

Caring for someone with dementia

Practical help and emotional support for you



Information written with you in mind.

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

Published: **June 2019**

Next review due: **June 2021**

We'd love to hear from you.

1) **Join our Readers' Panel.** Have your say and be involved in updating our guides by joining our Readers' Panel. You don't need any specialist knowledge at all.

Join our Readers' Panel at www.ageuk.org.uk/readers-panel.

2) **Tell us your story.** We want to include real voices of real people with real stories in our guides. If you have a story then we're here to listen.

Email us at stories@ageuk.org.uk.

This information guide has been prepared by Age UK and contains general advice only, it should not be relied on as a basis for any decision or action and cannot be used as a substitute for professional advice.

Neither Age UK nor any of its subsidiary companies or charities accepts any liability arising from its use and it is the reader's sole responsibility to ensure any information is up to date and accurate.

Please note that the inclusion of named agencies, websites, companies, products, services or publications in this information guide does not constitute a recommendation or endorsement by Age UK or any of its subsidiary companies or charities.

Contents

What this guide is about

Looking after yourself 5

About dementia

What is dementia? 8

Getting a diagnosis 10

Where to turn

Support and advice 12

Talking to family and friends 14

Doing things together 16

Things you can do

Financial 19

Legal affairs 23

Home 25

Care and future care 28

Help for you

Help with care 34

A break from caring 37

Your changing relationship 39

Communication and behaviour 40

Later-stage dementia

Signs of later-stage dementia 43

Thinking about care homes 44

Moving into a care home 45

End of life care 47

Loss and bereavement 48

Useful organisations

49



What this guide is about

If you care for someone with dementia, this guide is for you.

Everyone's experience of dementia is different. But being prepared can help you make the most of your time together, now and in the future. Inside this guide you'll find out what to expect, practical things you can do, strategies that could help you cope and where to turn for support.

It might be hard to find the time to sit and read the whole guide, so maybe just turn to the sections you'll find most helpful for now and come back to it when you can.

For more general information about being a carer, see our guide **Advice for carers**.

Where possible, the information given in this guide is also applicable across Wales and Northern Ireland. Please note that when we refer to the social services department, this term includes the Health and Social Care Trusts in Northern Ireland.



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

Looking after yourself

When was the last time you put your needs first? You may be so used to putting someone else first that you feel guilty if you think about yourself and how you're feeling.

Looking after yourself is an important part of being a carer – that's why we're starting this guide with you. Before we cover anything else, we want you to take a few minutes to think about what you need, guilt-free.

Emotional support

Caring for someone with dementia can take an emotional toll. You may be feeling overwhelmed, find yourself losing your patience – with the person you're caring for and others – or struggle to deal with how dementia is affecting someone close to you.

However you're feeling, it's good to try to talk to someone about it. That might be family or friends, carers' groups, or organisations like Dementia UK or Carers UK who have numbers you can call (see pages 50 and 51). Find someone you trust and be as honest as you can; there's no right or wrong way to feel. See page 12 for how to find local support.

Staying well

Try to eat well, exercise regularly and get enough sleep. It's easier said than done as it can often feel like there aren't enough hours in the day. But try to take time out for yourself as often as you can – even if it's only 10 minutes to relax with a cuppa, listen to the radio, or get some fresh air.

Tell your doctor you're a carer and see them whenever you need to – don't put off appointments or ignore any of your own health needs. Many practices offer phone consultations, which can be particularly useful if you feel you can't leave the person you care for alone at home.

You can also ask how to register to book appointments and order repeat prescriptions online. Your pharmacy may offer a home delivery service for repeat prescriptions.

Caring for someone can affect your mental wellbeing so tell the doctor if you feel stressed, anxious, or depressed. There's nothing wrong with admitting it's all getting a bit much. In fact, it's much better for everyone involved if problems are dealt with early so they don't reach crisis point. Our guide **Healthy living** has more tips to help you stay well.

Asking for a bit of help

Try to accept help when it's offered. It can be hard sometimes to think of someone else looking after the person you do most of the caring for, particularly if you're looking after your partner or parent. You may feel like you're letting them down or palming them off, but that's not the case.

You don't need to wait for help to be offered though. Consider asking friends and family to take on certain activities, like doing the shopping, popping round for half an hour so you can go out, or just calling every now and then for a chat. It can be a great opportunity for them to spend some time with the person you care for. People often like being told how they can help so it's clear what they can do.

If you care for someone from a distance, perhaps their neighbours or local friends could step in from time to time. You could also use a mobile phone app to coordinate care with friends and family, such as the app Jointly, created by Carers UK (see page 50).

Sometimes it's not easy to talk to people about how they can help you – you might feel nervous or annoyed about asking, or worried they'll think you're suggesting they don't care. We have some more information on page 14 that can help you plan what to say.

Help from social services

You're entitled to a carer's assessment from your local council to see what support you might need. Think carefully about how your caring role affects you and what would help you manage better – don't play down any problems you're experiencing. Ask about what help is available to give you a break from caring too. You can also ask about creating an emergency plan so you have peace of mind that, if for any reason you can't provide the care you usually do, someone else can step in. There's more practical information about this on page 34.

Options if you're working

If you're juggling work and caring, you could request flexible working. Your employer doesn't have to agree to it but they must have a sound business reason for refusing. You have the right to make a request if you've been working for your employer for at least 26 weeks. You can make one request per year but if your circumstances change, your employer may be willing to consider another request.

“I cared for my mum, and the one bit of advice I'd give to anyone else is to accept there's only so much you can do on your own – and that's OK.”

Tracey, 43





About dementia

What is dementia?

A lot of people aren't quite sure what the difference is between dementia and Alzheimer's disease. Dementia isn't a disease in itself, it describes a collection of symptoms that includes memory loss, mood changes, and problems with reasoning and communication. These occur when certain conditions, most commonly Alzheimer's disease and vascular dementia, affect the brain.

Good to know

Dementia is not an inevitable part of ageing, and being forgetful doesn't necessarily mean someone has dementia.

The likelihood of developing these conditions increases with age, but they can occur in younger adults too. They are progressive and affect everyone differently. The range of symptoms and how fast they develop depends on the person and the type of dementia. Medication and certain non-medical therapies can help with some of the symptoms.

A common symptom of dementia is short-term memory loss – the person you care for may forget things they’ve said or done recently, even though they might clearly recall things that happened years ago. But there’s more to it than just memory loss. Other dementia symptoms include fuzzy thoughts and confusion, problems with your vision, changes in mood and trouble sleeping.

Dementia-like symptoms can be caused by lots of other things such as depression, stress, vitamin deficiencies, thyroid problems or urinary tract infections, so don’t jump to conclusions. If you’re worried someone might have dementia, encourage them to talk to their doctor.



