Caring for someone with dementia

Practical help and emotional support

AgeUKIG47

Information written with you in mind.

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

This guide has been kindly peer reviewed by Dementia UK.

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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 and the person you care for – now and in the future. In this guide you'll find information on what to expect as the condition progresses, practical things you can do, strategies that could help you cope in your caring role, and where to turn for support.

You may not have time to sit and read the whole guide, so you might just want to turn to the sections you'll find most helpful for now and come back to it when you can.

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

Where possible, the information given in this guide also applies in Wales and Northern Ireland. Please note that where we refer to the social services department, this includes health and social care trusts in Northern Ireland.

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

Looking after yourself

You might be so used to putting someone else first that you feel guilty if you think about yourself and how you're feeling. But looking after yourself is an important part of being a carer, and can help you better look after the person you care for. Before we cover anything else, take some time to think about what you need, guilt-free.

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 or accessible appointments specifically for carers – these can be useful if you feel you can't leave the person you care for alone at home. You can also ask how to book appointments and order repeat prescriptions online. Your pharmacy might offer a home delivery service for repeat prescriptions.

Caring for someone can have an impact on how you're feeling, so tell your 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 before they reach crisis point.

Good to know

Our guides **Healthy living** and **Your mind matters** have 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 to think of someone else looking after the person you do most of the caring for – particularly if that person is a partner or parent. You might feel like you're letting them down, 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. Sometimes, people want to help but aren't sure how – so telling them what would be useful can work well.

If you care for someone from a distance, perhaps their neighbours or local friends could step in from time to time. You could use a mobile phone app to coordinate care with friends and family, such as Jointly, created by Carers UK (page 54).

Sometimes it can feel tricky to talk to others about how they can help. You might not know yourself what it is you need, you might feel annoyed you're having to ask, or you might worry they'll think you're suggesting they don't care. We have some information on pages 16-17 that can help you plan what to say.

Assessing your needs

You're entitled to a carer's assessment from your local council to see what support you might need and what's available. During the assessment, think carefully about how your caring role affects you and what would help you manage better – don't downplay 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 that if for any reason you can't provide care as usual, someone else can step in. There's more practical information about this on page 37.

Options if you're working

If you're juggling work and caring, you could consider requesting flexible working from your employer. 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 might be willing to consider another request.

Many employers also offer carer's leave, so it's worth asking about this too.

Emotional support

Caring for someone with dementia can take an emotional toll. At times, you may feel overwhelmed, find it difficult seeing how dementia affects the person you care for, or find yourself losing your patience – with them or with others.

However you're feeling, it's good to try to talk to someone about it, whether that's a family member or friend, someone from a carers' group, your doctor, an Admiral Nurse, or someone from an organisation such as Carers UK. Find someone you trust and feel comfortable talking to and be as honest as you can – there's no right or wrong way to feel. See pages 14-15 for more information about support that might be available to you.

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

Tracey, 43

About dementia

If you're caring for someone, knowing what dementia is and being familiar with the process of getting a diagnosis can help you support them in the best possible way.

What is dementia?

Dementia isn't a disease in itself – the word describes a collection of symptoms that can include memory loss, mood changes, and problems with reasoning and communication. These symptoms can occur when certain conditions, such as Alzheimer's disease, affect the brain.

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, such as Cognitive Stimulation Therapy (CST), can help.

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

A common symptom of dementia is short-term memory loss. The person you care for may forget things they've said or done recently or where they've put something, for example, 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:

- difficulty concentrating, communicating or following a conversation
- problems with vision
- changes in mood
- trouble sleeping.

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

Good to know

Dementia isn't an inevitable part of ageing, and being forgetful doesn't necessarily mean someone has dementia. You can find out more about different types of dementia and symptoms from specialist dementia organisations such as Alzheimer's Society (page 53) or Dementia UK (page 55).

Getting a diagnosis

Talking about the possibility of someone having dementia can be very worrying. But knowing what's wrong can help everyone plan ahead and make it easier to access help, support, services and medication, if appropriate.

