

Living with early-stage dementia

Living well in the present
and planning for the future

*Health &
wellbeing*



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 160 local partners.

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What this guide is about

This guide has been written for people with a diagnosis of dementia.

If you are 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 families and friends 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.

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.

Note that when we refer to the social services department, this term includes the Social Work Department in Scotland and Health and Social Care Trusts in Northern Ireland.

If you're worried about yourself

Perhaps you have had some problems remembering things that happened recently, or you've become confused in a familiar place. You may be worried these are signs of dementia and, if so, that it will affect your life and your plans for the future.

If you're worried that you've been more forgetful or confused, you may have been experiencing the following difficulties.

- Struggling to remember things that happened recently, even though you can easily remember things from longer ago.
- Struggling to follow conversations, particularly in groups.
- Forgetting the names of familiar people or things.
- Struggling to follow a story on television or in a book, or understand magazine and newspaper articles.
- Having trouble remembering the day or date.
- Having trouble remembering where you put something, or where things are kept.
- Repeating yourself or losing the thread of what you are saying.
- Finding your thinking is fuzzy.
- Struggling to do things you used to find easy.
- Feeling confused even in a familiar place.
- Having problems controlling your mood, or controlling your emotions.

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.

Often, these problems are caused by common conditions that can be treated. These include stress, depression, vitamin deficiencies, thyroid problems, constipation, dehydration or urinary tract infections.

But if you're worried, it's always best to talk to your doctor to discover what's causing it. You can either set your mind at rest or, if you do have early-stage dementia, get the help and support you need. Getting a diagnosis won't make things worse, but it can help you make changes to live as well as possible and make plans for the future.

Many people with dementia have found that although a diagnosis may be life-changing, it is certainly not life-ending. Although it can be a challenging condition, many people with dementia live active and fulfilling lives for many years.

Seeing your doctor

Your doctor should:

- discuss your concerns and 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 be due to 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 for a fuller assessment. The specialist will perform a more detailed assessment, including physical examinations, memory assessments and sometimes a brain scan.

You're entitled to ask for a referral, so if you think a referral would be helpful but your GP doesn't mention one, you should ask about this.

what
next?

Contact the Alzheimer's Society for their factsheet *Assessment and diagnosis* and other factsheets on different types of dementia (see page 37).



Dementia is a term used to describe a collection of symptoms including memory loss, mood changes and problems with reasoning and communication skills.

What is dementia?

There are many conditions that can cause dementia. Alzheimer's Disease is a common cause, as are small strokes. There are more than 100 conditions which can cause dementia.

Dementia is a term used to describe a collection of symptoms including memory loss, mood changes and problems with reasoning and communication skills. These symptoms occur when the brain is affected by certain diseases or conditions.

When someone has dementia they may have increasing problems with their memory, they may become more confused or they may have problems thinking or doing things they used to find easy. Dementia can affect speech and mood, and how people perceive the world around them.

What all conditions that cause dementia have in common is that they get worse over time, and can't be cured.

Most people affected by dementia are over 65, but there are many people younger than this.

It is worth remembering that while someone's symptoms of dementia may get worse over time, this doesn't mean that their quality of life will. This guide will help you to take the steps you need to give yourself the best possible chance of living well with dementia.

**what
next?**

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

What happens if it is dementia?

People react in different ways to getting a diagnosis of dementia.

It may seem overwhelming at first. You may feel shock, disbelief and a sense of loss that you may not be able to do some of the things you planned. You may be scared about the impact it will have on those close to you. Guilt is another common reaction – perhaps you think you’ve done something wrong, or could have prevented it. Remember that 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 wrong 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 other health specialist in charge of your care should tell you what they think the cause of your dementia is. They might suggest drugs you can take to slow down the progression of symptoms. They should arrange to see you regularly to check how you’re getting on.

Ask to be given someone as a point of contact. Their job title may vary from place to place, but they should be there to support you through your journey with dementia, helping you understand what is going on and explaining how to get the help you need when you need it.

what next?

