

Let's talk about dementia

21 things everyone
should know



For family carers

Welcome



Do you have an older loved one who has recently been diagnosed with dementia? If so, this is likely to be a worrying and uncertain time for everyone involved, particularly if it's the first experience your family has of dementia.

You may be wondering what to expect in the months and years to come.

How will your loved one change?

How will you cope?

In this, the sixth guide produced by Care UK to help families and friends understand and support people living with dementia, we've used the real life experiences of relatives of Care UK residents living with dementia*, plus the knowledge of our experienced home

managers, to tackle those common scenarios and frequently asked questions that families experience as they navigate their loved one's journey through dementia.

Some of these scenarios may echo your experience, while others may not. Nevertheless, we hope that this guide helps you to understand what to expect, why your loved one might be behaving differently, what you can do to support them and where you can find support and advice.

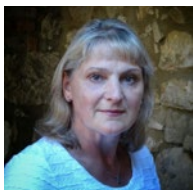
*The relatives' experiences come from an online survey we ran in February 2021 with 227 relatives of Care UK residents who were living with dementia. Research was conducted by QRS Ltd, an ISO and MRS-accredited market research company.

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Foreword from Suzanne Mumford

Care UK's Head of Nursing,
Care and Dementia



In the past, dementia was a much-misunderstood condition that was often hidden from view. Today, while we sadly don't yet have a cure for dementia, we do have the knowledge to help those who have it to live fulfilled and happy lives.

A dementia diagnosis can come as a shock or as confirmation of a worry you have had for some time, but please don't see it as 'the end'. I always encourage relatives to look upon a diagnosis as an opportunity: a chance to say the things you want to say to your loved one and to do the things with them that you want to do. It's also a chance to enjoy each day together for as long as you're able

while adapting to meet yours, and their, needs and abilities along the journey.

I also want you to know that you're not alone. There are thousands of people experiencing the same or similar challenges as you are right now, and there are thousands of people – and scores of organisations – who can help. At the back of this guide we've included

a list of sources where you can find help and support. Remember too, that the team at any of Care UK's care homes will be happy to answer your questions or point you to someone who can.

We'd like to thank all those who have contributed to this guide, including the many relatives who took part in our survey and the Care UK home managers who have shared their expertise.

"Relatives are often surprised at how much joy people with dementia can still feel. Your loved one may still have aspirations and dreams. So take each day as it comes, avoid having any expectations of them, and you might be amazed at what they achieve."

**Kirsten Bell, Home Manager,
Mowat Court, Stonehaven**



Introduction

What is dementia?

The Alzheimer's Society describes dementia as a set of symptoms that, over time, affect memory, problem solving, language and behaviour.

There are many different types of dementia – each with its own set of symptoms. And because dementia affects the brain, and therefore an individual's unique personality and memory, the experience of living with dementia is thought to be different for every person who is diagnosed with it.

However, common early signs include memory loss, difficulty concentrating or planning, problems with language and communication, confusion about time or place and difficulty controlling emotions.



The best care is personalised care

At Care UK we take huge pride in delivering high quality, responsive and dignified dementia care that's tailored to your loved one's needs.

By personalising our approach to every interaction with your loved one, we can ensure that they feel loved and valued, and that they experience the best possible quality of life.

How do we deliver such personalised care? In short, with your help.

Our starting point is the life history book that we complete with each new resident and their family. Relatives sometimes wonder why we focus so much on completing these books. The fact is, your loved one's life history details their unique life story, including the jobs they've had, the holidays they've enjoyed, the places they've lived, and the hobbies, family, friends and pets that are, or have been, important to them.

This information is crucial to enabling us to create care and lifestyle plans, and even menus, that will fulfil your loved

one's needs, interests and wishes. It shows us how to help them to enjoy each moment and how to soothe and distract them when they experience feelings of anxiety, agitation and sadness.

We recognise that you know more about your loved one than anyone: their likes, dislikes, routines, and the small signs that show when they are upset, angry or distressed. Quite simply, we need your help, as the better we know your loved one, the easier it is for us to give them the best possible loving care.



Make it meaningful

When a person with dementia is enabled to take part in activities, hobbies and experiences that they enjoy, this calms feelings of agitation, sadness and distress and is likely to spark happy memories – all of which boosts wellbeing and positive emotions.

Care UK homes focus on supporting all residents to enjoy fulfilling lifestyles. Using their life history book that's unique to every resident, we plan one-to-one and small group activities as well as entertainment and outings that each person will love. We even fulfil residents' wishes if there's something they'd like to achieve – from skydives to meeting the Pope.

“Play to a person's strengths and abilities. There's still so much that people with dementia can do, so focus on those things and make the most of them.”

**Jon Sneath, Regional Lifestyle Lead,
Care UK**

Choice is all-important. Residents are welcome to do light domestic tasks around the home which can help them to have a sense of purpose. Others love using the various facilities on offer in many of our homes, including cafés, cinema rooms, pubs and hair salons.

