

Living with dementia

From concerns and diagnosis to support and care



Information written with you in mind.

Our guides are produced with the help of older people, carers and expert peer reviewers.

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What this guide is **about**

This guide explains what dementia is, what to do if you think you might have dementia, and what kind of support is available.

It also covers things you can do to live as well as possible with dementia, and ways you can plan for the future.

You might be reading this guide for someone else. Lots of it is helpful for the friends and family of someone with a dementia diagnosis – but we also have a guide called **Caring for someone with dementia** which you might find handy too.



All of the information in this guide applies in England. This symbol indicates where it differs for Wales and Northern Ireland. If you're in Scotland, contact Age Scotland for advice.

Things to help you as you read

At the beginning of each section in this guide, there's a 'quick read' box with a short summary of the information it covers. These can help you find relevant sections for you – or just give you an overview of the key points if you don't want to read whole pages.

We've also included some easy-tear bookmarks that you can use to help find your place.

We also produce this guide in large print and audio formats. If you'd prefer one of these formats, call our friendly team on **0800 169 65 65** to order one for free.



Next steps

It's a good idea to find out the number for your local council. They'll be able to provide a lot of the support and information mentioned in this guide.

My local council phone number is:

What is dementia?

Quick read: Dementia is the term used for a range of conditions that affect the brain. These conditions cause symptoms including memory loss and problems with thinking.

Dementia is an umbrella term for a range of progressive conditions that affect the brain.

The symptoms of dementia vary depending on which type of dementia someone has and which parts of the brain are affected. They include:

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

There are many different types of dementia, such as Alzheimer's disease, vascular dementia and dementia with Lewy bodies. They all gradually worsen 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, there are things people with a diagnosis can do to live as well as possible.

Symptoms to look out for

Quick read: If you've been having problems with your memory or feeling confused, you might be worried these are signs of dementia. But other conditions can cause these symptoms too. If you're worried, it's important to speak to your doctor.

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

Examples of memory problems include:

- 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.

Examples of problems with thinking include:

- 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 symptoms like:

- problems with spatial awareness and depth perception
- difficulty understanding the things you see.

Some people experience emotional symptoms like:

- changes to your mood, or mood swings
- difficulty controlling your emotions.

Some people experience physical symptoms like:

- trouble with sleeping
- changes to your appetite.

Most of us experience some of these things now and again as we get older. Being forgetful or getting confused doesn't necessarily mean you have dementia. These problems can also be caused by:

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

If you're worried, talk to your doctor and share specific examples of symptoms you've experienced. They'll be able to get you the help and support you need, whether you're diagnosed with dementia or there's something else going on.

Getting a diagnosis of dementia 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 can bring, many people with dementia live fulfilling lives for many years.



Next steps

Talk to your doctor if you're worried about symptoms you're having. You can also call the Admiral Nurse Dementia Helpline (page 41) for support.

Diagnosis and support

Seeing your doctor

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

When you see your doctor, they should:

- review your medical history and ask about your symptoms, including how they affect your daily life – they may also ask someone close to you about any changes they've noticed, if you're happy for them to be 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 to a memory clinic for a more detailed assessment. This might include physical examinations, memory tests and possibly a brain scan.



Next steps

Ask your doctor about a referral if you think it would be useful. Dementia UK (page 41) has a leaflet called **Getting a diagnosis of dementia** that you might find helpful.

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 main 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's any appropriate medication or therapy-based treatment available, such as Cognitive Stimulation Therapy (CST).

Ask who you can contact to help you understand what's going on and explain how to get any help you need.

It can seem overwhelming at first. You might 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.

There's no right or wrong way to feel, so take time to process what it means for you.



Good to know

You can call Alzheimer's Society's helpline (page 40) or the Admiral Nurse Dementia Helpline (page 41) for support and advice following a diagnosis.

How might dementia affect me?

Quick read: Everyone experiences dementia differently. Many people live well and independently for many years with dementia. Planning for your future can reassure you that your affairs are in order and you'll be cared for and supported in the way you'd like.

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 enjoy.

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

Planning ahead can be reassuring – it means 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 31-38 for more advice about planning for the future.



“I was diagnosed 6 years ago, but my wife and I are still going on holidays together.”

