

# Dementia with Lewy bodies: Understanding your diagnosis







# About this booklet

**If you have recently been diagnosed with dementia with Lewy bodies, this booklet is for you. It will help you to understand more about the condition and how it can affect you. You might also want to share it with the people who are important to you, so that they can understand what you're going through and how to support you.**

This booklet covers how you might feel about your diagnosis and suggests ways of managing these feelings. It also has information on the types of support, including treatments, that can help you to live well with dementia.

Don't worry if you don't feel ready to read the whole booklet at once – it can be helpful to keep it and refer back to the relevant information as you need it.

You are not alone – around 850,000 people in the UK have dementia. About one in 13 of these people have dementia with Lewy bodies. Support is available for you and the people close to you.

We produce a number of other publications that can give you more information on particular topics. These are mentioned throughout this booklet. To order any of these you can:



**[go to alzheimers.org.uk/publications](https://www.alzheimers.org.uk/publications)**



**call 0300 303 5933**







# Contents

<b>1</b>	<b>Coping with your diagnosis</b>	<b>5</b>
<b>2</b>	<b>What causes dementia?</b>	<b>13</b>
<b>3</b>	<b>What are the symptoms of dementia with Lewy bodies?</b>	<b>17</b>
<b>4</b>	<b>Treatments</b>	<b>23</b>
<b>5</b>	<b>Living well</b>	<b>31</b>
<b>6</b>	<b>Planning ahead</b>	<b>39</b>
<b>7</b>	<b>Services and support</b>	<b>51</b>
	Alzheimer's Society support services	<b>58</b>
	Other useful organisations	<b>61</b>





A wooden fence with a grey post and a black dog's head in the bottom left corner.

# 1

## Coping with your diagnosis

It can be difficult to come to terms with a diagnosis of dementia with Lewy bodies (DLB). However, support is available and there are things you can do to help you cope. People can and do live well with dementia.

After a diagnosis of dementia with Lewy bodies, you may be feeling a range of emotions. Give yourself time to think things through.

# 1

Everyone's experience of dementia is different. There is no 'right' or 'wrong' way to respond – the way you feel is right for you. There will be some good times and some bad times. Don't worry if it all seems to be overwhelming at first – there is support available to help you to come to terms with the range of feelings you might have.

It may help to talk things over with your friends and family, or with a health or social care professional who understands dementia.

After a diagnosis, you might find it helpful to think about some specific things. These include adjusting to living with dementia, managing any symptoms you have and planning for the future. This booklet has more information and advice on these subjects, including:

- your feelings and how you can manage them
- your relationships and how they may change
- treatment options
- ways of staying active and healthy
- your finances





- planning for the future
- talking to your employer (if you work)
- driving (if you drive)
- practical and emotional support – from the NHS, social services and other organisations.

1

You don't need to think about all of these aspects straightaway, so take things at your own pace.

## Managing your feelings

You are likely to have a number of different feelings after a diagnosis. This is normal and there are ways to cope with them. Many people with dementia have described feeling a sense of shock, disbelief or denial. However you feel, you may need time before you can accept the diagnosis.

Some people feel a sense of sadness or loss after their diagnosis. You may worry you will no longer be able to do the things that you enjoy or that you had planned. It is true that having dementia may mean you need to change the way you do things. But with the right information and support, you can carry on doing the things you want to for some time.

Fear is another very common reaction to receiving a diagnosis. You may be afraid of what it could mean for you, and the people around you, now and in the future. You may also be afraid of losing control or feeling alone. Talking to someone else about your fears can help.



# 1

Some people wonder whether they did something wrong to get dementia with Lewy bodies, or did not do enough to prevent it. It is very hard to know what causes dementia in any individual person, so try not to dwell on this. It's unlikely to help and may just make you feel worse. Instead, try to think about how you can access the best information and support to help you manage your symptoms and live well.

Some people feel a sense of relief after receiving a diagnosis. This may sound strange, but it can help to have an explanation for the changes you have been experiencing. Once you have a diagnosis, you can also try to adjust, plan ahead and do what you need to live well.

**'To begin with we told nobody. I think we needed time to get used to the diagnosis ourselves. I then told close family as they were the ones who were most likely to see the changes. Gradually I told close friends. Many years down the line I now tell everyone. Everyone is different and it will depend on how your partner feels.'**

Wife of a person with dementia



# Coping with your diagnosis

However you're feeling, you may want to talk things over with people you trust. Equally, you may not want to talk about it at all yet. You might want some time and space before you are ready to find out more about dementia with Lewy bodies. It is important to go at your own pace.

1

Talking to others with a similar experience can help as well. You could try:

- finding a support group – where you can talk to other people living with dementia
- joining an online community (for example Alzheimer's Society's Dementia Talking Point)
- talking to a dementia support worker or dementia adviser
- talking to a qualified counsellor or psychotherapist.



