

# Living with dementia



From concerns and diagnosis  
to support and future care

# Information written with you in mind.

This information guide has been produced with the help of older people, carers and expert peer reviewers.

This guide has kindly been peer reviewed by Dementia UK.

Published: **June 2021**

## We'd love to hear from you.

**1) Join our Readers' Panel.** Have your say and be involved in updating our guides by joining our Readers' Panel. You don't need any specialist knowledge at all.

Join our Readers' Panel at **[www.ageuk.org.uk/readers-panel](http://www.ageuk.org.uk/readers-panel)**.

**2) Tell us your story.** We want to include real voices of real people in our guides. We'd love to hear about your experiences.

Email us at **[stories@ageuk.org.uk](mailto:stories@ageuk.org.uk)**.

This information guide has been prepared by Age UK and contains general advice only, it should not be relied on as a basis for any decision or action and cannot be used as a substitute for professional advice.

Neither Age UK nor any of its subsidiary companies or charities accepts any liability arising from its use and it is the reader's sole responsibility to ensure any information is up to date and accurate.

Please note that the inclusion of named agencies, websites, companies, products, services or publications in this information guide does not constitute a recommendation or endorsement by Age UK or any of its subsidiary companies or charities.

# Contents

<b>What this guide is about</b>	4
<b>What is dementia?</b>	
Symptoms to look out for	6
<b>Diagnosis and support</b>	
Seeing your doctor	9
What if it is dementia?	10
How might dementia affect me?	11
Talking about dementia	14
Finding support in your local area	17
<b>Living well with dementia</b>	
Making life easier	18
Driving	21
Holidays	22
Keeping engaged and active	23
Working	25
<b>Legal and financial considerations</b>	
Benefits	26
Getting your finances in order	27
Sorting your legal affairs	29
<b>Thinking about the future</b>	
Making your wishes known	31
Getting help when you need it	33
Housing options	35
What you can do next	37
<b>Useful organisations</b>	39

# What this guide is about

This guide explains what dementia is, what to do if you're concerned you might have dementia, and what kind of support is available. It also explains things you could do to help you live as well as possible with dementia and plan ahead.

This guide will also be helpful for the friends and family of someone with a diagnosis.



This symbol indicates where information differs for Wales and Northern Ireland.

## Before you start reading

It can be tricky to flick between pages in this guide without losing your place. We've included some easy-tear bookmarks which we hope will help.

We also produce this guide in large print and audio formats. Call **0800 169 65 65** to order one.

If you don't want to read the whole guide, you can just read the sections that are most relevant to you. As far as possible, the information given in this guide applies throughout the UK. Please note: reference to the social services department in this guide includes the Health and Social Care Trusts in Northern Ireland.

# What is dementia?

## Quick read

Dementia describes a collection of symptoms that includes memory loss and problems with thinking. There are many conditions which cause dementia, including Alzheimer's disease.

Dementia is a general term to describe symptoms that occur when certain diseases or conditions affect the brain.

Symptoms of dementia include:

- memory problems
- mood changes
- problems with thinking, speech and communication.

Symptoms vary depending on which underlying condition is causing the dementia and which parts of the brain are affected.

Many conditions cause dementia, such as Alzheimer's disease, vascular dementia, and dementia with Lewy bodies. All conditions that cause dementia get gradually worse over time, and can't be cured.

Most people affected by dementia are over 65 years old, but it can also affect people younger than this.

Everyone experiences dementia differently and although the symptoms of dementia may get worse, things can be done to help people with dementia live as well as possible.

# Symptoms to look out for

## Quick read

If you've been experiencing problems with your memory or you've been feeling confused, you may be worried these are signs of dementia. Other conditions can cause these symptoms too, so it's important to speak to your doctor.

Symptoms of dementia can include memory problems, sensory, emotional and physical changes, or problems with thinking and communicating.

### These are some examples of memory problems:

- Struggling to remember things that happened recently, even though you can remember things from longer ago.
- Struggling to remember the names of familiar people or things.
- Having trouble remembering the day or date.
- Forgetting where you put something, or where things are kept.



### **These are some examples of problems with thinking:**

- Feeling that your thinking is fuzzy.
- Struggling to follow conversations, particularly in groups.
- Struggling to follow a story on television or in a book, or to understand magazine and newspaper articles.
- Repeating yourself or forgetting what you were saying.
- Struggling to do things you used to find easy.
- Feeling disorientated, even in a familiar place.

### **Some people experience sensory changes:**

- Problems with spatial awareness and depth perception.
- Difficulty understanding the things you see.

### **Some people notice emotional changes:**

- Changes to your mood, or mood swings.
- Difficulty controlling your emotions.

### **Some people experience physical changes:**

- Trouble with sleeping.
- Changes to your appetite.