Lee, 74

Jenny found her own way to deal with her diagnosis.

Jenny, 72, went to her doctor 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 like 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.” They suggested I join a social group, and I love it. 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 still have down days but talking about my dementia with people who know what it’s like really helps. I’ve learned lots of tips, like writing things down and labelling cupboards, and I carry a card explaining I have memory problems 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 thinking that that’s it. 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: Most people with dementia find that talking honestly about their diagnosis with their friends and family or a counsellor can help them get the support they need.

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.

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 support you need, such as help with managing your finances. This is particularly important if you live on your own. But also remind them of what you can still do and how they can help you to stay as independent as possible.

If you have a spouse or partner, you might find that the dynamic of your relationship changes. Dementia UK (page 41) produces information and advice on remaining loving and close as the condition progresses.



Good to know

Friends and family can read our guide **Caring for someone with dementia** to find out more about how they can support you.

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 might 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 your dementia affects you, what you can manage and would like to continue doing, and what they can do to help. The more specific you are, the better they'll be able to 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.

Counselling

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

You may want to talk to a counsellor even if you have a lot of support from friends and family. Sometimes it's easier to be honest about difficult thoughts and feelings with a professional.



Next steps

See Alzheimer's Society's factsheet **Supporting children and young people when a person has dementia**. Alzheimer's Research UK's 'Dementia Explained' is a useful online resource for young people. See page 40 for contact details.

Finding support in your local area

Quick read: There's lots of help available for people with a dementia diagnosis, such as support groups, memory cafés, creative workshops and day centres.

You don't have to cope by yourself. In most areas there's 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 living with dementia so you can talk to people who know how you're feeling.
- **Memory cafés** offer information, support and friendship 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 enable 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 (page 40). In Wales, contact Age Cymru Advice and in Northern Ireland, contact Age NI.



Living well with dementia

Quick read: There are different strategies that can help you, such as writing down reminders, following a routine, and staying in touch with friends and family. You can also make your home safer with something as simple as good lighting.

Making life easier

When you're living with dementia, it's important to find ways of doing things that work for you. Sometimes, it can take a bit of trial and error to adapt. It's OK if things you used to manage easily take a little longer.

There are some ideas of ways to make life with dementia a bit easier on the next few pages.



Next steps

Alzheimer's Society's memory handbook (page 40) offers practical strategies to help you manage with memory problems.

Around the house

- Follow a routine. Doing things at the same time each day or week can feel reassuring and help stimulate your memory.
- Stick 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 bins.
- Carry a notebook to write down your daily tasks or reminders.
- Put important things such as your keys or glasses in the same place every time you finish using them, so you know where to find them.
- Try out some gadgets, such as a clock that shows the date and day of the week, or a pill box with compartments for different days and times to help you keep track of your medication.



“My daughter 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.

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 phone numbers by the phone so they're easy to find.
- Stay in touch with friends and family so you don't become isolated. If you find conversations between large groups hard to follow, try meeting just one or two people at a time.
- Carry a helpcard to let people know you have dementia. You can add details of an emergency contact, which can be useful if you need assistance. Helpcards are available from Alzheimer's Society (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 it's good to do what you can for as long as you can.

If you're an LGBT+ person

Living with dementia as an LGBT+ person can present certain challenges. For instance, you might forget who you've told about your sexual orientation or gender identity, or you might have concerns about accessing the right support.

Dementia UK (page 41) offer a support service for LGBT+ people with dementia, and those who support them. Contact them to find out more.

Your health

Quick read: Not being able to see or hear very well can make you feel isolated, and having trouble with your teeth can make it harder to eat. You should have regular check-ups with your optician, hearing clinic and dentist.

Struggling to see or hear well can be very unsettling. It can lead to feeling isolated from what's going on around you. Having trouble with your teeth can make eating harder and less enjoyable too.

It's important to have these check-ups:

- **Eye tests:** The NHS offers free eye tests for people over 60 every 2 years, or more often if needed.
- **Hearing tests:** Speak to your doctor about arranging a hearing test, or check whether your local audiology service accepts self-referrals. You may be able to get free hearing aids and batteries from the NHS. Some pharmacists and opticians also offer hearing tests for free – but you'd usually need to pay for any treatment after that.
- **Dental check-ups:** Your dentist will let you know how often you need to be seen for a check-up.



