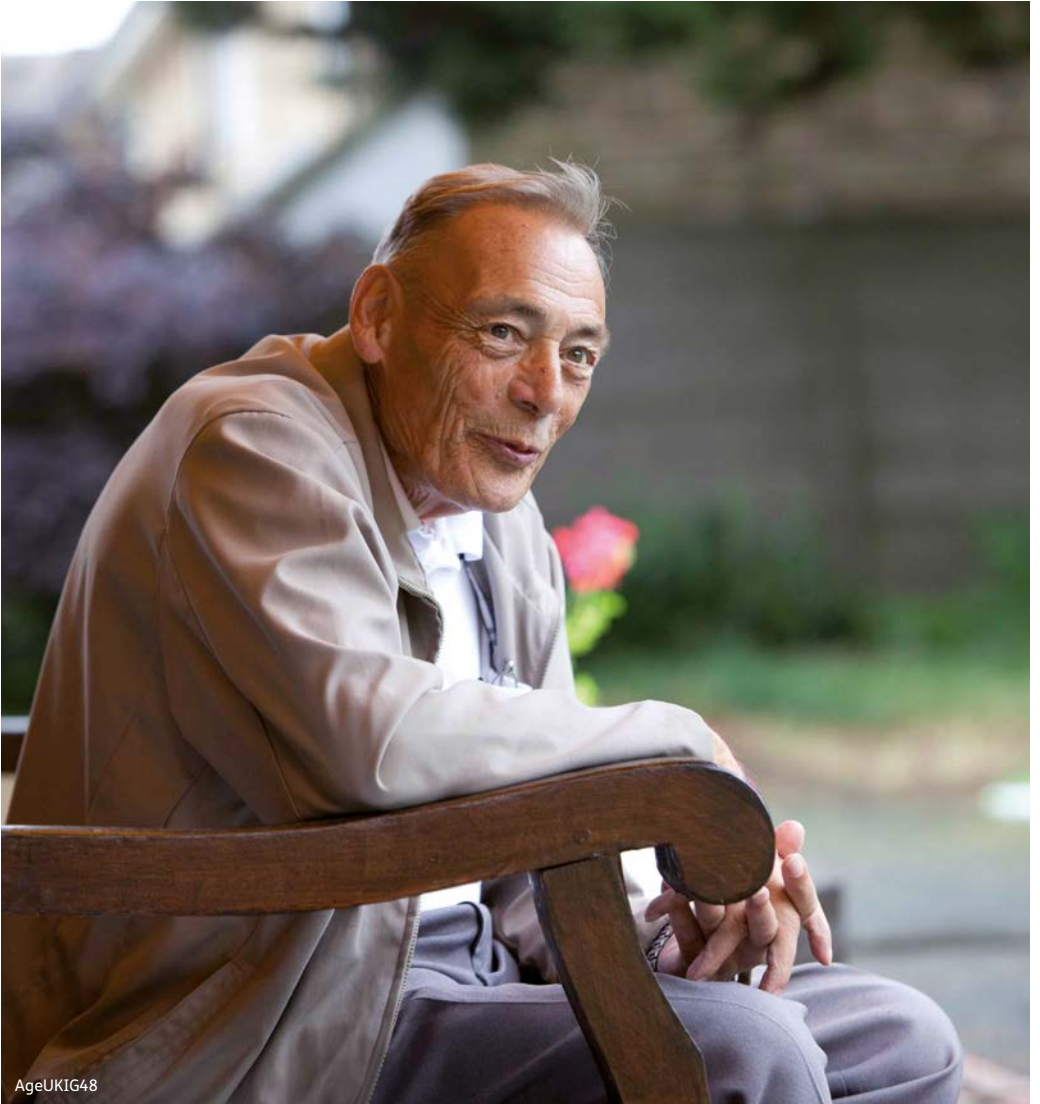


Living with early-stage dementia

Living well in the present
and planning for the future



Information and advice you need to help you love later life.

We're Age UK and our goal is to enable older people to love later life.

We are passionate about affirming that your later years can be fulfilling years. Whether you're enjoying your later life or going through tough times, we're here to help you make the best of your life.

Our network includes Age Cymru, Age NI, Age Scotland, Age International and more than 150 local partners.

