SUPPORT FOR PEOPLE AFFECTED BY DEMENTIA: organisations that can help
INTRODUCTION

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

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

This booklet was updated in January 2024 and is due for review in June 2026. It was written by Alzheimer’s Research UK’s Information Services team with input from lay and expert reviewers.

ANY QUESTIONS

This booklet does not contain detailed information on dementia symptoms, diagnosis or treatments. For more information, please visit our website, or contact us on 0300 111 5111 or infoline@alzheimersresearchuk.org.
WHAT IS DEMENTIA?

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

These symptoms may include:
- memory loss
- confusion
- language and communication problems
- issues with sight, mood and behaviour changes
- difficulty with day-to-day tasks.

Alzheimer’s disease is the most common disease that causes dementia, affecting over half a million 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 of our free dementia information.

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, known as informal carers, or paid professionals, known as formal carers.

Many carers feel they are doing what anyone else would do 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 an informal carer, and there is not always a clear-cut point when someone becomes another person’s carer.

Formal carers such as 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.

THERE IS NOT ALWAYS A CLEAR-CUT POINT WHEN SOMEONE BECOMES ANOTHER PERSON’S CARER.
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.

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.

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.

THERE IS A RANGE OF SUPPORT AVAILABLE FOR PEOPLE AFFECTED BY DEMENTIA, INCLUDING CARERS.

alzheimersresearchuk.org
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
- 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 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 nhs.uk

IN THE UK, YOUR LOCAL COUNCIL HAS A DUTY TO CARRY OUT A NEEDS ASSESSMENT FOR ANYONE WITH SUPPORT AND CARE NEEDS, AND THEIR CARER.
ALZHEIMER’S RESEARCH UK

Alzheimer’s Research UK 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.

0300 111 5 111
(9am-5pm weekdays) UK-wide

@ infoline@alzheimersresearchuk.org

alzheimersresearchuk.org
alzheimersresearchuk.org/kids
(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 help you find local dementia groups offering activities and support. They also provide legal and financial information about dementia care. Their Dementia Connect support service offers information, support, guidance and signposting to other organisations.

0333 150 3456 (England, Wales and Northern Ireland)
9am-8pm Mon-Wed, 9am-5pm Thurs-Fri
10am-4pm Sat-Sun

@dementia.connect@alzheimers.org.uk

alzheimers.org.uk
A live online advice service is available on the website at various times each day

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.

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

@ helpline@alzscot.org

alzscot.org
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.

@ info@lewybody.org
lewbody.org

PARKINSON’S UK

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

0808 800 0303 (UK-wide)
9am-6pm weekdays, 10-2 Saturday

@ hello@parkinsons.org.uk
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.

0300 0110 122 (UK-wide)
9am-5pm and 7pm-9pm weekdays

@ helpline@pspassociation.org.uk
pspassociation.org.uk

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.

@ contact@raredementiasupport.org
raredementiasupport.org

SOURCES OF SUPPORT FOR PEOPLE WITH SPECIFIC FORMS OF DEMENTIA

alzheimersresearchuk.org
SCOTTISH ASSOCIATION FOR MENTAL HEALTH

SAMH has over 60 services across Scotland providing mental health, addiction, homelessness and employment services. Alongside their free Helpline they also offer video calls via their virtual clinics service.

- **Infoline:** 0344 800 0550
  - 9am - 6pm weekdays
- **info@samh.org.uk**
- **samh.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
- suicidal thoughts or intentions.

- **116 123** (UK-wide)
  - 24 hours, seven days a week
- **jo@samaritans.org**
- **samaritans.org**

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.

- **Infoline:** 0300 123 3393
  - (9am-6pm weekdays, England and Wales)
- **Legal line:** 0300 466 6463
  - (9am-6pm weekdays, England and Wales)
- **Welfare benefits line:** 0300 222 5782
  - (9am-5pm weekdays)
- **info@mind.org.uk**
- **legal@mind.org.uk**
- **mind.org.uk**

**EMOTIONAL SUPPORT AND MENTAL HEALTH**

alzheimersresearchuk.org
RELATE

Relate provide 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.

Booking line: 0300 003 0396
relate.enquiries@relate.org.uk
relate.org.uk

MARIE CURIE

Marie Curie supports people living with a condition they’re likely to die from, and their family and friends. They also offer companionship and bereavement services, and expert nursing help.

0800 090 2309
(8am-6pm weekdays, 11am-5pm Saturday)
support@mariecurie.org.uk
mariecurie.org.uk
ORGANISATIONS FOR CARERS

The organisations in this section offer help and advice on finding and paying for care, legal and financial information about care 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 weekdays, 11am-4pm weekends

@ carersdirect@nhschoices.nhs.uk

nhs.uk/conditions/social-care-and-support-guide

Webchat: carersdirectenquiry.serco.com/visitor/EntryPage.htm
9am-8pm weekdays, 11am-4pm weekends

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.

Join the TIDE carers network online here

@ carers@tide.uk.net

carers@tide.uk.net

CARERS UK

Carers UK provides advice and information to carers, including advice on benefits and accessing care and support available through their website, booklets, factsheets and Carers UK’s Adviceline.

0808 808 7777 (UK-wide)
9am-6pm weekdays

@ advice@carersuk.org

@ carersuk.org

alzheimersresearchuk.org
CARERS TRUST

Carers Trust provides access to breaks for carers, information and advice, training and employment opportunities.

