

Living with dementia

Your essential guide



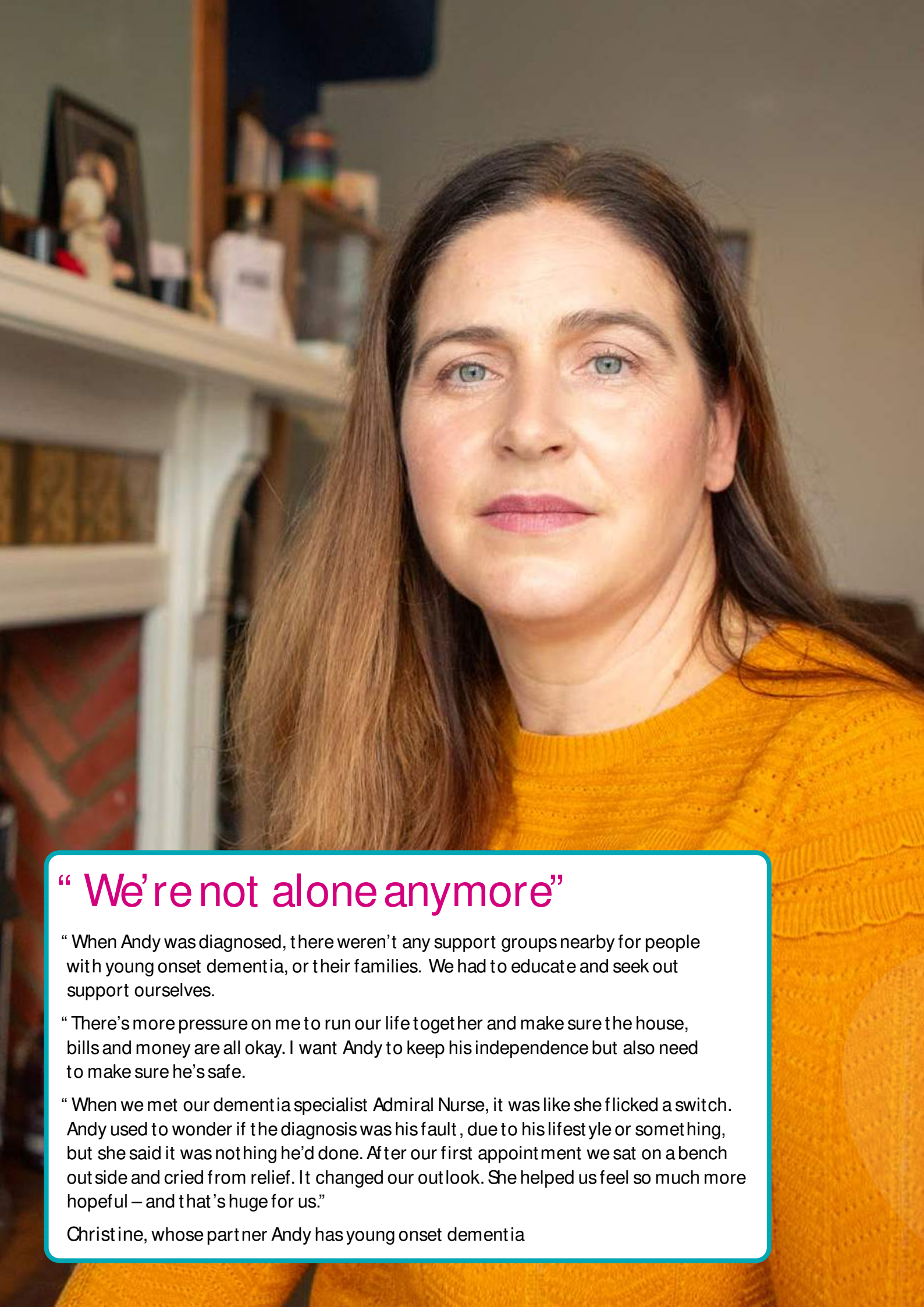
What's inside

Reliable expert advice
Written by our specialist dementia nurses

Practical tips
Hear from people with lived experience of dementia

Heard on the Helpline
Answers to the most commonly asked dementia questions





“ We’re not alone anymore”

“ When Andy was diagnosed, there weren’t any support groups nearby for people with young onset dementia, or their families. We had to educate and seek out support ourselves.

“ There’s more pressure on me to run our life together and make sure the house, bills and money are all okay. I want Andy to keep his independence but also need to make sure he’s safe.

“ When we met our dementia specialist Admiral Nurse, it was like she flicked a switch. Andy used to wonder if the diagnosis was his fault, due to his lifestyle or something, but she said it was nothing he’d done. After our first appointment we sat on a bench outside and cried from relief. It changed our outlook. She helped us feel so much more hopeful – and that’s huge for us.”

Christine, whose partner Andy has young onset dementia

I'm so pleased you're here.

At Dementia UK, we know that dementia doesn't just affect the person with the diagnosis – everyone around them is affected too. Often, people are left feeling exhausted, overwhelmed and alone.

Our specialist Admiral Nurses are a lifeline for families facing dementia – from giving practical advice on managing changes in behaviour to offering much needed emotional support.

Throughout my nursing career of over 40 years, I have supported thousands of families living with dementia, many of whom don't know where to turn for help. That's why we've created this guide, which is full of reliable, expert advice on coping with the daily challenges of dementia – and looking after yourself, too.

If you're looking for more in-depth information on living with dementia, you'll find everything you need on the Dementia UK website. But this guide covers the most important things you need to know, with advice and tips from our Admiral Nurses, people living with dementia and their families. I hope you find it helpful.

We've also put together five bite-size guides addressing some of the most common concerns that we hear about on our Helpline – putting at-a-glance information on key topics at your fingertips. [Download these guides](#) today.

And if you need to talk to us, please get in touch. You'll find our contact information at the end of this guide. Because when someone you love is living

What's inside

This guide is divided into eight sections. In each one, you'll find helpful information on looking after someone with dementia.

Along the way, you'll read advice and tips from our dementia specialist Admiral Nurses (you can meet some of them over the page), as well as people who've experienced what you're going through.

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All about diagnosis

How to get a diagnosis and what to do if you're waiting for an assessment.

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Managing behaviour changes

Advice to help prepare you for potential changes ahead.

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Top tips ✓

- ✓ You don't need to read this guide from front to back – skip to the sections that sound most useful right now
- ✓ Why not print out this guide at home? You can stick the most relevant pages on the fridge as a reminder
- ✓ We've included some space (page) to jot down notes – and you'll find useful contacts at the back

Section :
Going into
hospital

Meet the Admiral Nurses

If you love someone with dementia, we're here for you. This guide aims to make life easier by bringing together the most important information about living with dementia in one place.

To help, we've asked four of our dementia specialist Admiral Nurses to guide you through each section – highlighting the most useful tips and advice along the way. Let's meet them.

Meet Chief Admiral Nurse and Dementia UK CEO Hilda

After developing and leading specialist dementia teams and services throughout the NHS, I became the Chief Admiral Nurse and Chief Executive Officer of Dementia UK in 2015. I'm so proud of the positive difference our charity makes to people living with dementia. But this guide is for you: the carers, family and

Meet Admiral Nurse Vic

I became an Admiral Nurse in 2010. Three members of my own family have had dementia, and I've seen first-hand the impact the condition can have.

Like you, I long for the day when we can say we have a cure for dementia, or that we can prevent it.

Until that day, we need to make sure no family faces dementia alone by providing specialist support and advice when they need it. I know every family living with dementia is doing whatever they need to do – day in, day out. I feel privileged to share my time and knowledge to help in any way I can to make those days a little easier.

