HELPING CARERS COPE

DEMENTIA HELP

ISSUE 5

In partnership with DementiaNet

‘Key things I wish I’d known about dementia’

Scott Mitchell on the start of Barbara Windsor’s journey

Live-in or residential care?

☑ Expert advice on making the right choice
☑ How the two compare financially
☑ Key factors to consider

SELF-CARE SPECIAL

NEED A BREAK?

Your essential guide to respite care

What to do when swallowing becomes a problem

The best foods and therapies to help

Struggling to get a dementia diagnosis?

Why it’s important and how to get it resolved

Coping with challenging behaviour

How to stay calm and manage difficult days

PLUS

‘Did I just ask you that?’

7 best ways to deal with repetition

> ‘My system made a huge difference’

It was like a lightbulb moment when I realised I needed to start thinking of my mum’s care as a project that needed to be managed.

I had been a magazine editor for many years and knew that one of the most effective ways to meet a deadline and achieve a goal was to set a series of tasks and mini-deadlines, write them down and work through them. I needed to do the same for my mum’s care.

Once I realised that applying the same principles would help Mum, her care ran like clockwork. We had a routine that met her needs and it mostly worked. Yes, there were still unexpected events that arose, but having a system in place made a huge difference.

Helpful support

So, what was my system? It will be unique to everyone, but in my mum’s case, she was living at home alone. Mum needed reliable tradespeople ready to help when household appliances, such as her washing machine, went wrong, so I arranged for her to have British Gas Homecare. I could ring them directly when needed.

Her garden and property needed to be maintained, so I found a reliable local handyman, who came highly recommended. Mum already had Meals On Wheels and a cleaner. All of these people and resources were invaluable in supporting Mum’s care, on top of my regular visits. They all meant Mum could remain in her home for longer.

Practical advice

This issue is all about offering practical advice. Read how you can build your own support crew on page 28.

It’s also about being armed with helpful information. In this issue, Dame Barbara Windsor’s widower, Scott Mitchell, kindly shares his insights and what he wished he’d known about dementia at the start (page 36).

And if you feel like you really need a break, we have the lowdown on respite care on page 18, so that you can take some time out. As the saying goes, you can’t pour from an empty cup.

I hope you find the magazine useful. Take care of yourself.

Christina x

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> ‘We had a routine that met her needs and it mostly worked’

Issue 5

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Next issue out on 8/5/25

Our contributors have a wealth of knowledge and experience about dementia, as well as the help and support available to family carers

JILL ECKERSLEY

Jill is an author and journalist. Her book, *Coping with Early-Onset Dementia*, was published by Sheldon Press in 2011 and another title, *Helping Elderly Relatives*, was published in Sheldon Press' *Overcoming Common Problems* series. She also shared the care of her late mother, who had Alzheimer's and died in 2017, with her family.

MARY JORDAN

Mary is a carer to friends and relatives, and works with a dementia charity. Through her business, Adaptdementia Ltd, she supports people living with dementia and their carers. Mary is also known for her books, *The Essential Carer's Guide*, *The Fundholder's Handbook*, and *End of Life: the Essential Guide to Caring*.

SCOTT MITCHELL

Widower of Dame Barbara Windsor, Scott is an ambassador for Alzheimer's Research UK. He has completed three marathons for Alzheimer's Research UK and is People's Champion of The Dame Barbara Windsor Dementia Goals Programme, the first of its kind for dementia with a funding of £120 million.

LOUISE MORSE

Louise is an experienced Cognitive Behaviour Therapist and has extensively studied the effects of dementia on families. She has over 20 years' experience with the Pilgrims' Friend Society. She explores the importance of spiritual support for those with dementia. For more information, visit pilgrimsfriend.org.uk.

DR CAROL SARGENT

Dr Sargent is a scientist and consultant specialising in dementia-friendly holidays. She works with government organisations to help develop social tourism for those living with dementia, and founded Sargent Group Consulting to create a new service for the dementia community and raise awareness of living with dementia.

CAROLINE SAVAGE

Caroline is a professional carer providing care to the local community in North Devon. She cares for individuals within their own homes. She is trained to Level 3 in Adult Social Care and specialises in dementia care. She ran the London Marathon to fundraise for Alzheimer's Research UK.

JAYNE SIBLEY

Jayne is a co-founder and CEO of Sibstar, a flexible debit card and app. She was inspired to launch it after seeing her mother struggle to manage money. Jayne is an expert brand strategist and marketing professional with more than 20 years of experience. She has headed up teams in large corporations and run small businesses.

SUE STRACHAN

Sue was diagnosed with vascular dementia at the age of 56 and is keen to improve awareness and understanding of dementia and how it affects those living with the condition. She is an ambassador for Alzheimer's Research UK and a campaigner for more funding and support into research, with a view to finding a cure.

Contents

REGULARS

02 Editor's note
Christina reveals how having a system in place can help with dementia care

03 Meet the experts
The team behind the advice

05 The big question
Is dementia genetic?

06 Seven ways to...
Deal with repetition

43 Helpful directory
Supportive helplines and websites for carers

GOOD TO KNOW

08 Does your loved one really need a dementia diagnosis?
Why it's important and what to do if you're struggling to get one

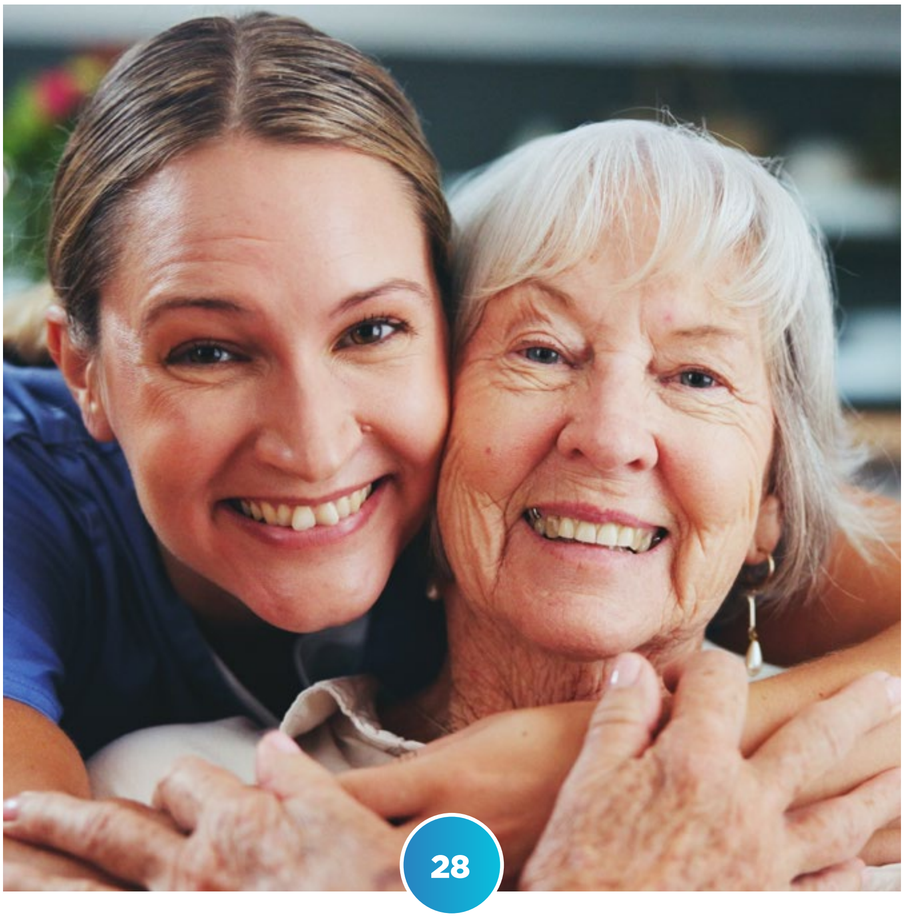
12 Live-in vs residential care
When the time comes for constant care, what's the best option? We look at the pros and cons of both

