The dementia guide

Living well after your diagnosis



Alzheimer's Society

Together we are help & hope
for everyone living with dementia

NHS



We are reviewing this publication. If you're able to, please go to our survey at **alzheimers.org.uk/dementiaguidesurvey**. Or you can contact us at **publications@alzheimers.org.uk** or **call 020 7423 7455** to answer some questions on **The dementia guide** and how it helps you after a diagnosis of dementia.

About this guide

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

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

This guide is just one of many ways to get information and support from Alzheimer's Society. To find out how to access support that is right for you, see page 144, visit our website at **alzheimers.org.uk/dementiasupport** or call **0333 150 3456**.

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



Foreword
Ronald Amanze

Getting a diagnosis of dementia can be upsetting. No one is prepared for life with dementia. You might feel scared, confused, or angry. However, with information, support and guidance along the way, you can be active and live well.

I struggled to accept my dementia diagnosis at first. Then I became very sad and isolated because I felt uncomfortable about sharing my thoughts. Alzheimer's Society was a supportive friend at that time, and still are. They helped me to access services and connected me with other people when I felt disheartened and excluded. When I needed advice or a good conversation, they were there for me.

With support, I certainly think it is possible to live well with dementia. For me, keeping socially active, making music, poetry and art help me to live well. Learning more about my diagnosis has also helped.

This is why I think **The dementia guide** is like an important road map. The information about symptoms, treatments, managing your money, planning for the future and keeping active can help you, and your family and friends. It helps you feel prepared for life with dementia. It also shows you how to keep doing things that you enjoy.

How to use this guide



You don't need to read all of this information at once. You can just 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 'your 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 give more information on the topics covered here. Find how to get these publications on page 158. There is a tick list there if you want to keep a note of which ones you would like.



You will find a list of Alzheimer's Society support services on page 144. Other useful organisations are listed on page 148. You can also find information about all our activities and how you can be involved in these on page 160.



There is an index on page 163. If you are interested in a specific topic, this is a good place to look for it.

Coming to terms with your diagnosis

Being diagnosed with dementia might make you feel 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.

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 982,000 people in the UK have dementia. There is support available for you and your family and, with the right support, it's possible to live well with dementia.

You might even want to help others – by getting involved in research, development of services, campaigns or volunteering.



You and the people around you

After your diagnosis, talk to friends and family about how you're feeling. Talking about things is often the first step to dealing with them.

Talking about how you feel 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 will be good for them too. You can also talk to specialist health and social care professionals, such as a counsellor or dementia adviser.

It is important that the people close to you look after themselves, as your diagnosis will also impact them. You will come across the term 'carer' a lot. This term usually refers to the main person who supports you. You may have a family member, friend or partner in your life like this, and you may or may not think of them as having a 'caring' role. They may not like being referred to as your 'carer' or it may take getting used to.

Sharing this guide with your friends and family can help them understand more about dementia and how best to help you. They may also find it useful to read booklet 600, **Caring for a person with dementia: A practical guide**. This gives a broad overview of taking on a caring role, and how someone can support a person with dementia and themselves.



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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 it can cause 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. There may also be changes in your mood and behaviour.

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

There are lots of 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 but can be other combinations.

There are also some rarer conditions that cause dementia. Together, they account for about 1 in 20 people diagnosed with dementia.

Various factors can increase a person’s risk of developing dementia. Ageing, genes, health and lifestyle (for example, physical activity, diet, alcohol and smoking) all play a part.

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

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 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 20.

1

For more information see factsheet 400, What is dementia?



Who gets dementia?

982,000

There are around 982,000 people in the UK who are living with dementia.

80+

Your chance of developing dementia increases a lot with age. Of people over the age of 65 years, 1 in 14 have dementia, and this rises to 1 in 6 for people over the age of 80.



Dementia is more common among women than men.

70,800+

There are 70,800 people living with dementia in the UK who developed symptoms before the age of 65. This is called 'young-onset dementia', or sometimes 'early-onset dementia'.

What are the symptoms?

Everyone experiences dementia in their own individual 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
- 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.

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 to your personality.



Changes over time

Dementia is progressive, which means that most of your symptoms will get worse over time. How quickly it progresses will vary greatly from person to person. Some people with dementia may need a lot of support soon after their diagnosis. Others may be mostly independent for many years.

As dementia progresses, you will need more and more support with regular jobs around the house and daily activities such as cooking. Eventually, you'll need greater help with your personal care, including things like washing and dressing. Dementia does shorten life expectancy, although some people live with it for many years.
For information on how to plan for the future, see section 4 'Planning ahead' on page 84.

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 section 3 'Living well' on page 52 and section 5 'Services for people with dementia' on page 116.

I was diagnosed with Alzheimer's three years ago and am very aware of gradually getting into increasingly bizarre difficulties. But I enjoy life and it is never boring!

Person with dementia

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 change, which causes nerve cells to die. As more nerve cells die, the brain becomes less able to work properly.

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 20.

Why do some people get dementia?

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



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



Call our Dementia Support Line on **0333 150 3456**

Types of dementia

There are many different types of dementia. Around 19 out of 20 people have a diagnosis that includes 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.

Alzheimer's disease

1

Inside the brain

Abnormal structures called 'plaques' and 'tangles' build up inside the brain. These structures stop nerve cells from working properly and communicating with each other. Over time this causes the cells to die, making the brain less able to do complex tasks.

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:

- getting lost more easily, even in familiar places
- 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 (3D)
- having difficulty with everyday activities – for example, getting muddled when paying for items at the shops
- becoming more withdrawn or having mood swings.

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 keep working properly. If they don't get enough blood these cells will eventually 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 the deep parts of the brain over a long period of time (called subcortical vascular dementia).

A stroke happens 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 happens after a large stroke (called post-stroke dementia).

More often though, it happens after a number of small strokes – this is called multi-infarct dementia. (An 'infarct' is an area where cells have died after their blood supply is cut off.)

Subcortical vascular dementia 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 may stay the same or, in the early stages, they might even get a little bit better over time. If you have another stroke, your symptoms might get worse again.

If you have a series of small strokes, your symptoms may stay the same for a while and then get worse in steps, rather than gradually.

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



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, Lewy bodies affect how the brain works. They reduce the levels of chemicals that carry messages around the brain and they cause nerve cells to die.

Lewy bodies are also found in people with Parkinson's disease. A person with Parkinson's is at a high risk of developing 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, and sometimes from moment to moment.

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 (3D)
- 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 Lewy Body Society in 'Other useful organisations' starting on page 148.



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. This dementia mostly affects people in their 40s, 50s and 60s (younger than most people who get Alzheimer's disease or vascular dementia).

Frontotemporal dementia is caused by damage to areas of the brain known as the frontal and temporal lobes. Clumps of abnormal proteins collect inside nerve cells in these lobes and cause the cells to die. Chemicals that carry messages around the brain are also affected. The frontal and temporal lobes control behaviour, emotional responses and language skills. They are also important for planning and solving problems.

Early changes

There are two broad types of frontotemporal dementia. One type mostly affects behaviour and personality (called behavioural variant FTD). The other type causes problems with language (called primary progressive aphasia or 'PPA').

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 may start to behave inappropriately in social situations. You may also become more impulsive – for example, reacting quickly to events without thinking about the results of your actions.

Primary progressive aphasia has two main subtypes with different early changes. One subtype is called semantic variant PPA. If you have this, you will gradually lose the meaning of words over time. The other subtype is called non-fluent variant PPA. With this subtype, you may have difficulty getting your words out and your speech may become slower.

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

“It’s hard to describe feeling confused a lot of the time but in a strange way you can get used to it because you have to. It helps when people are patient.”

Person with dementia

Mixed dementia

Some people have more than one type of dementia. This is called mixed dementia. The most common combination is Alzheimer's disease and vascular dementia. The next most common is Alzheimer's disease and dementia with Lewy bodies. If you have mixed dementia, you are likely to have symptoms from each type of dementia that you have been diagnosed with. For example, a person with Alzheimer's disease and vascular dementia might have problems with their memory (Alzheimer's disease) as well as difficulty thinking quickly (vascular dementia).



