

Dementia Guide

A simple guide to help you
navigate through life with
dementia.

A collaboration with citizens for citizens

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Diagnosis

If you have been diagnosed with dementia, or are supporting someone with dementia, this information can help you to understand the kind of support and services that are available in England.

There are different types of dementia. The rate at which dementia develops is different for each person. It can affect people in different ways. This can mean people need support at different stages – whether they are the person with dementia or they are helping to support and care for a family member or friend.

Your Care Plan

Following your diagnosis of dementia, you should have a care plan. Your care plan sets out what sort of care you and the people who care for you might need. It sets out how you will get the care and support.

A local service will help to develop your care plan. The local service could be a memory assessment service, your local council or your GP.

It can be a different local service in different parts of the country. You and your carer and any other family members can help to create your care plan. You should get a written copy of it. The care plan should include how you can keep doing the things that matter to you for as long as possible.

You may not need any extra care or support at this stage. If that is the case, your care plan may just be that you will have a check in the future to see if anything has changed for you. If you do not have a care plan, you are within your right to ask for one.

Making Decisions About Your Finances and Health

You must plan ahead for a time when it becomes harder for you to make decisions about your health and finances. Your care plan can cover the care you would like in the later stages of dementia.

You can arrange for someone like a family member or friend to make decisions for you if that is needed. This is called a 'lasting power of attorney'. You can also make a general statement about your wishes for the future. This is called an 'advance statement'. You can ask your care coordinator or your local council i.e. **Citizens Advice Bureau** for more information about setting up a lasting power of attorney or making an advance statement. There is also information on the office of the public guardian website.

Telephone: **0121 456 0300**

Website:

[Lasting power of attorney, being in care and your financial affairs - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

Textphone: **0121 934 2778**

Email: **customerservices@publicguardian.gsi.gov.uk**

Address: **PO Box 16185**
Birmingham B2 2WH

If a family member no longer has mental capacity you can no longer make power of attorney. In this case, you would have to apply to the **Court of Protection** to act on your behalf. For more information.

Telephone: **0121 250 6395**

Website: [Birmingham Civil and Family Justice Centre - GOV.UK \(find-court-tribunal.service.gov.uk\)](http://www.find-court-tribunal.service.gov.uk)

Email: **courtofprotection.birmingham.countycourt@justice.gov.uk**

Address: **Midlands Regional Hub**
Birmingham Civil and Family Justice Centre The Priory Courts
33 Bull Street
Birmingham
B4 6DS

A Named Person To Support You

Your care plan should give you the name of the person who will coordinate all the different support you should get. This named person will be your care coordinator. They will be the main point of contact for you and anyone who is helping to support you. A care coordinator is also sometimes called a care navigator. You must ask your GP for further advice about a care coordinator.

Your care coordinator can help you understand what help is available.

Your care coordinator should:

- Make sure your health is monitored
- Look at your care plan with you at least once a year to make sure you are getting support
- Make sure you know about the help you can get
- Work with your family or friends to make sure you are getting the help you need.

Support For Carers

Any family members or friends who regularly care for you should also get the help they need. If a person who cares for you appears to need support they should be offered an assessment.

The help that the person might get could be:

- Respite care to give them some rest
- Financial support, such as carer's allowance
- Your local council, a doctor or your care coordinator can put your carer in touch with the right local organisation to help them find out more.

Dementia Resources

The following organisations provide help and advice to carers of people with dementia.

Age UK

Telephone: **0121 437 0033**

Please visit the age uk website for information, advice, services, campaigns, training and research.

Alzheimer's society

Telephone: **0333 150 3456**

The Alzheimer's society provide help and advice as well as support for all forms of dementia. They also provide cafés as well as activities such as singing for the brain. Publications and factsheets are available to download from the Alzheimer's society website.

To self-refer to the Alzheimer's society visit this link:

[Dementia Connect – Make a Referral | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/dementia-connect-make-a-referral)

Carers Trust

Telephone: **0121 788 1143**

The Carers Trust is a charity that works to improve support, services and recognition for carers.

Carers UK

Telephone: **020 7378 4999**

Carers UK offers support, help and advice from other carers.

Dementia Carer

Website: **dementiacarers.org.uk**

The website allows carers of people living with dementia to share information about what helps them, what to do when things get tough and where to go to find help.

Dementia

Dementia UK

Telephone: **0800 888 6678**

Admiral nurses provide help and support for carers/families looking after a person with dementia.