If you're worried that someone is showing symptoms of dementia, the first step is for them to visit their GP. If they agree, 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 GP. The GP can't talk to you without the person's consent – but they could decide to look into your concerns at the person's next check-up or invite them for a general health check.

At the appointment, the GP will:

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

The GP is then likely to:

- 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 many different types of specialists, including psychologists, psychiatrists and nurses with specialist dementia training.

Some memory services offer sessions for a few weeks following a diagnosis, to go over things such as what dementia is, what medication and support services are available, and planning ahead. If the person you care for is referred to a memory service, it's worth asking about these sessions.

The person you care for might not be given a diagnosis or referral – for example, because the GP is unable to rule out other causes of the symptoms. But if either of you are still concerned, you have the right to ask for a second opinion or to go back to the GP if the symptoms continue.

Next steps

The person you care for might find our guide **Living with dementia** helpful.

Alzheimer's Society's factsheets **Diagnosing dementia** and **Understanding denial and lack of insight** may also be helpful (page 53).

Dealing with a diagnosis

Receiving a diagnosis of dementia can be difficult to accept for everyone involved. There can be lots of mixed feelings – you might even find you feel relieved when a diagnosis is made if you've been worried about someone for a while.

Sometimes, the person with dementia might struggle to accept their diagnosis. They may be in denial or be unaware of some of their symptoms. This may be their way of dealing with feeling overwhelmed, and go on for some time. It can even lead to the person refusing treatments or medication, which will be hard for you as a carer.

Try and be as patient and understanding as possible during this time. Reassuring the person you're there for them if they need help or if they want to talk can be a real support as they come to terms with their diagnosis.

Good to know

Dealing with a diagnosis can be difficult for both you and the person you care for. But you're not alone – there's support available. If you're finding things difficult, call Alzheimer's Society's Dementia Support Line (page 53) or Dementia UK's Admiral Nurse Dementia Helpline (page 55).

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 5 years ago.

'I'd suspected Kathleen had dementia for a long time but she always got frustrated and dismissed it when I brought it up. I went to our GP and we arranged for Kathleen to come to the surgery. During the consultation, the problem of Kathleen "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 some time.

'Having a diagnosis also meant we were put in touch with services including 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 Kathleen too many choices as she finds it hard to make decisions – I just say, "We're having tea and a cheese sandwich, OK?" 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 5 years in a sort of increasing contentment.'

Where to turn for support

Being a carer can sometimes feel isolating and overwhelming. As a carer, you need support too.

Support and advice

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

Your local Age UK

Your local Age UK may be able to offer help and support, such as benefits checks, befriending services, lunch clubs, support for carers or respite services. Some also provide Maintenance Cognitive Stimulation Therapy (MCST) sessions, which are weekly activity-based group sessions specifically for people living with dementia and their carers. Ask your local Age UK for more information. In Wales, contact Age Cymru Advice.

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 in your area.

Other 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. Visit Alzheimer's Society's website for a directory of services, activities and support groups in your area.

NHS

The NHS Dementia Information Service can send you a weekly email for 6 weeks with information on dementia and the support available. Go to the NHS website and search 'Dementia Information Service' to sign up. In Wales, visit NHS 111 Wales.

Dementia advisers

Dementia advisers 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 if there's a service in your area.

Admiral Nurses

Admiral Nurses are specialist dementia nurses who work alongside people with dementia and their families in some communities in the UK. Call the Admiral Nurses Dementia Helpline (run by Dementia UK) for expert advice and support.

Carers' groups

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

Online forums

Forums can be invaluable if it's difficult to get out and about, or if 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

Memory cafés provide 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, search on the Alzheimer's Society website or ask your local Age UK. In Wales, contact Age Cymru Advice.

Next steps

For contact details of these organisations, see pages 53-56.

Talking to family and friends

You might be wondering how to tell people about what's going on – or whether you should mention it at all.

Most people find that if they can be honest with friends and family about a dementia diagnosis, they're more likely to get the support they need.

It's a good idea to talk to friends and family about what they could do to support the person living with dementia, particularly if you could do with a bit of help as a carer. These conversations can be tricky and even lead to disagreements – for instance, you may feel people aren't helping out as much as they could or should be. All sorts of factors, such as relationship dynamics and where people live, can make things more difficult – but an honest, open conversation or family discussion is usually the best place to start.