Meet Admiral Nurse Kerry

I feel incredibly privileged to be an Admiral Nurse, supporting families living with dementia.

I joined Dementia UK in 2018 as the Consultant Admiral Nurse for Acute Services. I am now the Consultant Admiral Nurse for Frailty.

When you're looking after someone around the clock, you might find it difficult to think about your own needs. But you can only care for the person with dementia if you look after your own health and wellbeing. Reach out for help and remember we're here to support you too.

Meet Admiral Nurse Gary

I've been working for Dementia UK since 2015, where I cover both the Helpline and our virtual clinics. I've always been interested in dementia and helping families – I wanted to be an Admiral Nurse for 10 years, so I was really excited when the perfect role came up.

I know a lot of family members become a carer for someone with dementia without any preparation or training. That's why it's vital for them to have access to the right information, advice and expert support. I hope this guide will give you just that, helping you adjust to your new role and look after your own wellbeing.

All about Admiral Nurses

What is an Admiral Nurse?

Admiral Nurses are specialist dementia nurses – every one of us is a qualified nurse with a professional specialism in dementia. We provide

All about diagnosis

How to get a diagnosis of dementia is one of the most common questions people ask our dementia specialist Admiral Nurses.

What you need to know

- **Signs:** common symptoms of dementia include difficulties with short-term memory, problem-solving, communication, motivation and being able to carry out everyday tasks
- **Impact:** the impact of a diagnosis can affect the person with dementia and everyone around them: family, friends, colleagues and employers. Every situation is unique, and how you feel may change over time, too
- **Patience:** getting a dementia diagnosis may take time. Waiting lists for memory assessments differ around the UK and you could see a number of professionals before diagnosis. It can also take longer if the person is younger
- **Process:** you can ask for a second opinion if your GP won't refer your loved one to a specialist, but they don't have to agree
- **You're not alone:** our Admiral Nurses can answer your

Quick Q&A

Chief Admiral Nurse Hilda answers some common diagnosis questions.

Q. Do I really need to get an official diagnosis?

A. Getting a diagnosis may feel daunting, but it can help a person access benefits and support, plan for the future and protect them from discrimination if they're working (dementia is recognised as a disability).

For some types of dementia, the person may also be prescribed medications that might help with symptoms.

Q. What happens during a dementia assessment?

A. A GP will carry out a physical examination and order blood tests to check for other causes, then ask some simple questions to test memory and brain function.

If they have concerns, the GP may refer the person to a memory clinic, psychiatrist or neurologist for further assessment.



top tips

What are the best things to do when waiting for an assessment? Admiral Nurse Vic has these useful suggestions:

Try a cognitive stimulation therapy activity book. These are packed with games and puzzles to help memory, comprehension and attention.

Start a life story book. Include your loved one's interests, likes and dislikes, a bit about their childhood and working life. This will give health professionals a better understanding of

NHS this way

You can find information on [GP services](#) and [referrals for specialist care](#) on the NHS website.



What helped me most

“Coming to terms with my diagnosis—once I did that, it helped me find my new normal. My life doesn’t revolve around my diagnosis, but it has helped me learn to live life to the fullest. I think it’s incredibly important to keep doing the things you enjoy, and to get the most out of life.”

Jude (right), who has young onset dementia

Living well with dementia

When someone is diagnosed with dementia, it's natural to worry about how it will affect their day-to-day life. But there are steps you can take to help them live well with dementia.

What you need to know

- **Understanding:** living well with a diagnosis starts with understanding. The right information can explain what dementia is and how it's likely to affect your loved one, you and your whole family. Be mindful that this can change over time, but you can reach out to our Admiral Nurses at any point
- **Plan together:** make sure any lifestyle changes are right for the person with dementia. Try to involve them in important discussions before you make those changes
-

What helped me most

“Lester started refusing to change his clothes – he'd wear them for days on end and wouldn't let me wash them. Our Admiral Nurse Sam suggested I get lots of clothes that were exactly the same, all in one colour. Then I'd quickly swap them round when Lester was in bed.”

Diana, who cares for her husband Lester

“ Where can I find specialist dementia technology?”

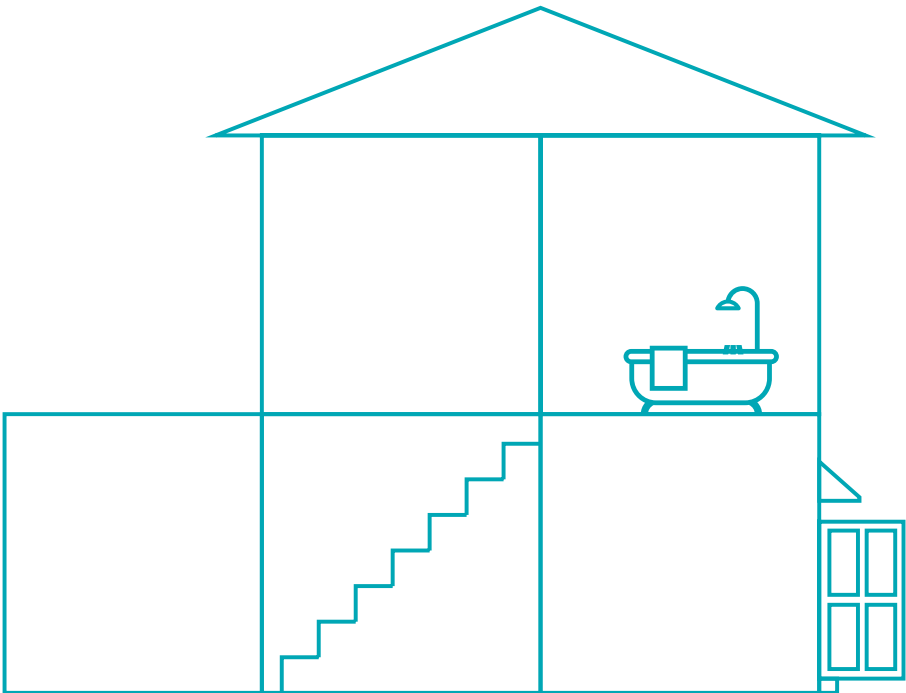
Many websites sell assistive technology for people with dementia, such as personal alarms, automatic pill dispensers, light timers or GPstrackers – find out more on [our website](#). However, many smartphone apps do the same job, while some simple home adjustments can be just as helpful – and cheaper!


“ Are we eligible for any grants to make home improvements?”

Talk to the GP or social services to arrange needs and/ or home assessments to work out what might help with everyday life. You can also ask to be referred to an occupational therapist who can provide practical support and advice. You may be able to get a grant from your local council to help pay for any improvements – our Admiral Nurses can help you find more information.

“ Dad’s having trouble sleeping. Can anything help?”

Disturbed sleep is very common. Keep a sleep diary of any changes in the person’s sleeping patterns. Make sure they’re comfortable, not too hot or cold, have been to the toilet, and their bedroom is calm and quiet. Putting on your own night clothes can show them it’s time for sleep.





Can you really live well with dementia?

“ I know receiving a diagnosis of dementia may be difficult , but your loved one can still live a full life and maintain their independence for as long as they can. Following a healthy diet , staying active and keeping up with friends and hobbies will help them live as well as possible, for as long as possible. Focusing on their strengths and what they can still do, rather than on the challenges of dementia, will also help boost their mental wellbeing. Don't forget our Helpline is always here when you need us.”

