Information guide AgeUKIG47

Caring for someone with dementia

Practical help and emotional support

Let's change how we age

Information written with you in mind.

Our guides are produced with the help of older people, carers and expert peer reviewers.

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The Readers' Panel is a group of volunteers who provide vital feedback on our guides and other resources.

Their feedback helps us ensure that our information is as useful as possible for older people and their carers, family and friends.

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What this guide is about

If you care for someone who has dementia, this guide is written for you.

Everyone's experience of dementia is different. But being prepared can help both you and the person you care for – now and in the future. This guide gives 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.

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

All of the information in this guide applies in England. This symbol indicates where it differs for Wales and Northern Ireland. Where the guide refers to social services, this includes health and social care trusts in Northern Ireland. If you're in Scotland, contact Age Scotland for advice.

Looking after yourself

You might be so used to putting someone else first that you feel guilty if you take time for your own needs. But looking after yourself important – and it can help you provide better care too.

Take a moment now 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, but try to take time out for yourself as often as you can – even if it's only 10 minutes to have a cup of tea or get some fresh air.

Don't put off appointments or ignore any of your own health needs. Tell your doctor that you're a carer – many practices offer phone consultations or accessible appointments if you feel you can't leave the person you care for. They can also tell you about the support that's available in your local area.

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 saying that things are getting on top of you.

Next steps

It's a good idea to find out the number for your local council. They'll be able to provide a lot of the support and information mentioned in this guide.

My local council phone number is:

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. But you aren't letting them down by getting some support.

Consider asking friends and family to take on certain activities, like doing some shopping or calling every now and then for a chat. Sometimes, people want to help but they 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 an app to coordinate care with friends and family such as Jointly, which was created by Carers UK (page 48).

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 page 15 that can help you plan what to say.

Assessing your needs

As a carer, you're entitled to an assessment from your local council to see what support might be available to help you continue in your caring role. Think carefully about how your caring role affects you and what would help your wellbeing.

You can use this opportunity to ask about what respite help is available. You can also ask about creating an emergency plan in case you're ever unable to provide care as usual. There's more information about this on page 32.

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.

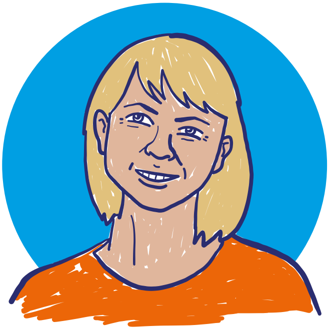
You have the right to make a request from the first day of your employment. You can usually make up to 2 requests per year – but if your circumstances change, your employer might be willing to consider another.

Many employers also offer carer's leave, so ask 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, or a professional. Find someone you trust and feel comfortable talking to and be as honest as you can – it can really help. See pages 13-14 for more information about support that might be available.



"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 – it's an umbrella term for a range of progressive conditions that affect the brain. Symptoms can include memory loss, mood changes, and problems with reasoning and communication. There are many different types of dementia, such as Alzheimer's disease and dementia with Lewy bodies.

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), may help.

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

A common symptom of dementia is short-term memory loss. For example, the person you care for may forget things they've said recently or where they've put something, while memories from years ago seem clear to them. 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
- disorientation.

Dementia-like symptoms can be caused by other things too – some of which may be reversible. Depression, stress, vitamin deficiencies, thyroid problems or urinary tract infections could be responsible, for example. 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 48) or Dementia UK (page 49).

Getting a diagnosis

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

If you're worried that someone is showing symptoms of dementia, the first step is for them to visit their doctor. 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 contact their doctor. They 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 doctor will:

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

The doctor may then:

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

Memory clinics employ different types of specialists, including psychologists, psychiatrists and nurses with specialist dementia training.

Some memory services offer sessions for a few weeks after a diagnosis. These sessions cover what dementia is, what medication and support services are available, and how to plan ahead. If the person you care for is referred to a memory service, it's worth asking whether these are available.

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 in future if the symptoms continue.

