



Alzheimer's
Research
UK

Support for people affected by dementia: organisations that can help



Introduction

This booklet is for anyone affected by dementia, including family, friends and carers of people with the condition.

This booklet provides contact details of organisations that provide care, support and/or information for people with dementia, their carers and loved ones.

There is also a description of the services each organisation provides.



Practical care
and support



Emotional
support



Housing
advice



Medical
advice



Legal
advice



Financial
advice

Most organisations listed provide their services free of charge. However, they may charge a fee. We have not listed commercial companies.

This booklet does not contain detailed information on dementia symptoms, diagnosis, or treatments. For information about dementia, please visit our website, or contact us on **0300 111 5 111** or **infoline@alzheimersresearchuk.org**. You can ask us questions over the phone or ask for our free information booklets.

This booklet was updated in June 2022. It is due to be reviewed in June 2024. It was written by Alzheimer's Research UK's Information Services team with input from lay and expert reviewers.

Contents

- 05 What is dementia?
- 06 Who is a carer?
- 07 Caring for someone with dementia
- 08 Finding local support
- 11 Sources of support:
dementia-specific organisations
- 18 Sources of support for people with
specific forms of dementia
- 23 Emotional support and mental health
- 30 Organisations for carers
- 36 Organisations for older people
- 41 Organisations that can help with
accommodation, housing, and care homes
- 44 Help finding care providers
- 48 Legal and financial information and advice
- 60 Other useful contacts
- 62 About us

What is dementia?

Dementia is not a disease itself, but a word used to describe a group of symptoms. These most commonly include:



The gradual and progressive loss of memory and communication skills



A decline in the ability to think and reason clearly



Difficulties in carrying out day-to-day activities

Alzheimer's disease is the most common disease that causes dementia, affecting over 500,000 people in the UK. Other causes of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

We have separate booklets about each of these conditions, which provide information about symptoms, diagnosis and treatment. Contact us using the details on the back of this booklet if you'd like to order more.

Who is a carer?

A carer is anybody who provides care for someone who needs help because of an illness or disability. They might be a partner, relative, friend or neighbour.

Many carers feel they are doing what anyone else would in the same situation by being there for their relative or friend. The care they give is usually unpaid, although they may be eligible for certain benefits. Anyone of any age can become a carer, and there is not always a clear-cut point when someone becomes another person's carer.

Care workers, support workers and personal assistants are different from unpaid carers. They are people who are paid for a specific service. This might be for domestic tasks like cleaning or shopping, or help with personal care, such as washing, dressing, or managing medication.

Caring for someone with dementia

People who provide unpaid care or support for someone with dementia may experience a range of different feelings.

Caring for someone can be rewarding; you may be supporting someone you love very much, and may gain new skills and build closer relationships in the process. But caring can also be challenging. At times it may be physically and mentally exhausting, and the needs of a person with dementia will usually increase over time. It's important that carers access support for themselves and those they care for when they need it and know that they are not alone.

There is a range of support available for people affected by dementia, including carers. Often people affected by dementia have many questions, worries and concerns. The organisations listed in this booklet can help to answer those questions as well as provide support and information.

08 **Finding local support**

Your GP surgery and local council should be able to help you find local sources of support.

As well as medical and social care support, there may be other helpful services in your area, such as befriending services, memory cafés, and social and peer support groups. National and local charities can provide advice and signpost you to other organisations that can help. Many of the organisations in this booklet will also be able to help you find local contacts for services available in your area.

Help from your local council, authority or trust

In England, your local council has a duty under the Care Act (2014) to carry out, when requested, a care needs assessment for anyone with care and support needs. There is also a carer’s assessment that assesses the needs of carers. These are usually done at the person’s home, face to face. You can request an assessment from your local council’s Adult Social Services Team for yourself or for someone else by phone, in writing or online.

In Scotland, Wales and Northern Ireland, carers and those they care for are also entitled to a needs assessment. In Scotland and Wales, contact your local council’s Social Services office. In Northern Ireland, contact your local Health and Social Care Trust.