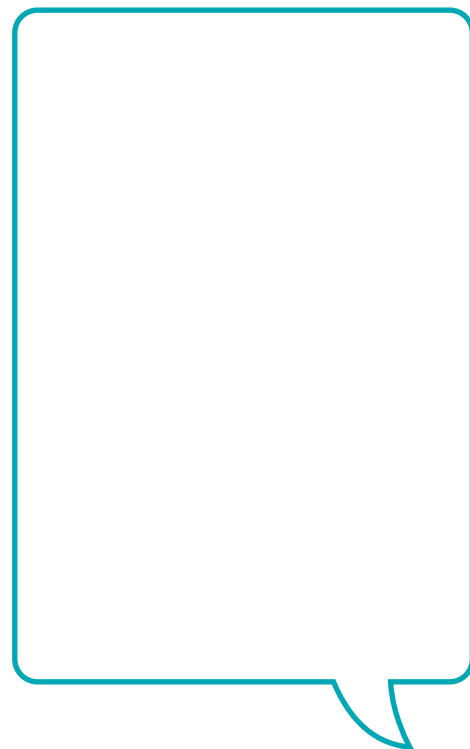
Admiral Nurse Vic

Your wellbeing

Taking care of yourself often comes way down the list when you're caring for someone with dementia. But looking after your own wellbeing is just as important. Making time for yourself can improve your mental and physical health, help you feel better equipped to care for your loved one, and improve your relationship with them.

What you need to know

- **Acceptance:** you may not think of yourself as a carer. You might feel your role is simply part of your relationship with the person with dementia. But if, for example, you help with their personal care, manage their bills or medication, or stay with them if they can't be left alone, you are a carer
- **Balance:** to make sure you're also looking after yourself, you first have to recognise what your needs are. Do you want to exercise? Do you need some time alone every day to read or relax? What about a night out with friends? Once you figure this out, you can ask others for help to rebalance your life
- **Keep checking in:** once a week, for example, do a mini assessment of how you and the person with dementia are coping. "What's this week been like for us? Are we doing okay? Is it safe for both of us to keep going this way?" If you spot any problems, you can sort them out sooner rather than later
- **Health checks:** if you're feeling unwell, have any niggling aches or pains, or experience anxiety or depression, don't



Quick Q&A

One way to get more support is to have a carer's assessment. Admiral Nurse Kerry takes us through some common questions.

Q. What is a carer's assessment?

A. A carer's assessment looks at how caring affects your life and what you might need to make it easier. It's often carried out at the same time as a needs assessment (see [section](#) for more information) by a social worker who will ask you about a typical day, what caring responsibilities you have, such as washing or dressing the person with dementia, and whether you get any time to yourself. They'll also want to know what would happen in a crisis – if you had an accident while out shopping, would anyone know you're a carer? Who would look after the person with dementia? Try to make some notes about these points before your assessment.

Q. Why have an assessment?

A. After the assessment, the social worker will draw up a care and support plan with ideas to ease some of the challenges you face. You may be eligible to get funding for home adaptations, such as fitting handrails next to the bath, or respite care for your loved one. Apart from funding, this may include details of support groups, help with housework, or tips to look after your wellbeing.

Q. How do I organise a carer's assessment?

A. Contact your GP or [local social services](#). Be aware that your finances will also be assessed to find out if you have to pay partly or in full for any help you need (called 'means testing'). If you're not eligible for funding, you should still be given free advice about other ways to find support in your community.



Heard on the Helpline

“ I never have enough time for myself.”

Being a carer is physically and mentally demanding, so it's incredibly important to look after your own health needs. Can you ask someone to sit with the person with dementia while you go out? Make sure you keep any GP or dentist appointments, get regular exercise and keep up with the social activities you enjoy, too. You deserve a life outside of being a carer.

“ Who can I ask for help?”

Your family and friends may not realise how much you're doing. Talk to them to see if they can take on some caring tasks. Look online (Facebook is a great place to start), or in local libraries or community centres for information about support groups. You could also be entitled to respite care from a paid carer or day centre, or even short stays in a care home. Contact your local social services to start the ball rolling.

Life hack

“ Having a smartphone is fantastic; you can check your emails, do an online shop, message friends, watch TV. But if you don't charge it, it can't do anything. You need to recharge your batteries in the same way – learn what helps to recharge you and make sure you 'plug in' to those resources.”



Admiral Nurse Gary

5 top tips

Although your relationship may change, you can still enjoy a close and meaningful connection to the person with dementia. Try these top five tips from Admiral Nurse Vic.



What hobbies did you enjoy doing together? If it was hiking, for example, can you recreate that sense of enjoyment by going for short walks in the park?



You can do other activities to help bring you closer, such as watching your favourite films, listening to music, or looking at old photos together.



Try not to let your role as a carer take over your relationship – always remember the person behind the condition.



When your partner has dementia, this can affect your sex life. Some people find their partner wants to be more intimate, while others do not. But you can stay connected in other ways, such as holding hands or cuddling. As dementia progresses, this may bring up questions of consent. Keep talking to each other or ask a professional for advice.



If the person gets distressed, they may start shouting, crying or even behaving aggressively. This may mean they're trying to communicate something they can't express. Try to find out why they're distressed and resolve it, if possible. You may want to practise some calming techniques, such as deep breathing exercises; comfort and reassure them; or you may just need to give them some space.

Heard on the Helpline

“ I feel guilty all the time – is that normal?”

Unfortunately, yes. You might feel guilty if you think you're not living up to what a carer 'should' be; if you have to reconsider a promise such as, “ I'll never move you into a care home;” or if you need some time to yourself. But remember, you're not trained in dementia care and are learning as you go.

Getting help and support will take some of the pressure off and help reduce feelings of guilt.



[Watch Chief Admiral Nurse Hilda talking about guilt](#)





Section

Managing behaviour changes

Some people experience changes in behaviour, from misinterpreting information to getting agitated around sunset. These changes may be distressing, but there are ways to manage what's happening.

What you need to know

- Find the cause: changes in behaviour could be caused by a specific trigger, like a noisy train station or busy supermarket. Ask yourself what happened just before your loved one's behaviour changed; what were they doing? What was happening around them? Who were they talking to?
- Medical reasons: agitated or aggressive behaviour is sometimes triggered by feeling unwell or being in pain. If you suspect they may be ill or experiencing pain, the person should see their GP
- Book a check-up: changes in hearing or eyesight can lead to difficulties with perception and confusion. When did they last have an eye test or hearing check?
- Extra advice: if you're still not sure what's behind your loved one's behaviour changes, our Admiral Nurses are here to offer more help and support



Hear from our panel



Listen to a discussion on behaviour changes, featuring Admiral Nurse Vic.

[Listen now](#)



Heard on the Helpline

“The doctor says my husband has delirium. What is it?”

Delirium is a state of intense confusion and lack of awareness of their surroundings. It often comes on suddenly. Some people experience paranoia, restlessness, aggression or hallucinations, while others become sleepy and hard to rouse. There are many different causes, including infection, dehydration, side effects of some medications or a mini stroke.

If your loved one has delirium, they need medical help right away, so contact their doctor. Stay with them and try to keep them calm – distract them by watching TV, offering a snack or drink, or walking around with them. Delirium can be treated but some people with dementia take some time to recover.

“Mum doesn't recognise me anymore, which is really upsetting.”

As dementia progresses, many people stop recognising those closest to them or mistake them for someone else. This could be caused by memory problems or damage to the part of the brain that recognises faces. Try not to correct your mum, as this can be distressing and frustrating for everyone – see [page](#) for advice on what to say instead. You could also put up photos that show people getting older or important events in your life together.

Quick Q&A

Admiral Nurse Gary explains a common change in behaviour known as sundowning.

Q. What is sundowning?

A. More than of people with dementia experience sundowning. It means the changes in behaviour that normally happen in the evening, around dusk.

