

Caring for someone with dementia

A practical guide to help you

Health & wellbeing



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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Date of publication: June 2015 © Age UK 2015

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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. You may be wondering what to expect as the illness progresses, and where to turn for help.

This guide takes you from getting a referral to a memory clinic, through 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 both 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.

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.

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.

What is dementia?

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

These diseases mainly affect people over 65 (although symptoms in younger people shouldn't be ignored), and the likelihood of developing them increases with age. They are progressive, and each person experiences them in their own way. The speed with which symptoms progress depends on the individual person and the cause of their dementia. While there are several treatments that can help with the symptoms of Alzheimer's disease, there is currently no cure.

A common early sign is a loss of short-term memory – someone may forget things they've said or done that day or ask the same question repeatedly, even though they can clearly recall events that happened years ago.

Dementia is not an inevitable part of ageing. 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: get professional help and advice from your doctor.

what next?



Contact the Alzheimer's Society or Dementia UK (see pages 37 and 40) to find out more about early signs and different types of dementia, including information about medication that may be suitable. In Scotland, contact Alzheimer Scotland (see page 37).

Talking to your GP

The thought that someone you care about might have dementia can be scary. But facing up to your fears is usually much better than trying to ignore the problem. A diagnosis won't make the condition worse, and knowing what's wrong can help you access help, support, services and medication if appropriate, as well as plan ahead.

If memory problems are beginning to have an impact on day-to-day life, you could visit the GP together to explain your concerns. Be patient but persistent, and talk to the GP about the impact the symptoms are having.

The GP may make a referral to a specialist or a memory clinic for a fuller assessment. Memory clinics offer ongoing assessments, support and advice for those with memory problems and their carers. Or they may refer you to a community mental health team for advice and support. The person you care for is entitled to a referral, so request one if the GP doesn't suggest it.

what
next?

See our free guide *Living with early-stage dementia* for more information on discussing dementia with your GP.

Finding support in your local area

Once someone has a diagnosis, they should ask to be given a named person to act as their contact person throughout the journey with dementia. Ideally this person should be able to help you both understand and access the local health and social care system and direct you to other services or local groups.

The National Dementia Strategies for England and Scotland aim to improve services for people with dementia and their carers. They highlight the importance of high-quality information in supporting people with dementia and their carers. This can come from support groups, a dedicated dementia adviser or another key contact. Adviser posts aren't yet available in all parts of the country, but make sure you ask who your named contact is when you receive a diagnosis.

-  The National Dementia Vision for Wales aims to improve information on dementia by developing bilingual information packs for people with dementia and their families, friends and carers. They have also set up the Wales Dementia Helpline (see page 42) which offers confidential emotional support and advice.
-  The Northern Ireland Executive's regional strategy for dementia aims to raise awareness and improve services and support for people with dementia in 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 41) to sign up for free.

**what
next?**

Contact the Alzheimer's Society or Carers Trust to find services and support groups in your local area (see pages 37 and 38).

'Mental illness is such a difficult illness to react to – it is an 'unseen' illness, which is hard to explain to others.'



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 judgemental, or overprotective, or will change towards you both. Some couples find that when one of them is diagnosed with dementia, friends aren't sure how to behave and may assume they can no longer go out or socialise. There can also be a stigma about dementia in certain communities. The national Dementia Friends scheme aims to change how society thinks about dementia by providing free awareness sessions. Find out more by visiting www.dementiafriends.org.uk

Most people find that if they can be honest with their 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 and try to gently explain how they can best help. Where possible, both of you could talk to them about what the person with dementia still enjoys, and what adjustments could help. For example, the person with dementia may prefer close-ended questions that can be answered with yes or no rather than open questions.

Dementia can be a difficult illness to explain to 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 41) or buy a copy for £1.50.

Creating the best possible home environment

The design and layout of your home can have a big impact on someone with dementia. Memory loss, confusion and difficulty learning new things can all mean they forget where they are, where things are and how they work.