A GP or hospital doctor can also arrange an assessment for you. The assessments will find out if someone is eligible and which care and support services they need.

Support may include:

- help in the home
- help with personal care
- access to day centres
- residential or respite/ replacement care
- adaptations and equipment

After a care needs assessment, a care plan should be agreed and written up. You can request a copy of your care plan in writing. The local council has a duty to meet a person’s needs when they are eligible, however, they can charge for services.

A financial assessment is used to determine whether charges are made or not. The council should provide a breakdown of how they calculate any costs.

Find your local social services department number in the phone book or online at **www.gov.uk/find-your-local-council**. The website also has information on topics such as benefits, tax and pensions.

To find details of GP surgeries and hospitals in your area you can visit **www.nhs.uk**



Sources of support: dementia-specific organisations

Alzheimer's Research UK

Alzheimer's Research UK is the UK's leading dementia research charity, and offers free information about dementia. This includes booklets about Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. We also provide information on getting a diagnosis, treatments, genetics and reducing your risk of developing dementia. The **Dementia Research Infoline** can answer your questions about dementia and dementia research, and can help you to take part in dementia research studies across the UK.



Alzheimer's Research UK
3 Riverside
Granta Park
Cambridge
CB21 6AD



0300 111 5111
(UK-wide)
9am - 5pm Monday to Friday



infoline@alzheimersresearchuk.org



www.alzheimersresearchuk.org
www.alzheimersresearchuk.org/kids/dementia-explained/
(for children and young people)

Alzheimer's Society

Alzheimer's Society provides practical care advice and emotional support for anyone affected by dementia. They can also help you find local groups offering different activities and support for people with dementia and provide legal and financial information about dementia care. Their **Dementia Connect** support service offers information, support, guidance and signposting to other organisations.



Alzheimer's Society
43-44 Crutched Friars
London
EC3N 2AE



0333 150 3456
(England, Wales and Northern Ireland)
9am - 8pm Monday to Wednesday
9am - 5pm Thursday and Friday
10am - 4pm Saturday and Sunday



dementia.connect@alzheimers.org.uk



www.alzheimers.org.uk
(England, Wales and Northern Ireland)

Alzheimer Scotland

Alzheimer Scotland provide personalised support services, community activities, information and advice for people living in Scotland. They run the **Scottish Dementia Helpline** which is open 24 hours a day.



Alzheimer Scotland
160 Dundee Street
Edinburgh
EH11 1DQ



0808 808 3000
(Scotland)
24 hours, seven days a week



helpline@alzscot.org



www.alzscot.org

Wales Dementia Helpline

This service offers help and support to people with dementia, their carers, family members or friends living in Wales.



0808 808 2235
(24 hours, seven days a week)



www.dementiahelpline.org.uk/

Dementia NI

Dementia NI campaigns to raise awareness of dementia and provides training and education on living well with the condition. They have groups around Northern Ireland helping people with dementia to meet and support each other.



Dementia NI
North City Business Centre
2 Duncairn Gardens
Belfast
BT15 2GG



02896 931 555



info@dementiani.org



www.dementiani.org

Dementia UK

Dementia UK is a specialist dementia nurse charity. Their nurses, called Admiral Nurses, provide ongoing support to families facing dementia. The Admiral Nurses help families manage complex needs, considering the person living with dementia and the people around them. They offer tailored clinical advice, provide practical and emotional support, advise people about benefits and financial issues, and help build links with other health and care professionals. Alongside their free Helpline they also offer video calls via their virtual clinics service.



