

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**

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

Telephone: **0808 802 6262**

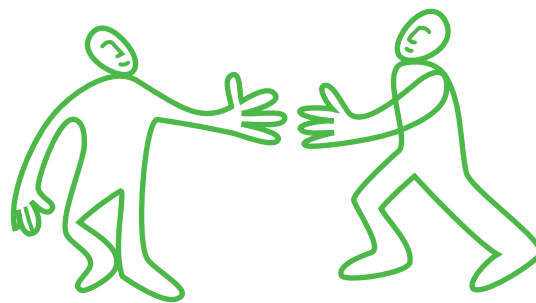
Email: **mndconnect@mndassociation.org**



**Living with
motor neurone disease**

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.*

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**

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, a member of our regional care staff or our MND Connect helpline can help arrange this, where an AV is available.

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 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.

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.

MND Association Benefits Advice Service:

We can provide free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: www.mndassociation.org/benefitsadvice or contact our MND Connect helpline for guidance.

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.

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 resources and publications. Our information is developed and revised under an accreditation through PIF Tick

<https://piftick.org.uk>

This means it is evidence checked, user tested and reviewed by experts.



Patient Information Forum

Online forum

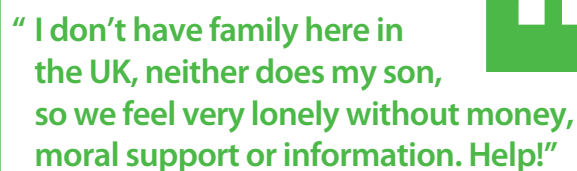
Our online forum is a safe place to share experiences, ideas and a wealth of information, with other people affected by MND. You can access the forum on our website or at

<https://forum.mndassociation.org>

Inclusion

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 enables you to join a community of people living with MND, their spouses, partners and carers. A community of people who all share the same vision of a world free from MND. As a unified force, our membership creates a powerful voice to support lobbying and campaigns on behalf of all people affected by MND.

By becoming a member, you will:

- have opportunities to influence the work of the Association
- be sent a welcome pack, including a membership card
- be able to link to your nearest branch or group
- receive Thumb Print, our quarterly magazine for our members
- be able to attend and vote at our AGMs
- have invitations to our conferences and events
- have access to a collectible pin badge every year.

To become a member, contact us by:

Telephone: **01604 611860**

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**

We work alongside people with MND or Kennedy's disease, and their carers, to develop and improve our information. If you would like to get involved, you will have opportunities to feed into a range of different content and formats.

You can pick and choose which tasks you want to work on and make a difference from the comfort of your own home. To find out more, contact:

infofeedback@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: **0800 121 7479**
Textphone: **0800 121 7579**
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.
Telephone: **0800 055 6112** (England)
0300 303 44 98 (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, Church Street
Neighbourhood Centre, Cherwell House,
Penfold Street, London NW8 8PT

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)

Email: info@carers.org (England)

wales@carers.org (Wales)

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**

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

Citizens Advice

Free information and advice on legal, money and other problems. Search for your local branch on their website.

Telephone: **0800 144 8848** (for England or contact your local branch)
0800 702 2020 (for Wales)

Website: **www.citizensadvice.org.uk**

For Northern Ireland, search on the website 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.

Disability Law Service, The Foundry,
17-19 Oval Way, Vauxhall, London SE11 5RR

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

See entry for *Living Made Easy*.

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.

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.

LGBT Foundation, Fairbairn House
(2nd Floor), 72 Sackville Street,
Manchester M1 3NJ

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: **https://lionsclubs.co/Public**

Living made easy

Previously known as the Disabled Living Foundation. An organisation providing products to support disabled people in their daily lives.

Email: **info@df.org.uk**

Website: **https://livingmadeeasy.org.uk**

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.

MedicAlert, Suite 1, Liscombe South,
Liscombe Park, Soulbury LU7 0JL

Telephone: **01908 951045**

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, 6th Floor, Merchant
Exchange, 20 Bell Street, Glasgow G1 1LG

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 111 Wales

Similar to NHS 111 for England, but for Wales.

Telephone: **111**

Website: <https://111.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: epa@courtsni.gov.uk

Website: bit.ly/EPAttorney

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

Outsiders Club

Support on relationships and sexuality for disabled people.

Outsiders Trust, WestEnd, Redwood Farm, Barrow Gurney, Avon, BS48 3RE

Telephone: **07900 957 393** or
01997 421 019

Email: members@outsiders.org.uk

Website: <https://outsiders.org.uk>

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* at: www.nhs.uk

For Northern Ireland:

Patient and Client Council

Freephone: **0800 917 0222**

Email: info.pcc@pcc-ni.net

Website: <https://pcc-ni.net>

For Wales:

Refer to your local Community Health Council (CHC):

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

For Northern Ireland:

Telephone: **0800 587 0892**

Website: www.nidirect.gov.uk/contacts/northern-ireland-pension-centre

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

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.

Freepost SAMARITANS LETTERS

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: **07984 740 271** (urgent enquiries only)

Email: through website contact page

Website: www.shopmobilityuk.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 c/o Buzzacott LLP,
130 Wood Street, London EC2V 6DL

Helpline: **0300 012 0312**

Email: through website contact page

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 staff contact.

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at:

<https://forum.mndassociation.org>

Document dates:

Last revised: November 2022

Next revision: November 2025

Version: 1

MND Association

Francis Crick House (2nd Floor)

6 Summerhouse Road, Moulton Park

Northampton NN3 6BJ

Tel: 01604 250505

Website: www.mndassociation.org

Registered Charity No. 294354

© MND Association 2016

All rights reserved. No reproduction, copy or transmission of this publication without written permission.

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

For references and acknowledgements please refer to the full guide, *Living 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**



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.