- Helpful gadgets can make day-to-day tasks easier and safer: for example, a clock that shows the date and day of the week, or a pill box with different compartments for different days and times.
- Good lighting can really help someone with dementia. And remember that making your home safe and comfortable doesn't have to be expensive. Visit the 'Home environment and dementia' section of NHS Choices for affordable ideas: www.nhs.uk/Conditions/dementia-guide/Pages/dementia-home-environment.aspx
- 'Telecare' refers to equipment and services that support someone's safety by monitoring changes or possible emergencies in the home. For instance, sensors in the bathroom could detect flooding and switch off the water and raise the alarm, or pressure mats by the bed can detect when someone has got up in the night and alert their carer. Telecare may be particularly useful if the person with dementia lives alone, or if you can't be with them all the time. Contact AT Dementia (see page 37) to find out more.

- As dementia progresses, home adaptations, repairs or improvements may help make life easier for someone with dementia or let them prolong their independence. Handrails, grab rails, ramps or bathing aids may be suitable and there may be grants available for them. Contact your local social services department to ask for an assessment (see page 23). See our free guide *Adapting your home* for more detailed information.

what next?

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

The booklet *10 helpful hints for dementia design at home* from the Dementia Services Development Centre offers simple and practical suggestions. It costs £7.50 and is available from www.dementiashop.co.uk

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. Carers can 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 early on.

Consider asking friends and family to help, by popping round while you do the shopping, staying overnight if the person with dementia is comfortable with this, or just calling you on a regular basis for a chat. Accept help when it's offered, as people may not think to offer again if they assume you can manage on your own.

You're entitled to a free carer's assessment from your local council to help you access support. 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.

Look after your own health. Caring can be hard work so try to eat well, take regular exercise and get enough sleep. Tell your GP you're a carer and see them when you need to – don't put off appointments. Let them know if you feel stressed, anxious, tired or depressed.

Our free guides *Healthy living* and *Healthy eating* have more ideas on staying well.

Don't neglect your emotional health. Family and friends, carers' groups, your GP, a counsellor, or organisations like Samaritans 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. 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, leaving you feeling very isolated, but it's important to acknowledge these feelings, and remember there's no right or wrong way to feel.

If you're working, you may need flexible working arrangements. If you've had to cut down on your working hours and are worried about money, see the section on benefits to make sure you're getting all the financial support you're eligible for (see page 22).

Carers' groups

Carers' groups can be a good way to get support from other carers who understand what you're going through, and can share their own experiences. Most groups meet regularly and may offer speakers, leisure activities, trips, and simply time to sit and chat. Even if you haven't been the type to join social groups before, it may be worth dropping in to a

 carers' group to see if it can give you the help you need. Ask your dementia adviser or social services department about local groups or contact the Alzheimer's Society, Alzheimer Scotland, Carers UK or Dementia UK for details (see pages 37–40).

Online groups can be invaluable if it's difficult to get out or you need someone to chat to when no-one else is around. Try the 'Talking Point' forums on the Alzheimer's Society website or the messageboards on the Carers UK website.

Memory cafés offer information and support in an informal setting. People with dementia and their carers can attend together. They are often run on a weekly or monthly basis, and you can drop in to meet up with other people in a similar situation. There may be health or care professionals available to talk to in confidence. To find out about local memory cafés, ask your dementia adviser, local Age UK, local

 Alzheimer's Society group or Alzheimer Scotland.

‘It was so reassuring to speak to other carers in similar situations and at different stages of their experience with dementia. It helped us to put our situation into perspective.’

'It's not the future we planned for but, with help, we've managed the last five years in a sort of increasing contentment.'

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 be seen. 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.

