

Telephone: 0808 802 6262
Email: wheelchairs@mndassociation.org

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

Care information and publications
We provide a wide range of information, developed and revised under The Information Standard, an accreditation run by NHS England. This means they are considered trustworthy. Look for the following marker:

"I have been asked to contribute to some of the resources. It’s so refreshing to see a version that has been significantly amended, on account of feedback which has clearly been absorbed. All too often, organisations consult but don’t listen… this is a great example of an organisation that consults effectively."

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).

Our website
The MND Association makes every effort to ensure it provides trustworthy information (see previous 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.
How do I get further help? / Help from the MND Association

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

“ The forum is so useful for all of us as carers and sufferers, it’s a lifeline… I still can’t leave it, even though I no longer need it.”

Access the forum on our website, or at: http://forum.mndassociation.org

“ The website and downloads have been extremely good – well-targeted and accurate, providing a wealth of very useful information.”

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 member, I find all the communication has been most helpful and I feel supported.”

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.

“ At the AGM last September we met people from all over the country. There were also people from the MND Association and a doctor from Sheffield talking about the latest research.”

To find out more, see: www.mndassociation.org/membership. To become a member, you can contact us on 01604 611855, or if preferred by email: membership@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.

Key points
• Our MND Connect helpline is not just here to provide information, the team can also offer a listening ear if you just need to talk. 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 will help you identify some of the organisations that are likely to become frequent sources of information or service.

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.

We keep this information updated, but the contact details may be subject to change before the next revision. If you need help locating an organisation, please contact our helpline MND Connect.

See Section 15: Help from the MND Association for all our service contact 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.

arrangingafuneral.co.uk, 142 Cromwell Road, Kensington, London SW7 4ET
Telephone: 0800 0198 451
Email: through the website contact page
Website: www.arrangingafuneral.co.uk

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, Simplify, 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, 32-36 Loman Street, London SE1 0EH
Telephone: 0300 772 9600 (England) 0292 009 0087 (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.

Childhood Bereavement Network, 8 Wakley Street, London EC1V 7QE
Telephone: 020 7843 6309
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. Search for your local branch on the Get Advice page of the website.

Telephone: 03444 111 444 (England) 03444 77 20 20 (Wales) 028 9023 1120 (Northern Ireland)
Website: www.citizensadvice.org.uk

Community Law Service
Independent advice and representation, including help on welfare benefits, debt and housing. Find your local service through your telephone directory or 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
Website: www.cruse.org.uk

Disability Law Service
Assistance on disability law.
Telephone: 0207 791 9800
Email: advice@dls.org.uk
Website: http://dls.org.uk

The Disabled Living Foundation
A wide range of support and advice for people with disabilities, including information on daily living equipment.
The Disabled Living Foundation, Unit 1, 34 Chatfield Road, Wandsworth, London SW11 3SE
Telephone: 0300 999 0004
Email: info@dlf.org.uk
Website: www.dlf.org.uk

Dying Matters
A membership organisation offering a wide range of resources to help people start conversations more easily about dying, death and bereavement. See also Find Me Help.
Dying Matters, c/o The National Council of Palliative Care, 34-44 Britannia Street, London WC1X 9JG
Telephone: 020 7697 1520
Email: through the website contact page
Website: www.dyingmatters.org

Find Me Help
Online service with a search facility to help you find local services that can assist with end of life needs. This is hosted on the Dying Matters website.
Website: http://help.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: 0845 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)
A regulatory body with a register of health professionals who meet their standards of practice, including psychologists, physiotherapists, occupational therapists and speech and language therapists. You can use their Check the Register facility to see if a relevant professional has been registered.
Health Professions Council, Park House 184 Kennington Park Road, London SE11 4BU
Telephone: 0300 500 6184
Website: www.hcpc-uk.co.uk

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.
British Humanist 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.
Institute of Civil Funerals, 186a Station Road, Burton Latimer, Kettering, Northamptonshire NN15 5NT
Telephone: 01480 861411
Email: info@iocf.org.uk
Website: www.iocf.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.
MedicAlert, MedicAlert House, 327 Upper Fourth Street, Milton Keynes MK9 1EH
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, 2nd Floor, City View, Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.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: http://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: http://saif.org.uk

**The National Council for Palliative Care**
A charity supporting all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. They work with government, health and social care staff, and people affected by end of life issues to improve end of life care for all.
The National Council for Palliative Care, 34-44 Britannia Street, London WC1X 9JG
Telephone: 020 7697 1520
Email: through the website contact page
Website: www.ncpc.org.uk

**Natural Death Centre**
A source of information and advice if you are thinking about arranging a funeral without a funeral director and using a natural burial ground.
Natural Death Centre, In the Hill House, Watley Lane, Twyford, Winchester SO21 1QX
Telephone: 01962 712 690
Email: rosie@naturaldeath.org.uk
Website: www.naturaldeath.org.uk
**NHS Choices**
Online information to help you make informed choices about health. NHS Choices also hosts an Information Prescription Service, for trustworthy healthcare information according to need or condition.
Telephone: see NHS 111 for helpline
Email: through the website contact page
Website: [www.nhs.uk](http://www.nhs.uk)

**NHS 111 (previously known as NHS Direct)**
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](http://www.nhs.uk)

**NHS Direct Wales**
Similar to NHS 111, but for medical advice in Wales.
Telephone: 0845 46 47
Website: [www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

**NHS Northern Ireland**
Information on NHS services in Northern Ireland. This is an online service.
Email: through the website contact page
Website: [http://online.hscni.net](http://online.hscni.net)

**NI Direct**
The equivalent of GOV.UK for Northern Ireland, providing government information, eg guidance on benefits. This is an online service.
Email: through the website contact page
Website: [www.nidirect.gov.uk](http://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: 028 9072 4733
Website: search for [enduring power of attorney](http://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](http://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: director@recordmenow.org
Website: [www.recordmenow.org](http://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](http://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, First Floor, 16 Upper Woburn Place, London WC1H OAF
Telephone: **0845 050 1953**
Email: info@sueryder.org
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](http://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: info@winstonswish.org.uk
Website: [www.winstonswish.org.uk](http://www.winstonswish.org.uk)
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.

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 care development adviser (RCDA).

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

Online forum:
Hosted by the MND Association at: http://forum.mndassociation.org for you to share information and experiences with other people affected by MND.