Forward Carers

Telephone: **0333 006 9711**

Forward Carers is a West Midlands based carer support service that aims to make a real difference to the lives of people caring for an elderly, frail, sick or disabled family member. The forward carers website also includes information on how to refer a carer to the Birmingham carers hub.

Lewy Body Society

Telephone: **0800 888 6678**

The Lewy Body Society provide specific information relating to dementia with Lewy Body and includes downloadable resources.

National Institute for Health and Care Excellence (NICE)

Website: [Overview](#) | [Dementia: assessment, management and support for people living with dementia and their carers](#) | [Guidance](#) | [NICE](#)

Nice provide health and social care guidelines for people with dementia and their carers.

NHS Choices

Website: [Dementia guide - NHS \(www.nhs.uk\)](http://www.nhs.uk)

The NHS choices website features information on dementia, signs and symptoms, living with dementia and carer support.

Pohwer Birmingham

Telephone: 0300 456 2370

Pohwer provide an advocacy service for people who lack capacity or who may need an independent mental capacity advocate (IMCA). Advice and information about the IMCA service can be obtained from the Birmingham section of their website.

Social Care Institute for Excellence (SCIE)

Website: [Social Care Institute for Excellence \(SCIE\)](#)

The SCIE website provides information for both professional and carers of people with dementia. A number of resources can be accessed such as videos and e-learning.

Support Group for Carers

Every Monday* 11am-1pm

Address: Banners Gate Community Hall, Reay Nadin Drive,
**Sutton Coldfield,
B73 6UR**

*not including bank holidays.

Every Tuesday 11am-1pm

Address: Quinborne Community Centre, Ridgacre Road,
**Quinton,
Birmingham B32 2TW**

Every Wednesday: 11am-1pm (from 29th Sept 2021)

Address: **Warstock Community Centre,**
1 Daisy Farm Road, Yardley Wood, Birmingham
B14 4QA

Every Thursday **11am-1pm**
Address: Clem Dench Scouting Centre,
Hamstead Hall Road, Handsworth Wood, Birmingham
B20 1HX

Every Thursday **2pm-4pm**
Address: Whitesmith Croft Sheltered Housing,
off Silver Street, Kings Heath, Birmingham
B14 7QR

Face-to-face sessions are **£2.00 per person**,
please pay on arrival at the venue.

Training For Carers

Caring for carers dementia awareness group sessions take place every Monday, Tuesday, Wednesday & Thursday at the times below. The sessions are approximately one hour long and are delivered via zoom. Afternoon awareness sessions, 2:30pm-3:30 pm are for carers who require 1-2-1 or family sessions via zoom. Day topic time:

Monday: **Dementia Explained** (except bank holidays)
10.30am-11.30am | 12.30pm-1.30pm | 2.30pm-3.30pm

Tuesday: **Behaviours & Carers Nips**
10.30am-11.30am | 12.30pm-1.30pm | 2.30pm – 3.30pm

Wednesday: **Nutrition Advanced Planning**
10.30am-11.30am | 12.30pm-1.30pm

Thursday: **Infection Control**
10.30am-11.30am

For more information or to book call **07523 515120**
or email: val.morganrichards@sandwellcrossroads.org

Reduction In Council Tax

Households where people suffer from severe mental impairment, including those with Alzheimer's may be entitled to a reduction in their council tax.

To qualify:

- Someone must be medically certified to show that their condition is permanent.
- Entitled to but not necessary receiving at least one of a number of qualifying benefits.

To apply for a council tax discount or exemption you will need fill in an application form. The form is included at the end of information pack.

Benefits Advice

There are different ways of getting information and advice on benefits, as well as help with filling in forms, which can be long and complicated. Don't be put off. You have a right to claim benefits that you are entitled to. You may need to be persistent to get what you need when you are applying. It may be useful to get help from:

- A professional, such as a social worker or welfare rights adviser at the local authority, who may be able to advise or tell you where you can get a benefits check locally
- The gov.uk website, where the department for work and pensions (DWP) provides information about benefits and claim forms
- The pension service or local jobcentre plus office, who should have information leaflets and claim forms. They may also be able to put you in touch with the DWP local visiting service, which offers home visits for vulnerable people to help with benefit applications
- Your local citizen's advice bureau

Qualifying For Benefits

Qualifying for benefits may depend on different things, such as the impact of the disability or a caring role, income and savings and national insurance contributions.