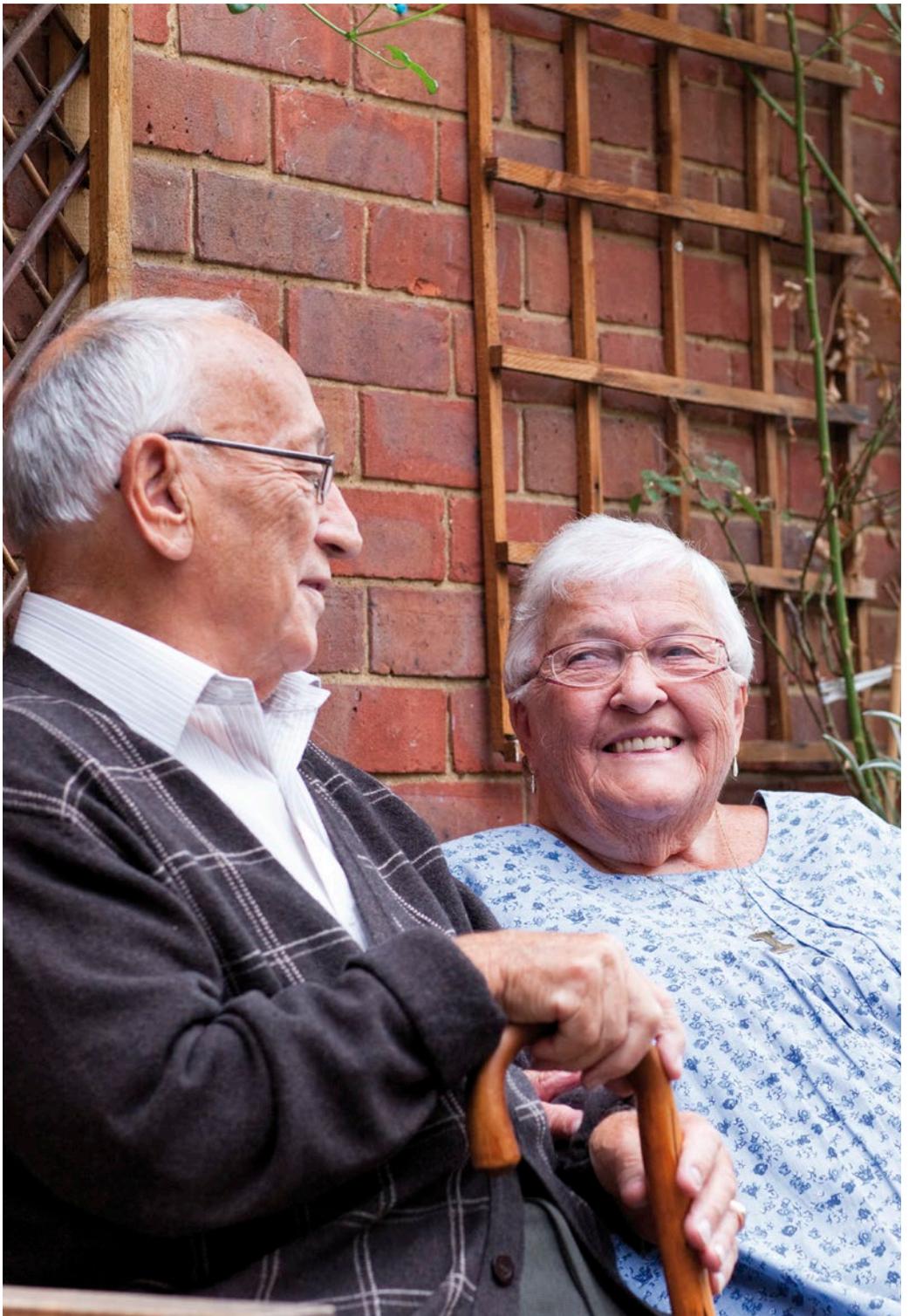
'When we got the diagnosis I was very upset and emotional, but also relieved as I'd known there was something wrong for a while. Having a diagnosis also meant we were put in touch with services like a dementia day centre, which

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.'





