Accessing services and support

12: How we can help you
13: Useful organisations

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: [www.mndassociation.org/publications](http://www.mndassociation.org/publications)

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

Telephone: **0808 802 6262**
Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)
12: How we can help you

This section explains how to access help from the MND Association.

We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. Scotland is supported by a different organisation called MND Scotland.

See Section 13: Useful organisations for contact details.

Our overall 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.

The earlier we can help you, the more we can accomplish on your behalf. You may at times feel very isolated, but you are not alone in this.

See the following for our service details.

MND Connect helpline

Our helpline provides support and information for:

• people living with MND or Kennedy’s disease
• their carers and families
• our volunteers
• health and social care professionals.

The team can provide emotional support, information and direct you to our own services and appropriate external organisations.

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 Connect is accredited by the Helplines Standard.

Association visitors (AVs)

AVs are trained volunteers who provide free and confidential guidance to people with MND or Kennedy’s disease, their carers, close family and friends. An AV can help you identify problems as they arise, answer questions and discuss how you might get support.

All AVs are carefully selected and undergo a Disclosure and Barring Service (DBS) check. They are based in the local community and can contact you by phone, email or through home visits.

If you would like to be supported by an AV, your local regional care development adviser (RCDA) can help arrange this, where an AV is available (see next heading for RCDAs).

If an AV is not available in your area, we can offer ongoing support and help through our helpline or your local branch or group. Please see other headings in this list for details.
Regional care development advisers (RCDAs)

RCDAs have expert knowledge about the management and care of people with MND. They influence local service providers to help ensure care and support is available at the right time.

With a professional health and social care background or significant experience to help them in this role, RCDAs provide guidance for families affected by MND in complex situations. They also manage the team of Association visitors (AVs) in their region.

Our RCDAs are listed on our website at www.mndassociation.org/rcda or contact our MND Connect helpline, as shown in this list.

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 sometimes 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.

Benefits Advice Service

Our trained advisers can help you identify benefits you may be able to claim if living with MND or Kennedy’s disease. This service is provided by Citizens Advice Cardiff and the Vale, or Advice NI.

The service is available by telephone or email for people living in England, Wales or Northern Ireland, and there is also a web chat facility for those living in England or Wales.

We may be able to arrange for an interpreter to join your call with our adviser, if you find English difficult and have nobody to speak on your behalf.

Telephone: 0808 801 0620
England and Wales
0808 802 0020 Northern Ireland

Email: through the webpage at www.mndassociation.org/benefitsadvice

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 regional care development adviser.

**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, regional care development advisers 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.

Communication Aids Service

Our Communication Aids Service helps people with MND, carers, families, and health and social care professionals, with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services.

Our aim is to improve provision and information on a local and national level, through collaboration with health and social care professionals.

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

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.

Our website
Please visit the MND Association website to find our information resources online and more about our services and the MND Association. Find our site at www.mndassociation.org which includes news about our research, volunteering, fundraising and campaigning activities.

Care information and publications
We provide a wide range of care information and publications. Our information is developed and revised using guidelines from The Information Standard, as provided by NHS England. This means it is evidence checked, user tested and reviewed by experts.

You can download the majority of our information from our website at www.mndassociation.org/publications or order printed copies from our MND Connect helpline, as shown in this list.

Online forum
Our online forum is a safe place to share experiences, ideas and a wealth of information, with other people affected by MND. You can access the forum on our website or at http://forum.mndassociation.org

Support for minority and ethnic groups
We are here for everyone living with or affected by MND or Kennedy’s disease in England, Wales and Northern Ireland. We acknowledge that people have differing needs, backgrounds, culture and faiths. Other aspects of diversity may also influence the way care and support should be offered and provided.

The MND Association supports 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.

“ I don’t have family here in the UK, neither does my son, so we feel very lonely without money, moral support or information. Help!”

Information in other languages and accessible formats
We provide introductory information in languages other than English and a limited service for further translations of care publications. We also have alternative formats for some resources, such as audio or easy read.

Find out more at www.mndassociation.org/languages or contact our MND Connect helpline. If needed on first enquiry, ask someone to contact the team on your behalf. They can help answer your questions or direct you to appropriate support.

Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org
Membership
Membership of the MND Association is free for people living with MND or Kennedy’s disease, their spouses, partners and carers. By becoming a member, you can access the following benefits:

- our quarterly magazine, Thumb Print, which features the latest news on care and research as well as inspirational stories from those affected
- an introduction to your nearest branch or group
- our Annual Impact Report, which demonstrates the difference made by us over the last financial year
- invitations to conferences and seminars, including our regional conferences
- the authority to vote at national and local AGMs, including the election of MND Association Trustees.