Dementia in younger people (young-onset dementia)

There are 70,800 people living with dementia in the UK who developed symptoms before the age of 65. This is called 'young-onset dementia', or sometimes 'early-onset dementia'.

You can develop any type of dementia if you are under 65. However, younger people are more likely to have a less common type. Only a third of younger people with dementia have Alzheimer's disease, compared with around two-thirds of older people with dementia.

You may have some similar symptoms to older people. But the challenges you face and the support you need will often be different. You may still be working and have financial commitments, such as a mortgage. It's likely that you will have different interests and expectations of living 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 in section 4 'Planning ahead' on page 84. Also see 'Services for younger people with dementia' on page 134.

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 get 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 and Korsakoff's syndrome

Alcohol-related brain damage (ARBD) is caused by regularly drinking too much alcohol over several years. It tends to affect people in mid-life (aged 40–50). ARBD is not a type of dementia but it can have similar symptoms, such as memory loss and problems with decision-making.

If you can stop drinking alcohol, eat a good diet and have cognitive rehabilitation (see page 47), you may be able to make a partial or even full recovery.

Korsakoff's syndrome is caused by deficiency of the vitamin thiamine, usually caused by excess alcohol.



For more information see factsheet 438,
What is alcohol-related brain damage (ARBD)?

Rarer causes of dementia

A wide range of other conditions can lead to dementia. These are less common, and together account for only about 1 in every 20 people who have dementia. People with rarer types of dementia may benefit from specialist help, for example, from Rare Dementia Support (for more details see 'Other useful organisations' starting on page 148).



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

2 Treatments

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Key points
Treatments

There is no known cure for dementia yet. Treatment includes medicine and non-medicine 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.

2

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

- donepezil
- rivastigmine
- galantamine
- memantine.

These medicines may reduce the symptoms of Alzheimer's disease or stop them getting worse for a while. You may also be given one of these if you have dementia with Lewy bodies, Parkinson's disease dementia or mixed dementia.

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

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

All types of dementia can also benefit from treatments that don't involve medicines. One example is cognitive stimulation, which might involve doing word puzzles or discussing the news to keep your brain active. Another example is life story work, where you build up a record of your life experiences. This could be in a scrapbook, photo album or online.

Medicines to treat dementia

Currently, there is no known cure for dementia. However, scientists are trying to find one. For more about this, see section 6 ‘Research’ on page 136.

Depending on your type of dementia, there are some medicines that can lessen some symptoms or stop them getting worse for a while. Speak to a pharmacist if you have any problems taking them.

You don’t have to take medicines for dementia if you feel that they are not working for you. They don’t work for everyone and some people may need to try different medicines to find one that works for them. If, after several weeks, you feel that the medicines you are taking are not improving your symptoms, tell the doctor or nurse who prescribed them to you.

Treatments without medicines (see page 46) and getting the right support (such as information and advice, talking to others and keeping your mind active) can be very valuable in helping you to manage your symptoms. Manage other illnesses or infections too – see ‘Staying healthy’ on page 64.

If you look online for information about treatments for dementia, it’s important to use trustworthy organisations, such as Alzheimer’s Society or the NHS. Many websites give false or unreliable information not based on proper scientific evidence.



Alzheimer's disease

Four medicines have been developed that target some of the chemical changes in the brain that happen in Alzheimer's disease. These medicines were designed to help with memory and thinking, but they may also help with other symptoms. They are also useful in some other types of dementia.

Donepezil, rivastigmine and galantamine

If you are in the early or middle stages of Alzheimer's disease, you may be prescribed one of three medicines:

- donepezil
- rivastigmine
- galantamine.

If you have mixed dementia you may also be prescribed one of these.

The medicines all work by increasing the amount of a chemical called acetylcholine. This helps messages to travel around the brain. People with Alzheimer's disease have a low amount of this chemical.

A doctor who specialises in dementia or older people will prescribe these medicines in the first place. This could be:

- a GP or nurse prescriber with special dementia expertise
- a psychiatrist (a doctor who specialises in mental health) at a memory service or a community mental health team for older people

- a geriatrician (a doctor who specialises in the health of older people)
- a neurologist (a doctor who specialises in diseases of the nervous system).

After this, your GP will generally prescribe most of the medicines you need, with regular reviews at least once a year by your GP or consultant.

Possible benefits of donepezil, rivastigmine and galantamine

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

Possible side effects of donepezil, rivastigmine and galantamine

The side effects of these medicines may include loss of appetite, nausea, vomiting and diarrhoea. They affect only around 1 person in 10, on average.

If one of the medicines causes difficult side effects, you might be able to switch and try another.

Memantine

If you are in the middle stages of Alzheimer's disease, you may have been taking donepezil, rivastigmine or galantamine since you were given your diagnosis. These might become less effective at controlling your symptoms as they get worse. If this is the case, you may be offered a medicine called memantine to take as well.

You could also be offered memantine by itself during the earlier stages of Alzheimer's disease if you are unable to take any of the other medicines (for example, because of their side effects).

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

Possible benefits of memantine

Memantine may 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 with agitation or aggressive behaviour. All of these behaviours are more common in the later stages of dementia.

Possible side effects of memantine

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



For more information see factsheet 407,
Medicines to help memory and thinking.



Vascular dementia

If you have vascular dementia, the medicines prescribed for Alzheimer's disease aren't recommended. However, they may be used if you have mixed dementia with both vascular dementia and another type of dementia that responds to these medicines (such as Alzheimer's disease, dementia with Lewy bodies or Parkinson's disease dementia).

It may be possible to slow down the progression of vascular dementia by taking medicines to treat the underlying conditions that cause it. These include:

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

You may already be taking medicines for one or more of these conditions.

Following a healthy lifestyle (for example, not smoking) can also help. It is important to follow medical advice and to go for medical check-ups.

Other dementias

Dementia with Lewy bodies (DLB)

If you have DLB, you might be offered one of the three medicines 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. You may also be offered memantine if you cannot take any of these medicines (for example, if you experience difficult side effects).

Other medicines can sometimes help if you have very disturbed sleep. For problems with movement or balance, you may be offered the medicine levodopa.

Frontotemporal dementia (FTD)

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

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

Research into new treatments

Many people with dementia want to know about research into new treatments. Some choose to take part in clinical trials. For more information see section 6 'Research' on page 136.



Questions to ask the doctor about medications

It can be useful to prepare or bring questions about medicines when you see the doctor, such as:

- Are there treatments without medicines 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 use a patch instead of a tablet?
  - Can I drink alcohol?
- What are the pros and cons of this medication?
  - How will it help with my symptoms?
  - How will it improve my day-to-day life?
  - Will I have any side effects?
  - What changes should I tell you about?
- Have you got any information I could take away?

To find out more about how a GP and other health professionals can support you, see 'Where to go for support' on page 120.

Treatments without medicines

Medicines 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 treatments without medicines are mentioned in this section and some other approaches to living well are covered in section 3 'Living well' on page 52.

The treatments without medicines that are available, and how to get them, can vary depending on where you live. Ask your GP, memory service or Alzheimer's Society for details.

You may be able to apply for or refer yourself to some of the services mentioned.

Cognitive stimulation therapy (CST)

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. They usually last about 45 minutes and are carried out over several weeks. One session, for example, might involve doing word puzzles or talking about the news. Then, in another session, you could be doing something creative like singing or playing a musical instrument. CST also includes elements of reminiscence work (see page 48).

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. You can do this with a family member, friend or support worker. Your goal could be learning to use a smartphone or relearning 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.

My culture and heritage have become much more important to me over the last few years.

Person with dementia

Life story and reminiscence work

Life story work is where you use a scrapbook, photo album or digital app to record the details of your life so that you can remember them. This could include 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, with the help of things like photos, familiar objects or music. It can help you to see your life as a whole and recognise your experiences and achievements. Sometimes this approach uses a memory box of favourite possessions or memorabilia. Techniques like this are popular because they draw on your early memories, which you tend to keep 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. Talking about who you are can help to remind you and others that you are someone with an interesting and varied life. It can help you to focus on your skills and interests, rather than on your dementia.