Q. What are the symptoms?

A. People who experience sundowning often become anxious, agitated and confused. They may have a strong sense that they're in the wrong place and want to, or try to, go home – even if they're already in their own home.

Q. What causes sundowning?

A. Possible causes are getting tired at the end of the day, feeling hungry or thirsty, or darkness falling and the street lights switching on. These changes can all make the person feel unsettled or as if they've forgotten to do something.

Q. How can you manage it?

A. Use distraction techniques, like offering them a drink or going for a walk. Ask them what's wrong in a low, soothing voice, and listen carefully to their answer. Turn off the TV or radio, as background noise can be overwhelming. Sit with them and hold their hand to comfort them, too.

Q. Can you prevent sundowning?

A. Try to limit naps during the day, so your loved one sleeps better at night. Also limit their intake of caffeinated drinks – switch to decaf coffee or herbal teas. Draw the curtains and put the lights on before it gets dark to soften the shift from day to night-time. Try to create a regular evening routine, such as eating a meal, having a relaxing bath, then dressing for bed.



I wish I'd known...

“Grandad would get very distressed every evening. He insisted he needed to go home, would try to pack a bag and demand to be taken to the airport so he could fly back to India where his parents and siblings, long since passed away, were waiting for him. After calling the Dementia UK Helpline, we learned to acknowledge what Grandad was saying but to quickly change the subject and distract him. We told him it was too late to go to the airport and asked him what he wanted for dinner.”

Liz, whose grandad, Sam, has Alzheimer's disease



Watch to
find out
more about
sundowning



Talking to someone with dementia

Don't say

Do say

You shouldn't ask people with dementia too many questions, but do you know why? Admiral Nurse Kerry says it's because a lot of human interaction is based on questions: "How are you? What did you do at the weekend? When did Jay come to see you?" For someone with dementia, this can be overwhelming and raise their anxiety levels if they don't know the answers. Try these simple alternatives instead.



"Don't you know who I am?"



"Hello Mum – it's Julie, your daughter."



"Did Danny get you those flowers?"



"Your grandson Danny came to see you today and left these flowers for you."



"Would you like some fruit?"



"I'm going to have fruit for pudding. Would you like some too?"



"What did you have for lunch?"



"It looks like you had a sandwich for lunch."



Want more information on behaviour changes?

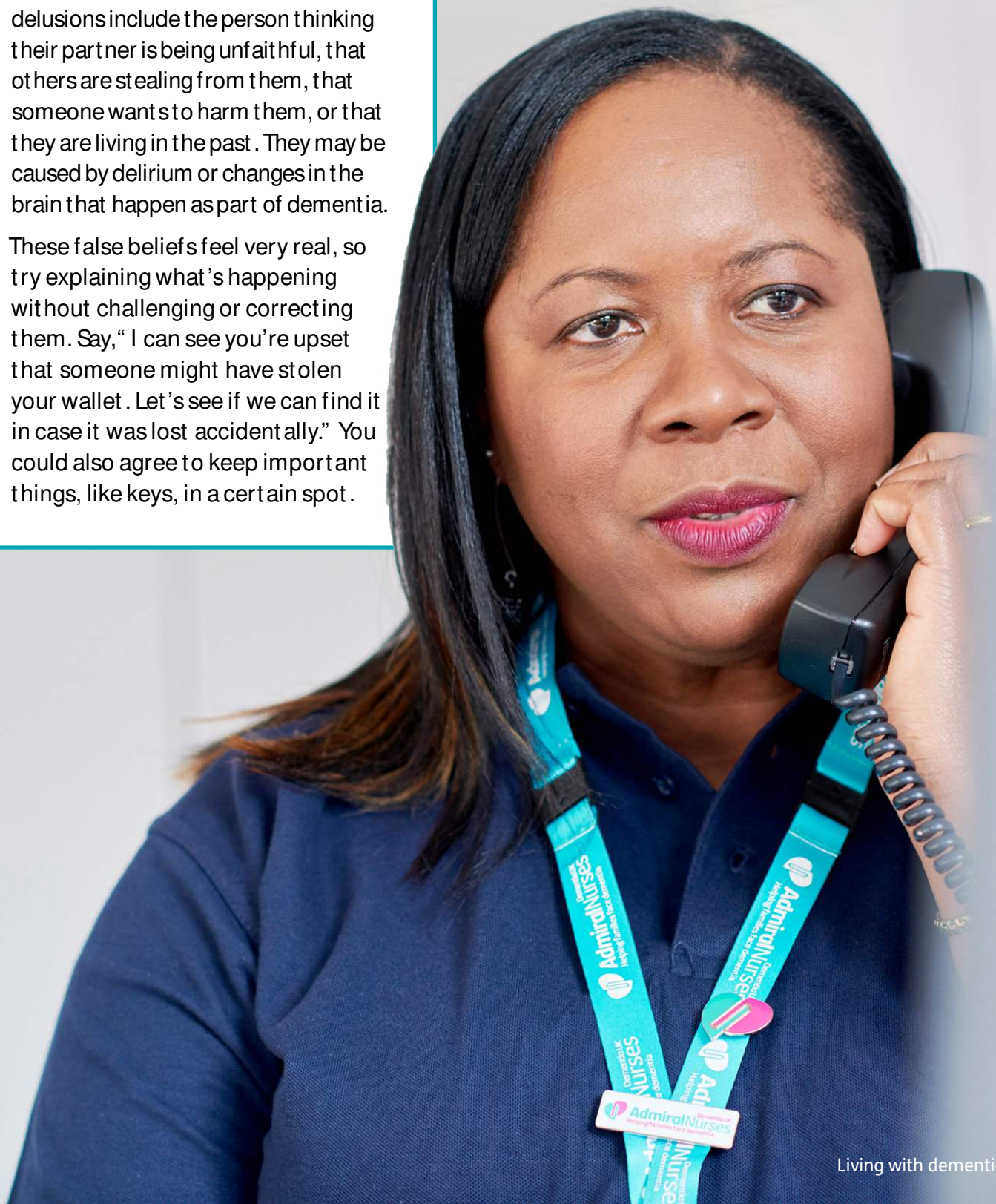
[Watch all of our videos online](#)

Heard on the Helpline

“ My partner thinks people are stealing from him. How can I reassure him?”

Some common false beliefs and delusions include the person thinking their partner is being unfaithful, that others are stealing from them, that someone wants to harm them, or that they are living in the past. They may be caused by delirium or changes in the brain that happen as part of dementia.

These false beliefs feel very real, so try explaining what’s happening without challenging or correcting them. Say, “ I can see you’re upset that someone might have stolen your wallet. Let’s see if we can find it in case it was lost accidentally.” You could also agree to keep important things, like keys, in a certain spot.



Section

Dementia and your family

Dementia can affect family and friends in lots of complex ways, and it will impact everyone differently.

What you need to know

- **Be open:** encourage your family and close friends to talk about your loved one's dementia. This means you can understand and support each other better
- **Share:** let other family members know what your caring responsibilities involve. Very often, people don't realise just how much you're doing
- **Ask for help:** if possible, split your caring tasks among other family members and close friends – it may be useful to create a rota
- **Avoid taking over:** it's tempting to take charge of all household tasks, but this can make the person with dementia feel a loss of responsibility and independence, and put a strain on your relationship
- **Be kind to yourself:** many people go above and beyond when it comes to looking after a loved one, but never feel like they're doing enough. Try to acknowledge what you're doing and how much you've achieved
- **Be prepared:** becoming 'a carer' doesn't mean you're no longer a partner, friend, sibling or child of the person with dementia, but you may need to adapt to a change in your relationship. Being prepared can help you understand and accept these changes and maintain close bonds



Heard on the Helpline

“I feel like I'm doing everything.”