- 0300 772 9600 (Carers Trust UK)
- 0300 772 9702 (Carers Trust Wales)
- 0300 772 7701 (Carers Trust Scotland)

@ info@carers.org
carers.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 weekdays

@ careinformationscotland@nhs24.scot.nhs.uk
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)

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

Young carers (Barnados)

- barnardos.org.uk/what_we_do/our_work/young_carers.htm

Include programme (Children’s Society)

- childrenssociety.org.uk/youngcarer/home

Action for Children

- 0300 123 2112
  9am - 5pm weekdays

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.

0800 055 6112 (Age UK)
8am-7pm every day
029 2043 1555 (Age Cymru)
9am-4pm weekdays
0808 808 7575 (Age NI)
9am-5pm weekdays
0800 124 4222 (Age Scotland)
9am-5pm weekdays

@ contact@ageuk.org.uk
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.

0800 319 6789 (UK-wide)
8:30am-5:30pm weekdays
@ helpline@independentage.org
independentage.org

THE SILVER LINE

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

0800 470 8090 (UK-wide)
24 hours a day, 365 days a year
@ info@thesilverline.org.uk
thesilverline.org.uk
ORGANISATIONS
THAT CAN HELP WITH
ACCOMMODATION,
HOUSING, AND CARE
HOMES

CARE RIGHTS UK
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.

0207 359 8136 (UK-wide)
9:30am-1pm weekdays, 6pm-8pm Thursday
helpline@carerightsuk.org
carerightsuk.org

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.

0800 377 7070 (UK-wide)
8am-7pm Monday, 8am-6pm Tuesday-Friday
info@firststopcareadvice.org.uk
firststopcareadvice.org.uk
HELP FINDING CARE PROVIDERS

There are a large number of care providers. Some agencies will offer care through your 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, contact details are listed below. 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.

0300 061 6161 (England)
8:30am-5:30pm weekdays
@ enquiries@cqc.org.uk
@cqc.org.uk

0300 790 0126 (Wales)
@ ciw@gov.wales
@ careinspectorate.wales

028 9536 1111 (Northern Ireland)
info@rqia.org.uk
rqia.org

0345 600 9527 (Scotland)
enquiries@careinspectorate.gov.scot
careinspectorate.com
LEGAL AND FINANCIAL INFORMATION AND ADVICE

CITIZENS ADVICE

You can search their website for your nearest Citizens Advice centre, or call one of the numbers below for details. The website provides advice on a wide range of subjects including finance, benefits, legal rights and healthcare.

- 0800 144 8848 (England)
- 0800 702 2020 (Wales)
- 0800 028 1456 (Scotland)

For Northern Ireland, phone lines are regional. Please see website for more information.

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 their own decisions. There are different government departments for Northern Ireland and Scotland (see page 30).

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.

- 0300 456 0300 (England and Wales)
- customerservices@publicguardian.qsi.gov.uk
- 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.

- 0300 456 4600 (England and Wales)
- courtofprotectionenquiries@justice.gov.uk
- gov.uk/courts-tribunals/court-of-protection
OFFICE OF CARE AND PROTECTION (NORTHERN IRELAND)

0300 200 7812 (Northern Ireland)
7am-1pm Monday-Thursday

@ OCP@courtsni.gov.uk


OFFICE OF THE PUBLIC GUARDIAN (SCOTLAND)

01324 678 300 (Scotland)
9am-5pm weekdays

@ OPG@scotcourts.gov.uk

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

0844 567 6173
9am-5pm weekdays

@ sfe.legal

SOCIETY OF LATER LIFE ADVISERS (SOLLA)

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

0333 2020 454

@ admin@societyoflaterlifeadvisors.co.uk

societyoflaterlifeadvisors.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).

- **0345 548 0300**
- **enquiries@beaconchc.co.uk**
- **beaconchc.co.uk**

**SHELTER**

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

- **0808 800 4444**
- 8am-6pm weekdays
- **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 if they wish to leave work.

- **0300 123 1100**
- 8am-6pm weekdays
- **acas.org.uk**

**ADVICE UK**

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

- **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.

- **lawworks.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.

- 0808 196 3651
- 10am-5pm Monday, Tuesday, Thursday and Friday
- 10am-8pm Wednesday
- [redcross.org.uk](http://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 weekdays
- [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)

**TOURISM FOR ALL** helps to make travelling and tourism (both abroad and within the UK) accessible for everyone regardless of their illness or disability.

- 0845 124 9971
- 10am-4pm weekdays
- [tourismforall.org.uk](http://tourismforall.org.uk)

ABOUT US

Alzheimer’s Research UK is the UK’s leading dementia research charity. We fund world-class research to find ways to prevent, diagnose and treat dementia. Since the charity was founded in 1992 we have funded over £194 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](https://joindementiaresearch.nihr.ac.uk), we provide opportunities for people with and without dementia to get involved in vital research studies. To find out more and register to take part visit [joindementiaresearch.nihr.ac.uk](https://joindementiaresearch.nihr.ac.uk) or call 0300 111 5111.

With your support, we will continue to fund many more studies into dementia. We promise we will not stop until dementia can no longer destroy lives.

We are Alzheimer’s Research UK.
We exist for a cure.
Alzheimer’s Research UK is the UK’s leading dementia research charity. 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 use the details below. If you’d like to help us review and improve our booklets, visit alzres.uk/reviewer

CONTACT US
0300 111 5111
infoline@alzheimersresearchuk.org

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

VISIT
alzheimersresearchuk.org/dementia-information

ORDER
alzheimersresearchuk.org/supporter-orders
Or scan the QR code

ALZHEIMER’S RESEARCH UK FOR A CURE