Finding out about local information, services and support

It can be hard to know where to start when you're looking for help or advice. Every area of the country does things differently, so services will differ. You should have a key contact person who can direct you to relevant help – see page 6. Some areas run courses on caring for someone with dementia that can give you information about dementia, tell you about your rights, and help you boost your confidence and recognise your limits. Visit the Alzheimer's Society website to search for services and support groups in your local area (see page 37).

Find your local Age UK by calling 0800 169 6565 or visiting www.ageuk.org.uk/local. Contact them and ask what help is available in your area. They should be able to signpost you to relevant services and give you a free benefits check; they  may also offer support and useful services. In Wales, contact Age Cymru and in Scotland, contact Age Scotland to find out about the help you can get. In Northern Ireland, contact Age NI to find out about their My Life, My Way project which aims to support older people who are living with dementia and their carers.

Admiral Nurses are specialist dementia nurses who work mainly in the community in some areas of England. They aim to improve the quality of life of people diagnosed with dementia and their carers. Dementia UK provides a helpline staffed by Admiral Nurses if you need practical advice and emotional support. Contact Dementia UK to find out more (see page 40).

Sorting out legal affairs

Making decisions about their future while they still have mental capacity (the ability to reliably make decisions for themselves) can help someone with dementia remain in control and feel more confident about their care and support. As their carer, you can feel reassured that a plan is in place so that their wishes are followed.

Wills

Talk to the person with dementia about making a will or reviewing their existing will to ensure it still reflects their wishes.

Lasting Powers of Attorney

The person with dementia 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 welfare decisions and the other covering property and financial matters. The health and welfare LPA can only be used when someone has lost mental capacity (meaning they no longer have the ability to make their own decisions), while the property and financial LPA can be used immediately if the person with dementia wishes. An LPA must be registered with the Office of the Public Guardian (see page 42) before it can be used, a process which takes up to eight weeks. 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 factsheet *Powers of attorney and other ways to help manage someone’s affairs*. Powers of attorney are not available in Northern Ireland. Contact Age NI for advice.

Applying for deputyship

If the person you care for has already lost the ability to make or communicate decisions but doesn't have an LPA, you can apply to the Court of Protection to be their deputy (see page 42). As a deputy you can make decisions 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 42). 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 37) may also be helpful.

If you need a solicitor, contact the Law Society in your nation (see page 41). Age UK Enterprises Limited* also offers legal services, which are provided by the law firm Irwin Mitchell. Call Irwin Mitchell on 0845 685 1076 for more information.

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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 dementia progresses. Recording these wishes while the person still has capacity means that 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 decision to refuse treatment

An advance decision lets someone decide to refuse certain types of medical treatment in certain situations, should they lack capacity to make or communicate the decision in the future. In England and Wales they are legally binding and must be followed by doctors and healthcare professionals.

i In Scotland, advance decisions are likely to be followed but aren't legally binding. In Northern Ireland, advance decisions are not legally binding.

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 like food preferences, beliefs and where they'd like to be looked after as their condition progresses. It isn't legally binding but should be taken into account by health and social care professionals.

**what
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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*.

Dealing with money

If you're caring for someone with dementia who is still able to manage basic finances, they may wish to set up direct debits to pay regular household bills. If they prefer not to, contact their fuel companies to let them know the person has dementia. Leave an alternative contact number with them so the person isn't suddenly cut off if they forget to pay their bills.

If the person you care for is your spouse, it may be that they handled money matters for the household. You may find yourself dealing with all the finances for the first time, which can be daunting. Start by finding all important documents, such as bank statements, insurance policies, wills and pension details, and putting them in a safe place. Age UK produces a free *LifeBook* that can help you get organised. Call 0845 685 1061 for a copy.

Joint accounts can be a useful way to manage your finances. However, most are set up to operate only when both people have capacity to use them. Keeping separate accounts is also a good idea when it comes to paying for care. 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.

what next?

