



12: Useful organisations

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

The following information is a section from our full guide *Caring and MND: support for you*.

Other sections, and the full guide, can be found online at: www.mndassociation.org/carerguide

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



**Caring and MND:
support for you**

12: Useful organisations



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

The organisations listed here have been split into two groups to help you find appropriate support:

1: Organisations for adult carers

These services may also help young carers, but their main focus is support for adult carers or related services that adult carers might use.

2: Organisations for children, young people and young carers

These services are aimed specifically at children and young people.

You can access a wider list of useful organisations on our website at: www.mndassociation.org/support-and-information and we list relevant organisations at the end of all our information sheets.

Your local authority or, in Northern Ireland, your local health and social care trust, can direct you to regional providers and may offer a directory of services on their website.

See our [Contact record in Part 4 of this guide to keep details for regular contacts.](#)

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 details may change between revisions. 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.

Organisations that can help adult carers

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**

Email: through website contact page

Website: www.ageuk.org.uk

Alzheimer's Society (AS)

For information about supporting someone with cognitive impairment or dementia.

Alzheimer's Society, Scott Lodge, Scott Road, Plymouth, PL2 3DU

Telephone: **0330 333 0804**

Email: through website contact page

Website: www.alzheimers.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 the website contact page

Website: www.taha.org.uk

BackCare

Information and advice on back pain and manual handling.

BackCare, Monkey Puzzle House,
69-71 Windmill Road, Sunbury-on-Thames
TW16 7DT

Telephone: **0208 977 5474**

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

Website: **www.backcare.org.uk**

Bereavement Advice Centre

Information about the legal and practical steps to take after someone's death, including a booklet called *What to do when someone dies*, a practical guide.

Bereavement Advice Centre, 1 Angel Square,
Manchester, M60 0AG

Freephone: **0800 634 9494**

Website: **www.bereavementadvice.org**

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

Email: through website contact page

Website: **www.bmehf.org.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**

Care Quality Commission (CQC)

Use the search facility to locate a care service in England, such as a nursing care home, to read the ratings from the last inspection. Contact the CQC if you are concerned about the care received from a provider in England.

Telephone: **03000 616161**

Email: **enquiries@cqc.org.uk**

Website: **www.cqc.org.uk**

Care Inspectorate Wales

Use the search facility to locate a care service in Wales, such as a nursing care home, to read the ratings from the last inspection. Contact the CSSIW if you are concerned about care received from a provider in Wales.

Welsh Government office, Sarn Mynach,
Llandudno Junction LL31 9RZ

Telephone: **0300 7900 126**

Email: through the website contact page

Website: **https://careinspectorate.wales**

Carer's Allowance Unit

For queries about Carer's Allowance.

Telephone: **0800 731 0297**

Website: search for *carers allowance* at:

www.gov.uk (includes online claim submission)

Northern Ireland:

Telephone: **0800 587 0912**

Website: search for *Carer's Allowance* at

www.nidirect.gov.uk/articles/carers-allowance

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)

028 3026 7015

(Northern Ireland)

Email: **info@carers.org** (England)

wales@carers.org (Wales)

info@carers-nm.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**

Email: through the website contact page

Website: **www.carersuk.org**

Chinese National Healthy Living Centre

Advice on health issues for people in the
Chinese Community, including support
for carers.

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 Bureau

Free information and advice on legal, money
and other problems. Contact your local
bureau for support – you can 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**

Community Law Service

Independent advice and representation,
including welfare benefits, debt and housing.
Contact your local service by searching for
community law service online.

Cruse Bereavement Care

Face-to-face bereavement support is
available through local branches across
England, Wales and Northern Ireland, with
a helpline and e-mail service for adults and
young people.

Cruse Bereavement Care, Unit 0.1,
One Victoria Villas, Richmond, TW9 2GW

Helpline: **0808 808 1677**

Website: **www.cruse.org.uk**

Disability Law Service

Contact the DLS for assistance on
disability law.

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

Telephone: **020 7791 9800**

Email: **advice@dls.org.uk**

Website: **www.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: **enquiries@disabilityrightsuk.org**

Website: **www.disabilityrightsuk.org**

Elderly Accommodation Counsel (EAC)

National register of all types of accommodation to help the elderly make informed choices about their housing and care needs.