When a condition is ‘**progressive**’, that means it gets worse over time.

Next steps



Contact Alzheimer’s Society or Dementia UK (see pages 49 and 51) to find out more about early signs and different types of dementia, including information about medication that may be prescribed.

Getting a diagnosis

Talking about the possibility of someone having dementia can be very worrying. Knowing what's wrong can help everyone plan ahead, access help, support, services and – if appropriate – medication.

If you're worried that someone might have symptoms of dementia, the first step is for them to visit their doctor. You could go with them to offer support or to help them explain their symptoms. If they don't want to go, you can write to their doctor. The doctor can't talk to you without the person's consent, but they could decide to look into your concerns at the person's next regular check-up or invite them for a general health check.

At the appointment, the doctor will:

- ask about any symptoms and when they started – it helps if you can give specific examples of how the symptoms affect everyday life
- look at the person's medical history and medicines, and may want to conduct tests to identify or rule out other conditions
- do a few quick tests for memory and thinking.

They may also:

- make a referral to a community mental health team for advice and support
- suggest a referral to a specialist or memory clinic for a fuller assessment.

Memory clinics employ several different specialists, including psychologists, geriatricians and nurses with specialist dementia training.

Most memory services offer sessions for a few weeks following a diagnosis that cover things such as medication, support services and planning ahead.

If the person you care for isn't given a diagnosis or a referral, they have a right to ask for a second opinion. They can also go back to the doctor if the symptoms continue.

Dealing with a diagnosis

Receiving a diagnosis can be very difficult to accept – for everyone involved. You might also find you feel relieved if you've been worried about someone for a while.

Quite often the person with dementia will struggle to accept their diagnosis, and may be in denial.

This can go on for some time and may be the person's way of dealing with their diagnosis, because it's overwhelming for them. It can even lead to the person refusing treatments or medication, which will be hard for you as someone who cares for them.

Try and be as patient and understanding as possible during this time. Reassuring the person you're there for them if they need help with certain tasks or if they want to talk can be a real support as they come to terms with their condition. If you're finding it difficult, there are people you can talk to, such as the National Dementia Helpline (see page 49).

Next steps

See our guide **Living with early-stage dementia**. Alzheimer's Society's factsheet **Assessment and diagnosis** may also be helpful (see page 49).

Where to turn

Support and advice

If you're caring for someone with dementia, you're not alone. There's support available for you both.

Local Age UK

Your local Age UK may be able to offer help and support including benefits checks, befriending services, cafés and lunch clubs, support for carers or respite services.

If you or the person you care for has difficulty getting around, ask your local council and your local Age UK if they know of transport services or voluntary car schemes to help you get to services and support groups.

Dementia advisers

They can offer support, advice and information to the person you care for. If you aren't given the name of one after the diagnosis, ask the doctor, memory clinic or the local adult social services.

Charities

Contact Alzheimer's Society, Carers Trust or Dementia UK to find out about their services, online forums and support groups, or if you just want to talk about how you feel.

NHS



The NHS Dementia Information Service can send you a weekly email for six weeks with information on dementia and the support available. Go to the NHS website and search 'Dementia Information Service' to sign up. Visit the NHS Direct Wales website in Wales.

Dementia Connect

Search on Alzheimer's Society's website for the Dementia Connect directory for services, activities and support groups in your area.

Admiral Nurses

Specialist dementia nurses who work in some communities in the UK. Call the Admiral Nurses Direct helpline (run by Dementia UK) for expert advice and emotional support.

Carers groups

These groups are a good source of support and information. Some offer speakers, leisure activities or simply time to chat. Ask your social services department about local groups, or contact Carers Trust or Carers UK.

Online forums

Forums can be invaluable if it's difficult to get out, or you need someone to chat to at any time of the day or night. Try the Talking Point forum on Alzheimer's Society's website or the message boards on the Carers UK website.

Memory cafés

Information and support in a relaxed setting. You can go together with the person you're caring for, and there may be health or care professionals available to talk to in confidence. To find local memory cafés, see the Dementia Connect directory or ask your local Age UK.

Next steps



For contact details of all these organisations, see pages 49-52.

Talking to family and friends

Are you wondering how to tell people about what's going on – or if you should at all? Most people find that if they can be honest with friends and family, they're more likely to get the support they need.

It's a good idea to talk about what they could do to support the person with dementia, particularly if you could do with a bit of help. These conversations can be tricky. You may feel that people aren't helping out as much as they could or should be. Relationship dynamics, where people live and even a person's pride can all play a part too. But an honest, open conversation is usually the best place to start.

People will naturally have their own ways of dealing with the situation. You might find that people are acting differently towards the person who's been diagnosed, or to you. It's worth reminding everyone that dementia doesn't define a person – they're still the same person they were before the diagnosis, and they'll have their own opinion on how they want to be treated and cared for.



If someone else is stepping in to help with caring, you may want to let them know about certain things that work and don't work. For example, the person with dementia may like doing things in smaller groups or places that aren't too noisy, or they may enjoy looking through old photographs. See the section 'Communication and behaviour' for more tips to share with friends and family (page 40).

Children and teens

Dementia can be difficult to explain to young people. Although it may be upsetting for both you and them, explaining what's going on is often the best idea.

Younger people will likely be aware something's going on. Being honest about the situation can be a relief, as a younger person might be worried about changes in behaviour and think it's directed at them personally, rather than because of the person's dementia.

Alzheimer's Research UK have a website specifically for children and young people at www.dementiaexplained.org.

Next steps

The national Dementia Friends scheme aims to change how society thinks about dementia by providing free awareness sessions. Your friends and family can find out more by visiting www.dementiafriends.org.uk.

Doing things together

Getting the right support can help you make the most of your time together. Doing the things together that you've always done is good for your relationship and the confidence of the person you care for, so keep it up as long as you can.

Singing classes and activity groups

Whether or not you can carry a tune, singing has been shown to be particularly therapeutic and uplifting for people with dementia. Singing for the Brain offers group singing for people with dementia and their carers. You may also find other local activity groups for both of you, like exercise classes, book groups or craft activities. Find local groups and activities by contacting Alzheimer's Society or using their Dementia Connect online directory (see page 49).

Holidays

Most people with early-stage dementia will be able to go on holiday as normal, it may just need a little extra planning. But if going away is becoming more difficult and you want to find out more about supported and specialist holidays, contact Dementia Adventure or Silver Travel (see pages 51 and 52). You should also make sure that you declare the diagnosis of dementia when looking for holiday insurance. These policies sometimes have higher premiums, so shop around. Some providers have specific insurance for people with dementia.