Next steps

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

Dealing with a diagnosis

Receiving a diagnosis of dementia can be difficult for everyone involved. There may be lots of mixed feelings – not necessarily all negative. If you've been worried about someone for a while, you might even find you're relieved when a diagnosis is made.

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 can go on for some time – and it can even lead to the person refusing treatments or medication, which can be difficult for you as a carer.

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

Good to know

Dealing with a diagnosis can be difficult, but you're not alone – there's support available. Call Alzheimer's Society's Dementia Support Line (page 48) or Dementia UK's Admiral Nurse Dementia Helpline (page 49).

Alzheimer's Society (page 48) also has factsheets called **Diagnosing dementia** and **Understanding denial and lack of insight**.

Where to turn for support

Being a carer can sometimes feel isolating and overwhelming. It's important that you get the support you need 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 or respite services. Some provide Maintenance Cognitive Stimulation Therapy (MCST) sessions, which are weekly activity-based group sessions specifically for people 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 about any transport services or voluntary car schemes in your area. In Wales, contact your local Age Cymru.

Other charities

Contact Alzheimer's Society, Carers Trust or Dementia UK to find out about their services 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. See pages 48-49 for contact details.

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 (page 49) 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 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 (page 49) for expert advice and support.

Carers' groups

Carers' groups are a good source of support and information. They might 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 (page 48).

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 (page 48).

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 the Alzheimer's Society website (page 48) or ask your local Age UK. In Wales, contact Age Cymru Advice.

Talking to family and friends

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

If you could do with help as a carer, it's a good idea to talk to friends and family about what they could do to support the person living with dementia. All sorts of factors, such as relationship dynamics and where people live, can make it tricky to find the right arrangement – but an honest, open discussion is usually the best place to start.

People will have their own way of dealing with the news that someone they know has dementia. You might find that people aren't sure how to act around the person who's been diagnosed, or around you. It can be worth reminding everyone that dementia doesn't define a person – many people with dementia still want to be included and involved as much as possible.

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 'Communication and behaviour' section on page 38 for more tips you can share with friends and family.

Next steps

Alzheimer's Society's Dementia Friends scheme helps people understand dementia through free awareness sessions. Visit **www.dementiafriends.org.uk** to find out more.

Children and teens

While it might be upsetting to talk about with younger people, it's usually best to explain what's going on. They'll probably 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.

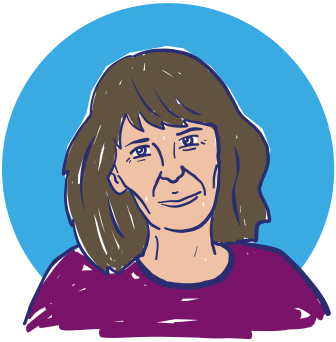
Dementia UK (page 49) has a leaflet called **Supporting children and adolescents** which could help.

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

Singing has been shown to be 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 (page 48) or using their online directory.



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

Harriet, 39

Holidays

Most people are able to go on holiday as normal in the early stages of dementia – it may just need a little extra planning. But if you want to find out more about supported and specialist holidays, contact Dementia Adventure (page 49).

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.

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 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 (page 49) has a template for making your own memory book. Go to their website and search 'life story' to download it.

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 can be helpful when someone has dementia – whether it's sorting legal affairs, dealing with money or making some changes at home.

Legal affairs

It might feel difficult to talk about legal matters at first, 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 the ability to make and understand the consequences of 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 (an 'attorney') to make decisions on their behalf. If they no longer have mental capacity, they can't create an LPA – 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 50) before it can be used. If the person with dementia loses mental capacity after they've signed the LPA, but before it's been registered, their attorney can still register it.

There are 2 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 (page 48) has a factsheet called **Making decisions and managing difficult situations**.

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 a caring role. 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 (such as Pension Credit) that the person you care for may claim, so make sure you check before claiming. 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

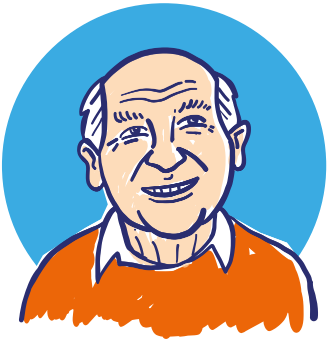
Caring can be tiring, and claiming any sort of benefit might just feel like an extra thing to do. It might help to contact your local Age UK for a benefits check or to see if they can help you fill in claim forms. In Wales, speak to your local Age Cymru.