As we get older, most of us experience some of these things now and again. Being forgetful or getting confused doesn't necessarily mean you have dementia. These problems can be caused by common treatable conditions, including:

- anxiety or depression
- side-effects of medication
- stress
- vitamin deficiencies
- thyroid problems
- constipation
- dehydration
- urinary tract infections.

If you're worried, it's always best to talk to your doctor and share specific examples of symptoms you've experienced. This will either set your mind at rest or, if you do have dementia, get you the help and support you need.

Getting a diagnosis can help you make changes to live as well as possible and make plans for your future.

A diagnosis may be life-changing but despite the challenges it brings, many people with dementia live fulfilling lives for many years.

## Next steps

Talk to your doctor if you're at all worried.



# Diagnosis and support

## Seeing your doctor

### Quick read

Your doctor will talk to you about your symptoms and ask some questions. They will check if anything else could be the problem. You may be referred to a memory clinic for further assessment.

### When you see your doctor they should:

- discuss your symptoms and how they affect your daily life – they may also ask someone close to you about any changes they've noticed, if you consent to them being involved
- ask questions to test your thinking and memory
- carry out some health checks, such as blood tests, to look for other conditions that might be causing your symptoms.

The doctor may refer you to a specialist or a memory clinic so a more detailed assessment can be carried out. This may include physical examinations, memory tests and possibly a brain scan.

Ask your doctor about a referral if you think it would be useful.

### Next steps



Contact Alzheimer's Society for their factsheet **Assessment and diagnosis** (page 40). Also contact the Admiral Nurse Dementia Helpline to discuss any concerns or questions (page 41).

# What if it is dementia?

## Quick read

There's no right or wrong way to react to a diagnosis of dementia. Your health specialist should discuss the cause of your dementia and possible medication. You can ask for a point of contact to support you.

The memory clinic or health specialist in charge of your care should discuss the cause of your dementia with you, and whether there is any appropriate medication or therapy-based treatment available, such as Cognitive Stimulation Therapy.

Ask for a point of contact. They can help you understand what's going on and explain how to get any help you need.

It may all seem overwhelming at first. You may feel shock or disbelief, or be worried about the impact the diagnosis will have on you and those close to you. On the other hand, you may feel relieved you can put a name to what's going on and better understand what's happening.

However you feel, take time to process what the diagnosis means for you.

## Next steps



You can call Alzheimer's Society's helpline or contact the Admiral Nurse Dementia Helpline for support and advice (pages 40-41).

# How might dementia affect me?

## Quick read

Everyone experiences dementia differently. You can live independently, and live well, for many years with dementia. Planning for your future can reassure you that your finances are in order and you will be cared for and supported.

Everyone experiences dementia differently and the progression of symptoms varies from one person to another.

Many people with dementia stay independent long after their diagnosis and continue to do many of the things they enjoyed before.

But over time, dementia can reduce your ability to remember people and places, look after yourself, and make decisions for yourself.

Planning for your future can reassure you that you have arrangements in place if there comes a time when you can no longer make or communicate your decisions. It also lets you think about how you would like to be supported and cared for. See pages 31-32 for more advice about planning for the future.

**“I was diagnosed six years ago, but me and my wife are still going on holidays together.”**

Lee, 74



## Jenny found her own way to deal with her diagnosis.

**Jenny, 72, went to her GP when she started worrying about her forgetfulness and confusion.**

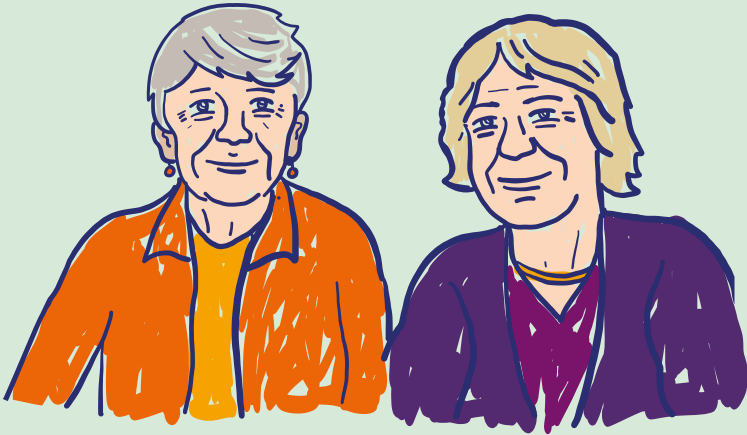
'When I was diagnosed with dementia, I went into a daze. I sat around and did nothing because I couldn't take it in. When you're told you've got something like this, you can feel you're the only person in the world who has it.

'I got into such a state that I went back to see my doctor and he told me about a local group for people with dementia. I went along and I said to them, "I need motivation." And they got me back on my feet. It's a social group and we'll try anything on our days out. We often go for walks in the countryside, and I know that when I get home from them, I'll feel on top of the world.

'I've lived here for 30 years and I've been to places that I've never seen before.