“Mum’s started to forget some people, but she still hasn’t forgotten Frank Sinatra. She loves singing along.”

Jen, 49





Creating a memory book

A memory book or life-story book can help you and someone with dementia remember special times. It's basically a collection of mementos and photos to represent familiar places and happy events like weddings, birthdays or holidays. Photos are particularly good at triggering memories and encouraging the person with dementia to talk about their life. The whole family can help contribute to making it and later on, it can help health and social care professionals appreciate the life and personality of the person they're caring for. Dementia UK has a template for making your own memory book, called a 'Life Story'. Go to their website and search 'life story' to download it (see page 51).

Good to know

Photos are likely to **trigger memories and encourage the person** with dementia to talk about their life.

Things you can do

This section focuses on the practical things that might be helpful for you and the person you're looking after.

They fall into four main categories:

1. Financial



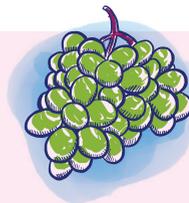
2. Legal affairs



3. Home



4. Care and future care



1. Financial

Carer's Allowance and other benefits

Make sure you're both claiming all the benefits that you're entitled to, as they could make a real difference.

For you

Carer's Allowance is the main benefit for people with caring roles. You may be able to claim it even if you don't see yourself as a 'carer' or live with the person. Just bear in mind that it may reduce certain income-related benefits (like Pension Credit) that the person you care for can claim, so make sure you check – your local Age UK can help with this.

If you receive State Pension at a higher rate than Carer's Allowance you won't receive Carer's Allowance, but extra money may be added to any means-tested benefits you claim, such as Pension Credit and Housing Benefit.

You could also qualify for reduced Council Tax if you live with someone with dementia. Councils run their own support schemes so you'll need to contact your local council to find out what they offer and whether you qualify.

Good to know



Caring can be tiring and claiming any sort of benefit might just feel like an extra challenge. Contact your local Age UK for a benefits check or to see if they can help you fill in claim forms.

For them

The person with dementia may be entitled to Personal Independence Payment or Attendance Allowance depending on their age, and whether they have care or mobility needs – or both. They won't automatically qualify just because they have dementia. Neither benefit is means-tested so you don't need to worry about their income or savings.



Use our free and simple online benefits calculator at www.ageuk.org.uk/benefits-check to find out whether you're entitled to financial support, or visit your local Age UK.

“Claiming Attendance Allowance makes life that bit easier. One less thing to worry about.”

Stanley, 80



Next steps

For more information, see our guides **Carer's Allowance** and **More money in your pocket**. Age Cymru and Age NI have their own versions of **More money in your pocket**. You should also go to www.ageuk.org.uk/benefits-check to try our online benefits calculator.



Dealing with money

You may already be looking after the finances of the person you're caring for, or you might have to in the future. It helps to have all important documents, like bank statements, insurance policies, wills and pension details, in a safe place.

Bills

If the person you care for still manages some of their finances, they may want to set up direct debits to pay regular household bills. If they can't or don't want to, ask them if you can tell their utility providers they have dementia and leave an alternative contact number so they're not cut off if they forget to pay.

Phone companies offer third-party bill management, so you can talk to the company on behalf of someone else, get copies of their bills and arrange payments.

Good to know

Age UK produces **LifeBook** that can help you get organised. It's a handy booklet that helps you keep important and useful information in one place. Call **0345 685 1061** for a copy.

Banking

Joint accounts can be useful, but only when both people have mental capacity.

If you have separate accounts, the person with dementia could set up a third-party mandate giving you permission to manage their bank account on their behalf. But again, these are usually only valid while they still have mental capacity. It's a good idea to set up a Lasting Power of Attorney for financial decisions with the person you care for so you can still look after their finances if they lose the ability to make their own decisions (see page 23).



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

Good to know



Alzheimer's Society's booklet **Accessing and sharing information: acting on behalf of a person with dementia** (see page 49) has more information.

The Office of the Public Guardian also has a guide called **Guidance for people wanting to manage a bank account for someone else** (see page 52). You can visit www.gov.uk and searching 'Deputy and attorney guidance' for a copy.

2. Legal affairs

It can be tempting to avoid talking about legal matters, but it can actually be very reassuring for you and the person you care for. Plus it can save a lot of stress down the line. You'll both know that a plan is in place, and their wishes are clear. It can help everyone focus on the here and now.

Wills

If the person you care for still has mental capacity, talk to them about making a will or reviewing their existing will to ensure it still reflects what they want.

Lasting Powers of Attorney

If the person you care for still has mental capacity, they may wish to set up a Lasting Power of Attorney (LPA). This allows them to appoint someone they trust (known as an 'attorney') to make decisions on their behalf. This process can get tricky (and more expensive) if left until someone loses mental capacity, so it's a good idea to set it up sooner rather than later.

You have to register an LPA with the Office of the Public Guardian (see page 52) before it can be used. If the person with dementia loses mental capacity after they've signed the LPA but it hasn't been registered yet, their attorney can still register it.

There are two types of LPA: one covering health and care decisions and another covering financial decisions.

The LPA for health and care decisions can only be used when someone has lost mental capacity, while the LPA for financial decisions can be used immediately if the person with dementia prefers.



Northern Ireland has a different system for LPAs and deputyship. Contact Age NI for advice.

Applying for deputyship

If the person you care for loses mental capacity but doesn't have an LPA, you can apply to the Court of Protection to be their deputy. As a deputy you can make particular decisions approved by the Court of Protection on their behalf. It's better to get an LPA in place while the person still has capacity, as applying to be a deputy is a more expensive and lengthy process.



In Northern Ireland you can apply to the Office of Care and Protection to become a controller. Contact Age NI for more information.

Next steps



See our guides **Powers of attorney** and **Wills and estate planning** for more information. Alzheimer's Society's factsheet **Making decisions and managing difficult decisions** may also be helpful (see page 49).



3. Home

Creating the best home environment

For a person living with dementia, the design and layout of where they live can have a big impact on their daily life. Worsening memory loss, confusion and difficulty learning new things can all mean they struggle to understand where things are and how they work.

Here are some tips for making changes in their home (or in yours if they spend a lot of time there or you live together).

- **Good lighting** is important because dementia can affect people's ability to understand what they see. Make sure the home is well lit, minimise shadowy areas, and let in as much natural light as possible.
- **Helpful gadgets** can make day-to-day tasks easier and safer. For example, you can get clocks that clearly show the date and day of the week, and pill dispensers with alarms to remind people when to take their medication. You can also set up alerts on the person's mobile phone.