**For more information about each of these, see 'Services and support' on page 51.**



**For advice and support call Alzheimer's Society on 0333 150 3456**

## Your relationships

### 1

Dementia can affect or change your relationships with people. You and the people close to you may have to work together to adapt to new situations. It's important to be aware of the challenges you might face, and talk about these together as openly as you can. This can be difficult, but there are people who can help you to have these conversations. You might find it helpful to seek professional support such as relationship counselling or support groups to help you adjust, even if this is not something you have considered before.

Over time, you are likely to need more help in daily life. A partner, family member or close friend may start to support you with this. Eventually they may need to do things for you that you have always done for yourself. However, until then it is important to keep doing the things you can do for yourself for as long as you can.

The people who support you will also need information and support. The following are good places to start.

- Go to [alzheimers.org.uk/publications](https://alzheimers.org.uk/publications) for information and advice.
- Ask your GP or local Alzheimer's Society about what's available in your area, or search online at [alzheimers.org.uk/dementiadiirectory](https://alzheimers.org.uk/dementiadiirectory)



## Talking to other people about your diagnosis

When you are first told you have dementia there are probably people you want to turn to first, or who it's important for you to tell. However, it can be difficult to talk to people about your diagnosis, especially if you're not sure how you feel about it yourself yet.

Some people will want to take time to understand their own feelings before talking to anyone else. Others may want to share their news and discuss it with people they trust straightaway. It's up to you to decide when you are ready to start talking about it with other people.

Remember that there is no 'right' or 'wrong' way to tell people about your diagnosis. It will depend on the relationship you have with that person, and what makes you feel most comfortable. You will find your own way to have these conversations, but generally it helps to be as honest as possible about how you are feeling.

Talking to other people about your diagnosis can be a good chance for you to let them know how they can support you. Some of the features of having dementia with Lewy bodies can be different to what many people typically think about dementia. You could show them this booklet to help them understand more about dementia with Lewy bodies and what it means for you and for them.



**For more information on how dementia can affect your relationships with others see booklet 1507, Your relationships.**



**For advice and support call Alzheimer's Society on 0333 150 3456**







# 2

## What causes dementia?

Dementia is not a natural part of ageing. It is the name for a group of symptoms that occur when the brain is affected by a disease.

## 2

The word ‘dementia’ describes a group of symptoms that may include memory loss, difficulties with thinking, problem solving or language, and often changes in mood, perception or behaviour. These changes are usually small to start with, but for someone with dementia they have become bad enough to affect daily life.

There are many different diseases that can cause dementia. Dementia itself is not a disease. The most common causes of dementia are Alzheimer’s disease and the diseases that cause vascular dementia. The disease that causes dementia with Lewy bodies is less common. Sometimes a person’s dementia has more than one cause – this is known as mixed dementia.

## What is dementia with Lewy bodies?

Dementia with Lewy bodies is caused by tiny clumps of abnormal proteins that build up in brain cells. The proteins are abnormal because they are the wrong shape, and this makes them clump together. The more they clump together into Lewy bodies, the more they interfere with communication inside and between brain cells. Eventually they stop working. Over time, the brain is left with fewer cells to do all its functions – this leads to problems with thinking, perception and emotions.

As well as these types of changes, many people with dementia with Lewy bodies (at least two-thirds) experience problems with movement.

The next section tells you more about how dementia with Lewy bodies commonly affects people.



**There is more information about dementia with Lewy bodies in factsheet 403, What is dementia with Lewy bodies (DLB)?**













# 3

## What are the symptoms of dementia with Lewy bodies?

Dementia with Lewy bodies affects everyone differently, and not everyone will have the same symptoms. This section tells you about some of the more common symptoms in both the early and later stages of dementia with Lewy bodies.

Some of the symptoms listed in the next few pages might be difficult for you to think about right now. You may want to come back to this section later on.

Dementia with Lewy bodies is progressive. This means it will get worse over time, although the speed at which this happens varies a lot between different people. You may recognise some symptoms described below, and others may affect you in the future.

## 3

### **Symptoms in the early stages of dementia with Lewy bodies**

The earliest symptoms of dementia with Lewy bodies can be mild, but they gradually get worse. Most people will usually have some of the symptoms of Alzheimer's disease (for example, memory loss) and also some of the symptoms of Parkinson's disease (for example, slow movements).

Dementia with Lewy bodies affects some of the same regions of the brain as Parkinson's disease, which is why the two diseases share a lot of similar symptoms. Sometimes, however, a person can have dementia with Lewy bodies without having any movement problems.

**'Don't focus on your condition.  
Focus on what you can do and  
what you want to do.'**

Person living with dementia

You may have difficulties with:

- understanding and alertness, which can vary a great deal during the course of a day
- judging distances, such as when walking around a room
- seeing and perceiving objects, for example when picking up objects
- visual hallucinations (seeing things that are not there, such as people or animals)
- movement, similarly to symptoms of Parkinson's disease (for example, slow, rigid movements and problems with balance)
- sleep disorders, including having very disturbed nights and falling asleep during the day. Some people yell out or physically act out dreams with their arms and legs. When this happens, it can be difficult for them to share a bed, as these dreams can become quite violent in nature.

