

# Caring for someone with dementia

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A practical guide to help you  
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# Information and advice you need to help you love later life.

**We're Age UK and our goal is to enable older people to love later life.**

We are passionate about affirming that your later years can be fulfilling years. Whether you're enjoying your later life or going through tough times, we're here to help you make the best of your life.

**Our network includes Age Cymru, Age NI, Age Scotland, Age International and more than 160 local partners.**

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# What this guide is about

If you've picked up this guide, you're probably caring for someone with dementia or with symptoms that suggest dementia.

The guide is for anyone caring for someone with dementia, including partners, family members and friends, whether you live with the person with dementia or not. Some information may be more relevant if you live with the person you're caring for.

You may be wondering what to expect as the illness progresses, and where to turn for help. This guide takes you through what to expect, from getting a referral to a memory clinic to talking to family and friends about the diagnosis, joining a carers' group and more.

You don't need to read it cover to cover – look at the sections that are relevant to you. While everyone's experience of dementia is different, being prepared can help you manage better, now and in the future.

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

As far as possible, the information given in this guide is applicable across the UK. Note that when we refer to the social services department, this term includes the Social Work Department in Scotland and Health and Social Care Trusts in Northern Ireland.

## Key



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



This symbol indicates who to contact for the next steps you need to take.

# What is dementia?

Dementia is a term used to describe a collection of symptoms that includes memory loss, mood changes and problems with reasoning and communication. These symptoms occur when the brain is affected by certain diseases or conditions. The most common are Alzheimer's disease and vascular dementia.

These conditions mainly affect people over 65 (although they can occur less frequently in younger people) and the likelihood of developing them increases with age. They are progressive and each person experiences them in their own way. The range of symptoms and the speed they progress at depends on the individual person and the type of dementia. While medication and a number of non-medical therapies for dementia can help with some of the symptoms, there is currently no cure.

A common symptom of dementia is a loss of short-term memory – the person you care for may forget things they've said or done recently, even though they can clearly recall events that happened years ago.

Dementia is not an inevitable part of ageing, and being forgetful doesn't necessarily mean someone has dementia. Dementia-like symptoms can be caused by depression, stress, vitamin deficiencies, thyroid problems or urinary tract infections. If you're worried about someone, don't jump to conclusions: encourage them to seek advice from their doctor.

## what next?



Contact the Alzheimer's Society or Dementia UK (see pages 43 and 45) to find out more about early signs and different types of dementia, including information about medication that may be prescribed. In Scotland, contact Alzheimer Scotland (see page 43).

# Getting a diagnosis

The thought that someone you care about might have dementia can be scary. But a diagnosis won't make the condition worse, and knowing what's wrong can help you and the person you care for access help, support, services and medication if appropriate, as well as plan ahead.

If memory problems start to have an impact on day-to-day life, the first step is for the person you care for to visit their GP. You could go with them to offer support or to help them explain their symptoms. If the person you care for doesn't want to go, you could write to or phone their GP to outline your concerns. GPs can't talk to you without the person's consent, but they can listen and take into account your concerns for future appointments. They may consider inviting them for a general health check, particularly if they have not seen them for a while.

The GP will ask about the symptoms and when they started. It can be useful to think of specific examples of how the symptoms impact on everyday life. The GP will also look at the person's medical history and medicines.

The GP may carry out some short tests for memory and thinking. They may also suggest a referral to a specialist or memory clinic for a fuller assessment. Alternatively they may make a referral to a community mental health team for advice and support.

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

## what next?

See our free guide *Living with early-stage dementia*. The Alzheimer's Society's factsheet *Assessment and diagnosis* may also be helpful (see page 43).

# Local support after diagnosis

A diagnosis of dementia can be overwhelming. You and the person you care for may feel shock, disbelief or fear about what the future holds. It's important to know what support is available should you need it.

Some areas have a dementia adviser who can offer support, advice and information to the person you care for. If you aren't given the name of someone you can contact after the diagnosis, ask the memory clinic, the GP or the local adult social services who you can speak to. In Scotland you have a right to a year's support after your diagnosis.



Contact the Alzheimer's Society, Carers Trust or Dementia UK (see pages 43–45) to find out about their services, online forums and support groups, or if you just want to talk to someone about how you are feeling. These organisations work in England, Scotland, Wales and Northern Ireland.

You may want to sign up to the NHS Choices Dementia Information Service. They will send you a weekly email for six weeks, giving you information and advice on dementia and the help and support available. Visit the dementia page on NHS Choices (see page 45) to sign up for free.



# Talking to family and friends

You may be wondering if, and how, to talk to other people about the diagnosis. Perhaps you're concerned they'll be uncomfortable, or overprotective of the person you care for. If you're caring for your partner, you may find that friends or family assume you can no longer go out or socialise as a couple. There can also be a stigma about dementia in certain communities.

Most people find that if they can be honest with friends and family, they are more likely to get the support they need. Remind friends and family that the person with dementia is still the same person they were before the diagnosis. Where possible, both of you could talk to friends and family about what adjustments could help and what the person you care for prefers. For example, the person with dementia may prefer doing things in smaller groups or in places that aren't too noisy. See the section 'Communication and behaviour that challenges you' for more tips to share with friends and family (page 28).