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Contents

What this guide is about	2
What is dementia?	3
If you're worried about yourself	4
Diagnosis and support	
Seeing your doctor	6
What if it is dementia?	7
How might dementia affect me?	8
Talking about dementia	9
Finding support in your local area	11
Living well with dementia	
Making life easier	14
Driving	16
Holidays	17
Keeping active	18
Working	20
Legal and financial considerations	
Sorting your legal affairs	22
Getting your finances in order	24
Benefits	26
Thinking about the future	
Thinking about future care and support	28
Getting help when you need it	30
Housing options	31
Further information	
What you can do next	34
Useful organisations	36

What this guide is about

This guide is written for people with a diagnosis of dementia.

But if you're worried that you or someone you know might have dementia, then this will be helpful for you too.

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 to live well with dementia and plan ahead. It will also be helpful for the friends and family of someone with a diagnosis.

If you don't want to read the whole guide, you can just read the sections that are most relevant to your situation.

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 Social Work Department in Scotland and Health and Social Care Trust in Northern Ireland.

Key



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



This symbol indicates who to contact for the next steps you need to take.

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
- problems with 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.

Most people affected by dementia are over 65, but it can also affect people younger than this. All conditions that cause dementia get worse over time, and they can't be cured.

However, although someone's symptoms of dementia may get worse over time, things can be done to improve their quality of life. This guide includes steps to take to help you live as well as possible with dementia.

**what
next?**

Contact Alzheimer's Society for their factsheet *What is dementia?* and other factsheets on different conditions that cause dementia (see page 37).

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 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 losing the thread of what you're 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.
- Problems with your vision.

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 these things from time to time. And 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 about what could be causing these things. You will either set your mind at rest or, if you do have early-stage dementia, get 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.

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 to see whether your symptoms could have other causes. This may take a few days – the doctor will be looking for treatable conditions that might be causing your problems.

The doctor may want to refer you to a specialist or a memory clinic. The specialist will perform a more detailed assessment, including physical examinations, memory tests and sometimes a brain scan.

You may be able to talk to a counsellor about the process of having memory tests and the implications of the results. Ask your GP about this option.

Ask your doctor for a referral for a fuller assessment if they don't mention one but you think it would be useful.

**what
next?**

Contact Alzheimer's Society for their factsheet *Assessment and diagnosis* (see page 37).

What if it is dementia?

Summary

There is no right or wrong way to react to a diagnosis of dementia. The health specialist should tell you what they think the cause of your dementia is and you might be prescribed drugs to slow the progression of the symptoms. 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 those close to you. Guilt is a common reaction – feeling you've done something wrong. But dementia is a physical condition and is not your fault.

On the other hand, you may feel relieved that 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. They might suggest drugs that can slow down the progression of your symptoms.

Ask to be given someone as a point of contact who can support you. They can help you understand what's going on and explain how to get any help you need.

**what
next?**



You can call Alzheimer's Society's helpline for support and advice. In Scotland, call Alzheimer Scotland (see page 37). Dementia UK can also give useful information and advice (see page 38).

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 (see pages 22-25).

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

The progression of symptoms will depend on the cause of your dementia and can vary from one person to another. Many people have time to adjust to changes in what they can and can't do.

Many people with a diagnosis of dementia stay independent for many years, 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. How you manage this, and what kind of help you might need or want, will depend on your personal circumstances.

Making plans for the future can reassure you that your finances will be in order and you'll get the kind of care and support you want.

Planning ahead in this way can leave you free to get on with living your life, knowing you have arrangements in place if there comes a time when you can no longer make or communicate your decisions. See pages 28–29 for more about planning for the future.

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 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 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'll be able to help.

Talking to children and young people

Dementia can be difficult to explain to young children. You may not want to upset 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.

what next?

Read Alzheimer's Society's booklet *Explaining dementia to children and young people* (see page 37). The Mental Health Foundation also have a useful guide called *The milk's in the oven*. Download it free from their website (see page 39). Alzheimer's Research UK's *Dementia Explained* is a useful online resource for younger people (see page 37).

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 free 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 37).

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 support you and listen without judging you or your situation. It can help you feel clearer about your concerns and find ways to manage them.

You could still talk to a counsellor even if you have a lot of support from friends and family. Sometimes talking to someone new is easier than talking to those closest to you.

**what
next?**

Speak to your GP or contact the British Association for Counselling and Psychotherapy (BACP) for a list of counsellors in your area (see page 37).

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 cafes, 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 to help you.

