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 5111
E: infoline@alzheimersresearchuk.org

www.alzheimersresearchuk.org

Registered charity number 1077089 and SC042474
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:

- **practical care and support**
- **medical advice**
- **emotional support**
- **legal advice**
- **housing advice**
- **financial advice**

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

This booklet does not contain information on dementia symptoms, diagnosis or treatments. For information about dementia, please contact us on **0300 111 5111**. You can ask us questions over the phone or ask for our free information booklets.

This booklet was updated in July 2020. It is due to be reviewed in July 2022. Please get in touch if you’d like a version with references or in a different format.
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 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. 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 someone becomes another person’s carer.

Care workers, support workers and personal assistants are different from unpaid 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; 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 everyone affected by dementia, including carers. Usually 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.
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 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 to 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

visit: www.alzheimersresearchuk.org

call: 0300 111 5 111
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, the latest 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 5555

enquiries@alzheimersresearchuk.org

www.alzheimersresearchuk.org

Dementia Research Infoline: 0300 111 5111
or email infoline@alzheimersresearchuk.org
• 9am - 5pm Monday to Friday

Alzheimer’s Society

Alzheimer’s Society provides practical care 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 Dementia Connect support service 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

Dementia Connect Helpline: 0333 150 3456
or email dementia.connect@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

visit: www.alzheimersresearchuk.org
Alzheimer Scotland

Alzheimer Scotland provide 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 1DQ

01312 431 453
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 living in Wales.

Helpline: 0808 808 2235
Website: www.dementiahelpline.org.uk
• 24 hours, seven days a week
• Wales

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
North City Business Centre
2 Duncairn Gardens
Belfast
BT15 2GG

02896 931 555
info@dementiani.org
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 memory.

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

Dementia UK

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

0300 365 5500
info@dementiauk.org
www.dementiauk.org

Helpline: 0800 888 6678
or email helpline@dementiauk.org
• 9am - 9pm weekdays
  9am - 5pm weekends
• UK-wide
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

visit: www.alzheimersresearchuk.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

0800 138 6593

hello@parkinsons.org.uk

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) 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

01327 322 410

info@pspassociation.org.uk

www.pspassociation.org.uk

Helpline: 0300 011 0122
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.
- frontotemporal dementia (FTD)
- posterior cortical atrophy (PCA)
- primary progressive aphasia (PPA)
- familial Alzheimer’s disease (FAD)
- familial frontotemporal dementia (fFTD)

For support and help regarding a diagnosis contact: 07388 220355 or 07341 776317.
Your enquiry will be passed onto an appropriate specialist advisor.

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

contact@raredementiasupport.org
For support groups contact
Roberta Mackee-Jackson:
rmckee-jackson@ucl.ac.uk
www.raredementiasupport.org

YoungDementia UK

YoungDementia UK provides information, advice and support for people under 65 who are diagnosed with dementia. The service also provides support to their family and friends.

YoungDementia UK
PO Box 315
Witney
Oxfordshire
OX28 1ZN

01865 794 311
web@youngdementiauk.org
www.youngdementiauk.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
- CarersDirect@nhschoices.nhs.uk

Helpline: 0300 123 1053
Website:
www.nhs.uk/conditions/social-care-and-support-guide/

- 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

0207 378 4999 (Carers UK)
0292 081 1370 (Carers Wales)
0141 445 3070 (Carers Scotland)
0289 043 9843 (Carers Northern Ireland)

info@carersuk.org
www.carersuk.org

Helpline: 0808 808 7777
or email: advice@carersuk.org
• 9am - 6pm 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
Unit 101
164-180 Union Street
London SE1 0LH

0300 772 9600 (Carers Trust UK)
0300 772 9702 (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 so you can locate services local to you.

Care Information Scotland

Helpline: 0800 011 3200
Website: www.careinfo.scot
• 8am - 10pm Monday to Friday
  9am - 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/helping-families/young-carers

- Include programme (Children’s Society)
  www.childrenssociety.org.uk/youngcarer/home

Action for Children

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

0300 123 2112
• 9am - 5pm Monday to Friday
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.

Tavis House
1-6 Tavistock Square
London
WC1H 9NA

0800 055 6112 (Age UK)
contact@ageuk.org.uk
www.ageuk.org.uk

Helplines:
0800 055 6112 (UK wide)
• 8am - 7pm Every day
0800 022 3444 (Wales)
• 9am - 5pm Monday to Friday
0808 808 7575 (NI)
• 9am – 5pm Monday to Friday
0800 124 4222 (Scotland)
• 9am - 5pm Monday to Friday

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

0207 605 4200
charity@independentage.org
www.independentage.org

Helpline: 0800 319 6789
or email advice@independentage.org
• 8.30am - 6.30pm Monday to Friday
• UK-wide
The Silver Line

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

Tavis House
1-6 Tavistock Square
London
WC1H 9NA

0207 224 2020
info@thesilverline.org.uk
www.thesilverline.org.uk

Helpline: 0800 470 8090
• 24 hours a day, 365 days a year
• UK-wide
### 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.

- **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 – 1pm 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**
  
  Suite A  
  202 Lambeth Road  
  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 Monday
  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 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.
Regulation and Quality Improvement Authority (RQIA)

Regulation and Quality Improvement Authority (RQIA)
9th Floor Riverside Tower
5 Lanyon Place
Belfast
BT1 3BT

0289 563 1111
info@rqia.org.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
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

0344 411 1444 (England/Northern Ireland)
0344 477 2020 (Wales)
0800 028 1456 (Scotland)

www.citizensadvice.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

0300 456 0300

customerservices@publicguardian.gsi.gov.uk
opg.safeguardingunit@publicguardian.gsi.gov.uk
(to report a concern about an attorney or deputy)

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 0300
courtofprotectionenquiries@justice.gov.uk
www.gov.uk/courts-tribunals/court-of-protection

Office of Care and Protection (Northern Ireland)

0300 200 7812
OCP@courtsni.gov.uk

Office of the Public Guardian (Scotland)

01324 678398
OPG@scotcourts.gov.uk

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 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.

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 regards 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 4BQ

0208 519 2122

supporterrelations@mind.org.uk

www.mind.org.uk

Mind Infoline: 0300 123 3393
or email info@mind.org.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
Glasgow G1 1UZ

0344 800 0550
9am - 6pm Monday to Friday

www.samh.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

0289 032 8475

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
PO Box 800
Richmond
Surrey TW9 1RG

0808 808 1677

info@cruse.org.uk

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

0208 394 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 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
Other useful contacts

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

- **Telephone:** 0344 871 1111
- **Website:** www.redcross.org.uk

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

- **Telephone:** 0300 999 0004
- **Website:** 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.

- **Telephone:** 0845 124 9971
- **Website:** 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 £136 million of research.

We strive to raise awareness and increase understanding of the diseases that cause dementia. Through our partnership with the Join Dementia Research service, we provide opportunities for people with and without dementia to get involved in vital research studies.

There are many ways you can help us to make progress. These include making a donation to help fund our breakthrough 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.

Find out more

If you have questions about dementia, dementia research or want to volunteer to take part in studies, contact our Dementia Research Infoline on 0300 111 5111 or email infoline@alzheimersresearchuk.org

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages.