

# Living with early-stage dementia

Living well in the present  
and planning for the future



# Information written with you in mind.

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

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## What this guide is about

**This guide explains what dementia is, and what kind of support is available for those living with it.**

It also explains things you might do to help you live well with dementia and plan ahead. It 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.

**“Following my diagnosis, I’m determined to still live life to the full.”**

Terry, 68



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 is applicable across the UK.

Please note: reference to the social services department in this guide includes the Health and Social Care Trust in Northern Ireland.

## **Before you start reading**

It can be tricky to flick between pages in this guide without losing your place. We’ve included a few 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.

# What is dementia?

## Summary

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 and vascular dementia.

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

These symptoms include:

- more frequent short-term memory problems
- mood changes
- problems with thinking, speech and communication.

Symptoms will depend on which condition is causing the dementia and which parts of the brain are affected.

There are many conditions that cause dementia. Alzheimer's disease is the most common cause but others include vascular dementia and fronto-temporal dementia. All conditions that cause dementia gradually get worse over time, and can't be cured.

Most people affected by dementia are over 65, but it can also affect people younger than this. However, everyone experiences dementia in their own way and although the symptoms of dementia may get worse, things can be done to improve quality of life.

# If you're worried about yourself

## Summary

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, so it's important to speak to your doctor.

If you're worried you've been noticeably more forgetful or confused, you may have experienced the following:

### Problems with your memory

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



## Problems with your thinking skills

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

## Sensory changes

- Problems with spatial awareness and depth perception.
- Visual problems that affect your understanding of what you see.

## Emotional changes

- Changes to your mood/mood swings.
- Having trouble controlling your emotions.

## Physical changes

- Having trouble sleeping.
- Changes to your appetite.



However, as we get older, most of us experience some of these things now and again. Being forgetful or getting confused doesn't 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.

But if you're worried, it's always best to talk to your doctor and share specific examples of things that have led you to worry. 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 the future.

A diagnosis may be life-changing but it is certainly not life-ending. 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

### Summary

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

Your doctor should:

- discuss your symptoms and how they affect your daily life
- ask questions to test your thinking and memory
- carry out a full health check. The doctor will be looking for treatable conditions that might be causing your problems.

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** (see page 40).

# What if it is dementia?

## Summary

There is no right or wrong way to react to a diagnosis of dementia. The health specialist should discuss that cause of your dementia and possible medication. You can ask for a main point of contact to support you.

It may seem overwhelming at first. You may feel shock, disbelief, and be worried about the impact it 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 is no right or wrong way to feel. Take your time to process what it means for you.

The memory clinic or health specialist in charge of your care should tell you which condition they think is causing your dementia. For some diseases causing dementia, there are drugs that can slow down the progression of symptoms.

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

## Next steps



You can call Alzheimer's Society's helpline or contact Dementia UK for support and advice (see pages 41-42).

# How might dementia affect me?

## Summary

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

Many people with a diagnosis of dementia stay independent long after their diagnosis and live well with dementia. But over time, it can reduce your ability to remember people and places, look after yourself and make decisions for yourself.

The progression of symptoms will depend on the cause of your dementia and can vary from one person to another.

Not everyone has the same difficulties, and everyone experiences dementia in their own way.

However, planning ahead can leave you knowing you have arrangements in place if there comes a time when you can no longer make or communicate your decisions. See pages 32–33 for more about planning for the future.

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

Lee, 64



# Talking about dementia

## Summary

It can feel difficult to talk to friends and family 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 rather not talk to friends or family then a counsellor can be a real help.

Talking about your diagnosis can be difficult, especially the first time you have the conversation with someone. You might get emotional, which is perfectly natural. You may 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 personal to you and there's no right way to do it. What is important is that you do it when you're ready and that you're honest about how you're feeling.

### Talking to friends and family

Many people don't fully understand dementia and you might be wondering what to tell people about your diagnosis – or even whether to tell anyone at all. You may be worried 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 what they can do to help. The more specific you are about the challenges you face, the more they can help.

## 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 their 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 (see page 41).

Alzheimer's Research UK's **Dementia Explained** is a useful online resource for young people (see page 41).

The Mental Health Foundation has a useful guide for children called **The milk's in the oven**. Download it from their website (see page 43).

## Changing relationships

As your circumstances change, keep your friends and family up to date with what kind of help you need, such as assistance with managing your finances or other daily tasks. 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. Alzheimer's Society's factsheet **Sex and intimate relationships** looks at ways people can remain loving and close as dementia progresses (see page 41).

## 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 contact the British Association for Counselling and Psychotherapy (BACP) for a list of counsellors in your area (see page 41).