Other symptoms of dementia with Lewy bodies include:

- delusions (thinking things that are not true, such as believing that a stranger is in the house, or that someone is stealing from you)
- falls, faints and 'funny turns'
- memory loss – you may find it difficult to recall recent events
- problems with planning and organising.





Dementia can also affect the way you feel. Some people go through feelings of:

- apathy – not feeling motivated to do anything, or not having interest in anything
- depression – feeling very sad for long periods of time and having no energy
- anxiety – feeling very worried for long periods. Some people with anxiety also have panic attacks.

3

Apathy, depression and anxiety can be some of the most difficult aspects of dementia to cope with, both for you and those around you. If you think you might be experiencing any of these, it is very important that you see your doctor. Don't ignore these symptoms or think they're not important.



**There are treatments for these symptoms. For more information see section 4, 'Treatments' on page 23.**

## Symptoms in the later stages of dementia with Lewy bodies

As your symptoms get worse over several years, you will need increasing amounts of help.

Everyone is different but, as the dementia progresses, your symptoms can include:

- more difficulty moving parts of your body – you may walk more slowly and be less steady, and your muscles may become more rigid



- changes in appetite and the foods you enjoy, and difficulties with swallowing or eating
- having more severe problems with communication and speech
- changes in behaviour – for example, becoming agitated or experiencing delusions
- becoming more confused about time and place
- forgetting events, names and faces as your memory problems become worse.

3

In the later stages of dementia with Lewy bodies, most people will need full-time care and support. This may be distressing for you to think about right now, but if you do, it may help you and those around you to be better prepared.

When you feel ready, and in your own time, you might want to consider where you want to live and be cared for (for example at home or in a care home) and the things that are especially important to you. You should note what makes you feel comfortable, safe or content. These might be routines you follow, the way you like certain things done, or your beliefs and needs.

You can use an advance statement or advance decision. These documents record your wishes and preferences and can help you plan ahead for your future and care. It can be reassuring for you to know that you have made these decisions. See 'Planning ahead' on page 39 for more information.



**You or someone supporting you may find it helpful to look at factsheet 417, The later stages of dementia.**



**For advice and support call Alzheimer's Society on 0333 150 3456**



# 4

## Treatments

Although there is currently no cure for dementia with Lewy bodies, there are treatments available to help you manage your symptoms. With the right support, you can live well with the condition.



You will probably be offered certain drugs which you can read about in this section. Treatments that don't involve drugs are also important for managing your symptoms (see 'Other treatments' on page 28). Details about both drug and non-drug treatments are given in this section.

## Drug treatments

There are drugs that can help with some of the symptoms of dementia with Lewy bodies. Health professionals should agree a treatment plan with you. Usually this will start with the symptoms that are causing you the most trouble. Often the same medications used in Alzheimer's disease (for example, rivastigmine or donepezil) are used in dementia with Lewy bodies to help with mental abilities, sleepiness, emotional disturbances and hallucinations.

### 4

**'The most important advice I can give you is to keep contact with whatever family and friends you have already and try to make new ones through whatever associations there are locally. Other people who have already been through the experience invariably have something useful to offer.'**

Wife of a person with dementia

Dementia with Lewy bodies may affect the same regions of the brain as Parkinson's disease does. Drugs used to treat problems with movement in people with Parkinson's disease tend not to work as well in people who have dementia with Lewy bodies, so they are less commonly used. If they are used, this tends to be in small doses to avoid unwanted side effects, such as greater levels of confusion or visual hallucinations.

## Hallucinations and delusions

Hallucinations and delusions will feel real while you are experiencing them, and sometimes they can be very distressing. People around you may offer reassurance or gently try to distract you. They should not deny that what you are experiencing is real to you.

If you wear glasses or use a hearing aid, get them checked regularly to make sure they are working correctly. If you can't hear or see things going on around you properly, this can make you confused, and may even trigger a hallucination.

Your doctor might suggest you take medicine if the hallucinations or delusions are becoming very distressing. This will usually be one of the drugs given to people with Alzheimer's disease (for example, rivastigmine).

Very occasionally, someone with dementia with Lewy bodies may be given a strong medicine to prevent very upsetting hallucinations or delusions. This drug is called an 'antipsychotic'. It can cause severe side effects and should only be given with extreme caution by a specialist doctor.





## Sleep disorders

You may experience serious problems with sleeping. This can involve very vivid dreams, violent physical movements, or calling out while you're asleep. You may also fall asleep easily during the daytime. If you find you're not sleeping properly, you can try the following.