Dementia can be a difficult condition to explain to teenagers and young children but there is a useful guide from the Mental Health Foundation called *The milk's in the oven*. Download it free from their website (see page 45). Alzheimer's Research UK have a website for children and young people at [www.dementiaexplained.org](http://www.dementiaexplained.org)

## what next?

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

# Finding local support and information

It can be hard to know where to start when you're looking for help or advice. Here are some suggestions of who to contact:

## **Dementia Connect**

Search on the Alzheimer's Society's Dementia Connect directory for services, stimulating activities and support groups in your local area (see page 43).

## **Admiral Nurses**

Admiral Nurses are specialist dementia nurses who work in communities in the UK. Call the Admiral Nurses Direct helpline (run by Dementia UK) if you need expert advice and emotional support (see page 45).

## **Carers groups**

Local carers groups are a good source of support and information. Some groups offer speakers, leisure activities or simply time to chat. Even if you haven't been the type to join social groups before, it may be worth seeing what's out there. Ask your social services department about local groups or contact Carers Trust or Carers UK (see pages 43 and 44).

## **Online forums**

Online groups can be invaluable if it's difficult to get out or you need someone to chat to at any time of the day or night. Try the Talking Point forums on the Alzheimer's Society's website (see page 43) or the message boards on the Carers UK website (see page 44).

## Memory cafés

Memory cafés offer information and support in an informal setting. People with dementia and their carers can attend together. There may be health or care professionals available to talk to in confidence. To find local memory cafés, see the Dementia Connect directory or ask your local Age UK.

## Local Age UK

Your local Age UK may be able to offer help and support. Different local Age UKs offer different services. These may include benefits checks, befriending services, ‘home from hospital’ or respite services. See page 42 for details of how to contact Age UK.

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



Your local **Age UK** may be able to offer help and support, **such as benefits checks, befriending or respite services.**

# Carer's Allowance and other benefits

Make sure you're claiming all the benefits you're entitled to. This may include Carer's Allowance, but claiming it can mean that the person you care for receives less in income-related benefits, such as Pension Credit. Check whether this is the case before making a claim.

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

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

You could qualify for reduced Council Tax if you live with someone with dementia. Some people are exempt when working out the number of people in your home, and this includes anyone with advanced dementia, as they are classed as 'severely mentally impaired'.

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

**what  
next?**

See our free 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*. In Scotland see **i** *Age Scotland's Benefits maze*. You could also try our online benefits calculator at [www.ageuk.org.uk/benefitscheck](http://www.ageuk.org.uk/benefitscheck)



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

# Looking after yourself

When you're caring for someone else, it's easy to overlook your own needs. Looking after your health and making time for yourself can help you feel better and cope better with your caring role. As a carer, you may be under immense pressure and you may need to be persistent and assertive when asking for help. Don't wait for a crisis – get help and support early on.

## Practical help

Consider asking friends and family to help with specific things that would be useful to you, such as helping with shopping, popping round for half an hour so you can get out, or just calling you on a regular basis for a chat. If you care for someone from a distance, perhaps the person's neighbours or local friends may be able to offer some help. Accept help when it's offered, as people may not think to offer again if they assume you can manage. You may find it helpful to use a mobile phone application to co-ordinate care with friends and family, such as the app Jointly, created by Carers UK (see page 44).

## Emotional health

Caring for someone with dementia may lead to feelings of guilt, sadness, confusion or anger. It can be difficult to share these feelings with someone with dementia, which might leave you feeling very isolated, but it's important to acknowledge these feelings – and remember: there's no right or wrong way to feel. Family and friends, carers' groups, online forums, your GP, a counsellor or organisations such as Admiral Nursing Direct or Samaritans (see pages 45 and 46) can all provide you with a space to talk about how you're feeling. Find someone you trust and be as honest as you can. See page 8 for how to find local support services.

## Help from social services

You're legally entitled to a free carer's assessment from your local council to see what help you might need. Think carefully about how your caring role affects you and what would help you manage better. Ask about what help is available to give you a break from caring too. See our guide *Advice for carers*



for more information on carer's assessments. In Scotland contact Care Information Scotland (see page 43).

## Staying well

Caring can be hard work so try to eat well, take regular exercise and get enough sleep. It's easier said than done, but try to take time out for yourself each day – even if it's only ten minutes to relax with a cup of tea, listen to the radio, or get some fresh air.

Tell your GP you're a carer and see them when you need to; don't put off appointments or ignore symptoms you really should follow up. Many practices let you book telephone consultations, which can be particularly useful if you feel you can't leave the person you care for alone at home. Tell your GP if you feel stressed, anxious, tired or depressed.

You can book GP or hospital appointments online, or ask if the pharmacy offers a home-delivery service for repeat prescriptions. Our free guides *Healthy living* and *Healthy eating* have more ideas on staying well.

## Options if you're working

If you're juggling work and caring, you could request flexible working. Your employer doesn't have to agree to it but they must have a sound business reason for refusing. You have the right to make a request if you've been working for your employer for at least 26 weeks. You can make one request per year but if your circumstances change, your employer may be willing to consider another request. For advice on work and caring, contact Carers UK (see page 44).

