



# The dementia guide

Living well after diagnosis



For more information  
[alzheimers.org.uk](http://alzheimers.org.uk)  
0300 222 1122





# About this guide

**If you have recently been told you have dementia, this guide is for you. It could be any type of dementia, such as Alzheimer's disease, vascular dementia or mixed dementia. Or it could be dementia with Lewy bodies (DLB) or a less common type, such as frontotemporal dementia (FTD).**

Close friends and family of someone with dementia will also find this guide useful, as it contains information for anyone taking on a caring or supporting role.

The guide will help you to understand more about dementia and the treatments, support and services that are available. It includes information about how you can live as well as possible with dementia, and about making plans for the future.

The first edition of this guide was produced by Alzheimer's Society with support and funding from the Department of Health. This is the second edition. It has been reviewed by people with dementia, carers and experts in dementia. We have taken all feedback into consideration.

If you'd like to talk about any of the information in this guide, please phone Alzheimer's Society's National Dementia Helpline. There is also more information on our website.



For advice and support call the National  
Dementia Helpline on **0300 222 1122**



**‘I became very depressed waiting for appointments to come through, but someone from Alzheimer’s Society helped and supported me. I don’t know what I would have done without this.’**

Liz Cunningham,  
Living with dementia

# Foreword

## Liz Cunningham

**It can be frightening to have to deal with a diagnosis of dementia. You might feel upset, insecure, agitated or confused. However you feel, the main thing to know is that you're not on your own.**

Before I was diagnosed, I used Alzheimer's Society's website to get information and to find out where to get help and support. I became very depressed waiting for appointments to come through, but someone from Alzheimer's Society helped and supported me. I don't know what I would have done without this – getting that continuous support was the start of being able to live again.

It is really important to get information and support after a diagnosis – it can make you feel reassured and allow you to get back to living your life again. This guide tells you everything you need to know about your diagnosis, treatments, the future, and how to live well with dementia. If you are worried about any of your symptoms you can look them up, and it gives advice on what you can do to make things easier.

There are contact details of other people who can give you support, including Alzheimer's Society services like the helpline. I have family carers, but talking to someone from the Society can remove the doubts or fears and explain things simply – it's important to have this kind of reassurance at the end of the line.



For advice and support call the National  
Dementia Helpline on **0300 222 1122**

# Coming to terms with your diagnosis

**If you have recently been diagnosed with dementia, you might be feeling sad, fearful, lost, alone, angry or even disbelieving. Or you may feel some relief that you now have an explanation for the problems you have been having. Everyone is different, but all these reactions are possible at different times and they are all normal. How you feel will probably vary from one day to the next.**

If you can, talk to friends and family about how you're feeling. Talking about things is often the first step to dealing with them. It can also help other people to understand what you're going through and how they can help you. They might also be finding things hard, so talking could be good for them too. There are also specialist health and social care professionals, such as counsellors or a dementia adviser, who you can talk to for support.

It can help to learn more about your diagnosis and what to expect. This can make planning for the future easier. You may want to do this right away, or you might not feel ready just yet – it's good to take things at your own pace. There is lots of information and advice available, when you feel ready.

It's important to know that you aren't alone – about 850,000 people in the UK have dementia. It's possible to live well with dementia and there is support available for you and your family. You might even want to help others – by getting involved in research, development of services, campaigns or volunteering.



# How to use this guide



You might choose to read the whole booklet, or, if you prefer, focus on the parts that seem most relevant to you. If you prefer to read an overview rather than the whole thing, there are summaries of the key points at the start of each section.



You will find a number of 'next steps' at the end of some chapters. These are things you might want to think about doing that can help you to live well now and plan for the future.



Throughout this booklet you will see suggestions for other Alzheimer's Society publications that will give you more information on the topics covered here. There is a fold-out tick list on page 147 if you want to keep a note of which ones you would like.



You will find a list of Alzheimer's Society services on page 131. Other useful organisations are listed on page 135.



There is an index on page 151. If you are interested in a specific topic, this is a good place to look for it.



For advice and support call the National Dementia Helpline on **0300 222 1122**



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## About dementia

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# 1

## Key points: **About dementia**

Dementia is not a normal part of ageing. It occurs when the brain is affected by a disease. Dementia affects everyone differently and you might experience a number of changes. These may include problems with memory, thinking, concentration and language. You may become confused or struggle to make sense of what you can see or hear. You may also experience changes in mood, emotions and behaviour.

Dementia is progressive, which means that your symptoms will get worse over time. However, many people living with dementia lead active and fulfilling lives for many years.

There are many different types of dementia. The most common are Alzheimer's disease and vascular dementia. Less common are dementia with Lewy bodies (DLB) and frontotemporal dementia (FTD). It is possible to have more than

one type of dementia, a condition known as 'mixed dementia'. This is most often Alzheimer's disease with vascular dementia.

There are also some rarer conditions that cause dementia. Together, they account for only about 5 per cent of all people diagnosed with dementia.

Various factors increase the risk of someone developing dementia. Ageing, genes, health and lifestyle (for example, exercise, diet or smoking) all play a part.

Most people with dementia are over 65 years of age, but dementia can also affect younger people.

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## What is dementia?

The word 'dementia' describes a group of symptoms that may include memory loss, difficulties with thinking, problem-solving or language, and often changes in mood, perception or behaviour. These changes are usually small to start with, but for someone with dementia they have become bad enough to affect daily life. Dementia isn't a natural part of ageing. It occurs when the brain is affected by a disease.

There are more than 100 known types of dementia. The most common are Alzheimer's disease and vascular dementia. To find out more, see Types of dementia on page 16.



**For more information, see factsheet 400, What is dementia?**

### Dementia statistics

- There are around 850,000 people in the UK who are living with dementia.
- Your chance of developing dementia increases a lot with age. Of people over 65 years of age, one in 14 has dementia, whereas it is one in six people over the age of 80. It is more common among women than men.
- At least 42,000 younger people (under the age of 65) in the UK have dementia. This is called early-onset or young-onset dementia.

# What are the symptoms?

Everyone experiences dementia in their own way. Different types of dementia can also affect people differently. However, some of the common symptoms are listed below. You might recognise some of your own experiences.

## Memory loss:

- problems recalling things that happened recently (although you might easily remember things from a long time ago)
- repeating things in conversation, such as asking the same question over and over.

## Difficulty thinking things through and planning:

- problems concentrating, following a series of steps, grasping new ideas or solving problems
- struggling with familiar daily tasks, such as following a recipe or managing your finances (for example, your pension or bank accounts).

## Problems with language:

- difficulty finding the right word
- struggling to follow a conversation or misinterpreting things you hear.

## Being confused about time or place:

- losing track of what time, date or season it is
- getting lost or not knowing where you are, even in a familiar place.

## Visual perceptual difficulties:

- problems judging distances (for example, on stairs)
- misinterpreting patterns or reflections in mirrors.



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## **Mood changes or difficulties controlling emotions:**

- becoming unusually anxious, sad, frightened, irritable or easily upset
- losing interest in things and becoming withdrawn
- lacking self-confidence.

## **Changes over time**

Dementia is progressive, which means that your symptoms will get worse over time. How quickly it progresses will vary greatly from person to person. Some people with dementia maintain their independence for many years.

In the middle and later stages of dementia, you will need more and more support with daily activities like cooking, or personal care such as washing and dressing. Dementia does shorten life expectancy, although some people live with it for many years.

However dementia affects you, and whatever stage you are at, there will be ways to make living with the condition better. To find out more, see *Living well* on page 39 and *Services for people with dementia* on page 87.

## **What are the causes?**

Dementia is caused by physical changes in the brain that happen as the result of a disease. As dementia progresses, the structure and chemistry of the brain changes, which causes nerve cells to die. As more nerve cells die, the brain becomes damaged.



Damage to different parts of the brain will have different effects. For example, damage to one area of the brain might affect a person's short-term (recent) memory, while damage to another part might affect their ability to organise things. To find out more about changes to the brain, see Types of dementia on page 16.



**For more information, see factsheet 456,  
Dementia and the brain**

If you use the computer you could also look at our animated guide to how dementia affects the brain. This can be found at [alzheimers.org.uk/braintour](http://alzheimers.org.uk/braintour)

## Why do some people get dementia?

It is not always clear why some people get dementia while others don't. It depends on a combination of age, genes, health and lifestyle (for example, exercise, diet or smoking).



**For more information see factsheet 450,  
Risk factors for dementia**

**'No two cases of dementia are the same, and just because someone is experiencing a certain set of symptoms doesn't necessarily mean you will go on to develop those same symptoms.'**

Carer for a person living with dementia

# 1

## Types of dementia

There are many different types of dementia. Around 95 per cent of people with a diagnosis will have one of the four main types – Alzheimer’s disease, vascular dementia, dementia with Lewy bodies (DLB) or frontotemporal dementia (FTD). These are all described on the following pages.

Alzheimer’s disease is the most common type, followed by vascular dementia. To find out about other causes of dementia, see page 23.

### Alzheimer’s disease

#### Inside the brain

Abnormal structures called ‘plaques’ and ‘tangles’ build up inside the brain. These disrupt how nerve cells work and communicate with each other, and eventually cause them to die.

There is also a shortage of some important chemicals in the brain of someone with Alzheimer’s disease. Reduced levels of these chemicals mean that messages don’t travel around the brain as well as they should.

#### Early changes

Alzheimer’s disease usually begins gradually with mild memory loss, such as difficulty recalling recent events or learning new information. This is because the first part of the brain that is affected is often the part for memory and learning. You might forget people’s names or where you have put things, for example.



Other early changes may include:

- problems with language, such as finding the right word for something
- feeling confused or finding it hard to follow what is being said
- problems with seeing objects in three dimensions
- having difficulty with everyday activities – for example, getting muddled with coins when paying for items at the shops
- becoming more withdrawn or experiencing mood swings.



**For more information see booklet 616, Alzheimer's disease: Understanding your diagnosis**

## Vascular dementia

### Inside the brain

Vascular dementia is the result of problems with the blood supply to the brain – the word 'vascular' relates to blood vessels. Nerve cells need oxygen and nutrients from the blood to survive. Without enough blood, these nerve cells will die.

There are several types of vascular dementia. One type is caused by stroke (called stroke-related dementia). Another is caused by poor blood supply to deep parts of the brain (called subcortical vascular dementia).

Strokes happen when a clot blocks the flow of blood to a part of the brain, or when a blood vessel bursts in the brain. Vascular dementia sometimes follows a large stroke (called post-stroke dementia). More often though, it comes after a number of small strokes (called multi-infarct dementia).



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Subcortical vascular dementia – when there is poor blood flow to the deep parts of the brain – is often due to narrowing of the small arteries that supply the brain with blood.

## Early changes

The changes you experience will depend on which part of the brain has been damaged. Common early changes include difficulty planning, thinking quickly or concentrating. There might also be short periods when you get very confused. You may also become depressed or anxious. Memory loss isn't always common in the early stages.

If you have had a large stroke, symptoms of vascular dementia can begin suddenly. They can then remain stable or, in the early stages, they might even get a little bit better over time. If you then have another stroke, your symptoms might get worse again.

If you have a series of small strokes, your symptoms may remain stable for a while and then get worse in stages, rather than experiencing a gradual decline.

If you have subcortical vascular dementia, your symptoms may get worse gradually or, less often, in stages.



**For more information see booklet 614,  
Vascular dementia: Understanding your diagnosis**

## Dementia with Lewy bodies (DLB)

### Inside the brain

This form of dementia gets its name from tiny clumps of protein that develop inside nerve cells, called Lewy bodies.



Similar to the plaques and tangles of Alzheimer's disease, they disrupt the way the brain functions. They reduce the levels of chemical messengers and cause nerve cells to die.

Lewy bodies are also found in people with Parkinson's disease. A person with Parkinson's is at high risk of going on to develop dementia as their condition progresses. If they do, this is called Parkinson's disease dementia.

### Early changes

In the early stages of dementia with Lewy bodies, you might find it hard to stay alert and have difficulty with planning ahead, reasoning and solving problems. These symptoms typically vary a lot from one day to the next.

You might also have problems with how you see things, such as:

- finding it hard to judge distances
- problems with seeing objects in three dimensions
- seeing things that aren't really there (visual hallucinations).

You may also develop symptoms like those in Parkinson's disease. These include:

- slow and rigid movements
- problems balancing
- trembling of an arm or leg.

Disturbed sleep patterns are also common. However, your memory will often be affected less than in someone with Alzheimer's disease.



**For more information see booklet 37, Dementia with Lewy bodies: Understanding your diagnosis**



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## Frontotemporal dementia (FTD)

### Inside the brain

The term frontotemporal dementia covers a range of different conditions. It was originally called Pick's disease and this term is sometimes still used. It is caused by damage to areas of the brain called the frontal and temporal lobes. These areas control behaviour, emotional responses and language skills.

In frontotemporal dementia, clumps of abnormal proteins collect within nerve cells in these lobes and cause the cells to die. Important chemicals that carry messages around the brain are also affected.

### Early changes

Frontotemporal dementia mostly affects people in their 40s, 50s and 60s (younger than most people who get Alzheimer's disease or vascular dementia). There are three different types of frontotemporal dementia, called behavioural variant, semantic dementia and progressive non-fluent aphasia.

**'Everyone's progression is different, I've learnt just to go one day at a time as no two days are the same, and each day certainly has enough troubles of its own. It's not I want to deny what might happen but neither do I want to think that "whatever it might be" is inevitable.'**

Person living with dementia

With behavioural variant frontotemporal dementia, changes in personality or behaviour are often noticed first. You might become withdrawn or not seem to care as much about other people, or you might make socially inappropriate remarks. You may also become obsessive or impulsive – for example, developing fads for unusual foods.