- **‘Telecare’** is equipment that can detect problems in the home and alert you or an emergency contact centre. Sensors in the bathroom, for example, can detect flooding, and pressure mats by the bed can detect if someone gets up in the night. This may be particularly useful if the person with dementia lives alone or if you can’t be with them all the time. Contact the social services department at the person’s local council and ask them about telecare or visit the AT Dementia website (see page 50) to find out more.
- **Home adaptations or improvements** could help to make life easier. Handrails, grab rails, ramps or bathing aids may be useful and you may be able to get some adaptations paid for. Contact the social services department at the person’s local council to ask for a needs assessment (see page 34).

“I made some labels for mum’s kitchen cupboards so she knew which was which. It seems to have really helped.”

Dave, 56



Good to know



Read our guides **At home with dementia** and **Adapting your home** for more advice. The Dementia Centre at Stirling University (see page 51) has also produced useful guides for people living with dementia, including **10 helpful hints for carers** – you can find them at www.johnsmith.co.uk/stir.



Driving

If the person you care for drives, they have to tell the Driver and Vehicle Licensing Agency (DVLA) and their insurance company about their diagnosis – it's the law. Call the DVLA on **0300 790 6806** or visit **www.dvla.gov.uk**. The diagnosis doesn't automatically mean they necessarily have to stop driving immediately – what matters is that they can drive safely.

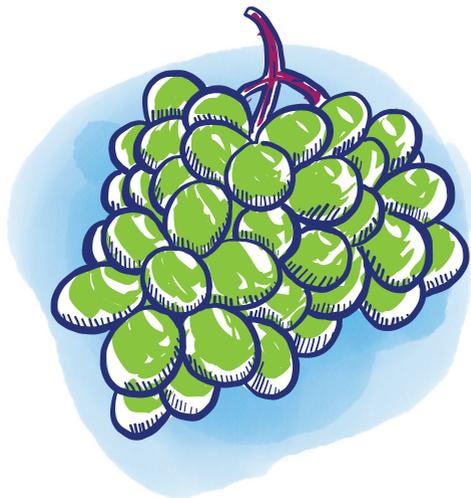


In Northern Ireland, contact the Driver and Vehicle Agency on **0300 200 7861**.

Next steps



Suggesting to someone that they stop driving can be a sensitive topic. See our guide **In the driving seat** and Alzheimer's Society's factsheet **Driving and dementia** (see page 49).



4. Care and future care

Staying healthy

If the person you care for seems withdrawn, upset or uncomfortable, there might be something going on that they're struggling to communicate.

Try the following:

- Discuss any concerns with the doctor so that physical causes, such as constipation, a urine infection, or reactions to medication can be ruled out.
- Check the person's glasses are clean and their hearing aid is in and working (if they use them). If they're struggling to see or hear they might be feeling isolated from what's going on around them, which can be very unsettling.
- See our guide **Healthy living** to find out about important health tests.
- See our guide **Bladder and bowel problems** to find out more about continence issues.

Eating and drinking

If the person you care for isn't eating properly, is losing weight or has lost their appetite, this could be because their dementia is affecting their smell and taste, or because they're struggling to use cutlery. Rather than a full meal, it might be worth trying small snacks throughout the day, like finger sandwiches or cheese and crackers.

They may also be having difficulty with chewing and swallowing – perhaps because of toothache or ill-fitting dentures. Make sure you help them brush their teeth thoroughly, if necessary, and pay regular visits to the dentist to stay on top of things.

Not drinking enough can make some symptoms worse. The person you care for may not recognise they're thirsty, and might need a nudge. Leaving a cup or beaker in front of them or just asking whether they'd like a drink can make a real difference.

If the person you care for lives alone and you're worried about them eating and drinking enough, raise this during their needs assessment (see page 34). You could also find out if there are local meal delivery services available, like Meals on Wheels. Chat to your local Age UK who can help you find out what might be available nearby.

Alcohol can cause confusion or react badly with certain medicines. If the person you care for enjoys a tipples, you could try weaker, non-alcoholic or watered-down drinks – just make sure it doesn't interfere with any medication.

Alzheimer's Society's factsheets **Staying healthy** and **Eating and drinking** have more information (see page 49).

Going into hospital

Going into hospital can be unsettling and confusing at the best of times. To make it a bit easier, make sure staff are aware of the person's dementia when they first go in.

If they have to stay in hospital for a while, here are a few things you could do to help.

Ask:

- who their named nurse is
- to be kept updated and involved in decisions about their treatment and the support they need when they leave
- if there are flexible visiting times for families of people with dementia.

Tell:

- someone at the hospital your contact details
- the hospital if you have a power of attorney for the person (see page 23), or if they have an advance statement or decision to refuse certain treatment (see page 31)
- the named nurse important information about them – it also helps to write this down. Include what reassures or upsets them and what practical help they need, what they like to eat and drink and how they prefer to be addressed.

Before they come home

As part of their needs assessment, make sure you discuss your ability to keep caring for the person, particularly if it looks like they'll need more (or different) care once they leave hospital. It might be a good time for a reassessment of your needs and additional support too (see page 6).

Read Alzheimer's Society's factsheet **Hospital care** and see our guide **Your hospital stay** for more information.

Thinking about future care

It's not easy, but it's a good idea to think about what might happen as the condition progresses. Discussing it while the person still has mental capacity means they're much more likely to receive the treatment and care they want if the time comes when they can't communicate their wishes for themselves. These can be difficult conversations, but being honest and open can give you both peace of mind. You should make sure anything you discussed is recorded somewhere.

Advance statement of wishes

An advance statement allows the person with dementia to record how they'd like to be cared for when they can no longer make decisions or communicate their views. Though not legally binding, it should be taken into account by health and social care professionals who are caring for them. It can cover where they'd liked to be looked after as their condition progresses and non-medical things like food preferences and beliefs.

Advance decision to refuse treatment



An advance decision is legally binding and lets someone refuse specific medical treatments in the future, and only applies if they lack capacity to make a decision or communicate their wishes when the time comes. These aren't legally binding in Northern Ireland.