EAC, Suite A, 202 Lambeth Road,
London SE1 7JW

Email: through website contact page
Website: www.eac.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 Professions Council (HPC)

A register of health professionals who meet HPC 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 Kennington Park Road, London SE11 4BU

Telephone: **0300 500 6184**
Website: www.hpc-uk.org

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

Hospice UK

Information on hospices and hospice care across the UK.

Hospice UK, 34-44 Britannia Street,
London WC1X 9JG

Telephone: **020 7520 8200**
Email: through website contact page
Website: www.hospiceuk.org

Independent Age

Independent advice on a range of care issues, including care 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. Search for your local office through the website.

Telephone: **0800 169 0190**
Textphone: **0800 169 0314**
Email: through website contact page
Website: search for either *employment* or *jobcentre plus* at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

LGBT Foundation

Information and advice for lesbian, gay and bisexual people, including carer support.

LGBT Foundation, PO Box 5577,
Manchester M61 0TT

Telephone: **0345 3 30 30 30**
Email: info@lgbt.foundation
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**

Website: **<https://lionsclubs.co/Public>**

Living made easy

Previously the Disabled Living Foundation. Provides guidance on aids for disabled people.

Telephone: **0300 999 0004**

Email: **info@dlf.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**

Website: **www.medicalert.org.uk**

Motability

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

Telephone: **0300 456 4566**

Email: through website contact page

Website: **www.motability.co.uk**

MND Scotland

Support 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**

National Debtline

An independent confidential helpline offering free advice about debt problems in England, Wales and Scotland.

National Debtline, Tricorn House, 51-53 Hagley Road, Edgbaston, Birmingham B16 8TP

Telephone: **0808 808 4000**

Email: through website contact page

Website: **www.nationaldebtline.org**

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>**

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.gov.uk

Website: search for *office of the public guardian* at: **www.gov.uk**

Outsiders Trust

Support on relationships and sexuality for people affected by disabilities, including advice to help health and social care professionals provide better guidance.

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

Telephone: **07872 681 982**

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

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

The Patient Advice and Liaison Service (PALS)

PALS is a local service at all NHS Trusts in England, providing confidential advice to families and carers about NHS and health matters.

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: **www.patientclientcouncil.hscni.net**

For Wales:

Please refer to your local Community Health Council.

Website: search for *community health councils* at: **www.wales.nhs.uk**

Pension Service

For queries and claims regarding pensions and pension credit.

Telephone: **0800 731 7898**

Textphone: **0800 731 7339**

Website: search for *pensions* at: **www.gov.uk**

For Northern Ireland:

www.nidirect.gov.uk

The Regulation and Quality Improvement Authority (RQIA)

Use the search facility to locate a care service in Northern Ireland, such as a nursing care home. You can then read the ratings from the most recent inspection. Contact the RQIA if you are concerned about the care received from a provider in Northern Ireland.

RQIA, 7th Floor Victoria House,
15-27 Gloucester Street, Belfast, BT1 4LS

Telephone: **028 9536 1111**

E-mail: **info@rqia.org.uk**

Website: **www.rqia.org.uk**

Relatives & Residents Association

For advice about moving to a residential or nursing home if you are older and need care.

Relatives and Residents Association, Unit 6,
Aztec Row, 1 Berners Road, London N1 0PW

Telephone: **020 7359 8136**

Email: **helpline@relres.org**

Website: **www.relres.org**

Ricability

Free, unbiased reports for people with disabilities, based on consumer research.

Ricability, Ground floor, Unit 10,
Blenheim Court, 62 Brewery Road,
London N7 9NY

Telephone: **020 7427 2460**

Email: **mail@ridc.org.uk**

Website: **www.ricability.org.uk**

The Royal Association for Deaf People

For information, support and advice if your first language is British Sign Language.

The Royal Association for Deaf People,
Block F, Parkside Office Village, Knowledge
Gateway, Nesfield Road, Colchester CO4 3ZL

Telephone: **0300 688 2525**

Textphone: **0300 688 2527**

SMS: **07851 423 866**

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

Website: **www.royaldeaf.org.uk**

The Royal National Institute of Blind People (RNIB)

For information, support and advice if you are affected by sight loss.

RNIB, 105 Judd Street, London WC1H 9NE

Helpline: **0303 123 9999**

Email: **helpline@rnib.org.uk**

Website: **www.rnib.org.uk**

Samaritans

Confidential 24-hour emotional support for people experiencing feelings of distress or despair. Their service is available by telephone, email, letter or face-to-face in most branches.

Write to: 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.