If you have semantic dementia, your speech is usually fluent but you might lose the meaning or understanding of some words.

If you have progressive non-fluent aphasia, your language is also affected. Your speech may become slow and need a lot of effort.

In the early stages of frontotemporal dementia, your day-to-day memory is unlikely to be affected.



**For more information see booklet 687, Frontotemporal dementia: Understanding your diagnosis**

## Mixed dementia

Some people have more than one type of dementia. This is called mixed dementia. The most common combination is Alzheimer's disease with vascular dementia. The next most common is a combination of Alzheimer's disease and dementia with Lewy bodies. If you have mixed dementia, you are likely to experience a combination of symptoms of the two types of dementia.



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## **Dementia in younger people (young-onset dementia)**

At least 42,000 people in the UK were diagnosed with dementia before they reached the age of 65. This is often called ‘young-onset dementia’, ‘early-onset dementia’ or ‘working age dementia’.

You can develop any type of dementia if you are under 65. However, you are more likely to have a less common type of dementia, such as frontotemporal dementia or another dementia with a genetic cause. Only a third of younger people with dementia have Alzheimer’s disease.

While some of your symptoms may be similar, you will often face different challenges and need different kinds of support to older people. You may have a younger family, financial commitments such as a mortgage, and you may still be working. You may also have different interests and expectations of how you can continue to live well with dementia.

For more about issues that are likely to face younger people with dementia, see the sections on Financial matters, Driving and Working. These are covered in Chapter 4, Planning ahead, starting on page 63. Also see page 100 for information on Services for younger people.



**For more detailed information see booklet 688, [Young-onset dementia: Understanding your diagnosis](#)**



## Dementia and learning disabilities

People with learning disabilities, including Down's syndrome, are more likely to develop dementia (usually Alzheimer's disease) at a younger age. If you have dementia and a learning disability, your early symptoms can be a bit different – you are more likely to experience changes in behaviour, for example. The support you receive should be adapted to your understanding and how you like to communicate.



**For more information see factsheet 430, Learning disabilities and dementia and Easy Read factsheet ER1, What is dementia?**

## Alcohol-related brain damage (including Korsakoff's syndrome)

Alcohol-related brain damage (ARBD) is caused by regularly drinking to excess over several years. It tends to affect people in middle age. ARBD is not a type of dementia but it can have similar symptoms, such as memory loss and problems with decision-making. If you stop drinking alcohol, eat a good diet and have cognitive rehabilitation, you may be able to make a partial or even full recovery.



**For more information see factsheet 438, What is alcohol-related brain damage?**

## Rarer causes of dementia

A wide range of other conditions can lead to dementia. These are rare, and together account for only about 5 per cent of all dementia. However, they are more common in younger people.



**For more information see factsheet 442, Rarer causes of dementia**



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## 2

# Treatments

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2

## Key points: Treatments

There is no known cure for dementia. Treatment includes both drug and non-drug approaches, looking after other medical conditions and making changes to your lifestyle. With a combination of these, it is possible to live well with dementia for many years.

Four drugs have been developed to treat Alzheimer's disease:

- donepezil
  - rivastigmine
  - galantamine
- } for people in the early and middle stages of the disease.
- memantine – for people in the later stages of dementia.

These drugs help with symptoms of Alzheimer's disease for a while in some people. You may also be given one of these if you have dementia with Lewy bodies, or mixed dementia that is a combination of Alzheimer's disease and vascular dementia.

If you have frontotemporal dementia, these drugs aren't suitable. You may be given antidepressant drugs for some of your symptoms.

If you have vascular dementia, you will usually be prescribed drugs to treat any underlying conditions you have, such as high blood pressure or heart problems.

You can also benefit from approaches that don't involve drugs. One example is cognitive stimulation, which might involve doing word puzzles or discussing current affairs to keep your brain active. Another example is life story work, where you build up a record of your life experiences to help with your memory. This could be in a scrapbook, photo album or using the computer.

## Drugs to treat dementia

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Currently, there is no known cure for dementia. However, scientists are trying to find one. For more see Research on page 123.

However, there are drugs that can help. Depending on the type of dementia you have, these drugs can lessen some of the symptoms or stop them getting worse for a while. Non-drug approaches and getting the right support after diagnosis (such as information and advice, talking to others and keeping your mind active) are also very valuable.

Other illnesses or infections need to be managed too – see Staying healthy on page 49.

### Alzheimer's disease

Four drugs have been developed that target some of the chemical changes in the brain that are seen in Alzheimer's disease. These drugs were at first designed to help with memory and thinking, but they may also be of benefit for other kinds of symptoms. They are also helpful in some other types of dementia.

### Donepezil, rivastigmine and galantamine

If you have mild to moderate Alzheimer's disease, you may be prescribed one of three drugs:

- donepezil
- rivastigmine
- galantamine.



If you have mixed dementia in which Alzheimer's disease is the main cause, you may also be prescribed one of these.

They all work in a similar way, by increasing the amount of a chemical called acetylcholine, which helps messages to travel around the brain. People with Alzheimer's disease have a shortage of this chemical.

These drugs will be prescribed by a dementia specialist in the first place. This could be:

- a GP with special dementia expertise
- a psychiatrist (a doctor who specialises in mental health) at a memory clinic
- a geriatrician (a doctor who specialises in the physical health of older people)
- a neurologist (a doctor who specialises in diseases of the nervous system).

After this, your GP will generally be able to do routine prescribing, with a regular review by your GP or consultant.

### Possible benefits

You might find these drugs help with your symptoms for a while. The benefits can include reduced anxiety and better motivation, memory, concentration and daily living skills.

### Possible side effects

The side effects of these drugs include loss of appetite, nausea, vomiting and diarrhoea. They affect only around one person in 10, on average. If one of the drugs causes problematic side effects, you might be able to switch and try another.



## 2

### Memantine

If you are in the middle stages of Alzheimer's disease but can't take any of the three drugs listed on page 28 – perhaps because of the side effects – you might be offered memantine. Memantine is also offered in the later stages of Alzheimer's disease, when a person's symptoms become severe. Sometimes this is together with donepezil, rivastigmine or galantamine.

Memantine works by protecting nerve cells from the effects of a natural substance called glutamate. People with Alzheimer's disease often have high levels of glutamate in their brains, which can be harmful.

#### Possible benefits

Memantine can slow down the progression of symptoms for people in the middle and later stages of Alzheimer's disease for a while. It may help with attention and also with agitation or aggressive behaviour, both of which are more common in the later stages of dementia.

#### Possible side effects

Memantine usually has fewer side effects than the other three drugs, although it can still cause dizziness, headaches, tiredness, raised blood pressure and constipation.



**For more information see factsheet 407,  
Drug treatments for Alzheimer's disease**



## Vascular dementia

If you have vascular dementia, the drugs prescribed for Alzheimer's disease aren't recommended, unless you have mixed dementia with both vascular dementia and Alzheimer's disease.

However, it may be possible to slow down the progression of vascular dementia by taking drugs to treat the underlying conditions that cause it, and by following a healthy lifestyle (for example, not smoking). These underlying conditions include:

- high blood pressure
- high cholesterol
- stroke
- diabetes
- heart problems.

The GP will often prescribe drugs for these conditions. You may already be taking them. It is important to follow medical advice and to go for regular check-ups.

**'The medication I am on for my Alzheimer's is Aricept [a brand name of donepezil] – I have been on this for about 10 months now. It has helped keep me on top of things, and although I know it isn't the cure, if it can give me another couple of years as I am now then I cannot complain.'**

Person living with dementia

## 2

### Other dementias

#### Dementia with Lewy bodies

If you have dementia with Lewy bodies, you might be offered one of the three drugs given to people in the early stages of Alzheimer's (donepezil, rivastigmine or galantamine). These can be particularly helpful if you have distressing symptoms, such as hallucinations or agitation.

There are other drugs that can sometimes help if you have very disturbed sleep. For problems with movement or balance, you may be offered the drug levodopa.

#### Frontotemporal dementia

The drugs given to people with Alzheimer's haven't been shown to offer any benefits to people with frontotemporal dementia. They may even be harmful. They are not approved for treating frontotemporal dementia and generally shouldn't be prescribed.

If you have behavioural variant frontotemporal dementia, it's common to be prescribed antidepressant medication. This can reduce inappropriate and obsessive or compulsive behaviours.

#### Research into new treatments

Many people with dementia want to know about research into new treatments. Some will choose to take part in clinical trials. For more see Research on page 123.



## Questions to ask the doctor about medications

It can be useful to prepare or bring questions about drugs when you see the doctor.

- Are there non-drug treatments I could try instead, or first?
- Why are you offering me this medication?
- How do I take this medication?
  - How long will I need to take it for?
  - What happens if I miss a dose?
  - Can I still take my other medication?
  - Can I drink alcohol?
- What are the pros and cons of this medication?
  - How will it help me?
  - How will it affect my symptoms?
  - How will it improve my day-to-day life?
  - Could I suffer any side effects?
  - What changes should I tell you about?
- Have you got any information I could take away?

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## Non-drug treatments

Drugs aren't the only way to treat or manage the symptoms of dementia. There are many other things that can help you to live well. Some common non-drug treatments are mentioned below and some other approaches to living well are covered in Chapter 3, Living well, starting on page 39.

The non-drug treatments that are available, and how to be referred for them, can vary around the country. Ask your GP, memory service or local Alzheimer's Society for details. You may even be able to refer yourself to some of the services mentioned.

### Cognitive stimulation therapy

Cognitive stimulation therapy (CST) aims to improve your mental abilities by keeping your brain active. This is done through a series of themed activity sessions carried out over several weeks. One session, for example, might involve doing word puzzles or talking about current affairs. Then in another session you could be playing an instrument along to music. CST also includes elements of reminiscence therapy (see below).

After the first set of sessions, you may be offered maintenance CST (less frequent, 'top-up' sessions) to keep the benefits going. There is evidence that approaches such as CST improve mental abilities and quality of life for people with dementia.



## 2

### **Cognitive rehabilitation**

In cognitive rehabilitation, a psychologist or occupational therapist will work with you and someone close to you to help you achieve an agreed goal. This could be learning to use a mobile phone or re-learning a life skill such as cooking. In the early stages of dementia, cognitive rehabilitation can help you to meet your goals and cope better with the condition. It works by getting you to use the parts of your brain that are working to help the parts that are not.

### **Life story and reminiscence work**

Life story work is where you use a scrapbook, photo album or electronic app to remember and record details of your life. This could be your experiences, values or beliefs. Life story work is usually a joint activity for you and a family member, friend or support worker.

Reminiscence work involves talking about things from your past, using prompts such as photos, familiar objects or music. It can help you see your life as a whole and recognise your experiences and achievements.

Sometimes these approaches are combined using a memory box of favourite possessions or memorabilia. Techniques like this are popular because they draw on your early memories, which you tend to retain for longer.

There is evidence that life story and reminiscence work, particularly when done one-on-one, can improve mood, wellbeing and some mental abilities such as memory. By talking about who you are, it can help you and others to focus on you as someone with an interesting and varied life who still has skills and interests, rather than on your dementia.



## Music and creative arts therapies

These are therapeutic sessions where you make music, sing, dance, paint and get to be creative. They may take place in a group or individually, and will be led by a qualified professional. Creative therapies can be good if you find it hard to talk about how you feel. They keep your brain active and can help you with your emotions and self-expression.

## Complementary therapies

Complementary therapy includes a broad range of treatments that are outside of conventional medicine. If you are thinking about trying these therapies, you should discuss them with your GP. There is some evidence of possible benefits for people with dementia from:

- aromatherapy – particularly with lemon balm and lavender (for relaxation)
- massage (for agitation)
- bright light therapy – sitting in front of a light box (for sleep disturbance or low mood).



## Your next steps



Ask your GP to explain what your drugs are for and how to take them.



Ask your GP or local Alzheimer's Society if there are any therapies or activities that could help you to live well.



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# 3

## Living well

### 3

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## Key points: Living well

If you've been diagnosed with dementia, there are lots of things you can do that will help you to live as well as possible. It's important to stay positive, and to focus on the things you can still do and enjoy.

Relationships might change when you have dementia, which can be hard to adjust to. It doesn't mean they will be any less valuable or caring though. Talking about things is important.

You might find it hard to communicate sometimes. Try to use the days when you find it easier to communicate to explain the problems you're having and how people can help you.

If you have memory problems, you could try using a large diary, and perhaps keeping it next to a calendar clock. You could also try keeping important items, such as keys or glasses, together in the same place – somewhere easily visible, not in a drawer or cupboard.

Having dementia doesn't mean you should feel unwell. It's important to try and stay healthy. Regular exercise and eating a balanced diet can help. If you smoke, try to stop.

Arrange regular check-ups with your GP, as well as regular dental, sight and hearing checks. Get the annual flu vaccine and see the doctor promptly if you feel unwell. Small things such as a urinary tract or chest infection may make you feel very confused if you don't get help right away.

You may experience depression or anxiety because of how your life is changing. If this is the case, you may be prescribed antidepressant drugs and may be offered a talking therapy, such as counselling or cognitive behavioural therapy (CBT).

**Continued on page 42**

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## Key points: Living well (continued)

Try to stay active and keep in touch with people. This can help you to retain your skills and memory, as well as improve your self-esteem, sleep and wellbeing. Wherever possible, keep doing what you enjoy, even if you have to do it a little differently. Ask an occupational therapist (a health professional who supports people to maintain everyday skills) for advice on activities you find difficult.