The Alzheimer’s Society produces a free booklet called *After a diagnosis* (see page 37).



You can also call their helpline for support and advice (in Scotland, call Alzheimer Scotland). Dementia UK can also give useful information and advice (see page 39).

How might dementia affect me?

Everyone experiences dementia differently.

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

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.

Although your symptoms will get worse over time, for many people the progression is slow, giving you time to adjust to changes in what you can and can't do.

Many people with a diagnosis of dementia stay independent for many years, and live well with dementia.

Making plans for the future can reassure you that your finances will be in order and you 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 24–27 for more about planning for the future.

**what
next?**

Read the Mental Health Foundation's guide to dementia, *Still Going Strong* (see page 40). It has an introduction written by someone living with dementia, and looks at how to plan for the future.

Talking to family and friends

Most people find that if they can be honest with their friends and family, they are more likely to get the support they need.

Perhaps you're wondering what to tell people about your diagnosis – or even whether to tell anyone at all.

You may be worried they'll avoid you, be overprotective, or change how they behave towards you.

Many people don't fully understand dementia and how it can affect those who have it. Your friends may not know how to respond or behave, or perhaps they think you can no longer socialise.

Talk to them 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 likely people are to be able to help.

Dementia can be particularly difficult to explain to young children, but there's a useful guide from the Mental Health Foundation called *The milk's in the oven*. Download it free from their website (see page 40) or buy a copy for £1.50.

As your circumstances change, keep your family and friends up to date on 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.

If you're working, see page 19 for advice on how to talk to your employer.

Counselling and other kinds of therapy

Friends and family can be a great source of support. But you may want to talk to someone else about how you're feeling.

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 a way to manage them.

You could talk to a counsellor even if you have a lot of support from friends and family. Sometimes talking to an outsider is easier than talking to those close 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 38).



Helpful strategies

Remember that dementia is an illness. Go easy on yourself.

Everyone has their own ways of dealing with the challenges of dementia. Here are some ideas that have helped other people.

- Follow a routine. Doing things at the same time each day or week can reassure you and help stimulate your memory.
- If there are things you need to do regularly, like locking the doors at night or putting out the recycling, pin notes up in prominent places.
- 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 different compartments for different days and times.
- Don't be afraid to ask questions or say 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 tells people you have dementia and includes the contact details of someone who can help. This can be useful if you're in a difficult situation and need assistance. These are available from the Alzheimer's Society (see page 37).
- Make sure other people don't take over your life – they could think they're being helpful by doing as much for you as possible.

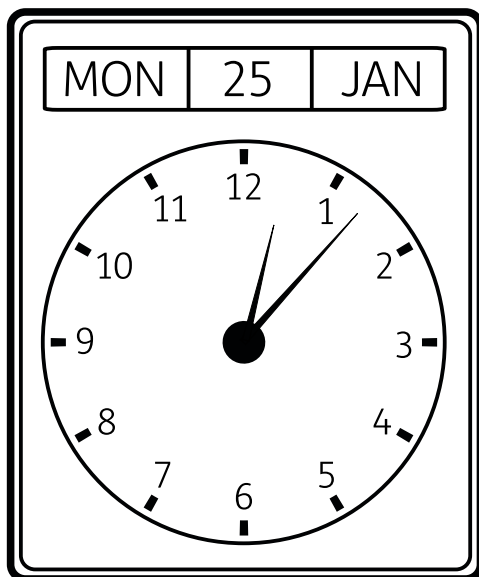
Making your home safe and comfortable doesn't have to be expensive. For instance, good lighting can make a big difference for someone with dementia. Visit the 'Home environment and dementia' section of NHS Choices for some affordable ideas: www.nhs.uk/Conditions/dementia-guide/Pages/dementia-home-environment.aspx

The website Ask Sara can help you decide what equipment might help you to stay independent and make your life at home easier. Visit www.asksara.dlf.org.uk


**what
next?**

Read our free guide *Home safety checker* for advice on possible safety risks in your home.