The Alzheimer's Society's booklet *Accessing and sharing information: Acting on behalf of a person with dementia* (see page 37) has more information. The British Bankers' Association also produces a free guide called *Guidance for people wanting to manage a bank account for someone else*. You can get a copy by calling 020 7216 8900 or by downloading it from www.bba.org.uk

Driving

If the person you care for drives, the law requires them to tell the DVLA (Driver and Vehicle Licensing Agency) and their insurance company about their diagnosis. Call them on 0300 790 6801 or visit www.dvla.gov.uk. A diagnosis of dementia doesn't automatically mean someone has to stop driving straightaway – what matters is that they can drive safely.

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

There is practical and emotional help available for both you and the person with dementia.



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 for a disability benefit 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 a reduction to your Council Tax bill if you live with someone with dementia. Some people aren't counted 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'. In Northern Ireland, contact Age NI.



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* to find out more. Age Cymru and Age NI have their own versions of *More money in your pocket*. You could also try our online benefits calculator at www.ageuk.org.uk/benefitscheck

Getting help from social services

Contact your local council social services department and ask for a free community care assessment for the person with dementia. The person you care for is entitled to an assessment, regardless of their income and savings and no matter what their needs are. The social services department will assess what their care needs are, and decide which services could help to meet them. This could include care at home, day care, home adaptations or telecare support. Make sure you get a carer's assessment too (see page 11).

People with dementia may be charged for services following a financial assessment. How much they're charged depends on the services they receive and where they live, as rules differ throughout the UK. See our free guide *Getting help at home* for more information.

If the person you care for is eligible for help and financial support and lives in England or Wales, they can choose between having the council arrange their care, or arranging it themselves through direct payments. This is a cash payment they can use to arrange and pay for their 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 they are getting what they need.

what next?



To find out more, see the Mental Health Foundation's booklet *Personal budgets for people with dementia* (see page 41). In Wales, see Age Cymru's free factsheet *Direct payments for community care services in Wales*. In Scotland, read Age Scotland's factsheet *Paying for care and support at home*. In Northern Ireland, contact Age NI.

Day centres

Day centres can be good for both you and the person you care for. They allow you to have a break from each other and can 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 you need time to yourself, and many people enjoy day care once they've settled in. A variation in routine can benefit you both.

Ask social services if the person you care for can attend a day care centre. Day centres can provide company and activities, and sometimes facilities like hairdressing and chiropody. They can also offer you a regular break from caring. There are some specialist dementia day care centres, while others may cater for people with mild dementia.

Try 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 for the person with dementia when they first go along. 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 staff if they seem upset or unhappy about going. 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.

Respite care

If you need a longer break from caring, your local council has a duty to arrange services that help you do this. This is known as respite care. It may include services at home, day care or residential care.

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

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To find out more information about respite care, contact Carers Trust (see page 38).

Your local Age UK

Your local Age UK may be able to offer help and support. Different Age UKs offer different services. These include:

- benefits check and help with filling in claim forms
- befriending services
- ‘home from hospital’ services
- respite services
- equipment hire – like wheelchairs or commodes
- nightsitting (this can have a high cost)
- handyperson services
- signposting to other services.

Call Age UK Advice on 0800 169 6565 to find your local



Age UK, or visit www.ageuk.org.uk/local. In Scotland, contact Silver Line Scotland (see page 36). In Northern Ireland contact Age NI.

Communicating with someone with dementia

As dementia progresses it affects people's ability to communicate, making them more likely to express themselves through their emotions. As their carer, chances are that you are best placed to understand them but you may need to learn new ways to understand and communicate with them.

- 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.
- Speak clearly and slowly, using simple language and short sentences.
- People with dementia can find choice confusing, so keep it simple. 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.
- Try not to get into arguments about what they say, even if you think they're mistaken. Simply listening to what they're saying rather than correcting them or disagreeing can help someone feel acknowledged.

what next?