Dementia UK Head Office
7th Floor
One Aldgate
London
EC3N 1RE



0800 888 6678
(UK-wide)
9am - 9pm weekdays
9am - 5pm weekends



helpline@dementiauk.org



www.dementiauk.org

The Young Dementia Network is hosted by Dementia UK. The Young Dementia Network is a free-to-join influencing community of people with young onset dementia, their families and professionals from health and social care, and the voluntary sector. Members work to improve support through creating resources, sharing information, offering opportunities for involvement and collaboration, and promoting a better understanding of young onset dementia. Find out more at **www.youngdementianetwork.org**

Guideposts

Guideposts has services for people with long-term or degenerative conditions, including dementia.



Guideposts
Willow Tree House
Station Lane
Witney
Oxfordshire
OX28 4BH



01993 893 560



info@guideposts.org.uk



www.guideposts.org.uk

Sources of support for people with specific forms of dementia

The Lewy Body Society

The Lewy Body Society offer information about dementia with Lewy bodies (DLB) and can signpost you to other organisations that can help.



Lewy Body Society
Unity House
Westwood Park
Wignam
WN3 4HE



01942 914 000



info@lewybody.org



www.lewybody.org

Parkinson's UK

Parkinson's UK can help with questions about dementia in Parkinson's disease and dementia with Lewy bodies. They can also provide care advice, emotional support, financial and legal information. They also have Parkinson's disease specialist nurses who provide medical advice and support.



Parkinson's UK
215 Vauxhall Bridge Road
London
SW1E 1VJ



0808 800 0303
(UK-wide)
9am - 7pm Monday to Friday
10am - 2pm Saturday



hello@parkinsons.org.uk



www.parkinsons.org.uk

The PSP Association

The PSP Association helps people with progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD) which are rare causes of dementia. They offer advice, support and information to people living with these conditions.



The PSP Association
Margaret Powell House
415a Midsummer Boulevard
Milton Keynes
MK9 3BN



0300 011 0122
(UK-wide)
9am - 5pm and 7pm - 9pm
Monday to Friday



helpline@pspassociation.org.uk



www.pspassociation.org.uk

Emotional support and mental health

Rare Dementia Support

Rare Dementia Support runs specialist support services for people living with, or affected by, five rare dementias.

- frontotemporal dementia (FTD)
- posterior cortical atrophy (PCA)
- primary progressive aphasia (PPA)
- familial Alzheimer's disease (FAD)
- familial frontotemporal dementia (fFTD)

The charity also provides regular support group meetings, newsletters, telephone contact networks and access to specialist information and advice.



0203 325 0828

Leave a message and you will be referred to the most appropriate team member who will call you back.



contact@raredementiasupport.org



www.raredementiasupport.org

Scottish Association for Mental Health (SAMH)

SAMH has over 60 services across Scotland providing mental health, addiction, homelessness and employment services.



SAMH
Brunswick House
51 Wilson Street
Glasgow
G1 1UZ



0344 800 0550
(England and Wales)
9am - 6pm



www.samh.org.uk

Mind

Mind provides information and advice on mental health problems and accessing support and treatments. As well as its Infoline, Mind has local teams that offer support including advocacy and counselling services. They also have a legal line which offers information and general advice on mental health law and rights.



2 Redman Place
London
E20 1JQ



0300 123 3393
(England and Wales)
9am - 6pm Monday to Friday

Legal line
0300 466 6463
9am - 6pm Monday to Friday
England and Wales



info@mind.org.uk
legal@mind.org.uk



www.mind.org.uk

Inspire (Northern Ireland)

Inspire offer a range of services providing support to people with mental health problems in Northern Ireland.



Inspire
Central Office
Lombard House
10-20 Lombard Street
Belfast
BT1 1RD



0808 189 0036



www.inspirewellbeing.org

Cruse Bereavement Care

Cruse Bereavement Care offers support, advice and information to people when someone dies. They also provide training for those who may encounter bereaved people in the course of their work.

There is a freephone national helpline and local services, and a website specifically for children and young people.