The booklet *10 helpful hints for dementia design at home* from the Dementia Services Development Centre offers simple and practical suggestions. It costs £7.50 and is available from www.dementiashop.co.uk



‘Life doesn’t end because you’ve got dementia or Alzheimer’s. You just need to learn to deal with what the future holds.’



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” that 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 or Alzheimer’s. You just need to learn to deal with what the future holds.’



Keeping active

Keeping active can help you feel more positive and remind you, and others, of what you still have to offer. There's lots you can do to make the most of every day.



- **Socialising.** Keep in touch with old friends so you don't become isolated. The Age UK Network has Friendship Centres which can be a great way to meet like-minded people in your area. Visit the 'Get involved' section of www.ageuk.org.uk or call 0800 169 6565 to find your nearest one. In Northern Ireland, contact Age NI 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 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 a basic kitchen timer can 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 41). They offer advice and practical solutions, like specially adapted tools, to make gardening easier. Thrive also runs gardening clubs for people under 65 with dementia.

- **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 both 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 a charity shop. Contact Volunteering England (see page 41) to find out about volunteering opportunities. There are separate organisations in Wales, Northern Ireland and Scotland (see pages 41–42).



*Simply getting outside
can raise your spirits.*



Driving

If you drive, you must tell the Driver and Vehicle Licensing Authority (DVLA) (see page 40) and your insurance company.

Having 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, they'll give you a driving licence that is valid for a limited period – usually one year – after which they will review your condition again.

what next?

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. The Alzheimer's Society's factsheet *Driving and dementia* (see page 37) has useful information too.



Working

If you're still working, you may be wondering what effect your diagnosis will have. You won't necessarily have to give up work – it depends on how dementia affects you and what your job is.

It's a good idea to tell your employer. Your employer won't be able to help you continue working if they don't know about your diagnosis. You must tell them if you're in the armed forces, work on a plane or ship, or your job involves driving (see page 18).

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 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 39). Some bank accounts and insurance policies also offer access to legal advice.

what next?

Read the Alzheimer's Society's guide *Employment for more help* (see page 37). Acas produces a booklet called *Promoting positive mental health at work* that could be useful for you and your employer (see page 37).

Holidays

Holidays can be a great way to relax. With some forward planning, you can still enjoy getting away from it all.

Think about the type of break you'd like. Many people, especially in the early stages of dementia, still enjoy new and exotic places and can manage well with a little planning and support. But if you find new environments confusing and overwhelming, you may prefer to go somewhere familiar.

It's certainly not impossible to travel on your own, but you may find it easier to have someone with you. You could be comfortable and independent in a familiar setting but welcome some extra support in a new environment or with a new routine.

You may be comfortable planning your holiday yourself or choosing a package holiday. 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 41) who provide 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 specialise in arranging holidays and short breaks for people with dementia (see page 39).

If you're going abroad, make sure you disclose your dementia when you're getting your travel insurance. If not, it might not cover you if you have an accident or illness linked to your dementia. These policies sometimes have higher premiums, so shop around.

**what
next?**

Contact [Silver Travel Advisor](#) (see page 41) for advice on planning a holiday, and read the [Alzheimer's Society's factsheet *Travelling and going on holiday*](#) (see page 37).

*If you're going abroad, make sure
you disclose your dementia when
you're getting your travel insurance.*

Your relationships

Dealing with a diagnosis of dementia is hard, not just for you but for those around you. You and your close friends and family may feel bad that the future you had planned together has changed. Remember that the present still has lots to offer.

Remind your loved ones of what you can still do so they don't try to do too much for you. Keep things as normal as possible and carry on doing things you enjoy. They can read our free guide *Caring for someone with dementia* to find out about the help and support available. If you have a partner, the Alzheimer's Society's factsheet *Sex and dementia* can be interesting for you both, as it looks at ways people can remain loving and close as dementia progresses (see page 37).