# Creating the best possible home environment

For a person living with dementia, the design and layout of where they live can have a big impact on their daily life and on your life as their carer. Increasing memory loss, confusion and difficulty learning new things can all mean they don't remember where things are and how they work. Here are some tips for making changes in their home (or in your home if they live with you or visit frequently).

- Good lighting is important because dementia can affect a person's ability to understand what they see. Make sure the home is well lit, minimise shadowy areas, and let natural light in as much as possible.
- Helpful gadgets can make day-to-day tasks easier and safer – for example, a clock that shows the date and day of the week. If you don't live with the person you care for and you're worried about them taking their medication at the right time, there are pill dispensers with alarms to remind people when to take their medication. You can also set up alerts on the person's phone.
- 'Telecare' refers to equipment that can detect problems in the home and raise an alert with the carer or through an emergency contact centre. Sensors in the bathroom, for example, can detect flooding, or pressure mats by the bed can detect when someone has got up in the night. Telecare may be particularly useful if the person with dementia lives alone or if you can't be with them all the time. Contact your local social services and ask them about telecare or visit the AT Dementia website (see page 43) to find out more.



- Home adaptations or improvements could help to make life at home easier. Handrails, grab rails, ramps or bathing aids may be useful and there may be grants available for this kind of equipment. Contact your local social services department to ask for a needs assessment (see page 24).

### what next?

Read our free guides *At home with dementia* and *Adapting your home* for more advice. The Dementia Centre at Stirling University (see page 44) has also produced useful guides for people living with dementia, including *10 helpful hints for carers*, which costs £5.

## Driving

If the person you care for drives, the law requires them to tell the Driver and Vehicle Licensing Agency (DVLA) and their insurance company about their diagnosis. Call the DVLA on 0300 790 6806 or visit [www.dvla.gov.uk](http://www.dvla.gov.uk). A diagnosis of dementia doesn't automatically mean someone has to stop driving immediately – what matters is that they can drive safely.

- i** In Northern Ireland, contact the Driver and Vehicle Agency on 0300 200 7861 or visit [www.nidirect.gov.uk/information-and-services/motoring/driver-licensing](http://www.nidirect.gov.uk/information-and-services/motoring/driver-licensing).

### what next?

Suggesting to someone that they stop driving can be a very sensitive conversation to have. See our guide *In the driving seat* and the Alzheimer Society's factsheet *Driving and dementia*.

# Doing things together

It's important to keep doing things together that you've always done for as long as possible. It's good for your relationship and helps maintain the self-esteem and confidence of the person you care for.

## **Singing classes and activity groups**

Singing can be an uplifting activity for many people and it's been shown to be particularly therapeutic for people with dementia. Singing for the Brain offers group singing for people with dementia and their carers. You may also find other local activity groups for people with dementia and their carers, such as exercise classes, book groups or craft activities. Find local groups and activities by contacting the Alzheimer's Society or using their Dementia Connect online directory (see page 43).

## **Holidays**

Holidays can be a great way to relax and with a bit of forward planning, you can still enjoy going away together. Most people with early-stage dementia will be able to go on holiday as normal, perhaps with just minor adjustments. But if going away is becoming more difficult and you want to find out more about supported and specialist holidays, contact Dementia Adventure or Silver Travel (see pages 44 and 46). You should also make sure that you declare the diagnosis of dementia when looking for holiday insurance. These policies sometimes have higher premiums, so shop around. Some providers have specific insurance for people with dementia.

## Creating a memory book

A memory book or life-story book can help you and someone with dementia remember special times. It is a collection of information, mainly photos, to represent familiar places and happy events such as weddings, the birth of children or holidays. Photos are likely to trigger memories and encourage the person with dementia to talk about their life. The whole family can help contribute to making it. Later on, the book can help health and social-care professionals appreciate the life and past experiences of the person they are caring for. Dementia UK has a template for making your own memory book. Download it from [www.dementiauk.org/information-support/life-story-work/](http://www.dementiauk.org/information-support/life-story-work/)



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

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

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

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

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

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

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

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



‘We’ve **adjusted**  
**to a different** life  
together now.’

# Sorting out legal affairs


Planning ahead can help both you and the person you care for feel confident and reassured that a plan is in place and their wishes are clear. It's important to do this sooner rather than later.

## Wills

If the person you care for still has mental capacity (the ability to reliably make decisions for themselves), talk to them about making a will or reviewing their existing will to ensure it still reflects their wishes.


## Lasting Powers of Attorney

If the person you care for still has mental capacity, they may wish to set up a Lasting Power of Attorney (LPA). This allows them to appoint someone they trust (known as an 'attorney') to make decisions on their behalf. There are two types of LPA: one covering health and care decisions and another covering property and financial matters. The LPA for health and care decisions can only be used when someone has lost mental capacity (meaning they no longer have the ability to make their own health and care decisions), while the LPA for financial decisions can be used immediately if the person with dementia so wishes. An LPA must be registered with the Office of the Public Guardian (see page 46) before it can be used. If the person with dementia loses mental capacity having already signed the LPA, their attorney can still register it.