- Get more physical exercise, especially outdoors if you can, and try to avoid taking naps during the day.
- Avoid alcohol, caffeine and nicotine during the evening.
- Keep your bedroom quiet and at a comfortable temperature.

If things don't improve, your GP might suggest medicines to help you sleep.

## Movement problems

If you're having difficulty with walking and balance, your doctor may refer you to other health professionals who can help you to stay independent. These include:

- a neurologist with expertise in movement disorders – they may prescribe the drug levodopa, which is given to people with Parkinson's disease
- a physiotherapist – they can help you with exercises to keep you moving safely
- an occupational therapist – they will help you to cope with daily living and can advise on aids and adaptations in your home (for example, handrails in the bathroom).

If you are taking medication to help manage your symptoms, you should have regular medication reviews with your GP. This can make sure that the medication is still effective, and is not causing any unnecessary side effects.



**For advice and support call Alzheimer's Society on 0333 150 3456**

## Other treatments

Staying active, doing things you enjoy and keeping in touch with people will all help you keep well. The list below gives details of some other activities and treatments that don't involve drugs and that may also help.

- **Talking therapies** such as counselling can help. One type of therapy is **cognitive behavioural therapy**, which may help if you start to feel depressed or anxious. It's a good idea to start this as early as you can. Your doctor may suggest you have cognitive behavioural therapy and take medication at the same time.
- **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 in small groups carried out over several weeks. One session, for example, might involve doing word puzzles or talking about what's happening in the news. Then in another session you could be playing an instrument along to music.

**'She sleeps better if she's [been out for] a walk, has participated in activities and has had a relatively anxiety free day.'**

Carer for a person with dementia



- **Life story work** is where you use a scrapbook, photo album or app on your mobile phone or tablet to remember and record details about you and your life. These could also 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** involves talking about a theme from your past such as schooldays, holidays or simply daily life. Reminiscence often includes prompts such as photos and objects from that time. It could help your mood as well as your memory.
- **Cognitive rehabilitation** is a type of therapy that allows you to set your own practical goals (for example, handling money confidently or learning to use a mobile phone). A professional such as a psychologist, occupational therapist or speech and language therapist will work with you and someone close to you to help you achieve your goals.
- **Mindfulness and relaxation** can help some people cope with feelings of anxiety. For more information go to [www.nhs.uk](http://www.nhs.uk)

To find out what support is available in your area, ask your GP or memory service, or search online at [alzheimers.org.uk/dementiadirectory](http://alzheimers.org.uk/dementiadirectory)

**The next section tells you about things you can do in your daily life to manage your condition.**



For advice and support call Alzheimer's Society on **0333 150 3456**



# 5

## Living well

There are many things you can do to help you live well with dementia with Lewy bodies. It may take some time to adjust and it might mean you have to do some things differently, but having dementia doesn't change who you are.

## Coping with memory loss

There are lots of things you can try to help you cope with memory loss and you might find some more helpful than others. You might also find that different ideas work better for you at different times. Here are some suggestions:

- Use a large diary or whiteboard to write down things you want to remember.
- Place useful telephone numbers by the phone or programme them into the phone so you can contact people by pressing a single number.
- Put a note on the door to remind yourself to lock up at night.
- Ask your pharmacist about putting your pills in a dosette box.
- Consider whether you want to use any gadgets or pieces of technology to make life easier. Many of these make everyday objects simpler to use, such as clocks, radios, TV remote controls or telephones.



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





## Keeping active

Keeping physically, mentally and socially active will help you to stay as healthy and independent as possible.

Try to keep up with your hobbies. You may need to change the way you do things, or let people know how they can support you with them. As long as you feel safe, you don't need to stop doing what you've always done just because you have dementia. You might also want to try something new. Joining groups and doing new activities can be good ways of learning about different things and getting to know people.

Other things you might enjoy and that can help you to keep active include:

- puzzles (for example crosswords)
- card or board games
- music – such as joining a singing group, or listening to music
- cooking
- visiting museums or art galleries
- taking part in or watching sport.



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

**5**

**For advice and support call Alzheimer's Society on 0333 150 3456**

## Staying healthy

Having dementia with Lewy bodies doesn't mean you should feel ill. It's important to see the doctor if you're in pain or feeling unwell, or if someone that you trust suggests you should. If you have other medical conditions (such as high blood pressure, diabetes or heart problems), it's especially important to have regular check-ups for these.

You might find the following tips useful.

- Eat balanced meals that have lots of different types of food in – for example, meat or pulses, starchy foods, dairy, fruits and vegetables. Drink plenty of fluids. You can still have the occasional alcoholic drink (unless you choose to stop because the alcohol makes you more confused, or your GP advises you to stop).
- Do regular physical activity, such as walking or gardening. This will help to keep you physically strong, and may also help if you're feeling sad or anxious.
- If you smoke, try to stop. Smoking makes it harder for your body to get blood around your brain and also makes most people feel more tired, so it may help to give up. Your GP can offer you advice or refer you to a local Stop Smoking Service, who can support you to make quitting easier.
- Take any medications prescribed for you and tell your doctor about any side effects, particularly if they are caused by drugs prescribed to help with your symptoms, such as levodopa or antipsychotics. Drugs for dementia can make some people feel sick, tired, or have trouble sleeping. If you have any of these problems after you start taking a drug for dementia, tell your GP and they may be able to switch you to another drug that might work better for you.