- **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 cafes** offer information and support in an informal setting. They allow you to meet up with others with dementia and there are sometimes health and care professionals to talk to in private.
- **Creative workshops**, such as arts and crafts or music workshops, can allow you to continue doing hobbies you've always enjoyed or learn a new skill while meeting people in a similar situation.
- **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.

what next?



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 37). In Wales, contact Age Cymru and in Scotland, contact Age Scotland 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, which aims to support older people living with dementia, as well as their carers.

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


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. 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’s positive 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.’



'My life is **positive**.
It wasn't when I first
got diagnosed,
but it's positive!

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.

Everyone has their own ways of dealing with the challenges of dementia. Here are some ideas that may help.

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.

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 'Home environment and dementia' section of NHS Choices for some affordable ideas (see page 40).

what next?

Our free 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 39).

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 meet friends one or two 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 37).
- Make sure others don't take over – they may think they're being helpful by doing as much for you as possible.

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 may have experienced in the past have certain implications. It could be you 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 free 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 your condition again, usually after a year.

If you drive, you must tell the Driver and Vehicle Licensing Authority (DVLA) (see page 39) 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.

what next?

Our free 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 37).

Holidays

Summary

You can still enjoy going on holiday. Think about whether you want to travel to somewhere new or somewhere familiar, on your own or with someone else. There are specialist companies that offer package holidays for people with dementia. You should disclose your dementia when you buy travel insurance.

Many people, especially in the early stages of dementia, enjoy new and exciting places and can manage with 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.

If you do need a little support, most train companies have assisted travel for disabled passengers. You can also request this at airports.

As your dementia progresses, you may find that you'd prefer a specialist holiday for people who need extra help and support. Contact Revitalise (see page 40), who provides short breaks for people with disabilities and their carers. Open Britain (see page 40) can also advise on accessible holidays throughout the UK for people with dementia. Dementia Adventure specialises in arranging holidays and short breaks for people with dementia (see page 38).

When going abroad, make sure you disclose your dementia when getting your travel insurance. If you don't and you have an accident or illness linked to your dementia, you could find you're not covered as these policies can have higher premiums. Price comparison websites, such as uSwitch (see page 41), can help compare a range of policies.

**what
next?**

Read Alzheimer's Society's factsheet *Travelling and going on holiday* (see page 37).

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, of what you still have to offer.



- **Socialising.** Keep in touch with old friends so you don't become isolated. Contact your local Age UK to find out if they 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 or call 0800 169 65 65 to find your local Age UK. In Northern Ireland, contact Age NI, in Wales contact Age Cymru and in Scotland, contact Age Scotland for details of groups or activities in your local area.
- **Exercise.** Exercise 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 free 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 40), 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, but still enjoy wildlife programmes. 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 41) 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, Northern Ireland and Scotland (see page 41).

Working

Summary

You may not have to give up work 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 how dementia affects you and what job you do.

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, if you work on a plane or ship, if your job involves driving (see page 16), 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
- using technology, such as a computerised diary, to remind you of meetings and deadlines

If you decide to stop working, get advice on your pension and any benefits you may be eligible for first.

Get advice and support from your trade union or local Citizens Advice (see page 38). Some bank accounts and insurance policies also offer access to legal advice.

what next?

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 37).



A diagnosis of dementia doesn't mean life has to grind to a halt - there's lots you can do to **make the most of every day.**

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 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 for you 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'. As dementia progresses, you may find there are some decisions you are unable to make. It's important to think in advance about who you want to make decisions on your behalf.

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.

i Scotland has a different system. See Age Scotland's factsheet *Power of attorney* for more information. In Northern Ireland, contact Age NI for information about powers of attorney, Enduring Powers of Attorney and Controllership.

**what
next?**

See our free guides *Powers of attorney and Wills and estate planning* for more information. Alzheimer's Society's factsheet *Lasting power of attorney* (see page 37) may also be helpful.

If you don't have one, it's important to **set up a will as soon as soon as possible.**

Getting your finances in order

Summary

Make sure you know where all of 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. Age UK produces a free, handy *LifeBook* in which you can keep financial and other useful information. Call 0345 685 1061 to order one.

Banking

Paying your bills by direct debit means you won't forget to pay a bill, as the money will automatically be paid from your account. Look on paper bills for details of how to do this. The information on paper bills will 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. See our free guide *Protecting yourself* for more ways someone can help manage your money.



In Scotland, see Age Scotland's factsheet *Help with managing financial affairs*.

i 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 (see page 23 for more information and how this may differ in Scotland and Northern Ireland).