You can also take steps to make your home safer. Remove things that are easy to trip over and have carbon monoxide detectors and smoke alarms fitted. You could also get automatic timers for plugs, lights and heating.

There are lots of pieces of technology that can help you to live well. These include electronic medication reminders, locator devices that can help if you misplace things, automatic lights and 'shut-off' devices in case you forget to turn off the gas, oven or tap.

If you are living alone with dementia, you might face extra challenges. It can be harder to stay in touch with people and stay safe in your home. It's important to ask friends and family for help and support, and to make your home dementia friendly.

## Staying positive

Living with dementia can be challenging and you may feel angry or frustrated about what is happening to you. Your plans for the future might change, but dementia doesn't change who you are.

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It's important to stay positive. Focus on the things you can and want to do rather than the things you can't, and try not to become isolated or cut off. Keeping busy and doing activities you enjoy may help you to feel more confident and fulfilled.

You don't need to stop doing the things that you like, you might just have to do them in a different way. There are lots of practical things that can help you to live well and keep doing what you enjoy – many of them are explained in this chapter.

**'I have had Alzheimer's for three years now. My hobby was building customised motorbikes, but now I can't remember how an engine works so I'm finding a new hobby. I tried guitar lessons, astronomy, and many others, but ended up with gardening. I thought it would be boring, but boy how wrong I was! I got a lot of help on Youtube and from gardeners' forums. It not only keeps my mind active but also my body.'**

Person living with dementia

## Changes to relationships

You might find that having dementia changes your relationships with other people. This can be hard to deal with, but there are things you can do to adjust, and there can be positives to take from it too.

- It may take other people time to come to terms with your diagnosis. They might not want to accept it, or they may not know what to do or say. This can be difficult, but you should give them time to adjust and remember that it may have taken you some time to adjust too.
- Some people may treat you differently to how they did before. This might be because they don't understand your diagnosis or what is happening to you. Try talking to them about your diagnosis, if you feel comfortable. You could even suggest they read this guide.
- Over time you might find it more difficult to communicate or cope with certain social situations, such as family gatherings. You and your family and friends will need to find ways to manage how you are feeling.
- You may find that you lose touch with some people as a result of your dementia. This could be because you don't do the things you used to do together anymore, such as work or hobbies, or because you find it harder to stay in touch. However, you may meet lots of new people through activity or support groups. Try to focus on the positives and on the people who are there for you.

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- Some people may not stay in touch because they can't cope with your diagnosis. This can be upsetting, but it's important to remember it's not your fault. It is the other person who has a problem, not you.
- You will become more reliant on other people for help and support as your condition progresses. You may find people trying to do everything for you and this may be hard for you to accept. It can help to talk to people about the kind of help you need and how they can provide it. Remember that people are just trying to be helpful.
- As time goes on, a partner, child, parent or friend may end up taking on the role of a 'carer'. Some people find that this changes their relationship. You may feel that things are less equal between you, or you may feel uncomfortable that roles have been reversed. It's important to try to talk about these feelings, if you have them.



**For more information see booklet 1507,  
Your relationships**

**'I often insert some odd-ball word into a sentence. There have been times when people have corrected me... usually they'll say, "Oh, you mean..." and then put in their own word. It used to make me feel self-conscious and angry. Now I just tell people that I like my word better.'**

Person living with dementia

# Communicating

You may find that communicating becomes more difficult over time. This can be very frustrating and can cause you to feel less confident. You may:

- struggle to find the right word
- repeat yourself in conversation
- struggle to understand what others are saying
- get confused about words and what they mean.

You will probably find that you have good days and bad days. It can make things easier if you talk to the people close to you about it on the good days. Tell them what you find hard, and how they could help. For example, you might find it helpful if people prompt you, or remind you of what you were talking about, or you might find it frustrating or annoying. Letting people know what they can do to help will make it easier for them and you.

There are lots of other things you can do as well.

- Make sure the environment is quiet and try to reduce distractions (for example, turn off the TV).
- Ask people to repeat things if you don't understand.
- Let people know what works for you (for example, talking slowly and giving you more time).
- Ask your GP or consultant for a referral to a speech and language therapist (SALT).
- Use technology that can help (for example, a tablet computer).



**For more information see factsheet 500, Communicating**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Coping with memory loss

Memory loss can be distressing and can knock your confidence. However, there are things you can do that will help. You might want to try some of the following:

- Keep a notebook or large 'week to view' diary. Write down things you want to remember, such as names, to-do lists or things you have done. Keep the diary somewhere easy to see, such as by the phone.
- Put labels and pictures on cupboards to help remind you of what's inside. Or you could keep frequently used items – such as cups, plates and cutlery – out on a table.
- Use reminders such as a notebook, diary or a wall calendar to help you remember appointments or things like putting the bins out.
- Keep a list of useful telephone numbers by the phone.
- Put a note on the door to remind yourself to lock up at night or to remember things like your keys and wallet when you go out.
- Keep useful items such as keys and glasses in the same place, and make it somewhere you can see them.
- Ask your pharmacist about putting your pills in a disposable dosette box. This box has compartments with the days of the week marked on them so you can keep track of what you have taken.
- Find out if there are any useful pieces of technology that could help – for more information see Technology on page 58.

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**For more on coping with memory loss see booklet 1540, The memory handbook**



## Staying healthy

Having dementia doesn't mean you should feel ill, depressed or anxious. It's important that you see the doctor if you're feeling unwell. Other illnesses and infections can make your dementia worse.

You might find the following tips useful:

- Try to eat balanced meals and drink plenty of fluids.
- Take regular physical exercise if you can.
- If you enjoy the occasional alcoholic drink, you might want to keep doing this (unless your GP advises you not to).
- If you smoke, consider stopping.
- Keep warm enough.
- Get enough sleep.
- If you find yourself regularly feeling low, anxious or irritable, you may be depressed. This can be treated (see page 51), so see your GP if it continues or gets worse.
- Get your hearing checked regularly. If you need a hearing aid, wear it, check the batteries and keep it clean.
- Have regular eye tests so you have a current prescription. If you wear glasses make sure they are clean and are the correct ones (for example, reading).
- See the dentist regularly.
- Pay attention to foot care and make sure your shoes and slippers fit well.
- Have the flu vaccine each year and ask about the pneumonia vaccine for over-65s and shingles vaccine for over-70s.



**For more information see factsheet 522, Staying healthy**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

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## Depression, stress and anxiety

Depression or low mood, stress and anxiety are all common in people with dementia. If you have mild symptoms, these may be managed without drugs. Some things that will help include:

- keeping physically active
- doing enjoyable activities (for example, reminiscence)
- joining a support or relaxation group
- talking about your feelings to friends and family
- eating a healthy diet
- not having too much alcohol or caffeine.

If your depression or anxiety is slightly worse, you may be offered a talking therapy (see below). This may sometimes be combined with drug treatment.

If you have severe depression or anxiety, or a non-drug approach on its own hasn't worked, your GP will generally offer you medication. This may be as well as – or followed by – a talking therapy.

There are many talking therapies that might help. The most common are counselling and cognitive behavioural therapy (CBT). They involve regular sessions with a qualified psychological therapist or counsellor who will work with you in confidence to help with your problems. It is important to find a therapist or counsellor that you get on well with.



**For more information see factsheet 445,  
Talking therapies (including counselling,  
psychotherapy and CBT)**



**For advice and support call the National  
Dementia Helpline on 0300 222 1122**

If you are offered a drug for depression you will need to take it for several months. You may need to give it a few weeks before you see any benefits. You may have some side effects. The GP may try different antidepressants to find what works for you. Common antidepressants work much less well for people with dementia than for those without.

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If you have severe anxiety you may also be given an antidepressant. Drugs called benzodiazepines, which are sometimes given for a short period to treat severe anxiety, aren't generally suitable for people with dementia. There are other drugs for anxiety that are available – speak to your GP.



**For more information see factsheet 444, Apathy, anxiety and depression**

### **Other health conditions**

Many people with dementia also have another long-term health condition. You might live with diabetes or have problems with your breathing, heart or circulation (including stroke), for example. It's important to manage any other conditions you have. If they aren't looked after they may make your dementia worse.

- Try to attend all regular check-ups and appointments. You can ask for a longer appointment if you feel you need one. Ask if you can see the same professional each time.
- Follow the advice set out in your care plan. It will include information about your medication and lifestyle (for example, exercise, diet).



- You may need to tell health professionals that you have dementia. You might have to repeat this information to a number of different professionals. You shouldn't assume that they will always know or have been told.
- Technology could help you manage your condition better – for example, by reminding you to take medication. There are also schemes such as MedicAlert and Message in a Bottle that allow health professionals to find out about your medical history in an emergency. Ask your community nurse, local pharmacist or dementia support worker (if you have one) about these or other schemes.

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## Do you know about delirium?

If you suddenly become more confused, easily distracted, very disorientated or unusually sleepy, this could be because of delirium. Other symptoms can include hallucinations, becoming agitated or 'rambling' speech. All of these may come and go throughout the day.

Delirium is serious, and it is much more common in people with dementia. It can be caused by an infection, a lack of fluids, constipation, pain and some medications. Delirium can be treated.

If you or anyone you know thinks you may have delirium, it is important to see a doctor urgently so they can find out what is causing it. Someone who knows you well should go with you – they will be able to explain to the doctor that how you are behaving is not normal for you.

## Being active

Having dementia doesn't mean you have to stop living your life. Being active can help you to stay independent, in touch with other people, and improve your quality of life. There are all sorts of activities that you can do – physical, mental, social and creative. You may want to try out new activities or continue with ones you enjoy.

### 3

There will be lots of opportunities to take part in different activities in your local area. Many communities are now becoming dementia friendly, including museums, leisure centres, art galleries and theatres. This means the venue will be more welcoming to people with dementia, and staff and volunteers will have more understanding of it.

You may want to try some of these activities:

- taking regular physical exercise such as swimming or walking
- gardening
- creating a scrapbook or photo album
- playing games or cards and doing word, number or jigsaw puzzles
- reading books, newspapers or magazines
- listening to audiobooks, the radio or music
- doing arts and crafts – for example, knitting, painting, singing, dance, writing and poetry
- visiting the theatre or a museum, day trips or holidays
- seeing friends and family
- studying – for example, with the University of the Third Age (see Other useful organisations starting on page 135)
- spending time with a pet.

You might find that some activities take you longer than they did before. You may need to make changes to the way you do things, or have some support to be able to do them.



It can be hard to adjust to this, but it's important to keep doing whatever it is you enjoy.



**For more information see booklet 1506,  
Keeping active and involved**

## Making things easier

Having dementia doesn't mean you need to stop doing the things you enjoy, but it can make things more difficult. The following tips might help:

- Put a regular routine in place – you might find it easier and more reassuring to do things at the same time each day or week. If you find you feel better at certain times of the day try to arrange activities for this part of the day (for example, in the morning).
- Keep things straightforward – simplify your routine or daily tasks to make them more manageable.
- Take things one step at a time – try to focus on one thing at a time and break each task down into smaller steps.
- Put out the things you need before starting an activity so that you have a visual prompt – for example, tools for gardening or ingredients for cooking.
- Try to reduce any distractions – for example, background noise if you are trying to read.
- Give yourself plenty of time and take things at a slower pace if you feel you need to.
- Don't be too hard on yourself if you find something more difficult than you used to.

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## Making your home dementia friendly

There is a lot that you can do to make your home a more supportive place. Making small changes can help you to stay independent, physically active and safe. It is a good idea to make these changes as soon as you feel comfortable to.

- Improve the lighting in your home, remove any trip hazards (such as loose rugs) and get rid of clutter and unused items. This can make your home safer.
- Use colour and contrast to help things to stand out. You could use plain, brightly coloured bed and table linen to contrast with the walls and floor. This also works well for crockery.
- Install smoke alarms and a carbon monoxide detector, if you don't already have them.
- Consider leaving a light on in the bathroom at night and use night lights to help with orientation.
- Ask your local fire service about a free home safety visit.
- Keep a list of ICE (in case of emergency) numbers near the telephone. These are the details of who you want to be contacted if anything happens to you.
- A list of important telephone numbers (people you can call when you need help and support) by the phone can also be helpful.
- There are lots of pieces of technology that can make your home more dementia friendly. See Technology on page 58.

An occupational therapist can offer advice with any of this. Contact your local social services or ask your GP to be referred to one.



**For more information see booklets 819, Making your home dementia friendly, and 1502, Keeping safe at home**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Technology

Many people with dementia find that technology can help them in their daily life. It could allow you to stay independent and keep doing many of the same things you did before. Technology could be simple items like clocks, or more high-tech things, like location devices. Collectively these are known as ‘assistive technology’. Some items that might help include:

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- **Calendar clocks** – these show the date and the day of the week, as well as the time. Keeping the clock next to a diary or weekly planner can help you to keep track of things like appointments.
- **Reminder messages** – a recorded voice message that plays when you go in or out of the house, reminding you to pick up your keys or lock the front door.
- **Locator devices** – these help you find frequently mislaid items such as keys. You attach a small electronic tag to the item. If you mislay it, you can click a button on the locator device to make the tag beep.
- **Medication reminders** – you could try a blister pack or dosette box (see Coping with memory loss on page 48). There are also automatic pill dispensers that will alert you when it’s time to take your medication. For more information speak to your pharmacist.
- **Telephones** – you can get phones with bigger buttons or with pictures on the buttons, if you find them easier. You can also get easy-to-use mobile phones, with fewer buttons and a simpler design, if you find mobile phones difficult.
- **Apps** – if you have a smartphone or tablet there are a range of apps that you might find useful. These include calendars, reminders and maps, as well as apps for life story work, relaxation exercises and mindfulness.