Read *Becoming a carer: a booklet about looking after someone with dementia* by the Mental Health Foundation (see page 41). It has ideas on maintaining and improving a relationship with someone who has dementia.

Your changing relationship

In the early stages of dementia, people's abilities are likely to remain relatively unchanged. Keep things as normal as possible and carry on doing things you both enjoy. Do things with the person, rather than for them, so they can stay involved in daily household life. It's important not to patronise them, or try to do too much for them. They may still be able to complete a task but just need more time.

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 your partner, you may find yourself feeling more like a parent than a spouse. The Alzheimer's Society factsheet *Sex and dementia* looks at ways in which people can adapt so that they remain loving and close to their partner.

Health matters

It can be easy to assume that any distress or discomfort in the person you care for is due to dementia, when in fact there could be a physical problem causing it, such as constipation, toothache or arthritis. Always 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 working if they use them.

See our guide *Healthy living* to find out about important health tests. Medical practitioners and opticians can adapt their techniques to suit people with dementia. Read our guide *Bladder and bowel problems* to find out more about continence issues.

Going into hospital

If the person you care for has to be admitted to hospital, it can be bewildering and disorientating, especially in the accident and emergency department. You can help make sure they get the best care possible.

Ask who the named nurse is – they are responsible for coordinating the person’s care as an in-patient. Tell them and other staff that the person has dementia. Ask to be involved in decisions and kept informed. And if you have power of attorney for the person, it’s a good idea to make sure the hospital is aware of this too (see pages 17).

Write down important facts about the person with dementia and give them to the named nurse. Include how the person’s dementia affects them, and ways that ward staff can help or communicate with them. Tell them how the person prefers to be addressed – as ‘Jean’ or ‘Miss Brown’, for instance – as well as what practical help they need and their likes and dislikes, such as what they enjoy eating and drinking. Carers know what works best for the person they care for, so listening to you can ensure patients feel secure and are treated with respect, and save staff a great deal of time. If the person has an advance statement or advance decision to refuse treatment, it’s a good idea to make sure the hospital is aware of this (see page 19).

A leaflet called *This is me* from the Alzheimer’s Society gives you space to write about the person’s hobbies and interests, things that may upset them, their personal care and mobility, sleep patterns and other relevant information.

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Download *This is me* from www.alzheimers.org.uk/thisisme or call 01628 529 240. Read the Alzheimer’s Society’s factsheet *Care on a hospital ward* and see our guide *Going into hospital* for information about a hospital stay.

Creating a memory book

A memory book or life story book can help someone with dementia remember special times. It is a collection of information, mainly photos, to represent happy events like weddings, the birth of children or holidays. The whole family can help contribute to making it. Photos may trigger memories in the person with dementia, and the book can help health and social care professionals appreciate their life and understand their past experiences.

Dementia UK has a template for making your own memory book. Download it from www.dementiauk.org/information-support/life-story-work/

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 17-19), they'll be reassured that their preferences are known and 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 problems 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 30). However, not everyone is affected in the same way or to the same degree.

Behaviour that challenges you

People with dementia sometimes behave in puzzling ways that are out of character, particularly if the part of the brain that controls emotions is affected. You may feel hurt, embarrassed or angry when this happens. Remember this is part of the illness. Getting into arguments isn't helpful – it may be better to distract them, or simply leave them to get on with it if they're not in danger or distressed.

Unusual behaviour may include agitation, rocking, calling out the same word, experiencing hallucinations, and movements such as wringing their hands or pulling at their clothes. It can include aggressive behaviour, either verbal or physical. The person is probably trying to communicate something so it may happen when they are frightened, frustrated, bored or in pain. You may also find that people with dementia lose their inhibitions, self-control or judgement as a result of the dementia.