Next steps



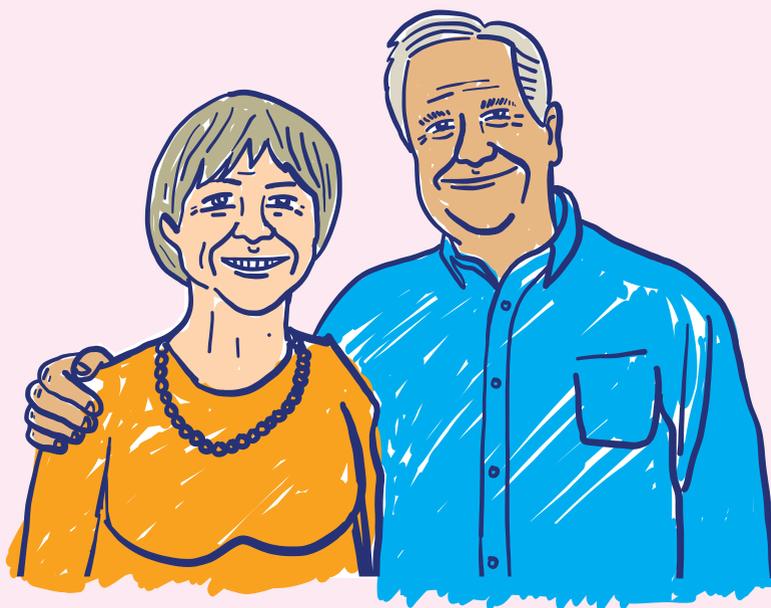
For more information about advance decisions, advance statements and thinking about future care, see our guide **Thinking about end of life** and our factsheet **Advance decisions, advance statements and living wills**.

John and Kathleen are finding ways to live well with dementia.

John, 77, cares for his wife Kathleen, who was diagnosed with Alzheimer's disease five years ago.

'I had suspected Kathleen had dementia for a long time but she always got frustrated and dismissed it when I brought it up. I went to my GP and we arranged for Kathleen to come to the surgery. During the consultation, the problem of 'forgetting things' was brought up and the GP discussed this with us. She suggested we see someone to assess it, and took some blood tests.

'When we got the diagnosis I was very upset and emotional, but also relieved because I'd known there was something wrong for a while.



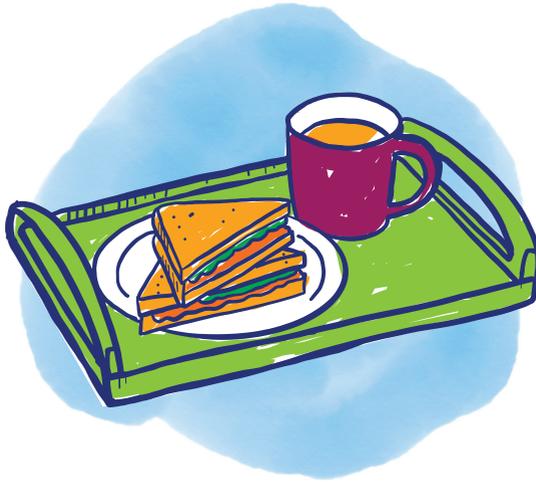
“We’ve adjusted to a different life together now with increasing contentment.”



‘Having a diagnosis also meant we were put in touch with services, like a dementia day centre – which Kathleen loves as she’s very sociable. I felt guilty to begin with as I felt day care showed I couldn’t cope but now I realise how beneficial it is to both of us.

‘I’ve had to learn different ways to manage. I don’t give her too many choices as she finds it hard to make decisions – I just say, “We’re having tea and a cheese sandwich, OK Kathleen?” And if she’s talking about something in full flow, I just listen and don’t interrupt. The facts might be wrong but I just enjoy listening.

‘We’ve adjusted to a different life together now. It’s not the future we planned for but, with help, we’ve managed the last five years in a sort of increasing contentment.’



Help for you

As time passes, you might find the person with dementia needs more (or different) care and attention. You don't have to provide this on your own. Support is available for you both.

Help with care

If the person needs help around the house with things like washing or getting dressed for example, contact the local council's social services department and ask for a needs assessment. They're entitled to an assessment regardless of their income or savings, and no matter what their needs are.

If the person with dementia is eligible for care and support, social services will agree a care plan with them detailing what support could help. This might include care at home, day care, home adaptations or telecare. They'll then have a financial assessment of their income and savings to see whether they will have to contribute towards support costs.

Even if the person isn't eligible for help, the council should still make sure they get information and advice.

As a carer, you also have the right to a carer's assessment. While you're thinking about changes that might help, it's a good time to consider what might help you too.

In England and Wales, if the person you care for is eligible for help and financial support, they can ask the council to arrange their care services. Or they can arrange it themselves through what's called direct payments – this can help them stay in control of how their needs are met. If they can't make their own decisions, you or someone else could manage these payments on their behalf. The local council can help with this and should still regularly check that they're getting what they need.

If the person's needs change or increase, they should be reassessed. It's important to do this as soon as possible so you can both get the right support straight away.



In Northern Ireland there's no financial assessment for community care services in the home.

Next steps



See our guide **Getting help at home** and our factsheet **Personal budgets and direct payments** for more information. In Wales, see Age Cymru's factsheets **Social care assessments for older people with care needs in Wales** and **Direct payments for community care services in Wales**. In Northern Ireland, contact Age NI.

Day centres

Day centres allow the person you care for to socialise with other people. They can offer an important change of scene and routine for you both, and give you a bit of much-needed time to yourself.

Day centres offer company, activities and sometimes facilities like hairdressing and chiropody. Some are suitable for everyone, including someone with mild dementia, while some areas may have specialist dementia day care centres. If the person you care for has a needs assessment (see page 34), social services may suggest a specific local centre.

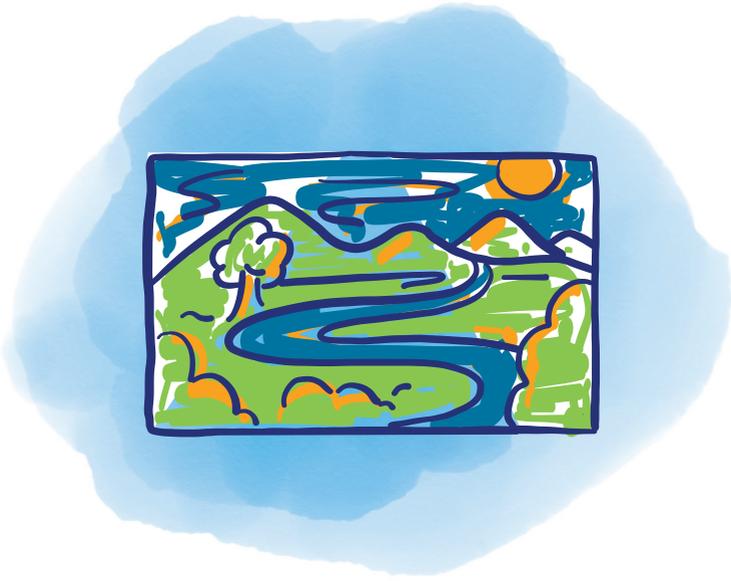
Some people with dementia don't take to day centres straight away, so allow them time to get used to it. If the person you look after isn't sure about going, ask if someone from the centre will come and chat with you both. A familiar face during your first visit can be comforting, and they might be able to stay with the person you care for the first few times to help them settle in. Encourage them to take their hobbies or possessions, like art materials, games or music, so they have something to do or talk about.