People will have their own reaction to and way of dealing with the news that someone they know is now living with dementia. You might find that people aren't sure how to act around 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 they got the diagnosis, and will have preferences about how they want to be treated and cared for. Many people with dementia still want to be included and involved as much as they can.

If someone else is stepping in to help with caring, let them know about certain preferences. For example, the person you care for may like doing things in small groups or places that aren't too noisy, or they might enjoy looking through old photographs. See the section 'Communication and behaviour' on page 42 for more tips to share with friends and family.

Children and teens

Dementia can be difficult to explain to younger people. But while it might be upsetting for both you and them, it's usually best to explain what's going on.

Younger people will likely already be aware something's not as it used to be. Being honest about the situation can be a relief to them, as they might be worried that changes in an older friend or relative's behaviour are directed at them personally, rather than being because of their condition.

Next steps

It might be worth sharing any information you read and find helpful, such as this guide, with family members and friends.

The national Dementia Friends scheme helps people understand dementia through free awareness sessions. You can find out more by visiting **www.dementiafriends.org.uk.**

Doing things together

Getting the right support can help you and the person you care for make the most of your time together. Doing the things you've always done is good for your relationship and the confidence of the person with dementia – so try to keep it up for 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, run by Alzheimer's Society, offers group singing for people with dementia and their carers. You might also find other local activity groups for both of you, like exercise classes, book groups or craft activities. Search for local groups and activities by contacting Alzheimer's Society or using their online directory (page 53).

Holidays

Most people in the early stages of dementia are 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 (page 54). Make sure you declare the diagnosis of dementia when you're looking for travel insurance. These policies sometimes have higher premiums, so it's worth shopping around. Some providers have specific insurance for people with dementia.

"Nan's started to forget some people, but she still hasn't forgotten Frank Sinatra. She loves singing along."

Harriet, 39

Creating a memory book

A memory book or life-story book can help you and the person you care for remember special times. It's a collection of mementos and photos of familiar places and happy events that mean a lot, such as weddings, birthdays or holidays. Photos are particularly good at triggering memories and encouraging the person to talk about their life.

The whole family can help contribute to making the book, and 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. Go to their website and search 'life story' to download it (page 55).

Good to know

Photos can trigger memories and encourage the person with dementia to talk about their life.

Practical things you can do

There are lots of practical things that might be helpful – whether it's getting affairs in order, dealing with money or making changes at home.

Legal affairs

It might feel difficult to talk about legal matters, but it can actually be very reassuring for you and the person you care for to have plans in place. Planning can save a lot of stress in the future too, as the wishes of the person with dementia are clear.

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.

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

Lasting powers of attorney

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

You need to register an LPA with the Office of the Public Guardian (page 56) before it can be used. If the person with dementia loses mental capacity after they've signed the LPA, but it's not yet been registered, 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 this is what 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 mental capacity, as applying to be a deputy is a more expensive and lengthy process.

Next steps

See our guides **Power of attorney** and **Wills and estate planning** for more information. Alzheimer's Society's (page 53) factsheet **Making decisions and managing difficult situations** may also be helpful.

Carer's Allowance and other benefits

It's important to 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 may claim, so make sure you check – your local Age UK can help with this. In Wales, speak to your local Age Cymru.

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.

If you live with the person you care for, your household may qualify for reduced Council Tax because of their condition. 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 thing to do. It might help to contact your local Age UK for a benefits check or to see if they can help you fill in claim forms. In Wales, speak to your local Age Cymru.

For the person you care for

The person you care for may be entitled to Personal Independence Payment or Attendance Allowance – depending on their age, 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.

They might be eligible for reduced Council Tax because they have dementia. If you don't live together, this would apply to their household instead of yours.

Use our free and simple online benefits calculator at **www.ageuk.org.uk/benefits-check** to find out whether you or the person you care for is entitled to other benefits and financial support, or visit your local Age UK. In Wales, contact your local Age Cymru.

"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**.

