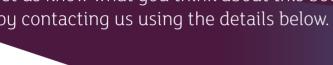
We are the UK's leading charity powering life-changing breakthroughs in dementia research.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.





Contact us

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



Supporter care

T: 0300 111 5555

E: enquiries@alzheimersresearchuk.org



Dementia Research Infoline

T: 0300 111 5 111

E: infoline@alzheimersresearchuk.org

www.alzheimersresearchuk.org



Registered charity number 1077089 and SC042474



This booklet was printed with support from The Perfume Shop who had no input into the content of the booklet.



Support for people affected by dementia:

Organisations that can help



Introduction

This booklet is for anyone affected by dementia, including carers, family and friends of people with the condition. This booklet provides contact details for organisations that provide care, support and/or advice for people with dementia, their carers and loved ones. There is also a description of the services each organisation provides.

These organisations can offer a range of services and advice, including:



Most organisations listed provide free services. However, there may be charges for some services. We have not listed commercial companies.

This booklet does not contain information on dementia symptoms, diagnosis or treatments. For information on these, please contact us for one of our free information booklets.

This booklet was updated in July 2018. It is due to be reviewed in July 2020. Please get in touch if you'd like a version with references or in a different format.

Contents

04

What is dementia?	05
Who is a carer?	06
Caring for someone with dementia	07
Finding local support	08
Sources of support – dementia-specific organisations	11
Sources of support for people with specific forms of dementia	18
Organisations for carers	23
Organisations for older people	28
Organisations that can help with accommodation, housing and care homes	32
Help finding care providers	
Legal and financial information and advice	
Emotional support and mental health	45
Other useful contacts	51
About us	53

What is dementia?

Dementia is not a disease itself, but a word used to describe a group of symptoms.

These can include:



The gradual 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, covering symptoms, diagnosis and treatment.

Contact us if you'd like to know more.

Who is a carer?

A carer is anybody who provides care or support 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. All the care they give is 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 this happens.

Care workers, support workers and personal assistants are different from carers. These 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 care or support for someone with dementia may experience a range of different feelings.

Caring for someone can be rewarding; a person may be supporting someone they 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 support for everyone affected by dementia, including carers. People affected by dementia may have many questions, worries and concerns. The organisations listed in this booklet can help by answering those questions and providing support and information.



Finding local support

Your GP 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 singing groups.

National and local charities can provide advice and can 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.

Help from your local council, authority or trust

08

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. 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

adaptations and equipment

help with personal care

access to day centres

residential or respite/replacement care.

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. Visit www.nhs.uk for details of GP surgeries and hospitals in your area.



Sources of support – dementia-specific organisations

Alzheimer's Research UK

Alzheimer's Research UK offers free information on dementia. This includes information about Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. We have information on symptoms, diagnosis, treatments and reducing your risk of developing dementia. We also run the **Dementia Research Infoline**, which can answer your questions about dementia research and help you to get involved in dementia research studies across the UK.



Alzheimer's Research UK 3 Riverside

Granta Park

Cambridge

CB21 6AD



0300 111 5333



enquiries@alzheimersresearchuk.org



www.alzheimersresearchuk.org www.dementiaexplained.org (for children and young people)

Dementia Research Infoline: **0300 111 5 111** or email **infoline@alzheimersresearchuk.org**

- 9am 5pm Monday to Friday
- UK-wide

Alzheimer's Society

Alzheimer's Society provides practical advice and emotional support for anyone affected by dementia. They have local groups around the country offering different activities and they also have dementia advisers providing practical advice. Their **National Dementia Helpline** offers information, support, guidance and signposting to other organisations.



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



0330 333 0804



enquiries@alzheimers.org.uk



www.alzheimers.org.uk

Helpline: **0300 222 11 22** or email **helpline@alzheimers.org.uk**

- 9am 8pm Monday to Wednesday
 9am 5pm Thursday and Friday
 10am 4pm Saturday and Sunday
- A Live Online Advice service is available on the website at various times each day.
- England, Wales and Northern Ireland

Alzheimer Scotland

Alzheimer Scotland provides personalised support services, community activities, information and advice. The Scottish **Dementia Helpline** is open 24 hours a day.