Cruse Bereavement Care
One Victoria Villas
Richmond
TW9 2GW



0808 808 1677
(UK-wide except Scotland)
9:30am - 5pm Monday to Friday

0845 600 2227
(Scotland)
10am - 4pm Monday to Friday



info@cruse.org.uk



www.cruse.org.uk
www.hopeagain.org.uk
(for children and young people)

Relate

Relate is the UK's largest provider of support for people experiencing a range of relationships problems, providing counselling and therapy over the phone, online and in person. They charge for some of their services.



Relate
Premier House
Carolina Court
Lakeside
Doncaster
DN4 5RA



0300 003 0396



relate.enquiries@relate.org.uk



www.relate.org.uk

Samaritans

You can contact the Samaritans at any time about anything that's troubling you, no matter how small, including:

- loss of a friend or a family member through bereavement
- financial worries
- loneliness and isolation
- depression
- painful or disabling physical illness.



Samaritans
The Upper Mill
Kingston Road
Ewell
Surrey
KT17 2AF



116 123
(UK-wide)
24 hours, seven days a week



jo@samaritans.org



www.samaritans.org

Organisations for carers

The organisations in this section offer help and advice on finding and paying for care, legal and financial information and support for carers, including replacement care (respite care).

Carers Direct

Carers Direct provides a confidential national helpline service for carers, providing information and advice. This service is part of the NHS.



0300 123 1053

(England)

9am - 8pm Monday to Friday

11am - 4pm Saturday and Sunday



CarersDirect@nhschoices.nhs.uk



**[carersdirectenquiry.serco.com/visitor/
EntryPage.html](https://carersdirectenquiry.serco.com/visitor/EntryPage.html)**



**[www.nhs.uk/conditions/social-care-and-
support-guide/](https://www.nhs.uk/conditions/social-care-and-support-guide/)**

tide (together in dementia everyday)

Tide provides support for dementia carers and past carers, providing a carer development programme, an opportunity to join up with other carers and also champion the rights of carers within the UK.



carers@tide.uk.net



www.tide.uk.net

Join the tide carers network online here
www.tide.uk.net/join-our-network

Carers UK

Carers UK provides advice and information to carers, including advice on benefits and accessing care and support. This is available through the website, booklets, factsheets and Carers UK's Adviceline.



Carers UK
 20 Great Dover Street
 London
 SE1 4LX



0808 808 7777
 (UK-wide)
 9am - 6pm Monday to Friday



advice@carersuk.org



www.carersuk.org

Care Information Scotland

Care Information Scotland offers information about care services for people in Scotland. This service is funded by the Scottish government and run by NHS 24. The website includes a 'Find my council' section so you can locate services local to you.



0800 011 3200

(Scotland)

9am - 5pm Monday to Friday



www.careinfoscotland.scot

Support for young carers

There are a number of websites providing help and advice for young carers. These include:



Young carers hub (NHS Choices)

www.nhs.uk/carersdirect/young/Pages/Youngcarershome.aspx

Young carers (Barnardos)

www.barnardos.org.uk/what_we_do/our_work/young_carers.html

Include programme (Children's Society)

www.childrenssociety.org.uk/youngcarer/home



Action for Children

0300 123 2112

9am - 5pm Monday to Friday



www.actionforchildren.org.uk/our-work-and-impact/children-and-families/young-carers/

Organisations for older people

Age UK

Age UK offers information and advice, support services, products and training for older people. They provide local services including information, advice and advocacy services; day centres and lunch clubs; home help and 'handyperson' schemes; and IT and other training. Their helplines can provide information, support and advice on how to access such services.



Age UK, Floor 7
One America Square
17 Crosswall
London EC3N 2LB



0800 678 1602 (Age UK)
8am - 7pm, every day

0800 022 3444 (Age Cymru)

0808 808 7575 (Age NI)

0800 124 4222 (Age Scotland)
9am - 5pm Monday to Friday



contact@ageuk.org.uk



www.ageuk.org.uk

Independent Age

Independent Age provides information and advice for older people, their families and carers. They focus on providing advice about social care and support, healthcare, mobility issues, money and benefits.

The helpline can give advice on accessing home care, care homes, NHS services and housing.