Benefits

You can apply for a friend, relative or other representative to 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.

Benefits

Summary

You may be able to claim a disability benefit if you need help with care. If you have a carer, they may be able to claim Carer's Allowance. You may also be able to apply for a Council Tax reduction or exemption.

Disability benefits

You may be entitled to a disability benefit: either Personal Independence Payment (PIP) or Attendance Allowance (AA) depending on your age or 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

Anyone living alone can apply for Council Tax exemption and may not have to pay any Council Tax. If you live with someone else, they may be entitled to 25% off the Council Tax bill for being your carer. As your dementia progresses further, they may be eligible for a further 25% reduction.

 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 they claim instead. See our free guide *Caring for someone with dementia* to find out more.

**what
next?**

Your local Age UK may be able to give you a benefits check or help you fill in claim forms.



Make sure you're **claiming all the benefits you're entitled to** and your affairs are in order. If you nominate someone to deal with your finances on your behalf, **make sure it's someone you trust.**

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 advanced 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 when 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 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, and in Scotland contact Age Scotland 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 decisions yourself and have no one to speak up for you, an Independent Mental Capacity Advocate (IMCA) will be appointed to help you. They would be involved in decisions about things like serious medical treatment or where you live.

-  There are no IMCAs in Scotland. People with a mental illness have an automatic right to independent advocacy.

what next?

Our free guide *Before you go* 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 community care 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 authority social services department to ask for a free community care 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. Our free guide *Getting help at home* has information about the assessment and possible charges.

If you qualify for help and financial support and live in England, you will be offered a 'personal budget'. You can then choose between the council arranging your care, or doing it yourself through direct payments. To find out more see Alzheimer's Society's factsheet *Personal budgets* (see page 37).

-  In Scotland, Age Scotland's factsheet *Care and support at home – assessment and funding* to find out how the system differs. 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 is a range of housing options for people who need more help 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 in future.

You may have many years of independent living ahead of you and thinking about future help can be hard. But thinking about it now should mean that your wishes are respected 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 is a range of housing options available to you.

- **Sheltered accommodation** is specially designed for older people. People live in their own accommodation but there is extra help 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 help available. Services will vary, but meals and personal care are often included. 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.

what
next?



See our free guides *Housing options and Care homes* for more information. In Scotland, see Age Scotland's version of *Housing options*.

‘These days I’m putting a lot of effort into doing anything that will help get rid of the stigma attached to the word dementia.’