**“Talking about my dementia with people who know what it’s like can really help.”**



‘I still get down days but I know that talking about my dementia with people who know what it’s like can really help. I’ve learned lots of tips, like writing things down and labelling cupboards, and I carry a card saying “I have problems with my memory. Please be patient”, which I can show people who don’t know me.

‘My life is positive. It wasn’t when I first got diagnosed, but it is now. I have to look at it as another adventure in life rather than saying, “That’s it, I’m finished.” Life is unpredictable. Life doesn’t end because you’ve got dementia. You just need to learn to deal with what the future holds.’

# Talking about dementia

## Quick read

It can feel difficult to talk to people you know about your diagnosis. But most people find that if they can be honest with their friends and family, they are more likely to get the support they need. If you'd prefer, talking to a counsellor can be a real help.

Talking about your diagnosis can be difficult, especially the first time you have a conversation about it. You might get emotional, which is perfectly normal. You might prefer to approach the topic differently with different people, and find it easier to talk about it with certain people.

The way you approach these conversations is up to you. What's important is that you do it at your own pace and that you're honest about how you're feeling.

## Changing relationships

As your circumstances change, let your friends and family know what kind of help you need, such as assistance with managing your finances. This is particularly important if you live on your own. But do remind them of what you can still do and retain as much independence as you feel you can.

Friends and family can read our guide **Caring for someone with dementia** to find out about the help and support available. Dementia UK's leaflet **Sex and intimacy** looks at ways people can remain loving and close as dementia progresses (see page 41).

## Talking to friends and family

Many people don't fully understand dementia and you might wonder what to tell people about your diagnosis – or even whether to tell anyone at all. You may worry they'll be overprotective, or change how they behave towards you.

But when you're ready, you should talk to your friends and family about how dementia is affecting you, what you can manage and would like to continue doing, and what they can do to help. The more specific you are about the challenges you face, the more likely they are to be able to help and support you.

## Talking to children and young people

Dementia can be difficult to explain to children and young people and you may worry about upsetting them. Keep your explanation simple, ask other adults (such as their parents) to help, and answer any questions as honestly as you can. It's OK if you get upset. This can let them know it's OK for them to show their emotions, too.

## Next steps



Read Alzheimer's Society's booklet **Explaining dementia to children and young people** (page 40). Alzheimer's Research UK's 'Dementia Explained' is a useful online resource for young people (page 40).

## Counselling

You may feel angry, upset or scared about your diagnosis and what the future may bring. Counselling gives you a chance to speak openly with someone who will listen to you without judging you or your situation. It can help you feel clearer about your concerns and find ways to manage them.

You may still want to talk to a counsellor even if you have a lot of support from friends and family. Sometimes sharing your thoughts and feelings with them is easier than talking to those closest to you.

Speak to your GP or dementia adviser if you have one, or contact the British Association for Counselling and Psychotherapy (BACP) for a list of counsellors in your area (see page 40).



## Good to know



There are different forms of support available, such as dementia specialist support services and peer support forums, that can help with how you're feeling. Contact a dementia specialist organisation such as Alzheimer's Society or Dementia UK for more information (pages 40-41).



# Finding support in your local area

## Quick read

A diagnosis of dementia can be daunting but there is lots of help available, such as support groups, memory cafés, creative workshops and day centres.

You don't have to cope by yourself. In most areas there is support available for people with dementia:

- **Specialist support groups** can give you advice on what to expect in the future, and put you in contact with other people so you can talk about how you're feeling.
- **Memory cafés** offer information and support in an informal setting. You can meet other people with dementia and there are sometimes healthcare professionals to talk to.
- **Creative workshops**, such as arts and crafts or music workshops, can allow you to continue hobbies you've always enjoyed or learn a new skill while meeting new people.
- **Day centres** can provide company and things to do. Some are for older people with or without dementia, while others are just for people with more advanced dementia. You may need to be referred to a day centre by a professional.



To find out about the range of help and support available in your local area contact your local Age UK, or search on Alzheimer's Society's website using Dementia Connect (page 40). In Wales, contact Age Cymru Advice to find out about the help you can get. In Northern Ireland, contact Age NI to find out about their My Life, My Choice project.

# Living well with dementia

## Making life easier

### Quick read

Different strategies – such as writing down reminders, following a routine, and staying in touch with friends and family – can help you deal with the challenges of dementia. You can also make your home safer with something as simple as good lighting.

Here are some ideas to make life with dementia a bit easier.

#### Around the house

- Follow a routine. Doing things at the same time each day or week can reassure you and help stimulate your memory.
- Pin notes up in prominent places to remind you of things you need to do regularly, such as locking the doors at night or putting out the recycling.
- Carry a notebook to write down your daily tasks or reminders.
- Put important things like your keys or glasses in the same place every time you finish using them, so you know where to find them.
- Try some simple gadgets, such a clock that shows the date and day of the week, or a pill box with compartments for different days and times to remind you to take your medication.