Dealing with money

You might already be looking after finances for the person you're caring for, or it might be something you have to do 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 like to set up direct debits to pay regular household bills. If they can't, or if they don't want to, ask them if you can tell their utility providers they have dementia. You can provide 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.

Banking

Joint accounts can be useful – but they can only be set up when both people have mental capacity.

If you have separate accounts, the person you care for could set up a third-party mandate, which gives 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 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 20 for more information).

Benefits

If the person you care for can no longer manage their benefits and State Pension, then you can apply to become their 'appointee' to manage them on their behalf. To do this, contact the Department for Work and Pensions (page 55) and explain the situation.

Good to know

Alzheimer's Society's (page 53) booklet **Accessing and sharing information** has more information.

The Office of the Public Guardian (page 56) has a guide called **Deputy and attorney guidance**. You can visit **www.gov.uk** and search 'Deputy and attorney guidance' for a copy.

Home

When someone has dementia, the design and layout of their home can have a big impact on daily life. Memory loss, confusion and difficulty learning new things can mean they struggle to understand where things are and how they work.

Creating the best home environment

Here are some tips for making helpful changes in the home:

- **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 also 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. For example, sensors in the bathroom can detect flooding, and pressure mats by the bed can tell if someone gets up in the night. This kind of equipment 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 options.
- **Home adaptations or improvements** could help make life easier. Handrails, grab rails, ramps or bathing aids may be useful, and you might 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 pages 36-37).

"I made some labels for Dad's kitchen cupboards so he knew which was which. It seems to have really helped."

Dave, 58

Good to know

See our guides **At home with dementia** and **Adapting your home** for more advice. Independent Age (page 55) also have a factsheet called **Technology to help you at home**.

The Dementia Centre at Stirling University (page 54) has produced useful resources for people living with dementia. You can find them at **www.dementiainformation.stir.ac.uk** – some are free and some have a fee.

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 search 'DVLA' at **www.gov.uk.** Having dementia doesn't automatically mean they have to stop driving straight away – what matters is that they can drive safely.

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

Next steps

Suggesting that someone stops driving can be a sensitive conversation. See our guide **In the driving seat** and Dementia UK's (page 55) **Driving and dementia** leaflet.

Health and care

The person you care for may have other health and care needs. As dementia can make these needs more difficult to communicate, it's important to know what to look out for and what to consider if someone's needs change.

Staying healthy

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

It might not always be obvious what the matter is. It could be something very practical that's simple to get sorted – or it could be something a bit more complex. There are things you can do if you think something's wrong.

Try the following:

- Talk to the person about how they're feeling.
- Discuss any concerns with the doctor as soon as possible so any causes of the distress – such as depression, constipation, a urine infection, or reactions to medication – can be ruled out or treated.
- If they wear them, check that the person's glasses are clean and that their hearing aid is in and working. 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. Make sure they attend regular appointments with the optician, dentist and hearing clinic.
- See our guide **Healthy living** to find out about important health tests and the importance of keeping active.
- See our guide **Bladder and bowel problems** to find out more about continence issues.

"I knew something was wrong, Frank just didn't seem himself."

June, 81

Eating and drinking

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

The person might also be having difficulty with chewing and swallowing – perhaps because of toothache or ill-fitting dentures. Help them brush their teeth thoroughly if needs be, and visit the dentist regularly to stay on top of things.

Not drinking enough can make some symptoms of dementia worse. The person you care for may not recognise they're thirsty, and might need prompting to drink. Suggesting a drink together, offering them a drink, or leaving a cup or beaker within easy reach and where they can see it 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 pages 36-37). 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's available nearby. In Wales, speak to your local Age Cymru.

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

Next steps

If there are issues with eating or weight loss, it's a good idea to have this assessed by a specialist, such as a dietician. Alzheimer's Society's (page 53) factsheets **Staying healthy** and **Eating and drinking** have more information.