Music and creative arts therapies

These are therapeutic sessions where you make music, sing, dance and paint – or get to be creative in other ways. They may take place in a group or one-on-one, and will be led by a qualified professional. Alzheimer's Society's Singing for the Brain® groups are an example of these sessions. 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 to express your emotions.

To find music and creative therapy groups in your area, search on **alzheimers.org.uk/dementiadirectory**

For more activity ideas and ways to keep doing the things you enjoy, see booklet 1506, **Keeping active and involved.**

I often join my local Singing for the Brain group on a Tuesday afternoon and even though many of the songs I don't really know as I'm the youngest there with dementia I still enjoy it and everyone makes me welcome.

Person with dementia

Complementary therapies

Complementary therapy includes a broad range of treatments that are outside of conventional medicine. It may be helpful to think about these types of therapies and if any are right for you. If you are interested in trying them, you should discuss this with your GP. Always make sure the person offering the therapy is properly qualified.

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 medicines are for and how to take them.**
- **Ask your GP or Alzheimer's Society if there are any therapies or activities that could help you to live well.**

3 Living well

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Key points
Living well

When you're 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 try to stay positive, and to focus on the things you can still do and enjoy.

Your relationships might change when you have dementia, which can be hard to adjust to. The people close to you will help support you. Talking about things with family and friends 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 let people know how they 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. Put them somewhere you can easily see them, 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. Find out if you need any vaccines and see the doctor quickly if you feel unwell. Things such as pain, an infection or constipation may make you feel very confused if you don't get help early on.

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

(continued on page 56)

Key points
Living well

Try to stay active and keep in touch with people. This can help you to maintain 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 ways technology can help you to live well. These include smartphones and tablets, 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 consider what changes you could make to your home to make it safe and supportive.

Staying positive

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

Living with dementia can be challenging, and you may feel angry or frustrated about what is happening. Your plans for the future might need to change, but 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.

> **Grasp each day, turn everything into an opportunity, learn new skills and live in the moment.**
>
> Person 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. There can also 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 give them time to adjust.

- 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 may 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. It could be 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.

- Some people may not stay in touch because they can't cope with your diagnosis. This can be upsetting, but it's important to keep in mind that it's not your fault. This is the other person's problem, not yours.

- You will rely on other people more for help and support as your dementia progresses. This may be hard for you to accept. Some people might try to do everything for you – even things you can still do. It can help to talk to them about the kind of help you need and how they can best provide it.

- As time goes on, someone may end up taking on the role of a 'carer'. This could be a partner, child, parent or friend. 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.**

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 can help. For example, you might find it helpful if people remind you of what you were talking about, or you might find it frustrating. Telling people 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).
- Use technology that can help (for example, a virtual assistant like Alexa, or an app on a smartphone or tablet).
- Ask your GP or consultant about a referral to a speech and language therapist (SALT).

Coping with memory loss

Memory loss can be distressing and can make you feel less confident. 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.
- Use reminders such as a notebook, diary or wall calendar to help you remember appointments or things like putting the bins out. Electronic devices such as smartphones can also be used for this.
- Keep a list of useful telephone numbers by the phone.
- Keep useful items such as keys and glasses in the same place – somewhere you can see them easily.
- Put a note on the door to remind yourself to lock up at night or to take things like your keys and purse or wallet when you go out.

- 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 ways technology could help – for more information see 'Technology' on page 77.

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

If I've got something to do or I need to remember something, I try to put alerts on my phone, to use it as a memory box.

Person with dementia

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.
- Exercise regularly.
- If you enjoy the occasional alcoholic drink, speak with your GP to make sure this won't be a problem (for example, with medication you are taking).
- If you smoke, try to stop. There are different services that can help with this. Your GP can tell you what's available in your area.
- Keep warm enough.
- Get enough sleep.
- If you often feel low or irritable, you may be depressed. There are treatments for depression and anxiety (see page 65), 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 glasses).

- See the dentist regularly, and keep your teeth and mouth healthy.

- Pay attention to foot care, and make sure your shoes and slippers fit well.

- Ask your GP about vaccines, such as for flu, coronavirus, pneumonia (for over-65s) and shingles (for over-70s).

Depression, stress and anxiety

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

- keeping physically active
- doing enjoyable activities (for example, doing a puzzle, gardening or cooking)
- 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 page 66). This may sometimes be combined with medication.

Talking therapies

If you have severe depression or anxiety, or treatment without medicine 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. They will work with you in confidence to help you with your problems.

It is important to find a therapist or counsellor that you get on well with. There are organisations, such as the British Association for Counselling and Psychotherapy (BACP), that can provide more information about how to do this (see 'Other useful organisations' starting on page 148).

If you are offered a medication 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 which you should discuss with your GP. Your GP should try different antidepressants to find what works for you.

If you have severe anxiety, you may also be given an antidepressant. There are also a number of medicines for anxiety that are available. Your GP can let you know about these.

Other health conditions

Many people with dementia live with other long-term health conditions. You might have diabetes or 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 and diet). For more information see section 5 'Services for people with dementia' on page 116.

- You may need to tell health professionals that you have dementia. You might have to repeat this to different professionals. Don't assume that they will always know or have been told.

- Technology could help you manage 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 adviser (if you have one) about these or other schemes.

Hospital stays

If you are unwell or need medical treatment, you may need to go to hospital. Hospitals can be unfamiliar and confusing but there are things you can do to make your stay easier. The following tips may be useful when planning a hospital stay:

- Make sure you have all the information you need about your stay – for example, where you need to go, the time to be there, any preparations you need to make and how long you will be there. Ask the hospital for this information if they haven't provided it.

- Ask someone you trust to help you with:
  - any personal organisation – for example, packing a bag, getting your home ready for your return or arranging for your pets to be looked after
  - getting to and from the hospital
  - communicating with hospital staff
  - collecting any prescribed medication
  - arranging or restarting support for after your discharge from hospital – the hospital's discharge coordinator can also help you with this.

- Tell the hospital that you have dementia – fill in Alzheimer's Society's **This is me** leaflet (code 1553) and bring this with you. You can record details about yourself on this form so that health professionals can better understand who you are, and your needs and preferences.

- If you are receiving benefits, let the office that pays your benefit know about your stay – being in hospital may affect the benefits that you receive.

If you have an accident or there is a sudden change in your health, you may have to make an unplanned visit to hospital. This can be distressing for you and those close to you. It can be useful to have a list of things to pack in a hospital bag or one already packed, in case this happens.





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 pain, an infection, a lack of fluids, constipation 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 doing the things that you enjoy. Being active can help you to stay independent and in touch with other people, and it can 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 new activities or keep doing ones that you like.

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, shopping centres and cinemas. This means the venue will be more welcoming to people with dementia, with staff and volunteers understanding dementia better.

You could also speak with your GP about 'social prescribing'. This is a way for health professionals to refer people to community-based support and activities.

I have always had a passion for cycling and now that I cannot work, I have more time to cycle... When I cycle, I feel powerful, in control and strong. I get to see the countryside, and sometimes it's like I am seeing it for the first time.

Person with dementia

You may want to try some of these activities, if you haven't already:

- taking regular physical exercise, such as swimming, walking or cycling
- 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, podcasts or music
- doing creative activities – for example, knitting, painting, singing, dancing, writing or poetry
- visiting the theatre or a museum
- going on day trips or holidays
- seeing friends and family
- studying – for example, with u3a, the University of the Third Age (see 'Other useful organisations' starting on page 148)
- spending time with a pet.

You can also get involved with Alzheimer's Society events and volunteering as a way to keep active. Visit **alzheimers.org.uk/get-involved** for more information.

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. However, it can sometimes 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 plan activities for these times.
- 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 small 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.

Making your home dementia friendly

There is a lot you can do to make your home a more supportive place. Sometimes just a small change (such as those listed here) can help you to stay independent, physically active and safe. It is a good idea to make any necessary 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 stand out. You could use plain, brightly coloured bed and table linen to contrast with the walls and floor. This also works well for eating and drinking items (such as cups, plates and cutlery) and bathroom items (like taps, towels and the toilet seat).
- Install smoke alarms and a carbon monoxide detector, if you don't already have them.
- At night, consider leaving a light on in the bathroom and use night lights to help you get around and find things.
- 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 people you want to be contacted if anything happens to you suddenly.