-  Scotland and Northern Ireland have different systems. Find out more in Age Scotland's guide on Powers of Attorney. In Northern Ireland you can get an Enduring Power of Attorney. Contact Age NI for advice.


## Applying for deputyship

If the person you care for has already lost the ability to make or communicate decisions about their finances or health and care but doesn't have an LPA, you can apply to the Court of Protection to be their deputy (see page 46). As a deputy you can make particular decisions approved by the Court of Protection on behalf of that person. It is better to get an LPA in place while the person still has capacity to make one, as applying to be deputy is a more expensive and lengthy process.

-  In Scotland you can apply to the sheriff court to become an intervener or a guardian. Find out more from the Office of the Public Guardian (Scotland) (see page 46). In Northern Ireland you can apply to the Office of Care and Protection to become a controller. Contact Age NI for more information.

### what next?

See our free guides *Powers of attorney* and *Wills and estate planning* for more information. The Alzheimer's Society's factsheet *Making decisions and managing difficult decisions* (see page 43) may also be helpful. See Age Scotland's guide on powers of attorney in Scotland and factsheet *Legal options for someone who has lost capacity*.

-  If you need a solicitor, contact the Law Society in your nation (see page 45). Age UK Enterprises Limited\* also offers legal support and advice through the law firm Irwin Mitchell. Call Irwin Mitchell on 0800 055 6314 for more information.

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# Dealing with money

If the person you care for needs help with money matters, you may find yourself dealing with their finances and banking. Start by putting all important documents, such as bank statements, insurance policies, wills and pension details, in a safe place. Age UK produces *LifeBook* that can help you get organised. Call 0345 685 1061 for a free copy.

## Bills

If the person you care for can still manage basic finances, they may wish to set up Direct Debits to pay regular household bills. If they prefer not to, ask them if you can tell their utilities providers they have dementia. Leave an alternative contact number with the companies so the person isn't cut off if they forget to pay.

Phone companies offer third-party bill management, so a customer's chosen friend or relative can talk to the company on their behalf, get copies of their bills and arrange payment.

## Banking

Joint accounts can be useful but most are set up to operate only when both people have capacity. If you have separate accounts, the person with dementia could set up a third-party mandate to give you permission to manage their bank account on their behalf. However, like joint accounts, most of these are only valid while the person still has capacity. Alternatively, the person you care for could set up a Lasting Power of Attorney for financial decisions (see page 20).

### what next?

The Alzheimer's Society's booklet *Accessing and sharing information: acting on behalf of a person with dementia* (see page 43) has more information. The British Bankers' Association also has a free guide called *Guidance for people wanting to manage a bank account for someone else*. Get a copy by calling 020 7216 8900 or from [www.bba.org.uk](http://www.bba.org.uk)



# Thinking about future care

It's a good idea for the person with dementia to think about the treatment and care they would like to receive as their condition progresses. Recording these wishes while they still have capacity means their wishes are likely to be followed, and can give you peace of mind that they are receiving the treatment and care that they wanted.

## Advance statement of wishes

An advance statement allows someone to record how they would like to be looked after and cared for when they can no longer make decisions or communicate their views. It can cover non-medical matters such as food preferences, beliefs and where they'd like to be looked after as their condition progresses. It isn't legally binding but it should be taken into account by health and social-care professionals who are caring for them.

## Advance decision to refuse treatment

An advance decision lets someone decide to refuse specific medical treatments in situations that may arise in the future. It would only apply if they lack capacity to make a decision or communicate their wishes. In England and Wales an advance decision is legally binding and must be followed by doctors and healthcare professionals. In Scotland advance decisions are likely to be followed but aren't legally binding. In Northern Ireland, advance decisions are not legally binding.




**what  
next?**

For more information about advance decisions, advance statements and thinking about future care, see our guide *Before you go* and our factsheet *Advance decisions, advance statements and living wills*.

# Getting help from social services

If the person with dementia needs help at home, for example, with washing and bathing or getting up and dressed, contact the local council's social services department and ask for a free needs assessment. The person you care for is entitled to an assessment regardless of their income and savings and no matter what their needs are. You as a carer also have the right to have a free carer's assessment (see page 13).

If the person with dementia is eligible for care and support, social services will agree a care plan with them detailing what support could help. This could include care at home, day care, home adaptations or telecare. The person you care for will then have a financial assessment to see whether they will have to contribute towards the cost of the support. This is known as a means test and it will look at their income and savings. Even if the person isn't eligible for help, the council should make sure they get free information and advice.

-  In England and Wales, if the person you care for is eligible for help and financial support, they can choose either for the council to arrange their care services or arrange it themselves through direct payments. This is a cash payment they can use to arrange and pay for care at home. Direct payments can help someone remain in control and decide how best to meet their own needs. If they are unable to make their own decisions, you or someone else could manage it on their behalf. The local council should help and regularly check that they are getting what they need.

If the person's needs change or increase, ask for them to be reassessed. It's important to do this as soon as possible so you can both get the right support when it's needed.

- ① In Scotland if your care is classed as Free Personal and Nursing Care, it is free. For more information contact Care Information Scotland (see page 43).
- ① In Northern Ireland there is no financial assessment for community care services in the home.