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 and whether they have care or mobility needs. 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.

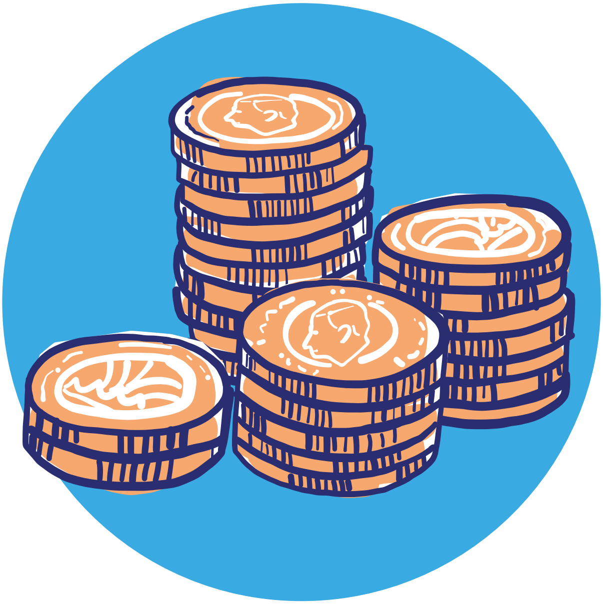


"My Attendance Allowance makes life that little bit easier."

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 can help 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 18 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 49) and explain the situation.

Good to know

Alzheimer's Society (page 48) has more information in its factsheet **Accessing and sharing personal information**.

The Office of the Public Guardian (page 50) has more detailed guidance. Go to **www.gov.uk** to find out more.

Home

When someone has dementia, adjusting the design and layout of their home to suit their needs can be really helpful. Memory loss and confusion can mean they don't understand where things are or how they work as they used to.

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 page 32).

Good to know

See our guides **At home with dementia** and **Adapting your home** for more detailed advice. Independent Age (page 49) also has a factsheet called **Technology to help you at home**.

The Dementia Services Development Centre (page 49) has useful resources for people living with dementia. Some are free and some have a fee. Find out more at **www.dementiainformation.stir.ac.uk**.

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**.

Talking to someone about their driving can be a sensitive conversation. Our guide **In the driving seat** has more detailed advice. Dementia UK (page 49) also has a leaflet on **Dementia and driving**.

Health and care

The person you care for may have other health and care needs. As dementia can make communication more challenging, it's important to know what to look out.

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 sort out – or it could be something a bit more complex. There are things you can try if you think there's some kind of problem.

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 a reaction 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.

Good to know

Sometimes, someone with dementia might be in pain and be unable to understand or communicate it. Dementia UK (page 49) has a useful leaflet on **Pain and dementia**.

Eating and drinking

If the person you care for isn't eating properly, is losing weight or has 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 a full meal, it might be worth offering smaller snacks through the day, like sandwiches or cheese and crackers.

The person might also be finding it difficult to chew and swallow – 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 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 page 32). 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 needs be.

Next steps

Dementia UK (page 49) has a leaflet called **Eating and drinking** with 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 if they don'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 18) or if they have an advance statement or decision to refuse certain treatment (see page 31).
- 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 (page 48) produces a booklet called **This is me** which is very helpful for people with dementia who go into hospital.

Before they come home from hospital

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 care or different care once they leave hospital. It might be a good time to reassess your needs and additional support too (see page 32).

See our guide **Your hospital stay** for more information.

Some people with dementia qualify for continuing healthcare (CHC) funding. Dementia UK (page 49) has a **Guide to NHS continuing healthcare (CHC)** with more information.

Future care

As their condition progresses, the needs of the person you care for might change. 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.

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 going forwards.

Our **LifeBook** is a helpful tool to record the details of someone's life, from important contacts and documents to treasured possessions and final wishes. Search 'LifeBook' on our website or call **0800 169 65 65** to order a free print copy.