## 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.**

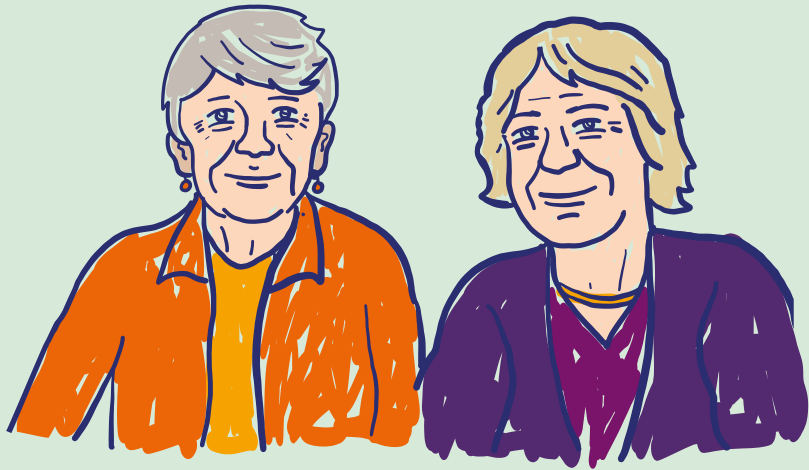
'When I was diagnosed with early-stage dementia, I went into a daze. I sat around and did nothing because I couldn't take it in. When you're told you've got something like this, you can feel you're the only person in the world who has it.

'I got into such a state that I went 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.





## ‘Talking about my dementia with people who know what it’s like can really help.’



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

‘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.’

# Finding support in your local area

## Summary

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

You don't have to go through the dementia journey by yourself. In most areas there is a range of support available.

- **Specialist support** groups can give you advice on what to expect in the future, and put you in contact with other people so that you can talk about how you're feeling.
- **Memory cafés** offer information and support in an informal setting. You can meet up with others 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.



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 (see page 41). In Wales, contact Age Cymru to find out about the help you can get. In Northern Ireland, contact Age NI to find out about their My Life, My Way project.

# Living well with dementia

## Making life easier

### Summary

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 that may help you live well.

### 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.
- Put important things, like your keys or glasses, in the same place every time so that you know where to find them.
- Use simple gadgets, for example, a clock that shows the date and day of the week, or a pill box with compartments for different days and times.

Living with dementia day-to-day is a very personal thing and it's important you find things that work for you, which might take a bit of trial and error.

Making your home safe and comfortable doesn't have to be expensive. For instance, good lighting can make a big difference for someone with dementia. Visit the 'How to make your home dementia friendly' section of the NHS website for some affordable ideas (see page 44).

**“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 Disabled Living Foundation website has an 'Ask Sara' section, which can help you decide what might help you stay independent and make your life at home easier (see page 43).

## Interacting with others

- Don't be afraid to ask questions, 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 that 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 41).
- 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 as an LGBT+ person with dementia

Living with dementia as an LGBT+ person can present certain challenges. Some of the symptoms of dementia can mean daily decisions, memories and changes you have experienced in the past have certain implications. You could find it harder to remember who you have told about your sexual orientation or gender identity, or you may find it more difficult to access support. For more specific information as an LGBT+ person living with dementia, see Alzheimer's Society's guide **LGBT: Living with dementia**.



# Driving

## Summary

You must tell the DVLA and your insurance company about your diagnosis. You may not have to stop driving straight away. If they decide you can continue driving they will review this again, usually after a year.

If you drive, you must tell the Driver and Vehicle Licensing Authority (DVLA) (see page 43) 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 they decide you can continue to drive, you'll be issued a driving licence that is valid for a limited period – usually one year – after which they will review your condition 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 (see page 41).

# Holidays

## Summary

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 disclose your dementia when you buy travel insurance.

People with dementia can enjoy new and exciting places and manage with just a little 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 disclose your 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 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** (see page 41). Contact Dementia Adventure or Revitalise (see pages 42-44), who arrange different types of holiday and short break for people with dementia and carers.

# Keeping active

## Summary

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 or volunteering.

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

- **Socialising.** Keep in touch with old 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. Visit the 'Find my local Age UK' section of [www.ageuk.org.uk](http://www.ageuk.org.uk) or call 0800 169 65 65 to find your local Age UK.



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

- **Exercise.** Physical activity is not only good for your health, it can also improve your mood and lift your spirits. Walking, swimming, 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 manage 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 kitchen 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 (see page 44), who offer advice on practical solutions, such as choosing specially adapted tools, to make gardening easier. 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 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 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 local church or faith group, your favourite charity, or at a charity shop. Contact Volunteering England (see page 45) to find out about volunteering opportunities. It's important to be open about your diagnosis so you can be best supported in your role.