If it's just not for them, talk to staff to see if there's a reason they seem upset or unhappy about going there. Different day centres offer different activities and environments – if they don't like one, they might feel happier at another.

“Jimmy didn't like the day centre at first, but it just took some getting used to. It gave me a break for a few hours too.”

Sarah, 76





A break from caring

When was the last time you took some time away from caring? You might feel you just can't take a break, even if you wanted to, or you might feel guilty for thinking about yourself.

Taking a supported break away from caring can give you much-needed regular time out from your caring responsibilities, allowing you to do things that you want or need to do, like meet up with friends, go to the doctor, or go out for dinner.

Why not think about your options:

- Is there a relative or friend that can step in for a bit to give you a break?
- Contact Alzheimer's Society to see if there's any local support they can help arrange (see page 49).
- Ask the local council if there's anything they can arrange to give you a break – this is known as respite care.

In some areas, respite care is provided as a result of your carer's assessment, while in others, it follows a needs assessment for the person you look after.

Any help from the council is means-tested, so you or the person you care for may have to contribute towards the cost.

Following an assessment, the council might be able to help by arranging:

- someone to come and look after the person you care for on a regular basis
- a holiday for you, either with or without the person you care for
- for the person you care for to attend an activity group or a day centre
- a temporary stay in residential care for the person you care for.

Even if you don't feel like you can take a break, it doesn't do any harm to know what help you could get if you changed your mind.

Next steps

Talk to your local council about getting a carer's assessment to work out what kind of respite care or other support could help you. Carers UK have a factsheet on respite care called **Taking a break**, which you can download from www.carersuk.org/break or contact them to order a copy (see page 50). Use the Carers Trust website (see page 50) to find local services for carers, including respite care, in your area.

Your changing relationship

As the person's dementia progresses, it's likely that your relationship will change. But that won't happen overnight.

Following a diagnosis, you might naturally start doing a lot of things for the person that they used to do themselves, thinking you're making life easier or it's saving time. But it's important to help them stay involved in daily household life as much as possible. Try to do things **with** them rather than **for** them.

There may well come a time when you have to do things for them, but until then, encourage them to remain as independent as possible for as long as possible. This may require a bit of patience.

If it's your partner you're caring for, you may find yourself feeling more like a parent than a spouse at times. Alzheimer's Society's factsheet **Sex and intimate relationships** looks at ways you can remain loving and close to your partner.

If you're looking after a parent, you might feel like your roles have been somewhat reversed – but they're still mum or dad.

You may even question your relationship at times as the result of certain behaviour or changes in personality. The next section addresses this in more detail.

Good to know



Do things **with** them, rather than **for** them, **so they can stay involved** in daily household life.

Communication and behaviour

Dementia can affect people's communication and behaviour in ways that can be hard to deal with at times. This is all part of the condition, especially as it progresses.

Unusual behaviour may include agitation, rocking, calling out, experiencing hallucinations, or movements like wringing their hands or pulling at their clothes. It can also include aggressive behaviour, both verbal and physical. The person you care for might be trying to tell you something – perhaps that they're frightened, frustrated, bored or in pain. See if you can spot anything that might be triggering this to help you get to the cause.

You may also find that the person loses their inhibitions, self-control or judgement as a result of their dementia.

This behaviour is hard to deal with and can be really upsetting. Sometimes you may not feel like you're helping or they may seem angry or upset with you, but just being there and staying calm and patient can be a comfort.

Even though difficult behaviour may become more frequent, they're still the same person and there might still be some very special moments you can enjoy together.

“Dad gets very agitated sometimes, it's horrible to see him like that. But I do my best to be there for him and it's all worth it when he's having a better day and we can have a chuckle.”

Sue, 43



Here are some practical tips you may find helpful for general communication and handling behaviour that challenges you:

When you talk

- Speak clearly, slowly and calmly, using simple language and short sentences – even if the conversation is frustrating.
- Touch can be very important for people with dementia. A hug, holding hands, or a touch on the shoulder can be comforting and reassuring, even if they may not understand what you are saying.
- Avoid testing the person's memory or decision-making. It might help to ask questions with 'yes' or 'no' answers like 'do you fancy a coffee?', rather than 'what would you like to drink?'.
- Try talking about 'we' and 'us' rather than 'you'. This makes them feel they are part of a team rather than someone being catered for.

When they talk

- If their words are not making sense, try to think laterally and about what they might be trying to say. If they can no longer talk, facial expressions or gestures might help you understand how they're feeling.
- Try not to correct them when they make mistakes. As long as you can understand them, it's sometimes best to just listen and acknowledge.
- If they keep asking the same questions, try not to get annoyed or frustrated.
- If either of you does get frustrated, try walking away and coming back in a few minutes to see if the situation has calmed down.

In general

- Chat to other carers to see if you can learn anything from how they tackle difficult situations.
- Remember the person you care for may have other health needs. Make sure they have regular sight and hearing tests, as well as dental and GP check ups (see page 28).
- If they like to go for walks but find it hard to keep their bearings, go with them or, if you can't, consider buying a tracking device which lets you keep an eye on where they are – just remember to balance their right to privacy with their need to stay safe. For more information see Alzheimer's Society's factsheet on assistive technology (see page 49).

These are just suggestions – you may find your own ways to deal with difficult behaviour simply through trial and error, or from your understanding of and relationship with the person you're caring for.

Next steps

Dementia UK has a useful guide on **Tips for better communication with a person living with dementia** (see page 51) and some really helpful videos on their website. Alzheimer's Society's factsheets **Dealing with aggressive behaviour** and **Walking about** contain helpful information and tips for carers (see page 49). For further advice and support, call the Dementia UK Admiral Nurse helpline (see page 51) or speak to the person's GP.

Later-stage dementia

Signs of later-stage dementia

In the later stages of dementia, the person will become increasingly dependent on others. It's an easy topic to avoid because it's not nice to think about, but knowing what to expect can help you both prepare.

Everyone is different, but you may find that as the condition progresses the person's memory gets worse, they struggle to recognise you, or they find it harder to communicate or understand things. They may also lose weight (especially if chewing and swallowing are difficult), lose their ability to walk, become incontinent and behave unusually.

This is why the person with dementia should set up an advance decision or Lasting Power of Attorney sooner rather than later (see pages 23). That way you both know that every effort will be made to care for them in the way they would like.

Good to know



If someone struggles to recognise you, it can be very hard to deal with. Dementia UK has a great page on their website about it. Go to www.dementiauk.org and search 'Things to try when someone with dementia stops recognising you'.