- Ask your GP to review any medication you're taking. Many people with dementia have other health conditions that are treated with drugs, such as problems with their heart, blood pressure or diabetes. It's a good idea to review these every now and then to make sure your medication plan is right for you.
- If you find yourself regularly feeling low, anxious or irritable, see your GP.
- Keep up to date with your vaccinations. Make a date to get your free flu jab at your local GP surgery towards the end of the year.
- Have regular check-ups for your eyesight, hearing, teeth and feet.
- See your GP if you start to feel unwell. Some illnesses or infections can worsen the symptoms of dementia, for example, infections in someone with dementia with Lewy bodies can sometimes bring on hallucinations.

**'The first thing we did was take up walking and change our diet.'**

Person living with dementia

## Getting involved

You might be interested in ways to get involved in different types of activities connected with dementia. This includes work focused on understanding more about the condition and opportunities to support people who are living with dementia.

### Research

Sharing your experiences can help research into the cause, cure, care and prevention of dementia. There are two main ways you can do this:

- **Taking part in research** – this could involve completing questionnaires or interviews about your experiences, or trials for new treatments, for example. You can register your interest by contacting Join Dementia Research. This service helps anyone interested in dementia research to be matched with studies taking place in their area. For more information see [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)
- **Planning and designing research** – this gives you an opportunity to influence our research at every stage including identifying topics for research. Involving people with dementia helps to make sure that research focuses on benefits for people living with the condition now and in the future. To find out more about contributing to research go to [alzheimers.org.uk/researchnetwork](http://alzheimers.org.uk/researchnetwork)





## Other ways to get involved

There are lots of other ways to get involved in the work of organisations that support people living with dementia:

- At Alzheimer's Society we are keen to hear from people who are living with or affected by dementia to contribute to our work in different ways. These include reviewing information and publications about dementia, and sharing your experience of dementia with the media. For more information go to [alzheimers.org.uk/yoursay](https://alzheimers.org.uk/yoursay)
- The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia. For more information go to [www.dementiavoices.org.uk](https://www.dementiavoices.org.uk)
- The Dementia Action Alliance is a network of organisations across England that aim to transform the lives of people with dementia. For more information go to [www.nationaldementiaaction.org.uk](https://www.nationaldementiaaction.org.uk)

5

**'It's important to remember that no two cases of dementia are the same, and just because someone who has been diagnosed is experiencing a certain set of symptoms doesn't necessarily mean you will go on to develop those same symptoms.'**

Carer for a person with dementia





# 6

## Planning ahead

After a diagnosis of dementia, it can be difficult to think about the future. However, it is important to do so as soon as you feel comfortable.

Everyone needs to make decisions from time to time about their health, care, finances and housing. As dementia progresses, it will become harder for you to do this. There may come a time when you no longer have the ability (known as ‘mental capacity’) to make some decisions for yourself.

## Advance care planning

You can make decisions now so that your wishes are recorded and will be respected in the future. This can be reassuring for you, and also for your family and friends. It makes it easier for them to do the right thing for you if you have made it clear what you want to happen and what your preferences are.

Advance care planning can be done in a number of ways:

6

- Lasting power of attorney (or ‘Enduring power of attorney’ in Northern Ireland)
- an advance statement – this involves writing down how you would like to be cared for
- an advance decision to refuse treatment (called an advance directive in Northern Ireland) – where you create a legal document to refuse certain medical treatments (for example, resuscitation) in the future.

Talking about care as your needs change and increase – including care at the end of life – can be difficult for you and those closest to you. However, it is best to start these conversations early on, as you may not be able to make these decisions at a later stage.







**You might want to read our booklet 1510, Planning ahead. For information about advance statements and advance decisions in England and Wales see our factsheet 463, Advance decisions and advance statements, and for laws that relate to Northern Ireland see factsheet NI467, Financial and legal tips.**

## Lasting power of attorney

Many people with dementia choose to give someone they trust 'power of attorney'. This person – the 'attorney' – will make certain decisions for you if you lose the ability to do this.

The legal document that is used to give someone this power is called a 'Lasting power of attorney' (LPA). There are two types:

- LPA for health and welfare – for things like medical treatment or where you will live
- LPA for property and affairs – for things like accessing bank accounts, paying bills or selling your house.

6



**For more information see factsheet 472, Lasting power of attorney.**

If you live in Northern Ireland you will need to make an 'Enduring power of attorney' (EPA). You can only do this for property and affairs, not health and welfare. For more information on this, talk to a solicitor or Citizens Advice. New laws about mental capacity are due to be brought in to Northern Ireland but it is currently unclear when this will happen.



