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](http://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](mailto:mndconnect@mndassociation.org)
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](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](http://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](http://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](http://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](http://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](http://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](http://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.hcpc-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
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
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
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
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
Website: 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 0288 840**
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](http://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](http://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](mailto:ask@winstonswish.org)
Website: [www.winstonswish.org.uk](http://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](http://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](mailto:admin@youthaccess.org.uk)
Website: [www.youthaccess.org.uk](http://www.youthaccess.org.uk)