Going into hospital

Going into hospital can be unsettling and confusing at the best of times. To make things a bit easier, make staff aware of the person's dementia and how it affects them 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 the best person is to talk to about being kept up-to-date.
- If the person with dementia consents or doesn't have mental capacity, ask to be kept updated and involved in decisions about their treatment and the support they need when they leave hospital.
- Find out if there are flexible visiting times for families of people with dementia.
- Give someone at the hospital your contact details.
- Tell the hospital if you have a power of attorney for the person (see page 20) or if they have an advance statement or decision to refuse certain treatment (see page 50).
- Give a named nurse important information about the patient – it's helpful to write this down. Include what reassures or upsets them, what practical help they need, what they like to eat and drink, and how they prefer to be addressed.

Good to know

Alzheimer's Society produce a booklet called **This is me** which is very helpful for people with dementia who go into hospital.

Before they come home

As part of their discharge planning, discuss your ability to keep caring for the person with their doctor or nurse – particularly if it looks like they'll need more, or different, care once they leave hospital. It might be a good time to reassess your needs and additional support too (see page 36).

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

Some people with dementia qualify for continuing healthcare (CHC) funding. Dementia UK's **Continuing healthcare funding** leaflet (page 55) explains CHC in detail.

Future care

As their condition progresses, the needs of the person you care for might change. It's not always easy to think about this, but it is important. Where possible, discuss this with them while they still have mental capacity – this way, you know what their preferences are. They can feel reassured that they're much more likely to receive the treatment and care they want, if a time comes when they can't communicate their wishes themselves.

These can be difficult conversations, but being honest and open can give you both peace of mind. If the person you care for expresses preferences about what happens to them in the future, make sure these are recorded somewhere – you can then share them with any doctors or carers involved in the person's care.

Advance care planning

An advance statement of wishes allows someone 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, an advance statement should be taken into account by health and social care professionals caring for them. It can cover where they'd liked to be looked after as their condition progresses, as well as non-medical things like food, music preferences and beliefs.

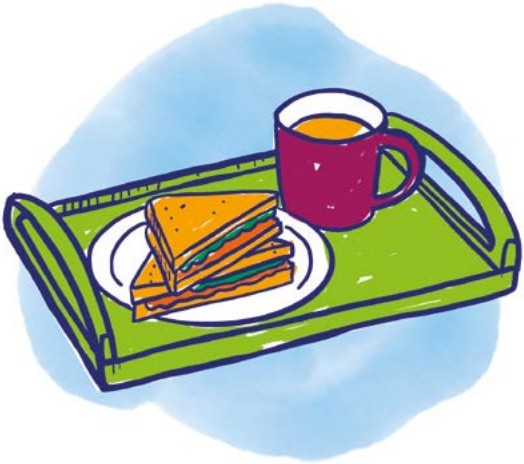
An advance decision is legally binding and lets someone decide what specific medical treatments they would want to refuse in the future, and the circumstances under which any decision they've made would apply. It only applies if they lack capacity to decide or communicate their wishes when the time comes.

In Northern Ireland, an advance decision isn't legally binding.

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**.

Our **LifeBook** can be a helpful tool to record the details of someone's life, from important contacts and documents to treasured possessions and final wishes.



Help with care

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 from the council

If the person you care for starts to need help with domestic tasks like washing or getting dressed, contact the local council's social services department and ask for a care needs assessment. The person you care for is entitled to an assessment regardless of their income or savings, or their level of need.

If the person with dementia is eligible for care and support, social services will agree a care plan with them. This explains what types of support might help them, taking account of your ability to provide – or continue providing – care. It might include care at home, day care, home adaptations or telecare. They'll then have an assessment of their income and savings to see whether they need to contribute towards support costs.

Even if the person isn't eligible for help, the council should provide information and advice on other sources of support.

As a carer, you also have the right to your own carer's assessment. While you're thinking about support that might help the person you care for, it's a good time to consider what might help you too.

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 direct payments, which 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 the person being cared for is 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 social care services in Wales**. In Northern Ireland, contact Age NI.

Day centres

Day centres give the person you care for the opportunity to socialise with other people. They can offer routine and a change of scenery – 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 people with mild dementia, while some areas may have specialist dementia day care centres. If the person you care for has a needs assessment (see pages 36-37), social services may suggest a specific local centre.

Some people with dementia don't take to day centres straight away, so give 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 the first visit can be comforting, and you might be able to stay 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 the person doesn't settle in, 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 – so if they don't like one, they might feel happier at another.