Independent Age
18 Avonmore Road
London
W14 8RR



0800 319 6789
(UK-wide)
8.30am - 6.30pm Monday to Friday



advice@independentage.org



www.independentage.org

The Silver Line

The Silver Line offers confidential telephone support for older people including emotional support, information, advice and friendship schemes.



The Silver Line Helpline 7th Floor
One America Square
17 Crosswall
London EC3N 2LB



0800 470 8090
(UK-wide)
24 hours a day, 365 days a year



info@thesilverline.org.uk



www.thesilverline.org.uk



Organisations that
can help with
accommodation,
housing, and care
homes

The Elderly Accommodation Counsel

The Elderly Accommodation Counsel helps older people make choices about housing and care. They run the FirstStop Advice service. This offers advice and information to older people, their families and carers about housing and care options.



Elderly Accommodation Counsel
Suite A
202 Lambeth Road
London
SE1 7TP



0800 377 7070
(UK-wide)
8am - 7pm Monday
8am - 6pm Tuesday to Friday



info@firststopcareadvice.org.uk



www.firststopcareadvice.org.uk

Relatives and Residents Association

The Relatives and Residents Association provides information and support to family and friends helping their loved ones to move into a residential home. They can also give advice if you have concerns about care in a residential home.



Unit 6
Aztec Row
1 Berners Road
London
N1 0PW



0207 359 8136
(UK-wide)
9:30am - 1pm Monday to Friday



info@relres.org



www.relres.org

Help finding care providers

Help finding care providers

There are a large number of care providers. Some agencies will offer care through the local council, as well as privately.

A good place to start looking for services is through the Care Quality Commission (CQC). They are the regulator for health and social care services in England. There are equivalent regulators in the other countries of the UK.

They publish reports on care homes and care services in the home (domiciliary care), that highlight the quality of care provided. You can search for local care services on their websites.

**Care Quality Commission (CQC)**

Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

**0300 061 6161****enquiries@cqc.org.uk****www.cqc.org.uk****Care Inspectorate Wales (CIW)**

Welsh Government Office
Sarn Mynach
Llandudno Junction
LL31 9RZ

**0300 790 0126****ciw@gov.wales****www.careinspectorate.wales****RQIA (Northern Ireland)**

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

**02895 361 111****info@rqia.org.uk****www.rqia.org.uk****Care Inspectorate (Scotland)**

Compass House
11 Riverside Drive
Dundee
DD1 4NY

**0345 600 9527****enquiries@careinspectorate.gov.scot****www.careinspectorate.com**

Legal and financial information and advice

Citizens Advice

You can search on the main website for your nearest Citizens Advice, or call one of the numbers below for details. Local branches should also be listed in your phone book and online. The website provides advice on a wide range of subjects including finance, benefits, legal rights and healthcare.



3rd Floor North
200 Aldersgate Street
London
EC1A 4HD



0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

For Northern Ireland, phonelines are regional, please see website for more information



www.citizensadvice.org.uk

Office of the Public Guardian (OPG)

The Office of the Public Guardian is a government body that is responsible for protecting people living in England and Wales who lack the mental capacity to make decisions. There are different government departments for Northern Ireland and Scotland (see page 41).

The OPG is also responsible for registering Lasting Powers of Attorney (LPA) and can be contacted for any information about LPA and the application process. You can also report concerns about an attorney or deputy to the OPG.



Office of the Public Guardian
PO Box 16185
Birmingham
B2 2WH



0300 456 0300



customerservices@publicguardian.gsi.gov.uk



www.gov.uk/government/organisations/office-of-the-public-guardian

Court of Protection (COP)

The COP (England and Wales) appoints and supervises deputyships for people who no longer have the mental capacity to appoint an attorney for themselves.



