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 across the UK 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.

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Date of publication: August 2014 © Age UK 2014
# Contents

- What this guide is about .................................................. 2
- If you’re worried about yourself ....................................... 3
- Seeing your doctor .......................................................... 5
- What is dementia? ............................................................ 6
- What happens if it is dementia? ......................................... 8
- How might dementia affect me? ........................................ 9
- Talking to family and friends ............................................ 10
- Counselling and other kinds of therapy ............................. 11
- Helpful strategies .......................................................... 12
- Driving ........................................................................... 16
- Working .......................................................................... 17
- Holidays ......................................................................... 18
- Creating the best possible home environment .................... 20
- Keeping active ............................................................... 22
- Your relationships .......................................................... 24
- Getting involved in dementia research .............................. 26
- Organising your finances ............................................... 27
- Sorting out your legal affairs .......................................... 28
- Benefits ......................................................................... 30
- Memory cafes .................................................................. 32
- Day centres ...................................................................... 32
- Getting help from social services .................................... 33
- Housing ......................................................................... 34
- Checklist of what to do next ............................................ 35
- Useful organisations ....................................................... 36

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1 Living with early-stage dementia
What this guide is about

This guide has been written for people with dementia.

It 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 are worried that you or someone you know might have dementia, then this will be helpful for you too.

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

Where you see this symbol it means that information is different in Scotland, Wales and Northern Ireland.

This symbol tells you who to contact for the next steps you need to take.
If you’re worried about yourself

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

If you’re worried about becoming more forgetful or confused recently, 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 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 can be caused by common conditions which 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 while a diagnosis might be life-changing, it is certainly not life-ending. Although it can be a challenging condition, many people live active and fulfilling lives for many years.
Seeing your doctor

Your doctor should:
• discuss your concerns and symptoms
• 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 like vitamin deficiency that might be causing your problems
• if necessary, the doctor may 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 usually a brain scan. You’re entitled to a referral, so ask for one if they don’t suggest it.

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

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

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

What all forms of 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 might 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.
While someone’s symptoms of dementia might get worse over time, this doesn’t mean that their quality of life will.
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 the type of dementia they think you have. They might suggest drugs you can take to slow down the progression of symptoms. They should arrange to see you regularly to see how you’re getting on.

You should ask to be given someone as a point of contact. Their job title will 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 get the help you need.

The Alzheimer’s Society produces a free booklet called What your diagnosis means for you (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 them 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 page 28 for more about planning for the future.

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.

You may be wondering what to tell people about your diagnosis - or even whether to tell anyone at all?

Perhaps you’re worried they’ll avoid you, be overprotective, or will change how they behave towards you?

People can have the wrong idea about dementia and what people with dementia need or what they can do. 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. Consider sharing the Alzheimer’s Society’s factsheet Supporting a person with dementia during visits, holidays and celebrations with them (see page 37).

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 help with managing your finances or other daily tasks. This is particularly important if you live on your own.

If you’re working, see page 17 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 may want to 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.

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.

• Don’t be afraid to ask questions or say you don’t understand or have forgotten what was said.

Carry a helpcard that tells people you have dementia and includes contact details of someone who can help.
• 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 help. These are available from the Alzheimer’s Society.
• 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.
‘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.’
Driving

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

Having 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.

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 16).

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

Read the Alzheimer’s Society’s guide *Employment* for more help. Acas produces a booklet called *Promoting positive mental health at work* that could be useful for you and your employer (see page 36).
**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. If you’d prefer a specialist holiday for people who need extra help and support, contact Vitalise (see page 41) who provide short breaks for people with disabilities and their carers. Tourism for All (see page 40) can also advise on accessible holidays 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.

Contact Silver Travel Advisor (see page 40) for advice on planning a holiday, and read the Alzheimer’s Society’s factsheet *Travelling and going on holiday* (see page 37).
If you are going abroad, make sure you disclose your dementia when you’re getting your travel insurance.
Creating the best possible home environment

There might be some changes you can make to your home to make it easier for you. Making small changes now could make it easier for you in future.

• Simple gadgets can be a big help: 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.

• If you need them - home adaptations, repairs or improvements such as handrails, grab rails, ramps or bathing aids may make life easier, and there may be grants available to help with the cost. Contact your local social services department to ask for an assessment (see page 33). See our free guide Adapting your home for more information.