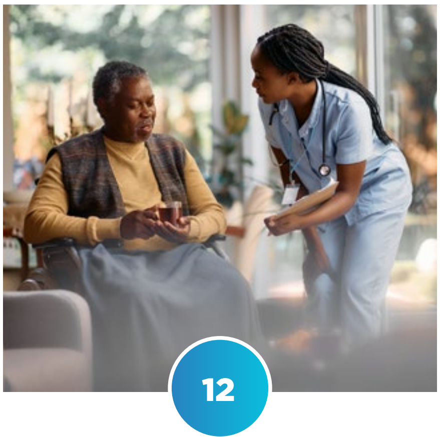
16 DementiaNet – making it personal
Find out more about accessing information tailored to your own situation

18 COVER FEATURE
Give yourself a break
All you need to know about respite care

24 Driving and dementia
Is it a good idea for your loved one to drive?

26 Five ways to improve sleep
Tips to ensure your loved one gets the rest they need





28 Find your support crew
How to enlist the right type of help and support, to make your caring role easier

INTERVIEWS

36 'What I wish I'd known about dementia'
Barbara Windsor's widower, Scott Mitchell, shares his memories, along with some valuable insights

40 'How I deal with challenging behaviour'
Professional carer, Caroline Savage, reveals how she manages difficult situations

NUTRITION

32 Dealing with dysphagia
Problems swallowing can be highly distressing. Here's what to do if your loved one is struggling with meals

Is dementia genetic?

If you're caring for a parent or other relative with dementia, you might wonder if you're likely to develop it in future. Should you be worried?

Alzheimer's disease can affect people at different ages, and genetics can play a role. Early-onset Alzheimer's occurs under the age of 65 and affects an estimated 40,000 people in the UK, though this number is likely to be higher due to undiagnosed cases. Around 10 per cent of early-onset cases display a strong family inheritance pattern.

GENETIC LINKS

Inherited forms of Alzheimer's are typically caused by mutations in three genes – APP, PSEN-1 and PSEN-2, with PSEN-1 linked to around 80 per cent of familial Alzheimer's cases. These mutations are rare, accounting for less than one per cent of all Alzheimer's cases.

However, if you do inherit a mutation in one of these genes, it is likely that you will develop Alzheimer's disease. A child of a parent with one of the three genes has a 50 per cent chance of developing it.

The more common late-onset Alzheimer's, occurring after 65, is influenced by a complex mix of genetic, lifestyle and environmental factors. The APOE gene is the most significant genetic risk factor. Having one copy of a gene called APOE e4 increases the risk, while inheriting two copies raises it further. However, not everyone with this gene variant develops Alzheimer's disease.

> 'Making small lifestyle changes in middle age can significantly reduce your risk'

AGE IS A KEY FACTOR

Age remains the biggest risk factor. After 65, the likelihood of developing Alzheimer's or vascular dementia doubles every five years, with one in 14 people over 65 and one in six over 80 affected.

Vascular dementia is less likely to have genetic causes. Links to the APOE gene have shown mixed results, suggesting further research is needed.

REDUCING YOUR RISK

Regular cardiovascular exercise, such as cycling, running and swimming, alongside a heart-healthy diet, can lower the risk of vascular dementia.

Exercise has also been shown to reduce the impact of genes linked to Alzheimer's, potentially cutting the risk of developing dementia by 30 per cent and Alzheimer's by 45 per cent.

Taking care of your brain health earlier in life is wise, as changes in the brain leading to dementia often begin many years before symptoms appear. Making small lifestyle changes in middle age can significantly reduce your risk. DH

7 ways to deal with repetition

You may find it challenging to deal with repetitive questions or behaviours. Here's how to cope with a person asking you the same thing or asking difficult questions. Words: **Christina Collison**

Asking repetitive questions is a common trait of dementia, but it can also be one of the most taxing aspects for carers. Repetition is a symptom of memory loss. The person may forget they've asked a question or performed a task and feel compelled to repeat the process. My late mum Hazel, who had vascular dementia, often had a nagging feeling she'd already asked a question. She would often enquire: 'Did I just ask you that?' However, she wasn't sure and needed reassurance. This behaviour can stem from feelings of anxiety, insecurity or a need for reassurance. Here are some ways of dealing with it...

1. DON'T POINT OUT THE REPETITION

Avoid pointing out that the person has said the same thing. Saying: 'I just told you that,' or, 'You keep asking the same thing,' will likely just cause unnecessary distress. Answer as if they're asking for the first time.

Answer repetitive questions as though they're asking for the first time

2. DON'T REMIND THE PERSON A LOVED ONE HAS DIED

It can be upsetting when a person with dementia repeatedly asks about someone who has passed away, but reminding them the person has died can bring about fresh grief, as if they're hearing it for the first time all over again. Instead, gently redirect the conversation in a compassionate way. For instance, if they ask when someone is coming back, you might simply try saying, 'They're not able to come right now,' or mention something positive about the person, such as, 'They always loved this time of year.'

3. PROVIDE VISUAL CUES

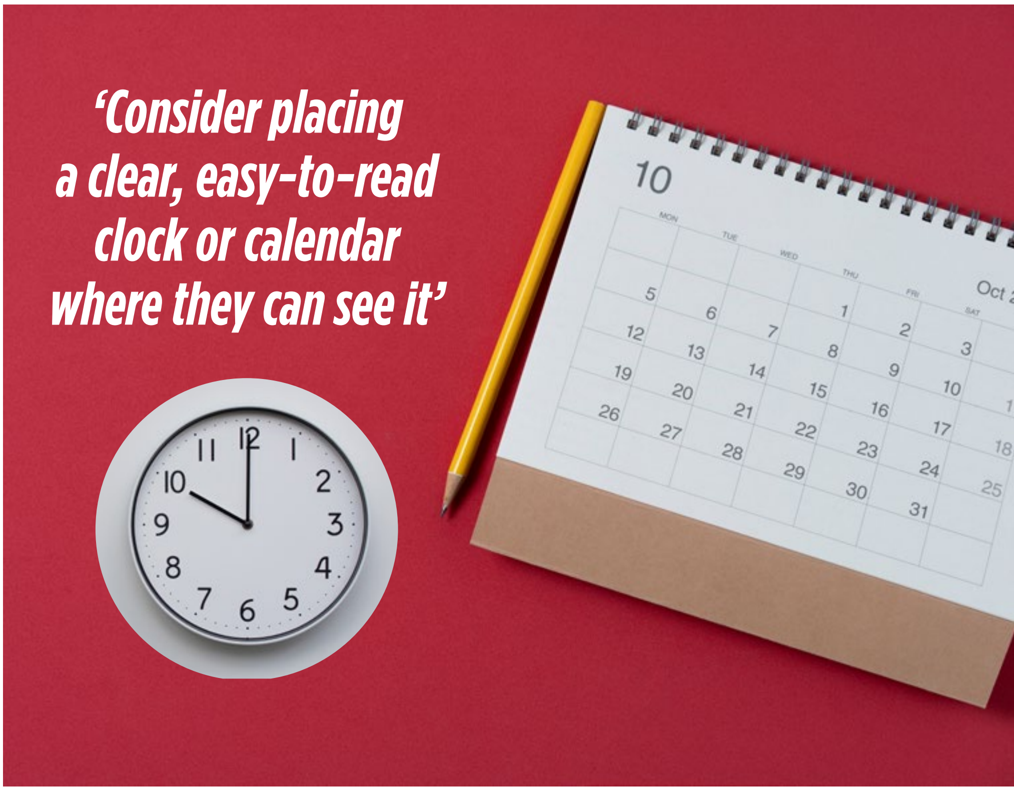
If your loved one frequently asks for the time or date, consider placing a clear, easy-to-read clock or calendar where they can see it. This might reduce the need for them to ask.