Speak to the person's GP to get a referral to your community mental health team, if you're not already in touch with them. Talk to other carers about how they tackle difficult behaviour to see if you can learn from them. You can also call the Dementia UK Admiral nurse helpline for advice (see page 40). Remember that sometimes the distress and confusion may be caused by health needs other than dementia. Make sure the person has regular sight and hearing tests, and dental and GP check-ups (see page 27).

what next?

The Alzheimer's Society's factsheet *Dealing with aggressive behaviour* has useful information including how to react, working out triggers, and dealing with your own feelings.

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 the person with dementia is becoming harder to care for, a care home can be the best option for both of you.

what next?

See our free guides *Care homes*, *Care home checklist* and *Housing options* for more information. Read the Alzheimer's Society's factsheet *Selecting a care home too*.

'My mother's experience of dementia is not how I imagined it – I thought she might become violent, aggressive or anxious, but she hasn't.'



If the person you care for moves into a care home

Carers can experience mixed emotions if the person they care for moves into a care home. You may feel guilty, relieved, lonely, tired, redundant, or a mixture of all these. Take it easy, and remember there is no right or wrong way to feel. If your routine revolved around being a carer, try to find some other structure to your day.

If you still want to be involved in caring, there are many ways you can ensure the person receives the best possible care. You can ask to be actively involved in the person's care and to be included in any decisions. For example, you may be able to visit several times a week and help out at mealtimes. Give the staff information about likes, dislikes and behaviour, perhaps recorded in a *This is me* leaflet (see page 28). Bring in belongings that mean a lot to them. Ask if the care home has a group for relatives.

Although familiar furniture, belongings, and music can help, it can take a while for someone to settle into a care home. However, if you have any worries, start by speaking 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 it, 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 *Local authority assessment for community care services in Wales*. 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.



Contact the Relatives and Residents Association (see page 42), which supports care home residents and their relatives. They have a helpline and a network of local groups.

End of life care

People 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 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 19).

If you're caring for the person with dementia at home, speak to your GP about local services available to support you to continue to care 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.

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 39). If you're feeling particularly low or anxious, talk to your GP.

It takes 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 website has a section called 'After dementia – dealing with loss' that you may find helpful.

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

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

In Wales, contact

Age Cymru: 0800 022 3444

www.agecymru.org.uk

In Northern Ireland, contact

Age NI: 0808 808 7575

www.ageni.org

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

www.agescotland.org.uk

Alzheimer's Society

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

Helpline: 0300 222 1122
www.alzheimers.org.uk
www.alzheimers.org.uk/wales

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

Helpline: 028 9066 4100
www.alzheimers.org.uk/northernireland

In Scotland, contact **Alzheimer Scotland**

Helpline: 0808 808 3000
www.alzscot.org

AT Dementia

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

Tel: 0115 748 4220
Email: info@trentdsdc.org.uk
www.atdementia.org.uk

Care and Social Services Inspectorate Wales

National regulatory body of care and social services in Wales. Can provide lists of care homes for a specific area, care home inspection reports and domiciliary care providers.

Tel: 0300 7900 126
Email: cssiw@wales.gsi.gov.uk
www.cssiw.org.uk

Care Inspectorate

Independent scrutiny and improvement body for social care and social work services in Scotland.

Tel: 0345 600 9527

Email: enquiries@scswis.com

www.scswis.com

Care Quality Commission (CQC)

National independent regulator of all health and social care services in England. It can provide lists of care homes for a specific area and care home inspection reports.

Tel: 03000 616161

Email: enquiries@cqc.org.uk

www.cqc.org.uk

Carers Direct

Government organisation offering help and support to carers.

Helpline: 0300 123 1053

www.carersdirectenquiry.nhs.uk/newcarersemail

Carers Trust

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

Tel: 0844 800 4361

Email: info@carers.org

www.carers.org

Carers UK

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

Helpline: 0808 808 7777

Email: advice@carersuk.org

www.carersuk.org

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

Cruse Bereavement Care

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

Tel: 0844 477 9400

Email: helpline@cruse.org.uk

www.crusebereavementcare.org.uk

In Northern Ireland, contact:

Cruse Bereavement Care Northern Ireland

Tel: 0844 477 9400

www.cruse.org.uk/northern-ireland

In Scotland, contact:

Cruse Bereavement Care Scotland

Tel: 0845 600 2227

www.crusescotland.org.uk

Dementia UK

Works to improve the quality of life of people with dementia. Contact them to find out if you have an Admiral Nurse service in your local area.