There are separate volunteering organisations in Wales and Northern Ireland (see page 45).

# Working

## Summary

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 – it depends on your job and how dementia affects you.

Telling your employer about your diagnosis will help 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. This could include: 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 (see page 42). Some bank accounts and insurance policies also offer access to legal advice.

## Next steps



Read Alzheimer's Society's guide **Employment** for more help. They also have a guide **Creating a dementia-friendly workplace: A practical guide for employers** (see page 41).

# Legal and financial considerations

## Benefits

### Summary

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 a disability benefit: either Personal Independence Payment (PIP) or Attendance Allowance (AA) depending on your age and whether you need help with care or getting around. 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 more information.

### 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

## Summary

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

Paying your bills by direct debit means you won't forget to pay, as the money will automatically be paid from your account. Look on paper bills for details of how to do this. Paper bills will also allow you to ensure you're paying what you should.

Online banking can also 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, giving someone permission to manage your bank account(s). 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 have Lasting Power of Attorney set up to ensure this doesn't cause problems down the line.

## 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. This means that if there comes a time when you can't manage your benefits, someone else can 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.

# Sorting your legal affairs

## Summary

Set up a will as soon as you can. If you already have one, check to make sure 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.

### Wills

If you don't have a will, set one up as soon as possible. And if you do, 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 if the time comes when you're no longer able to do so. Whether someone is able or not to make a particular decision relates to their 'mental capacity'.



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



### There are two types of LPA:

- **Property and Financial Affairs.** This 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.
- **Health and Care.** This covers decisions about things such as medical treatment and moving 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 Controllingship.

### 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** (see page 41) may also be helpful.

# Thinking about the future

## Thinking about future care and support

### Summary

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

Thinking about your future health and care needs, and planning for them now, can give you peace of mind that you will receive the treatment and care that you want.

### **Making your wishes known**

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 to say how you want to be looked after**

You can set up an advance statement to explain your preferences and how you would like to be looked after and cared for. For example, you can specify 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 is important for people to know about how you want to be supported.



## Advance decision to refuse medical treatment

An advance decision to refuse medical treatment is legally binding. It lets you say which types of medical treatment you wouldn't want to have in certain situations. It is only used if you can't make or communicate the decision yourself. This 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.

## Who will speak for me if I don't have anyone else?

If in the future you can't make certain important health or care decisions yourself and have no one to speak up for you, an Independent Mental Capacity Advocate (IMCA) must be appointed. Their role is to 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



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

# Getting help when you need it

## Summary

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, dressing or have difficulty with domestic tasks, contact your local council's social services department to ask for a care needs assessment.

They will look at your needs and decide what support would best help meet them. Even if you're not eligible for help, social services should give you information and advice. If you have a carer, their needs should be taken into account as well. They are also entitled to a separate carer's assessment.

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 is 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 make a contribution to the cost of care covered by your personal budget.

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

Samira, 75



## 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

## Summary

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. Thinking about these options now and planning ahead means your wishes can be respected and taken into account in future.

You may have many years of independent living ahead of you and thinking about help you might need in the future can be hard. But thinking about it now should mean that your wishes are respected and taken into account if you can't make the decision in the future.

Thinking and planning ahead doesn't mean you have to move before you're ready. Moving house can be quite disorientating for people with dementia, so talk it over with friends, family and the professionals involved in your care.

There are different options to suit your needs. These options are outlined on the next page.

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

Trudy, 75





There are lots of housing options available for you to buy or rent.

- **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, 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, you can move in to 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.

## Next steps

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

# What you can do next

## Summary

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 now want to do to help you live well with dementia.

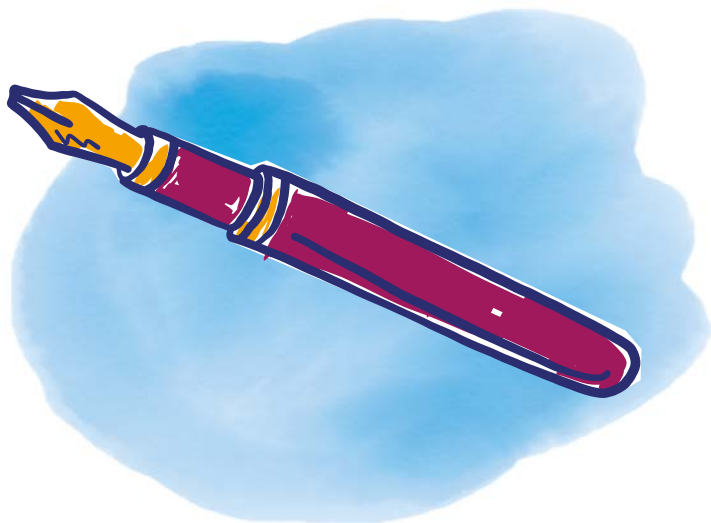
- Tell the DVLA and your insurance company about your diagnosis if you drive (see page 22).
- Make sure you (and your carer, if you have one) are claiming all the benefits you're entitled to (see page 27).
- Set up direct debits to pay your bills (see page 28).
- Set up a Lasting Power of Attorney (LPA) (see page 31).
- Make a will if you don't have one or, if you do, check it still reflects your wishes (see page 30).
- Think about setting up an advance decision and/or an advance statement (see pages 32-33).
- If you're having difficulties managing at home, contact your local council social services department and ask for a community care needs assessment (see page 34).
- Think about your home – does it need changes or adaptations, or would you be more comfortable living somewhere with more support (see page 36)?