Talking to young children or grandchildren about your dementia can be daunting. You may not want to upset them. However, children can often pick up that something is wrong and may worry less if you tell them what the problem is. How you explain dementia to them will depend on their age, how close you are, and how well they can cope with difficult things. 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. Read the Alzheimer's Society's booklet *Talking to children about your illness*.

Organising 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 0845 685 1061 to order one.

Banking

Paying your bills by direct debit means you'll never forget to pay a bill, as the money will automatically be paid from your account. Look on each bill for details of how to do this.

A joint account is a useful way to get help with managing your finances. You could add the name of a friend or relative to your bank account. This means they can get access to your money if you need them to. Or you could set up a third party mandate, giving someone permission to manage your bank account on your behalf. Think carefully and make sure you choose someone you trust. See our guide *Protecting yourself* for more ways someone can help manage your money. In Scotland, see Age Scotland's factsheet *Help with managing financial affairs*.



All third party mandates and most joint bank accounts will only operate when both people have the capacity to run the account.

Benefits

If your benefits are paid into a Post Office Card Account (POCA), you can nominate someone to access this account. 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.

Sorting out your legal affairs

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 dealt with in the way that you wish.

Wills

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

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 are no longer able to do so.

Whether someone is able or not to make a particular decision is known as their 'mental capacity'. As dementia progresses, you may find that 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.

- **Health and Welfare.** This covers decisions about things like medical treatment and moving into sheltered housing or a care home.
- **Property and Financial Affairs.** This covers decisions about things like paying bills or dealing with your home.

You can arrange for a Property and Financial Affairs LPA to be used while you still have mental capacity. A Health and Welfare LPA can only be used when you've lost capacity.

-  Scotland has a different system. Find out more in Age Scotland's factsheet *Power of attorney*. 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. The Alzheimer's Society's factsheet *Making decisions and managing difficult decisions* (see page 37) may also be helpful.

It's important to think in advance about who you want to make decisions on your behalf.



Thinking about future care

It's also a good idea to think about the treatment and care you would like to receive as your dementia progresses. Doing this now means that your wishes are known and can give you peace of mind that you will receive the treatment and care that you want.

Advance decision to refuse medical treatment

It can be hard to think about the future – but making decisions about how we want to be treated towards the end of our life will make it easier for those around us and ensure our wishes are respected.

An advance decision lets you say which types of medical treatment you would not 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.

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.

Our free guide *Before you go* and our factsheet *Advance decisions, advance statements and living wills* have more information. 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.



It's a good idea to think about the treatment and care you would like to receive as dementia progresses.



Benefits

Disability benefits

You may be entitled to a disability benefit: either Personal Independence Payment or Attendance Allowance depending on your age. These aren't means-tested so your income and savings won't be taken into consideration. Whether you qualify depends on whether you need help with care or getting around.

Help with Council Tax

If you live alone, you can apply for a 25% reduction on your Council Tax bill. Also, if you live with someone else, they may be entitled to a 25% discount on their Council Tax bill because of your dementia. This is because anyone who is judged to be 'severely mentally impaired' isn't counted when working out how much Council Tax is due. If your dementia progresses to this stage, this may entitle them to a discount in future. 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 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.



Finding support in your local area

A diagnosis of dementia can be daunting but there is help and support available.

It's important to remember that you don't have to go through the dementia journey by yourself. 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 other people who have a diagnosis of dementia and there are sometimes professional carers available to talk to in confidence.
- Creative workshops, such as arts and crafts or music workshops can allow you to continue doing the hobbies you've always enjoyed, or learn a new skill while meeting people in a similar situation.
- Day centres can provide you with 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 for services and support groups on the Alzheimer's Society website. 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 who are living with dementia and their carers.



Getting help from social services

Social services can help in all sorts of ways, so it's a good idea to ask for an assessment.

If you're having difficulty managing domestic tasks or need help with things like washing or dressing, contact your local authority social services department and ask for a free community care assessment.