- **Automatic lights** – these are connected to a sensor and come on when you move around, helping to prevent trips and falls.
- **Shut-off devices** – you can have devices installed that turn off the gas, a cooker or a tap if they've been left on.
- **Computer programs and social media** – for example, Skype, Twitter and Facebook, can be a good way of keeping in touch with people. They can also be good for talking to people in similar situations and hearing stories of other people living well with dementia.

Many of these devices can be bought independently. However, it is a good idea to speak to a professional to find out what will suit your needs. Contact your local social services team or independent or assisted living centre. The Disabled Living Foundation and AT Dementia can also provide you with information and advice – see Other useful organisations, starting on page 135. We also sell a number of products that might be useful – go to [shop.alzheimers.org.uk](http://shop.alzheimers.org.uk)



**For more information see factsheet 437, Assistive technology – devices to help with everyday living**

**‘A diary is a great idea. I use post it notes too, to remind me of what I need to do. That way there’s more chance of me actually doing them. I stick them on the wall at the foot of my bed so when I wake up I can see them. Doesn’t always work but it helps a bit.’**

Person living with dementia

## Living alone

If you are living alone, you may face extra challenges. It can be harder to stay active and in touch with people, and to stay safe at home. However, you may be able to stay living at home for some time, if you want to. There are a lot of things you can do to live well when living alone.

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It's important to ask for help, and to have a support network around you. This could be family, friends or neighbours who can help out or check in on you now and again. Ask them for help with things, if you need it. For example, they could go to the shops with you, or you could leave a spare set of keys with a trusted neighbour in case they need to get in. Talk to people about how they can help.

You should also think about what kinds of help and support you might need from professionals. You might benefit from having meals delivered, or from visits by a homecare worker. See Services for people with dementia on page 87.

**'I was diagnosed with vascular dementia six years ago and although I have had to make many adjustments to my life I am living life the best I can. I hope this inspires you a bit. I have just joined a creative writing group and I am loving it!'**

Person living with dementia

It can be harder to stay active and in touch with people when you live alone. You could try joining a local activity group for people with dementia or going to a dementia café. Technology such as Skype and social media can also help you to keep in touch (see Technology on page 58).

If you live alone, you might not have as much help with things you find difficult, or have people on hand if something goes wrong. This can make it more important to make sure your home is safe and dementia friendly. Technology like 'shut-off' devices and telecare systems can help to keep you safe (see Technology on page 58).

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**For more information see booklet 1508,  
Living alone**



## Your next steps



Try some methods to help you to cope with memory loss.



Make some changes to your home that will make it dementia friendly, such as removing trip hazards and improving the lighting.



Introduce exercise to your daily routine and try to eat a balanced diet.



Organise regular check-ups with your GP, dentist, optician and chiropodist.



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# 4

## Planning ahead

### 4

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# 4

## Key points: Planning ahead

After you've had time to adjust to your diagnosis, make sure your finances and affairs are in good order, and all your paperwork is in one place.

There are things you can do to make managing money easier. You can talk to your bank about allowing someone else to deal with your bank account for you. Consider getting a 'chip and signature' or contactless card, so you don't have to remember a PIN number.

You may be entitled to a range of benefits, including Attendance allowance or (if under 65) the new Personal independence payment. Your carer may also be eligible for Carer's allowance. Ask social services, Citizens Advice or Age UK for advice. You will find their contact details in the Other useful organisations section starting on page 135.

It can be difficult, but it is a good idea to plan ahead and talk to those close to you about the future. If you're able, try to do it as soon as you can.

Make sure you have an up-to-date will. Consider setting up a Lasting power of attorney. This will allow someone you trust to make decisions on your behalf if you're no longer able. You can also set up an advance decision to refuse treatment or an advance statement, which allow you to have a say in your future medical care. Talk to your GP or solicitor about this.

If you drive, you may not have to stop immediately but you must tell the Driver and Vehicle Licensing Agency (DVLA) in Great Britain or Driver and Vehicle Agency (DVA) in Northern Ireland about your diagnosis. You will find their contact details on page 140. You must also tell your car insurer.

If you're still working, you may choose to carry on doing so. It's important to talk to your employer. If you stop working or reduce your hours, you may be able to claim some further benefits, such as Employment support allowance or, in some areas, Universal credit.

## Financial matters

Once you have had a chance to adjust to your diagnosis, you might want to start thinking about your finances and how to manage your money in the future. There are things you can do to make paying for things simpler, and there are ways you can plan your finances for the future.

Take some time to ensure your affairs are in order and that all your essential documents can be found easily. This includes details of your bank accounts, tax, benefits and pension, as well as mortgage or rent documents, insurance policies and your will.

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It can help you to know how much money you have for the future. This is useful when it comes to thinking about help with care, or buying equipment. It might also allow you to think about things you can do now, such as going on holiday, which might get harder as your dementia progresses.

### Ways to pay

There are ways that can make paying for everyday things easier. If they aren't already in place, consider setting up direct debits for regular payments such as gas and electricity bills. This means they will get paid automatically and may also be cheaper.

If you have memory problems, you may find it difficult to remember PIN numbers for debit or credit cards. Talk to the bank about alternatives, such as a 'chip and signature' card, or a contactless payment card.



You might also want to set up limits on your debit or credit cards. This means that only so much money can be taken out at one time. This can be a good idea if you lose or misplace things often.

### **Bank accounts**

If you have a joint bank account – for example, with your partner – your bank might advise you to have separate accounts instead. This can make some things simpler. Your benefits and pension, for example, can be paid directly into your account. Having separate accounts may also make means-testing for benefits more straightforward.

If you want to have your own account but want someone else to help manage it, you can arrange a ‘third-party mandate’. This allows a third party to sign cheques and make payments for you. It is only valid while you have the ability (capacity) to manage your own account. If you want someone to manage your finances for you after this you will need to make a Lasting power of attorney – see page 75 for information.

### **Trusts**

If you have property or savings, you might want to set up a trust. This allows someone else to manage these assets on your behalf. It will ensure things are managed the way you have chosen, now and in the future. Seek advice from a solicitor or financial adviser.



**For more information see booklet 1501,  
Managing your money**



**For advice and support call the National  
Dementia Helpline on 0300 222 1122**

## Benefits

You and your carer, if you have one, may be entitled to a range of benefits. Some are 'means-tested', meaning that whether or not you can get them will depend on your financial situation. Others depend on your National Insurance record or your health and individual needs.

Getting the benefits you are entitled to can seem complicated, but there are people who can help. This might include giving you advice on what benefits you can get, and helping you to complete the forms (which can be long and detailed).

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Help may be available from:

- a social worker (contact your local authority)
- a local welfare rights service
- Citizens Advice, Age UK or other local not-for-profit organisations
- Department for Social Development in Northern Ireland.

The government website GOV.UK also provides useful information. For some benefits, the Department for Work and Pensions (DWP) can arrange for someone to visit you at home. You can also call the Disability Benefits Helpline (in England and Wales) or the Benefits Enquiry Line (in Northern Ireland). See Other useful organisations starting on page 135 for contact details.



## Types of benefits

### Attendance allowance, Disability living allowance and Personal independence payment

These are the main benefits that people with dementia can claim. Whether or not you can claim them depends on your daily living, care and mobility needs, not on having a diagnosis of dementia. These benefits aren't means-tested or based on National Insurance contributions. They are tax-free. See page 139 for the relevant enquiry line for each benefit.

Attendance allowance (AA) is a benefit you can apply for if you are 65 or older. It is to support people who need help with personal care – for example, with taking medication, washing or dressing or if they need help to remain safe. There are two different rates that are paid. If you need help either during the day or at night you will get the lower rate. If you need help both during the day and at night you will get the higher rate.

You will need to fill out a form to claim Attendance allowance. You can get this by calling the Disability Benefits Helpline (see Other useful organisations for contact details on page 140). The claim form will include questions about which activities you find difficult or impossible to carry out. It will also ask about what care and supervision you need, such as whether you need help with bathing or cooking. Some of these questions may be quite personal, but it's important you answer honestly. A medical assessment isn't always required for Attendance allowance.

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Two other benefits you might receive, if you claimed when you were under 65, are Disability living allowance (DLA) or Personal independence payment (PIP). These benefits are to support people who have daily living, care and mobility needs. Whether or not you can claim them depends on your needs, not on your diagnosis. They aren't means-tested or based on National Insurance contributions.

PIP is the benefit you can apply for if you are under 65. It has two parts or 'components' – one for daily living (for example, washing, preparing meals, managing money) and one for mobility (for example, difficulty walking outside or being unable to plan and follow a route). There are two rates for each component, and which one you get depends on how much help you need.

DLA was the benefit that was in place before PIP, but no new claims can now be made. If you were born before 8 April 1948 and are already receiving DLA you will continue to receive it and won't be transferred to PIP. If you were born after 8 April 1948 and are receiving DLA you will be transferred to PIP over the coming years.

Everyone who was in receipt of DLA or PIP before the age of 65 will continue to receive one of these benefits beyond this age. All of these benefits can be claimed whether you live alone or with other people. If you are admitted to hospital or residential care for a prolonged period, they may be suspended temporarily.



### Carer's allowance

If you have someone who looks after you for at least 35 hours a week, that person may be entitled to Carer's allowance. This is an amount paid to a carer to support them in their caring role. They will only be able to claim if you receive Attendance allowance, the DLA care component at the highest or middle rate, or the daily living component of PIP at either rate.

Your carer doesn't have to be related to you or live with you to claim Carer's allowance, but they must be 16 or over and earning less than a set amount each week. If they receive Carer's allowance, you could lose some of your benefits as a result. You should get advice before deciding whether your carer should claim.

Your carer will need to fill out a form to claim Carer's allowance. You can get this by calling the Carer's Allowance Unit on 0345 608 4321 or going to the GOV.UK website.

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**'It's very important that you get advice on which benefits you can get and claiming everything that you are entitled to.'**

Carer for a person living with dementia

# 4

## Other benefits

There are other benefits that you or you carer might be entitled to. For example:

- **State pension or Pension credit** – if you or your carer are retired, check that you are getting all the State pension or Pension credit you are entitled to. Phone the Pension Service or go to the GOV.UK website – see Other useful organisations starting on page 135 for details.
- **Housing benefit or Council tax support** – if you are on a low income, you may also be able to claim means-tested Housing benefit (if you are renting) or Council tax support. Your local authority can advise. Many people with dementia will already qualify for reductions on their Council tax bill, regardless of their income.
- **Winter fuel and Cold weather payments** – if you are over the qualifying age you will usually be entitled to Winter fuel payments to help with your heating bills. You might also qualify for Cold weather payments during very cold spells – this depends on your income, not on your age.

For information about benefits specifically for people of working age, see page 83.



**For more information see factsheet 413, Benefits**

## Putting someone else in charge of benefits

If you choose to, you can ask someone you trust – known as an ‘appointee’ – to receive and manage the money you get in benefits. To do this, you will need to contact the Department for Work and Pensions (DWP). The appointee will have to prove that they are managing your money with your best interests in mind.





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## Making decisions for the future

After a diagnosis of dementia, it can be difficult to think about the future. However, it is important to do so as soon as you feel comfortable. Everyone needs to make decisions from time to time about their health, care, finances and housing. As dementia progresses, it will become harder for you to do this. There may come a time when you no longer have the ability (known as ‘mental capacity’) to make decisions for yourself.

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Putting things in place now means you know that your wishes have been recorded and will be respected in the future. This can be reassuring for you, and also for your family and friends. They will be more able to do the right thing for you if you have made it clear to them what you want to happen and what your preferences are.

If you have dementia, the law protects your right to:

- make your own decisions and be involved in any decisions that affect you
- get support with making decisions that you find difficult
- put plans in place in case you are unable to make decisions in the future
- appoint someone you trust to make decisions for you in future – for example about your care, or your finances.

### Wills

Everyone should make a will. It allows you to choose who inherits your money and your possessions. Talk to a solicitor about making or updating a will.

If you are living with dementia, you can still make or change your will, as long as you understand the decision you’re making and what it will mean. A solicitor will be able to help.



## Lasting power of attorney

A Lasting power of attorney (LPA) is a legal tool that gives someone you choose the power to make decisions on your behalf, if you can no longer make them yourself. The person (or people) you choose will be known as an ‘attorney’. They will often be family members or friends, but if you don’t have a suitable family member or friend you could ask a professional such as a solicitor or accountant. In all cases they must make decisions in your best interests.

LPAs aren’t currently available in Northern Ireland because the law there is different. For the system in Northern Ireland see Enduring power of attorney on page 77.

There are two types of LPA:

- **LPA for health and welfare** – this allows the attorney to make decisions about a person’s day-to-day care and treatment, including decisions about whether to refuse or give consent to medical treatment. It can also cover decisions about where the person lives.
- **LPA for property and affairs** – this allows the attorney to do things such as paying bills, collecting income and benefits, accessing bank accounts and selling a house on behalf of the person with dementia.

If you decide to set up an LPA, you will need to do this while you still have the mental capacity to do so. A health and welfare LPA can only be used once you no longer have mental capacity. A property and affairs LPA can be used even if you still have mental capacity.



To make an LPA you will need to fill out a number of forms. These are available from the Office of the Public Guardian. See Other useful organisations starting on page 135 for contact details. The LPA will then need to be registered with the Office of the Public Guardian before it can be used. There is a fee for this.