When living with dementia, it's important you find things that work for you – it's OK if it takes a bit of trial and error.

Making your home safe and comfortable doesn't have to be expensive. You can visit the 'How to make your home dementia friendly' section of the NHS website for some affordable ideas (see page 43).

**“My daughter has stuck up labels around the kitchen to remind me where things go. They've really helped.”**

Violet, 81



## Next steps



Our guide **At home with dementia** has tips on how to make your home more dementia-friendly. The Living Made Easy website has an 'Ask Sara' section, which can help you decide what might help you stay independent and make your life at home easier (page 42). Alzheimer's Society's publication **The Memory Handbook** offers many practical strategies to help you live well with memory problems (page 40).

## Interacting with others

- Carry on doing the things you enjoy with the people you enjoy doing them with.
- Don't be afraid to ask questions, or to say that you don't understand or have forgotten what was said.
- Put important telephone numbers by the phone.
- Stay in touch with friends and family so you don't become isolated. If you find conversations between large groups hard to follow, perhaps try to meet just one or two friends at a time.
- Carry a helpcard, which can be used to let people know you have dementia and includes the contact details of someone who can help. This can be useful if you need assistance. These are available from Alzheimer's Society (see page 40).
- Make sure others don't take over – they may think they're being helpful by doing as much for you as possible, but do what you can for as long as you can.

## Living with dementia as an LGBT+ person

Living with dementia as an LGBT+ person can present certain challenges. For instance, you could find it harder to remember who you have told about your sexual orientation or gender identity, or you may have concerns about accessing the support you need. For more specific information as an LGBT+ person living with dementia, see Alzheimer's Society's guide **LGBT: Living with dementia**.

# Driving

## Quick read

You must tell the Driver and Vehicle Licensing Authority (DVLA) and your insurance company about your diagnosis. You may not have to stop driving straight away – the DVLA takes each case individually.

If you drive, you must tell the Driver and Vehicle Licensing Authority (DVLA) (see page 41) and your insurance company about your diagnosis.

A diagnosis of dementia doesn't necessarily mean you'll have to stop driving straight away. The DVLA takes each case individually.

If the DVLA decide you can continue to drive, you'll be given a driving licence that is valid for a limited period – usually one year – after which your condition will be reviewed again.

## Next steps



Our guide **In the driving seat** has more information about what the DVLA will do and ideas on how to manage if you have to stop driving. Alzheimer's Society's factsheet **Driving and dementia** also has useful information (page 40).

# Holidays

## Quick read

You can still enjoy going on holiday. Think about the type of holiday that will suit you. There are specialist companies that offer package holidays for people with dementia. You should tell your travel insurer you have dementia.

People with dementia can enjoy new and exciting places with some planning and support. But if you find new environments confusing and overwhelming, you may prefer to go somewhere familiar. Think about what suits you.

When you go abroad, make sure you say you have dementia when getting your travel insurance. If you don't, you could find you're not covered. Policies for people with pre-existing medical conditions can have higher premiums. Price comparison websites can help you compare a range of policies.

As your dementia progresses, you may find that you'd prefer a specialist holiday for people who need extra help and support. Most train companies and airports offer assisted travel.

## Next steps



Read Alzheimer's Society's factsheet **Travelling and going on holiday** (page 40). Organisations such as Dementia Adventure or Revitalise (pages 41-43) arrange different types of holidays and short breaks for people with dementia and carers.

# Keeping engaged and active

## Quick read

There's lots you can do to make the most of every day. Socialising stops you from becoming isolated. If you have hobbies, keep them going. Or you could try something new, like cooking, gardening, puzzles, volunteering or exercise groups.

Keeping engaged and active can help you feel more positive and remind you, and others, that you can live well with dementia. Here are some ideas:

### Socialising

Keep in touch with friends so you don't become isolated. Your local Age UK may run social groups, which can be a great way to meet people in your area. You can visit [www.ageuk.org.uk/inyourarea](http://www.ageuk.org.uk/inyourarea) or call **0800 169 65 65** to find your local Age UK.



In Northern Ireland contact Age NI, and in Wales contact Age Cymru Advice for details of groups or activities in your local area.

### Exercise

Physical activity is good for your health and can also improve your mood. Walking, swimming, chair exercises, dancing and gentle exercise classes are all good options. Our guide **Healthy living** has more suggestions. As your dementia progresses, you may find it easier and safer to take part in group activities rather than exercising alone.

## **Cooking**

If it's hard to follow the recipes you used to use, try to adapt them to suit you. For instance, if you find it hard to concentrate on a recipe with lots of different steps, look for a shorter one. You can also get adapted kitchen tools, and use a talking timer to remind you to check on what's in the oven.