### what next?

See our free guide *Getting help at home* and our free factsheet *Personal budgets and direct payments* for more information. In Wales, see Age Cymru's free factsheets

- ① *Social care assessments for older people with care needs in Wales* and *Direct payments for community care services in Wales*. In Scotland, read Age Scotland's factsheet *Care and support at home: assessment and funding*. In Northern Ireland, contact Age NI.

# Day centres

Day centres can be good for both you and the person you care for. If you live with the person with dementia, or spend a lot of time with them, a day centre can allow you to have a break from each other and provide an opportunity for the person with dementia to socialise.

Some carers feel mixed emotions about day care. You might feel guilty or think it's a sign you can't cope. Remember that you need time to yourself and many people enjoy day care once they've settled in. A variation in routine can benefit you both.

Day centres can provide company, activities and sometimes facilities like hairdressing and chiropody. Some centres are suitable for everyone, including someone with mild dementia, while some areas may have specialist dementia day care centres. If the person you care for has a needs assessment (see page 24), social services may suggest a local centre.

To make the transition to day care gradual and smooth, ask if someone from the centre will come and talk to you both about attending. They can be a familiar face during the first visit. Staying with the person you care for the first few times can also help them settle in. Encourage them to take their hobbies or possessions, such as art materials, games or music, so they have something to do or talk about.

It may be difficult at first for the person with dementia so allow them time to get used to it. Talk to the centre's staff if the person you care for seems upset or unhappy about going there. Remember that different day centres offer different activities and environments. You may find the person's social and cultural needs are better met by a different one.

# A break from caring

If you need a break from caring, your local council has a responsibility to arrange services that help you do this. This is known as respite care. Respite care covers a variety of different things, such as:

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

Respite care can give you a much-needed regular break and time to do things that you want or need to do, such as attend medical appointments, meet up with friends, attend classes or support groups, or take time to exercise.

Respite services are means-tested so you or the person you care for may have to contribute towards the cost of them.

In some areas respite care is provided as a result of your carer's assessment (see page 13), while in others it's provided through a needs assessment for the person you look after (see page 24).

## what next?

Talk to your local council about getting a carer's assessment (see page 13) to work out what kind of respite care could help you. Carers UK have a factsheet on respite care called *Taking a break*, which you can download from [www.carersuk.org/break](http://www.carersuk.org/break) or contact them to order a copy (see page 44). Use the Carers Trust website (see page 43) to find local services for carers, including respite care, in your area.

# Communication and behaviour that challenges you

As dementia progresses it can affect people's ability to communicate and cause them to behave in puzzling ways. You may feel hurt, embarrassed or angry when this happens. Remember this is part of the condition.

Unusual behaviour may include agitation, rocking, calling out the same word, experiencing hallucinations, or movements such as wringing their hands or pulling at their clothes. It can include aggressive behaviour, both verbal and physical. The person is probably trying to communicate something so it may happen when they are frightened, frustrated, bored or in pain. Try to see if you can identify anything that triggers these behaviours so you can understand what might be the cause.

You may also find that the person loses their inhibitions, self-control or judgement as a result of the dementia. People with dementia may like to go walking but can get lost, which can also be very worrying.

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

- Speak clearly and slowly, using simple language and short sentences.
- Questions that only need a 'yes' or 'no' answer can make things easier – so ask 'Would you like coffee?', rather than 'What would you like to drink?'.
- Avoid testing the person's memory by, for example, asking what they did earlier.

- If what the person is saying doesn't seem to make sense, look for the meaning behind the words. They are usually trying to communicate how they feel.
- If they can no longer talk, you may be able to understand what they are feeling through their facial expressions or gestures.
- Your tone of voice is important. Try to talk slowly and calmly, even if the conversation is difficult or frustrating.
- Try not to get into arguments about what they say. Simply listening to what they're saying rather than correcting them can help someone feel acknowledged.
- If they or you become frustrated, you could walk away, wait a few minutes and then go back to see if the situation has calmed down.
- Try talking about 'we' and 'us' rather than 'you'. This makes the person with dementia feel that they are part of a team rather than being told what to do.
- Touch can be very important for people with dementia. A hug, holding hands, or a touch on the shoulder can be comforting and reassuring, even if they may not understand what you are saying.
- If they keep asking repeated questions, try not to get annoyed or frustrated, as this will also affect their mood.
- Talk to other carers about how they tackle difficult situations to see if you can learn from them.
- Remember the distress and confusion may be caused by health needs other than dementia. Make sure the person has regular sight and hearing tests, as well as dental and GP check-ups (see page 32).

- If the person you care for likes to go for walks but finds it hard to remember the way home or where they are, you can buy tracking devices which allow you to see where the person with dementia is. It's important to balance the rights of the person and their need to be safe. For more information the Alzheimer's Society has a factsheet on assistive technology (see page 43).

## what next?

Dementia UK has a useful guide on *Tips for better communication with a person living with dementia* (see page 45). The Alzheimer's Society's factsheets *Dealing with aggressive behaviour* and *Walking about* contain helpful information and tips for carers (see page 43). For further advice and support, speak to the person's GP or call the Dementia UK Admiral Nurse helpline (see page 45).