- 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 different ways technology can make your home more dementia friendly – see 'Technology' on page 77.

An occupational therapist or independent or assisted living centre can offer advice about this. Contact your local social services or ask your GP to refer you to one.



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

Technology

Many people with dementia find that technology can help them in their daily life. It could allow you to keep doing many things that help you stay independent and that you enjoy. Technology includes simple items like clocks or more high-tech things, like virtual assistants. Collectively these are known as 'assistive technology'. Some items that might help include:

- **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 items you might often misplace, such as keys. You put a small electronic tag on 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 62). 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 pictures on the buttons. You can also get easy-to-use mobile phones with fewer buttons and a simpler design.

- **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 making video calls.

- **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.

- **Smartphones, tablets and laptop computers** – to access social media (such as X/Twitter and Facebook) and online communities (such as our Dementia Support Forum). These platforms 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 about people living well with dementia. It is important to never share any personal information online.



You can easily buy many of these devices. 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 Living Made Easy website can also help you – see 'Other useful organisations' starting on page 148. We also sell a number of products that might be useful – go to **alzheimers.org.uk/shop**

For more information see factsheet 437,
Using technology to help with everyday life.

Call our Dementia Support Line on **0333 150 3456**

Living well with dementia as an LGBTQ+ person

If you are lesbian, gay, bisexual or transgender, or you identify as queer (LGBTQ+), you may feel that living well with dementia brings a different set of challenges. It's important to know that you aren't alone and that there are advice and services designed to support you.

For more information about this and your rights, see booklet 1511, **LGBTQ+: Living with dementia.**

3



Living alone

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

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 the 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 section 5 'Services for people with dementia' on page 116.

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 cafe. You can find out what's in your local area by searching on **alzheimers.org.uk/dementiadirectory**

Technology such as video calling and social media can also help you to keep in touch (see 'Technology' on page 77). You can also join our online community, Dementia Support Forum at **forum.alzheimers.org.uk**

If you live alone, you might not have as much help with things you find difficult, or have people around if something goes wrong. This means it's very 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 77).

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

I've lost a lot of old friends but gained a lot of new friends. When I was first diagnosed it was quite a dark time, and they understand me more.

Person with dementia



Your next steps

- **Try some of the tips for coping with memory loss.**
- **Make changes to your home that will help keep you safe, such as removing trip hazards and improving the lighting.**
- **Add exercise to your daily routine and try to eat a balanced diet.**
- **Book regular check-ups with your GP, dentist, optician and chiropodist.**



Call our Dementia Support Line on **0333 150 3456**

4 Planning ahead

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Key points
Planning ahead

After you've had time to adjust to your diagnosis, make sure your finances and affairs (such as wills, powers of attorney and advance decisions) are in good order. Also make sure all your paperwork is in one place or in a safe place known to those you trust.

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. You can also talk to them about getting a 'chip and signature' or contactless card, so you don't have to remember a PIN number every time.

You may be entitled to a range of benefits, including Attendance allowance or (if you are under State pension age) Personal independence payment. If you have a carer, they 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 'Other useful organisations' starting on page 148.

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 to plan ahead, 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 to. You can also set up an advance decision to refuse treatment or an advance statement – these 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 & Vehicle Agency (DVA) in Northern Ireland about your diagnosis. Find their contact details in 'Other useful organisations' starting on page 148. You must also tell your car insurer.

If you're still working, you may be able 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 further benefits, such as Employment and support allowance and, in some cases, Universal credit.

Financial matters

Once you have started to adjust to your diagnosis, think about your finances and how to manage your money in the future. There are things you can do to make paying for things simpler. There are also ways you can plan your finances for the future.

Take some time to ensure that all your important documents, including any saved electronically, can be found easily by anyone who will need to see them. This includes details of your bank accounts, tax, benefits and pension, as well as mortgage or rent documents, insurance policies and your will.

Online services, such as online banking, can make it easier to manage your finances. They might be a good option if you find it hard to get to your bank or you prefer to do things at home.

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 that might get harder as your dementia progresses, such as going on holiday.

Some banks offer services such as longer appointments or Easy Read information. Speak to your bank to see what support they offer for people with dementia.



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 you can only take out so much money at one time. This can be a good idea if you lose or misplace things often.

4



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'd like to have your own account but want someone else to help manage it, you can arrange a 'third-party mandate'. This allows someone else to sign cheques and make payments for you. It is only valid while you have the ability (known as 'mental 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 'Lasting power of attorney' on page 100 for more information.

Trusts

If you have assets such as property or savings, you might want to set up a trust. This allows someone else to manage these 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.

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 help to complete the forms (which can be long and detailed).

Help may be available from:

- a local welfare rights service
- Citizens Advice, Age UK or other local not-for-profit organisations
- Department for Communities (Northern Ireland) – visit their website at **www.communities-ni.gov.uk**

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 Service Centre (in England and Wales) or the Make the Call Service (in Northern Ireland). See 'Other useful organisations' starting on page 148 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. They are not meant to replace your earnings. Rather, they are meant to help you with the extra costs of living with a disability. Whether or not you can claim them depends on how you manage daily living, the care that you need and your mobility. It does not depend on having a diagnosis of dementia. These benefits aren't means-tested or based on National Insurance contributions, and they are tax-free. Getting them may even mean you get more in other benefits like Housing benefit or Pension credit. See 'Other useful organisations' on page 148 for the relevant enquiry line for these benefits.

Attendance allowance is a benefit that you can apply for if you are over State pension age. It is to support people who need help with personal care – for example, with washing or dressing – or if they need help taking medication, or 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 Attendance allowance helpline or downloading it from the **gov.uk** website (see 'Other useful organisations' starting on page 148 for contact details).

The claim form includes 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 dressing. Some of these questions may feel quite personal, but it's important you answer honestly. A medical assessment isn't usually needed for Attendance allowance.

Disability living allowance (DLA) or Personal independence payment (PIP) are benefits you might get instead of Attendance allowance, if you claimed when you were under State pension age. 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.



DLA was the benefit that was in place before PIP, but no new claims can now be made except for people aged under 16. If you were born before 8 April 1948 and are already getting DLA, you will continue to get it and won't be transferred to PIP. If you were born after 8 April 1948 and are getting DLA, you will be assessed for PIP at some point before 2021/22.

PIP is the benefit you can apply for now if you are under State pension age. It has two parts or 'components' – one for daily living (for example, washing, preparing meals or 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.

Everyone who got PIP before they reached State pension age will continue to get it beyond this age. DLA and PIP can be claimed whether you live alone or with other people. Couples can both qualify. If you are admitted to hospital or a care home for more than four weeks, DLA or PIP may be stopped temporarily, unless you are paying the full cost of this care yourself.

I didn't think I would qualify but a benefits adviser at a hospital showed me how I do. I get the higher tier for daily living and lower for mobility.

Person with dementia

Carer's allowance

If you have someone who looks after you for at least 35 hours a week, they may be entitled to Carer's allowance. They will only be able to claim if you get Attendance allowance at either rate, 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, not a student, and either not working or 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.

There is no upper age limit to get Carer's allowance, but it cannot be paid if your carer gets another benefit like a State pension. It can still be useful to claim it though, as it can act as proof that they are a carer, which may mean they get extra Pension credit, Housing benefit or Universal credit.

Your carer will need to fill out a form to claim Carer's allowance. You can get this by going to the **gov.uk** website or calling the Carer's Allowance Unit. For details see 'Other useful organisations' starting on page 148.



For more information see factsheet 413,
Benefits for people affected by dementia.



Other benefits

There are other benefits that you or your 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 148 for details.

- **Housing benefit and 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. Regardless of their income, many people with dementia, or their carers, will already qualify for reductions on their Council tax bill. Your local authority can advise further.

- **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, 'Benefits for people of working age with dementia' on page 113.