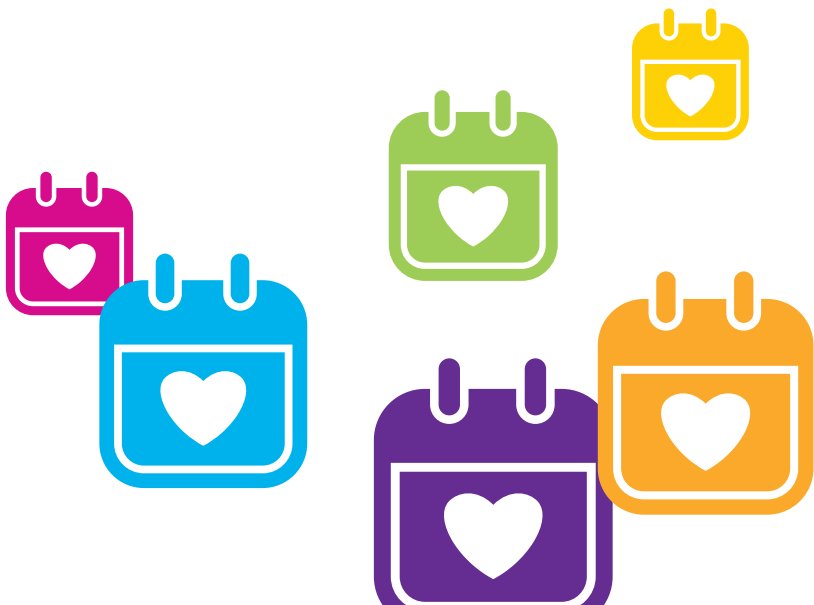
Further reading

Dr Nori Graham, Care UK's Specialist Advisor in Mental Health and Dementia, is co-author of 'A pocket Guide to Understanding Alzheimer's Disease and other dementias'. You can download a copy at careuk.com



Chapter one

Early days



1 My father seems lucid much of the time. Might there have been a mistake with his diagnosis?

It's unlikely that there's been a mistake but you may want to pursue a second opinion for your own peace of mind.

Dementia is a **progressive disease** and different types of dementia progress in different ways. For example, Alzheimer's tends to have a slow progression, while vascular dementia usually involves sudden changes. Whichever type of dementia your father has been diagnosed with, it sounds like he is in the early stages, so his symptoms may be less pronounced.

This is a great time to help your father to keep his brain and memory, as well as his overall health and wellbeing, in as good a shape as possible. Supporting him to do hobbies he's always enjoyed, to stay physically and mentally active and engaged is crucial and can help **slow the progression** of dementia.

It's important to remember that normal ageing slows our ability to process information, and this can be made worse if we are stressed, tired or in pain. This is the same for a person with dementia, although their responses may be more exaggerated.

"It can be so hard to see a person who you've looked up to all your life, someone who was always in charge, becoming vulnerable. The key is to understand that a person with dementia can change from day to day, moment to moment."

**Maureen Barrett, Home Manager,
Tor-Na-Dee, Aberdeen**



Top Tips

If your loved one has enjoyed quizzes, crosswords and puzzles all their life, encourage them to keep doing them, as these are perfect for ensuring their brain stays active.

2 My mum is refusing to accept her diagnosis of Alzheimer's. She's already doing things that are causing us concern for her safety, but she simply refuses to talk about the future.

Your mum is most likely feeling extremely afraid, depressed and even ashamed. Taking a **gentle approach** to find out what she's feeling may achieve a breakthrough. Stay positive about the future; don't get angry or force a conversation if she's not ready. It may be that she is more prepared to open up to a friend, another relative or even her GP.

However, many people never accept that they have memory problems. If this is the case for your mother, you may need to adapt your approach rather than try to make her understand.

Dementia UK runs an Admiral nurse helpline (**0800 888 6678**), and the Alzheimer's Society has various forums, all of which you may find

useful. Contact your local Care UK care home as the team there will be very experienced in this issue.

In our survey...

64% of the relatives we spoke to said they wish they'd known more about the possibility of their loved one denying, or being reluctant to accept, that anything's wrong.



Top Tips

Local dementia cafés and dementia action alliances are a fantastic source of information and support, and places to meet people experiencing the same challenges as you. Many of our homes run dementia cafés when open to visitors, or you can talk to your local Age Concern branch to find out what's available in your area.



3

How long will it be before my loved one can't cope alone?

Some types of dementia progress faster than others, and then there's the individualised nature of dementia – all of which makes this question difficult to answer. Some people live well with dementia for many years while others can have progressed to advanced dementia within 18 months.

Take time to learn more about your loved one's type of dementia, and give

yourself time to come to terms with the diagnosis. People with dementia have good days and bad days, so relatives can find it easier to cope by being in the moment with their loved one – enjoying happy times together on the good days, and recognising, on the bad days, that they don't last.