Alzheimer Scotland 160 Dundee Street Edinburgh EH11 1D0



0131 243 1453



info@alzscot.org



www.alzscot.org

Helpline: 0808 808 3000

or email helpline@alzscot.org

- 24 hours, seven days a week
- Scotland

Wales Dementia Helpline

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

Helpline: 0808 808 2235

Website: www.dementiahelpline.org.uk

- 24 hours, seven days a week
- Wales

14

Dementia NI

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



Dementia NI 54 Elmwood Avenue Belfast BT9 6AZ



02890 686 768



info@dementiani.org

AT Dementia

This website has information about assistive technology for people with dementia. Assistive technology can be any device or system that helps someone perform a task. This includes devices like calendar clocks, automatic lighting and fall sensors.



www. at dement ia. or g. uk

Dementia UK

Dementia UK provides mental health nurses who specialise in dementia, called Admiral Nurses. They provide practical and emotional support to families affected by dementia. They can also provide advice on referrals to appropriate services and liaise with other healthcare professionals on your behalf. To find out if Admiral Nurses are available in your area, you can call their helpline.

The **Admiral Nurse Dementia Helpline** gives advice and information about dementia. This is for carers, people with dementia and those worried about their memoru.



Dementia UK 2nd Floor 356 Holloway Road London N7 6PA







Helpline: **0800 888 6678** or email **helpline@dementiauk.org**

9am - 9pm weekdays9am - 5pm weekends

• UK-wide

Guideposts

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



Guideposts

Willow Tree House

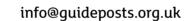
Station Lane

Witney

Oxfordshire

OX28 4BH







www.guideposts.org.uk

Sources of support for people with specific forms of dementia

The Lewy Body Society Parkinson's UK

Both organisations offer support and information about dementia with Lewy bodies (DLB). As well as supporting people with Parkinson's disease, Parkinson's UK can also help with questions about Parkinson's dementia. They also provide care and benefits advice, and they have Parkinson's disease specialist nurses who provide medical advice.



Lewy Body Society

Hudson House 8 Albany St Edinburgh EH1 3QB



Parkinson's UK

215 Vauxhall Bridge Road London SW1E 1VJ



0131 473 2385



020 7931 8080



info@lewybody.org



hello@parkinsons.org.uk



www.lewybody.org

www.parkinsons.org.uk

Helpline: **0808 800 0303** or email **hello@parkinsons.org.uk**

- 9am 7pm Monday to Friday 10am - 2pm Saturday
- UK-wide

The PSP Association

The PSP Association helps people with progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD). It offers advice, support and information to people living with these conditions.



The PSP Association

PSP House

167 Watling Street West

Towcester

Northamptonshire

NN12 6BX



01327 322410



psp@pspassociation.org.uk



www.pspassociation.org.uk

Helpline: 0300 0110 122 or email helpline@pspassociation.org.uk

- 9am 5pm and 7pm 9pm Monday to Friday
- UK-wide

Rare Dementia Support

Rare Dementia Support runs specialist support services for people living with, or affected by, five rare dementias. For support and help regarding a diagnosis call:

- frontotemporal dementia (FTD) 07341 776 317
- posterior cortical atrophy (PCA) 07388 220 324
- primary progressive aphasia (PPA) 07388 220 355
- familial Alzheimer's disease (FAD) 07388 220 323
- familial frontotemporal dementia (fFTD) 07592 540 555

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

contact@raredementiasupport.org

For support groups contact Laura King: laura.king@ucl.ac.uk

www.raredementiasupport.org

20

Support for people with specific forms of dementia

YoungDementia UK

YoungDementia UK gives information, advice and support for people under 65 diagnosed with dementia, their family and friends.