CASE STUDIES

Dealing with difficult questions

My mum would often ask why my dad wasn't home from work (he'd died five years before), so I would simply say that there were traffic delays and offer her a cup of tea. The offer of tea was usually an effective distraction.

Scott Mitchell was a carer for his late wife, Dame Barbara Windsor. He says: 'She'd constantly ask, "Is my mum coming to see me today?" to which my answer was, "She might be later". That was so much easier, because the distressing part would have been to remind her that her mum hadn't been alive for many years.'



> 'Consider placing a clear, easy-to-read clock or calendar where they can see it'

4. ADDRESS ANY UNDERLYING NEEDS

Sometimes, repetitive questions can stem from a deeper concern. For example, if they keep asking, 'Did we go to the supermarket?' it might indicate that they're worried about running out of food. Reassure them that everything is stocked or show them the pantry.

5. CREATE A DESIGNATED PLACE FOR SPECIFIC ITEMS

If the person keeps asking for a specific item, such as their glasses or keys, set up an allocated spot for those belongings where they can easily find them. This might be effective in the early stages of the person's dementia. Make sure it's visible and consistent – this may reduce anxiety around searching for lost items.

6. USE LIFE HISTORY FOR CONTEXT

A person's past can often provide helpful clues. For example, if they used to work in a café or pub, they may feel the need to wipe down surfaces repetitively. Instead of discouraging this, engage them in manageable daily tasks, like wiping a table. A resident living in my late mum's care home would often ask me if I'd had enough to eat. It turned out she'd enjoyed hosting dinner parties when she lived at home.

7. ADDRESS SIGNS OF ANXIETY

Some repetitive behaviours, such as zipping and unzipping a cardigan or twisting fingers, may indicate anxiety. Fidget toys, sensory blankets or twiddle muffs can provide a calming outlet. DH

Getting a dementia diagnosis

What can you do if you think your loved one has dementia and you can't get a diagnosis? How important is it to get a formal diagnosis?

Words: **Lyndsey Mitchinson**

If your loved one is experiencing memory problems and you're worried they might have dementia, the first step is to make an appointment with their GP, to discuss their symptoms. Getting a diagnosis can help manage symptoms and ensure they get the support and care they need, both now and in the future.

Types of dementia

In simple terms, dementia isn't a single illness – it's a term used to describe a group of symptoms that affect memory, thinking and how we go about our daily lives. There are different types of dementia, each affecting people in slightly different ways:

Alzheimer's disease is the most common type of dementia. It causes memory loss, confusion and changes in behaviour, making everyday tasks harder.

Vascular dementia happens when blood flow to the brain is reduced, often after a stroke or mini strokes. It can cause problems with thinking, concentration and movement.

Lewy body dementia is a condition that can cause memory loss, but people can also have symptoms such as visual hallucinations (seeing things that aren't there) or problems with movement.

Frontotemporal dementia is a type of dementia that often affects younger people (those under 65).

A dementia diagnosis can help your loved one access appropriate care and support

Symptoms include personality changes, language difficulties and movement problems.

Why diagnosis matters

A dementia diagnosis can help you understand your loved one's condition, and find the right care and support. It can mean getting medication to manage symptoms and, in some cases, slow things down. It also opens the door to helpful resources, such as support services, financial benefits and advice on planning for the future.

A GP will ask questions and may carry out some initial tests

STEPS TO TAKE

Make a doctor's appointment

To start the process, make an appointment with their GP. Let the doctor's surgery know you'd like your loved one to be assessed for dementia – the receptionist may need to book a longer appointment. You can also contact the doctor in advance of the appointment and give some examples of their symptoms – this can be particularly useful if they are reluctant to go and may underplay their symptoms during the appointment.

Keep a record

Keep a record of any concerning changes in your loved one's behaviour, by noting details such as forgetting appointments, having difficulty with everyday tasks (for example, managing finances or cooking), changes in mood or personality, and withdrawal from social activities. This information will be helpful when discussing your concerns with their GP.

> *'Keep a record of any concerning changes in your loved one's behaviour, by noting details such as changes in mood'*

Overcoming the fear of seeking help

Many people resist seeking help due to fear, denial or stigma. Talk to your loved one about the importance of ruling out other treatable conditions that may mimic dementia, such as vitamin deficiencies or thyroid issues. Or frame the appointment as a general health check-up, which may encourage them to go.

What to expect at the appointment

At the appointment, the GP will ask questions and may carry out some initial tests. It's important to attend the appointment with your loved one, to offer support and help provide information. To rule out other possible causes, they may be sent for blood or urine tests. If their GP suspects dementia, they may refer them for further tests with a specialist. This could take place at a hospital, memory clinic or GP surgery, depending on where you live.

Understanding the assessment process

Once your loved one is referred to a specialist or memory clinic, they will typically undergo a series of assessments.


Imaging scans may be conducted to identify any physical changes in the brain

These will help to pinpoint the cause of their symptoms. Cognitive tests are used to evaluate problem-solving abilities, memory and language skills. Imaging scans, such as MRI or CT, may also be conducted, to identify any physical changes in the brain. These appointments can take time, with the entire process often taking a few months or in some cases a lot longer.

What is a memory clinic?

A memory clinic is a friendly and supportive place where specialists help to assess and understand memory problems or other symptoms related to dementia. The team, which may include doctors, nurses and therapists, work together to provide tests, scans and guidance tailored to your loved one's needs. They aim to identify the cause of the symptoms, so that they can then offer advice on treatment, care and support options to improve your loved one's quality of life.

> ‘A memory clinic is a friendly and supportive place where specialists help to assess memory problems’

What to do if your GP isn't taking your concerns seriously

In some instances, you may find the person's GP isn't taking your concerns seriously and you may want a second opinion. If this is the case, politely insist on a referral to a specialist. You can also seek a second opinion from another GP within the same practice. If you're not getting the help you need, you can reach out to Patient Advice and Liaison Services (PALS) for support. PALS is a free and confidential service that can assist with any concerns you may have about NHS services and care. You can locate your nearest PALS office on the NHS website or by asking at your GP surgery.

Waiting for an assessment
There can be a long wait for specialist dementia assessments, depending on where you live. In the meantime, stay proactive by continuing to monitor symptoms. Do your own research on how best to care for your loved one – this could include keeping them active, encouraging healthy eating and enjoying hobbies together. You can also seek support and advice over the phone from organisations like Age UK or Admiral Nurses. There may also be a local dementia support group in your area, where you can meet people going through the same process.