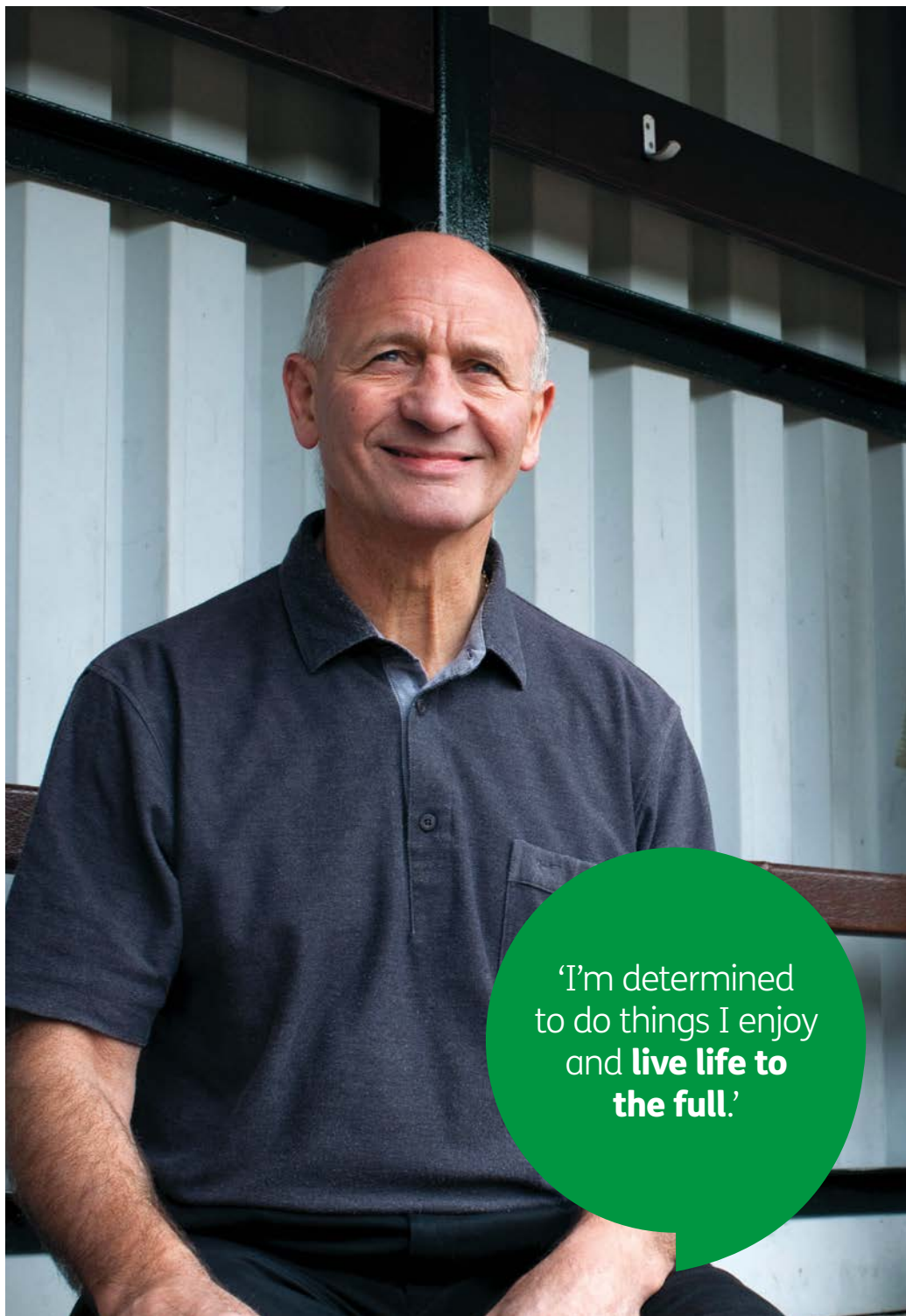
Roger, 61, thought he’d had a minor stroke when he went to his GP, but was diagnosed with dementia.

‘I was diagnosed with early-stage dementia when I was 55, which seemed incomprehensible. It was a shock, but I felt fortunate that I got my diagnosis when I did because the uncertainty was more draining than knowing what I was dealing with.

‘An early diagnosis meant I could get my affairs in order. I updated my will, and discussed both my finances and my health with my family and got any documentation in order.

‘My wife and I have always said when one door closes another opens, and I’m determined to do things I enjoy and find interesting, and to live life to the full. We are still able to take our annual trip to Australia, it just takes a bit of extra planning.’

‘I used to be a headteacher, and these days I’m putting a lot of effort into doing anything that will help get rid of the stigma attached to the word dementia. I’m a dementia ambassador for my local Health Trust and have delivered lectures on the condition.’



‘I’m determined
to do things I enjoy
and **live life to
the full.**’

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.

Use this checklist to help you plan what to do next.

- Tell the DVLA and your insurance company about your diagnosis if you drive (see page 16).
- 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 to pay your bills (see page 24).
- Set up a Lasting Power of Attorney (LPA) (see pages 22–23).
- Make a will if you don't have one or, if you do, check it still reflects your wishes (see page 22).
- Think about setting up an advance decision and/or an advance statement (see pages 28–29).
- If you're having difficulties managing at home, contact your local authority social services department and ask for a community care assessment (see page 30).
- Think about your home – does it need changes or adaptations, or would you be more comfortable living somewhere with more support (see page 31)?
- Call 0845 685 1061 for a copy of Age UK's free *LifeBook* so you can keep all your useful information in one place.
- Call Age UK Advice on 0800 169 6565 for helpful information guides on these topics. In Wales, Scotland or Northern Ireland, contact Age Cymru, Age Scotland or Age NI. See page 36 for their contact details.

Getting involved in dementia research

Your experience of living with dementia can be extremely valuable to researchers and benefit 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, Alzheimer's Society and Alzheimer Scotland (see page 37). 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 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.

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

You can find the website at www.ageuk.org.uk

In Wales, contact

Age Cymru: 08000 223 444

www.agecymru.org.uk

In Northern Ireland, contact

Age NI: 0808 808 7575

www.ageni.org

In Scotland, contact

Age Scotland: 0800 12 44 222

www.agescotland.org.uk

The evidence sources used to create this guide are available on request. Contact resources@ageuk.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.