Very often, one member of the family feels as if all the caring responsibilities fall on their shoulders. If other family members can't (or won't) help – even after you've suggested sharing tasks – you may need extra support. Talk to our Admiral Nurses to find out what's available near you.

“As a family, we can't agree on how to look after Dad.”

When family members have different opinions about how their loved one should be cared for, it can be difficult to agree on and plan the next steps. Some may feel excluded from caring or feel uncomfortable volunteering as they don't know exactly what to do. If you're struggling to work things out, contact our Helpline or organise a virtual appointment. Our expert Admiral Nurses can help the whole family find ways to care for the person with dementia.

Quick Q&A

If you don't live near your loved one, it can be difficult trying to care for them from a distance. Chief Admiral Nurse Hilda has the answers to these common questions.

Q. How can I keep the person with dementia safe?

A. The first step is to ask the local social services team to carry out a needs assessment. This will help them work out what equipment or extra support the person needs to live safely and independently at home. See [section 3](#) for more advice.

Q. What if something happens when I'm not there?

A. Build up a local network of trusted people, such as neighbours, family and friends, who can keep an eye on your loved one and contact you if anything happens. You could give a select few friends a spare key or door code, so they can get in should they need to – just make sure the person with dementia is comfortable with them. It may also help to keep all the information about the person in one place, such as their care needs or doctor's details, so it's easy to find in an emergency: you could use a folder or notebook.

Q. What happens if/ when they get worse?

A. Try to have open discussions with the person with dementia and other family members about future plans, care options, finances and everyone's expectations to avoid conflict later on. It's also important to draw up a lasting power of attorney while the person still has capacity – this will allow you to make decisions on their behalf if they're unable to. See the [Legal and financial issues section](#) for more.

Loved, not lost

"If someone develops dementia, it doesn't change the person you love and respect. A grandparent will still be a grandparent, a parent will still be a parent, a friend will still be a friend. People may have dementia but dementia does not have them."

Rueben, Healthcare Assistant



Life hack



"Sign up for schemes that could help in a crisis. The Lions Clubs' 'Message in a Bottle' scheme keeps all the person's important information in a bottle in the fridge, so it's easy for emergency services to find if need be. The Herbert Protocol is a national programme that gives police, social services and other local services the ability to share information about your loved one if they go missing."

Admiral Nurse Vic

5 top tips for talking to children

It can be tough talking about dementia to children, who may be struggling to understand any changes in their parent or grandparent. Admiral Nurse Kerry shares five useful tips:



When you're explaining what dementia is, be honest about what's happening and how it may affect your family, but try not to overwhelm them. See our [book recommendations](#).



Make time to listen to their concerns. Give them the chance to open up and reassure them it's okay to feel a range of emotions.



Create a memory box – put in photos, cards and keepsakes to help them remember their loved one before they were diagnosed with dementia.



Make new memories, too. Spend quality time walking, playing board games, or watching some family films together.



Ask their teachers to look out for any behaviour changes, which could be a sign they're not coping. If you need more support, please call our Helpline.



Heard on the Helpline

“ I don't have enough time to spend with the rest of my family.”

If caring for the person with dementia takes more of your time, that will have an impact on your other family relationships. Partners can feel neglected or upset, children may be confused and frustrated if you have less time to spend together and you might feel split between them all. But if other family members can help out with shopping, cleaning, taking your loved one for a walk, or even just picking up a prescription, that can give you back some time to spend with everyone else, or some much-needed time to yourself. You need looking after, too.



Let's talk dementia

We ask children to share their tips for eight- to -year-olds.

[Watch now](#)



“ Mam’s dementia has affected us all ”

“ When you have young children, you want your mum. You want to talk to her about parenting. Mam was an amazing grandmother to my brother’s kids, but my twins will never have that experience. They’ll never meet the real Mam, and I feel really robbed of that.

“ After Mam was diagnosed, I became her carer alongside Dad. But it was really tough; you feel stuck in a spiral of trying to get everything right, every day. I once lost Mam on a walk when she stormed off while the twins were on the swings – I couldn’t cope. It felt like we were totally on our own.

“ That’s when I heard about Dementia UK and called the Helpline. The Admiral Nurses I spoke to were always so understanding and suggested a couple of ideas to help us cope. They also gave us practical advice about funding and finding the right care home.

“ Their comfort and support gave me the extra strength to keep going. Having someone to turn to, who understands dementia and knows how traumatic it can be caring for your relative, is crucial.”

Clare, whose mum has vascular dementia

Section

Legal and financial issues

Are you worried about the financial impact of caring for someone with dementia? Perhaps you're feeling anxious about making future decisions about health, money and long-term care if your loved one can't do it themselves. Figuring all this out can feel daunting, but we're here to help guide you through it.

What you need to know

- Help is out there: many carers don't know they can claim certain benefits or get financial support, so it really is worth finding out if you're eligible
- Legal issues: there are steps you and your loved one should take sooner rather than later, like setting up a lasting power of attorney, to help them feel more confident about the future
- Simplify your finances: managing money can be tricky – especially if your income suddenly drops – but there are ways to make it easier, such as setting up direct debits for bills
- Ask an expert: negotiating your way through unfamiliar legal jargon or benefits forms can be overwhelming. Our dementia specialist Admiral Nurses are here for you and have helped thousands of people make sense of it all



Heard on the Helpline

“Are we eligible for any financial benefits?”

People with dementia and their carer may be entitled to a significant Council Tax reduction, Attendance Allowance, Disability Premium, Universal Credit or Personal Independence Payments. You could also claim Carer's Allowance or Carer's Credit. Receiving benefits will depend on many factors – your loved one will need to meet various criteria, such as State Pension age.

“What is NHS continuing healthcare funding?”

Continuing healthcare funding is for adults with long-term complex health needs, including dementia. It's designed to cover social care costs, such as home carers or care home fees, and is paid for by the NHS. However, the application process is often very difficult, so we strongly advise getting help from a dementia specialist who understands continuing healthcare, like our Admiral Nurses.



[Watch Admiral Nurse Kerry talk about continuing healthcare](#)

Quick Q&A

Admiral Nurse Vic answers the most important questions about lasting power of attorney (LPA).

Q. What is lasting power of attorney?

A. A person with dementia can choose one or more trusted people (such as their partner, family member or close friend) to make financial, legal or healthcare decisions for them in the future. This person is called an ‘attorney’ and is appointed by a formal document called lasting power of attorney. There are two types of LPA: one for health and welfare, and one for property and financial affairs.

Q. Why have lasting power of attorney?

A. Many people with dementia reach a point where they can no longer make decisions about their own money or healthcare – this is called ‘loss of mental capacity’. Making an LPA before this point means your loved one can make choices about their future care and finances while they’re still able. The attorney is then legally bound to respect their wishes and make decisions in their best interests. But if the person with dementia loses mental capacity and doesn’t have an LPA, it can be very difficult for you to legally make those decisions for them.

Q. How do I set up lasting power of attorney?

A. You can contact a solicitor or [download and complete the form](#) from the Office of the Public Guardian. Once you’ve filled it in and got it signed by everyone, you need to post the form to the [Office of the Public Guardian](#) to be registered.

Q. My dad won’t agree to an LPA – how can we encourage him?

A. Many people, whether they have dementia or not, worry that having an LPA means someone else will make decisions about their health or finances that they don’t agree with. But not having an LPA could mean your loved one doesn’t have any say in what they want – and explaining this could help change their mind. There are ways you can ‘normalise’ the process too. Try completing the forms together, or set them up for other family members too to show it’s something everyone needs. It’s also worth pointing out that an attorney cannot take advantage of the person for their own benefit. If they do, the LPA may be cancelled, and the attorney could be prosecuted.