Next steps

See our factsheet **Help with health costs** for more information about what you might be entitled to. In Wales, see Age Cymru's version of this factsheet.

Driving

Quick read: You must tell the Driver and Vehicle Licensing Agency (DVLA) and your insurance company about your diagnosis. You might not have to stop driving straight away. The DVLA looks at each case individually.

If you drive, you need to let the Driver and Vehicle Licensing Agency (DVLA) (page 42) and your insurance company know about your diagnosis.

A diagnosis of dementia doesn't necessarily mean you'll have to stop driving straight away. The DVLA looks at each case individually. If they decide you can continue to drive, you'll be given a driving licence that's valid for a limited period – usually a 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 to help you if you want to stop driving. Dementia UK (page 41) also has a leaflet on **Dementia and driving**.

Holidays

Quick read: You can still enjoy going on holiday. There are specialist companies that offer package holidays for people with dementia. You should tell your travel insurer you have dementia.

People who have dementia can still 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 might suit you best.

Make sure you say you have dementia when getting any 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, but comparison websites can help you compare a range of policies.

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



Next steps

Organisations such as Dementia Adventure (page 41) 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 can help stop you from becoming isolated. If you have hobbies, it's good to keep them going – or you could try something new like gardening or volunteering.

Keeping engaged and active can help you feel more positive and remind you and others that you can live well with dementia.

There are some ideas below, but you might also be able to speak to your doctor about 'social prescribing' to help you access services and activities in your area.

You might also like to take a look at our **Feeling lonely?** information guide which has lots of suggestions of things that have helped others feel connected.

Socialising

Keep in touch with friends where possible. Your local Age UK may run social groups, which can be a great way to meet new people in your area too. Call **0800 169 65 65** or visit www.ageuk.org.uk/inyourarea to find your local Age UK.



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

Exercise

Physical activity is good for your health and can 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, you could choose a shorter version of a recipe if following lots of steps is tricky. 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 42) for advice on practical solutions, such as choosing specially adapted tools. You can also attend Thrive gardening projects.

Reading and puzzles

If it's hard to focus on or follow books, try reading short stories, or newspaper and magazine articles. Keep doing crosswords or 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 than you're used to doing.

Television and radio

Some people with dementia find it hard to concentrate on programmes with complicated plots or lots of characters. Some find listening to the radio or an audio book easier. Music is an enjoyable way to bring back memories too.

Voluntary work

Think about the kinds of things you like doing, what you're good at, and what sort of organisation you might 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.

Working

Quick read: You might not have to give up work just because you've been diagnosed with dementia. But 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 what your job involves 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 your employment contract says you have to.

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

If you decide to stop working, get advice on your pension and any benefits you may be eligible for from your trade union or local Citizens Advice (page 40). Some bank accounts and insurance policies also offer access to legal advice.



Next steps

Alzheimer's Society (page 40) has a factsheet on **Work and dementia** which gives more advice.

Legal and financial considerations

Benefits

Quick read: If you're living with dementia, you might 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 could be entitled to Personal Independence Payment or Attendance Allowance, depending on your age and the support you need. These benefits 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 could be entitled to a Council Tax reduction or even exemption. Contact your local council or Age UK to find out more.



In Wales, contact your local council or Age Cymru Advice. In Northern Ireland, contact Age NI for information on rate relief.

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, could 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 nominate someone to deal with your benefits for you. 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.

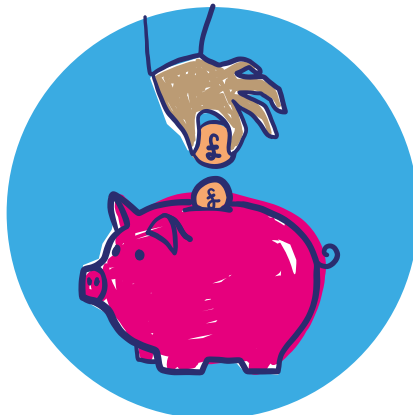
When dealing with your finances, start by making sure you know where important documents are, such as your mortgage or tenancy agreement, insurance policies and bank statements.