## Your changing relationship

It's important to carry on doing things you both enjoy for as long as possible. Do things with the person you care for, rather than for them, so they can stay involved in daily household life. It's important not to make them feel patronised or try to do too much for them. They may just need more time to complete a task.

Becoming a carer for someone can change your relationship with them, and this is especially true when caring for someone with dementia. If you're caring for a parent it can feel like a reversal of the roles you have been used to.

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





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

# Supporting the person to stay healthy

If the person you care for shows distress or discomfort, it may be caused by a physical problem, such as constipation, a urine infection, toothache or arthritis. Try the following:

- Discuss any concerns with the GP so that physical causes or reactions to current medication can be ruled out.
- Check the person's glasses are clean and their hearing aid is in and working, if they use them.
- See our guide *Healthy living* to find out about important health tests.
- Read our guide *Bladder and bowel problems* to find out more about continence issues.

## Eating and drinking

If the person you care for is struggling to eat, is losing weight or has lost their appetite, this could be due to the effects of dementia on their smell and taste. Or perhaps they have difficulty with chewing and swallowing, or painful teeth. Brush teeth thoroughly and make regular visits to the dentist to ensure good oral health and avoid unnecessary problems.

You may find that they don't want a full meal or struggle to use cutlery. Try small healthy snacks throughout the day instead, such as finger sandwiches or cheese and crackers. If they live alone and you're worried about them eating enough, you could raise this when they have a needs assessment (see page 24). You could also find out if there are local meal delivery services such as meals on wheels. Contact your local Age UK to find out what might be available nearby.

Alcohol can cause confusion or react with certain medicines. If the person you care for enjoys a drink, you could try weaker, non-alcoholic or watered-down drinks. You need to balance their right to enjoy a drink with the risks it might pose.

The Alzheimer's Society's factsheets *Staying healthy* and *Eating and drinking* have more information (see page 43).

# If the person you care for goes into hospital

If the person you care for needs to go to hospital, it can be bewildering and disorientating for them, especially in the accident and emergency department. If the person you care for is admitted to hospital, you can help make sure they get the best care possible by following the suggestions below.

- Ask who their named nurse is. This is the person responsible for co-ordinating the person's care. Make sure the named nurse knows and informs other staff that the person has dementia.
- Ask to be involved in decisions about their treatment and need for support on discharge, and to be kept updated. Make sure the hospital has your contact details.
- Find out if there are flexible visiting times for families of people with dementia.
- Tell the hospital if you have a power of attorney for the person (see page 20).
- Write down important facts about the person with dementia and give them to the named nurse. Include what reassures or upsets them and what practical help they need.
- Tell them how the person prefers to be addressed – as 'Jean' or 'Miss Brown', for example.
- Tell staff what the person enjoys eating and drinking.
- Tell the hospital if the person has an advance statement or advance decision to refuse treatment (see page 23).

Make sure you are asked about your ability to continue caring, particularly if it looks as though more care will be needed after the hospital stay. You may benefit from a reassessment of your needs and additional support if the person you care for now has needs that are different or increased compared with before (see page 13).

### what next?

A leaflet called *This is me* from the Alzheimer's Society gives you space to write about the person you care for and include relevant information such as their likes and dislikes. Download it from [www.alzheimers.org.uk/thisisme](http://www.alzheimers.org.uk/thisisme) or call 0300 303 5933. Read the Alzheimer's Society's factsheet *Hospital care* and see our guide *Your hospital stay* for more information.

## Signs of later-stage dementia

In the later stages of dementia, the person can become increasingly dependent on others for their care. Knowing what to expect can help you both prepare. If the person with dementia has set up an advance statement, advance decision and Lasting Power of Attorney (see page 20–23), they'll be reassured that their preferences are known and that every effort will be made to care for them in the way they would wish.

The person you care for may have severe memory loss, fail to recognise those close to them and have increased difficulty with communication and understanding. They may lose weight (especially if chewing and swallowing are difficult), lose their ability to walk, become incontinent and behave in unusual ways (see page 28). However, not everyone is affected in these ways or to the same degree.

# Thinking about care homes

If the person's needs become too great for you to manage at home, you may need to consider other long-term care options, such as a care home. Remember that everyone's experience of dementia is unique and it progresses in different ways for different people. Not everyone with dementia will need care home accommodation. Every effort should be made to find out what the person thinks and feels.

A move to a care home can be a difficult decision and you may feel you have let down the person you care for. Remember there are limits to the care you can provide at home and there may come a time when the support you get from your local council or care agency is no longer sufficient. If you're becoming exhausted, or if it's becoming harder to care for the person with dementia, a care home can be the best option for both of you.

If it seems as though a care home may be something you'll need to consider, you could find out about local homes so you can be prepared if one may be needed. You should also contact your local social services for an assessment to see if residential care is the best option or if other support might be available (see page 24).

## what next?

See our free guides *Care homes*, *Care home checklist* and *Housing options* for more information. The Alzheimer's Society also has a factsheet on *Selecting a care home*.



Remember that **everyone's experience of dementia is unique** and it progresses in different ways for different people.

# If the person you care for moves into a care home

If the person you care for moves into a care home, you may feel guilty, relieved, lonely, tired, redundant or a mixture of these things. Remember, there is no right or wrong way to feel. If your routine revolved around being a carer, think about what else might give structure and meaning to your day.