Access to day centres and availability varies depending on location. You can search on the Alzheimer's Society website for support near you (page 53).

A break from caring

When did you last take time away from caring?

You might feel like 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. This means you can do things that you want or need to do, like meet friends, go to the doctor, or go out for dinner.

There are various ways to find someone to take on your caring responsibilities for a short time:

- Consider if there's a relative or friend who can step in for a bit to give you a break.
- Contact some of the organisations in the back of this guide to see if there's any local support they can help you to arrange (pages 53-56).
- During your carer's assessment, ask the local council if they can arrange respite care to give you a break.

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 regularly look after the person you care for
- a holiday for you, with or without the person you care for
- for the person you care for to attend an activity group or a day centre
- for the person you care for to have a temporary stay in residential care.

Even if you don't feel you can take a break, it doesn't do any harm to find out 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 (page 54) has a factsheet on respite care called **Taking a break**. You can order this by emailing them, or download it online at **www.carersuk.org/break**. Use the Carers Trust website (page 54) to find local services for carers, including respite care, in your area.

Your changing relationship

As the person's dementia progresses, your relationship might change, but it's unlikely to all happen overnight. The topics covered in the rest of this section are very complex, and can be different for everyone. We've listed some useful resources which give more information on pages 53-56.

Following a diagnosis, you might start doing things for the person that they used to do themselves, thinking you're making life easier or saving time. But it's important to encourage the person you care for to remain as independent as possible for as long as possible. Where possible, try to do things with them rather than for them.

If you're caring for your partner or spouse, you might find yourself feeling more like a parent at times. Alzheimer's Society's factsheet **Sex, intimacy and dementia** looks at ways you can remain loving and close.

If you're looking after a parent, you might feel like your roles have been reversed – but they're still Mum or Dad. Dementia UK's **Changing relationships and roles** leaflet has more advice on this.

Sometimes, you might even question your relationship as the result of certain behaviour or changes in personality. The next section addresses this in more detail.

Good to know

Do things with the person you care for, rather than for them, so they can stay involved.

Communication and behaviour

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

Unusual behaviour may include agitation, rocking, calling out, having hallucinations, or movements like wringing their hands or pulling at their clothes. It can also include aggressive behaviour, both verbal and physical. It might be that the person you care for is trying to communicate 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 might also find that the person loses their inhibitions, self-control or judgement as a result of their dementia.

This behaviour can be very 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.

Good to know

Dementia UK (page 55) has a useful guide called **Tips for better communication**. Alzheimer's Society's (page 53) factsheets **Aggressive behaviour** and **Walking about** contain helpful information and tips for carers. For further advice and support, call the Dementia UK Admiral Nurse helpline (page 55) or speak to the person's GP.

Tips for communicating and coping with behaviour you find challenging

Here are some practical tips you might find helpful when communicating with the person you care for and handling behaviour you find difficult:

When you talk

- Speak clearly, slowly and calmly, using simple language and short sentences – even if the conversation is frustrating.
- 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 can help the person to feel they're part of a team.
- Allow the person time between sentences to process and respond.

When they talk

- If their words aren't making sense, try to think about what they might be trying to say. For example, if they can no longer talk, facial expressions or gestures might help you understand how they're feeling.
- Try not to correct or interrupt 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 for a few minutes to calm the situation down a little.

In general

- Chat to other carers to see if you can learn anything helpful from how they tackle difficult situations.
- Remember that 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.
- If the person you care for likes to go for walks but finds it hard to keep their bearings, go with them, or consider buying a tracking device which lets you keep an eye on where they are – but try to balance their right to privacy with their need to stay safe.
- Touch can be very important when someone has dementia. A hug, holding hands, or a touch on the shoulder can be comforting and reassuring. There may be times that they don't want to be touched, though – and how much physical contact is appropriate depends on the closeness of your relationship.

These are just suggestions – you might 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.

Good to know

The Herbert Protocol is an initiative that encourages carers to collect useful information about vulnerable people they care for that can be shared with the police in case they go missing. You can find the form by visiting **www.met.police.uk** and searching 'Herbert Protocol'.