They will look at what needs you have and decide what support would help you meet your needs. 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 for the support you receive, based on your savings and income. Our guide *Getting help at home* has more 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 having the council arrange your care, or arranging it yourself through direct payments. To find out more, see the Mental Health Foundation's booklet *Personal budgets for people with dementia* (see page 40). In Scotland, find out how the system differs by reading Age Scotland's factsheet *Council assessment for care and support at home*. In Wales, see Age Cymru's factsheet *Direct payments for community care services in Wales*.



Housing

There are a range of housing options for people who need more help as their dementia progresses.

It's worth considering what you want to happen if your dementia progresses to the stage where you need a lot more help. You may have many years of independent living ahead of you and thinking this far ahead can be a hard thing to do. 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 home can be quite disorienting for people with dementia, so it's worth talking it over with friends, family, and the professionals involved in your care.

If you're no longer able to manage in your own home, there are a range of options.

- **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 in to 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 guides *Housing options* and *Care homes* to find out more about the options available.

Getting involved in dementia research

Your experience of living with dementia can be extremely valuable to researchers.

‘Join dementia research’ is a national service run by the National Institute for Health Research in partnership with the Alzheimer’s Society, Alzheimer’s Research UK and Alzheimer Scotland. 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, along with people without dementia to help them carry out their research.

To register your interest and find out what research you could take part in, visit www.joindementiaresearch.nihr.ac.uk

Checklist of what to do next

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 18).
- Make sure you (and your carer, if you have one) are claiming all the benefits you're entitled to (see page 28).
- Set up direct debits to pay your bills (see page 23).
- Set up a Lasting Power of Attorney (LPA) (see pages 24–25).
- Make a will if you don't have one or, if you do, check it still reflects your wishes (see page 24).
- Think about setting up an advance decision and/or an advance statement (see pages 26–27).
- If you're having difficulties managing at home, contact your local authority social services department and ask for a community care assessment (see page 31).
- Think about your home – does it need changes or adaptations, or would you be more comfortable living somewhere with more support (see page 32)?
- 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.

Remind your loved ones of what you can still do so they don't try to do too much for you. Keep things as normal as possible and carry on doing things you enjoy.



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 8 o'clock in the morning to 7 o'clock in the evening.

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

In Wales, contact

Age Cymru: 0800 022 3444

www.agecymru.org.uk

In Northern Ireland, contact

Age NI: 0808 808 7575

www.ageni.org

In Scotland, contact **Age Scotland** by calling Silver Line Scotland: 0800 470 80 90 (This is a partnership between The Silver Line and Age Scotland)

www.agescotland.org.uk

Acas (Advisory, Conciliation and Arbitration Service)

Acas can give you information and advice on rights at work.

You can call the helpline on 0300 123 1100

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

Alzheimer's Society

Alzheimer's Society offers advice, information and support in England and Wales to people with dementia, their families and carers through its helpline and local branches.

You can call the helpline on 0300 222 1122

You can find the Alzheimer's Society website at www.alzheimers.org.uk

In Wales, you can find the website at www.alzheimers.org.uk/wales

To order publications, call 01628 529240 or email publications@alzheimers.org.uk

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

You can call the helpline on 028 9066 4100

You can find the website at www.alzheimers.org.uk/northernireland

In Scotland, contact **Alzheimer Scotland**

You can call the helpline on 0808 808 3000

You can email them at helpline@alzscot.org

You can find the website at www.alzscot.org

AT Dementia

AT Dementia provides information about equipment that can help people with dementia live independently.

You can call them on 0115 748 4220

You can email them at info@trentdsdc.org.uk

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

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.

You can call them on 01455 883300

You can email them at bacp@bacp.co.uk

You can find the website at www.bacp.co.uk

Care and Social Services Inspectorate Wales

This is the national regulatory body of care homes and care at home services in Wales. It can give you a list of care services in your area, as well as copies of inspection reports.