**For more information see factsheets NI467, Financial and legal tips, and NI472, Enduring power of attorney and controllership.**



**For advice and support call Alzheimer's Society on 0333 150 3456**

## Financial matters

You should choose a safe place to keep all your essential documents (whether digital or on paper) – for example, your bank and pension details, and your will. Let someone you trust know where this place is.

You might start to find some aspects of managing money more difficult. There are lots of things you can do to make this easier.

### Ways to pay

Find a way to pay that works best for you. This might be using:

- cash
- a Chip and PIN debit card (if you find it difficult to remember your PIN you can visit your bank branch for support)
- a Chip and signature card
- a contactless bank card
- direct debit
- cheques.



## Bank accounts

There are things you can do to make managing your bank accounts easier, including:

- using telephone banking, which allows you to access your account and make payments over the phone
- registering for online banking, which allows you to do many of the things you do in your branch, including:
  - viewing your balance and statements
  - making payments
  - managing standing orders
  - setting up direct debits.

**‘As you get your financial circumstances sorted, with help, you will feel better. No it won’t take the symptoms away but it will relieve some of your stress. If you can try and put things in place that may help you remember some of the important things that you need or want to do.’**

Person living with dementia

## Trusts

If you have property, savings or other assets, you might want to set up a trust. This is a legal arrangement that allows someone to hold your assets on your behalf. It will help to ensure that your money is managed in the way that you want. You should ask for legal advice about this.

## Keeping money safe

There are things you can do to help keep your money safe. This includes making yourself less vulnerable to financial scams and people who are looking to trick you out of your money. Keep good records of your finances, and ask your bank to put a limit on how much money can be taken from your account at any one time. If you are employing a carer or people to support you at home, you can run background and reference checks through a Disclosure and Barring Service (DBS) check.

6



**For more information on managing finances see booklet 1501, Managing your money.**

## Benefits

You may be able to claim a range of benefits even if this is not something you've ever received before. If you qualify, this is financial support you are entitled to and it can help you to live well with dementia. If someone supports you as your carer, they might also be entitled to benefits.

If you are working, you may be entitled to working tax credit and statutory sick pay. If you are not working, you may be entitled to employment and support allowance (ESA) or income support (or pension credit, depending on your age).





Whether or not you are working, you may be entitled to Personal independence payment (PIP), or Attendance allowance if you are aged 65 or over. You may also be entitled to housing benefit or council tax support, and cold weather payments. Some of these benefits are means-tested so they depend on income or savings. Accessing them can seem complicated but there are people who can advise on what to claim for and help you to complete the forms (which can be long and detailed).

Try to get help from someone who can complete these forms with you. Help may be available from:

- a social worker
- a local welfare rights service
- charities such as Citizens Advice or Age UK
- the GOV.UK website
- the Department for Social Development (in Northern Ireland).



**For some benefits, the Department for Work and Pensions (DWP) can arrange for someone to visit you at home. For more information see factsheet 413, Benefits for people affected by dementia.**

It's worth noting that Universal credit is currently being rolled out and will eventually affect many benefits.



## Legal matters

### Making a will

Making a will is an important way to prepare for the future. A will is a legal document that states who your possessions, property and other assets should go to when you die. Speak to a solicitor for more information.

Alzheimer's Society can put you in touch with an approved solicitor through our Will to Remember scheme. Go to [alzheimers.org.uk/willtoremember](https://alzheimers.org.uk/willtoremember) for details.

### Driving

Having dementia doesn't necessarily mean you have to stop driving straightaway, although you may already have stopped driving or be thinking about giving up soon. If you have a driving licence and are diagnosed with dementia, the law says you must:

- inform the Driver and Vehicle Licensing Agency (DVLA) in Great Britain, or the Driver and Vehicle Agency (DVA) in Northern Ireland, as soon as possible
- inform your car insurance company.

The DVLA or DVA will ask your doctor for a report. They may also ask you to take a driving assessment, or you can ask to take one. These will determine whether you are still able to drive. The DVLA or DVA may decide you can no longer drive safely – or you may decide to give up driving voluntarily. This could be for different reasons – for example, if you're feeling less confident, getting more irritated, or if you're getting lost on roads you know well or struggling to judge distances.



If you do need to give up driving, you might find this difficult to come to terms with. Sometimes people feel they have lost their independence or freedom and it can take time to adjust to this. Some people are relieved they no longer have to try and find a place to park or remember routes. You may also find you save money by no longer having to pay for car insurance, road tax, petrol or maintenance costs.

You might find it helpful to think about other ways of getting around. Find out what public transport services are running in your area.