Court of Protection
PO Box 70185
First Avenue House
42-49 High Holborn
WC1A 9JA



0300 456 4600



courtofprotectionenquiries@justice.gov.uk



www.gov.uk/courts-tribunals/court-of-protection

Solicitors for the Elderly (SFE)



Department of Justice
Block B
Castle Buildings
Stormont Estate
Belfast
Northern Ireland
BT4 3SG



0300 200 7812



OCP@courtsni.gov.uk

Office of the Public Guardian (Scotland)



The Office of the Public Guardian
Hadrian House
Callendar Business Park
Callendar Road
Falkirk
FK1 1XR



01324 678 398



OPG@scotcourts.gov.uk

Office of Care and Protection (Northern Ireland)

SFE is an independent organisation of lawyers and solicitors who specialise in areas of law concerning later life issues, including making wills, living wills, powers of attorney, managing assets and funding care.



SFE Administrator
Aston House
Cornwall Avenue
London
N3 1LF



0844 567 6173



www.sfe.legal

Society of Later Life Advisers (SOLLA)

SOLLA puts people in contact with accredited financial advisers with expertise in later life financial needs.



Society of Later Life Advisers
PO Box 590
Sittingbourne
Kent
ME10 9EW



0333 202 0454



admin@societyoflaterlifeadvisers.co.uk



www.societyoflaterlifeadvisers.co.uk

Beacon CHC

Beacon provides advice for people who are applying for NHS continuing healthcare funding, a type of funding where the NHS pays for a person's social care package. There are lots of resources on Beacon's website that can help, and they also provide up to 90 minutes of free telephone advice (after which fees apply).



Beacon
10 Napier Court
Barton Lane
Abingdon
Oxfordshire
OX14 3YT



0345 548 0300



www.beaconchc.co.uk

Shelter

Shelter offers legal services, support and advice to anyone experiencing housing issues or facing homelessness.



0808 800 4444

8am - 8pm Monday to Friday



www.shelter.org.uk

ACAS

ACAS provides independent advice and information on rights in the workplace, including advice for people with illnesses and disabilities and carers who are in work, who may need extra support from their employer, need to take leave, reduce hours, or consider their options in regards to leaving work.



0300 123 1100

8am - 6pm Monday to Friday



www.acas.org.uk

Advice UK

An online hub signposting to organisations advising on benefits, legal matters, financial and other issues.