Benefits

If there comes a time when you can't manage your benefits, then a friend, relative or other representative can apply to become your **appointee** and deal with your benefits and State Pension for you. To do this, they should contact the Department for Work and Pensions (page 41) and explain the situation.



An **appointee** is someone who has the right to deal with someone else's benefits when they can no longer manage them themselves.



Bills and banking

Consider paying your bills by Direct Debit or standing order – the money will automatically be paid from your account, so you don't need to remember to do it. If you don't use online banking, look on paper bills for details of other ways to set up a Direct Debit or standing order, and to check 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.

Setting up a joint bank account with a trusted friend or family member can be helpful when 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'll 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 for financial decisions (see pages 29-30). In Northern Ireland, contact Age NI for more advice.



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 out your legal affairs

Quick read: Make a will as soon as you can. If you already have one, check it still reflects your wishes. You might 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, make one as soon as possible. If you have one already, check to make sure it's up to date and still reflects your wishes.

Knowing that your estate (your money, property and possessions) will go to the people and causes you care about can be very reassuring. Having a will can also save loved ones worry in the future.

Lasting powers of attorney

It can be a good idea 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 lose **mental capacity** to make them yourself.



When we talk about **mental capacity**, we mean the ability to make and understand the consequences of decisions.

There are 2 types of lasting power of attorney:

- **An LPA for financial decisions** covers decisions about things such as paying bills, selling your home or arranging repairs on 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.
- **An LPA for health and care decisions** covers decisions about things such as medical treatment and where you live, including whether it's appropriate for you to move into sheltered housing or a care home. This can only be used when you've lost mental 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 **Power 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

Quick read: An advance statement of wishes explains how you want to be looked after in the future. An advance decision explains which types of medical treatment you wouldn't want.

Making your wishes known

It can be hard to think about the future, but making decisions ahead of time can make things easier for those around you as your dementia progresses. It can also ensure your wishes are respected if a time comes you can no longer explain them.

Advance care planning

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

You can set up an advance decision to say which types of medical treatment you wouldn't want in certain situations. It's only used if a time comes when you lose mental capacity (see page 29).

An advance decision to refuse medical treatment is legally binding as long as it meets certain criteria. It'll make sure that you aren't given most medical treatments that you don't want. However, if you want to refuse life-sustaining treatment, then other conditions need to be met – for example, the advance decision would need to be witnessed.



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

Independent Mental Capacity Advocates

If you can't make certain important health or care decisions yourself in the future, and there isn't anyone who knows you well to speak on your behalf, an Independent Mental Capacity Advocate (IMCA) must be appointed.

IMCAs 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 our factsheet **Advance decisions, advance statements and living wills**.

Dementia UK (page 41) has an **Advance care planning** leaflet as well as an advance care planning template on their website.

Getting help when you need it

Quick read: Social services can help you with things like washing, getting dressed or domestic tasks. It's a good idea to ask for a care needs assessment. And if you have a carer, they're entitled to a separate carer's assessment.

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



In Northern Ireland, contact your local Health and Social Care Trust.

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 also entitled to a separate carer's assessment to identify any additional support they might need.

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, which is based on your savings and income.



If you qualify for help and financial support, you'll be allocated a 'personal budget' that should be enough to meet your needs. You can then choose between the council arranging your care and doing it yourself through direct payments. Depending on your income and savings, you may have to contribute towards 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 they’re coming to 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 and make your wishes known.

Considering your options doesn't mean you have to move, or move before you're ready. If you live independently, you may be able to carry on doing so for many years.

Moving house can be quite disorientating for people with dementia, so it's a good idea to 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 in future you can't make the decision about where you'd like to live.



These are the main types of housing where there's support for people living with dementia:

- **Sheltered accommodation** is specially designed for older people. People live in their own accommodation but there's 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.

Dementia UK (page 41) has a leaflet called **Considering a care home for a person with dementia**.

What you can do next

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

- If you drive, tell the Driver and Vehicle Licensing Agency (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 28).
- Make a will if you don't have one or, if you do, check it still reflects your wishes (see page 29).
- Set up a lasting power of attorney (see pages 29-30).
- Think about setting up an advance decision, an advance statement, or both (see pages 31-32).
- If you're having difficulties managing at home, contact your local council's social services department and ask for a 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 (page 40) is a national service run by the National Institute for Health Research in partnership with Alzheimer's Research UK and Alzheimer's Society. 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 to help carry out their research.