**‘Sort out the legal aspects like  
Power of attorney and your will.  
Having done this, get up, get out  
and get on with your life.’**

Person living with dementia



## Employment

If you're working, you don't have to give up work just because you have dementia. You will know what's best for you. You may decide that you no longer want to work, or that the type of work you do means it isn't possible to carry on. Work may be important to you for lots of reasons, not just financial. It may give you independence and a community, and may be part of your identity.

It's best to tell your employer about your diagnosis of dementia and let them know whether you want to carry on working. Check your contract as it may state that you are required to tell your employer.

By telling your employer you gain certain legal rights. Your employer cannot discriminate against you on the basis of your diagnosis, and they must try to make 'reasonable adjustments' – changes to your working practice and environment that will enable you to carry on working for longer.



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







A large, bold, blue number 7 is positioned at the top left of the page. The background of the page is a photograph of a green lawn with a dark, leafy hedge in the background. The number 7 is the first part of a section header.

# 7

## Services and support

Asking for help can feel difficult, particularly if you've always been independent. However, the right support can help you to live well with dementia.

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 for you and your carer and family. This includes help from the following organisations.

- **The NHS** – your GP, psychiatrist, neurologist, community nurse, dietitian, occupational therapist or psychologist (and other specialists, see page 54) can help you with a number of health problems.
- **Social services** – a social worker from the local council can work with you to see what care and support is you need. Ask your GP or look up ‘social services’ in the phone book or online and ask for a needs assessment (also called a ‘community care assessment’ in Wales and Northern Ireland).
- **Charities and not-for-profit organisations** – these can be a good source of local support, advice and information. As well as Alzheimer’s Society, national organisations include Dementia UK, the Lewy Body Society and Age UK.
- **Private companies** – these can provide care and support services at home, which you may have to pay for. Professional care workers could help you with cooking, dressing, medication or going to work. Ask your local social services or contact the United Kingdom Homecare Association to see what is available in your area.





# Health and social care professionals

As you come to need more care, many different professionals are likely to be involved. These include doctors and other health and social care professionals.

## Doctors

Your GP can support you in many different ways, including talking to you about your symptoms and any other problems you have with your health (not just dementia). They can carry out physical examinations, arrange further tests with a consultant or hospital specialist and review whether your drugs are working.

You may also receive support from different consultants. These might include a psychiatrist and a neurologist. Psychiatrists can help with dementia, as well as any issues related to mental health (such as depression and anxiety). Neurologists specialise in the brain and nervous system.

## Other health professionals

Different types of nurses may provide care for you, and the people who support you, in a number of ways. These might include community nurses (including community mental health nurses known as CPNs) who can provide support at home. Admiral Nurses specialise in dementia care, especially supporting carers.

## Social care professionals

Social workers and social care workers can help you in non-medical ways. Social workers assess your needs and advise on the best support for you. Social care workers help with practical things like washing, dressing and eating.



You can get support from other specialist health professionals to help with many different areas of your physical and mental health as shown below.

Issues	Who can help?
communication, eating, drinking and swallowing	speech and language therapist
maintaining skills and independence	occupational therapist or adult social services telecare team
exercising and moving around	physiotherapist
foot care	podiatrist/chiroprapist
eyesight and vision	optometrist
hearing	audiologist
behaviours that challenge (such as aggression), anxiety and restlessness	clinical psychologist or a specialist such as a music therapist
relationship and emotional issues	counsellor or clinical psychologist
nutrition	dietitian
toilet and continence problems	continence adviser



## Support from other people living with dementia

Support from other people living with dementia, especially those who also have dementia with Lewy bodies, may be important to you. There are a range of different groups and activities for people living with dementia, although they may not all be available in the area where you live.

Groups and activities include the following:

- **Support groups** – for people with dementia to talk about their experiences and learn from each other.
- **Activity groups** – for people with dementia to come together regularly and take part in different activities, such as singing (see Alzheimer’s Society services on page 58).
- **Dementia cafés** – a safe and supportive environment where people with dementia and their carers can socialise.
- **Dementia Talking Point** – Alzheimer’s Society’s online community for people living with dementia and carers. Go to [alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)



To find services in your area, go to [alzheimers.org.uk/dementiadiirectory](https://alzheimers.org.uk/dementiadiirectory)



## Paying for social care and support

You might reach a stage of your dementia when you will need professional care and support at home to help you live well with the condition. Your friends and family or your carer may also need support to carry out this role.

Some people with dementia and their carers will be entitled to support with all or some of the costs of this care. You must meet certain criteria for this support to be provided.

### England

In England, a local authority has a duty to carry out a 'care needs assessment' for anyone with dementia who needs care and support. The assessment is to determine what care needs you have. You will then have a financial assessment to decide whether the local authority will contribute towards meeting your needs.

### Wales

In Wales, a local authority has a duty to carry out a 'community care assessment' for anyone with dementia who may require community care. They also have a duty to provide financial support based on certain criteria.

### Northern Ireland

In Northern Ireland, the local health and social care (HSC) trust has a duty to carry out a 'community care assessment' for anyone with dementia who may be in need of support. Financial support is available if you meet certain criteria.