You can call them on 0300 7900 126

You can email them at cssiw@wales.gsi.gov.uk

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

Care Inspectorate

This is the inspectorate of care services in Scotland.

You can call the inspectorate on 0345 600 9527

You can email them at enquiries@careinspectorate.com

You can find the website at www.scswis.com

Care Quality Commission (CQC)

This is the national regulator of all health and social care services in England. All hospitals, dentists, ambulance services, care homes and home care agencies must be registered with the CQC. It can provide lists of care homes for a specific area, care home inspection reports and hospital performance ratings.

You can call them on 03000 616161

You can email them at enquiries@cqc.org.uk

You can find the website at www.cqc.org.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 advice 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.

To find details of your nearest Citizens Advice in:

England or Wales: www.citizensadvice.org.uk

Scotland: www.cas.org.uk

Visit www.adviceguide.org.uk for online information.

Dementia Adventure

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

You can call them on 01245 237 548

You can email them at info@dementiaadventure.co.uk

You can find the website at 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 that can support you at home.

You can call the Admiral nurse helpline on 0845 257 9406

You can email the helpline at direct@dementiauk.org

You can call Dementia UK on 020 7697 4160

You can email them at info@dementiauk.org

You can find the website at www.dementiauk.org

Driver and Vehicle Licensing Agency (DVLA)

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

You can find the website at 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

Mental Health Foundation

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

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

Open Britain

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

You can call them on 0845 124 9971

You can email them at info@tourismforall.org.uk

You can visit the website at www.openbritain.net

Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority in Northern Ireland has similar responsibilities to those of the CQC (page 38).

You can call them on 028 9051 7500

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

Revitalise

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

You can call them on 0303 303 0145

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

Silver Travel Advisor

Silver Travel Advisor provides travel reviews and advice for travellers over 50.

You can email them at service@silvertraveladvisor.com

You can find the website at www.silvertraveladvisor.com

Thrive

Thrive helps people with disabilities enjoy gardening.

You can call them on 0118 988 5688

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

Volunteering England

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

You can call them on 020 7713 6161

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

In Wales, contact **Volunteering Wales**

You can call them on 0800 2888 329

You can email them at volunteering-wales@wcva.org.uk

You can find the website at www.volunteering-wales.net

In Northern Ireland contact, **Volunteer Now**

You can call them on 028 9023 2020

You can find the website at www.volunteernow.co.uk

In Scotland, contact **Volunteering Scotland**

You can call them on 01786 479 593

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

Wales Dementia Helpline

The Wales Dementia Helpline offers confidential emotional support and advice from trained volunteers.

You can call them on 0808 808 2235

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

Can you help Age UK?

Please complete the donation form below with a gift of whatever you can afford and return to: Age UK, Tavis House, 1-6 Tavistock Square, LONDON WC1H 9NA. Alternatively, you can 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.

Personal details

Title:	Initials:	Surname:
Address: _____ _____		
Postcode: _____		
Tel:	Email:	

By providing your email address and/or mobile number you are agreeing to us contacting you in these ways. You may contact us at any time to unsubscribe from our communications.

Your gift

I would like to make a gift of: £

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

Card payment

I wish to pay by (please tick) MasterCard Visa CAF CharityCard
 Maestro American Express

(Maestro only)