These forms can be complicated, and many people pay a solicitor to help complete them, but you don't have to. You can now create your own LPA using the government's online tool at [www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney)

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If you don't have access to the internet, or are not confident using a computer, Alzheimer's Society offers a Lasting power of attorney digital assistance service. One of our trained volunteers will be able to complete the online form on your behalf over the phone. To access this service contact Alzheimer's Society **National Dementia Helpline** on **0300 222 1122**.



**For more information see booklet 1510, Planning ahead**

**‘Get [Lasting power of attorney] done ASAP, as everyone says. Send the forms off to be registered quickly as it takes time for them to be returned. It also gives you a chance to amend any mistakes. You can then just keep it until such time as it is needed. You don't have to put it to use straight away.’**

Daughter of a person living with dementia

## Enduring power of attorney

To give someone power of attorney in Northern Ireland you will need to make an Enduring power of attorney (EPA). This is like an LPA, but it only covers property and affairs, not health and welfare. Talk to your solicitor about making an EPA.

EPA was the old system in England and Wales too. You can no longer make an EPA. However, if you made an EPA before 1 October 2007 and it was correctly filled in, it is still valid and can still be registered and used.



**For more information see factsheet NI472, Enduring power of attorney and controllership**

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## Deputies and controllers

If you don't make an LPA or EPA while you still have capacity, it can cause problems for those close to you later on. If a carer or a family member wants to be able to make decisions for you if you no longer can, they will have to apply to become a 'deputy' (in England and Wales) or a 'controller' (in Northern Ireland). This is more expensive than registering a power of attorney, more time consuming, and can take several months. It also doesn't give you the choice of who will make these decisions for you, or what decisions they can make.



**For more information see factsheet 530, Becoming a deputy for a person with dementia**



**For advice and support call the National Dementia Helpline on 0300 222 1122**

## Getting legal advice

If you decide to pay for a solicitor, you may want to talk to a few different ones and compare prices and services. It's important to find a solicitor you are comfortable with and whose advice you trust and understand.

Your local Citizens Advice may be able to offer advice, or you can search the Solicitors for the Elderly website or phone them to find a solicitor in your area. You can also find a local solicitor on the Law Society website. See Other useful organisations starting on page 135 for contact details.

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For more information see booklet 1510, **Planning ahead**

## Other ways to plan your care in the future

You can make decisions about your future care in a range of ways. Talking to family and health or social care professionals about your preferences for the future is often referred to as advance care planning. This can include:

- Lasting power of attorney (see page 75)
- an advance statement (see page 79)
- an advance decision to refuse treatment (see page 80).

Talking about your care in the future, and particularly at the end of life, may be difficult for you. You shouldn't feel you have to have these discussions, if you don't want to.

However, keep in mind that if you do want to plan for the future, you will need to do so while you still have capacity. If you're thinking about advance care planning, it's important to do it as soon as you can.



### Advance statement

One thing you can do to plan ahead is write something called an advance statement. This explains your likes and dislikes, and your priorities and preferences for the future. It might cover where you would like to be cared for or what day-to-day things you like to do, for example. It's used if you're in a position in the future where you cannot decide these things for yourself.

Unlike other ways to plan for the future (such as LPAs or advance decisions), an advance statement isn't legally binding. But it must be taken into account when deciding what is in your best interests.

You can make an advance statement verbally by telling those close to you, or professionals, what your wishes are. But it is better to write it down, if you can, or have someone else write it down for you. This means it is a permanent record of your wishes. You can then put it somewhere safe and tell people where you have put it. It is a good idea to sign it too, though you don't have to do this.

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**'The important thing is to get your affairs in order regarding a will and power of attorney, and to get in touch with charities like Alzheimer's Society, Age UK or a Carers centre for emotional support and practical help.'**

Carer for a person living with dementia

## Advance decision to refuse treatment

If you would like to be able to make decisions now about your future medical care, you can make an advance decision (in England and Wales) or an advance directive (in Northern Ireland). These are legal documents that allow you to refuse, in advance, specific medical treatments or procedures that you would not want. This might include whether to be resuscitated if your heart stops, for example. You can't use an advance decision or advance directive to refuse basic care such as food, drink and pain relief.

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If you're thinking about making an advance decision, talk to your GP. They can talk you through the advantages of choosing or refusing particular medical treatments. Your GP will also record your advance decision on your care plan. You should speak to your close friends or relatives about your advance decision, as this will help them to understand your wishes.



**For more information see booklet 1510, Planning ahead**

**'All I can do is hold on to what works for me right now, and I am learning that sometimes not everything that worked well for me last week will work for me today.'**

Person living with dementia

## Driving

Having a diagnosis of dementia doesn't necessarily mean you have to stop driving straightaway. But it does mean telling certain people, following their advice and possibly taking a driving assessment. As your dementia progresses, there will come a time when you have to stop driving.

If you have a driving licence, the law says you must tell the Driver and Vehicle Licensing Agency (DVLA) in Great Britain or Driver and Vehicle Agency (DVA) in Northern Ireland promptly about your diagnosis of dementia. For contact details see Other useful organisations, starting on page 135. You must also tell your car insurance company.

The DVLA or DVA will ask your doctor about your condition. They might also ask you to take a driving assessment. They will then make a decision about whether you can still drive.

Many people with dementia choose to stop driving voluntarily. It's best to stop if you feel less confident or get lost even on familiar routes. Having to stop driving can be difficult to adjust to but there can be some benefits to it. These include feeling less stressed and saving money on insurance and fuel. Taking advantage of alternative travel options, such as getting a free bus pass and using taxis or 'dial a ride' services, can help you adapt to the change. Talk through how you feel with family and friends.



**For more information see booklet 1504,  
Driving**



**For advice and support call the National  
Dementia Helpline on 0300 222 1122**

## Working

If you are still working, it's possible to keep doing so after a diagnosis of dementia. Dementia affects everyone differently, and it might be better for your physical and emotional wellbeing to continue working. Alternatively, you might feel that stopping work is the best thing for you. You may want to volunteer for a few hours each week instead.

### Getting help

If you're having difficulties in your job, you should think about talking to your employer or asking for professional advice about what to do next. Help and advice is available from a range of places, including:

- your human resources department at work
- your GP
- the Advisory, Conciliation and Arbitration Service (ACAS)
- your trade union, if you have one
- Citizens Advice
- an occupational therapist, who can advise on making adjustments to your role
- a specialist work coach at your local Jobcentre Plus office.

### Talking to your employer

In some jobs you're legally obliged to tell your employer about your diagnosis, so you should check your contract to see if this is the case. If you drive as part of your job, you need to let your employer know straightaway. You might feel anxious about doing this, but telling them about your diagnosis means you will be protected under the law. Once your employer knows, the law says they must try to make 'reasonable adjustments' so you can keep working if you're able to and want to.



## Leaving work

At some stage, you might decide to stop working or retire early. It's important to seek advice about your pension rights. This is particularly important because the State pension age is changing for some people.

## Benefits for people of working age with dementia

If you are of working age and have dementia, you might be able to claim a range of 'working age' benefits.

Depending on your circumstances these can include:

- **Personal independence payment (PIP)** or – if you claimed before June 2013 – **Disability living allowance (DLA)**.

These are to support people who have daily living, care and mobility needs. Whether or not you can claim them depends on your needs, not on your diagnosis. For more information see Benefits on page 68.

- **Working tax credit** – this is a means-tested benefit that you can claim if you are in work but on a low wage. Working tax credit is being phased out and replaced by Universal credit (see page 84).
- **Statutory sick pay** – this is the minimum that an employer must pay you by law, though some employers have an occupational sick pay scheme that is more generous. It can be paid for up to 28 weeks if you have a job but have been sick and unable to work. It isn't affected by any savings you may have. This benefit is paid by your employer, who can give you information about claiming.



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- **Employment and support allowance** – this is the main benefit for people of working age who are unable to work due to ill health. It can be based on either your National Insurance contributions record or on a means test. ESA can also provide you with support for paying mortgage interest, if you need it.
- **Income support** – this is a means-tested benefit paid to certain people, including some carers, who aren't expected to look for work. It can provide you with money for basic living expenses and can be paid on top of other benefits such as Carer's allowance or statutory sick pay. Most people who were receiving Income support because of sickness or disability will have had this replaced with income-related Employment and support allowance (see above).
- **Housing benefit and Council tax support** (see Other benefits on page 72).

After your diagnosis, it's important that you have a full benefits check. Speak to an adviser at Age UK or Citizens Advice.

## Universal credit

Universal credit, introduced in 2013, is replacing many working-age means-tested benefits. These include income-related Employment and support allowance, Housing benefit and Working tax credit. Universal credit is being rolled out across the country. At first it only applies to new claims, but by 2022 it will also apply to existing claims.



Universal credit is paid as one single monthly amount to meet living costs, housing costs, amounts for children (if any) and extra costs arising from disability or caring responsibilities. It doesn't include Carer's allowance, National Insurance benefits, Council tax support or Pension credit.



**For more information see booklet 1509, Employment**

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## Your next steps



Get your finances in order and make sure all your paperwork is in one place.



Write or update your will and appoint an attorney or attorneys.



Arrange a benefits check for you and your carer, if you have one.



Tell the DVLA or DVA, as well as your car insurer, about your diagnosis (if you drive).



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# 5

## Services for people with dementia

### 5

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## Key points: **Services for people with dementia**

There is support available to help you live well and stay independent for as long as possible. The main sources of information and support are the NHS, social services, private companies, and charities and not-for-profit organisations.

Services available can vary from region to region. To find services in your area, start by contacting your GP, local memory service or local authority (council) social services department. You could also try Alzheimer's Society, Citizens Advice or NHS Choices.

Organisations such as Alzheimer's Society, Dementia UK, Age UK and Carers UK can support people with dementia, their families and carers in a range of ways. These include dementia support workers and support groups, telephone helplines and information materials. There are contact details on pages 136–144.

There is lots of support available from health and social care professionals, such as community nurses, dementia support workers and occupational therapists. If you need non-medical support at home, such as help with cooking, the first step is to ask the social services department of your local authority for a needs assessment.

Social services will draw up a care or support plan with you that says how you would like your needs to be met. They may ask you to pay for some services. All local authorities in England are now using a system called personal budgets. This may be received in the form of a direct payment. This is money that is paid straight to you that you can use for different types of care and support.

There are some services specifically designed for younger people with dementia. Your memory clinic, GP or local Alzheimer's Society can tell you what is available in your area.

## Where to go for support

Finding out you have dementia can be daunting and raises many questions about the future. Asking for help can be difficult, particularly if you've always been independent. You might not feel you need it straightaway, but it can be useful to know that a wide range of information and support is available when you do.

There is lots of support out there that can help you. For example, by going to a support group you can meet people in a similar situation and share your feelings, experiences and useful information. This can help you to enjoy a good quality of life. There is also support that can help you to live in your own home for longer, if you want to.

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You will probably know to contact your GP about your health. But you might not know as much about the social care and support that your local authority (council) can offer. It can provide or arrange different types of non-medical care and help. Some services are free but you may have to pay for others, depending on your income and savings.

The way that care and support are delivered is changing. Within England in particular there is a move towards much closer working between the NHS, social care and other organisations. You might find that you visit a 'hub' (where lots of different professionals work together) rather than go to your usual GP practice. The things that matter most to you should be at the heart of all discussions. You may find that, if you have several different long-term conditions, you get help with all these in one visit rather than needing lots of different appointments.



## National Health Service (NHS)

Most people will have already used health services through the NHS, such as a GP or a specialist (for example a consultant). You may also have attended a memory clinic. Services provided by the NHS are free.

There are a wide range of NHS professionals who can help, such as:

- GPs
- medical specialists, such as psychiatrists (for mental health), geriatricians (for physical illnesses of older people) and neurologists (for diseases of the brain and nerves)
- nurses, such as practice nurses, district or community nurses, community psychiatric or community mental health nurses, and specialist dementia nurses such as Admiral nurses
- occupational therapists – they help you maintain everyday skills (in some areas they are accessed through social services not the NHS)
- psychologists – for detailed assessment of memory problems and other mental abilities, support with changes in behaviour and talking therapies such as CBT
- audiologists – for hearing
- optometrists – for sight
- dentists – for teeth and oral health
- physiotherapists – for exercise and mobility
- chiropodists – for feet
- speech and language therapists (they can also help with problems related to swallowing)
- counsellors – for talking therapies
- dietitians – for advice on diet and nutrition.



## Social services and social care

Social services can help you to work out what care and support you and your carer might need. They may also arrange care and support for you, though this will often be provided by a different organisation. Homecare workers and personal assistants can help you to stay independent for as long as possible and stay living in your own home, if you want to.

Services provided or arranged by the local authority might include:

- help in and around the home – for example, with shopping, cooking, cleaning, or washing and dressing
- equipment and adaptations to make life easier or make your home safer – for example, a raised toilet seat, hand rails or a carbon monoxide detector
- help with meals at home
- help with taking medication
- arranging a place at a day centre or support group
- help with managing money and paying bills, dealing with paperwork and claiming benefits
- respite care (temporary care to allow regular carers to take a break)
- intermediate care or re-ablement (support and services that help people to regain their ability to live independently at home after a hospital stay)
- extra care housing (homes where care and support are available on site).

Most information and advice from social services is free. It's also free to have your needs assessed (see How to access social care on page 96). When it comes to receiving care and support services at home, some people will get them for free but others will need to pay. This will depend on the kind of support you need, and your financial situation.



If someone is caring for a person with dementia, they can have their own needs assessed too. See Support for carers on page 103.