YoungDementia UK PO Box 315 Witney Oxfordshire OX28 1ZN



01865 794311



support@youngdementiauk.org



www.youngdementiauk.org

Organisations for carers

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

Carers Direct

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



0300 123 1053



www.nhs.uk/carersdirect

Helpline: 0300 123 1053

Website: www.nhs.uk/carersdirect

- 9am 8pm Monday to Friday
 11am 4pm Saturday and Sunday
- A webchat service is available on the website during the same hours.
- England

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



020 7378 4999 (Carers UK)
02920 811 370 (Carers Wales)
0141 445 3070 (Carers Scotland)
02890 439 843 (Carers Northern Ireland)



info@carersuk.org



www.carersuk.org

Helpline: **0808 808 7777** or email: **info@carersuk.org**

- 10am 4pm Monday to Friday
- UK-wide

Carers Trust

Carers Trust, previously The Princess Royal Trust for Carers and Crossroads Care, provides access to breaks for carers, information and advice, training and employment opportunities.



Carers Trust 32-36 Loman Street London SE1 0EH



0300 772 9600 (Carers Trust UK) **02920 090 087** (Carers Trust Wales) **0300 772 7701** (Carers Trust Scotland)



info@carers.org



www.carers.org

Care Information Scotland

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

Helpline: 0800 011 3200

Website: www.careinfoscotland.scot

- 8am 10pm Monday to Friday9am 5pm Saturday and Sunday
- Scotland

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



Include programme (Children's Society)

www.childrenssociety.org.uk/youngcarer/home

Action for Children



www.actionforchildren.org.uk/what-we-do/supportfor-young-people/supporting-young-carers



01923 361 500

• 9am - 5pm Monday to Friday

Organisations for older people

Age UK

Age UK offers information and advice, services, products and training for older people. Local services can include: information, advice and advocacy services; day centres and lunch clubs; home help and 'handyperson' schemes; and IT and other training. The helplines can provide information and advice on all of these.



Tavis House 1-6 Tavistock Square London WC1H 9NA



0333 32 32 400 (Age Scotland)





Helplines:

0800 169 2081 (England) 8am - 7pm, every day
0800 022 3444 (Wales) 9am - 5pm Monday to Friday
0808 808 7575 (NI) 9am - 4.45pm Monday to Friday
0800 12 44 222 (Scotland) 9am - 5pm Monday to Friday

28

Independent Age

Independent Age provides information and advice for older people, their families and carers. They focus on advice regarding social care and support, healthcare, mobility issues, money and benefits. The helpline can give advice on home care, care homes, NHS services and housing.



Independent Age 18 Avonmore Road London W14 8RR



020 7605 4200



charity@independentage.org



www.independentage.org

Helpline: **0800 319 6789** or email **advice@independentage.org**

- 8.30am 6.30pm Monday to Friday 9am - 1pm Saturday
- UK-wide

30

The Silver Line

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



The Silver Line Trade Tower Calico Row London

SW11 3YH



020 7224 2020



info@thesilverline.org.uk



www.thesilverline.org.uk

Helpline: 0800 4 70 80 90

- 24 hours a day, 365 days a year
- UK-wide

Organisations
that can help with
accommodation,
housing and care
homes

Relatives and Residents Association

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



Relatives and Residents Association

1 The Ivories

6-18 Northampton Street

London

N1 2HY



0207 359 8148



info@relres.org



www.relres.org

Helpline: **0207 359 8136** or email **info@relres.org**

- 9.30am 4.30pm Monday to Friday
- UK-wide

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 3rd Floor 89 Albert Embankment London SE1 7TP



0207 820 1322



info@firststopcareadvice.org.uk



www.firststopcareadvice.org.uk

Helpline: 0800 377 7070

or email info@firststopcareadvice.org.uk

- 8am 7pm Mondau 8am - 6pm Tuesday to Friday
- UK-wide

Help finding care providers

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

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.