Later stages of dementia

During the later stages of dementia, the person you care for will become increasingly dependent on others. While it might be difficult or upsetting to think about, knowing what to expect can help you both prepare.

As the condition progresses

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 become 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 for health and care decisions sooner rather than later (see page 20). That way, you both know that every effort will be made to care for them in the way they would like.

Next steps

As the person's dementia progresses, you may both face lots of different issues, and it can be a very emotionally challenging time. Contact specialist organisations listed in the back of this guide for more information and support (pages 53-56).

Thinking about care homes

Are you struggling to look after the person you care for at home? If their needs change or just become too much for you to manage, you may need to consider other long-term options.

Make every effort to find out what the person with dementia wants and needs, if they're still able to communicate this to you. If they're not able to, you might have to decide on their behalf whether they would be better off living in a care home.

Finding the best option

Depending on where the person you care for lives, contact your local council or theirs for an assessment to see if residential care is the best option for them, or if additional support at home might be available instead (see pages 36-37).

Deciding whether to move the person you care for to a care home can be difficult. You might feel like you've let them down. But there are limits to the care you can provide at home, and there may come a time when they need more help than you can provide.

There are many different ways to care for someone – so maybe it's the right time to hand over some of your caring responsibilities to professionals so you can focus on the time you spend together.

Good to know

If you think 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 (page 53) also has a factsheet called **Selecting and moving into a care home**.

Moving into a care home

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

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

Moving into a care home can be unsettling, especially for people with dementia. It can take time for them to get used to new surroundings and 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 that helps them get to know the person – for example, their likes, dislikes and routines.
- Tell staff about 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 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, such as 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.

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.

"When we visited Mum, she'd never have her glasses on. It must have been horrible for her. I made sure I mentioned it to the manager."

Billy, 51

Next steps

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 **How to resolve problems and make a complaint about social care in Wales**.

Contact the Relatives and Residents Association (page 56), which supports care home residents and their families. In Wales, contact Age Cymru Advice.

End of life care

There isn't currently a cure for dementia. 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. This is sometimes called 'anticipatory grief'.

As the condition progresses, it can become harder to care for someone and to recognise when they're reaching the end of their life. It can be very hard to think about, but 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. If they live in a care home, ask their doctor or care home staff what support would be available to help make sure they're in familiar surroundings when they die 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 35).Dementia UK's (page 55) **End of life** care leaflet has more information about this.

Advance statements and decisions

If the person with dementia has made an advance decision to refuse treatment, or if they've addressed care preferences in an advance statement, tell their doctor and care staff about it. If the person hasn't recorded their care preferences, key health professionals involved in their care can talk to you to ensure these preferences are known, written down and respected.

"I think I'd started to come to terms with Dad's death before it actually happened."

Joe, 42

Next steps

See our guide **Thinking about end of life** for more information on planning and support for the end of life. Our booklet **Let's talk about death and dying** may be helpful when talking about and coming to terms with a death. The specialist organisations listed in the back of this guide can also provide more information and support (pages 53-56).

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 personality they had, for the relationship you shared, 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. Lots of people find they don't actually 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, so you can share memories and support each other. Or you might prefer to contact an organisation that supports bereaved people, such as Cruse Bereavement Care (page 54). If you're feeling particularly low or anxious, talk to your doctor.

Don't rush yourself. It may take time to start looking forward and feeling positive about what the world has to offer, 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' (page 53).

Good to know

Our guide **Bereavement** has more advice on the emotional side of coping with death, as does Dementia UK's (page 55) **Bereavement** leaflet.

Following a death, there are also lots of practical things that need to be done. For some, this can feel overwhelming – but for others, these things are a welcome distraction. See our guide **When someone dies** for more information about what practical things to do following a death.