• You may have heard people talk about ‘telecare’. This refers to equipment that can help keep you safe and let others know what is going on. For instance, sensors in the bathroom could detect flooding and switch off the water and raise the alarm, or pressure mats by the bed can detect when someone has got up and then alert their carer. Contact AT Dementia (see page 37) to find out more.
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/CarersDirect/guide/practicalsupport/Pages/home-environment.aspx

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

Read our free Home safety checker for advice on possible safety risks in your home and Staying steady to find out more about preventing falls.

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
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.

- **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, Scotland and Northern Ireland (see page 41).

- **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.
• **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 Sudokus 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.

• **Socialising.** Keep in touch with old friends so you don’t become isolated. The Age UK Network has Friendship Centres across Britain 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 Scotland, contact Age Scotland for details of groups in your area.

• **Gardening.** Simply getting outside can make you feel a lot better. If you’re finding gardening harder than you used to, contact Thrive (see page 40). They offer advice and practical solutions, like specially adapted tools, so anyone with a disability can still enjoy gardening. Thrive also runs gardening clubs for people under 65 with dementia.

• **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.

• **Television and radio.** Some people find it hard to concentrate on the television and find it confusing. Some people find programmes with complicated plots or lots of characters difficult to follow, but can still enjoy wildlife programmes, for example. Some find listening to the radio easier as the brain only has to concentrate on sound, rather than both sound and pictures. Music can help to bring back memories, which can be very reassuring and enjoyable.
Your relationships

Dealing with a diagnosis of dementia is hard, not just for you but for those around you. If you have a partner, you may both feel bad that the future you had planned together has changed. Remember that the present still has lots to offer.

Remind your partner 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 both enjoy. They can read our free guide *Caring for someone with dementia* to find out about the help and support available. And 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*. 
Children can often pick up that something is wrong and may worry less if you tell them what the problem is.
Getting involved in dementia research

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

The Alzheimer’s Society has a research network of volunteers made up of people with dementia and carers. They help the Alzheimer’s Society decide what to research and help select projects for funding. You don’t need any special knowledge, all activities are optional and you can do the work from home. Contact the Alzheimer’s Society for more information and an application form, or email research@alzheimers.org.uk. In Scotland, contact Alzheimer Scotland for details of their research and how to get involved (see page 37).

You might want to get involved with clinical trials. They’re an important way to develop new drugs and treatments for dementia, and even provide a cure in future. Clinical trials don’t just test new medications, they also look at other ways to manage the symptoms of dementia.

Find out more by calling the Alzheimer’s Society or visiting their website (see page 37) and searching for ‘clinical trials’.
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 help. 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.
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.

**Lasting powers of attorney**
You may want to set up a lasting power of attorney (LPA). This lets you appoint a trusted person as an ‘attorney’ to make decisions for you when you are no longer able to do so.

Whether someone is able or not to a 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, and what those decisions should be.

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. Find out more, including the costs involved, in our free guide *Powers of attorney*.

Scotland has a different system. Find out more in Age Scotland’s factsheet *Powers of attorney and other ways to help manage someone’s affairs*. Powers of attorney are not available in Northern Ireland. Contact Age NI for advice.
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. Read our free guide Wills and estate planning (or in Scotland, see Age Scotland’s Making your will).

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 life easier for those around us and make sure 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 to say how you want to be treated
You can set up an advance statement to explain how you would like to be treated. For example, you can state what kind of food you want to eat, what sort of music you want to hear, 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 factsheet Advance decisions, advance statements and living wills has more information.

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.
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.

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 our more.

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

what next?
Memory cafes

Meeting other people living with dementia can help us feel less alone – and be a good source of mutual support.

Memory cafes offer information and support in an informal setting. You and your carer, if you have one, can go together. They let you drop in to meet up with other people in a similar situation. There are sometimes professional carers available to talk to in confidence. To find out about local memory cafes, ask your dementia adviser, local Age UK, local Alzheimer’s Society group or Alzheimer Scotland.

Day centres

Day centres can provide you with company and things to do. Some are for older people, with or without dementia. Others are just for people with more advanced dementia.

For people in the early stages of dementia, the idea of going to a day centre can be daunting. Certainly, day centres just for people with more advanced dementia are not suitable for most people in the early stages.

If you find one that you want to try, ask if someone from the centre will come and talk to you about what it’s like. They can be a familiar face for you when you first go along. Your partner or carer could stay with you the first few times to help you settle in. If you want to, you can take your own hobbies or personal possessions, like art materials, games or music. This gives you something to do, as well as something to talk about or share with others.