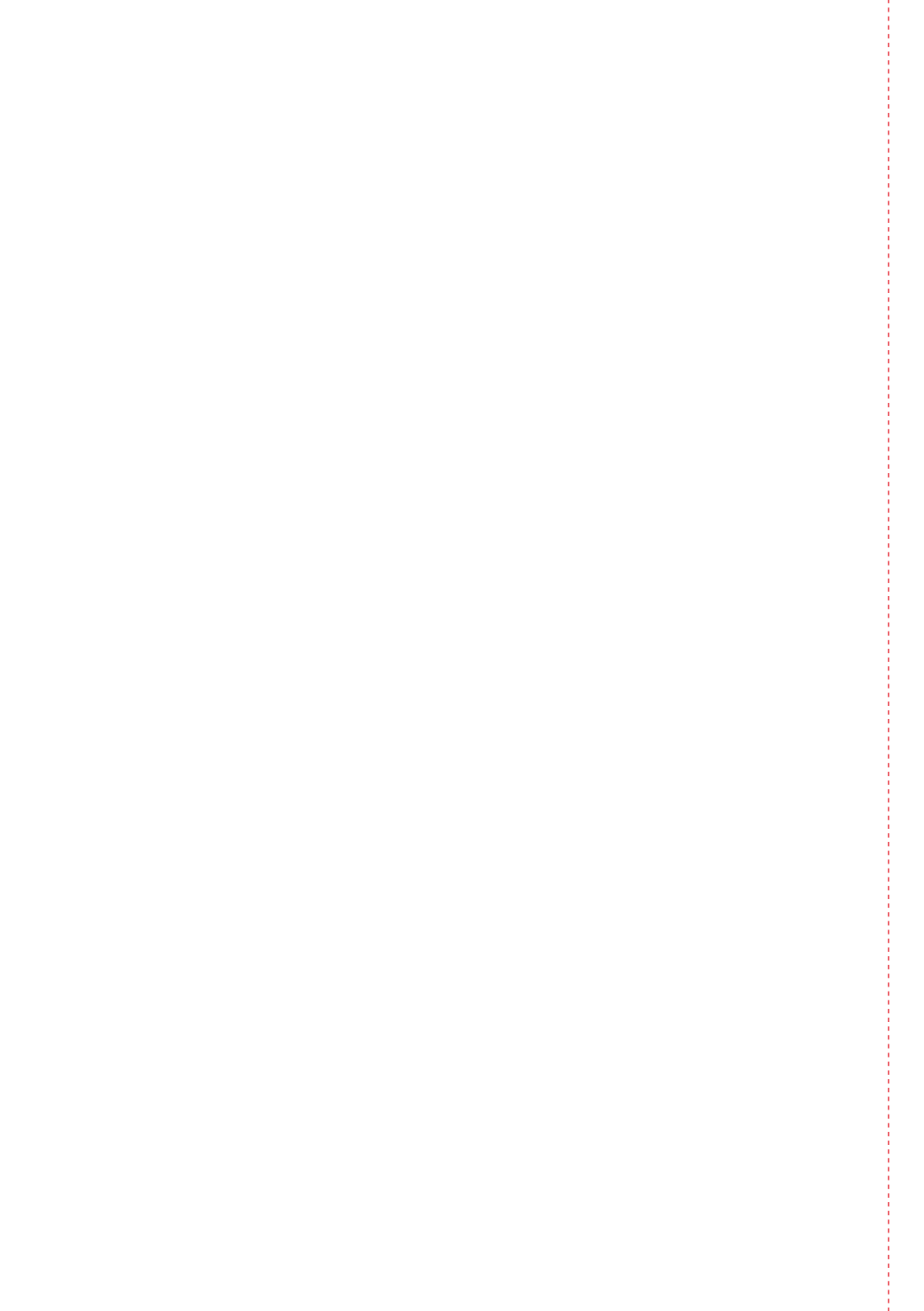
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Gift aid declaration

(please tick) 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 confirm I pay an amount of income tax and/or capital gains tax at least equal to the tax that the charity will reclaim on my donations in the tax year. Date: ___/___/___ (please complete). *Age Cymru, Age Scotland and Age NI



The Age UK Group may use the information you have supplied to tell you about our other charitable services or to ask you to support our work. Age UK (registered charity no 1128267) comprises the Charity, its group of companies and national partners (Age Cymru, Age Scotland & Age NI). If you would prefer not to hear from us do let us know by phoning 0800 107 8977 or by writing to us at our registered address. The registered address is Tavis House, 1-6 Tavistock Square, London WC1H 9NA.



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 following Age UK information guides may be useful:

- *Before you go*
- *Getting help at home*
- *Wills and estate planning*

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**.