## Charities and not-for-profit organisations

Charities and not-for-profit organisations can be a valuable source of local support, advice and information for you, as well as your carer or family. National organisations include Alzheimer's Society, Dementia UK, Age UK, Carers UK and Carers Trust. You can call their national helplines, visit their websites or drop into a local office (if there is one) for more information. Ask whether the following services are available locally and how to access them:

- dementia advisers
- dementia support workers
- specialist dementia nurses
- dementia support groups
- dementia cafés
- day centres
- befriending
- singing groups
- advocacy services
- telephone helplines
- discussion forums
- information – online and in print, such as books and leaflets.

For organisations and contact details see Alzheimer's Society services and support on page 131 and Other useful organisations starting on page 135.



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## Private companies

There are a wide range of private companies that provide care and support services at home (sometimes called ‘domiciliary care’) for people with dementia. You could pay for a homecare worker or personal assistant using your personal budget (see page 98) or from your own money.

For a list of registered agencies in your area, contact your local social services, the UK Homecare Association, or visit the website of the relevant regulator. This would be:

- the Care Quality Commission (CQC) in England
- the Care and Social Services Inspectorate in Wales (CSSIW)
- the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland.

For contact details see Other useful organisations starting on page 135.



**For more information see booklet 1503,  
Health and social care professionals**

**‘Ask social services to send an occupational therapist to make a home visit and assess the situation – they can recommend and provide things around the house that will help to keep you safe.’**

Carer for a person living with dementia

## How to access social care

### Needs assessment (or 'community care assessment')

If you think you need help and support from your local authority, the first step is to ask for a needs assessment, which used to be called a 'community care assessment'. This looks at your physical, mental and emotional wellbeing. It aims to identify what your needs are, what is important to you and what types of care and support would help you.

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### When seeing a health or care professional

- If you're unsure about who someone is or what their role is, ask them to explain it.
- Consider asking a friend or relative to be with you when you go to appointments.
- Think about what you want to discuss at the meeting before you go, and write it down in case you forget.
- Write down anything important they tell you. You can also ask them to write to you with a summary of what you talked about and any actions agreed.
- Alzheimer's Society produces a booklet called **My visitor book** that can help you to keep track of the different professionals you might see.

The assessment will involve a discussion between you, people involved in your care (such as family or friends), and someone from social services. You will probably also be asked to fill in a questionnaire – social services can help you with this if you need it, or you could ask someone you trust to help.

The assessment might cover living arrangements, what you are and aren't able to do for yourself, any worries you may have and how you would like to be supported. Friends or family members can also give their thoughts. Social services may also ask your GP and other professionals for their opinions.

To arrange an assessment, you can contact social services directly. Your GP, consultant or other professional involved in your care will also be able to refer you. The assessment and most information and advice from social services are free.

### **Getting care and support**

Once your needs have been assessed, if social services decide that you qualify for help, they will appoint someone to help you plan your care and support. This will usually be a social worker. They should work with you to agree how to meet your needs in a way that suits you best. They will then write something called a 'care and support plan' with you, and give you a copy.

Social services might provide some of the services you need themselves, or they might suggest private companies or charities that can help. Some people choose to arrange services for themselves, often with the help of a relative or friend.



You may have to pay towards the cost of your care and support. This will depend on your financial situation, such as your income, savings and other assets. The value of your home won't normally be taken into account if you are living there.



**For more information see factsheets 418, Assessment for care and support in England, W418, Assessment for care and support in Wales, or NI418, Community care assessment, for those in Northern Ireland**

## 5

### **Personal budgets**

If the local authority is paying for some or all of your care, they should talk to you about a personal budget. This is an amount of money allocated to you by the local authority to meet your care and support needs. Personal budgets are designed to give you control and choice over the care you receive.

You can ask social services to manage your personal budget for you. This means you don't have to deal with the paperwork, but you should still have choice about how you want to be supported. Or you can choose to receive your personal budget as a direct payment. This means that you or a family member or friend is responsible for keeping records of how it's spent in line with your support plan. Social services can tell you of local organisations to support you to manage your direct payments.



You can use the money in a range of ways, as long as they are set out in your care and support plan. This plan will identify things that matter to you and help you stay independent for as long as possible. It will have been agreed with your social worker. Everyone is different but some people will choose to spend their money on a personal assistant or home carer. Others may spend it on a social activity, equipment to help them remain independent, or technology that allows them to stay in touch. However, it could be spent on other things as well – it depends what is agreed in your plan.

Ask social services for help and information about personal budgets. They can tell you about local organisations that can help you understand how to use one.



**For more information see factsheets 532, Paying for care and support in England, W532, Paying for care and support in Wales, and 473, Personal budgets**

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**‘Pop along to your local dementia café and speak to one of the advisers and hopefully you’ll meet other people and their carers. The dementia cafés are there to help and not everyone is old.’**

Daughter of a person living with dementia

## Services for younger people

If you have been diagnosed with dementia and are in your 40s, 50s or early 60s, you will have very different interests, care and support needs from someone diagnosed in their 80s or 90s. For example, you are more likely to be physically active and working (or have a partner who is), have dependent children or possibly dependent parents, and still have a mortgage. Your symptoms may also be different.

Services for people with dementia have often been developed with older people in mind, and in some cases they are only available to those over 65. Even where a service is open to younger people, the type of care and support provided may not always be appropriate or able to meet your needs.

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The number of activity groups and services suitable for younger people is still limited. You may have to travel to find something or to meet people with similar interests. Ask your memory clinic, consultant, GP or social services about activities, support and services for younger people with dementia. Contact Alzheimer's Society about putting you, your family or carers in contact with others in the local area, or in similar circumstances.

Alzheimer's Society's online discussion forum, Talking Point, includes a section for younger people with dementia and their carers. See page 132 for more information on this. You might also find it helpful to contact, visit the websites of, or subscribe to newsletters from organisations that support people with a particular type of dementia.



As a younger person, if you're eligible for funded social care then you may find that a direct payment gives you the flexibility you need to make your own arrangements and pay for care. This can make it easier for you to get support that is right for you.



**For more information see booklet 688,  
Young-onset dementia: Understanding your diagnosis**



## Your next steps



Ask social services for a needs assessment. If you have a carer, they can also ask for a carer's assessment.



Get in touch with Alzheimer's Society to find out about local services for you and your carer.



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# 6

## Support for carers

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# 6

As your dementia progresses, you will need more support. Often one person – maybe your partner or a family member – will care for you most of the time. This section has been written for them, to help them to understand how best to help and support you, as well as how to look after themselves.

## Key points: **Support for carers**

Caring for someone with dementia can be rewarding, and it can bring positive feelings, such as satisfaction from being able to support the person. But it can also be very stressful and at times upsetting. You may go through a wide range of emotions, including loss, guilt and anger. This is normal, but it's important to talk about how you feel and try to deal with your emotions.

It's important to look after your own health and wellbeing. This will be good for you and the person you care for. Try to eat a balanced diet, and to get enough sleep and exercise. Make sure you also have some time to yourself.

You have a right to a carer's assessment and to support to help you in your caring role. A lot of information and advice is also available. Sources of support for carers include family and friends, health professionals, memory services, social services, carers' support groups and organisations such as Alzheimer's Society.

There are practical ways to make caring for someone with dementia a little easier. Try to see things from their point of view, and encourage them to keep doing the things they are able to, as this helps them to stay independent.

When communicating, make eye contact, listen carefully and speak clearly. Try not to ask too many questions at once and give the person time to respond.

You may find changes in the person's behaviour difficult to cope with. They might repeat themselves, follow you around, pace or shout out. They aren't doing these things deliberately, so try not to take it personally. This will often be their way of trying to tell you something – they may be in pain, bored or frustrated, for example. Talk to a doctor – ideally a specialist – or a member of a specialist dementia team if the person's behaviour is causing either of you distress or worry. There are things that can be done to help.

## Looking after yourself

If someone close to you has been diagnosed with dementia, it can have a big impact on your relationship with them, whether they are your partner, parent or friend. You might find that you take on the role of a 'carer' without making a conscious decision to do so.

You may not think of yourself as a carer, or like being referred to as one. You may still think of yourself as a partner or friend. However you think of yourself, if you are caring for someone with dementia you will face the same challenges and sometimes both of you will need support.

Caring for and supporting someone with dementia can be rewarding, but it can also be stressful and at times upsetting. Even when it feels difficult and you don't feel like you have the time, it's important that you look after your own health and wellbeing, and turn to others for support when you need it. This is important for you and the person you care for. There is advice available to help you understand dementia and support the person you care for as well as possible.

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### Emotional support

One of the most difficult things about caring for a person with dementia is the range of different emotions you experience. You might get satisfaction from supporting the person, but you may also have feelings of loss, grief, guilt, embarrassment and anger. Some carers find that they become physically very tired or depressed. It can help to know that these feelings are normal – lots of other carers will feel the same way.



However, it's important to try and work out why you're feeling this way, and talk about it to someone you trust. You might choose a professional, a friend or family member, or someone at a carers' support group. You could also try an online discussion and support forum like Talking Point. For more information see Alzheimer's Society services and support (starting on page 131) and Other useful organisations (starting on page 135).

### Staying positive

Caring for a person with dementia can be difficult, but trying to stay positive can help. Focusing on the positives in your life may help you to feel better about things and help you face challenges. A positive attitude can make you feel better and improve your wellbeing. It may also have a positive effect on the person you care for.

You will have hard times, but there will be lots of rewarding moments too. It can help to try and focus on these, especially when things feel difficult. You should also try to remember how much you are helping the person you care for.

Things may change between you, but there will still be lots that you can do together – for example, listening to music, going for a walk, or looking through old photographs. Try to focus on the things you can do together, not the things you can't. You might even find new ways of spending time together.



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## Your health and wellbeing

When you are caring for a person with dementia, it can be easy to put their needs before your own. However, it's important to look after yourself properly. It will improve your health and wellbeing, and this means you can do your best to care for the person with dementia.

### Your health

- It's important that you eat a balanced diet and make time for regular exercise. Gardening, walking the dog or swimming can all help.
- See your GP about your own health regularly and check that you are on the carers' register at the practice.
- If you have to help move or lift the person you're caring for, ask your GP to refer you to a physiotherapist for advice so you don't risk injuring yourself.
- If you're having problems sleeping, ask your doctor for advice. Waking up early and not going back to sleep can be a sign of depression.
- If you feel overwhelmed, sad, anxious or depressed a lot of the time, talk to your GP. They may refer you to a psychological therapist to talk through your feelings and try to address them.

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**'Whether a carer or cared for, we all need to be positive.'**

Former carer for a person with dementia

## Your wellbeing

Try to regularly make time to relax or do something for yourself, such as going for a walk, reading or just enjoying a cup of tea. This can have a big impact on your wellbeing. Try to get out regularly to meet friends too. It's important to keep socially active and in touch with people.

If possible, consider an outing or short break, as this can relieve stress and leave you feeling refreshed. Find out about day care or respite (replacement) care. This is temporary care for the person you support that allows you to take time out knowing they are well looked after. You should also speak to your friends and family about how they can help with this.



**For more information see factsheet 523, Carers – looking after yourself, or booklet 600, Caring for the person with dementia: A handbook for families and other carers**

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**‘It does take time to adjust to a new way of living, and at times it can be really hard, but along the way there are smiles and certainly understanding, support and empathy.’**

Carer for a person living with dementia

## Practical support for you

Caring for a person with dementia can become more demanding as their condition progresses, both physically and emotionally. Getting the right support will make it easier for you to cope, and it will be better for the person you care for. There are many sources of support, including:

- **Social services and the carer's assessment** – as a carer you're entitled to have your own needs assessed by social services. This is called a carer's assessment, and will consider the impact the care and support you provide is having on your wellbeing and your life. Even if you live in a different area, you may be eligible for support from the local authority (council) where the person with dementia lives. They will offer you advice and guidance to help you with your caring responsibilities. The local authority might charge for some of these services, depending on your financial situation.
- **Friends and family** – you might find it difficult to ask for or accept help, but you should try to involve family, if possible. You could share out some responsibilities, which will take the pressure off you a little. Telling them what they can do may be helpful. It might also help to talk to them about what would happen if you became unwell or in an emergency – it can help to have support and a plan in place.
- **Benefits and your employer** – if you work, talk to your employer about your options. You might be able to arrange flexible working. If you decide to stop working, take advice about your pension entitlements. You should also find out about any benefits you might be entitled to.

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For advice and support call the National Dementia Helpline on **0300 222 1122**

- **Support workers** – many not-for-profit organisations have trained dementia support workers who can give practical information, guidance and support about caring for someone with dementia. They can come to your home or provide support over the phone.
- **Dementia specialist nurses** – these are nurses who specialise in dementia, such as an Admiral nurse. They provide practical, clinical and emotional support to families living with dementia to help them cope.
- **Support groups** – local carers' support groups give you a chance to chat to other people going through similar experiences. You can share practical tips and get emotional support. Ask your memory service or local Alzheimer's Society about groups in your area.
- **Online discussion forums** – these can be a helpful source of support at any time of the day or night. You can talk online with other people who are going through similar things. They may be able to give advice, share practical suggestions, or just offer understanding. Visit Alzheimer's Society's Talking Point at [alzheimers.org.uk/talkingpoint](http://alzheimers.org.uk/talkingpoint)
- **National Dementia Helpline (0300 222 1122)** – trained advisers can provide information, advice and support.
- **Respite care (also known as replacement care)** – temporary care for the person you support that allows you to take a break. This could be for a few hours or a few weeks. Your local authority might provide this, or you can arrange it independently.



**For more information see factsheet 462, Replacement care (respite care) in England, W462, Respite care in Wales, or NI462, Respite care in Northern Ireland**



## Tips for supporting a person with dementia

How you care for the person will mostly be down to your relationship with them. It will be based on instinct and your understanding of the person. You will probably know the person best, and you shouldn't underestimate how important this is to the care you provide. It's important to continue to see the person – with their life history, interests and desires – and not just as a person defined by their dementia.