Commercial care providers

Care Quality Commission (cQC)



Care Quality Commission (CQC)

Citygate

Gallowgate

Newcastle upon Tyne

NE1 4PA



03000 616161



enquiries@cqc.org.uk



www.cqc.orq.uk

Care and Social Services Inspectorate Wales (CSSIW)



Care and Social Services Inspectorate Wales (CSSIW)

Welsh Government Office Rhydycar Business Park

Merthyr Tydfil

CF48 1UZ



0300 790 0126



cssiw@wales.gsi.gov.uk



www.cssiw.org.uk

Regulation and Quality Improvement Authority (RQIA)



Regulation and Quality Improvement Authority (RQIA)

9th Floor Riverside Tower

5 Lanyon Place

Belfast

BT1 3BT



028 9536 1111



info@rqia.orq.uk



www.rqia.org.uk

Care Inspectorate



Care Inspectorate

Compass House

11 Riverside Drive

Dundee

DD1 4NY



0345 600 9527



enquiries@careinspectorate.com



www.scswis.com

Legal and financial information and advice

38

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. 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



03444 111 444 (England/Northern Ireland)

03444 77 20 20 (Wales)

0808 800 9060 (Scotland)



www.citizens advice.org.uk

(England, Wales, Northern Ireland)

www.cas.org.uk (Scotland)

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).

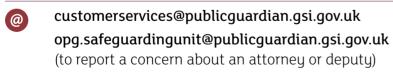
The OPG is also responsible for registering Lasting Powers of Attorney (LPA) and can be contacted for any information about LPA and the application process.

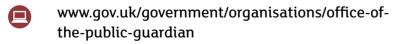
You can also report concerns about an attorney or deputy to the OPG.



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







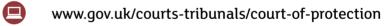
Court of Protection (COP)

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







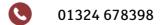


Office of Care and Protection (Northern Ireland)

0	0300 200	7812



Office of the Public Guardian (Scotland)





40

Solicitors for the Elderly (SFE)

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

Studio 209

Mill Studio Business Centre

Crane Mead, Ware

Hertfordshire SG12 9PY



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 2020 454



admin@societyoflaterlifeadvisers.co.uk



www. society of later life advisers. 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.



Helpline: 0808 800 4444

8am - 8pm Monday to Friday

9am - 5pm Saturday and Sunday



Emergency helpline: 0808 1644 660



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 regard to leaving work.



Helpline: 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

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

Emotional support and mental health

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.



15-19 Broadway Stratford London E15 4B0



020 8519 2122



supporterrelations@mind.org.uk



www.mind.org.uk

Mind Infoline: 0300 123 3393 or email info@mind.orq.uk

- 9am 6pm Monday to Friday
- England and Wales

Legal line: 0300 466 6463 or email legal@mind.org.uk

- 9am 6pm Monday to Friday
- England and Wales

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



0141 530 1000



www.samh.org.uk

Inspire (Northern Ireland)

Inspire offers 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



028 9032 8474



www.inspirewellbeing.org

47

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

PO Box 800

Richmond

Surrey TW9 1RG



020 8939 9530



info@cruse.orq.uk



www.cruse.org.uk www.hopeagain.org.uk

(for children and young people)

Helplines: 0808 808 1677

- 9.30am 5pm Monday and Friday (excluding bank holidays)
- 9.30am 8pm Tuesday to Thursday
- England, Wales, Northern Ireland

0845 600 2227

- 10am 8pm Monday to Wednesday
- 10am 9pm Thursday 10am 4pm Friday
- 12pm 3pm Saturday
- Scotland

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



020 8394 8300



admin@samaritans.org



www.samaritans.org

Helpline: 116 123

or email jo@samaritans.org

- 24 hours, seven days a week
- UK-wide

Relate

Relate is the UK's largest provider of support for people experiencing a range of relationship 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 00 30 396



relate.enquiries@relate.org.uk



www.relate.org.uk

Other useful contacts

Other useful contacts

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



0344 871 11 11



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 00004



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



www.tourismforall.org.uk

About us

Alzheimer's Research UK is the UK's leading dementia research charity funding world-class research to prevent, treat and cure dementia.

We help people to understand dementia and the progress we are making, as well as providing an opportunity for people with dementia and their carers to get involved in research.

There are many ways you can help us to make progress faster. These include making a donation towards our pioneering 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 us make breakthroughs possible, contact us – our contact details are on the back of this booklet.