Care UK has Dementia Champions in each of its homes, as well as a central Approach to Care team, all of whom are an excellent source of information and support and are very happy to help you.





Top Tips

To help you feel more in control of the situation, you may want to explore the practical considerations. Will you or your loved one's house need to be adapted? What are the care options in your area if you need more help with your loved one's care? Do you have Lasting Power of Attorney documents in place to help manage your loved one's health and finances?

"In our relative support group, grown up children often say how strange it feels to be taking responsibility for their parent's finances. It's a significant shift for families to make."

**Gill Dunn, Deputy Manager,
Bishops Manor, Sutton Coldfield**

In our survey...

**More than a third, or 36%,
of relatives said they found their
loved one's struggle to manage
everyday tasks and thoughts the
hardest part to deal with.**

4 What can we do about Mum's tendency to walk?

It's very common for a person with dementia to 'walk with purpose'. This is often referred to as wandering, but few of us walk without a goal in mind, even if it's simply to get a breath of fresh air. Your mum may be searching for something she thinks she's lost, for example. If she lives with you, can you channel your mum's walking into something **meaningful** – going for a regular stroll together, or getting out into the garden?

If she's leaving the house on her own it's a good idea to ensure she has a mobile phone with her so she can make contact, or to enable you to track her location. It's also useful to have a card in her purse or handbag that has her name and an emergency number.

If you feel your mum is no longer safe, it may be time to look at different care options. In a well-designed care home, she can continue to walk with purpose and explore destination points around

the home where she can find **safe and engaging activities** to enjoy. Care colleagues will be trained to recognise this walking as a need to be actively engaged, and will support your mum to take part in activities or meaningful tasks. There will also be secure gardens and outside areas where she can still walk but remain safe.



"One of the big selling points of Appleby House is the physical freedom that residents with dementia have to explore the home and gardens independently. They can browse in our shop, have a drink in our café, and enjoy activities that are happening on other suites. Residents are relaxed and happy exploring at their own pace."

**Shona Bradbury, Home Manager,
Appleby House, Epsom**



Top Tips

Keeping the layout the same around the house will enable your loved one to stay independent and find the things they need. Consider putting labels or pictures on cupboard doors to remind them of what's inside.



Chapter two

Companionship and affection



In our survey... 49% of relatives said they found most challenging the feeling that their loved one had become a different person.

5 My dad's started a relationship with another resident in his care home. They hold hands and kiss. Is this normal?

What surprises many relatives is that their loved one still has a need for companionship and physical affection. These are basic human needs that we all have, whatever our situation.

When faced with the likely isolation of living with dementia, it can be understandable that a person may seek out the physical and emotional comfort, affection and sense of security another person can provide. If your loved one has had a lifelong partner it will seem completely natural to have a close relationship with another person – they may even think the other person is their lifelong partner.

Some families are happy for their loved one to form a new relationship while others aren't. Either way, we always assess the situation, the best interests of the people involved,

and work sensitively with families to find the best outcome.

"Every Care UK home runs regular Namasté sessions which involve a trained carer delivering individual caring touch – for example, a foot or hand massage – to small groups of residents who are living with advanced dementia. Receiving caring attention from another person can be hugely powerful, giving the resident the affection and reassurance they need so they feel valued."

Suzanne Mumford, Head of Nursing, Care and Dementia, Care UK



6 When I visited the other day, Mum was cradling a doll and talking to it. Why is she playing with dolls at her age?

Doll therapy – cuddling and caring for a lifelike doll – is a proven, drug-free way to soothe the agitation, isolation and sadness that can be associated with living with dementia. While it may look like she’s playing with a doll, your mum is re-engaging with the emotions – the joy and wellbeing – that she experienced when caring for you.

As well as bringing back happy memories of parenting, caring for a ‘baby’ can provide a person who is living with dementia with a strong sense of purpose. They may take over its care: dressing it, feeding it and pushing it around in a pram. This can have huge all-round benefits, encouraging them to eat, socialise and communicate.

For the same reason, cuddly animal toys can be popular with people with dementia. On the most basic level, the

act of stroking a pet’s fur is known to soothe, and lower the heart rate. Many people have had much-loved cats, dogs and other pets during their life and miss the companionship.