In England, Wales and Northern Ireland, carer's assessments are also available to determine if the person who is caring for you can receive support to help them with their caring role.



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

## Support in the later stages of dementia

As your dementia progresses further, it may become difficult for you to make decisions about the care and support you receive. It can be reassuring to have a plan in place now, or to start thinking about your options. One area that people do often consider and plan for is where they might want to live and receive care.

In the later stages of dementia, most people live in a care home or supported living accommodation. Some people receive care and support in their own homes. A professional such as a doctor or social worker, your local Alzheimer's Society or another charity may be able to give you advice on housing options, including choosing a care home.



**For more information on making plans for the future, and making these known, see section 6, 'Planning ahead' on page 39.**

7



**For advice and support call Alzheimer's Society on 0333 150 3456**



7

# Alzheimer's Society support services

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

## Online

Visit [alzheimers.org.uk/get-support](https://alzheimers.org.uk/get-support) whenever you need online advice and support. 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 online community Dementia Talking Point, and search for local services through our Dementia Directory.

## Phone

You can contact us by calling **0333 150 3456** seven days a week. Our dementia advisers are available to tackle problems, share advice and practical information or simply provide a listening ear. They can send out information that's right for you via email or post and connect you to help in your local area.

Alzheimer's Society offers a Lasting power of attorney digital assistance service to help people 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. Please note that we do not provide legal advice. Call us on **0333 150 3456**.



**For advice and support call Alzheimer's Society on 0333 150 3456**



## Face-to-face services

Face-to-face support is available through our network of support services in your local area. Our trained staff and volunteers provide someone to talk to who can connect you to practical advice and information. This can make things easier and help you continue doing things important to you. We can also signpost you to further local support in your area.

Alzheimer's Society also oversees support groups such as Singing for the Brain®, peer support for people with dementia, and information and support groups for carers.

Contact your local office to find out what support is available in your area or call us on **0333 150 3456**.



# Other useful organisations

## **Age UK**

0800 678 1602 (advice line, 8am–7pm)  
contact@ageuk.org.uk  
www.ageuk.org.uk

## **Age Cymru (in Wales)**

0800 022 3444 (advice line, 9am–5pm, Monday–Friday)  
advice@agecymru.org.uk  
www.ageuk.org.uk/cymru

## **Age NI (in Northern Ireland)**

0808 808 7575 (advice service, 8am–7pm)  
info@ageni.org  
www.ageuk.org.uk/northern-ireland

Age UK provides information and advice for older people.

## **Citizens Advice**

03444 111 444 (Adviceline – England, 9am–5pm,  
Monday–Friday)  
03444 77 20 20 (Adviceline – 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.



For advice and support call Alzheimer's  
Society on **0333 150 3456**

## **Dementia Engagement and Empowerment Project (DEEP)** [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk)

DEEP brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia.

**Dementia UK**  
0800 888 6678 (Admiral Nurse Helpline, Monday–Friday  
9am–9pm, Saturday and Sunday 9am–5pm)  
[helpline@dementiauk.org](mailto:helpline@dementiauk.org)  
[www.dementiauk.org](http://www.dementiauk.org)

Dementia UK provides Admiral Nurses to support people living with dementia and their families.

**GOV.UK**  
[www.gov.uk](http://www.gov.uk)

GOV.uk is the government services and information website, covering benefits, driving, housing, money and tax, working and pensions.

**Lewy Body Society**  
01942 914000  
[info@lewybody.org](mailto:info@lewybody.org)  
[www.lewybody.org](http://www.lewybody.org)

The Lewy Body Society raises awareness of dementia with Lewy bodies. It also has resources for people affected by dementia.



## **NHS**

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

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

## **Office of the Public Guardian (OPG)**

0300 456 0300

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

The OPG protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finances. It provides free booklets on Enduring powers of attorney, Lasting powers of attorney and Deputyship.

## **United Kingdom Homecare Association (UKHCA)**

020 8661 8188

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

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

The United Kingdom Homecare Association is the professional association of homecare providers from the independent, voluntary, not-for-profit and statutory sectors.

7



For advice and support call Alzheimer's Society on **0333 150 3456**

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.

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

To give feedback on this booklet, or for a list of sources, email **[publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)**

© Alzheimer's Society, 2019. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

Last reviewed: October 2018  
Next review due: October 2021

Registered charity no 296645. A company limited by guarantee and registered in England no 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.





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

If you have any concerns about Alzheimer's disease or any other form of dementia, visit [alzheimers.org.uk](https://alzheimers.org.uk) or call **Alzheimer's Society** on **0333 150 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

**Alzheimer's Society**

43–44 Crutched Friars  
London EC3N 2AE

**0330 333 0804**  
**info@alzheimers.org.uk**  
**alzheimers.org.uk**

Code 37