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) at **www.gov.uk/dwp**. The appointee will have to prove that they are managing your money with your best interests in mind.



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, housing and much more. 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 some decisions for yourself.

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 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
- make decisions about your future, in case you are unable to make them later
- 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.

Alzheimer's Society can put you in touch with a solicitor through our Will to Remember scheme. For more information go to **alzheimers.org.uk/willtoremember**

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 is known as an 'attorney'. They will often be family members or friends you trust. If you don't have a suitable family member or friend, you could ask a professional such as a solicitor or accountant. However, professionals can charge for acting as an attorney. In all cases, an attorney must make decisions that are best for you.

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 103.

There are two types of LPA:

- **Health and welfare LPA** – this will allow your attorney to make decisions about your day-to-day care and treatment. This includes decisions about your medical care and (if you say so on the form) whether to refuse or allow life-sustaining medical treatment on your behalf. It can also cover decisions about where you live.

- **Property and affairs LPA** – this will allow your attorney to do things such as pay your bills, collect your income and benefits, access your bank accounts and sell your house if needed.

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 when you lack capacity to make a certain decision that is needed. A property and affairs LPA can be used if you still have mental capacity – as long as you allow this when you set it up and agree to it being used.

To make an LPA you will need to fill out several forms. These are available from the Office of the Public Guardian. For contact details see 'Other useful organisations' starting on page 148. 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, but this may be reduced or removed if you are on a low income or you receive certain means-tested benefits.

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

If you don't have access to the internet, or you 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, call Alzheimer's Society Dementia Support Line on **0333 150 3456**.

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

4

I gave my wife power of attorney as soon as I got the diagnosis and this is registered... Our bank has been helpful and has limited my card to only £10. Bigger things are put through on my wife's card.

Person with dementia

Enduring power of attorney

If you live in Northern Ireland, you can make an Enduring power of attorney (EPA). This is like an LPA, but it only covers property and affairs, not health and welfare decisions. Talk to your solicitor about making an EPA.

EPA was the old system in England and Wales. You can no longer make an EPA if you live in these countries. 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 on Northern Ireland, see factsheet NI472, **Enduring power of attorney and controllership.**



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 family member wants to be able to make decisions for you when 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 and is more time-consuming as deputy (or controller) applications 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, **Deputyship.**

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 help. Or you can search the Association of Lifetime Lawyers website or phone them to find a solicitor in your area. You can also find a local solicitor on the Law Society website. For contact details see 'Other useful organisations' starting on page 148.



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

Planning your care in the future

There are some specific ways to prepare and make decisions about your future care. Talking to family and health or social care professionals about your preferences for the future is often referred to as advance care planning and can include:

- Lasting power of attorney (see page 100)
- an advance statement (see page 106)
- an advance decision to refuse treatment (see page 107).

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

However, keep in mind that if you 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 feel able.

Advance statement

One way of planning ahead is to write an advance statement. This explains your likes and dislikes, and what you want for the future. It might cover where you would like to be cared for or what day-to-day things you like to do. The statement is used when 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. This means that the law does not say it has to be followed. However, it must be considered when deciding what is best for you. There must also be good reasons for going against an advance statement.

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. This may involve saving it electronically, for example, on a personal laptop or tablet computer. Make sure you tell people where you have put your advance statement and how to access it. It is a good idea to sign it too, though you don't have to do this.

Advance decision to refuse treatment

If you would like to make decisions 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.

If you're thinking about making an advance decision, talk to your GP. They can talk you through the benefits 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 family members about your advance decision, as this will help them to understand your wishes.



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



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 England, Wales and Scotland or Driver & Vehicle Agency (DVA) in Northern Ireland promptly about your diagnosis of dementia. For contact details see 'Other useful organisations' starting on page 148. You must also tell your car insurance company.

With your permission, DVLA or DVA will ask your doctor about your condition. They might also ask you to take a driving assessment. DVLA or DVA 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.**



Working

If you are still working, you don't have to stop just because you have a diagnosis of dementia. You may need to keep working for financial reasons, especially if you are a younger person with dementia. With the right support and adjustments, you may be able to keep working for a while.

Dementia affects everyone differently. It might be better for your physical and emotional wellbeing to keep working. Alternatively, you might feel that stopping work is the best thing for you. You may want to explore other interests or do some volunteering 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 (HR) department at work
- your GP
- the Advisory, Conciliation and Arbitration Service (Acas)
- your trade union, if you have one
- Citizens Advice or a local law centre
- an occupational therapist, who can suggest changes to how you work or to the equipment you use so you can keep doing your job
- a specialist work coach at your local Jobcentre Plus office
- a solicitor specialising in employment issues.

Talking to your employer

Not everyone with dementia has to tell their employer about their diagnosis. However, legally you may have to if your job impacts the health and safety of other people, such as work that involves driving or using machinery. Check your employment contract and get legal advice if you need more help.

You might feel anxious about telling your employer about your diagnosis, but it can be a positive thing. Telling them makes sure you will be protected under the law. Once your employer knows about your diagnosis, the law says they must try to make 'reasonable adjustments' so you can keep working if you're able to and want to. These adjustments will depend on your situation, but they could include changes to your work environment or routine, or the equipment you use. They may even include a change of job role.

> **With the support of the occupational therapist I continued to work until my retirement.**
>
> Person with dementia

Leaving work

At some stage, you might decide to stop working or retire early. Or you may have to stop working for legal reasons or because you can't carry on, even with extra support. It's important to seek advice about your pension rights. This is particularly important because the State pension age is changing for some people.

For more information on working, see booklet 1509, Employment.



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)** – see 'Attendance allowance, Disability living allowance and Personal independence payment' on page 93.

- **Statutory sick pay** – this is the minimum that an employer must pay you by law. Some employers have an occupational sick pay scheme that is more generous. Statutory sick pay 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.

- **'New style' Employment and support allowance (ESA)** – you can make a claim for ESA if you are of working age and are unable to work due to ill health. Whether you get ESA or not is based on your National Insurance contributions record. If you have not made enough National Insurance contributions, you may be able to claim Universal credit instead (see page 114). Universal credit is means-tested so it may also be paid to 'top-up' your ESA, especially if you pay rent or have dependent children.

- **Housing benefit and Council tax support** – see 'Other benefits' on page 97.

Universal credit

Universal credit is replacing many working age means-tested benefits. This means getting it depends on your financial situation and your partner's, if you have one. Universal credit is available anywhere in the UK for new claims.

If you currently claim any of the 'old' working age benefits on this page, you will be notified when you need to switch to Universal credit. Universal credit is paid as one single monthly amount to meet living costs, housing costs, caring for children (if any) and extra costs arising from disability or caring duties. It doesn't include Carer's allowance, National Insurance benefits or Council tax support.

The benefits listed below are being replaced by Universal credit. New claims for these are not normally accepted. If you are claiming any of the following benefits, at some point you will be invited to claim Universal credit instead:

- **Working tax credit** – this is a means-tested benefit that you may get if you are in work but on a low wage.
- **Income-related Employment and support allowance (ESA)** – this is a means-tested version of ESA that you could claim if you were unable to work due to illness or disability.

- **Income support** – this is a means-tested benefit paid to people who aren't expected to look for work, such as carers. It can provide you with basic living expenses and can be paid alongside other benefits such as Carer's allowance.

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



Your next steps

- **Get your finances in order, and make sure all your paperwork is in one place and stored safely.**
- **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 DVLA or DVA, as well as your car insurer, about your diagnosis (if you drive).**
- **If you are working, think about talking to your employer.**

5 Services for people with dementia

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Key points
Services for people with dementia

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

The services available to you will depend on where you live. To find services in your area, start by contacting your GP, local memory service or local authority (council) social services department (which is sometimes called adult services). You could also try Alzheimer's Society, including our online directory at **alzheimers.org.uk/dementiadirectory**, or Citizens Advice.

Organisations such as Alzheimer's Society, Dementia UK, Age UK and Carers UK can support people with dementia, their families and carers in many ways. For example, they can offer support through dementia advisers, phone support and information materials. There are contact details in 'Other useful organisations' starting on page 148.