You can go to 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 information and advice 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

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

www.agecymru.org.uk

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

www.ageni.org

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

www.agescotland.org.uk

Alzheimer's Research UK

Provides information about dementia and funds research projects to beat dementia.

Tel: **0300 111 5111**

www.alzheimersresearchuk.org

Alzheimer's Society

Offers advice, information and support to people living with dementia, their families and carers. You can also contact **Join Dementia Research** through the helpline.

Tel: **0333 150 3456**

www.alzheimers.org.uk

To order publications, email **orders@alzheimers.org.uk** or call the team on **0300 303 5933**.

British Association for Counselling and Psychotherapy (BACP)

National body representing counsellors and psychotherapists. Provides a list of counsellors and psychotherapists in your area.

Tel: **01455 883300**

www.bacp.co.uk

Citizens Advice

Network of centres offering free, confidential and independent advice.

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**

In Wales: **www.citizensadvice.org.uk/wales**

Dementia Adventure

Provides dementia-friendly activities and holidays for people with dementia, as well as training for family and friends.

Tel: **01245 237548**

Email: **info@dementiaadventure.co.uk**

www.dementiaadventure.co.uk

Dementia UK

Specialist dementia nursing charity that provides advice, information and support. Contact their helpline to speak to an Admiral Nurse or visit their website to find out if you have a service in your local area.

Dementia Helpline: **0800 888 6678**

Email: **helpline@dementiauk.org**

www.dementiauk.org

Department for Work and Pensions (DWP)

Contact them for information about having an appointee manage your benefits for you.

www.gov.uk/become-appointee-for-someone-claiming-benefits

Driver and Vehicle Licensing Agency (DVLA)

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

GOV.UK

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

www.gov.uk

In Wales, visit **GOV.WALES** at **www.gov.wales**

In Northern Ireland, visit **NI Direct** at **www.nidirect.gov.uk**

Living Made Easy

Provides information about adaptations and aids to make life easier.

www.livingmadeeasy.org.uk

National Council for Volunteering Organisations

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

Tel: **020 7713 6161**

www.ncvo.org.uk/ncvo-volunteering

In Wales, contact **Volunteering Wales**

www.volunteering-wales.net

In Northern Ireland, contact **Volunteer Now**

www.volunteernow.co.uk

NHS

Provides information about health conditions, treatments and services

Tel: **111**

www.nhs.uk

In Wales, visit **NHS 111 Wales** at 111.wales.nhs.uk

In Northern Ireland, visit **NI Direct** at www.nidirect.gov.uk

Thrive

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

Tel: **0118 988 5688**

www.thrive.org.uk

Tourism for All

Provides information about accessible holidays in the UK for people with disabilities.

www.tourismforall.org.uk

Help us be there for someone else

We hope you found this guide useful. When times are tough, it's so important to get some support. You can help us reach everyone who needs us:

1

Tell us your story. If Age UK's information and advice has helped you, we'd love to hear about it. Email stories@ageuk.org.uk.

2

Donate to us. We rely on donations to support older people when they need us most. To make a donation, call us on **0800 169 8787** or go online at www.ageuk.org.uk/donate.

3

Volunteer with us. Our volunteers make an incredible difference to people's lives. Find out more at www.ageuk.org.uk/volunteer or contact your local Age UK.

4

Campaign with us. We campaign to make life better for older people, and rely on the help of our strong network of campaigners. Add your voice at www.ageuk.org.uk/campaigns.

5

Remember us in your will. A gift to Age UK in your will is a very special way of helping older people get expert support in the years to come. Find out more by calling **020 3033 1421** or visit www.ageuk.org.uk/legacy.

What should I do now?

You might want to read some of our relevant information guides and factsheets, such as:

- **At home with dementia**
- **Caring for someone with dementia**
- **Getting help at home**

You can find all of our guides and factsheets on our website, along with lots more useful information. Visit **www.ageuk.org.uk** to get started.

You can order free printed copies of any guide or factsheet by emailing **orders@ageuk.org.uk** or calling our Advice Line on **0800 169 65 65**. Our friendly advisers can also help with any questions.

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

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



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