Heard on
the Helpline

“How do I apply for Carer’s Allowance?”

You can claim Carer’s Allowance if you look after someone who receives other benefits, like Attendance Allowance. But you’re not eligible if you already receive a State Pension and – most importantly – it may affect the benefits your loved one could claim, too. Get help with an application by calling the Carer’s Allowance Unit on



Download our bite-size guide to [planning for the future](#).

5 top tips

Dementia can change your loved one's relationship with money. For example, if your partner was diagnosed with dementia while working and needs to leave their job, this could have a huge impact on your income. The condition can change how a person handles money, too; they might start giving it away, for example. Chief Admiral Nurse Hilda shares some tips to help you and the person with dementia manage their finances:



Set up standing orders or direct debits for all of the person's regular bills. Signing up for online banking also makes it easier to track their transactions.



If you want to limit someone's spending, prepaid cards are a great idea. Or you can set a spending limit on debit and credit cards.



Create a household budget – list all your incomings and outgoings so you know exactly what you're spending every month.



If you have multiple joint bank accounts, consider combining them and closing some to avoid confusing your loved one.



Separate bank accounts can be helpful – if the person with dementia has a financial assessment for their own care needs, only their finances will be considered, and not yours.



I wish I'd known...

"The biggest issue I had with accessing NHS continuing healthcare funding (CHC) was that it was so difficult to find my way around the system. There was a real lack of consistency – if you rang up and spoke to someone you hadn't been talking to before, they didn't know who they were dealing with. I wish I'd known how important it was to record every bit of information, otherwise you feel like you are always starting again at the beginning."

Mary, who cared for her mum who had Alzheimer's disease



What helped me most

“ It was really worth spending the time to get our heads around the benefits available to us as a family after Mum’s diagnosis. Although completing the Attendance Allowance form took time, including a couple of weeks to get all the information together, having it in place then unlocked other benefits for us, such as Council Tax reductions.”

Claire, who cares for her mum who has dementia

Life hack



“ Both you and the person with dementia could be entitled to different benefits that you may not be aware of. Use the Government’s [online benefits calculators](#) to see what you could claim.”

Admiral Nurse Gary



Section

Going into hospital

Any hospital stay – whether planned or an emergency – can be stressful for the person with dementia, and for you. From packing a ‘grab bag’ to advice on speaking to staff, our tips will help you feel better prepared for a hospital visit.

What you need to know

- **Get packing:** it’s a good idea to pack a ‘grab bag’ with all the things the person might need if they’re admitted to hospital unexpectedly. As well as toiletries, include nightwear and supplies of medication. If they’re going into hospital for a planned stay, you might want to pack comforts such as noise-cancelling headphones or a favourite blanket that will help them feel at home
- **Essential info:** you could fill in an advance care plan, which includes all the important information hospital staff might need to look after the person. Go to the next page to download our PDF
- **Explain their needs:** check that the hospital knows your loved one has dementia, understands their needs and can communicate with them clearly; and that you’re comfortable that they will care for them properly
- **Extra support:** ask if the hospital has an Admiral Nurse or other Dementia Team who can support both you and your loved one during their stay. Make sure the ward staff have your phone number so they can contact you
- **Keep moving:** many people with dementia like to walk around. If they’re prevented from doing so, they may become distressed. Talk to hospital staff to see if it’s okay for the person to walk around the ward, visit the day room, or go for a coffee in the hospital grounds with a visitor. And ask if they have any resources to help reduce your loved one’s anxiety or distress



Heard on the Helpline

“ How can I help Mum feel more comfortable in hospital?”

Involve the person with dementia in packing their bag by discussing what they’d like to take, such as clothes, books, magazines or a favourite shower gel. Label all their items clearly so they don’t worry about losing them, and advise them to leave valuables (like wedding rings) at home. If you can’t visit them, ask the ward staff if there is a good time to phone or video call them. Some hospitals also take part in [John’s Campaign](#), which allows friends and family of people with dementia to visit at any time. Agree with your family and friends who will visit and when, so your loved one is never alone for too long.

“ Do I need a lasting power of attorney (LPA) if they go into hospital?”

Not necessarily. If the person with dementia is still able to make their own decisions (ie if they have mental capacity) then an LPA isn’t needed. But if their condition progresses, or their mental capacity comes and goes, then a trusted family member or friend may need to make decisions about their healthcare. It’s a good idea to make an LPA soon after diagnosis to avoid problems further down the line.

Quick Q&A

Most people receive excellent care in hospital, but if you feel your loved one isn't being properly cared for, Admiral Nurse Kerry recommends these steps to make a complaint.

Q. Have you spoken to their named nurse?

A. This is usually the first step to resolving any issues. Check that they know about the person's dementia and are following their advance care plan, if they have one. If this doesn't work, ask to speak to the ward manager.

Create an advance care plan

[Download our PDF](#) tailored for families living with dementia.

Q. What's your specific complaint?

A. Write down your concerns, including dates, days, times, what happened and who you spoke to. Then you can be precise when making a complaint. For example, "Yesterday, Mum's breakfast was cleared away before she had finished eating. I spoke to staff at 10 am who did not know she had dementia and needed more time. But then her lunch was also cleared away early." Be clear about what you want them to do to fix the situation.

Q. Has this solved the problem?

A. If you still have concerns, or the problem keeps happening, speak to the hospital's [Patient Advice and Liaison Service \(PALS\)](#). They support patients and families with resolving issues during or after a hospital stay and can advise on making a formal complaint.

What helped me most

"Find out if there's a dementia specialist in the hospital, either before the person goes in or as soon as they're admitted. Admiral Nurse Kerry came into our lives a few hours after Dad was taken to A&E. She gave us practical help, regular updates, messages of reassurance and advice, and support in finding him a care home place. But crucially, she made us feel like someone cared about our dad, not just that he was being cared for."

Neil, whose father had Alzheimer's disease



Life hack



"Set up a family WhatsApp or group chat so everyone gets the same updates about the person with dementia at the same time. The main carers don't have to be in the group themselves – to save them from too many notifications buzzing on their phone all day – and it can be really handy for delegating responsibilities too."

Admiral Nurse Gary

5 top tips

When people with dementia stay in hospital, they may lose their appetite. Admiral Nurse Vic has these top tips to keep them eating and drinking well:



Tell nurses and other care staff about any allergies or food and drink they like and don't like.



Ask if there are picture menus so the person with dementia can easily see what food is available, especially if they struggle with words.



Is there a snack menu? They may find it easier to eat smaller, more regular portions rather than three large meals a day.



Some hospitals have a 'red tray scheme' which shows the person may need more help during mealtimes. Or find out if you can be there to help your loved one with eating meals.



If the person has trouble chewing or swallowing, ask if they can have softer food or thickened drinks to make it easier for them to eat. The hospital will be able to refer them to a speech and language therapist (SALT) or dietitian to help with this.

I wish I'd known...