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

Social services will then draw up a care or support plan with you that says how you would like your needs to be met. You should think about the support you need, not just what is on offer. Social services will ask you about your finances, and they may ask you to pay for services such as a care worker helping you at home. All local authorities in England use a system called personal budgets. This is money that you can use for different types of care and support. You can get your personal budget paid to you directly.

There are some services specifically designed for younger people with dementia. Your memory clinic or GP can tell you what is available in your area, or you can search for them at **alzheimers.org.uk/dementiadirectory**

Where to go for support

Finding out you have dementia can be overwhelming 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.

Contacting your GP is not the only way to get support after your diagnosis. However, this will often be the first place to start if you're concerned about how you are feeling. You should also visit your GP for an annual review to discuss your symptoms, available treatments and how you are getting on.

There is lots of other 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 life as best as you can. There is also support available that can help you to live in your own home for longer, if you want to, such as equipment that could make your life easier.

Your local authority (council) can offer or organise a range of non-medical care and help. Some services are free but you may have to pay for others, depending on your income and savings. Services vary locally so contact your local authority or Alzheimer's Society to see what is available in your area.

In many places, the NHS, social care and other organisations now work closely together. You might get help from a 'hub' or multidisciplinary team where lots of different professionals work together to support you.

Professionals should let you make decisions and plans about your health and wellbeing or be involved in these. The things that matter most to you should be at the centre of all discussions. You may find that if you have several different long-term conditions or disabilities, you get help with all of these in one visit rather than needing lots of separate appointments. However, if this is not the case, it is helpful to tell the professional you're speaking with about all your treatment and support, including all the professionals that you see.

National Health Service (NHS)

Most people with dementia will have already used the NHS, such as a GP and sometimes a specialist (for example, a consultant or community nurse). You may have also been to a memory clinic.

Services provided by the NHS are free.

There are a wide range of NHS professionals who can help you after your diagnosis, such as:

- **GPs**
- **medical specialists** – such as psychiatrists (for mental health), geriatricians (for 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** – for help maintaining everyday skills (you can find them through the NHS, social services or independently)
- **psychologists** – for detailed assessment of memory problems and other mental abilities, support with changes in behaviour, and talking therapies
- **audiologists** – for hearing
- **optometrists** – for sight
- **dentists** – for teeth and oral health
- **physiotherapists** – for exercise and mobility
- **chiropodists** – for feet
- **speech and language therapists** – who can also help with problems related to swallowing
- **counsellors** – for talking therapies
- **dietitians** – for advice on diet and nutrition
- **social prescribers** – for help finding local community services that can improve your overall wellbeing (they are also known as link workers or navigators).

If you are worried about your health or notice any changes, always speak to your GP first. They can then refer you to one or more of these professionals.

Social services and social care

Your local authority social services department (sometimes called adult services) can help you to work out what care and support you 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 keep 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
- delivering frozen meals to your 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 or short-term care to allow you or those who care for you to take a break)
- intermediate care or reablement (support and services that help people to live independently at home again after a hospital stay)
- extra care housing (homes that you can rent or buy where care and support are available on site).

Most information and advice is free. Your local authority can tell you what's available in your area and the possible costs. It's also free to have your needs assessed (see 'How to access social care' on page 129).

When it comes to receiving care and support services at home, some people will get this for free, but others will need to pay. This will depend on the kind of support that you need and your financial situation.

If someone is caring for a person with dementia, they can have a carer's assessment where their own needs are assessed too.



For more information see booklet 819, **Making your home dementia friendly**.
See also factsheet 462, **Respite care in England**, W462 (for Wales) or NI462 (for Northern Ireland).

Charities and not-for-profit organisations

Charities and not-for-profit organisations can be a valuable source of support for you, as well as for your carer or family.

Alzheimer's Society provides a range of services, whatever you are dealing with. Our Dementia Support includes telephone, face-to-face and online advice and information. Find out more on page 144.

Other national organisations that can help include Dementia UK, Age UK, Carers UK and Carers Trust. For all these organisations, including Alzheimer's Society, you can call them, 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:

- **Phone support lines** – to get information and support on topics such as your diagnosis, maintaining independence or planning for the future. Or just to have someone to talk to and listen to your concerns.

- **Local dementia advisers and dementia support workers** – who can go out and meet you face-to-face to offer support, practical advice and information. This can be particularly useful if you struggle to read lots of information, have complex needs or find it hard to communicate over the phone.

- **Specialist dementia nurses** – who can provide practical, clinical and emotional support to you and your family, such as Admiral nurses.

- **Befriending** – to be paired with a volunteer who can help you stay active in your community.

- **Activity groups** – to meet people in a similar situation to you while doing what you enjoy or trying something new, such as singing, crafts or exercise.

- **Day centres** – where you can do activities and connect with others in a friendly and safe place outside of your home.

- **Advocacy services** – to find trained advocates who can help you make informed decisions. They can do this by helping you to express your views, access information and services, and know your rights.

- **Online discussion forums** – online communities where you can ask for advice from those in a similar situation, read other people's stories, express your concerns or share helpful information.

- **Information** – online and in print, such as guides and leaflets.

There may also be smaller organisations in some areas who offer local services for people affected by dementia.

For organisations and contact details, see section 7 'Alzheimer's Society support services' on page 144 and 'Other useful organisations' starting on page 148.

While no one can change the outcome of dementia, with the right support I think you can change the journey.

Person with dementia

Private care providers

Many private companies provide care and support services at home (sometimes called 'domiciliary care' or 'homecare') for people with dementia. You could pay for a homecare worker or personal assistant using your personal budget (see page 132) or from your own money.

For a list of registered agencies in your area, contact your local social services, the Homecare Association, or visit the website of the organisation that regulates and inspects them. This is:

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

For contact details see 'Other useful organisations' starting on page 148.



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. This used to be called a 'community care assessment'. A needs assessment 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.

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 answer a series of questions – social services can help you with this if you need it, or you could ask someone you trust for help.

The assessment might cover living arrangements, what you can and can't 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 may also refer you. The assessment and most information and advice from social services are free. There can be long waiting times for assessments so get in touch as soon as you can if you need some support.



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 family member 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 the professional tells you. You can also ask them to write to you with a summary of what you talked about and any next steps that you agreed.
- Alzheimer's Society produces a booklet called **My appointments** (code 923) that can help you to keep track of the different professionals you might see.

Getting care and support

Once the social services team has assessed your needs, they will decide if you qualify for help. If you do qualify, they will choose someone to help you plan your care and support. This will usually be a social worker. They should talk with you and agree how to meet your needs in a way that suits you best. They will put all this information together in what's called a 'care and support plan' and give you a copy.

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

Social services might provide some of the services you need, 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 family member or friend.

If you don't qualify for help from social services following the assessment but want more help anyway, you can arrange services yourself, such as home care or a live-in carer, and pay with your own money.

For more information see factsheet 418, **Assessment for care and support in England,** W418 (for Wales) or NI418 (for Northern Ireland).

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 that the local authority gives you to meet your care and support needs. Personal budgets are designed to give you control and choice over the care you get. They are used in all local authorities in England and in some areas in Northern Ireland.

You can use your personal budget in a range of ways, as long as they are set out in your care and support plan. This plan will point out what matters to you and what you need in order to stay independent for as long as possible. It will be agreed with your social worker.

Everyone is different, but some people will choose to spend their money on a personal assistant or a home carer. Others may spend it on a social activity, additional equipment to help them remain independent or technology that allows them to stay in touch with other people. However, a personal budget can be spent on other things as well – it depends on what is agreed in your plan.

You can ask social services or a care provider to manage your personal budget for you. This means you don't have to deal with the paperwork. You should still get to choose how you want to be supported, but this choice is usually limited to a list of approved service providers held by your local authority.

Alternatively, you can choose to receive your personal budget as a direct payment. This means that you or a family member or friend needs to keep a record of how your budget is spent in line with your support plan. Direct payments give you the most choice over who provides your care. For example, you could use this money to organise your own support team of personal assistants. This could include family or friends, as long as they don't live at the same address as you. You can choose to receive part of your personal budget as a direct payment and ask the local authority to manage the rest.