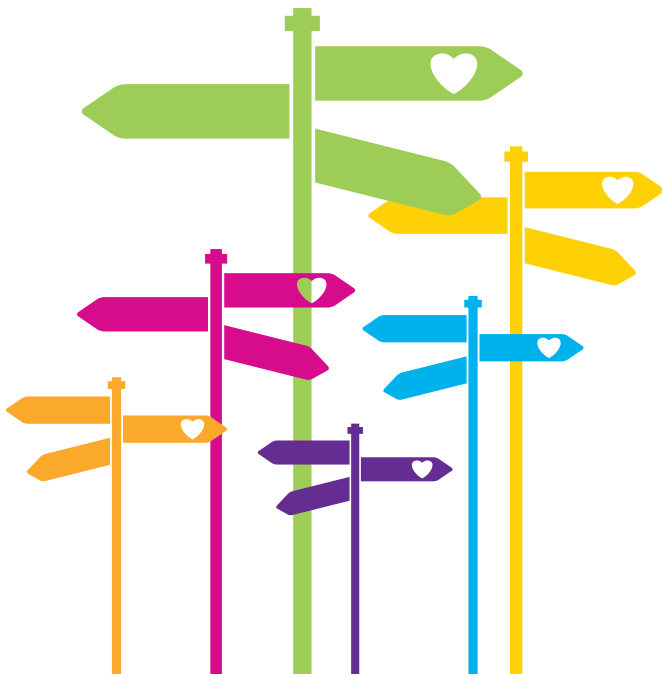
We regularly invite therapy animals into our homes for visits. And many Care UK homes have their own pets, which residents enjoy caring for. It’s incredible to see residents with dementia – who may usually be withdrawn or unable to communicate – suddenly smile and start stroking a friendly cat, dog, rabbit or guinea pig.



If a loved one has formed a connection with a doll or toy that they believe is real, it’s important that you treat it as though it’s real too. Handle the doll like you would a baby and ask your loved one how the baby is.

Chapter three

Changes in behaviour





Jude
careix

7 My mum has started being physically aggressive. She swears and sometimes shouts at me. This is utterly out of character.

Dementia can damage the areas of the brain that deal with verbal communication and inhibitions. This can mean they lose their judgement around social norms and start behaving in a way that may seem shocking and out of character.

While it's hard to adjust to, this is your mum's new way of communicating. She's alerting you to her frustration or that something else is wrong – for example, she might be in pain or be bored, her surroundings might be too noisy, or there may be too many strangers (visitors) around, causing her to feel unsettled.

It's therefore important not to take this behaviour personally. Stay calm and don't challenge her, as this will only cause your mum more confusion and distress. Can you put some music on that usually calms her, or divert the

conversation to a familiar topic? If she is in a noisy or busy space, can you go somewhere quieter?

In our survey...

71% of the relatives we asked wish they'd known more about the increased anxiety levels and mood swings that their loved one would experience with dementia.

"When we admitted a resident with a history of displaying extreme distress, we found out all about him, with his family's help. We have created a relaxing, tailored environment for him where we play his favourite music and, knowing that he dislikes television, we've removed the one from his room and the TV in the lounge is switched off whenever he's walking around the suite. He's displayed no extreme behaviours since he joined us."

**Katherine Matthews, Home Manager,
Perry Manor, Worcester**



8 Mum has started to take off her socks and slippers and hide them, as well as other possessions – even food. Why is this happening?

Lost items of clothing and hearing aids is one of the most common issues relatives talk to us about. People with dementia remove clothing for various reasons: they're hot or uncomfortable or they may not like them. They may experience sensations like itching or numbness due to the changes in their brain. While we can't resolve these sensations, they will feel very real to the person with dementia and they may remove clothing to try to stop the feeling.

People with dementia sometimes remove clothing because the damage to their brain means they've lost their inhibitions. If this happens in a communal area of a home, we gently escort them back to their room to get dressed, or quickly pop up a privacy screen to maintain their dignity while we help them.



Why do people with dementia hide things? Most likely, they're trying to make sense of their reality and establish some control over it. It could be that they don't know what to do with the items, they want to throw them away or they want to put them somewhere safe. A person who walks with purpose may be searching for something they've put away for safe keeping. We've all put something down, then been unable to find it, only to have it turn up in the most unlikely place.

If your mum seems to want to go barefoot, it's important to accept that it's her choice. If she often hides things, keep anything of sentimental or monetary value somewhere safe.



“Several residents always walk around barefoot. We’ve encouraged them to wear socks, shoes or slippers, but these always come off. Many people kick off their shoes when they get home – I know I do. That’s may be all it is.”

**Angie Bookham, Home Manager,
Broadwater Lodge, Godalming**

9 Around three or four o'clock each afternoon my normally inactive mum completely changes. She'll start pacing and will become anxious. She'll also often ask when Dad will be back from work (he died ten years ago). What's going on and what can I do?

Sundowning syndrome is associated with dementia and is often triggered by the changing light and the time on the clock. However we need to look at other cues to understand a person's behaviour. Your mum may have a longstanding memory of expecting

your dad to come home, ensuring his dinner is ready and looking forward to their evening plans. Other people say they have to go and collect the kids from school.

In these circumstances it's often best to copy the activity that they would normally have done at this time, perhaps going for a walk to "meet the children from school" or making supper together. These tasks will engage the person in a meaningful activity and they'll often be distracted from the original thought that was causing anxiety.