ShopMobility UK, c/o Driving Mobility,
The Old Carriage Works, Moresk Road,
Truro TR1 1DG

Email: through website contact page

Website: **https://shopmobilityuk.org**

Social Services

Contact your local authority if you need to speak to someone in social services or book a carer's assessment. For Northern Ireland, search for *Health and Social Care Trusts* at **www.nidirect.gov.uk**

Step Change Debt Charity (Consumer Credit Counselling Service)

Free and confidential advice on
debt management.

StepChange Debt Charity, 123 Albion Street,
Leeds LS2 8ER

Telephone: **0800 138 1111** (helpline)
Email: through the website contact page
Website: **www.stepchange.org**

Way Widowed and Young

Supporting people under the age of 50 who
have been widowed.

WAY Widowed and Young, Suite 14,
College Business Centre, Uttoxeter New Road,
Derby DE22 3WZ

Email: through website contact page
Website: **www.widowedandyoung.org.uk**

Turn2us

Help to find out available benefits, grants,
financial support or funding.

Website: **www.turn2us.org.uk**

Working Families

Helping parents, carers 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**

Organisations that can help children and young people

Action for Children

Help for vulnerable children and young people, including young carers.

Action for Children, 3 The Boulevard,
Ascot Road, Watford WD18 8AG

Telephone: **0300 123 2112**

Email: **ask.us@actionforchildren.org.uk**

Website: **www.actionforchildren.org.uk**
(search for young carers)

Barnardo's

A charity supporting children across the UK, including services for young carers.

Barnardo's, Tanners Lane, Barkingside,
Ilford, Essex IG6 1QG

Telephone: **0800 008 7005** (England)

029 2049 3387 (Wales)

028 9067 2366

(Northern Ireland)

Email: through the website contact page

Website: search for young carers at:

www.barnardos.org.uk

Bullying UK

Help on bullying issues, with advice for children and young people. You can find your local office on their website.

Telephone: **0808 800 2222**

(confidential helpline)

Email: through the website contact page

Website: **www.bullying.co.uk/advice**

Child and adolescent mental health services (CAMHS)

Specialist NHS children and young people's mental health services, offering assessment and treatment when children find it emotionally hard to cope with daily life. If family, friends or GPs are unable to provide the necessary support, CAMHS may be able to assist. The child will need to be referred by a professional – ask your GP or the child's school for assistance. You can search online for *Child and adolescent mental health services* in your area or on your local NHS trust website.

Child Bereavement Charity

Support for families, children and young people during bereavement.

Child Bereavement UK, Unit B Knaves
Beech Way, Knaves Beech Industrial Estate,
Loudwater, High Wycombe, Bucks HP10 9QY

Telephone: **0800 0288840**

Email: **helpline@childbereavementuk.org**

Website: **www.childbereavementuk.org**

Childhood Bereavement Network

Support for bereaved children, young people and their families across the UK.

Email: **cbn@ncb.org.uk**

Website: **www.childhoodbereavementnetwork.org.uk**

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 website and confidential login
(does not require your real name)

Website: **www.childline.org.uk**

The Children's Society

Support and services for children and young carers. The website includes details about the annual Young Carer Festival.

The Children's Society, Whitecross Studios,
50 Banner Street, London EC1Y 8ST

Telephone: **0300 303 7000**

Email: through the website contact page

Website: **www.childrenssociety.org.uk**

The Children's Society – Include Programme

Support and services for young carers, including details about the annual Young Carer Festival.

Telephone: **01962 711511**

Email: through the website contact page

Website: **www.youngcarer.com**

Winston's Wish

Support for bereaved children, young people and their families.

Winston's Wish, 3rd Floor, Cheltenham House,
Clarence Street, Cheltenham GL50 3JR

Helpline: **08088 020 021**

Email: **ask@winstonswish.org**

Website: **www.winstonswish.org.uk**

Young Minds

Information and support for emotional wellbeing and mental health, for children and young people. They may be able to provide guidance if you are waiting to see CAMHS.

Telephone: **0808 802 5544**

Textline: text **YM** to **85258** for free,
24/7 support

Website: **www.youngminds.org.uk**

Youth Access

A national membership organisation for young people's information, advice, counselling and support services.

Youth Access, 1-2 Taylors Yard,
67 Alderbrook Road, London SW12 8AD

Telephone: **020 8772 9900**

Email: **admin@youthaccess.org.uk**

Website: **www.youthaccess.org.uk**

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please refer to the full guide, *Caring and
MND: support for you*.

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.**



Patient Information Forum