## **Gardening**

Simply getting outside can raise your spirits. If you're finding gardening harder than you used to, contact Thrive (page 43) for advice on practical solutions, such as choosing specially adapted tools. You can also attend Thrive gardening projects.

## **Reading and word puzzles**

If it's hard to focus on or follow books, try reading short stories, or newspaper and magazine articles. Keep doing crosswords and Sudoku puzzles if you enjoy them, and don't worry if it takes you longer to complete them or you need to switch to an easier version.

## **Television and radio**

Some people with dementia find it hard to concentrate on the television. They may find programmes with complicated plots or lots of characters difficult to follow. Some find listening to the radio or talking book easier as the brain only has to concentrate on sound, rather than sound and pictures. Music often brings back memories, which can be very reassuring and enjoyable.

## **Voluntary work**

Think about the kinds of things you like doing, what you're good at, and what kind of organisation you want to help. You could ask at your place of worship or faith group, your favourite charity, or at a charity shop. Contact the National Council for Volunteering Organisations (page 42) to find out about volunteering opportunities. It's important to be open about your diagnosis so you can find the best role for you.

There are separate volunteering organisations in Wales and Northern Ireland.



# Working

## Quick read

You may not have to give up work just because you have been diagnosed with dementia. It can help to tell your employer so that they can help you to continue working.

You won't necessarily have to give up work after a diagnosis of dementia – it depends on your job and how your symptoms affect you.

Telling your employer about your diagnosis will allow them to help you continue working. You must tell them if you're in the armed forces, work on a plane or ship, if your job involves driving, or if it's written into your contract of employment.

Your employer has a legal duty to take reasonable steps to help you continue working, for example by changing your work schedule, simplifying your routine, or using technology.

If you decide to stop working, get advice on your pension and any benefits you may be eligible for first, from your trade union or local Citizens Advice (page 41). Some bank accounts and insurance policies also offer access to legal advice.

## Next steps

See Alzheimer's Society's guide **Employment** for more help (page 40).

# Legal and financial considerations

## Benefits

### Quick read

If you're living with dementia, you may be able to claim a disability benefit or apply for a Council Tax exemption. If you have a carer, they may be able to claim Carer's Allowance.

### Disability benefits

You may be entitled to Personal Independence Payment (PIP) or Attendance Allowance (AA), depending on your age and the support you need. These aren't means-tested, so your income and savings won't be taken into consideration.

### Help with Council Tax

You, and anyone you live with, may be entitled to a Council Tax reduction or even exemption. Contact your local council or Age UK to find out more. In Northern Ireland, contact Age NI for information on rate relief. In Wales, contact your local council or Age Cymru Advice.

### Benefits for carers

If you have a carer, they may be entitled to Carer's Allowance. However, if they claim it, any income-related benefits you receive, like Pension Credit, may be reduced – so they should check before making a claim. If their State Pension is higher than Carer's Allowance, they won't receive Carer's Allowance but may get extra money added to any means-tested benefits.

# Getting your finances in order

## Quick read

Make sure you know where all your important documents are. You can pay bills using direct debit, or create a joint bank account or third-party mandate so that a friend or family member can help you manage your money. You can nominate someone to deal with your benefits for you.

When dealing with your finances, start by making sure you know where important documents are, such as your mortgage or tenancy agreement, insurance policies, and bank statements.

## Banking

Consider paying your bills by direct debit or standing order – as the money will automatically be paid from your account, you don't need to remember to do it. If you don't use online banking, look on paper bills for details of how to do this and to ensure you're paying what you should.

Online banking can make things easier. It saves trips to the bank and allows you to do most things from home.

A joint account is a useful way to get help managing your finances. Or you could set up a third-party mandate so that a friend or family member can help you manage your money. You can nominate someone to deal with your benefits for you, too. Think carefully and make sure you choose someone you trust, as they will have access to your finances.

All third-party mandates and most joint bank accounts only operate when both people have the capacity to run the account. In England or Wales, it's best to set up a Lasting Power of Attorney (LPA) for financial decisions, to ensure this doesn't cause problems later (see pages 29-30).

## Benefits

You can apply for a friend, relative or other representative to become your 'appointee' and deal with your benefits and State Pension on your behalf. If there comes a time when you can't manage your benefits, your appointee can then do it for you. They should contact the Department for Work and Pensions and explain the situation.



## Next steps

See our guide **Looking after your money** for more ways someone can help manage your money. There's more financial and legal information on Dementia UK's website (page 41).

# Sorting your legal affairs

## Quick read

Set up a will as soon as you can. If you already have one, check it still reflects your wishes. You may want to set up a Lasting Power of Attorney, which lets someone make decisions for you when you no longer can.

Getting organised now means you can feel confident that the care and support you receive in the future will be right for you, and your affairs will be managed in the way you wish.

## Writing a will

If you don't have a will, write one as soon as possible. If you have a will already, check it to make sure it still reflects your wishes.