Should you lie to your loved one? Lying to a person may affect your relationship. However, telling your mum the truth – that your dad is dead – can be devastating if she has forgotten. It's essential to understand the importance of not pulling a person with dementia into your reality if that will cause them emotional distress.

We all take time to grieve, and after a lifetime together it will be understandable if your mum has forgotten your dad's death and finds it difficult to accept.

Care UK's Approach to Care Leads are happy to help you to identify when this 'therapeutic lying' is the only course of action.

"I've cared for a lady who was a night nurse for many years. In the care home she was often awake late into the night, most likely because, in her mind, she'd returned to this time. Sundowning syndrome or changes in a person's normal day/night rhythms may also be the result of tiredness, hunger, thirst or pain so try distracting your loved one with a drink, a snack, an activity, or some music. Always maintain a soothing, reassuring approach."

Jon Sneath, Regional Lifestyle Lead





10 My dad has always been so well presented, but now refuses to bathe and will only have a quick shower once a week.

In a Care UK home his carers would gently explain to him the benefits of more frequent washing, but, ultimately, if this is what makes him happy, and it's not causing a risk to his health, then it's important to **respect his choice**.

This is a good example of how understanding your dad's early life might be helpful in accepting his attitude now. For example, it's only since the arrival of indoor bathrooms in the 1960s that daily showers have become the norm. When your father was young it could be that the only loo was a chilly outdoor privy and the kitchen tap was the only source of fresh water in the house. Many people only had a proper wash once a week.

If your dad's dementia has reached a point where his clearest memories are of his early life, it may explain his disinterest in personal hygiene.

While there's nothing particularly wrong in washing less often, we do advise keeping an eye on the condition and integrity of your dad's skin as older skin is more vulnerable to damage or infection.



"One gentleman used to take huge pride in his appearance, but has become increasingly resistant to showering. He will now only allow his daughter to shower him. He can't remember her name, but he recognises her voice and trusts her. It means she still has an important role to play in his life. They still have a relationship. It's just a different one now."

**Zita Turner, Home Manager,
The Potteries, Poole**

"When you know a person well, you can find ways to lift their mood which will make it easier to support them with things like personal care. We care for a lady who loves the music of Tom Jones. We put the music on and have a chat and she's then more relaxed about having a shower."

**Sarah Diamond, General Manager,
Bishops Manor, Sutton Coldfield**

11

Why does my mum call me by her sister's name? She also asks me where her mum is, and I don't know how to respond. It's so upsetting that she no longer seems to know me. Is there any point in visiting anymore?



Unfortunately, as your mum's dementia worsens her more recent memories will become ever more patchy, while her older memories will be more lasting. One of the key things to remember when a person has dementia is to **be in the moment and in their reality with them.**

It's likely that your mum's reality is now based in her earlier life, when her mum was still alive, and she's doing what all children do – asking for her mum. **People with dementia may lose memories but they don't lose feelings.** When she sees you, your mum will still feel love for you and will feel safe with you, even though her memory of who you are is confused.

It's also important to remember that there are a number of difficult questions that people with dementia ask which will link into their emotional state and feelings. Most commonly when someone is feeling sad, lonely, or in pain they often ask for their mum, so finding out if something hurts, or supporting your mum with something she likes doing, and asking if she used to do this with her mum, may alleviate her distress.

"It's not who you are that matters now. It's how your loved one feels when they're with you."

Gill Dunn, Deputy Manager, Bishops Manor, Sutton Coldfield

“Residents with dementia often ask for their mum or dad. It’s important to minimise their distress. We all tell “white lies” at times, but we need to exercise caution. Therapeutic lying has a place, but a more general ‘I don’t know, but I can find out’ may be enough.

When a person’s dementia progresses to a point that they no longer recognise family members it can be extremely painful for those relatives, making it natural to question the point of visiting. If you can cope emotionally with visiting your loved one, we do encourage you to keep doing so because your loved one will benefit from the positive feelings from your visit.”

**Sharlene Von Tonder, Home Manager,
Heathlands House, Cambridge**

12 Sometimes when I visit his care home, Dad tells me he's been left alone all day, hasn't eaten anything and is bored and lonely. I know this isn't the case so why does he do this?

Anxiety and fear are commonly experienced by people with dementia and their short-term memory loss can mean they forget things they've just done, people they've just seen or meals they've just eaten. They will look for reassurance and feelings of safety from people they trust – loved ones – all of which may explain your dad's comments.

Understandably, if a loved one has just moved into a care home and you hear these comments you may worry that mum or dad isn't getting adequate care. If you are concerned, you should always ask a member of the team. It's vital that you **trust the team who are caring for your loved one**, and carers should reassure you by showing photos or other evidence of activities that your loved one has been doing or food they've been enjoying.

At Care UK the teams in our homes use the Relish app which families can access to see the activities their loved one has been doing.

"Our team takes an honest, open and transparent approach, always giving relatives frequent feedback about how their loved one is getting on physically, mentally, emotionally and socially."