Day centres are all different. If you’re not happy at one, you might find another one suits you better.
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 your housekeeping 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 kind of help you need and decide which services you can have. This could include help at home, day care or home adaptations. If you have a carer, their needs should be taken into account as well. They can ask for a separate carer’s assessment too.

There may be a charge for these services. The amount will depend on the services you receive and where you live, as rules differ throughout the UK. Our guide Care at home has more information about the assessment and possible charges.

If you qualify for help and live in England, you may be offered a ‘personal budget’. This is money you can use to arrange and pay for your care. To find out more, see our guide Personal budgets in social care and 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 Self-directed support.
There are a range of housing options for people who need more help as their dementia progresses.

It is worth thinking about 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 that decision if that time comes.

Should you no longer be 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 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 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.

Thinking and planning ahead doesn’t mean you have to move before you’re ready to. 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.

See our guides *Housing options* and *Care homes* to find out more.
**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 16).
- Set up direct debits to pay your bills (see page 27).
- Set up a Lasting Power of Attorney (LPA) (see page 28).
- Make a will if you don’t have one or, if you do, check it still reflects your wishes (see page 29).
- Think about setting up an advance decision and/or an advance statement (see page 29).
- Make sure you (and your carer, if you have one) are claiming all the benefits you’re entitled to (see page 30).
- If you need extra help at home, contact your local authority social services department and ask for a community care assessment (see page 33).
- Think about your home – does it need changes or adaptations, or would you be more comfortable living somewhere with more support (see pages 20–21 and page 34)?
- Call 0845 685 1061 for a copy of Age UK’s free LifeBook so you can keep all your useful information in one place.

In Wales, you can use Age Cymru’s My future booklet to record your preferences on a range of matters, so people caring for you in future can understand what a good quality of life means to you. Download it from www.agecymru.org.uk or call 029 2043 1555 for a copy.

- Call Age UK Advice on 0800 169 6565 for helpful information guides on these topics.
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 them on 08457 47 47 47
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 alzheimers@xcalibrefs.co.uk

In Scotland, contact **Alzheimer Scotland**

You can call the helpline on 0808 808 3000
You can email them at alzheimer@alzscot.org
You can find the website at www.alzscot.org

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

**AT Dementia**

AT Dementia provides information on 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 their inspection reports.

You can call them on 0300 062 8800
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 0845 600 9527
You can email them at enquiries@scswis.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
Dementia Adventure
Dementia Adventure organises short breaks and holidays for people with dementia and their carers.

You can call them on 01245 230661
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 email them at eftd@dvla.gsi.gov.uk
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 call them on 020 7803 1150
You can find the website at www.mentalhealth.org.uk

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

You can call them on 028 9051 7500
You can find the website at www.rqia.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

**Tourism for All**
Tourism for All advises on accessible holidays for people with disabilities.

You can call them on 0845 124 9971
You can email them at info@tourismforall.org.uk
You can find the website at www.tourismforall.org.uk
**Vitalise**
Vitalise provides breaks for people with disabilities and their carers. They also run breaks especially for people with dementia.

You can email them at info@vitalise.org.uk
You can find the website at www.vitalise.org.uk

**Volunteer Now**
Volunteer Now provides information about volunteering opportunities in Northern Ireland, including those especially suited to older people.

You can call them on 028 9020 0850
You can find the website at www.vsb.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 0845 305 6979
You can find the website at www.volunteering.org.uk

**Volunteering Scotland**
Volunteering Scotland offers information and advice about getting involved in volunteering in Scotland.

You can call them on 01786 479 593
You can find the website at www.volunteerscotland.org.uk

**Volunteering Wales**
Volunteering Wales offers information and advice about getting involved in volunteering in Wales.

You can find the website at www.volunteering-wales.net
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: RSXZ-KTTS-KSHT, 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)

Expiry date / ___________ Issue no. (Maestro only) / ___________

Signature X

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

We will use the information you have supplied to communicate with you according to data protection guidelines. Age UK (registered charity number 1128267) comprises the charity, its group of companies and national partners (Age Cymru, Age Scotland and Age NI). If you would prefer not to hear from them or carefully selected third parties, let us know by phoning 0800 107 8977.
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](http://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](http://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:

- Adapting your home
- More money in your pocket: a guide to claiming benefits for people over pension age
- 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.