Useful organisations

Age UK

We provide information and advice 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

In Wales, contact Age Cymru Advice: **0300 303 44 98**
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, Wales and Northern Ireland to people living with dementia, their families and carers through its helpline and local offices. You can contact Join Dementia Research through the helpline.
Dementia support line: **0333 150 3456**
England: **www.alzheimers.org.uk**
Wales: **www.alzheimers.org.uk/wales**
Northern Ireland: **www.alzheimers.org.uk/about-us/alzheimers-society-northern-ireland**

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

Carers Trust
Offers practical help and assistance to carers, including information on respite care via local networks. Call them to find details of local services.
Tel: **0300 772 9600**
www.carers.org

Carers UK
National charity providing a free information and advice service for carers.
Helpline: **0808 808 7777**
Email: **advice@carersuk.org**
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

Dementia Adventure
Specialises in adventure and nature activities and holidays for people living with dementia and their friends and family.
Tel: **01245 237548**
Email: **info@dementiaadventure.co.uk**
www.dementiaadventure.co.uk

Dementia Services Development Centre, Stirling University
Produces useful guides for people affected by dementia.
Tel: **01786 467740**
Email: **dementia@stir.ac.uk**
www.dementiainformation.stir.ac.uk

Dementia UK

Works to improve the quality of life of people with dementia and provides online and printed information resources. Contact their helpline to speak to an Admiral Nurse and visit their website to find out if you have an Admiral Nurse service in your local area.
Admiral Nurse Dementia Helpline: **0800 888 6678**
Email: **helpline@dementiauk.org**
www.dementiauk.org

Department for Work and Pensions

You can contact the DWP about becoming an appointee for the person you care for if they're no longer able to manage their benefits and State Pension.
www.gov.uk/become-appointee-for-someone-claiming-benefits

Independent Age

Provides advice and support for older people, their families and carers.
Tel: **0800 319 6789**
www.independentage.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.
www.mentalhealth.org.uk

NHS

Provides information about NHS services, healthy living and health conditions.
Tel: **111**
www.nhs.uk

In Wales, visit **111.wales.nhs.uk**

In Northern Ireland, visit **www.nidirect.gov.uk**

Office of the Public Guardian

Provides information about making a lasting power of attorney or applying to the Court of Protection.
Tel: **0300 456 0300**
Email: **customerservices@publicguardian.gov.uk**
www.gov.uk/power-of-attorney

In Northern Ireland, contact the **Office of Care and Protection**
Tel: **0300 200 7812**
www.nidirect.gov.uk/contacts/office-care-and-protection

Relatives & Residents Association

Supports care home residents and their relatives in England. Operates a helpline and has a network of local groups.
Tel: **020 7359 8136**
Email: **info@relres.org**
www.relres.org

Samaritans

Confidential helpline offering support to talk about callers' feelings. Lines are open 24 hours a day, 365 days a year.
Tel: **116 123**
www.samaritans.org

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Can you help Age UK?

If you're able to, please complete the donation form below to make your gift and return to: **Freepost Age UK REPLY**. Alternatively, you can phone **0800 077 8751** or visit **www.ageuk.org.uk/donate**. If you prefer, you can donate directly to one of our national or local partners. Thank you.

Your details

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We'd† like to keep in touch with you to tell you about the vital work we do for older people, our fundraising appeals and opportunities to support us, as well as the products and services you can buy.

Please tick the boxes to let us know how you'd like to hear from us:

☐ **I would** like to receive communications by email.

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

☐ **I do not** wish to receive communications by post.

If you don't want to hear from us, or change your mind about how we contact you, please email **contact@ageuk.org.uk** or call **0800 169 8787**. For further details on how your data is used and stored by the Age UK network go to **www.ageuk.org.uk/help/privacy-policy.**

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Please accept my one-off gift of: **£10** ☐ **£15** ☐ **£20** ☐ **My choice £**

☐ I enclose a cheque/postal order made payable to Age UK, **or**

I wish to make payment by (please tick):

☐ MasterCard ☐ Visa ☐ CAF CharityCard

Card number Expiry date

Age UK provides a range of services and your gift will go wherever the need is the greatest.

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:

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/readers-panel**.

Donate to us

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

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**.

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**.

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 relevant information guides and factsheets, such as:

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

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

Our friendly advisers are there to help answer any questions.

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

There's plenty of really useful information on our website, too. Visit **www.ageuk.org.uk/dementia** to get started.

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

0800 169 65 65
www.ageuk.org.uk

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