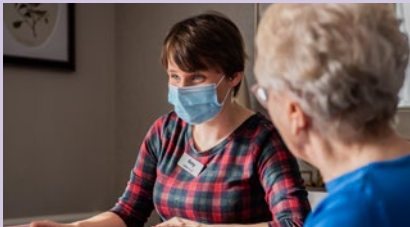
Sharlene Von Tonder, Home Manager, Heathlands House, Cambridge

Top Tips

The life history book we create with every new resident and their family is a living document, capturing details of the person's past – and their present, including the activities they continue to enjoy. Many relatives use their visits to update these books with their loved one, helping them to remember the positive feelings from the activities.

13 I made a vow to care for my wife 'til death do us part'. I feel so guilty that I'm no longer able to care for her, and she's had to move into a care home. Every time I leave her after a visit I'm wracked with guilt.

Please be reassured that your feelings are absolutely natural, normal and understandable. Dementia is an extremely complex disease and its symptoms can feel overwhelming to manage on your own.



We support many spouses and partners who feel the same way as you. As time goes on, they start to see the positives of their loved one's move into a care home. It may have been years

since you felt like your wife's husband, rather than her carer. Now, free from all the responsibilities of care, you and she can rediscover your relationship.

The team at your wife's home will also introduce you to relatives of other residents and may offer you the chance to do dementia training, enabling you to understand more about your wife's condition. Free from the pressures of care, and with more moral support and knowledge of dementia, we hope you'll start to feel more reassured.

"I run regular dementia training sessions for residents' relatives. As well as building relatives' knowledge and confidence in navigating their loved one's condition, the sessions bring people together who are going through the same experiences and emotions. You can feel relatives' relief when they realise they're not alone, and they go on to develop friendships and support groups."

**Donna White, Head of Dementia,
Perry Manor, Worcester**

14 My aunt has been a keen church-goer for many years but since she moved into a care home, she seems to have lost her faith.



A good care home should know all about your aunt's faith and support her to attend appropriate religious services. Carers should also give her the opportunity to talk about her religion if she wishes to.

Care UK teams work hard to help residents of all faiths maintain their religious routines and rituals. Where and when appropriate, religious leaders are warmly welcomed into

care homes to hold services for groups of residents or share individual prayers and blessings.

However, despite gentle encouragement, we do sometimes find that residents who were previously religious, now don't want to get involved. We also find it happens the other way around: that people who haven't had a strong faith during their life then become religious. It's important to respect an individual's personal choice, to adjust and accept the changes.

Top Tips

Supporting your loved one to stay connected to their community – whether it's a favourite place of worship, or a local group like the WI or Rotary – will help to preserve their self-esteem and confidence, spark happy memories and maintain their communication skills.



Chapter four

Diet and appetite



15 My aunt has been a strict vegetarian all her life, but I visited her yesterday and she'd had roast chicken for lunch. What's happening?

Research shows that dementia leads to a deficiency in the vitamins contained in meat, leading the body to crave it. Couple this with a person's potential inability to remember some of their long-held beliefs and you can see how a person who has been a vegetarian for a long time may suddenly change what they want to eat. However, the team in your aunt's care home should be well prepared to plan and create dishes designed around her tastes, needs and beliefs so her past choices can be respected and maintained.

The challenge can come when someone living with dementia wants to eat what others in the dining room are having. When this happens in a Care UK home, our team will gently explain to the resident that they're a vegetarian or have different cultural beliefs, and offer them the appropriate dishes. However,

the resident may insist that they want to eat something new or different. In that case, we would support their **freedom to choose**.

With the variety of plant-based meat alternatives that are now available, it should be possible for your aunt to eat a vegetarian option that she's happy with.

At Care UK, our chefs are skilled in helping all residents to meet their needs, whether a person has certain religious or cultural beliefs that affect the foods they eat, or if they have an allergy or special nutritional needs.

"We cared for a lady with dementia who stopped eating altogether at one point. Working with her family, we realised that, in her reality she'd returned to her twenties. This was a time when she had been anorexic for a long time. We researched how to encourage a person with anorexia to start eating again."

Donna White, Head of Dementia Care, Perry Manor, Worcester

16

My mum has dementia and we do our best to give her nutritious meals but she's lost all interest in my home cooked meals and just wants to eat crisps and biscuits.

Dementia and certain medications can impact a person's sense of taste, and age has a large part to play too – taste buds become less sensitive and even shrink with age. Food may taste different or bland, leading people to lose interest in meals they used to enjoy, or even losing their appetite completely. The desire to eat crisps and savoury biscuits, or developing a 'sweet tooth' may indicate a craving for things with a stronger texture or flavour.

An important area to be aware of is the **potential for choking** that dementia brings. This symptom, called **dysphagia**, leads to pain, an inability to swallow or the sensation of food getting stuck in the throat. A soft-texture diet can help ease the symptoms and dangers.