Advance care planning

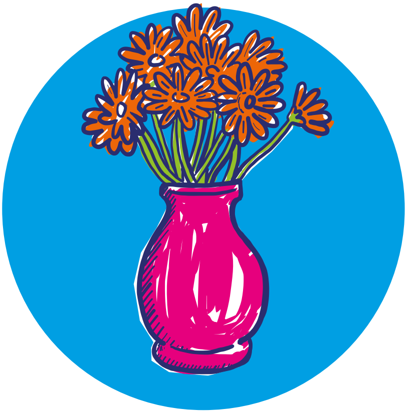
An **advance statement of wishes** lets someone record how they'd like to be cared for when they can no longer make decisions or communicate their views. Though not legally binding, an advance statement should be taken into account by health and social care professionals caring for them. It can cover where they'd like 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 as long as certain criteria are met. It lets someone decide what specific medical treatments they'd want to refuse in the future, and the circumstances in which their decision 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, see our guide **Thinking about end of life** and our factsheet **Advance decisions, advance statements and living wills**.



Help with care

As time passes, you might find the person with dementia needs more care or different care. You don't have to provide this on your own – there's support 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 (see page 25). 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 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 page 32), social services may suggest a specific local centre.

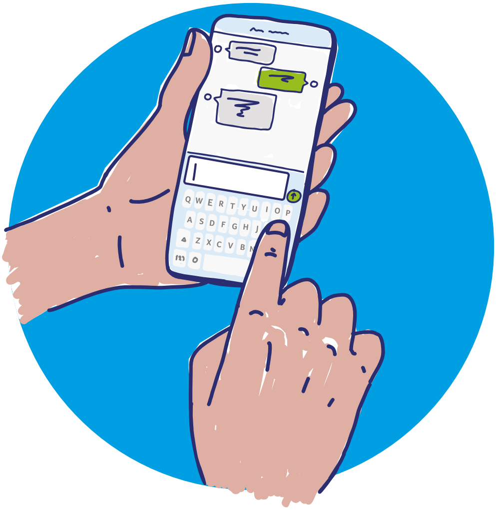
Some people with dementia don't take to day centres straight away, so give them time to get used to it. If the person you look after isn't sure about going, ask if someone from the centre can come and chat with you both. A familiar face during the first visit can be comforting, and you might be able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

Day centre access and availability varies depending on location. You can search for one on the Alzheimer's Society website (page 48).

"It look Frank a while to settle in at the day centre. But now he wouldn't miss it for anything."

June, 81



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. But 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 or go to the doctor.

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 48-50).
- 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 – 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 48) has a factsheet on respite care called **Taking a break**. Use the Carers Trust website (page 48) 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.

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 (page 48) has a factsheet called **Sex, intimacy and dementia** which looks at ways you can remain loving and close as a couple.

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 (page 49) has a **Changing relationships and roles** leaflet that 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.

Communication and behaviour

Dementia can affect people's communication and behaviour in ways that can be hard to deal with – 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 49) has a useful leaflet called **Tips for better communication**. Alzheimer's Society (page 48) has factsheets called **Aggressive behaviour** and **Walking and dementia** which contain helpful information and tips for carers.

For further advice and support, call the Dementia UK Admiral Nurse helpline (page 49) or speak to the person's doctor.

Communication tips

Here are some practical tips you might find helpful when you're 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 to process and respond to things.

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.
- You can mirror back or paraphrase what they've said to help them know you've heard and understood them.
- Try not to correct or interrupt them when they make mistakes. As long as you can understand them, it's sometimes best just to listen and acknowledge.
- If they keep asking the same questions, try not to get 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 doctor 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

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.

See page 31 for more information about advance statements and advance decisions.

This is why the person with dementia should think sooner rather than later about advance care planning (see page 31) or a lasting power of attorney for health and care decisions (see page 18). 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 48-50).

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.

Try to find out what the person with dementia wants and needs, if they're still able to communicate this to you. If they can't, 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 page 32).