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. If you feel your council is unfairly limiting what you can spend your budget on, or you don't feel your budget is enough to meet your needs, you can challenge this using the complaints process. You may ask for an advocate to help you do this.

If you live in Wales, personal budgets are not used. However, you can still access direct payments if you wish to arrange your own care and support.



For more information see factsheet 532, **Paying for care and support in England**, W532 (for Wales) or NI532 (for Northern Ireland). See also factsheet 473, **Personal budgets** (for England and Wales) or NI431, **Direct payments** (for Northern Ireland).



Call our Dementia Support Line on **0333 150 3456**

Services for younger people with dementia

If you have been diagnosed with dementia and are under 65, you may have very different interests and support needs from someone diagnosed in their 80s or 90s. For example, you are more likely to:

- be physically active
- still work (or have a partner who does)
- have dependent children or possibly dependent parents
- 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 some of these services 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 be right for you or able to meet your needs.

The number of activity groups and services suitable for younger people is still limited. You may have to travel outside of your local area 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. You can also search for them at **alzheimers.org.uk/dementiadirectory** or contact Dementia UK (which now includes the Young Dementia Network). For details see 'Other useful organisations' starting on page 148.

Alzheimer's Society's online community, Dementia Support Forum at **forum.alzheimers.org.uk**, includes a section for younger people with dementia and their carers. 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 social care from your local authority 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

- **Consider asking 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 or visit alzheimers.org.uk/dementiadirectory to find out about local services for you and your carer.**



Call our Dementia Support Line on **0333 150 3456**

6 Research

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Key points
Research

Research is the answer to stopping dementia. Every day, 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 with dementia today.

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** or call Alzheimer's Society on **0333 150 3456**. If you attend a memory service, you can also ask there about trials in your area.

There are opportunities to take part in research for people with dementia and carers, as well as their friends and family. For example, you could take part in a clinical trial to test new ways of treating or managing dementia, or you might be involved in giving blood for genetic research. Or you could give your views on the healthcare and support services you have received.

You can get advice and guidance on getting involved in health research from the NHS.
Find contact details in ‘Other useful organisations’ starting on page 148.

Research into dementia

Researchers around the world are working hard to find a cure for dementia and ways to better support people with dementia and those close to them. Dementia is a complex condition and there are many 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 laboratory 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 affects 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. Many people who take part in research enjoy and value the opportunity to make a difference. They welcome the chance to try new treatments or services, and to influence and improve care. Research can also provide opportunities for you to share your opinions and experiences, and to have your condition monitored more closely.

If you would like to take part in research, there are several ways you can do this. Ask your 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** – a national online service that helps match people affected by dementia with suitable research studies in their area.

Each study or trial will need different people. Factors that can affect your suitability for a trial include the type of dementia that you have, your age, the medication you are taking, other health conditions you have and where you live. Your circumstances might mean that there isn't always a suitable study available for you. However, you will be informed when new studies come up that may match your profile. If you aren't online or you need help to register with Join Dementia Research, you can call Alzheimer's Society on **0333 150 3456**.

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 support.

You can find out more about ongoing research into dementia from Alzheimer's Society or Alzheimer's Research UK at **www.alzheimersresearchuk.org**

If you don't want to participate in clinical research studies yet but would like information about dementia research, you can join our Involvement programme. For more information see 'Get involved' on page 160

6



Your next steps

- **Find out if there are any research studies going on in your area by registering with Join Dementia Research.**
- **See page 160 for more information about ways to hear about dementia research and other opportunities to get involved.**

Call our Dementia Support Line on **0333 150 3456**

7 Alzheimer's Society support services

We provide a range of services and resources to support people living with dementia, including carers, families and friends.



Dementia Support from Alzheimer's Society

Alzheimer's Society provides a range of information, advice and support to anyone affected by dementia in England, Wales and Northern Ireland. You can reach us online, on the phone and face-to-face.

Online

Visit **alzheimers.org.uk/getsupport** for online advice and support whenever you need. Here, you'll find information on any aspect of dementia and the option to download or order what you need from our wide range of publications.

You can also connect to others affected by dementia on our Dementia Support Forum (**forum.alzheimers.org.uk**) and search for services in your area using our dementia directory at **alzheimers.org.uk/dementiadirectory**

Phone

You can contact our Dementia Support Line by calling **0333 150 3456** seven days a week. If you speak Welsh, call our Welsh-speaking support line on **03300 947 400**. Our dementia advisers are available to listen, give support and advice, and connect you to help you need in your local area. They can send out information that's right for you via email or post.

If you have speech or hearing difficulties and have a textphone or an adapted computer, you can **use Text Relay** to call our English-speaking dementia support line on **18001 0300 222 1122**.



Lasting power of attorney digital assistance service

We offer a Lasting power of attorney digital assistance service to help people living with dementia create LPAs online. If you don't have access to the internet, we can help you to create an LPA through a series of telephone appointments. The service does not provide legal advice. Call us on **0333 150 3456**.



Face-to-face services

Our local dementia advisers and volunteers can meet you to offer further support, advice and information. They can also connect you to other face-to-face services in your area.

These include Singing for the Brain®, activity groups and peer support for people with dementia, and information and support groups for carers.

Other useful organisations

AcTo Dementia
www.actodementia.com

AcTo Dementia is a website that gives independent recommendations and advice on touchscreen apps designed for people living with dementia.

Advisory, Conciliation and Arbitration Service (Acas)
0300 123 1100 (helpline, 8am–6pm Monday–Friday)
www.acas.org.uk

Acas gives free and independent advice on workplace issues and employment law.

Age UK
0800 055 6112 (advice line, 8am–7pm Monday–Sunday)
www.ageuk.org.uk

Age Cymru
0300 303 44 98 (advice line, 9am–4pm Monday–Friday)
advice@agecymru.org.uk
www.ageuk.org.uk/cymru

Age NI

0808 808 7575 (advice line, 9am–5pm Monday–Friday)
advice@ageni.org
www.ageuk.org.uk/northern-ireland

Age UK, Age Cymru and Age NI aim to improve later life for everyone through information and advice, services, campaigns, products, training and research.

Association of Lifetime Lawyers

020 8234 6186 (9am–5pm Monday–Friday)
www.lifetimelawyers.org.uk

The Association of Lifetime Lawyers (formerly Solicitors for the Elderly) is an independent, national organisation of lawyers who provide legal advice to older people. They can also help you to find a solicitor.

British Association for Counselling and Psychotherapy (BACP)

01455 883300 (10am–4pm Monday–Friday)
bacp@bacp.co.uk
www.bacp.co.uk

The BACP provides information about counselling and psychotherapy services in your local area. It can also advise on what to look for in a therapist.

The British Psychological Society (BPS)

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

The BPS provides access to a list of chartered psychologists who offer various psychological therapy and assessment services.

Care Inspectorate Wales (CIW)

0300 7900 126 (9am–5pm Monday–Thursday, 9am–4.30pm Friday)
ciw@gov.wales
www.careinspectorate.wales

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

Care Quality Commission (CQC)

03000 61 61 61 (8.30am–5.30pm Monday–Friday)
enquiries@cqc.org.uk
www.cqc.org.uk

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

Carer's Allowance Unit

0800 731 0297 (8am–6pm Monday–Friday)
www.gov.uk/carers-allowance-unit

The Carer's Allowance Unit provides information on Carer's allowance, including how to make a claim.

Carers Trust

0300 772 9600 (England)
0300 772 9702 (Wales)
info@carers.org (England)
wales@carers.org (Wales)
www.carers.org

The Carers Trust 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 (helpline, 9am–6pm Monday–Friday)
advice@carersuk.org
www.carersuk.org

Carers UK provides information and advice about caring, alongside practical and emotional support for carers.

Citizens Advice

0800 144 8848 (Adviceline England, 9am–5pm Monday–Friday)
0800 702 2020 (Advicelink Wales, 9am–5pm Monday–Friday)
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.