Knowing your estate will go to the people and causes you intended can be very reassuring. Having a will also saves loved ones a lot of worry down the line.

## Lasting Powers of Attorney

You may want to set up a Lasting Power of Attorney (LPA). This lets you appoint someone you trust as an 'attorney' to make decisions on your behalf, if the time comes when you no longer have **mental capacity** to make them yourself.



When we talk about 'mental capacity', we mean someone's ability to make and understand the consequences of their decisions.

## There are two types of LPA:

- **The Property and Financial Affairs LPA** covers decisions about things such as paying bills or dealing with your home. You can arrange for this to be used while you still have mental capacity if you no longer want to manage some aspects of your finances.
- **The Health and Care LPA** covers decisions about things such as medical treatment and where you live, such as whether it's appropriate for you to move into sheltered housing or a care home. This can only be used when you've lost capacity to make such decisions.



In Northern Ireland, contact Age NI for information about powers of attorney, Enduring Powers of Attorney and Controllership Orders.

## Next steps



See our guides **Powers of attorney** and **Wills and estate planning** for more information. Alzheimer's Society's factsheet **Lasting power of attorney** (page 40) may also be helpful.



# Thinking about the future

Thinking about your future health and care needs, and planning for them now, can give you peace of mind that your preferences and wishes are known.

## Making your wishes known

### Quick read

An advance statement of wishes lets you explain how you want to be looked after in the future. An advance decision lets you say which types of medical treatment you wouldn't want.

It can be hard to think about the future, but making decisions about what's important to you as your dementia progresses can make it easier for those around you, and ensure your wishes are respected if you can no longer explain them.

### Advance statement of wishes

You can set up an advance statement of wishes to explain how you'd like to be looked after and cared for in the future. For example, you can outline what kind of food you like to eat, what sort of music you like to listen to, how your spiritual needs should be met, or anything else you think people should know would be important to you.

## Advance decision

An advance decision lets you say which types of medical treatment you wouldn't want in certain situations. It is only used if a time comes when you can't make or communicate the decision yourself.

An advance decision to refuse medical treatment is legally binding, when properly worded. It will make sure that you aren't given medical treatment that you don't want.



In Northern Ireland, contact Age NI for information about advance decisions and advance statements.

## Independent Mental Capacity Advocates

If in the future you can't make certain important health or care decisions yourself, and there isn't anyone who knows you well who can speak on your behalf, an Independent Mental Capacity Advocate (IMCA) must be appointed. They help identify and represent your views to the doctor or social worker who must make a 'best interests' decision on your behalf. An IMCA would be involved in decisions about things like serious medical treatment or where you live.

## Next steps



For more information, see our guide **Thinking about end of life** and factsheet **Advance decisions, advance statements and living wills**.



# Getting help when you need it

## Quick read

Social services can help with things like washing or dressing, or with domestic tasks. It's a good idea to ask for a care needs assessment. If you have a carer, they are entitled to a carer's assessment.

If you need help with things like washing or dressing, or with other domestic tasks, ask your local council's social services department for a care needs assessment.

A social services assessor will look at your needs and decide what support would be best for you. If you have a carer, their ability to provide support should be taken into account – they're entitled to a separate carer's assessment, too.

Even if you're not eligible for help through social services, they should give you information and advice about other local support services.

There may be a charge if you receive support, based on your savings and income.



If you qualify for help and financial support, you will be allocated a 'personal budget' that should be sufficient to meet your needs. You can then choose between the council arranging your care, and doing it yourself through a direct payment. Depending on your income and savings, you may have to contribute to the cost of care covered by your personal budget. In Wales, things are very similar but there are no personal budgets.

**“I called up the council and have arranged for them to come and do an assessment. I’m hoping it makes life easier.”**

Samira, 77



## Next steps

See our guide **Getting help at home** for more information about getting an assessment.

In Wales, see Age Cymru’s factsheets **Social care assessments for older people with care needs in Wales** and **Direct payments for social care services in Wales**.

# Housing options

## Quick read

There are lots of housing options for people who need more support as their dementia progresses, such as sheltered accommodation, extra-care housing and care homes. Think about these options, plan ahead, and ensure your wishes are known – they should be respected and considered in the future.

Considering your options doesn't mean you have to move, or move before you're ready – you may have many years of independent living ahead of you.

Moving house can be quite disorientating for people with dementia, so talk it over with friends, family and the professionals involved in your care.

Thinking about these things now should mean that your wishes are respected and taken into account if you can't make the decision in the future.



These are the main types of housing where there is support for older people and people living with dementia:

- **Sheltered accommodation** is specially designed for older people. People live in their own accommodation but there is support if you need it. If you have a partner or spouse, you can move into sheltered accommodation together.
- **Extra-care housing** is similar to sheltered accommodation but has more practical help available. Services will vary, but can include meals and personal care. The cost will depend on how much help you need. If you have a partner or spouse, you can move into extra-care housing together.
- **Care homes** offer personal care and some offer nursing care too. They are staffed 24 hours a day. In some homes, staff have specialist training in dementia care.