Thinking about care homes

Are you struggling to look after the person liked you used to? If the person's needs change or just become too much for you to manage at home, you may need to consider other long-term options, like a care home. Remember that everyone's experience of dementia is unique, so not everyone will need care home accommodation (also known as residential care).

You should also make every effort to find out what they want as well as what they need, if they're still capable of making their own decisions. However, if they can't, it might be a decision you have to ultimately make for them.

Finding the best option

You should first contact your local social services for an assessment to see if residential care is the best option or if other support might be available (see page 34).

The move to a care home can be a difficult decision. You may feel you've let the person you care for down. But there are limits to the care you can provide at home and there may come a time when they need more help. Maybe the time's come to hand over some of your caring responsibilities to professionals so you can focus on the time you spend together? You can care for someone in many different ways.

Good to know



If it seems like a care home might be the next step, see our guide **Care homes** for more information – it comes with a handy checklist. Alzheimer's Society also has a factsheet on **Selecting a care home**.

Moving into a care home

If the person you care for moves into a care home, you may feel a whole range of emotions, from relief to guilt – this is perfectly natural. If your routine revolved around care, you might even feel your life lacks a sense of purpose and find it hard to think about new ways to give structure to your day.

It's important to know there is no right or wrong way to feel, and that just because you're no longer caring for someone, it doesn't mean you've stopped caring about them.

When someone first moves into a care home it can be unsettling. This can be particularly true for someone with dementia as they get used to new surroundings and new faces. Here are a few tips to help make the transition as smooth as possible for both of you.

- Bring belongings that mean a lot to the person and, if possible, some familiar furniture.
- Give the staff information about their likes, dislikes and behaviour.
- Let staff know anything else you think they should know, such as making sure the person has their glasses on when they're up and about.
- Ask if the care home has a group for relatives or a regular newsletter.
- Find out how the home encourages residents and loved ones to continue to enjoy activities together.
- If you like, you can ask to be involved in their care, for example by helping out at mealtimes.

Even if you do all these things, it can still take time for someone to settle into a care home. If you have any worries, speak to a member of staff or the manager to see if anything can be done.

Dealing with concerns



If you're concerned about any aspects of care in the care home, including staff attitudes and behaviour towards residents, discuss them informally with the manager. If that doesn't resolve your concerns, ask about the home's formal complaints procedure. See our factsheet **How to resolve problems and make a complaint about social care** to find out more. In Wales, see Age Cymru's factsheet **Social care assessments for older people with care needs in Wales**.

If you're concerned about neglect or abusive behaviour, contact the safeguarding adults team at your local council, who are responsible for looking into it.

“It wasn't an easy decision at all, but the time came when I knew my Margaret would get better care in a care home. It's what was best for her. I still go and keep her company whenever I can.”
Felix, 82



Next steps



Contact the Relatives and Residents Association (see page 52), which supports care home residents and their families.

End of life care

At the moment, dementia isn't curable. While people can live for very different lengths of time and with different experiences following a diagnosis, everyone who has dementia will die with the disease – though not necessarily because of it. Coming to terms with this can mean you go through a form of grief – even while the person is still alive.

Caring for people with dementia can become harder as their condition progresses. This decline can make it harder to recognise that someone is reaching the end of their life. If you're looking after someone with dementia at home, speak to your doctor about what local services could help you keep caring for them as their symptoms worsen. If they live in a care home, ask their doctor or care home staff what support would be available to help them die in the familiar surroundings of the home and avoid unnecessary admission to hospital. Let the relevant professionals know if your loved one has made an advance statement or advance decision (see page 31).

Advance statements and decisions

If the person with dementia has made an advance decision to refuse treatment or addressed care preferences in an advance statement, make sure their doctor and care staff know about it (see page 31). If the person hasn't recorded their care preferences, key health professionals involved in their care can talk to you to ensure these are known, written down and respected.

Good to know



See our guide **Thinking about end of life** for more information on planning and support for the end of life.

Loss and bereavement

Grief isn't a straightforward journey, and dementia can make it even more complicated and confusing. You're likely to experience feelings of loss even before the person you're caring for dies – for the person they once were, for the relationship you had, and for the life you had planned for yourselves.

Dementia robs us of many things, so it's natural to feel very sad at times. And we can't plan when those times will be. It's often the fact that you've been seeing the person get worse over time that makes grief more complex with dementia. Lots of people find they don't have a strong emotional reaction when the person dies. This is quite normal, and there's no right or wrong way to grieve. It can take a long time to come to terms with a person's death, especially if you were their carer.

It may help to talk to friends and family who knew the person you cared for, to share memories and support each other. Or you might prefer to contact an organisation that supports bereaved people, such as Cruse (see page 50). If you're feeling particularly low or anxious, talk to your doctor as soon as you can.

Good to know



Don't rush yourself. It may take time to start looking forward and feeling positive about what the world has to offer you, and what you can offer in return. Support from others – especially those who have been through similar experiences – could help. The Talking Point forum on Alzheimer's Society's website has a section called 'After dementia – dealing with loss' (see page 49). Our **Bereavement** guide also has more advice on the emotional side of coping with death.

Useful organisations

Age UK

We provide advice and information for people in later life through our Age UK Advice line, publications and website.

Age UK Advice: 0800 169 65 65

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

www.ageuk.org.uk

Call Age UK Advice to find out whether there is a local Age UK near you, and to order free copies of our information guides and factsheets.

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: **0800 124 4222**

www.agescotland.org.uk

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.

National Dementia helpline: **0300 222 1122**

www.alzheimers.org.uk

www.alzheimers.org.uk/wales

For the Dementia Connect directory, see

www.alzheimers.org.uk/local-information/dementia-connect

In Northern Ireland, contact Alzheimer's NI

Helpline: **028 9066 4100**

www.alzheimers.org.uk/northernireland

AT Dementia

Provides information on assistive technology that can help people with dementia live more independently.

Tel: **0115 748 4220**

www.atdementia.org.uk

Carers Trust

Offers practical help and assistance to carers, including information on respite care.

Tel: **0844 800 4361**

www.carers.org

Carers UK

National charity providing a free information and advice service for carers.

Helpline: **0808 808 7777**

www.carersuk.org

In Wales, visit **www.carersuk.org/wales**; in Northern Ireland, visit **www.carersuk.org/northernireland**

Cruse Bereavement Care

Counselling and advice service for bereaved people that offers information and practical support.

Tel: **0808 808 1677**

www.cruse.org.uk

In Northern Ireland, contact:

[Cruse Bereavement Care Northern Ireland](#)

Tel: **0808 808 1677**

www.cruse.org.uk/northern-ireland

Dementia Adventure

Specialise in adventure and nature activities and holidays for people living with dementia and their friends and family.