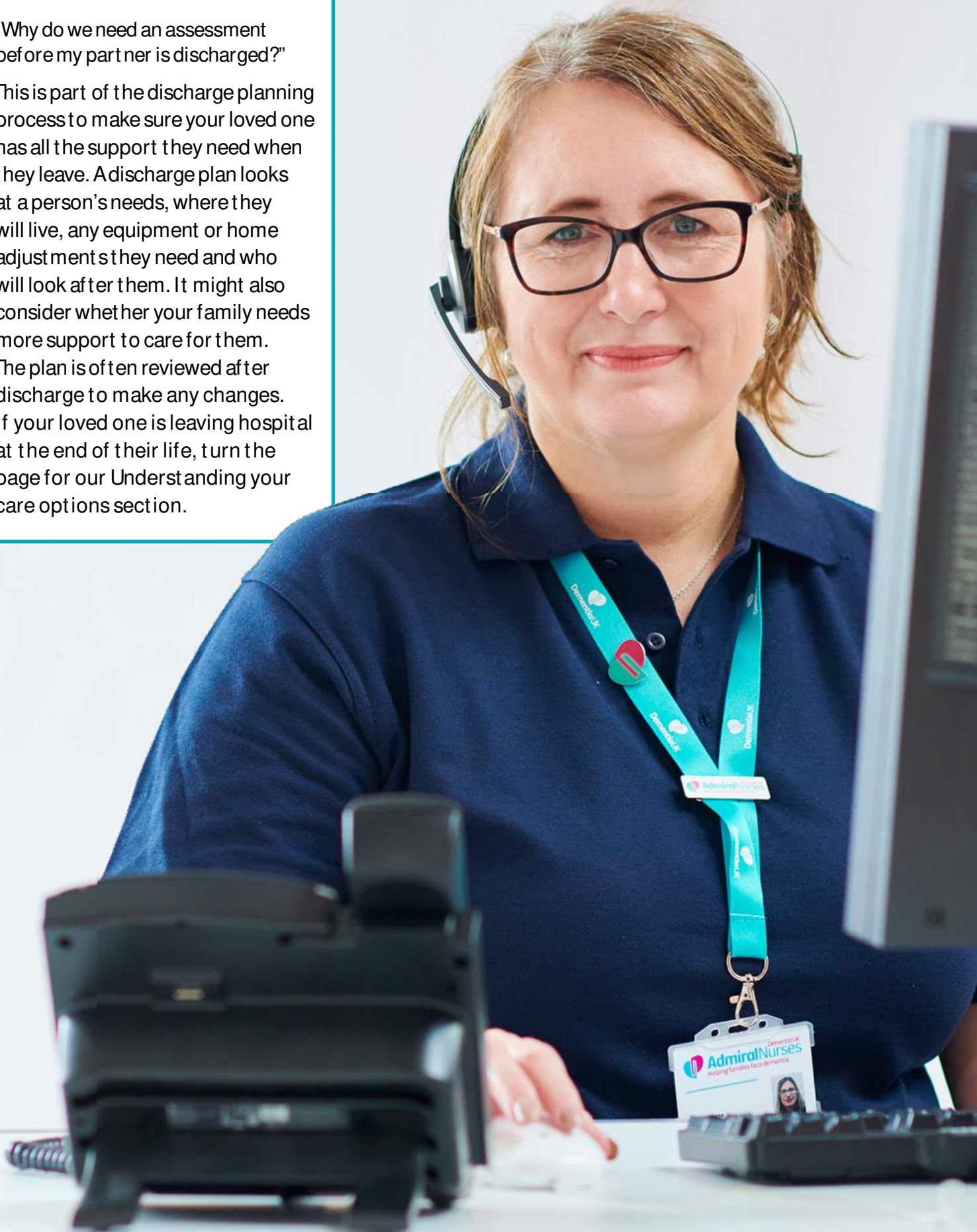
"Check if doctors or nurses have changed your loved one's medication, like adding something new, or increasing or lowering a dose. This can have a huge impact: I remember Nana suddenly changed; she was more sleepy and hardly spoke. My family had no idea this was because her meds were different. You need to ask questions: why have they been changed? What are the benefits? Is it just while they're in hospital? You all deserve to know what's happening."

Sarah, whose grandmother had Alzheimer's disease

Heard on the Helpline

“ Why do we need an assessment before my partner is discharged?”

This is part of the discharge planning process to make sure your loved one has all the support they need when they leave. A discharge plan looks at a person's needs, where they will live, any equipment or home adjustments they need and who will look after them. It might also consider whether your family needs more support to care for them. The plan is often reviewed after discharge to make any changes. If your loved one is leaving hospital at the end of their life, turn the page for our Understanding your care options section.



Section

Understanding your care options

It's not easy looking after someone living with dementia and at some point, you may need extra help. That could be hiring carers to support your loved one at home or moving them into a care home. You may also be looking at end of life care. So, what's available and how do you make those decisions?

What you need to know

- It's personal: there's no 'one size fits all' when it comes to dementia care. Every family needs different levels of support at different times, so it's important to get advice, and realistically work out what's best for your loved one and for you
- Cost: paying for care can be a huge concern. Find out if you're eligible for any funding by asking social services for a needs assessment. You could also apply for a carer's assessment; see the [Your wellbeing](#) section for more advice
- Quality care: every care home in England is inspected by the Care Quality Commission (CQC). You can see all the ratings on its [website](#). Care agencies that provide carers are also regulated by the CQC. Details of care inspectorates in Northern Ireland, Scotland and Wales are on the back page
- End of life needs: recognising when someone with dementia is nearing the end of their life can help you plan appropriately, helping to ensure their care needs are met, and final wishes are carried out respectfully. [Read our leaflet](#) for more information

So, what are your options?

For more advice on care options, read our information about [finding help and support at home](#), [choosing a care home](#), and [a stay in hospital](#).

Heard on the Helpline

“Is there a right time to move my loved one into a care home?”

Some people set themselves a personal limit, such as ‘When Mum becomes doubly incontinent, she'll be better cared for in a home’. But that point varies for everyone. It could be following discharge from hospital after an emergency when they need specialist support, or if the person's dementia progresses to the stage where they need 24-hour care. A home may also be more practical if you, or their regular carer, are unable to keep looking after them.



Life hack



“When you book viewings at care homes take note of other things apart from the decor and furniture – are the residents dressed appropriately? Has their hair been brushed? Are they engaged in some sort of meaningful activity? Listen to how the staff talk to the residents – is it respectful? And do they look happy in their job? All this can help you make the right decision.”

Alison, who works in a dementia care home



Quick Q&A

If you're thinking about end of life care, or your loved one is close to dying, Chief Admiral Nurse Hilda says these are the key questions to ask.

Q. Has the person with dementia got an advance care plan?

A. An advance care plan (ACP) sets out how your loved one wants to be cared for as they approach the end of life. It often includes their wishes for medical treatment, plus details like funeral plans or caring for pets. If possible, it's important to make an ACP while the person can still make decisions, so you know you're following their wishes. [We have a template you can use.](#)

Q. Does the plan cover where they'd like to die?

A. If you haven't yet discussed where the person would like to die, have that conversation sooner rather than later. Some people prefer the idea of dying in their own home; others may have to be in hospital to meet their needs at this important time. They could prefer the idea of a care home, or the support of a hospice. Whichever feels right for your loved one, make sure their requests are in the advance care plan – and followed as closely as possible.

Q. What about advance decisions, or a 'living Will'?

A. While an advance care plan is not a legal document, an advance decision to refuse treatment (ADRT) – also known as a living Will – is legally binding. This sets out what medical treatment your loved one does not want, such as ventilation or resuscitation. It needs to be signed by the person and a witness.

Q. Have you got support during this time?

A. Dementia is a progressive condition, so everyone with the diagnosis will die with it or from it. If your loved one is nearing the end of their life, you will need plenty of support. Keep talking to family, friends or a professional counsellor, or call our Helpline. Our Admiral Nurses can offer support and put you in touch with grief charities or local bereavement support groups.



Heard on the Helpline

“How can we choose the best care home?”

The first step is to involve the person with dementia as far as possible. Do you know what type of home can best meet their needs now, and what support they might need in the future? Ask friends or local dementia support groups for any recommendations. You can also ask social services or visit carehome.co.uk for a list of care homes. Finally, arrange viewings for you and your loved one. Talk to other residents and their families to get a feel for whether the home suits the person's needs.