Below are some tips on how to make the transition as smooth as possible for both of you.

- If you want to, you can ask to be involved in the person's care, such as helping out at mealtimes.
- Give the staff information about likes, dislikes and behaviour, perhaps recorded in a *This is me* leaflet (see page 35).
- Bring in belongings that mean a lot to the person you care for.
- Ask if the care home has a group for relatives or a regular newsletter.
- Find out how the home encourages residents and carers to continue to enjoy activities together.

Although familiar furniture and belongings can help, it can take a while for someone to settle into a care home. If you have any worries, speak to a member of staff or the manager.



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



If your concerns relate to abusive behaviour, contact the safeguarding adults team at your local council. They are responsible for responding to allegations of abuse.

**what  
next?**

**Contact the Relatives and Residents Association (see page 46), which supports care home residents and their families.**

# End of life care

People with dementia often experience a gradual, long-term decline in their condition, so clear indications of when they may be approaching death are difficult to recognise and agree on. They may die with dementia, from an unrelated condition such as a heart attack or cancer, or deterioration arising from a relatively minor illness. It's important to ensure that their GP, hospital staff and care home staff know if they have prepared an advance decision to refuse treatment or addressed end of life care in an advance statement, as this will help them offer the most appropriate care (see page 23).

If you're caring for the person with dementia at home, speak to your GP about what local services are available to support you to continue to care for them as their condition deteriorates. If the person with dementia hasn't recorded their preferred care plans, key health professionals involved in the person's care can talk to you to ensure the person's wishes are known and respected. If they live in a care home, ask their GP or care home staff what support would be available to help them die in the familiar surroundings of the home and avoid unnecessary admission to hospital.

**what  
next?**

See our free guide *Before you go* for more information on planning and support for the end of life.

# Loss and bereavement

When someone develops dementia, you are likely to experience feelings of grief and bereavement before they die, as the illness progresses. You may grieve for the loss of the person they once were, the loss of your future together, their support, your freedom and lifestyle, or something else.

When they die, you may find you have already grieved so much that you have no strong emotions, or you may feel overwhelmed by the loss. It can take a long time to come to terms with a death, especially if you have been a carer for someone. Whatever you're feeling is quite normal.

It may help to talk to friends and family who knew the person you cared for, to share memories and support each other. Or you might prefer to contact an organisation that supports bereaved people, such as Cruse (see page 44). If you're feeling particularly low or anxious, talk to your GP.

It can take time to regain your confidence, make sense of the world again and start to look forward and realise what you still have to offer. Help and support from others, especially those who have been through a similar loss, may help you work your way back to recovery. The Talking Point forum on the Alzheimer's Society's website has a section called After dementia – dealing with loss that you may find helpful (see page 43).

In time, you may want to pick up old hobbies, discover new interests or volunteer to help a good cause.

**what  
next?**

See our free guide *Bereavement* to read more about the emotional side of coping with a death.

# Useful organisations

## Age UK

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

Age UK Advice: 0800 169 65 65

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

[www.ageuk.org.uk](http://www.ageuk.org.uk)

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

In Wales, contact

**Age Cymru:** 0800 022 3444

[www.agecymru.org.uk](http://www.agecymru.org.uk)

In Northern Ireland, contact

**Age NI:** 0808 808 7575

[www.ageni.org](http://www.ageni.org)

In Scotland, contact **Age Scotland** by calling Silver Line Scotland: 0800 470 8090 (This is a partnership between The Silver Line and Age Scotland)

[www.agescotland.org.uk](http://www.agescotland.org.uk)

The evidence sources used to create this guide are available on request. Contact [resources@ageuk.org.uk](mailto:resources@ageuk.org.uk)

## **Alzheimer's Society**

Offers advice, information and support in England and Wales to people with dementia, their families and carers through its helpline and local branches.

Helpline: 0300 222 1122  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)  
[www.alzheimers.org.uk/wales](http://www.alzheimers.org.uk/wales)

For the Dementia Connect directory, see [www.alzheimers.org.uk/local-information/dementia-connect](http://www.alzheimers.org.uk/local-information/dementia-connect)

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

Helpline: 028 9066 4100  
[www.alzheimers.org.uk/northernireland](http://www.alzheimers.org.uk/northernireland)

In Scotland, contact **Alzheimer Scotland**

Helpline: 0808 808 3000  
[www.alzscot.org](http://www.alzscot.org)

## **AT Dementia**

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

Tel: 0115 748 4220  
[www.atdementia.org.uk](http://www.atdementia.org.uk)

## **Care Information Scotland**

Provides information and advice on topics relating to care, including help for carers and care services.