Sometimes, getting one benefit may increase your entitlement to another benefit, or it may stop you from claiming something else. It's best to get advice on this.

If you have a diagnosis of dementia you can often claim various benefits. Some carers may be entitled to Carer's Allowance – check whether you can claim this and other benefits by talking to a benefits adviser. Age UK and Forward Carers can also support you with the above. See the Dementia Resource page for contact details.

Where To Claim Benefits

Where to Claim?

Type of benefit/who organises it?

Benefits for people of working age (including Universal Credit):

Job Centre Plus

Telephone: **0800 169 0190**

State Pension and other benefits for people at state pension age:

Pension Service

Telephone: **0800 731 7898 / 0800 731 0469**

Disability Benefits:

Disability Service Centre

Telephone: **0800 1214433**

Carer's Allowance:

Carer's Allowance Unit

Telephone: **0800 731 0297**

You can claim benefits either by filling in the relevant forms yourself and sending them in the post, or phoning a contact centre where an adviser will complete the form and send it to you to sign and return. Some benefits can be claimed by completing an online form on the gov.uk website.

Even if you don't have all the information you need you should not delay making a claim. Some benefits can start on the day you first make contact to say you want to claim the benefit, whether you do this in person, by letter or by phone.

You will usually need to send in your claim form as soon as possible. If you're required to send evidence you don't yet have, such as a letter from your doctor, explain on the form that you will send it later. Some benefits can be backdated (where you can claim for an earlier period) if you were eligible before you made the claim. However, you will usually need to ask for this to happen.

Disability and Mobility Benefits

Types Of Disability and Mobility Benefits

If you're living with dementia, you may be entitled to a disability benefit. These include:

Attendance Allowance (AA)

Personal Independence Payment (PIP)

Disability living Allowance (DLA)

These disability benefits are paid at different rates depending on your needs. The amount that you receive has nothing to do with your income, savings or national insurance contributions. They are also tax free. You can claim these benefits even if you are working, whether you live alone or with people.

The forms that you need to fill out can be very detailed and lengthy. They include questions about the activities that you find difficult or impossible to carry out, and about your need for care and supervision.

When answering these questions, consider the days when you need more help as well as days when you don't need as much. It will help your claim if you can provide supporting evidence such as information about medication, care plans or medical reports from your doctor.

It's very important to get advice on filling in the form to make sure all the information that is needed is provided. Contact an **Citizens Advice** or **Age UK** for advice.

DLA (Disability Living Allowance), **PIP** (Personal Independence Payment) and **AA** (Attendance Allowance) are benefits for people who are seriously disabled and need help with their personal care or someone to look after them to avoid harm, or need help to get around (PIP and DLA only). This includes people with dementia.

They might need help or supervision for activities such as washing, dressing, eating, going to the toilet, turning over or settling in bed, taking medication, avoiding danger, or doing social activities.

DLA is now only for children aged under 16, although some adults who were on it before the rules changed still get it.

To claim DLA order a printed form by calling the **Disability Benefits helpline** on: **0345 712 3456**.

PIP is for adults aged between 16 and 64. To claim PIP you must call the **DWP** on: **0800 917 2222**.

You'll need to have the following information: contact details and date of birth, National Insurance number, bank or building society details, doctor's or health worker's name, details of any time you've spent abroad, or in a care home or hospital.

AA is for persons aged 65 and over. To claim AA call the **Attendance Allowance** helpline on: **0345 605 6055**.

Carers Allowance

Carers allowance can be paid to carers who spend at least 35 hours per week looking after or supervising someone who is receiving **DLA** (care component at the highest or middle rate), **PIP** (daily living component at either rate) or **Attendance Allowance** (at either rate).

The rate is to do with the amount of benefit that is given to the person. This is dependent on the level of help they need. The rate is categorised as low, middle or high.

You do not have to be related to, or living with, the person you care for.

The benefit does not depend on national insurance contributions, but it is taxable and can affect the amount you receive of some other benefits.

You must be 16 or over when you first claim carer's allowance. In some cases, the person being cared for could lose some of their means-tested benefits if carer's allowance is paid, so it is important to seek advice before making a claim. You are not eligible for carer's allowance if you earn more than a limited amount each week or if you are in full-time education.

For more advice on benefits and help with filling out forms telephone: 0344 477 1010

Textphone for the deaf/hard of hearing: **18001 03444 111445**

Birmingham CAB Facebook Group:
<https://en-gb.facebook.com/BirminghamCAB/>

For housing benefits and maximisation of income:

Ring the contact centre **0121 216 3030** and request an “**income maximisation**” with the **Neighbourhood Office**.