“I feel like a failure for moving my loved one into a home.”

Accepting that you need more help looking after someone with dementia is a big step. It doesn't mean you've failed or given up on them. In fact, finding the right home for your loved one can provide them with vital care and social contact, and give you back some time to resume the activities you enjoyed before becoming a carer. It will feel like a major transition, and some people with dementia may be reluctant to move at first, but it can have huge benefits for everyone involved. If you're struggling with the change, our Helpline nurses are here to offer support.

Home carers or a care home?

There are so many care options to choose from that it can be hard to know what's best. We've broken down the key differences between at-home support and care homes to help make your decision a little easier.

Will it...?	Home carers	Care home
...relieve some of the strain on you?	Professional carers can help with challenging tasks such as lifting, dressing or personal care.	Moving your loved one into a care home can relieve you of some of the day-to-day stresses of caring, but if it's far away, expensive, or a poor fit for your loved one, that could be a strain on you.
...keep the person in their own home for longer?	This choice means your loved one will stay at home – as their dementia progresses, just keep checking their needs are being met and they're still able to live safely at home, and compare the costs to other options.	As dementia progresses, the person may need specialist, round-the-clock care that isn't possible in their own home.
...keep them connected to their community?	If your loved one stays at home, they can keep up with the activities they enjoyed before and see local friends and family.	If your loved one was becoming isolated at home, a care home can provide a new community that understands their needs.
...provide 24-hour care for your loved one?	Some home carers provide live-in care, or you may be able to use an agency that provides carers to work shifts, including nights.	If your loved one is in a home, they will be looked after both day and night.
...give them specialist dementia care?	Make sure carers are trained in dementia care and find out what caring tasks they are able to do.	Ask how many dementia specialist work in the home, about their training (what they've done and how regularly), and how much contact they'll have with your loved one.
...support someone with young onset dementia?	You can ask for carers who specialise in young onset dementia, but they are quite rare.	Not many homes care for people with young onset dementia, so finding age-appropriate care can be difficult.
...strengthen your relationship?	Being relieved of some of your caring duties can make the time you have together more enjoyable.	If you're no longer responsible for tiring or stressful tasks, you can focus on your loved one during visits.
...improve everyone's quality of life?	Giving you some much-needed time to yourself, or reducing your loved one's isolation if they live alone, can help everyone live better with dementia.	Once you've adapted to the change, a care home can lead to better health and quality of life, with more time for meaningful activities, for everyone.



“ We’ve learned to live in the moment ”

“ Gran was a constant source of support in my life. My parents worked a lot, so she’s cared for me since I was born. She was always my first port of call for advice or to tell her some good news. Now, it’s like she’s not there anymore. She doesn’t want to eat, and food used to be a massive part of our relationship.

“ We want to keep Gran in her own home for as long as possible. Although we have carers coming in every day, Mum is her main carer. But it’s tough for her as she has her own health problems, and now she’s become a mum to her mum.

“ Talking to the Admiral Nurses on the Helpline is really useful. Their advice helped us to just be in the moment and enjoy each other’s company, to create more special memories together. Hearing a professional say, ‘You’re doing the right thing’ is such a relief.”

Ricky with his mum, who cares for his gran who has Alzheimer’s disease

Notes

As you go through this guide, you may want to make notes or remember an important phone number – you can use this section to jot these down.

A series of horizontal dotted lines for taking notes.



We live with dementia

Find out more about our campaign for everyone affected by dementia. [Visit now](#)

Contact us

To speak to a dementia specialist Admiral Nurse, call our Dementia UK Helpline free on (Monday-Friday 9am-5pm, Saturday, Sunday and bank holidays 9am-5pm – closed 25th December) or email helpline@dementiauk.org

Sometimes our Helpline can get busy. If you cannot get through straight away, there is an option to leave a voicemail and an Admiral Nurse will get back to you within 24 hours.

To book a free video or phone appointment with an Admiral Nurse at a time and date that suits you, visit dementiauk.org/book

Our free advice and information resources are written by our Admiral Nurses and can help you with everything from getting a diagnosis to legal and financial support.

You can find all of our resources at dementiauk.org/get-support



Some of our information leaflets are also available in [other languages](#):

Bengali

Chinese (traditional and simplified)

Gujurati

Polish

Punjabi

Tamil

Urdu

Welsh



“ When I called the Helpline, I broke down. I shared all my worries and for the first time, I felt listened to and understood.”

Denise, whose mum had Alzheimer’s disease



More useful contacts





Here are some of the most important contact details from each section. Print this page out and keep it somewhere safe so you have it to hand for any emergencies. And if you've got any questions, you can always call the Helpline or book an appointment in our virtual clinic. Our dementia specialist Admiral Nurses are happy to help.

Organisations that support carers

Carers Trust

 (Monday-Friday am- pm)
 [carers.org](https://www.carers.org)

Carers UK



 (Monday-Friday am- pm)
 [carersuk.org](https://www.carersuk.org)

DEEP: the UK Network of Dementia Voices

 [dementiavoices.org.uk](https://www.dementiavoices.org.uk)

Care homes and respite breaks

Carehome.co.uk

 (Monday-Friday am- pm)
 [carehome.co.uk](https://www.carehome.co.uk)

Dementia Adventure

 [dementiaadventure.org](https://www.dementiaadventure.org)

Revitalise

 [revitalise.org.uk](https://www.revitalise.org.uk)

Living aids and home adaptations

Living Made Easy by the Disabled Living Foundation

 [livingmadeeasy.org.uk](https://www.livingmadeeasy.org.uk)

Healthcare Pro

 [healthcarepro.co.uk](https://www.healthcarepro.co.uk)

AlzProducts

 [alzproducts.co.uk](https://www.alzproducts.co.uk)

Young onset dementia

Young Dementia Network



 [youngdementianetwork.org](https://www.youngdementianetwork.org)
 youngdementianetwork@dementiauk.org

Legal and finance

The Government benefits calculator



 [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)

Carer's Allowance Unit

 (Monday-Friday am- pm)
 [gov.uk/carers-allowance/how-to-claim](https://www.gov.uk/carers-allowance/how-to-claim)

Support and protection at work

Acas

 (Monday-Friday am- pm)
 [acas.org.uk](https://www.acas.org.uk)

Access to Work grant

 [gov.uk/access-to-work](https://www.gov.uk/access-to-work)
(England, Wales and Scotland)

 [nidirect.gov.uk/articles/access-work-practical-help-work](https://www.nidirect.gov.uk/articles/access-work-practical-help-work)
(Northern Ireland)

Care home inspections

Care Quality Commission (England)

 [cqc.org.uk](https://www.cqc.org.uk)

Care Inspectorate (Wales)

 [careinspectorate.wales](https://www.careinspectorate.wales)

Regulation and Quality Improvement Authority
(Northern Ireland)

 [rqia.org.uk](https://www.rqia.org.uk)

Care Inspectorate (Scotland)


 [careinspectorate.com](https://www.careinspectorate.com)


Thank you for reading this guide

Bookmark this guide in your browser, save it to your desktop or smart phone files or print a copy to have handy.

If you have any questions or need further advice, please speak to one of our specialist dementia nurses. We're here for you:

 Call our free Helpline on

 Email us at helpline@dementiauk.org

 Book a virtual appointment at dementiauk.org/book

If you have found the information in this guide useful and would like more families to benefit from our advice and support, please consider making a kind gift.



To donate call 0800 462 000, visit dementiauk.org/donate-to-help or scan the QRcode. Thank you.




DementiaUK
Helping families face dementia