'I PUSHED FOR A DIAGNOSIS FOR MY MUM'

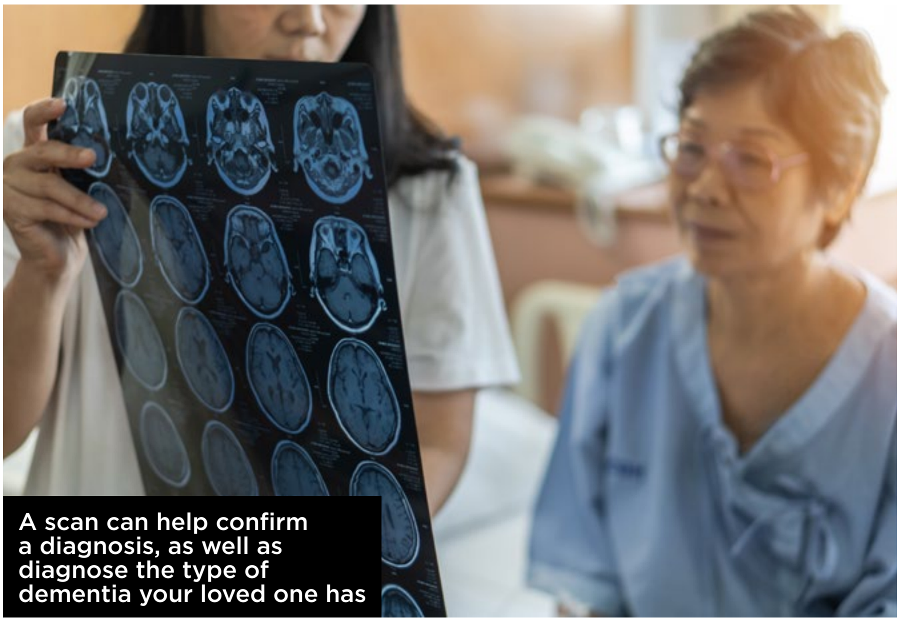
Dementia Help founder, Christina Collison, pushed for her mum's diagnosis, after the GP was initially convinced everything was fine. 'I took her to the GP several times,' remembers Christina. 'On one occasion she correctly drew a clock face, so the GP said she seemed OK. However, when I pointed out Mum wouldn't remember what day it was, what she'd had for breakfast or what her cat's name was, the GP took my concerns seriously. In the end, we got a diagnosis of vascular dementia after she was referred for a scan. If the doctor catches the person on a good day, it can be hard to get a diagnosis. Persistence pays off.'

What happens after testing?
At the end of the testing process, the specialist will be able to provide a diagnosis, confirming whether your loved one has dementia and, if so, the specific type they have. The specialist will discuss what symptoms to expect as the condition progresses, helping you prepare for what's ahead. They will also provide advice on whether medications might be helpful in managing symptoms and slowing progression.

ACCESSING SUPPORT AFTER DIAGNOSIS

What is a needs assessment?
After diagnosis, you can arrange for a needs assessment to be carried out by your local adult social services care team. During the assessment, they will discuss the support your loved one might need. They can help find solutions for things like dressing, preparing meals and staying active. You can find more information on your local council's website or by calling their main phone number.

Financial support
A formal dementia diagnosis might mean your loved one is eligible for benefits, such as Attendance Allowance, Personal Independence Payment (PIP) or Carer's Allowance if you're providing care. It can also make it easier to apply for other financial help, such as council tax reductions or support from local social care services. For more information on benefits, you can visit the GOV.UK website. DH



A scan can help confirm a diagnosis, as well as diagnose the type of dementia your loved one has

Later stage care options

When care needs intensify, it can become difficult to manage at home and many switch to live-in care or a residential setting. We look at the pros and cons of each. Words: **Kay Worboys**

No matter which form of dementia you're dealing with, at some point you will have to reconsider care options.

As the disease moves into the later stages, a person with dementia will be unable to wash or dress themselves, or eat unaided. Choking can become a problem and incontinence is usual. Physical problems will increase, with the person losing mobility over time. Safety is difficult to ensure at this stage and falls can occur.

With the best will in the world, it's very tiring and extremely difficult to provide full-time dementia care at this level all by yourself. Once dementia has reached this stage, in most cases people call upon professional help to assist with the 24/7 nature of caring responsibilities.

There are two main options for dementia care once you reach the later stages:

Live-in care
This is provided by a carer who stays in your home and provides caring duties (sometimes around the clock, sometimes in shifts with another carer).

Residential care
This is when your loved one moves to a care home staffed by professional carers who can provide 24/7 care. This can either be in a residential care home or a nursing home.

'I FOUND THE DECISION HARDER THAN ANYTHING'

Dame Barbara Windsor was diagnosed with Alzheimer's disease in 2014, after experiencing memory-related symptoms for five years. Her widower, Scott Mitchell, talks to us about making the very hard decision to move Barbara to a residential setting.

'I found it [the decision] harder than anything, because that was the point where I felt I'd let her down. I felt by allowing strangers, literally, to take over – although they were the most caring, wonderful people – and to leave her in a place that wasn't her home... that was the thing that really tore my heart in half and made me feel incredibly guilty. I look back now and realise it was the best decision. Our home wasn't equipped in the same way. We didn't have the right-sized bathroom. In the care home, they had seats under the shower. You have two people helping to shower. Those things make a hell of a difference. There was more space for her to move around within that environment. And, of course, there were people there 24/7 seeing what was happening.'

If your loved one has specific medical needs, a nursing home might be a better option. An NHS continuing healthcare check (CHC) should be used to identify what level of need is required. Your local authority or a medical professional can organise a CHC.

Which is best?

Both have their pros and cons. Live-in care means less upheaval for the person living with dementia – they can remain in the familiar surroundings of their own home, and you can be with them and have a say about how they're looked after – but have a break when you need it. It can also be less of an emotional wrench for you.

Residential care usually takes place in a care home – ideally this would be a specialist dementia care home, a nursing home or a regular care home with a dementia unit with specially trained staff. Everything should be tailored to your loved one's changing needs: from dementia-friendly toilets and bathing facilities to an enrichment schedule designed to keep someone living with dementia active, busy and happy.

> 'Having carers living in your home with you can be less costly than residential care'

Live-in care

Having carers living in the person's home can be less costly than residential care. However, you have to get used to having people in your space, and work with them to carry out tasks to your liking and follow your preferred routine.

On the plus side, your loved one can receive consistent care with someone who knows them and understands their needs.


Residential care can give you peace of mind knowing everything is taken care of

‘There was more space for her to move around within that environment and there were people there 24/7 seeing what was happening’

You can receive emotional support from sharing the caring responsibilities.

Some people use a care agency to provide live-in carers, while others hire privately (which can be less expensive). If you hire a carer privately, you’ll be responsible for carrying out relevant checks and references, and will have to organise cover in case of sickness and holiday. If there are any issues, you will have to address them yourself and be responsible for finding a new carer or carers if things don’t work out, which can be time consuming.

Residential care means cooking will be taken care of

Residential care

If you choose residential care, you have the peace of mind of knowing everything is taken care of, from cooking to feeding and personal care. However, as you are not able to be present at all times, it can be difficult to know whether the quality of care is consistent. It can feel impersonal and some people don’t like the noise and atmosphere of living with others who have dementia.

Ultimately, residential care can be expensive. However, you might be eligible to receive financial help, depending on your circumstances.

What to consider

Making the choice between moving a loved one to residential care or hiring a live-in carer is a deeply personal one. Here are some key questions to consider:

- Do you have the space at home for a live-in carer?
- How are you with personal boundaries – will you cope with someone in your space?
- Do you have the patience to teach someone else about your routine?
- Can you afford residential care – how will you fund it?

- Will your loved one be happy in a care home?
- Will you be OK with carers you don't know caring for your loved one when you're not around to oversee things?
- If you currently live with the person, how will you feel about living apart?
- What is the option that suits you both best?