Deciding whether to move the person you care for to a care home can be difficult, and you might feel like you've let them down. But there are limits to the care you can provide at home. Handing over some of your caring responsibilities to professionals can let you focus on the time you spend together.

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.

Good to know

If you think a care home might be the next step, see our guide **Care homes** for more information.

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 are meaningful to the person and, if possible, some familiar furniture.
- Give the staff information that helps them get to know the person – such as 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, 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.

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.

See page 31 for more information about advance statements and advance decisions.

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**.

Care Rights UK (page 48) supports care home residents and their families.

End of life care

There isn't currently a cure for dementia. While people can live for very different lengths of time and have different experiences following a diagnosis, everyone who has dementia will die with the disease – though not necessarily because of it.

This can mean you go through a form of grief even while the person is still alive. This is sometimes called 'anticipatory grief'.

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 at the end of their life.

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 31). Dementia UK (page 49) has an **End of life care** leaflet with more information about this.

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 48-50).

Loss and bereavement

Grief isn't a straightforward journey, and dementia can make it even more complex.

It's natural to feel very sad after a death – but seeing a condition progress over time can make grief more complex. Lots of people are surprised to find they don't actually have a strong emotional reaction when the person they care for dies. Lots of people experience feelings of relief that the person they love isn't suffering anymore.

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 48). If you're feeling particularly low or anxious, talk to your doctor.

Support from others – especially those who have been through similar experiences – could help. The Talking Point forum on Alzheimer's Society's website (page 48) has a section called 'After dementia – dealing with loss'.

Good to know

Our guide **Bereavement** explores the emotional side of coping with death. Dementia UK (page 49) has a **Grief, bereavement and loss** 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 to people living with dementia, their families and carers. You can also contact Join Dementia Research through the helpline.
Tel: **0333 150 3456**
www.alzheimers.org.uk

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

Care Rights UK

Supports care home residents and their friends and relatives.
Tel: **0207 359 8136**
www.carerightsuk.org

Carers Trust

Offers practical help and assistance to carers, including information on respite care via local networks.
Tel: **0300 772 9600**
www.carers.org

Carers UK

Provides information and advice on caring and helps carers connect with each other.
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

Offers counselling, advice and practical support to bereaved people.
Tel: **0808 808 1677**
www.cruse.org.uk

Dementia Adventure

Provides dementia-friendly activities and holidays for people with dementia, as well as training for family and friends.
Tel: **01245 237548**
www.dementiaadventure.co.uk

Dementia Services Development Centre, Stirling University

Produces useful guides for people affected by dementia.
Tel: **01786 467740**
www.dementiainformation.stir.ac.uk

Dementia UK

Specialist dementia nursing charity that provides advice, information and support. Contact their helpline to speak to an Admiral Nurse or visit their website to find out if you have a service in your local area.
Dementia Helpline: **0800 888 6678**
www.dementiauk.org

Department for Work and Pensions

Contact them about becoming an appointee for the person you care for if they can't 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

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**
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

Samaritans

Helpline offering confidential support to people in distress, 24 hours a day, 365 days a year.
Tel: **116 123**
www.samaritans.org

Help us be there for someone else

We hope you found this guide useful. When times are tough, it's so important to get some support. You can help us reach everyone who needs us:

1. **Tell us your story.** If Age UK's information and advice has helped you, we'd love to hear about it. Email **stories@ageuk.org.uk**.

2. **Donate to us.** We rely on donations to support older people when they need us most. To make a donation, call us on **0800 169 8787** or go online at **www.ageuk.org.uk/donate**.

3. **Volunteer with us.** Our volunteers make an incredible difference to people's lives. Find out more at **www.ageuk.org.uk/volunteer** or contact your local Age UK.

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 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 might 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 find all of our guides and factsheets on our website, along with lots more useful information. Visit **www.ageuk.org.uk** to get started.

You can order free printed copies of any guide or factsheet by emailing **orders@ageuk.org.uk** or calling our Advice Line on **0800 169 65 65.** Our friendly advisers can also help with any questions.

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

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

age UK
Let's change how we age

0800 169 65 65
www.ageuk.org.uk

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