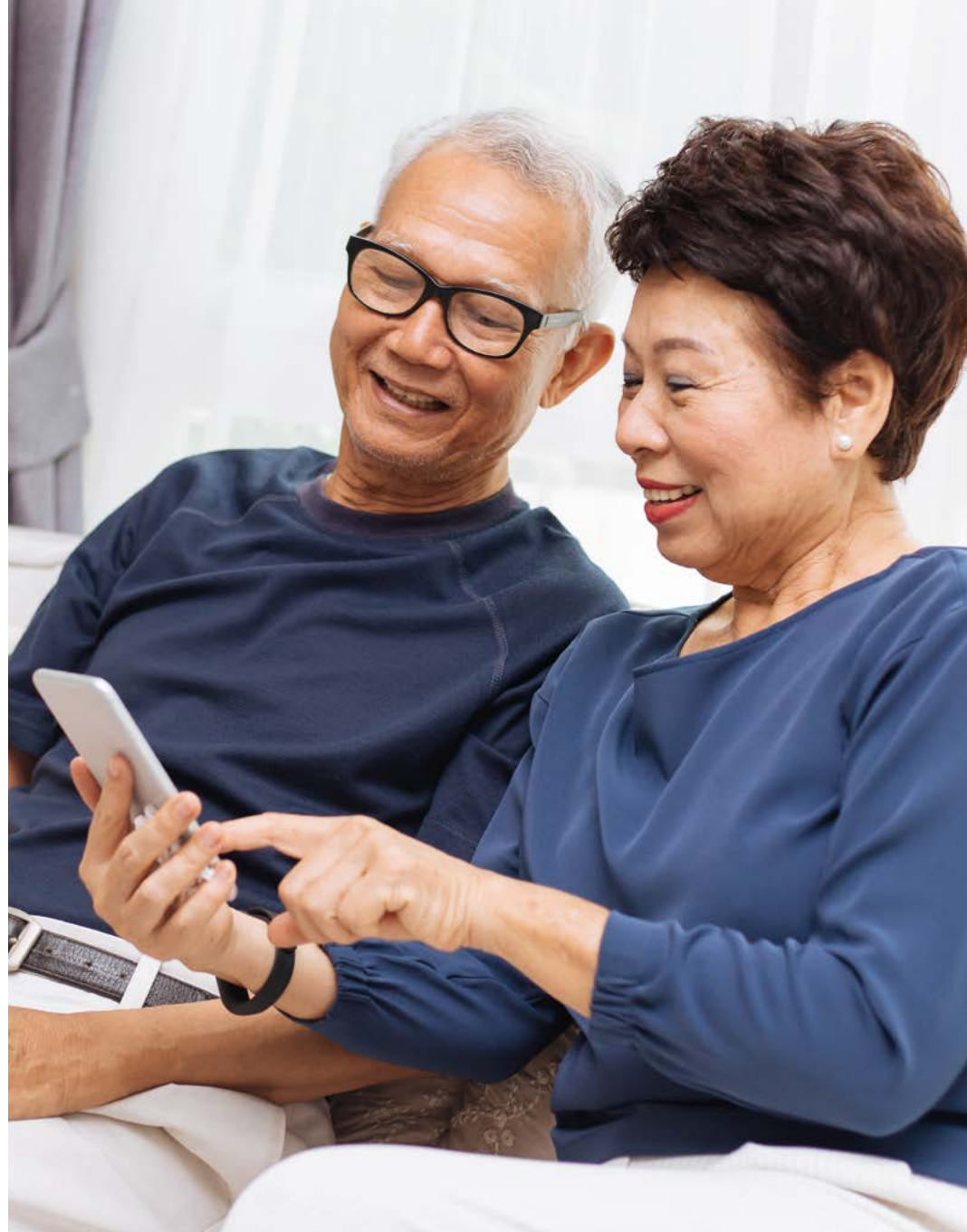
www.adviceuk.org.uk

LawWorks

Connects volunteer lawyers with people in need of legal advice who are not eligible for legal aid and cannot afford to pay.



www.lawworks.org.uk



Other useful contacts

British Red Cross - can help people following a stay in hospital by providing extra support and care at home.



0808 196 3651

10am - 6pm everyday



www.redcross.org.uk

Disabled Living Foundation - advises on daily living aids and assistive technology for people with disabilities including those caused by dementia.



0300 999 0004

10am - 4pm Monday to Friday



www.dlf.org.uk

Tourism for all - helps to make travelling and tourism (both abroad and within the UK) accessible for everyone regardless of illness or disability.



0845 124 9971

10am - 4pm Monday to Friday



www.tourismforall.org.uk

About us

Alzheimer's Research UK is the UK's leading dementia research charity funding world-class research to find ways to prevent, diagnose and treat dementia. Since the charity was founded in 1992 we have funded over £159 million of research.

We strive to raise awareness and increase understanding of the diseases that cause dementia. **Join Dementia Research** is a service that provides opportunities for people with and without dementia to get involved in vital research studies. To find out more visit www.joindementiaresearch.nihr.ac.uk

There are many ways you can help us to make progress. These include making a donation to help fund our research, volunteering to help at our events or sharing your story to raise awareness of dementia. If you would like to find out more about how you can help our contact details are on the back of this booklet.



Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

We provide free dementia health information, like this booklet and others. If you would like to view, download or order any of our other booklets please details below.

Contact us

0300 111 5 111

infoline@alzheimersresearchuk.org

Alzheimer's Research UK
3 Riverside, Granta Park, Cambridge CB21 6AD

Visit

www.alzheimersresearchuk.org/dementia-information

Or scan the QR code



**Alzheimer's
Research
UK**