People with dementia may also forget to eat, or may think they've just eaten

a meal when they've actually not eaten all day. They may also walk with purpose, which will burn more calories. All of this means weight loss can be a risk. If your loved one has a small appetite, a good approach is to encourage them to have sweet food first, which will trigger their savoury tastebuds. Fortifying foods with cream and butter is also a good way to add extra calories to dishes.

Your loved one's GP can refer them to a dietitian who will help you to support them to get the right nutrition and hydration.



Top Tips

Care UK's Eating as we Age guide, available at careuk.com/help-advice/eating-as-we-age is full of tips to help you with a range of food and eating challenges.



Chapter five

Physical changes



17 My father was diagnosed with dementia some months ago and has rapidly become physically frail. Is something else going on?

It would be a good idea to have him checked over by his GP to put your mind at ease, however, dementia can lead to various physical, as well as mental, changes because it can affect parts of the brain related to movement and balance. People with dementia can gradually lose the ability to walk or stand, and will have a heightened risk of falling. Their vision can be affected too.

Certain types of dementia can result in physical symptoms as well. Vascular dementia, for example, may progress as a result of mini strokes, so talk to your father's GP so you know what to expect, and so they can treat the underlying cause, whether it is diabetes, high blood pressure or an abnormal heart rhythm. If your father has an **additional condition**, such as Parkinson's disease, this may also unfortunately speed up the deterioration.

Occupational therapists can advise on useful equipment and strategies to tackle everyday activities like getting dressed or washed, or moving around. Your father's GP or his local authority's social services team can help you access this support. There are things you can do to ensure your father's home is as low-risk as possible, including removing rugs and small items of furniture which may cause a trip hazard.



"Residents with dementia tend to walk with purpose, which puts them at greater risk of falls. We're always clear with relatives that, while we'll do our best to keep their loved one safe, we can't always prevent falls. We believe residents with dementia should have maximum independence as they're happiest that way, but being free to move around the home means a heightened risk of falling."

**Angie Bookham, Home Manager,
Broadwater Lodge, Godalming**

18

All Dad wants to do is sleep all day. Is this normal? Should I wake him?

If your father is in the early or middle stages of dementia his daytime sleeping could be the result of a disrupted wake-sleep cycle. This is more common with Alzheimer's and leads to napping during the day particularly as the damage caused by the disease means a person needs to 'think harder' to achieve activities that they used to find easy.

It's best to let your dad sleep when he needs to but try to ensure he gets plenty of exercise and stimulation during the day, and to create a calming time an hour before bedtime. It may be worth checking whether his bedroom is too warm or too light, whether he's consuming too much caffeine, or even whether his sleepiness is a medication issue. His GP can help there.

People with advanced dementia do tend to sleep more than usual. The brain is working harder to do normal

functions, and it's natural for the brain to try to repair damage. All of this means that your dad will be tired and will want to nap frequently during the day.



Top Tips

People often sleep if they're bored. Make sure you keep your dad busy by tailoring an activity he liked to do to his current abilities.

19 I'm dreading Dad becoming incontinent. How likely is it?

This will vary from person to person and depend on the type of dementia they have. It's helpful to be aware of your dad's normal toilet routine and to recognise the tell-tale signs that he needs to go. That way you should be able to support him to maintain continence for as long as possible. Most people will feel embarrassed about becoming incontinent and may try to hide it, so empathy and discretion are key, and it's crucial to **maintain your dad's dignity** at all times.

Make sure that your dad keeps well hydrated as this will help to reduce the incidence of infections or constipation, which can make symptoms worse.



In the advanced stages of dementia bladder incontinence is common and sometimes bowel incontinence too. If your dad is still living at home, talk to your GP or local pharmacy to help manage the issue. Our home teams will be happy to help too.

In our survey...

Nearly half - **46%** - of relatives said they had been unprepared for the speed at which their loved one changed. Some **41%** said they were least prepared for anxiety or mood changes.

Top Tips

Care UK runs regular free online information sessions on a host of different topics, including falls prevention and caring for a loved one who is living with dementia. Simply visit the website of the home nearest to you to find out when the next session is taking place.

20 My mother was born in Spain but has lived in the UK for most of her adult life and spoken good English. As her dementia has progressed, she has gradually forgotten how to speak English. I wasn't brought up bilingual, so I'm losing my ability to communicate with her.

As your mother's dementia worsens it's affecting the parts of her brain that deal with language and memory so she is reverting to her earlier abilities and knowledge. This is something our home teams see a lot with residents for whom English is a second language.

Do what you can to meet her where she is now, rather than forcing her to speak English. There are various apps available now that translate speech, so this may be an easy way to retain communication with your mum. Using picture cards that show everyday items and feelings may also be an option.



If she's in a care home there may be a member of staff who speaks Spanish. If not, does she have a Spanish-speaking friend or relative who can help you? Can you learn some of the basics of your mother's language? It may lead to some lovely moments with your mum which you'll treasure in times to come.