**“I think the time’s come  
that I could do with a bit  
more support.”**

Trudy, 75



## Next steps

See our guides **Housing options** and **Care homes** for more information.

# What you can do next

## Quick read

There's a lot of information in this guide, and it may all seem a little overwhelming. But there are some important things you may want to do now to help you live well with dementia.

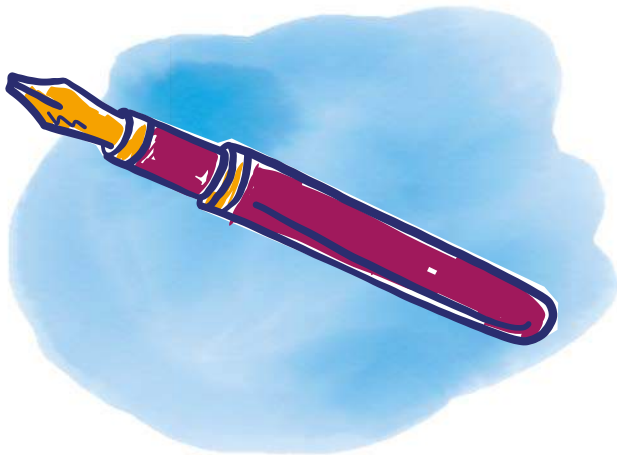
- If you drive, tell the DVLA and your insurance company about your diagnosis (see page 21).
- Make sure you (and your carer, if you have one) are claiming all the benefits you're entitled to (see page 26).
- Set up direct debits or standing orders to pay your bills (see page 27).
- Set up a Lasting Power of Attorney (LPA) (see pages 29-30).
- Make a will if you don't have one or, if you do, check it still reflects your wishes (see page 29).
- Think about setting up an advance decision and/or an advance statement (see pages 31-32).
- If you're having difficulties managing at home, contact your local council social services department and ask for a community care needs assessment (see pages 33-34).
- Think about your home – does it need changes or adaptations, or would you be more comfortable living somewhere with more support (see pages 35-36)?

## Getting involved in dementia research

Your experience of living with dementia can be extremely valuable to researchers, and it can help those diagnosed with dementia in the future, too.

Join Dementia Research is a national service run by the National Institute for Health Research in partnership with Alzheimer's Research UK and Alzheimer's Society (see page 40). It carries out research into the causes of dementia and hopes to find effective treatments, care and even a cure in the future. Join Dementia Research is looking for people with dementia and their carers, as well as people without dementia, to help carry out their research.

You can go to [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk) to register your interest and find out what research you could take part in.



# Useful organisations

## Age UK

We provide advice and information for people in later life through our Age UK Advice line, publications and website.

**Age UK Advice: 0800 169 65 65**

Lines are open seven days a week from 8am to 7pm.

**[www.ageuk.org.uk](http://www.ageuk.org.uk)**

In Wales, contact Age Cymru Advice: **0300 303 44 98**

**[www.agecymru.org.uk](http://www.agecymru.org.uk)**

In Northern Ireland, contact Age NI: **0808 808 7575**

**[www.ageni.org](http://www.ageni.org)**

In Scotland, contact Age Scotland: **0800 124 4222**

**[www.agescotland.org.uk](http://www.agescotland.org.uk)**

## **Alzheimer's Society**

Alzheimer's Society offers advice, information and support in England, Wales and Northern Ireland to people with dementia, their families and carers through its helpline and local offices. You can contact Join Dementia Research through the helpline.

General customer careline in England: **0330 333 0804**

Dementia Connect support line: **0333 150 3456**

**[www.alzheimers.org.uk](http://www.alzheimers.org.uk)**

To order publications, call **0300 303 5933** or email **[orders@alzheimers.org.uk](mailto:orders@alzheimers.org.uk)**

National Helpline Wales: **0300 222 1122**

**[www.alzheimers.org.uk/wales](http://www.alzheimers.org.uk/wales)**

In Northern Ireland, contact **Alzheimer's NI**

Tel: **028 9066 4100**

## **Alzheimer's Research UK**

Alzheimer's Research UK provide information about dementia and fund research projects to beat dementia across the UK and beyond.

Tel: **0300 111 5555**

**[enquiries@alzheimersresearchuk.org](mailto:enquiries@alzheimersresearchuk.org)**

**[www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)**

## **British Association for Counselling and Psychotherapy (BACP)**

A national body representing counsellors and psychotherapists. It can provide a list of counsellors and psychotherapists in your area.

Tel: **01455 883300**

Email: **[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)**

**[www.bacp.co.uk](http://www.bacp.co.uk)**



## Citizens Advice

National network of advice centres offering free, confidential and independent advice, face-to-face or by telephone.

