



## 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/MNDguides](http://www.mndassociation.org/MNDguides)

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)



**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 that can help 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 that can help children and young people

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/gettingsupport** 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 169 2081** (England)

**08000 223 444** (Wales)

**0808 808 7575**

(Northern Ireland)

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, Devon House, 58 St Katharine's Way, London E1W 1LB

Telephone: **0300 222 11 22**

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

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, 3rd Floor, Regal House,  
70 London Road, Twickenham TW1 3QS

Telephone: **08977 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, Simplify,  
8 Clifford Street, London W1S 2LQ

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, 80a Church Street,  
London NW8 8ET

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: **0844 871 11 11**

Email: **information@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.

CQC National Customer Service Centre,  
Citygate, Gallowgate, Newcastle upon Tyne  
NE1 4PA

Telephone: **03000 616161**

Email: through the website contact page

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

## Care and Social Services Inspectorate Wales (CSSIW)

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, Rhydycar Business  
Park, Merthyr Tydfil CF48 1UZ

Telephone: **0300 7900 126**

Email: through the website contact page

Website: **http://cssiw.org.uk**

## Carer's Allowance Unit

For queries about Carer's Allowance.

Telephone: **0345 608 4321**

Website: search for carers allowance at: **www.gov.uk** (includes online claim submission)

### Northern Ireland:

Telephone: **028 9090 6186**

Website: search for *Carer's Allowance* at **www.nidirect.gov.uk/carersallowance**

## Carers Direct (part of NHS Choices)

Online information, help and advice about care and support, including advice for carers.

For Northern Ireland, see NI Direct.

Telephone: **0300 123 1053**

Email: through the website contact page

Website: search for *carers* at: **www.nhs.uk**

## Carers Trust

Support for carers.

Carers Trust, 32-36 Loman Street,  
London SE1 0EH

Telephone: **0844 800 4361** (England)

**0292 009 0087** (Wales)

**028 3026 7015**

(Northern Ireland)

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

**wales@carers.org** (Wales)

**info@carers-nm.org**

(Northern Ireland)

Website: **www.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**

## 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: **0207 534 6546**

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:

**03444 111 444** (for England or contact your local branch)

**03444 77 20 20** (for Wales)

Website:

**www.citizensadvice.org.uk** (for England)

**www.citizensadvice.org.uk/wales**  
(for Wales)

**www.citizensadvice.co.uk**

(for Northern Ireland)

## 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.

## 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, PO Box 800,  
Richmond, Surrey, TW9 2RG

Helpline: **0844 477 9400**

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

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

## DIAL UK

Disability Information and Advice Line services (DIALs) are run by and for disabled people. These provide information and advice on all aspects of living with a disability. DIAL UK is now hosted by Scope.

DIAL UK (Scope) St Catherine's, Tickhill Road, Doncaster, South Yorkshire, DN4 8QN

Helpline: **0808 800 3333**

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

Website: **www.scope.org.uk/support**

## 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: **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, Ground Floor, CAN Mezzanine, 49-51 East Rd, London N1 6AH

Telephone: 020 7250 8181

Email: **enquiries@disabilityrightsuk.org**

Website: **www.disabilityrightsuk.org**

## The Disabled Living Foundation

For a wide range of support and aids for people with disabilities.

Disabled Living Foundation, 4th Floor, Jessica House, Red Lion Square, 191 Wandsworth High Street, London SW18 4LS

Telephone: **0207 289 6111**

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

Website: **www.dlf.org.uk**

## 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, 3rd Floor, 89 Albert Embankment, London SE1 7TP

Telephone: **0800 377 7070**

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

Website: **www.eac.org.uk**

## Fit for Work

Provides advice on health at work for England and Wales.

Telephone: **0800 032 6235**

Email: through website contact page

Website: **http://fitforwork.org/employee**

## 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.

Email: [info@healthtalk.org](mailto:info@healthtalk.org)

Website: search for motor neurone disease at: [www.healthtalk.org](http://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: [info@hospiceuk.org](mailto:info@hospiceuk.org)

Website: [www.hospiceuk.org](http://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](mailto:advice@independentage.org)

Website: [www.independentage.org](http://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: **0345 604 3719**

Textphone: **0345 608 8551**

Email: through website contact page

Website: search for either *employment* or *jobcentre plus* at: [www.gov.uk](http://www.gov.uk) or for

Northern Ireland at: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

## Lesbian and Gay Foundation

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

Lesbian and Gay Foundation,  
5 Richmond Street, Manchester M1 3HF

Telephone: **0345 3 303030**

Email: [info@lgf.org.uk](mailto:info@lgf.org.uk)

Website: [www.lgf.org.uk](http://www.lgf.org.uk)

## 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: **0845 833 9502**

Email: [enquiries@lionsclubs.co](mailto:enquiries@lionsclubs.co)

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**

Email: [info@medicalert.org.uk](mailto:info@medicalert.org.uk)

Website: [www.medicalert.org.uk](http://www.medicalert.org.uk)

## Motability

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

Motability Operations, City Gate House,  
22 Southwark Bridge Road, London SE1 9HB

Telephone: **0300 456 4566**

Email: through website contact page

Website: [www.motability.co.uk](http://www.motability.co.uk)

## MND Scotland

Support for people affected by MND in Scotland.