To become a member, contact us by:

Telephone: **01604 611855**
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](http://www.mndassociation.org/volunteering)

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

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

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

Or contact enquiries:

Telephone: **01604 250505**
Email: **enquiries@mndassociation.org**

Key points
- We support everyone with or affected by MND or Kennedy’s disease in England, Wales and Northern Ireland (support is provided in Scotland by MND Scotland).
- Our services are free for people with MND or Kennedy’s disease, their partners and carers.
- If you need assistance to contact any of our services or external services, contact our MND Connect helpline, as listed in this section.

Further information:
A list of other contacts can be found in Section 13: **Useful organisations**.

A **Publications order form** is included in the folder with this guide. You can order further copies of this form or any of our resources from our MND Connect helpline, as listed in this section.
13: Useful organisations

This section will help you identify some of the organisations that can provide further information or support.

Access more links to useful organisations at: www.mndassociation.org/usefulorgs.
We also list relevant organisations in our information sheets.

Contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland, to find out about services in your area. They may offer a directory on their website.

See the Contact record in Part 4: Helping you to keep track, to group details.

If you would like to know more about organisations that support carers, children or young people affected by MND, we provide publications to meet their needs:

See Further information at the end of Section 5: Family, children and friends.

Organisations

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 a product.

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

Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org
The helpline team can also direct you to our services and local support.

Access to Work
To help you and your employer support your work routines.
Telephone: 0345 268 8489
Textphone: 0345 608 8753
Website: search for access to work at www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

Adult Social Care Services
Contact your local authority for a needs assessment, carer’s assessment or social care advice. For Northern Ireland, search for health and social care trusts at www.nidirect.gov.uk

Advicenow
Online information on rights and legal issues.
Website: www.advicenow.org.uk

Age UK
Information, advice and advocacy for people in later life, including guidance on benefits.
Age UK, Tavis House, 1-6 Tavistock Square, London WC1H 9NA
Telephone: 0800 678 1602 (England)
08000 223 444 (Wales)
0808 808 7575 (Northern Ireland)
Email: through website contact page
Website: www.ageuk.org.uk

Asian Health Agency
Information and support for Asian elders, disabled people and carers across the UK, with care services across many London boroughs.
Email: through website contact page
Website: www.taha.org.uk
Blue Badge Scheme
A blue badge enables access to a range of parking benefits and other motoring concessions for people with severe mobility difficulties. Contact your local authority or look online at GOV.UK
Website: search for blue badge at: www.gov.uk or in Northern Ireland at: www.nidirect.gov.uk

BME Health Forum
An organisation helping to improve health services for black and minority ethnic groups. Their work is based in London, but their site includes patient information on rights for healthcare and how to access support.
BME Health Forum, 80a Church Street, London NW8 8ET
Telephone: 07958 479 217
Email: through website contact page
Website: www.bmehf.org.uk

BACP (British Association for Counselling and Psychotherapy)
A body representing counselling and psychotherapy in the UK who can direct you 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

British Red Cross
For health and social care assistance, equipment hire (eg standard wheelchairs) and various disability living aids for purchase.
British Red Cross, 44 Moorfields, London EC2Y 9AL
Telephone: 0344 871 11 11
Email: contactus@redcross.org.uk
Website: www.redcross.org.uk

Carers Trust
Support for carers.
Carers Trust, Unit 101, 164-180 Union Street, London SE1 0LH
Telephone: 0300 772 9600 (England)
0300 772 9702 (Wales)
07826 930508 (Northern Ireland)
Email: info@carers.org (England)
wales@carers.org (Wales)
ni@carers.org (Northern Ireland)
Website: https://carers.org

Carers UK
Information, advice and campaigning for the rights of carers.
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

Childline
Counselling and a free 24-hour helpline for children or young people in distress or danger.
Childline, Via NSPCC, Weston House, 42 Curtain Road, London EC2A 3NH
Telephone: 0800 1111
Email: through the website contact page
Website: www.childline.org.uk

Chinese National Healthy Living Centre
Advice on health issues for people in the Chinese Community.
Chinese National Healthy Living Centre, 29-30 Soho Square, London W1D 3QS
Telephone: 020 3802 0350
Email: info@cnhlc.org.uk
Website: www.cnhlc.org.uk
Citizens Advice
Free information and advice on legal, money and other problems. Search for your local branch on their website.
Telephone: 03444 111 444 (for England or contact your local branch)
03444 77 20 20 (for Wales)
Website: www.citizensadvice.org.uk
In Northern Ireland, search online for your local Community Advice

Community Law Service
Independent advice and representation, including welfare benefits, debt and housing. Contact your local service through your telephone directory or by searching for community law service online.