Top Tips

Stressful experiences can lead to a decline in a person's dementia. That's why keeping your loved one calm and happy is so important to their health and wellbeing.



21

How will I know when the end is coming for Mum?

Dementia is a progressive condition, so there will come a time when every family with a loved one with dementia will have to say goodbye. This can be extremely hard to accept, even if your loved one has reached a significant age and has been living with dementia for some time. It's important to note though, that sometimes a dementia can progress so slowly that a person may pass from **another condition** or disease.

When a person is entering the final stages of dementia they will become less engaged with what's going on around them, and they will eat and drink less, leading to weight loss. They will also sleep for long periods of time.

A fundamental part of the dementia care we provide at Care UK is **end of life care**. We care deeply that residents are supported to have the end of life they want and that they die with dignity and respect.

We aim to complete a 'respect form' with you and your loved one early on in their stay in a Care UK home.

This is because, if they still have some capacity, it's vital that your loved one's wishes are taken into account. The respect form details such things as the medication to be used, how your loved one wants their room set up (music, lighting, layout), and who they'd like with them.

Our teams continue to deliver the **best care** as a person enters their last days and hours, including ensuring they have pain relief, keeping them comfortable, and supporting them to continue eating and drinking small amounts wherever possible.

We understand that this is a distressing subject. However, it's crucial that we know your and your loved one's wishes so we can avoid unnecessary hospitalisations in their final days and hours, and ensure they receive seamless loving care until the end.



“People understandably can struggle with the speed at which their loved one may deteriorate, particularly if their loved one has a secondary health condition alongside their dementia. We work extremely closely with the palliative care team and the local hospice so relatives always have the information and emotional support they need at this difficult time.”

Rohan Mathew, Home Manager, Buchanan Court, Harrow

Chapter six

Finding the support you need



“Many relatives we meet as strangers we part from as friends. It’s so important that relatives have the support to offload and share their feelings. Our care teams will never judge you or your decision to move your loved one to our care.”

Eileen Coyle-Jones, Regional Director, West London

Finding the support you need

This section includes a list of resources and sources of support that you may find helpful.

Please remember that you're welcome to contact us if you have any questions. Here at Care UK we're experienced in caring for people with different types of dementia, who are at various stages of their dementia journey. Call our friendly team now on **0330 057 9738**.

Take a look at Care UK's other helpful guides

Our guides have been created with support from our experts, colleagues and residents' family members, and are an invaluable source of advice and inspiration across a range of topics. They can all be downloaded for free from our website.

- **Listen, talk, connect** – to help you continue to have meaningful conversations with a loved one living with dementia

careuk.com/help-advice/listen-talk-connect-guide



- **Good to go** – how to prepare and plan for varied and fun outings with a loved one with dementia

careuk.com/help-advice/good-to-go-guide



- **Eating as we age** – a guide full of professional tips and advice on supporting an older loved one to get the nutrition and hydration they need
careuk.com/help-advice/eating-as-we-age



- **As easy as ABC** – how to enable an older loved one to stay active and engaged and getting the most out of every day
careuk.com/help-advice/keeping-active-and-independent



- **A helping hand** – practical and emotional advice for family carers to support you through every step of the caring journey
careuk.com/help-advice/a-helping-hand-for-carers



Join one of our information sessions

Many Care UK homes host events with our experts like Dr Nori Graham as well as professionals from the local community. Topics include different areas of dementia care, preventing falls at home, and care fees planning. These events are helpful for gaining new insights, and for meeting people in a similar situation. Take a look at the website of the Care UK home near you to see what's coming up.

Other sources of help and support

Age UK

Age UK has been helping older people across the UK for more than 60 years.

ageuk.org.uk and ageuk.org.uk/Scotland

Alzheimer Scotland

Specialist services for people with dementia and their carers.

alzscot.org

Alzheimer's Society

For information, advice and local services for those looking after someone living with dementia.

alzheimers.org.uk

Care Information Scotland

For information about care services for older people living in Scotland.

careinfoscotland.scot

Care Inspectorate Scotland

The independent body for care services in Scotland.

careinspectorate.com

Care Quality Commission

The CQC is the health and social care regulator for England.

cqc.org.uk

Care and Social Services Inspectorate Wales

The care regulator for Wales.

careinspectorate.wales

Carers UK

Offers advice on benefits and services available to carers.

carersuk.org

Carers Trust

Information and local support services for carers.

carers.org

Dementia Action Alliance

Supports communities and organisations to enable people to live well with dementia.

dementiaaction.org.uk

Dementia UK

Provides expert care and support to people living with and affected by dementia.

dementiauk.org

NHS Choices

Information and advice on a range of healthcare concerns, helping people to live well.

nhs.uk

Silver Line

Free confidential helpline providing advice to older people. Open 24 hours a day, seven days a week. Call **0800 470 8090**

thesilverline.org.uk

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