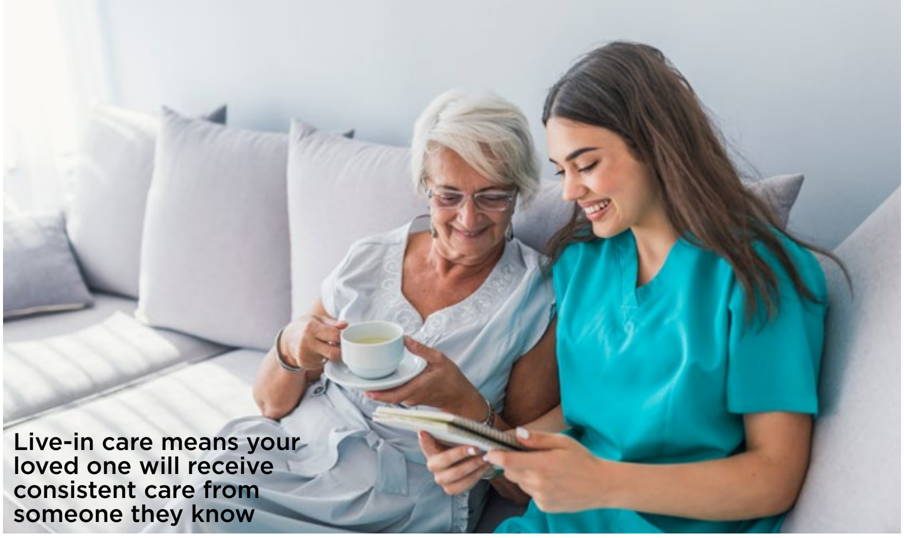
It's a good idea to start having open and honest questions with your loved one sooner rather than later about the type of care and care setting they'd prefer. It's also sensible to start researching agencies who provide live-in carers and getting word-of-mouth recommendations. It's important to do this as early as possible in the person's diagnosis, so that you're well prepared.

Similarly, visit a few residential homes together and get a feel for each. Chat with staff and carers, and note whether they look happy and engaged. Ask about activities, as well as accommodation. Finally, look at all funding options before you make plans for the future.

Paying for later stage care

Whichever option you choose, later stage dementia care involves high levels of care carried out by trained care professionals. It's labour intensive and can be physically demanding, and therefore there are significant costs attached.

How much you pay will depend on your personal financial circumstances. Your local authority can help, but will have to carry out a means test first. If your loved one has assets over a certain threshold, they will have to fund both care options. In certain circumstances, they might be able to access NHS financial support. For example, the NHS Continuing Healthcare package is a care package that offers full funding of care home fees for those who qualify. DH


Live-in care means your loved one will receive consistent care from someone they know

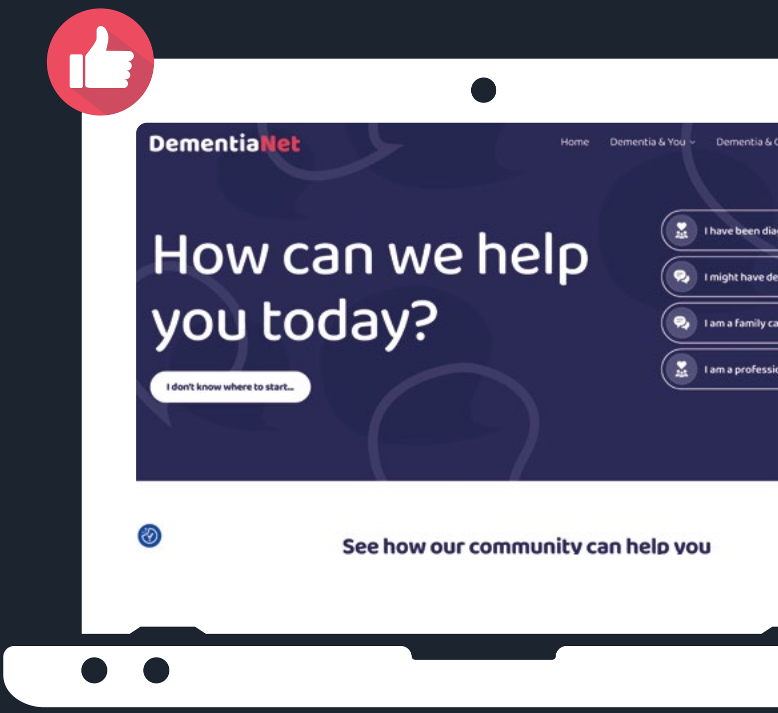
'I WANTED TO BE INSTRUMENTAL IN MUM'S CARE'

Ellen McGee has chosen to care for her 93-year-old mum at home, with the help of a live-in carer

'My dad spent the last few years of his life in a great nursing home with Lewy Body dementia, because I knew I couldn't care for both him and my elderly mother at the same time. Five years after he died, Mum was diagnosed with severe Alzheimer's. I struggled to care for her and work full time from home, so decided to try a live-in carer: I wanted to be instrumental in my mum's care and keep her at home for as long as possible. I interviewed three carers from two care agencies and chose the person I thought bonded with us both. And it's been life changing. Mum is well looked after and I'm no longer exhausted. It's the right choice for us at the moment.'

The dementia website designed to your needs

Brian Schur, co-founder and technical & digital director of DementiaNet, reveals how the new website is helping carers and people with dementia make sense of their situation, with its easy-to-use format and personalised approach



How can we help you today?

When Brian Schur’s mother-in-law was finally diagnosed with dementia, he struggled to collate all the information needed.

‘Just finding out what to do was impossible,’ he recalls. ‘When she was diagnosed, we got two leaflets from the GP and we were sent on our way.’

So along with his co-founders, Angela Walton and Hugh McGouran, he set about creating a platform that would reduce the nightmare of information gathering, planning to save carers time.

The result is DementiaNet – a simple, user-friendly website where you can search for exactly what you need and get quick results and keep all your care plans and important documents securely in one place. You’ll also find helpful articles, advice on making things easier, and information about groups and events in your area. Plus, there is a recently created discussion forum, where an online community will be able to grow and, in time, provide support to each other.

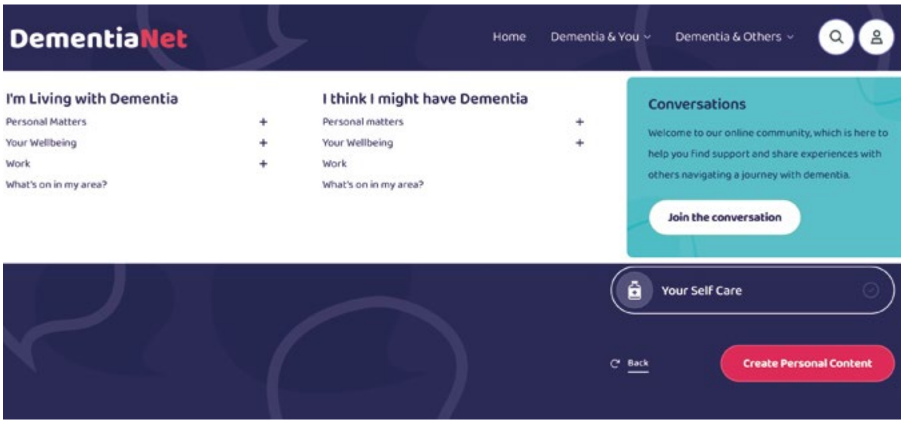
USER-FRIENDLY DESIGN

DementiaNet’s goals are to be welcoming, user-friendly and fully accessible, regardless of individual challenges. ‘Usability and accessibility go hand in hand,’ says Brian. ‘We’ve chosen a clear colour palette and large fonts. We’ve also added an accessibility tool that allows you to, whatever your personal needs, change the site to suit you. So, you can click on a button saying, “I’m visually impaired,” and it will start reading out the website out to you. You can say, “I am elderly,” and it places a focus bar that you can move down the screen, so you’re only focusing on certain parts of the site. If you’re colour blind, it will change to contrast completely. Accessibility is something we’ve thought of from day one.’

