We are the UK’s leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

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

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

Registered charity number 1077089 and SC042474
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
- emotional support
- housing advice
- medical advice
- legal advice
- financial advice

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.
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

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

visit: www.alzheimersresearchuk.org

call: 0300 111 5 111
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 1DQ

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

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.atdementia.org.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 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 893560
info@guideposts.org.uk
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
info@lewybody.org
www.lewybody.org

020 7931 8080
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). 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:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>frontotemporal dementia (FTD)</td>
<td>07341 776 317</td>
</tr>
<tr>
<td>posterior cortical atrophy (PCA)</td>
<td>07388 220 324</td>
</tr>
<tr>
<td>primary progressive aphasia (PPA)</td>
<td>07388 220 355</td>
</tr>
<tr>
<td>familial Alzheimer’s disease (FAD)</td>
<td>07388 220 323</td>
</tr>
<tr>
<td>familial frontotemporal dementia (fFTD)</td>
<td>07592 540 555</td>
</tr>
</tbody>
</table>

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

Contact: **contact@raredementiasupport.org**

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

www.raredementiasupport.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.

**YoungDementia UK**

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

- **Email**: YoungDementia UK
  PO Box 315
  Witney
  Oxfordshire
  OX28 1ZN
- **Phone**: 01865 794311
- **Email**: support@youngdementiauk.org
- **Website**: www.youngdementiauk.org
<table>
<thead>
<tr>
<th>Organisations for carers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carers Direct</strong></td>
<td><strong>Carers UK</strong></td>
</tr>
<tr>
<td>Carers Direct has a national helpline service for carers, providing confidential information and advice. This service is part of the NHS.</td>
<td>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.</td>
</tr>
</tbody>
</table>
| **Helpline:** 0300 123 1053 | **Carers UK**  
20 Great Dover Street  
London  
SE1 4LX  
**Helpline:** 0808 808 7777  
or email: info@carersuk.org  
• 10am - 4pm Monday to Friday  
• UK-wide |
| **Website:** www.nhs.uk/carersdirect |  |
| * England |  |
|  |
|  |
|  |  |
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](http://www.nhs.uk/carersdirect/young/Pages/Youngcarershome.aspx)

- **Young carers (Barnardos)**
  [www.barnardos.org.uk/what_we_do/our_work/young_carers](http://www.barnardos.org.uk/what_we_do/our_work/young_carers)

- **Include programme (Children’s Society)**
  [www.childrenssociety.org.uk/youngcarer/home](http://www.childrenssociety.org.uk/youngcarer/home)

- **Action for Children**
  [www.actionforchildren.org.uk/what-we-do/support-for-young-people/supporting-young-carers](http://www.actionforchildren.org.uk/what-we-do/support-for-young-people/supporting-young-carers)

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Organisations for carers

**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](http://www.careinfoscotland.scot)
  - 8am - 10pm Monday to Friday
  - 9am - 5pm Saturday and Sunday
  - Scotland
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

0800 055 6112 (Age UK)
02920 431 555 (Age Cymru)
02890 245 729 (Age NI)
0333 32 32 400 (Age Scotland)

contact@ageuk.org.uk
www.ageuk.org.uk

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
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

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

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)

Care Quality Commission (CQC)
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

0300 616 161
enquiries@cqc.org.uk
www.cqc.org.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.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.scsswis.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

- **03444 111 444** (England/Northern Ireland)
- **03444 77 20 20** (Wales)
- **0808 800 9060** (Scotland)

- [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) (England, Wales, Northern Ireland)
- [www.cas.org.uk](http://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@hmcts.gsi.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 2020 454
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 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
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

020 8519 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

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
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.org.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**
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.