Disability Law Service
Contact the DLS for assistance on disability law.
Telephone: 0207 791 9800
Email: advice@dls.org.uk
Website: https://dls.org.uk

Disability Rights UK
Information, products and services designed by and for disabled people.
Disability Rights UK, Plexal, 14 East Bay Lane, Here East, Queen Elizabeth Olympic Park, Stratford, London E20 3BS
Telephone: 0330 995 0400
Email: see website for contact details
Website: www.disabilityrightsuk.org

The Disabled Living Foundation
For a wide range of support and aids for people with disabilities.
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

GOV.UK
Online government information about financial help and benefits.
Website: www.gov.uk (England and Wales)
www.nidirect.gov.uk (Northern Ireland)

Health in Wales
Online information about NHS services in Wales including a directory of the Welsh health boards. (See also NHS Direct Wales).
Email: through the website contact page
Website: www.wales.nhs.uk

Health and Care Professions Council (HCPC)
A register of health professionals who meet HCPC standards of practice, with a search facility to find professionals, including psychologists, physiotherapists, occupational therapists and speech and language therapists.
Health Professions Council, Park House, 184-186 Kennington Park Road, London SE11 4BU
Telephone: 0300 500 6184
Website: www.hcpc-uk.org

Health and Social Care Online (Northern Ireland)
Online information about health and social care services in Northern Ireland.
Email: through the website contact page
Website: https://online.hscni.net

Healthtalk.org
A website of personal health experiences, including a series of interviews with people affected by or living with MND.
Email: info@healthtalkonline.org
Website: search for motor neurone disease at: www.healthtalk.org
Independent Age
Independent advice on a range of care issues, including assessments, getting help at home, paying for care, benefits and hospital discharge.
Independent Age, 18 Avonmore Road, London W14 8RR
Telephone: 0800 319 6789
Email: advice@independentage.org
Website: www.independentage.org

Jobcentre Plus
Contact your local Jobcentre Plus for advice about employment and some benefit claims.
Website: search for jobcentre plus at: www.gov.uk to find your local office. This will also link you to jobs and benefits offices for Northern Ireland, or search for these at: www.nidirect.gov.uk

Lesbian and Gay Foundation
Information and advice for lesbian, gay and bisexual people.
Lesbian and Gay Foundation, 5 Richmond Street, Manchester M1 3HF
Telephone: 0345 3 30 30 30
Email: info@lgbt.foundation or through website contact page
Website: https://lgbt.foundation

Lions Clubs International (British Isles and Ireland)
A community service organisation, helping to promote the Message in a Bottle scheme to assist paramedics in case of emergencies.
Lions Clubs International, 257 Alcester Road South, Kings Heath, Birmingham B14 6DT
Telephone: 0121 441 4544
Email: enquiries@lionsclubs.co or through website contact page
Website: http://lionsclubs.co

Medic Alert
An identification system for individuals with medical conditions, usually in the form of bracelets or necklets, supported by a 24 hour emergency telephone service.
Medic Alert, MedicAlert House, 327-329 Witan Court, Upper Fourth Street, Milton Keynes MK9 1EH
Telephone: 01908 951045
Textphone: 0300 037 0100
Email: info@medicalert.org.uk or through website contact page
Website: www.medicalert.org.uk

Motability
For details about vehicle leasing or hire purchase through the Motability scheme.
Telephone: 0300 456 4566
Textphone: 0300 037 0100
Email: through website contact page
Website: www.motability.co.uk

MND Scotland
Support for people affected by MND in Scotland.
MND Scotland, 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

NHS (online information)
Health information according to need. For Wales, see NHS Direct Wales. For Northern Ireland, see Health and Social Care Online.
Website: www.nhs.uk

NHS 111
The NHS online/telephone help and support service, providing health advice and information, 24-hours a day, 365 days a year.
Telephone: 111 for urgent, but non-emergency medical advice
Email: through the website contact page
Website: https://111.nhs.uk
NHS Direct Wales
Similar to NHS Direct, but particular to Wales and the Welsh NHS structure.
Telephone: **0845 46 47** or **111** if available in your area
Website: [www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

Office of Care and Protection
Information about Enduring Power of Attorney for Northern Ireland. For Lasting Power of Attorney in England and Wales, see Public Guardianship Office.
Office of Care and Protection, Room 2.02, First Floor, Royal Courts of Justice, Chichester Street, Belfast, BT1 3JF
Telephone: **0300 200 7812**
Email: enquiries@ncpc.org.uk

Office of the Public Guardian
Information about Lasting Power of Attorney and the Mental Capacity Act. For Enduring Power of Attorney in Northern Ireland, see Office of Care and Protection.
Public Guardianship Office, PO Box 16185, Birmingham B2 2WH
Telephone: **0300 456 0300**
Textphone: **0115 934 2778**
Email: customerservices@publicguardian.gov.uk
Website: [www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney)

Outsiders Club
Support on relationships and sexuality for disabled people.
Outsiders Trust, WestEnd, Redwood Farm, Barrow Gurney, Avon, BS48 3RE
Telephone: **07770 884 985** (helpline)
**07410 544318** (club)
Email: [sexdis@outsidersorg.uk](mailto:sexdis@outsidersorg.uk) (helpline)
[info@outsiders.org.uk](mailto:info@outsiders.org.uk) (club)
Website: [www.outsiders.org.uk/outsidersclub](http://www.outsiders.org.uk/outsidersclub)

The Patient Advice and Liaison Service (PALS)
Confidential advice about NHS services and complaints.
Telephone: contact your local hospital, GP or health clinic
Website: search for PALS on the NHS Choices website: [www.nhs.uk](http://www.nhs.uk)
For Northern Ireland:
Patient and Client Council
Freephone: **0800 917 0222**
Email: [info.pcc@hscni.net](mailto:info.pcc@hscni.net)
Website: [www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)
For Wales:
Refer to your local Community Health Council (CHC):
[www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils](http://www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils)

Pension Service
For queries and claims regarding pensions and pension credit.
Telephone: **0800 731 7898**
Textphone: **0800 731 7339**
Website: [www.gov.uk/contact-pension-service](http://www.gov.uk/contact-pension-service)
For Northern Ireland:
Telephone: **0800 587 0892**
Website: select pensions and retirement planning at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

REMAP
A charity of volunteers who make bespoke aids for disabled people.
Remap Head Office, D9 Chaucer Business Park, Kemsing, Sevenoaks, Kent TN15 6YU
Telephone: **01732 760209**
Email: through the website contact page
Website: [www.remap.org.uk](http://www.remap.org.uk)
Scope
This charity offers local disability advice, having combined with Disability Information and Advice Line services (previously known as DIAL).

Helpline: 0808 800 3333
Email: helpline@scope.org.uk
Website: www.scope.org.uk

Samaritans
Confidential 24-hour emotional support by telephone, email, letter or face-to-face in most branches.

Samaritans, The Upper Mill, Kingston Road, Ewell, Surrey KT17 2AF
Telephone: 116 123 (or contact your local branch)
Email: jo@samaritans.org
Website: www.samaritans.org

Shopmobility
A scheme in many towns and shopping centres, providing manual or powered wheelchairs or scooters, for loan or hire.

Telephone: 01933 229644
Email: shopmobility@bhta.com
Website: https://nfsuk.org

Turn2us
Online help about financial support, grants or funding, including a benefits calculator.
Website: www.turn2us.org.uk

Working Families
Helping people and employers find a better balance between work and home.

Working Families, Spaces, City Point, 1 Ropemaker Street, London EC2Y 9AW
Helpline: 0300 012 0312
Email: advice@workingfamilies.org.uk
Website: www.workingfamilies.org.uk

Key points

- Before selecting or purchasing any specialist equipment or aids, have your needs assessed by an appropriate health or social care professional, as items may not be suitable for everyone and mistakes can be costly.

- You can note details of local organisations on the contact record, in the Helping you to keep track pages at the back of this guide.

Further information:
We offer a range of publications to help you manage life with MND. Each resource lists organisations relevant to the subject being covered.

Download our publications at:
www.mndassociation.org/publications
Or order them from MND Connect, our support and information helpline:
Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See Section 12: How we can help you.

Online forum:
A safe place to share information and support with others affected by MND at:
http://forum.mndassociation.org
The MND Association would like to thank the Tesco Charity Trust, and the Evan Cornish Foundation for their support which has made the production of Living with motor neurone disease possible.