## Getting involved in dementia research

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

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 41). It carries out research into the causes of dementia and hopes to find effective treatments, care and even provide a cure in the future. Join Dementia Research is looking for people with dementia and their carers, and 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.

You can call Age UK Advice on 0800 169 65 65 to find out whether there is a local Age UK near you, and to order free copies of our information guides and factsheets.

### **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: **08000 223444**

**[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 12 44222**

**[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.

National Dementia Helpline: **0300 222 1122**

**[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)**

## **Alzheimer's Research**

Alzheimer's Research UK 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)**

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

Tel: **01455 883300**

**[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 Wales there is a national phone service on **0344 477 2020**. It is available in some parts of England on **0344 411 1444**.

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

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

Northern Ireland: **[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

## Dementia Adventure

Dementia Adventure organises short breaks and holidays for people with dementia and their carers.

Tel: **01245 237548**

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

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

## Dementia UK

Dementia UK works to improve the quality of life of people with dementia. In some areas there are Admiral Nurses, who are specialists in dementia care and can provide advice and guidance to you and your family. Admiral nurses also staff their helpline.

Tel: **0800 888 6678**

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

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

## Disabled Living Foundation

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**

**info@dlf.org.uk**

**www.dlf.org.uk**

## Driver and Vehicle Licensing Agency (DVLA)

The 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.

You can call them on **0300 790 6806**

**www.gov.uk/dvla-medical-enquiries**

## GOV.UK

This is the official government website, providing information on public services such as benefits, pensions and health services.

You will find it at **www.gov.uk**

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

In Wales, visit the Welsh Government at **www.gov.wales**

## Mental Health Foundation

The Mental Health Foundation produces a range of information on mental wellbeing.

**www.mentalhealth.org.uk**

## **NHS website**

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

**www.nhs.uk**

In Wales, visit **NHS Direct Wales**

Tel: **0845 46 47**

**www.nhsdirect.wales.nhs.uk**

In Northern Ireland, visit **NI Direct**

**www.nidirect.gov.uk**

## **Revitalise**

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**

## **Tourism for all**

Tourism for all advises on accessible holidays throughout the UK for people with disabilities.

Tel: **0845 124 9971**

**info@tourismforall.org.uk**

**www.tourismforall.org.uk**

## **Thrive**

Thrive helps people with disabilities enjoy gardening.

Tel: **0118 988 5688**

**info@thrive.org.uk**

**www.thrive.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**

## **Volunteering England**

Volunteering England 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**

Tel: **0800 2888 329**

**volunteering-wales@wcva.org.uk**

**www.volunteering-wales.net**

In Northern Ireland, contact **Volunteer Now**

Tel: **028 9023 2020**

**info@volunteernow.co.uk**

**www.volunteernow.co.uk**

# Notes

Dotted lines for writing notes.

# Help us be there for someone else

We hope you found this guide helpful. When times are tough, it's so important to get some support. Did you know you could help us reach someone else who needs a little help? Here's how:

1

## Give your views on guides like this

Our Readers' Panel helps make sure the information we produce is right for older people and their families. We'd love you to join. Go to [www.ageuk.org.uk/publications/readers-panel](http://www.ageuk.org.uk/publications/readers-panel).

2

## Donate to us

Every donation we receive helps us be there for someone when they need us. To make a donation, call us on **0800 169 8787** or go to [www.ageuk.org.uk/donate](http://www.ageuk.org.uk/donate).

3

## Volunteer with us

Our volunteers make an incredible difference to people's lives. Get involved by contacting your local Age UK or at [www.ageuk.org.uk/volunteer](http://www.ageuk.org.uk/volunteer).

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 to our latest campaigns at [www.ageuk.org.uk/campaigns](http://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](http://www.ageuk.org.uk/legacy).

## What should I do now?

You may want to read some of our other relevant guides, 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 will also be able to help answer any questions you have about anything you've read.

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)**



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