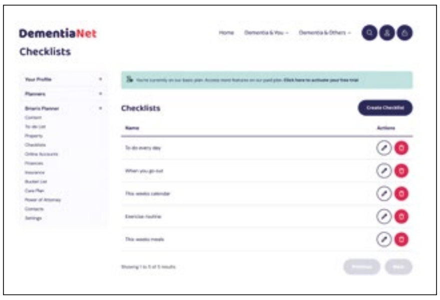
UNIQUE FUNCTIONS

So, what can you use DementiaNet for? The carefully planned site allows you to tailor your experience; you can make it unique to you and click on any of the following…

- ‘I have been diagnosed with dementia’



Welcome to our online community, which is here to help you find support and share experiences with others navigating a journey with dementia.



- 'I think I might have dementia'
- 'I'm a family carer'
- 'I'm a professional carer'

Unlike any other site, DementiaNet will then tailor information suitable for you, which you can choose to save to read later or again. There's also an option to save your personal documents, information and care plans in a secure planner, which can be accessed and shared with family members or others.

'DementiaNet will tailor information suitable for you, which you can save'

'In the planner, you can also set up reminders and to-do lists,' explains Brian. 'For example, if your parent has dementia and you have carers going to visit and support them, you can pull together a to-do list, save it as a PDF and send it to the carer or print it out and leave it on the fridge. This is bespoke, so you can create whatever you want in that list, so. It could be a meal plan, either for a carer or for the individual, if they're still able to cook.

'The planner, which is essentially a safe vault, also helps people get their affairs in order, because many people don't have a list of all the bank accounts and pension pots and properties they have, or details of what they want to happen if they go into care. We've created a system that allows people to store information in a secure, private area and they can share it with trusted people or family members.'

In addition, if you run local dementia activities or support groups, you can upload details of them to an online directory that other carers and healthcare professionals can see, free of charge.

'We're building the directory daily,' says Brian. 'We want people to be able to find out what's on locally to them that might help. Currently, a lot of these activities are only on Facebook or on noticeboards in the local area which can be hard to find. Most of them don't have websites, so anyone who wants their event on our directory can join, and we hope to be the biggest dementia event listing site in future. It's free to post your event.'

EASY ACCESS FOR ALL

Brian and the team would love you to visit the site, so you can see how it could help make your life easier.

'Any feedback is welcome,' he says. 'Anybody who reads this article and then visits the website can email me their feedback at info@dementianet.com.' DH

More information

To find out more or to create an account, simply visit dementianet.com. Much of the site content is accessible free of charge and if you'd like to access the secure planner to manage your loved one's paperwork, it costs just £3.99 per month or £39.99 for a year's subscription. For help or enquiries, please email info@dementianet.com

Give yourself a break

Burned out and exhausted? You need a break, but you might wonder how that's even possible. Respite care may be an option

You know you need a break, but right now the thought of being able to take one seems completely unrealistic. You might also feel it's pointless. If you've attempted a break before, but found your holiday interrupted by problems, you may feel there's little point in even trying. Or you may feel you'd be worried about your loved one the entire time, which would defeat the purpose of a holiday.

LOOK INTO RESPITE CARE

Have you thought about respite care? Respite care is short-term care that allows carers to take a break while your loved one is looked after by someone else. It could be ideal if you simply need a week or two to recuperate. It's also suitable for carers who need a day off, or even a few hours to do something they enjoy.

FLEXIBLE OPTIONS

There are various options for respite care – if it's just a few hours you need, the person could go to a day centre. If you need a proper holiday, you could look into care at home from a paid carer, a short stay in a care home or getting friends or family to help.

For many carers, help from family members may not be an option. So you may be wondering whether the local council will fund professional care, or whether you'll have to pay for it yourself. According to the NHS website, local councils will only fund respite care for people they have assessed as needing it.

GET ASSESSED

The first step, then, is to get your loved one assessed if you haven't already. Contact the local council and ask for an assessment.

'We would recommend that anyone who hasn't had a financial assessment should do so before planning a holiday,' says Amanda Tomlinson, team leader for Rotherham Dementia Carer Support.

CHOOSING THE RIGHT RESPITE CARE FACILITY

- Check the CQC website first and foremost.
- Speak to the care home to see what activities they offer and how flexible the schedule is.
- Find out if they speak to the people staying to enquire about what they enjoy and whether they plan activities around their preferences.
- Always visit in advance.
- Speak to residents, visitors and carers about the quality of care.
- Look at the menus, décor and schedules – you'll get a good feel for whether your loved one will feel comfortable there.

'It can make a huge difference to the options available. Every local authority website will have a section about carers.'

FIND OUT WHO PAYS FOR CARE

Whether or not you have to pay for respite care depends on your situation.

'It all depends on whether you've had a financial assessment with the council to see whether you qualify for funding,' says Amanda. 'The council has a list of approved providers that offer respite. If your loved one qualifies for funding, you'll need to choose a service approved by the local authority. If you don't have funding and you are paying privately, that would open you up to all private respite providers. Many residential and nursing homes will provide this service.'

> *'Local councils will only fund respite care for people they have assessed as needing it'*

DON'T LEAVE IT UNTIL THE LAST MINUTE

Planning ahead is key, though, so make sure it's not a snap decision. Care homes and other providers will need notice.

'It's important to plan well in advance, as places are usually limited,' adds Amanda.

Respite care could afford you the break you need – and deserve

Unwind on your break knowing your loved one is in good hands

'There is emergency respite available for safeguarding issues or illness, but for a holiday, the carer would need to allow a minimum of three months to identify a suitable care setting and carry out the necessary visits.'

USE THE CARE QUALITY COMMISSION'S WEBSITE

Naturally, you'll want to ensure that the care your loved one receives is good quality. How can you identify suitable options?

'The first place to look is the Care Quality Commission's website at cqc.org.uk,' says Amanda. 'You can use this to look for services in your area and also check the most recent reports. The report summary and the score will give a good indication of the quality of care. Word of mouth and personal recommendations are also really important. Speak to other carers at local groups and dementia cafés, to find out where they take their loved ones.'