Tel: 0800 011 3200  
[www.careinfoscotland.scot](http://www.careinfoscotland.scot)

## **Carers Trust**

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

Tel: 0844 800 4361  
[www.carers.org](http://www.carers.org)

## **Carers UK**

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

Helpline: 0808 808 7777

[www.carersuk.org](http://www.carersuk.org)

In Wales, visit [www.carersuk.org/wales](http://www.carersuk.org/wales); in Northern Ireland, visit [www.carersuk.org/northernireland](http://www.carersuk.org/northernireland); in Scotland, visit [www.carersuk.org/scotland](http://www.carersuk.org/scotland)

## **Cruse Bereavement Care**

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

Tel: 0808 808 1677

[www.cruse.org.uk](http://www.cruse.org.uk)

In Northern Ireland, contact:

### **Cruse Bereavement Care Northern Ireland**

Tel: 0808 808 1677

[www.cruse.org.uk/northern-ireland](http://www.cruse.org.uk/northern-ireland)

In Scotland, contact:

### **Cruse Bereavement Care Scotland**

Tel: 0845 600 2227

[www.crusescotland.org.uk](http://www.crusescotland.org.uk)

## **Dementia Adventure**

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

Tel: 01245 237 548

[www.dementiaadventure.co.uk](http://www.dementiaadventure.co.uk)

## **Dementia Services Development Centre, Stirling University**

Produces useful guides for people affected by dementia.

Tel: 01786 467 740

## **Dementia UK**

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

Admiral Nursing Direct helpline: 0800 888 6678  
[www.dementiauk.org](http://www.dementiauk.org)

## **Law Society of England and Wales**

Helps people find a solicitor in their local area.

Tel: 020 7320 5650  
[www.lawsociety.org.uk](http://www.lawsociety.org.uk)

In Northern Ireland, contact **Law Society of Northern Ireland**

Tel: 028 9023 1614  
[www.lawsoc-ni.org](http://www.lawsoc-ni.org)

In Scotland, contact **Law Society of Scotland**

Tel: 0131 226 7411  
[www.lawscot.org.uk](http://www.lawscot.org.uk)

## **Mental Health Foundation**

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

[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

## **NHS Choices**

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

[www.nhs.uk](http://www.nhs.uk)

In Wales, visit [www.wales.nhs.uk](http://www.wales.nhs.uk); in Northern Ireland, visit [www.nidirect.gov.uk](http://www.nidirect.gov.uk); in Scotland, visit [www.nhsinform.co.uk](http://www.nhsinform.co.uk)

## **Office of the Public Guardian**

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

Tel: 0300 456 0300

[www.gov.uk/government/organisations/office-of-the-public-guardian](http://www.gov.uk/government/organisations/office-of-the-public-guardian)

In Northern Ireland, contact

## **Office of Care and Protection**

Tel: 028 9072 5953

[www.courtsni.gov.uk](http://www.courtsni.gov.uk)

In Scotland, contact

## **Office of the Public Guardian (Scotland)**

Tel: 01324 678 300

[www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

## **Relatives and Residents Association**

Supports care home residents and their relatives.

Operates a helpline and has a network of local groups.

Tel: 020 7359 8136

[www.relres.org](http://www.relres.org)

## **Samaritans**

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

Tel: 116 123

[www.samaritans.org](http://www.samaritans.org)

## **Silver Travel Advisor**

Specialist travel information and advice for people over 50.

Tel: 01753 740 169

[www.silvertraveladvisor.com](http://www.silvertraveladvisor.com)



# Can you help Age UK?

Please complete the donation form below with a gift of whatever you can afford and return to: Age UK, Tavis House, 1-6 Tavistock Square, LONDON WC1H 9NA. Alternatively, you can phone 0800 169 87 87 or visit [www.ageuk.org.uk/donate](http://www.ageuk.org.uk/donate). If you prefer, you can donate directly to one of our national or local partners. Thank you.

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I would like to make a gift of: £

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 Maestro  American Express

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Expiry date	<input type="text"/>	/	<input type="text"/>	Issue no. (Maestro only)	<input type="text"/>	

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



# Supporting the work of Age UK

Age UK aims to enable all older people to love later life. We provide vital services, support, information and advice to thousands of older people across the UK.

In order to offer free information guides like this one, Age UK relies on the generosity of its supporters. If you would like to help us, here are a few ways you could get involved:

**1 Make a donation**  
To make a donation to Age UK, simply complete the enclosed donation form, call us on **0800 169 8787** or visit **[www.ageuk.org.uk/get-involved](http://www.ageuk.org.uk/get-involved)**

**2 Donate items to our shops**  
By donating an unwanted item to one of our shops, you can help generate vital funds to support our work. To find your nearest Age UK shop, visit **[www.ageuk.org.uk](http://www.ageuk.org.uk)** and enter your postcode into the ‘What does Age UK do in your area?’ search function. Alternatively, call us on **0800 169 8787**

**3 Leave a gift in your will**  
Nearly half the money we receive from supporters come from gifts left in wills. To find out more about how you could help in this way, please call the Age UK legacy team on **020 3033 1421** or email **[legacies@ageuk.org.uk](mailto:legacies@ageuk.org.uk)**

Thank you!

# What should I do now?

For more information on the issues covered in this guide, or to order any of our publications, please call Age UK Advice free on **0800 169 65 65** or visit [www.ageuk.org.uk/healthandwellbeing](http://www.ageuk.org.uk/healthandwellbeing)

Our publications are also available in large print and audio formats.



The Age UK Group offers a wide range of products and services specially designed for people in later life. For more information, please call **0800 169 18 19**.

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