Tel: 0300 222 11 22
www.alzheimers.org.uk

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

In Scotland, contact **Alzheimer Scotland**

Tel: 0808 808 3000
helpline@alzscot.org
www.alzscot.org

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
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
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. In Scotland, there is a national phone advice service on 0808 800 9060.

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

England or Wales: www.citizensadvice.org.uk

Northern Ireland: www.citizensadvice.co.uk

Scotland: www.cas.org.uk

Dementia Adventure

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

Tel: 01245 237548

info@dementiaadventure.co.uk

www.dementiaadventure.co.uk

Dementia UK

Dementia UK works to improve the quality of life of people with dementia. In some areas it provides Admiral Nurses, who are specialists in dementia and can support you at home.

Tel: 0800 888 6678

info@dementiauk.org

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 website**
www.gov.wales

Mental Health Foundation

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

www.mentalhealth.org.uk

NHS Choices

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 Scotland, visit **NHS Inform**

Tel: 0800 22 44 88

www.nhsinform.scot

In Northern Ireland, visit **NI Direct**

www.nidirect.gov.uk

Open Britain

Open Britain advises on accessible holidays throughout the UK for people with disabilities.

Tel: 0845 124 9971

info@tourismforall.org.uk

www.openbritain.net

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

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

<https://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

In Scotland, contact **Volunteering Scotland**

Tel: 01786 479 593

hello@volunteerscotland.org.uk

www.volunteerscotland.net

Can you help Age UK?

Please complete the donation form below with a gift of whatever you can afford and return to: **Freepost Age UK Supporter Services**. Alternatively, phone 0800 169 87 87 or visit www.ageuk.org.uk/donate. If you prefer, you can donate directly to one of our national or local partners. Thank you.

We'd[†] like to let you know about the vital work we do for older people, our fundraising appeals and opportunities to support us, as well as the Age UK products and services you can buy.

Personal details

Title:	Initials:	Surname:
Address:		
Postcode:		

We will never sell your data and we promise to keep your details safe and secure.

Please tick here if you **do not** wish to receive communications by post.

You can change your mind at any time by telephoning us on 0800 169 8787 or by writing to Supporter Services at the registered address below.

Your gift

I would like to make a gift of: £

I enclose a cheque/postal order made payable to Age UK

Card payment

MasterCard Visa CAF CharityCard

I wish to pay by (please tick) Maestro American Express

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Signature **X**

Expiry date /

Gift aid declaration

Yes, I want Age UK and its partner organisations* to treat all donations I have made for the four years prior to this year, and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations. I am a UK tax payer and understand that if I pay less income tax and/or capital gains tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Date __/__/__ * Age Cymru, Age Scotland and Age NI



[†] We, includes the charity, its charitable and trading subsidiaries, and national charities (Age Cymru, Age Scotland and Age NI). Age UK is a charitable company limited by guarantee and registered in England (registered charity number 1128267 and registered company number 6825798). The registered address is Tavis House, 1-6 Tavistock Square, London WC1H 9NA. **Age UK provides a range of services and your gift will go wherever the need is the greatest.**

Supporting the work of Age UK

Age UK aims to enable all older people to love later life. We provide vital services, support, information and advice to thousands of older people across the UK.

In order to offer free information guides like this one, Age UK relies on the generosity of its supporters. If you would like to help us, here are a few ways you could get involved:

1 Make a donation
To make a donation to Age UK, simply complete the enclosed donation form, call us on **0800 169 8787** or visit **www.ageuk.org.uk/get-involved**

2 Donate items to our shops
By donating an unwanted item to one of our shops, you can help generate vital funds to support our work. To find your nearest Age UK shop, visit **www.ageuk.org.uk** and enter your postcode into the ‘What does Age UK do in your area?’ search function. Alternatively, call us on **0800 169 8787**

3 Leave a gift in your will
Nearly half the money we receive from supporters come from gifts left in wills. To find out more about how you could help in this way, please call the Age UK legacy team on **020 3033 1421** or email **legacies@ageuk.org.uk**

Thank you!

What should I do now?

For more information on the issues covered in this guide, or to order any of our publications, please call Age UK Advice free on **0800 169 65 65** or visit www.ageuk.org.uk/healthandwellbeing

Our publications are also available in large print and audio formats.



The Age UK Group offers a wide range of products and services specially designed for people in later life. For more information, please call **0800 169 18 19**.

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