In England, call Adviceline: **0800 144 8848**

In Wales, call Advicelink: **0800 702 2020**

For online information and to find details of your nearest Citizens Advice in:

England: **[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

Wales: **[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

## Dementia Adventure

Organises short breaks and holidays for people with dementia and their carers.

Tel: **01245 237548**

Email: **[info@dementiaadventure.co.uk](mailto:info@dementiaadventure.co.uk)**

**[www.dementiaadventure.co.uk](http://www.dementiaadventure.co.uk)**

## Dementia UK

Works to improve the quality of life of people with dementia. Contact them to find out if you have an Admiral Nurse service in your local area.

Tel: **020 8036 5400**

Email: **[info@dementiauk.org](mailto:info@dementiauk.org)**

**[www.dementiauk.org](http://www.dementiauk.org)**

Admiral Nurse Dementia Helpline: **0800 888 6678**

Email: **[helpline@dementiauk.org](mailto:helpline@dementiauk.org)**

## Driver and Vehicle Licensing Agency (DVLA)

Provides information and keeps a record of drivers and vehicles. Contact them to report a diagnosis of dementia or any other medical condition that may affect your driving.

Tel: **0300 790 6806**

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

## GOV.UK

Official government website, providing information on public services such as benefits, pensions and health services.

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

In Northern Ireland, visit NI Direct at **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

In Wales, visit the Welsh Government at **[www.gov.wales](http://www.gov.wales)**

## Living Made Easy

Provides impartial advice, information and training on daily living aids. There's an 'Ask Sara' section, which can help you decide what equipment might help you to stay independent and make your life at home easier.

Tel: **0300 999 0004**

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

**[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)**

## Mental Health Foundation

Produces a range of information on mental wellbeing. Does not advise people directly on their personal circumstances.

**[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)**

## National Council for Volunteering Organisations

Has details of local volunteer centres in England and how to find volunteering opportunities across the UK.

Tel: **020 7713 6161**

Email: **[membership@ncvo.org.uk](mailto:membership@ncvo.org.uk)**

**[www.ncvo.org.uk/ncvo-volunteering](http://www.ncvo.org.uk/ncvo-volunteering)**

In Wales, contact **[Volunteering Wales](#)**

Tel: **0800 2888 329**

Email: **[volunteering-wales@wcva.org.uk](mailto:volunteering-wales@wcva.org.uk)**

**[www.volunteering-wales.net](http://www.volunteering-wales.net)**

In Northern Ireland, contact **[Volunteer Now](#)**

Tel: **028 9023 2020**

Email: **[info@volunteernow.co.uk](mailto:info@volunteernow.co.uk)**

**[www.volunteernow.co.uk](http://www.volunteernow.co.uk)**

## **NHS**

Provides information about health conditions, treatments and services in England.

Tel: **111**

**www.nhs.uk**

In Wales, visit Health in Wales: **www.wales.nhs.uk**

In Northern Ireland, visit **www.nidirect.gov.uk**

## **Revitalise**

Provides breaks for people with disabilities and their carers. They also run breaks especially for people with dementia.

Tel: **0303 303 0145**

**www.revitalise.org.uk**

## **Thrive**

Helps people with disabilities enjoy gardening. There are three regional centres in Reading, London and Birmingham, and a database of over 600 garden projects. Staff can put you in touch with one nearest to you.

Tel: **0118 988 5688**

Email: **info@thrive.org.uk**

**www.thrive.org.uk**

## **Tourism for All**

Advises on accessible holidays throughout the UK for people with disabilities.

Tel: **0845 124 9971**

Email: **info@tourismforall.org.uk**

**www.tourismforall.org.uk**

## **uSwitch**

A free, impartial online and telephone comparison and switching service that helps people compare prices on a range of products and services.

Tel: **0800 6888 557**

**www.uswitch.com**

# What should I do now?

You may want to read some of our relevant factsheets, such as:

- **At home with dementia**
- **Caring for someone with dementia**

You can order any of our guides or factsheets by giving our Advice Line a ring for free on **0800 169 65 65** (8am-7pm, 365 days a year).

Our friendly advisers are there to help answer any questions.

All of our publications are available in large print and audio formats.

There's plenty of really useful information on our website, too. Visit **[www.ageuk.org.uk/dementia](http://www.ageuk.org.uk/dementia)** to get started.

If contact details for your local Age UK are not in the below box, call Age UK Advice free on **0800 169 65 65**.



**0800 169 65 65**  
**[www.ageuk.org.uk](http://www.ageuk.org.uk)**



Age UK is a charitable company limited by guarantee and registered in England and Wales (registered charity number 1128267 and registered company number 6825798). Registered address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA. Age UK and its subsidiary companies and charities form the Age UK Group, dedicated to helping more people love later life. ID204660 07/21