Dementia UK

0800 888 6678 (Admiral Nurse Helpline, 9am–9pm Monday–Friday, 9am–5pm Saturday and Sunday)
helpline@dementiauk.org
www.dementiauk.org

Dementia UK provides Admiral nurses, who are mental health nurses specialising in dementia care.

Disability Service Centre

www.gov.uk/disability-benefits-helpline

Attendance allowance (AA)

0800 731 0122 (8am–6pm Monday–Friday)

Personal independence payment (PIP)

0800 121 4433 (9am–5pm Monday–Friday)

The Disability Service Centre provides information and advice about Attendance allowance, Disability living allowance and Personal independence payment.

Driver & Vehicle Agency (DVA)

0300 200 7861 (9am–4pm Monday–Friday)
dva@infrastructure-ni.gov.uk
www.nidirect.gov.uk/contacts/driver-vehicle-agency-driver-licensing

DVA is a 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, 8am–7pm Monday–Friday, 8am–2pm Saturday)
www.gov.uk/contact-the-dvla

DVLA is a government-funded agency that issues driving licences and vehicle registration documents in Great Britain.

GOV.UK

www.gov.uk

GOV.UK provides online government services and information covering benefits, driving, housing, money and tax, working and pensions.

Homecare Association

020 8661 8188
enquiries@homecareassociation.org.uk
www.homecareassociation.org.uk

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

Law Society

020 7320 5650 (to find a solicitor, 9am–5pm Monday–Friday)
solicitors.lawsociety.org.uk (online directory of solicitors)
www.lawsociety.org.uk

The Law Society is the body representing solicitors in England and Wales. They can support you in finding a solicitor in England and Wales.

Law Society of Northern Ireland

028 9023 1614
www.lawsoc-ni.org
www.lawsoc-ni.org/solicitors (solicitor directory)

The Law Society of Northern Ireland represents and regulates solicitors in Northern Ireland. It has an online directory to help you find a solicitor or you can call them on the above number.

Lewy Body Society

0800 888 6678 (helpline answered by Dementia UK Admiral nurses, 9am–9pm Monday–Friday, 9am–5pm Saturday and Sunday)
01942 914000 (information)
info@lewybody.org
www.lewybody.org

The Lewy Body Society supports people living with dementia with Lewy bodies and their carers. It produces a popular guide to Lewy body dementia which you can download or order on their website.

Living Made Easy

lme-enquires@shaw-trust.org.uk
livingmadeasy.org.uk

Living Made Easy (formerly the Disabled Living Foundation) provides information and advice on equipment and technology that can help people with dementia to live more independently.

Make the Call Service

0800 232 1271 (9am–5pm Monday–Friday)
makethecall@dfcni.gov.uk
www.nidirect.gov.uk/contacts/make-call-service

The Make the Call Service (previously the Benefits Advice Line) provides advice on benefits to people in Northern Ireland.

NHS

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 NHS website provides a wide-ranging health information service that aims to put people in control of their healthcare.

NI Direct

www.nidirect.gov.uk

NI Direct is the official government website for people in Northern Ireland. It provides information and services about benefits, driving, housing, money and tax, pensions, health and wellbeing.

Office of the Public Guardian (OPG)

0300 456 0300 (9am–5pm weekdays, except Wednesdays 10am–5pm)
customerservices@publicguardian.gov.uk
www.gov.uk/opg

The OPG is set up to protect people in England and Wales who lack the mental capacity to make certain decisions for themselves. It is responsible for registering Lasting and Enduring powers of attorney and dealing with complaints about how attorneys are acting.

Pension Service

0800 731 7898 (State pension claim line, 8am–6pm Monday–Friday)
0800 731 0469 (State pension information line, 8am–6pm Monday–Friday)
0800 99 1234 (Pension credit claim line, 8am–6pm Monday–Friday)
www.gov.uk/contact-pension-service
www.gov.uk/pension-credit/how-to-claim

The Pension Service helps with State pension eligibility, claims and payments, including Pension credit.

Rare Dementia Support

020 3318 0243
contact@raredementiasupport.org
www.raredementiasupport.org

Rare Dementia Support provides information and support for people affected by less common or inherited forms of dementia. These include frontotemporal dementia, posterior cortical atrophy, primary progressive aphasia, familial or young-onset Alzheimer's disease and Lewy body dementia.

Regulation and Quality Improvement Authority (RQIA)

028 9536 1111 (9am–5pm Monday–Friday)
info@rqia.org.uk
www.rqia.org.uk

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

Turn2us

0808 802 2000 (helpline, 9am–5pm Monday–Friday)
turn2us.custhelp.com (contact form)
benefits-calculator.turn2us.org.uk (online benefits calculator)
www.turn2us.org.uk

Turn2us provide information on benefits, grants and other financial support. Their website includes an online benefits calculator.

u3a (University of the Third Age)

020 8466 6139 (9.30am–4.30pm Monday–Friday)
info@u3a.org.uk
www.u3a.org.uk

u3a is an 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.

Order publications

Use this tick list to note the different publications you would like to read.

You can view and download our factsheets and booklets online at **alzheimers.org.uk/publications**

You can also access audio and video versions of our information at **alzheimers.org.uk/accessible-resources**

To order print copies, you can:

- go to our website at **alzheimers.org.uk/orderpublications**
- email **orders@alzheimers.org.uk**
- call **0300 303 5933**.

All the publications mentioned in this guide are free for people affected by dementia.

Factsheets

- ☐ What is dementia? Code 400
- ☐ Easy Read: What is dementia? Code ER1
- ☐ Medicines to help memory and thinking Code 407
- ☐ Rarer causes of dementia Code 442

Booklets

- [ ] Young-onset dementia: Understanding your diagnosis Code 688
- [ ] Making your home dementia friendly Code 819
- [ ] My appointments Code 923
- [ ] Managing your money Code 1501
- [ ] Keeping safe at home Code 1502
- [ ] Driving Code 1504
- [ ] Keeping active and involved Code 1506
- [ ] Your relationships Code 1507
- [ ] Living alone Code 1508
- [ ] Employment Code 1509
- [ ] Planning ahead Code 1510
- [ ] LGBTQ+: Living with dementia Code 1511
- [ ] The memory handbook Code 1540

Get involved

Alzheimer's Society has a range of different ways to find out more about our activities, get involved and influence our work. This includes opportunities for your experience to help other people affected by dementia.

Read our magazine

Keep in touch by reading **Dementia together** in print or online. You can also listen to the CD version or podcast. Our magazine comes out every two months. Find out more about its real-life stories and ideas and how to subscribe at **alzheimers.org.uk/magazine**

Share your thoughts and ideas

Find out about ways to share your experiences and interests with our Involvement programme. You'll receive a monthly email newsletter with lots of opportunities to learn more about activities across the Society and help to shape a better world for people with dementia. To find out more email us at **yoursay@alzheimers.org.uk** or visit **alzheimers.org.uk/involvement**

Volunteer

You, your friends and family can get involved in a variety of activities such as supporting services in your local area, campaigning and fundraising. Email **volunteers@alzheimers.org.uk**, call **0300 222 5706** or go to **alzheimers.org.uk/volunteer** to find out more.

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Alzheimer's Society would like to acknowledge all who contributed to the production of this guide.

We consulted a large number of people with dementia in the process of updating this guide.

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- Birmingham and Solihull Focus on Dementia Network Group
- Greater Manchester Focus on Dementia Network Group
- Twickenham Focus on Dementia Network Group
- Amber Valley Dementia Friendly Community
- Belfast Focus on Dementia Group
- Dementia Voice National Group
- Alzheimer's Society's Feedback Forum

We would also like to thank the players of the People's Postcode Lottery for their support in funding this guide. To find out more about the work that they support, please take a look at their website at **www.postcodelottery.co.uk**

We would also like to acknowledge the following organisations for their endorsement of this guide:

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.

The 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. It is responsible for promoting the unique value and benefits of occupational therapy to the public, service commissioners and political representatives.

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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

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It has also been reviewed by people affected by dementia.

This booklet can be downloaded from our website at **alzheimers.org.uk/dementiaguide**

To give feedback on this publication, or for a list of sources, please email **publications@alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Adjusting to living with dementia**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

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