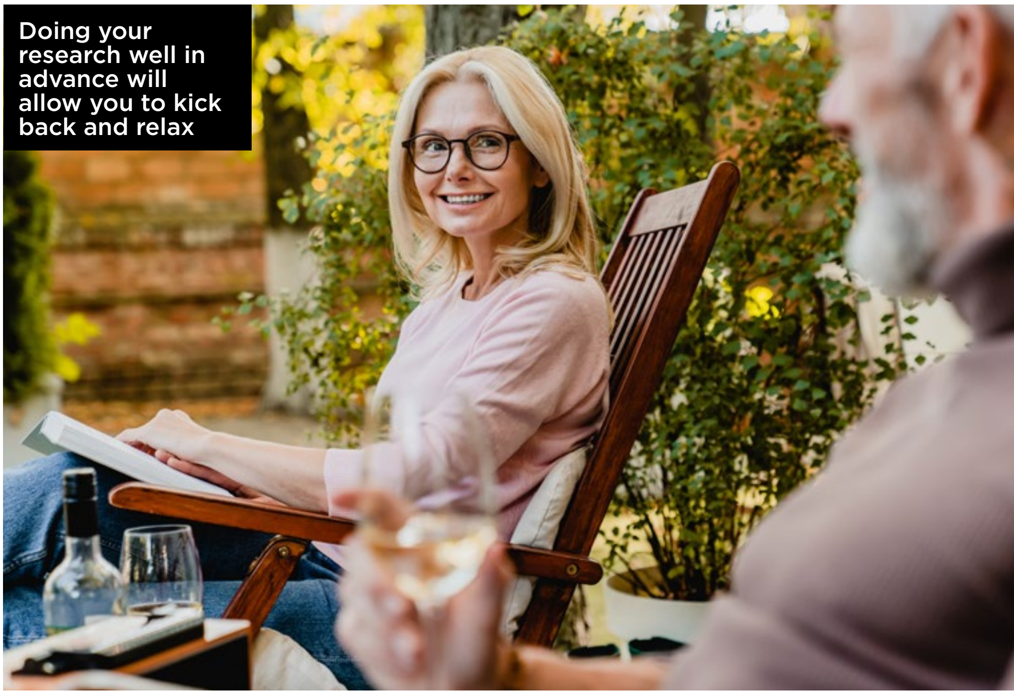
VISIT THE CARE HOME IN ADVANCE

If you want to place your loved one in a care home while you go away, you may be concerned about how they will cope with a new environment. Is this something worth worrying about?

'It very much depends on the person and where they are in their dementia journey,' says Amanda. 'Some people look forward to respite and even see it as a holiday. Others can be confused and angry. In every case, it's important to visit the care home, speak to the team, see how the person with dementia settles in and whether it's a good fit. Visit for a day at first and then overnight if possible. Don't be afraid to raise any issues with the care team – they should be just as keen as you are to make sure the person living with dementia is happy, comfortable and well settled.'

SEEK EXPERT HELP

The national charity and healthcare provider, Making Space, offers people who use its dementia services a 'respite passport'. This includes all the relevant information about likes, dislikes and routine, so the care team can use that to help the person with dementia settle in and adjust to their new surroundings.



Doing your research well in advance will allow you to kick back and relax

> ‘Another option is respite care at home, where your loved one remains in their own home’

CHECK THE LOCAL AUTHORITY WEBSITE

To find carers and respite help in your area, the local authority will have a section for carers on its website that has all the services available where you live. Making Space can also offer guidance and support, as can other charities and services that offer dementia care – they can be found online by searching for dementia services in the area.

DO YOU QUALIFY FOR A FREE HOTEL?

There’s an organisation called Carefree Breaks (carefreespace.org) that offers free hotel breaks for carers around the country – you just need to pay a small admin fee. The carer will need a referral, which they can get by visiting a Making Space dementia service or another similar service in their area. This is only for the carer, not the person with dementia – respite will need to be arranged separately. But it’s a great way to get a break and keep costs to a minimum.

ASK OTHER FRIENDS OR FAMILY MEMBERS TO VISIT

While you’re away, ask other relatives to visit the person if they are staying in a care home. Seeing familiar faces will help your loved one feel more comfortable.

‘They can visit and spend time doing activities they know the person with dementia enjoys,’ says Amanda. ‘Also, temporarily being registered as the person to contact or next of kin will be helpful, so the person with primary care can have a proper break.’

CARE AT HOME

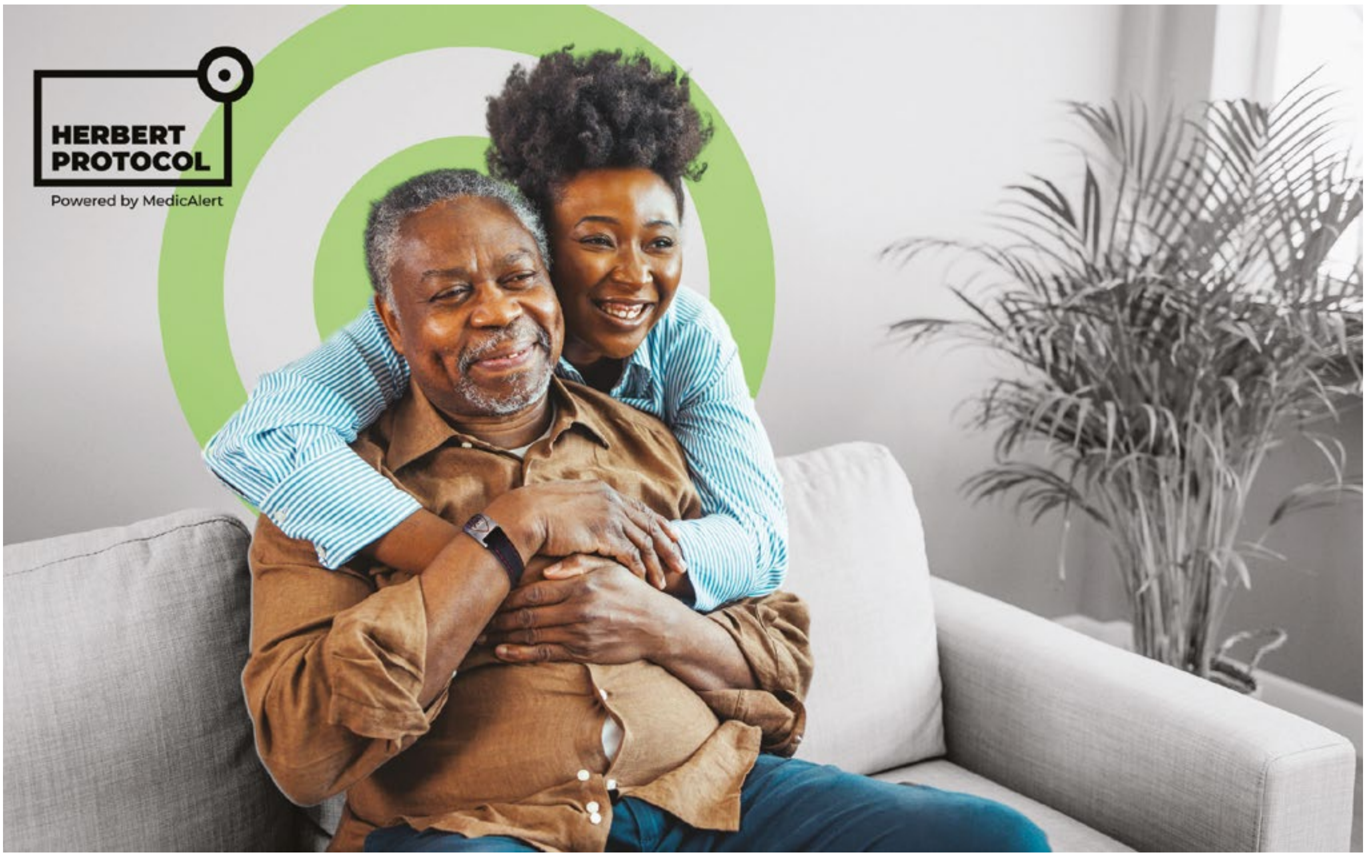
Another option is respite care at home, where your loved one remains in their own home and paid carers come in to look after them. Many home-care agencies provide this service, and it can be tailored to suit your loved one’s care needs. They usually offer visiting respite care or live-in respite care. Fees vary, but costs on average range from £700 to £800 per week for visiting carers. For live-in respite care or a care home, the cost is likely to be around £1,500 per week.