Tel: **01245 237 548**

www.dementiaadventure.co.uk

Dementia Services Development Centre, Stirling University

Produces useful guides for people affected by dementia.

Tel: **01786 467 740**

Dementia UK

Helps families face dementia through the work of Admiral Nurses. Contact them to find out if you have an Admiral Nurse service in your local area.

Admiral Nursing Direct helpline: **0800 888 6678**

www.dementiauk.org

Law Society of England and Wales

Helps people find a solicitor in their local area.

Tel: **020 7320 5650**

www.lawsociety.org.uk

In Northern Ireland, contact Law Society of Northern Ireland

Tel: **028 9023 1614**

www.lawsoc-ni.org

Mental Health Foundation

Works to improve the lives of those with mental health problems or learning disabilities.

www.mentalhealth.org.uk

NHS Choices

Provides web-based information about NHS services, healthy living and health conditions.

www.nhs.uk

In Wales, visit **www.wales.nhs.uk**; in Northern Ireland, visit **www.nidirect.gov.uk**

Office of the Public Guardian

For information about making a Lasting Power of Attorney or applying to the Court of Protection.

Tel: **0300 456 0300**

www.gov.uk/government/organisations/office-of-the-public-guardian

In Northern Ireland, contact

Office of Care and Protection

Tel: **028 9072 5953**

www.courtsni.gov.uk

Relatives and Residents Association

Supports care home residents and their relatives.

Operates a helpline and has a network of local groups.

Tel: **020 7359 8136**

www.relres.org

Samaritans

Confidential helpline offering support to talk about your feelings. Lines are open 24 hours a day, 365 days a year.

Tel: **116 123**

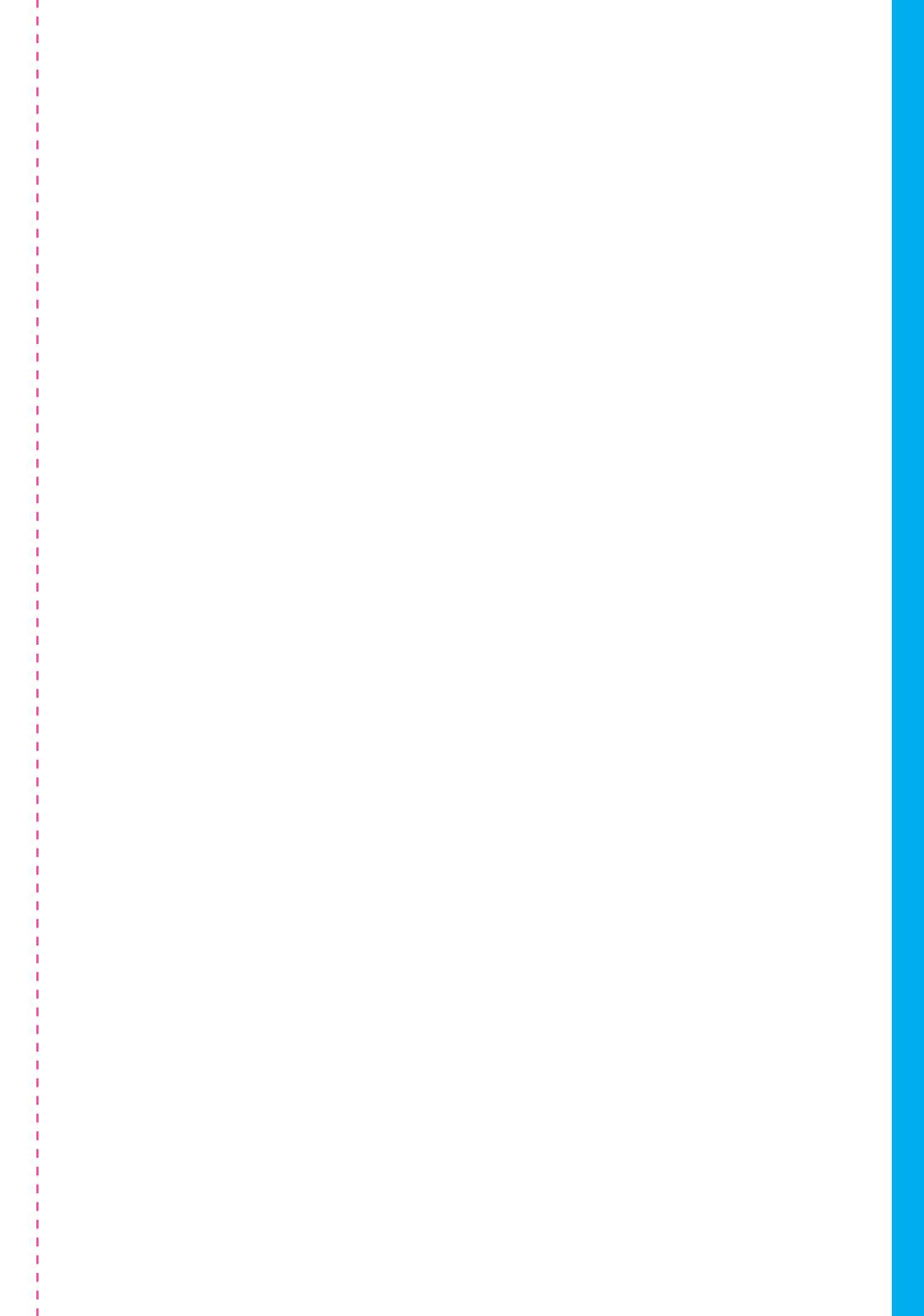
www.samaritans.org

Silver Travel Advisor

Specialist travel information and advice for people over 50.

Tel: **01753 740 169**

www.silvertraveladvisor.com



Help us be there for someone else

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

1

Give your views on guides like this

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

2

Donate to us

Every donation we receive helps us be there for someone when they need us. To make a donation, call us on **0800 169 8787** or go to www.age.uk/donate.

3

Volunteer with us

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

4

Campaign with us

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

5

Remember us in your will

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

What should I do now?

You may want to read some of our other relevant guides, such as:

- **Advice for carers**
- **At home with dementia**
- **Living with early-stage dementia**

You can order any of our guides or factsheets by giving our Advice Line a ring for free on **0800 169 65 65** (8am-7pm, 365 days a year).

Our friendly advisers will also be able to help explain any questions you have about anything you've read.

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

There's plenty of really useful information on our website, too. Visiting **www.ageuk.org.uk/dementia** is probably a good place to start.

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



0800 169 65 65
www.ageuk.org.uk



Age UK is a charitable company limited by guarantee and registered in England and Wales (registered charity number 1128267 and registered company number 6825798). Registered address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA. Age UK and its subsidiary companies and charities form the Age UK Group, dedicated to helping more people love later life. ID204176 05/19