### Understanding and supporting the person

Many people describe the experience of living with dementia as a series of losses. Dementia will affect how they think, feel and behave, and will make it more difficult to do some everyday things that they used to find straightforward. This can be hard for them and you to adjust to.

Everyone will experience dementia differently. It will depend on their personality, past experiences, relationships, environment and the support they receive. Understanding how a person is experiencing dementia can help you to support them in the best possible way.

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**'We concentrate on what we can do rather than what we can't. He can get very frustrated with struggling to find the right words and his ability to read and write are reduced but we still have lots of lovely days and enjoy each other's company.'**

Wife of a person living with dementia



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The following tips may help you to support a person with dementia, both emotionally and practically:

- The person's world will be very different to yours, so try to see things from their point of view, rather than expecting them to see it from yours.
- Put yourself in their shoes – try to understand how the person might be feeling and how they may want to be cared for. Listen and observe carefully.
- They may find it hard to remember or concentrate on things, so try to be flexible and patient.
- Try to make the person feel valued and included – support them to do as much for themselves as they are able to, rather than doing everything for them. When you help out, try to do things with them, not for them.
- Include the person in conversations and activities as much as possible.
- Focus on what they can do rather than on what they can't. This will help them to feel more independent. For example, lay clothes out for them to dress themselves, if this is possible.
- The person is likely to remember how things in the past made them feel even if they can't remember the facts of the event. It can help to focus on how something or someone makes the person feel – for example, that someone makes them feel happy, even if they don't remember their name.

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- Think what is important to the person, such as maintaining their relationships, social activities, routines, hobbies and interests. Support them to continue with these. Doing things together can help.
- Enjoy the moment – try not to focus on what has been lost or what may be to come.
- People develop different coping strategies for living with dementia. It can be hard to adjust to these, but they are the person's way of managing their situation.
- Help the person to keep their sense of identity – they are a unique individual and not someone who is defined by having dementia.
- Relationships can be more difficult when someone has dementia. Try to focus on the positive aspects of your relationship with the person. Activities such as life story work and reminiscence can help with this.

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**For more information, see factsheet 524, Understanding and supporting a person with dementia, and booklet 600, Caring for a person with dementia: A handbook for families and other carers**

## Communicating

Dementia can make it hard for people to communicate. How it affects the way someone communicates will vary from person to person. In most types of dementia, people will at times struggle to find the right words or follow a conversation.



This can be upsetting and frustrating both for the person and for you. However, there are lots of ways to support each other:

- Make sure you're in a good place to talk – quiet, with good lighting and without too many distractions (for example, no radio or TV on in the background).
- Get the person's full attention before you start, and try to make eye contact.
- Use body language, such as gestures, facial expressions and touch. You can give a lot of reassurance through physical contact, if it feels right.
- Speak clearly and think about the words you use. If the person is still having difficulty with understanding, use simpler words or try to explain things differently.
- Stick to one topic at a time and make sure questions are straightforward. For example, 'Would you like tea or coffee?' might be better than 'What would you like to drink?' Having too many choices can make decisions difficult.
- Give the person plenty of time to respond.
- If it feels right, humour can help with misunderstandings and mistakes. Laughing together can ease tension, but you will need to judge how the person responds to this.
- Talk to the person with respect.

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- Involve the person in the conversation when others are around, and don't talk over them.
- Problems with hearing or eyesight, pain or the side effects of medication can affect a person's communication. If you think this is the case, your GP may be able to help.



**For more information see factsheet 500,  
Communicating**

## Changes in behaviour

A person may start to behave differently as their dementia progresses. Many carers find dealing with this more difficult than adjusting to changes such as memory loss. Some common changes you may see include:

- repetition – for example, asking the same question, or repeating an action, over and over
- restlessness – for example, pacing or fidgeting
- lack of inhibition, such as socially inappropriate behaviour in public – this is particularly common in the behavioural form of frontotemporal dementia
- night-time waking, sleeplessness and 'sundowning' (increased agitation or confusion in the late afternoon and early evening)
- following you around or calling out to check where you are
- putting things in unusual places, and then forgetting where they are
- suspicion – for example, the person thinking someone has taken something belonging to them, when they have actually mislaid it.



Lots of factors can affect someone's behaviour and it's important not to just dismiss it as being due to the person's dementia. Often it is their way of trying to communicate something, such as being in pain or being bored. Think about how the person is feeling and what they might be trying to say. Working out what the problem is, if there is one, will be the first step to being able to address it.

In some cases, the behaviour might be because of a health problem that can be treated, such as pain or discomfort from constipation or an infection. See the GP for a medical assessment.

It can help to try and work out if there are any patterns or triggers for the person's behaviour, or anything that may be affecting them. For example, does it happen at a certain time of day? Is the environment too hot or too noisy? Writing things down in a diary might help with this.

Changes in behaviour can be difficult to deal with, but there is a lot you can do to help the person:

- Try to stay calm. If you need to, take some deep breaths or leave the room.
- Remember that the person isn't being deliberately difficult – their condition may be affecting their sense of reality. Try to think of things from their perspective and offer reassurance.
- Consider whether the behaviour is really a problem. If it is interrupting an activity it may be best to come back to it later. Sometimes it can be best just to make sure the person is safe and support them to do what they want.

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- Use what you know about them – for example, if they used to work nights they may be used to being awake at night.
- Make sure the environment is supportive – not too hot or cold, not too noisy or overstimulating and with familiar objects in it.
- See if engaging them in meaningful activities or social interaction can help. You could also try physical exercise, hand massage or music therapy. Other useful activities include life story or reminiscence work. See Non-drug treatments on page 35 for more information.
- If a person's behaviour causes distress, seek advice and support from the GP, memory service, clinical psychologist, community mental health nurse or Admiral nurse (registered nurses who specialise in dementia). If their behaviour continues and you're not in contact with a dementia specialist, ask for a referral to one.



**For more information see factsheet 525,  
Changes in behaviour**

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### **Behaviours that challenge**

As a person's dementia progresses, they may start to exhibit 'behaviours that challenge'. You may still hear these included under the broader term 'behavioural and psychological symptoms of dementia' (BPSD). These types of behaviour can become severe and very distressing, for the person with dementia and for carers.

Behaviours that might be challenging include:

- becoming very agitated
- shouting or screaming – perhaps in response to mistaking something they can see for something else (misperceptions), or seeing things that aren't there (hallucinations)
- behaving aggressively, either physically or verbally.



With these kinds of behaviour, you should firstly check whether there is a medical or physical cause – for example, pain or an infection. You might also find that there are ‘triggers’ for the behaviour. Identifying and avoiding these triggers and knowing what meaningful activities the person enjoys may help. However, if they don’t, or a person’s behaviour is severe or very distressing, the doctor might refer you to a specialist (for example, a clinical psychologist) or suggest medication.

In some circumstances the doctor will recommend an antipsychotic drug. If so, ask them about the possible benefits and risks. These drugs don’t work for everyone and they can have serious side effects. An antipsychotic drug should only be offered for severe symptoms or after non-drug options have been exhausted, and only then for a short period (up to 12 weeks).



**For more information see factsheets 509, Aggressive behaviour, and 408, Drugs for behavioural and psychological symptoms in dementia**

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**‘Please don’t get too upset as that puts more pressure on yourself. Just go with the flow and make the best of the good days and try to wave the bad ones away.’**

Wife of a person living with dementia



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# 7

## Research

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## Key points: Research

Researchers are finding out more about what causes dementia and how to diagnose it better. They are also developing new treatments and ways to improve quality of life for people living with the condition.

There are opportunities to take part in research for both people with dementia and carers. This could be taking part in a clinical trial to test a new treatment or approach, or giving blood for genetic research. Or you could give your views on the healthcare and support services you have received.

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You can go online to register your interest in getting involved in dementia research – go to Join Dementia Research at [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk) – or you can call Alzheimer’s Society **National Dementia Helpline** on **0300 222 1122**. You can also ask at your memory service about trials in your area.

You can get advice and guidance on getting involved in health research from NHS Choices. You will find their contact details on page 141.

Alzheimer's Society has a Research Network that you can join to help influence how we fund research. Email [research@alzheimers.org.uk](mailto:research@alzheimers.org.uk) or phone **020 7423 5153** to get involved.

## Research into dementia

Researchers are working hard to find a cure for dementia, with the help of many people with dementia and carers. Dementia is a complex condition and there are lots of different types of research taking place. Researchers are:

- trying to better understand what causes dementia and what happens in the brain as it progresses
- finding better ways to diagnose dementia earlier using lab tests and complex brain scans
- designing new treatments and testing them in clinical trials
- testing what works in dementia care to improve quality of life for people with dementia and their families
- looking at what things affect a person's risk of developing dementia so they can find ways to prevent it.

## Taking part in research

Research into dementia would not be possible without the help of people living with the condition. This help can take many forms. It might mean being involved in a clinical trial to test a new treatment, giving blood for use in genetic research, or giving your views on the quality of healthcare and support services.

Many hospitals and universities support research into dementia. You have a right to choose to take part in relevant and appropriate research as part of your care within the NHS. Most people who take part in research value the opportunity to make a difference.

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They say that they welcome the chance to try new treatments or services, and to influence and improve care. It can also provide opportunities for you to share your opinions and experiences, and have your condition monitored more closely.

If you or your carer would like to take part in research, there are several ways you can do this. Ask the GP or at the memory service about research happening in your area. You can also register your interest with Join Dementia Research – [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk) – a national online service that helps match people affected by dementia with suitable research studies in their area.

Each study will need different people. Your age, the medication you are taking and any other health conditions you have might mean that there isn't always a suitable study for you available. However, you will be informed when new studies come up that may match your profile. If you aren't online or need help to register with Join Dementia Research, you can call the **National Dementia Helpline** on **0300 222 1122**.

If you do take part in research, you will be fully informed and asked to give your consent. You can leave the study at any time without affecting the rest of your care.

You can find out more about ongoing research into dementia from Alzheimer's Society or Alzheimer's Research UK (see Other useful organisations starting on page 135 for contact details).

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## Influencing dementia research

If you do not want to take part in a study, there are other ways that you can still contribute to dementia research. Alzheimer's Society works with people affected by dementia to improve the quality and relevance of the research that is funded in the UK.

Alzheimer's Society's Research Network is a group of over 270 people with dementia, carers and former carers. These volunteers share their views by reviewing research proposals, discussing projects with researchers, helping to set research priorities and raising awareness of the importance of dementia research. All volunteers get training and support to be able to do this.

Volunteers can be involved as little or as much as they want to and they can volunteer from home. If you'd like to find out more about the Research Network, visit [alzheimers.org.uk/researchnetwork](https://alzheimers.org.uk/researchnetwork), email [research@alzheimers.org.uk](mailto:research@alzheimers.org.uk) or call **020 7423 5153**.



### Your next steps



Find out if there are any research studies going on in your area by registering with Join Dementia Research.



Join Alzheimer's Society's Research Network.



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# 8

## Alzheimer's Society services and support

**Alzheimer's Society provides a range of services and resources to support people affected by dementia**

## National services

These are available wherever you live in England, Wales and Northern Ireland.

### **National Dementia Helpline – 0300 222 1122**

The Helpline is for anyone who is affected by dementia or worried about their memory. Trained advisers provide information, support, guidance and signposting to other appropriate organisations. The Helpline is open 9am–8pm Monday–Wednesday, 9am–5pm Thursday and Friday, and 10am–4pm Saturday and Sunday. You can also contact the Helpline by email at [helpline@alzheimers.org.uk](mailto:helpline@alzheimers.org.uk)

### **Talking Point online community**

Talking Point is an online support and discussion forum for anyone affected by dementia. It's a place to ask for advice, share information, join in discussions and feel supported. Talking Point is available 24 hours a day, every day of the year. Visit [alzheimers.org.uk/talkingpoint](http://alzheimers.org.uk/talkingpoint)

### **Dementia Connect**

Dementia Connect is our online dementia services directory for anyone affected by dementia in England, Wales and Northern Ireland. It has over 17,000 listings of local information, support and services. You can enter your postcode or place name to find services nearest and most relevant to you. It includes services run by voluntary or charity organisations (such as Alzheimer's Society or Age UK), your local authority and registered care services. Each listing includes a map and clear, essential information about that service. Visit [alzheimers.org.uk/dementiacconnect](http://alzheimers.org.uk/dementiacconnect)



## Information

Alzheimer's Society produces a wide range of information for people with dementia, carers, family and friends. This includes the factsheets and booklets listed in this guide. You can read this information at [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications). To request printed copies, go to the order form on our website or phone **0300 303 5933**.

## LPA digital assistance service

Alzheimer's Society offers a Lasting power of attorney digital assistance service to help people create and register LPAs online. If you don't have access to the internet, or don't feel confident using a computer, we will complete the forms on your behalf. Call the Alzheimer's Society **National Dementia Helpline** on **0300 222 1122**.

## Local services

Alzheimer's Society provides a range of local services in England, Wales and Northern Ireland. These include dementia advisers and dementia support workers, Singing for the Brain® groups, dementia cafés, Side by Side (where people with dementia are paired with volunteers so they can keep doing the things they love) and support for carers.