Becoming an Appointee and Benefits

If someone is not able to manage their benefits themselves, another person can be chosen to receive the benefits on their behalf. This person is known as an appointee.

For example, if you have dementia and someone else is prepared to act on your behalf, they should contact the Department of Work and Pensions (DWP) and request an appointeeship assessment. If you are the person's carer you might do this.

The DWP must agree that the person is suitable to act as an appointee. Wherever possible, the appointee should be a close relative who either lives with the person with dementia or visits them regularly. In certain circumstances, the appointee might be a friend, neighbour, or professional, including a representative from the local authority or solicitor.

An appointee is responsible for making and maintaining benefit claims, and collecting payments on the person's behalf. The appointee is also responsible for reporting any changes in the person's circumstances to the DWP.

Appointeeship is only used to manage the person's benefits. If they have other assets there are other ways that these can be managed on their behalf, such as with a lasting power of attorney or deputyship (See page 5 for more information).

Occupational Therapy

Occupational Therapy gives patients the tools they need to complete tasks that used to come easily to them. By simplifying tasks throughout the home and in public, it can greatly reduce the behavioural issues that many dementia patients struggle with.

Maximising Independence

Occupational Therapy offers practical support to:

- Empower you
- Help your recovery
- Help you overcome barriers so that you can engage in important activities
- Maximise your independence
- Help you to achieve satisfaction in all aspects of your life

Assessment

The aim of an **Occupational Therapy** assessment is to get information about your general health and how your diagnosis is impacting your ability to do everyday activities such as:

- Getting in and out of bed or chair
- Getting on and off the toilet
- Dressing yourself
- Feeding yourself
- Managing the stairs
- Your ability to prepare drinks, snack and or meals

Graded approaches

An Occupational Therapist Worker will use the assessment to decide the best support to meet your needs. To begin with, the Occupational Therapist Worker will consider minor adaptations such as grab rails, bannister rails, alterations to steps for safe access. If these adaptations have been made and you still need support to maximise your independence, an Occupational Therapist Worker might look at other options such as a level access shower. Occupational Therapy also offers enabling programmes. They can teach you useful techniques to help you complete simple tasks with reduced pain and discomfort. Such as, transferring from you bed to a chair or transferring on and off the toilet.

Technology Enabled Care

Other preventative methods can include TEC (technology enabled care). Maximising the use of technology and equipment offers tremendous opportunities to enhance the experience and quality of life for citizens by:

- Enhancing independence and dignity by enabling citizens to exercise greater control over their daily lives, live at home and be less dependent upon other people
- Reducing isolation by connecting citizens to their social networks and to opportunities in their communities
- Supporting carers by providing reassurance remotely or allowing a break to go out, easy means of communication, and reducing demands on their capacity.

There are different ways you can access TEC:

- You may be eligible for help from your local council. Contact your local council. Depending on your needs, you may have a TEC services provided. Ask whether there's a trial TEC scheme in place so you can make sure it's suited to your needs.
- Speak to your GP or an occupational therapist. They may recommend a TEC as part of a continuing health or care package, but there's often a charge for TEC services.
- Referrals can be made by Occupational Therapy Workers and Social Workers.

How to access the **Occupational Therapy Service**:

Depending on your situation you can speak to your GP about a referral or you can make a referral for yourself or someone else via your local council by calling **0121 303 1234**.

Social Care and Social Workers

Social care professionals can help you with non-medical support. This could include support at home with dressing or bathing, social activities, day care or respite care.

Social Workers have been specially trained to assess a person's needs and advise on what services best suit them. They can also help you if you just need to talk things through. Social Workers, also referred to as 'care managers', work in Social Services departments, hospitals and care homes.

To talk to a Social Worker, contact your social services department or ask your GP. Social Workers can also help sort out funding support and are the primary contact for requesting continuing care funding.

Getting an assessment and advice is always free. You can ask for an assessment yourself, or a family member, your GP or another health and social care professional can ask for one on your behalf. Many people will have to pay towards these services. You could ask social services or a list of companies and then arrange for the service privately.

Depending on your situation you can speak to your GP about a referral or you can make a referral for yourself or someone else via your local council by calling **0121 303 1234**.

Notes

You can use this space to make notes of information regarding support referenced in this booklet.