MND Scotland, 6 Eagle Street,  
Glasgow G4 9XA

Telephone: **0141 332 3903**

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

Website: **www.mndscotland.org.uk**

## National Council for Palliative Care

For information on palliative and end of life care.

National Council for Palliative Care,  
34-44 Britannia Street, London WC1X 9JG

Telephone: **020 7697 1520**

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

Website: **www.ncpc.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 Choices

Online health information including the Information Prescription Service, for information according to need.

Telephone: **111** for urgent, but non-emergency medical advice

Email: through the website contact page

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 (see NHS Choices)

Website: **www.nhs.uk**

## NHS Direct Wales

Similar to NHS Direct, but particular to Wales and the Welsh NHS structure.

Telephone: **0845 46 47**

Website: **www.nhsdirect.wales.nhs.uk**

## NHS Northern Ireland

Online information about NHS services in Northern Ireland.

Email: through the website contact page

Website: **www.hscni.net**

## 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 2.2A,  
Second Floor, Royal Courts of Justice,  
Chichester Street, Belfast, BT1 3JF

Telephone: **028 9072 5953**

Website: find Office of Care and Protection (Patient's Section) at: **www.courtsni.gov.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**

Email: **customerservices@publicguardian.gsi.gov.uk**

Website: search for *lasting power of attorney* 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: **07074 993 527**

Email: **sexdis@Outsidersorg.uk**

Website: **www.outsiders.org.uk/outsidersclub**

## 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* on the NHS Choices website: **www.nhs.uk**

### For Northern Ireland:

Patient and Client Council

Freephone: **0800 917 0222**

Email: **info.pcc@hscni.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.

The Regulation and Quality Improvement Authority, 9th Floor Riverside Tower, 5 Lanyon Place, Belfast BT1 3BT

Telephone: **028 9051 7500**

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 & Residents Association, 1 The Ivories, 6-18 Northampton Street, London N1 2HY

Telephone: **020 7359 8136**

Email: **info@relres.org**

Website: **www.relres.org**

## Ricability

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

Ricability, Unit G03, The Wenlock, 50-52 Wharf Road, London N1 7EU

Telephone: **020 7427 2460**

E-mail: **mail@ricability.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,  
Century House South, Riverside Office Centre,  
Royal Station Road, Colchester CO1 1RE

Telephone: **0845 688 2525**

Textphone: **0845 688 2527**

SMS: **07851 423866**

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.

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

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**

E-Mail: **shopmobility@bhata.com**

Website: **http://nfsuk.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.

Consumer Credit Counselling Service, Wade House, Merrion Centre, Leeds LS2 8NG

Telephone: **0800 138 1111** (helpline)

Email: through the website contact page

Website: **www.stepchange.org**

## The Way Foundation

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

The WAY Foundation, Suite 17,  
College Business Centre, Uttoxeter 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.

Turn2us, Unit 9, Cefn Coed Parc,  
Nantgarw, Cardiff CF15 7QQ

Email: through website contact page

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

## Working Families

Helping parents, carers and employers find a better balance between work and home.

Working Families, Cambridge House,  
1 Addington Square, London SE5 0HF

Helpline: **0300 012 0312**

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

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: **01923 361 500**

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: **0208 550 8822** (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**

### Carers Trust (young carers)

#### Babble and Matter

Support for young carers – for further contact details, see Carers Trust in previous list for adult carers. Babble is an online service and forum for young carers aged up to 18. Matter is an online service and forum for young carers aged 16 to 25.

Website for Babble: **https://babble.carers.org**

Website for Matter: **https://matter.carers.org**

### 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 Charity, Clare Charity Centre, Wycombe Road, Saunderton, Buckinghamshire HP14 4BF

Telephone: **0800 0288840**

Email: **support@childbereavementuk.org**

Website: **www.childbereavementuk.org**

### Childhood Bereavement Network

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

Childhood Bereavement Network, 8 Wakley Street, London EC1V 7QE

Telephone: **020 7843 6309**

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, Edward Rudolf House,  
Margery Street, London WC1X 0JL

Telephone: **0300 303 7000**

Email:

**supportercare@childrenssociety.org.uk**

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.

Include Programme, Unit 4 Calford House,  
Wessex Business Park, Wessex Way,  
Colden Common SO21 1WP

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: **08452 030405**

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

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.

Young Minds, Suite 11, Baden Place,  
Crosby Row, London, SE1 1YW

Telephone: **020 7089 5050**

Email: **ymenquiries@youngminds.org.uk**

or through the website contact page

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**

## Document dates:

Created: 01/16

Next revision: 01/19

Version: 1

MND Association

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Tel: 01604 250505

Website: [www.mndassociation.org](http://www.mndassociation.org)

Registered Charity No. 294354

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For references and acknowledgements 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](mailto:mndconnect@mndassociation.org)**



The MND Association has been certified as a producer of reliable health and social care information.

**[www.england.nhs.uk/tis](http://www.england.nhs.uk/tis)**