Admiral nurse helpline: 0845 257 9406

Helpline email: direct@dementiauk.org

Tel: 020 7697 4160

Email: info@dementiauk.org

www.dementiauk.org

Disabled Living Foundation

Runs an equipment demonstration centre and provides information about equipment for daily living.

Tel: 0300 999 0004

Email: info@dlf.org.uk

www.dlf.org.uk

www.allaboutequipment.org.uk (can help you decide on suitable equipment for independent living)

Driver and Vehicle Licensing Agency (DVLA)

Maintains a register of drivers and vehicles, and provides information for drivers. To report a medical condition, contact:

Tel: 0300 790 6806

www.dft.gov.uk/dvla

Gov.uk

Official government website, providing information on public services such as benefits, pensions and health services.

www.gov.uk

In Northern Ireland, visit **NI Direct**

www.nidirect.gov.uk

Law Society of England and Wales

Helps people find a solicitor, advises on what to expect when they visit one and produces guides to common legal problems.

Tel: 020 7320 5650

www.lawsociety.org.uk

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

Tel: 028 9023 1614

www.lawsoc-ni.org

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

Tel: 0131 9023 1614

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

NHS Choices

Find out about local NHS services in England and get information to help you choose which hospital to go to for treatment. Provides information on a wide range of health conditions and advice on keeping healthy.

www.nhs.uk

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

NHS Inform

National health information service for Scotland providing general information on medical conditions and patient rights.

Tel: 0800 22 44 88

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

Email: customerservices@publicguardian.gsi.gov.uk

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

In Northern Ireland, contact **Office of Care and Protection**

Tel: 028 9072 4733

www.courtsni.gov.uk

In Scotland, contact

Office of the Public Guardian (Scotland)

Tel: 01324 678 300

www.publicguardian-scotland.gov.uk

Regulation and Quality Improvement Authority

Has similar responsibilities to those of the CQC (page 38) in Northern Ireland.

Tel: 028 9051 7500

www.rqia.org.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

Email: info@relres.org

www.relres.org

Wales Dementia Helpline

Offers confidential emotional support and advice from trained volunteers.

Tel: 0808 808 2235

www.dementiahelpline.org.uk

Can you help Age UK?

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

Personal details

Title:	Initials:	Surname:
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Address: _____ _____	Postcode: _____
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Tel:	Email:
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By providing your email address and/or mobile number you are agreeing to us contacting you in these ways. You may contact us at any time to unsubscribe from our communications.

Your gift

I would like to make a gift of: £

I enclose a cheque/postal order made payable to Age UK

Card payment

I wish to pay by (please tick) MasterCard Visa CAF CharityCard
 Maestro American Express

(Maestro only)

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

Gift aid declaration

(please tick) Yes, I want Age UK and its partner organisations* to treat all donations I have made for the four years prior to this year, and all donations I make from the date of this declaration until I notify you otherwise, as gift aid donations. I confirm I pay an amount of income tax and/or capital gains tax at least equal to the tax that the charity will reclaim on my donations in the tax year. Date: ___/___/___ (please complete). *Age Cymru, Age Scotland and Age NI



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

Supporting the work of Age UK

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

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

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

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** and enter your postcode into the ‘What does Age UK do in your area?’ search function. Alternatively, call us on **0800 169 8787**

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

Thank you!

What should I do now?

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

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

The following Age UK information guides may be useful:

- *Advice for carers*
- *Healthy living*
- *Living with early-stage dementia*

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**.