The services that are available can vary from place to place. Contact your local Alzheimer's Society office or the National Dementia Helpline for more information about Society services in your area or visit [alzheimers.org.uk/dementiaconnect](https://alzheimers.org.uk/dementiaconnect)

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For advice and support call the National Dementia Helpline on **0300 222 1122**



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## Other useful organisations

### **Age UK**

0800 169 6565 (advice line, 8am–7pm every day)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

### **Age Cymru**

08000 223 444 (helpline, 9am–5pm weekdays)  
[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

### **Age NI**

0808 808 7575 (advice line, 9am–5pm weekdays)  
[www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)

Aims to improve later life for everyone through information and advice, services, campaigns, products, training and research.

### **Alzheimer's Research UK**

0300 111 5555  
[enquiries@alzheimersresearchuk.org](mailto:enquiries@alzheimersresearchuk.org)  
[www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)

A leading dementia research charity.

### **AT Dementia**

0115 748 4220  
[www.atdementia.org.uk/contactus.asp](http://www.atdementia.org.uk/contactus.asp) (contact form)  
[www.atdementia.org.uk](http://www.atdementia.org.uk)

Provides information on assistive technology that can help people with dementia live more independently.

### **Benefit Enquiry Line Northern Ireland**

0800 220 674  
[www.nidirect.gov.uk/benefit-enquiry-line](http://www.nidirect.gov.uk/benefit-enquiry-line)

Provides advice on benefits to people in Northern Ireland.



### **British Psychological Society**

0116 254 9568  
enquiries@bps.org.uk  
www.bps.org.uk

Provides access to a list of clinical and counselling psychologists who offer private therapy services.

### **Care Quality Commission**

03000 61 61 61  
www.cqc.org.uk/content/contact-us-using-our-online-form  
(contact form)  
www.cqc.org.uk

The independent regulator of health and social care services in England.

### **Care and Social Services Inspectorate Wales**

0300 7900 126  
cssiw@wales.gsi.gov.uk  
www.cssiw.org.uk

The independent regulator of health and social care services in Wales.

### **Carers Trust**

0300 772 9600  
029 2009 0087 (Wales)  
support@carers.org  
www.carers.org

Works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend.



### **Carers UK**

0808 808 7777 (advice line, 10am–4pm weekdays)  
advice@carersuk.org  
www.carersuk.org

Provides information and advice about caring, alongside practical and emotional support for carers.

### **Citizens Advice**

www.citizensadvice.org.uk

Citizens Advice offers free, confidential, impartial and independent advice to help people resolve problems with debt, benefits, employment, housing and discrimination. To find your nearest Citizens Advice, use the website above or look in the phone book.

### **Court of Protection**

0300 456 4600  
courtofprotectionenquiries@hmcts.gsi.gov.uk  
www.gov.uk/courts-tribunals/court-of-protection

The Court of Protection helps people who have difficulty making their own decisions by making the decisions for the person or appointing someone else to do so.

### **Dementia UK**

0800 888 6678 (Admiral Nurse helpline)  
direct@dementiauk.org (Admiral Nursing Direct)  
www.dementiauk.org

National charity committed to improving quality of life for all people affected by dementia. Provides Admiral Nurses who are mental health nurses specialising in dementia care.



### **Department for Work and Pensions**

[www.gov.uk/government/organisations/department-for-work-pensions](http://www.gov.uk/government/organisations/department-for-work-pensions)

Government website with details of benefits and pensions, and how to claim them.

### **Disability Benefits Helpline**

[www.gov.uk/disability-benefits-helpline](http://www.gov.uk/disability-benefits-helpline)

#### **Attendance allowance (AA)**

0345 605 6055

#### **Disability living allowance (DLA)**

If you were born on or before 8 April 1948 – 0345 605 6055

If you were born after 8 April 1948 – 0345 712 3456

#### **Personal independence payment (PIP)**

0345 850 3322

Provides information and advice about Attendance allowance, Disability living allowance and Personal independence payment. All phone lines open 8am–6pm weekdays.

### **Disabled Living Foundation**

0300 999 0004 (helpline, 10am–4pm

Tuesday, Wednesday and Thursday)

[info@dlf.org.uk](mailto:info@dlf.org.uk)

[www.dlf.org.uk](http://www.dlf.org.uk)

Provides information and advice on equipment and technology that can help people with dementia to live more independently.



### **Driver and Vehicle Agency (DVA)**

0300 200 7861

[dva@infrastructure-ni.gov.uk](mailto:dva@infrastructure-ni.gov.uk)

[www.nidirect.gov.uk/contacts/contacts-az/driver-vehicle-agency-driver-licensing](http://www.nidirect.gov.uk/contacts/contacts-az/driver-vehicle-agency-driver-licensing)

Government-funded agency that issues driving licences and vehicle registration documents in Northern Ireland.

### **Driver and Vehicle Licensing Agency (DVLA)**

0300 790 6806 (for queries about medical conditions, including dementia)

[www.gov.uk/contact-the-dvla](http://www.gov.uk/contact-the-dvla)

Government-funded agency that issues driving licences and vehicle registration documents in Great Britain.

### **GOV.UK**

[www.gov.uk](http://www.gov.uk)

Online government services and information covering benefits, driving, housing, money and tax, working and pensions.

### **Law Society**

020 7320 5650 (to find a solicitor)

[www.lawsociety.org.uk/get-in-touch](http://www.lawsociety.org.uk/get-in-touch) (contact form)

[www.lawsociety.org.uk](http://www.lawsociety.org.uk)

The body representing solicitors in England and Wales.



### **Mind**

0300 123 3393 (helpline, 9am–6pm weekdays)  
info@mind.org.uk  
www.mind.org.uk

Mental health charity that provides information on all aspects of mental health and provides a range of support through local associations.

### **NHS 111 service**

111  
www.nhs.uk/111

Information on a wide range of health topics. 24-hour telephone service gives access to clinical information, confidential advice and reassurance on next steps.

### **NHS Choices**

0300 123 1053 (Carers Direct helpline, 9am–8pm weekdays, 11am–4pm weekends)  
www.nhs.uk  
www.nhs.uk/service-search (for local services)  
www.nhs.uk/conditions/clinical-trials (guidance on getting involved in health research)

The UK's biggest health website, providing a comprehensive health information service that aims to put people in control of their healthcare.

### **NHS Direct Wales (Galw Iechyd Cymru)**

0845 4647 (helpline, 24-hour)  
www.nhsdirect.wales.nhs.uk

NHS Direct service for people in Wales – it provides information in English and Welsh.



For advice and support call the National Dementia Helpline on **0300 222 1122**

## **NI Direct**

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

Official government website for people in Northern Ireland. Information and services about benefits, driving, housing, money and tax, pensions, health and wellbeing.

## **Office of the Public Guardian**

0300 456 0300 (9am–5pm weekdays, except Wednesdays  
10am–5pm)

[customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)

[www.gov.uk/government/organisations/office-of-the-public-guardian](http://www.gov.uk/government/organisations/office-of-the-public-guardian)

Provides information and advice on powers of attorney and deputyship. It also helps attorneys and deputies to carry out their duties and protects people who lack mental capacity to make decisions for themselves.

## **Pension Service**

0800 731 7898 (State pension claim line)

0800 99 1234 (Pension credit claim line)

0345 606 0265 (general queries)

[www.gov.uk/contact-pension-service](http://www.gov.uk/contact-pension-service)

Helps with State pension eligibility, claims and payments, including Pension credit. All lines open 8am–6pm weekdays.

## **Regulation and Quality Improvement Authority**

028 9051 7500 (9am–5pm weekdays)

[info@rqia.org.uk](mailto:info@rqia.org.uk)

[www.rqia.org.uk](http://www.rqia.org.uk)

The independent regulator of health and social care services in Northern Ireland.



### **Royal College of Occupational Therapists**

020 7357 6480

[www.rcot.co.uk](http://www.rcot.co.uk)

The professional body for occupational therapists. Offers advice on how to find an occupational therapist and what occupational therapy can offer.

### **The Silver Line**

0800 4 70 80 90 (helpline, 24 hour)

[info@thesilverline.org.uk](mailto:info@thesilverline.org.uk)

[www.thesilverline.org.uk](http://www.thesilverline.org.uk)

Provides a 24 hour helpline for older people across the UK. Also provides telephone and letter friendship schemes.

### **Society of Later Life Advisers**

0333 2020 454

[admin@societyoflaterlifeadvisers.co.uk](mailto:admin@societyoflaterlifeadvisers.co.uk)

[www.societyoflaterlifeadvisers.co.uk](http://www.societyoflaterlifeadvisers.co.uk)

Independent organisation that helps people find trusted accredited financial advisers who understand financial issues of later life.

### **Solicitors for the Elderly**

0844 567 6173 (for help finding a solicitor)

[admin@sfe.legal](mailto:admin@sfe.legal)

[www.sfe.legal](http://www.sfe.legal)

An independent, national organisation of solicitors, barristers and legal executives who provide specialist legal advice for older and vulnerable people, their families and carers.



**UK Homecare Association Ltd**

020 8661 8188

[enquiries@ukhca.co.uk](mailto:enquiries@ukhca.co.uk)

[www.ukhca.co.uk](http://www.ukhca.co.uk)

The national association for organisations who provide social care, including nursing services, to people in their own homes.

**University of the Third Age**

020 8466 6139

[www.u3a.org.uk/contact-us.html](http://www.u3a.org.uk/contact-us.html) (contact form)

[www.u3a.org.uk](http://www.u3a.org.uk)

Organisation that provides courses, learning opportunities and activity groups for retired and semi-retired people at lots of centres in local communities, as well as online.





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## Factsheets



### **What is dementia?**

Code 400



### **Dementia and the brain**

Code 456



### **Easy Read: What is dementia?**

Code ER1



### **Drug treatments for Alzheimer's disease**

Code 407



### **Rarer causes of dementia**

Code 442

## Booklets – about dementia



### **Alzheimer's disease: Understanding your diagnosis**

Code 616



### **Vascular dementia: Understanding your diagnosis**

Code 614



### **Dementia with Lewy bodies: Understanding your diagnosis**

Code 37



### **Frontotemporal dementia: Understanding your diagnosis**

Code 687



### **Young-onset dementia: Understanding your diagnosis**

Code 688

## Booklets – practical support

 **Making your home dementia friendly**  
Code 819

 **Keeping active and involved**  
Code 1506

 **My visitor book**  
Code 923

 **Your relationships**  
Code 1507

 **Managing your money**  
Code 1501

 **Living alone**  
Code 1508

 **Keeping safe at home**  
Code 1502

 **Employment**  
Code 1509

 **Health and social care professionals**  
Code 1503

 **Planning ahead**  
Code 1510

 **Driving**  
Code 1504

 **The memory handbook**  
Code 1540

# Order publications

**Use the tick list overleaf to make note of the different publications you would like to read.**

You can view and download factsheets (as a pdf) at [alzheimers.org.uk/factsheets](https://alzheimers.org.uk/factsheets)

You can order at least one of all the publications in this guide for free, except booklet 600, **Caring for a person with dementia: A handbook for families and other carers**. If you want more than one, you may have to pay.

To place an order go to our website, email [orders@alzheimers.org.uk](mailto:orders@alzheimers.org.uk) or call **0300 303 5933**. You can make a payment by card or cheque.

# Stay in touch

**Alzheimer's Society is the UK's leading dementia support and research charity, touching the lives of millions of people affected by the condition. Over 100,000 people rely on our local support services, and thousands more benefit from our information, helpline advice and online support.**

We campaign for a better quality of life for people with dementia and for greater understanding of the condition. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia.

## **Join us – become a member**

Become a member of Alzheimer's Society for free and keep in touch through our magazine, **Living with dementia**.

For more information call our Membership team on **0330 333 0804** (Monday–Friday, 9am–5pm) or visit **[alzheimers.org.uk/membership](https://alzheimers.org.uk/membership)**

You can also keep in touch through our e-newsletters. Sign up to receive these on our website **[alzheimers.org.uk/enewsletter](https://alzheimers.org.uk/enewsletter)**

## **Get involved**

There are a number of ways you and your family can get involved in things like campaigning, dementia-friendly communities and helping to raise funds.

Call us on **0845 504 9300** to find out more about volunteering opportunities or visit **[alzheimers.org.uk/volunteer](https://alzheimers.org.uk/volunteer)**



# Feedback

**We hope that you found this publication helpful. If you have any comments, and in particular suggestions for how it could be improved in the future, please get in touch. You can email us at [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)**

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- The DMU Demons
- Food for Thought
- The Hornsey Review Group
- The Merton Co-Production Panel
- The Mid Sussex Dementia Friendly Group
- The South-East London Service User Review Panel
- Through Our Eyes
- The Yorvik Group



For advice and support call the National Dementia Helpline on **0300 222 1122**

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- The Royal College of Psychiatrists – the professional and educational body for psychiatrists in the UK.
- The Royal College of General Practitioners – a network of more than 50,000 family doctors working to improve care for patients. It works to encourage and maintain the highest standards of general medical practice and acts as the voice of GPs on education, training, research and clinical standards.
- The Association of Directors of Adult Social Services – the body that represents all the directors of adult social services in England.
- British Psychological Society – the representative body for psychology and psychologists in the UK, responsible for the promotion of excellence and ethical practice in the science, education, and practical applications of the discipline.
- The Royal College of Occupational Therapists – the professional body representing occupational therapists across the UK.



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# Notes

This booklet has been reviewed by health and social care professionals and people affected by dementia.

It can be downloaded from our website at [alzheimers.org.uk/dementiaguide](https://alzheimers.org.uk/dementiaguide)

A list of sources is available on request.

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**Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.**

If you have any concerns about Alzheimer's disease or any other form of dementia, visit [alzheimers.org.uk](http://alzheimers.org.uk) or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



Royal College of Occupational Therapists



Royal College of General Practitioners



The British Psychological Society

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