More information

Amanda Tomlinson is team leader for Rotherham Dementia Carer Support, which supports people who are caring for someone with memory loss or dementia. They can offer one-to-one support, carers’ needs assessments, dementia cafes, including live music, and courses. The service is operated by national health and social care charity, Making Space. For further information and advice, please email rotherhamcarers@makingspace.co.uk or call 01709 910889.

Keep your loved one safe with a Herbert Protocol

Get peace of mind by signing up to MedicAlert UK's new safeguarding scheme for people with dementia



When your loved one has dementia, fear of them going missing is a very real concern. Latest figures state that nearly one million people are currently living with dementia in the UK and approximately 40,000 are reported missing for the first time each year, with some 70 per cent of people living with dementia reported missing at least once.

If your loved one wants their independence for as long as possible, perhaps by living alone in the early and mid stages, it's of course important to try to respect their wishes as much as possible. But how can you gain peace of mind when you're constantly worried they could go missing?

SAFEGUARDING LAUNCH

Thankfully, MedicAlert UK has announced the launch of its new safeguarding scheme and website dedicated to the Herbert Protocol, filled with invaluable resources for those living with dementia, their loved ones and carers. The website, herbertprotocol.com, provides comprehensive resources designed to support those affected by dementia. In addition, MedicAlert UK has introduced an innovative feature that allows users to create a profile to store a Herbert Protocol within the MedicAlert emergency service database free of charge. This initiative is part of a broader effort to enhance safeguarding measures and ensure the safety of vulnerable individuals across the UK, and is also endorsed by the National Police Chiefs Council (NPCC).

HERBERT PROTOCOL
Powered by MedicAlert

‘A completed Herbert Protocol form provides the police and emergency services with essential information’

WHAT IS A HERBERT PROTOCOL?

The Herbert Protocol is named after George Herbert, a Normandy war veteran who lived with dementia and who inspired its creation after going missing. It’s a proven tool in safeguarding those living with dementia. A completed Herbert Protocol form provides the police and emergency services with essential information that can aid with a search if a person living with dementia goes missing. By storing this information centrally in the MedicAlert emergency service database, it becomes readily accessible to the authorities, significantly reducing search times and increasing the chances of bringing vulnerable individuals home safely and quickly.

KEY FEATURES OF THE SCHEME

If you’re a carer for a loved one with dementia, visit herbertprotocol.com online to find:

- **Dedicated resources**
The website offers a wealth of information tailored to the needs of people living with dementia, their families and carers, including guidance on how to complete the Herbert Protocol form.
- **Free user profiles**
Individuals can create a free user profile to securely store their Herbert Protocol information in the MedicAlert emergency service database.
- **Enhanced accessibility**
The new safeguarding scheme is accessible to anyone affected by dementia, providing a critical resource that can be activated if a loved one goes missing.
- **Support for the police and other emergency services**
By having immediate access to vital information, police and emergency services can respond more effectively and efficiently, ensuring a quicker and safer resolution.

FREE FOR ALL

MedicAlert UK invites all individuals, families and carers affected by dementia to visit herbertprotocol.com to take advantage of the new resources and sign up.

‘We are thrilled to launch this new website and offer a free safeguarding scheme that will have a profound impact on the safety and wellbeing of those living with dementia,’ says Rob Burley, CEO at MedicAlert UK. ‘Making the Herbert Protocol information easily accessible to emergency services provides peace of mind to individuals, families and carers, giving them the confidence that help is readily available if their loved one goes missing.’ DH

Further information
MedicAlert UK provides life-saving support to people with medical conditions. It is the first and only medical ID charity and has been providing this service in the UK for more than 60 years. Through its comprehensive database and medical ID system, MedicAlert UK ensures medical details are available when needed most. Visit herbertprotocol.com to complete your Herbert Protocol or email herbertprotocol@medicalert.org.uk or call 01908 951045 for more details.

Driving and dementia

Can your loved one still legally drive if they have a dementia diagnosis and, if so, is it a good idea? **Christina Collison** reports

It's often said that you should encourage a person with dementia to remain as independent as possible for as long as possible. I generally support this advice, but driving can be a worry, because you might be concerned that your loved one could go out and get lost or drive erratically.

When my mum had dementia, she continued driving for a year or two, but gradually it became a problem. One day, she parked her car and forgot where she'd left it. Another time, she got lost taking her cat to the vets, even though it was a short trip and a very familiar journey for her. It became apparent it was no longer safe for her to drive. I reluctantly suggested she stop driving and although she agreed, she was understandably very frustrated about the loss of independence. She also forgot later on that she had agreed to stop driving, so there were times when I had to ensure her keys weren't around for her to access.

So, should a person with dementia continue to drive? It's a legal requirement that a person in England or Wales diagnosed with dementia must inform the DVLA. If not, they could face a fine of up to £1,000.

To notify the DVLA, you or your loved one need to go to the website and fill in a medical condition form called a CG1, then send it to the DVLA. The DVLA will then take steps to decide whether they are safe to drive.

Once the person has informed the DVLA, the DVLA will send them a questionnaire to complete and ask for medical reports from their GP. The DVLA will also speak to the person's doctor.

The DVLA will then decide whether the person can still drive. If they can, the DVLA will send the person a new driving licence, valid for one year – although it could be for up to three years if your loved one has early dementia. The person may be asked to take an assessment before the DVLA decides. If the DVLA decides the person shouldn't drive, their licence will be revoked.

Your loved one must also notify their insurer of their diagnosis. If they don't, their policy could be invalid.

It's important for your loved one to have regular medical checks and for you to keep an eye on their driving. It may be best for the person to stick to short journeys and familiar routes, and to only drive in daylight. It's also important to ensure the person only drives when they feel well rested. DH

'It may be best for the person to stick to short journeys and familiar routes'

Case study

'I WOULD KNOW IF I WAS NOT SAFE'

Sue Strachan has vascular dementia and is still able to drive. Here, she explains how she manages the situation...

Every year now, I get a form from the DVLA, which I must fill in saying whether I've had any episodes of increased problems with dementia. I photocopy them so that I've got them, because from year to year, it rarely changes, and I don't want to put something on a form that isn't right. So, I need to check last year's form and test myself and say, 'Well, hang on, is this still the case?' That also must go to the GP, and then I have a double appointment with the GP.

The last two years, on both occasions, I've gone on my own to the GP, who has said, 'The fact you've come here on your own is already an indication that you still have some independence.' I would know if I was not safe. There are mornings when I wake up and think, 'I don't want to drive today'. If I don't feel comfortable about it, I don't. And when I do drive, I don't go very far. If I do go far, it's usually to places I'm familiar with.

Five ways to improve sleep

Sleep disturbances in people with dementia are common, but with the right approach, you can help your loved one get the rest they need and ensure their safety at night. Words: **Angelina Manzano**

A person with dementia may become more restless at night and can be prone to waking. Dementia affects the parts of the brain that control the body's circadian rhythm – the natural sleep-wake cycle – and when these areas are damaged, it becomes harder for a person to regulate their internal body clock. This can result in disrupted sleep, as well as episodes of confusion or agitation during the evening and into the night, which is commonly referred to as 'sundowning'.

Sleep problems in a person with dementia may also be exacerbated by physical discomfort, such as the need to use the bathroom, hunger, thirst or anxiety – all of which are harder to communicate as the disease progresses.

These disruptions are also exhausting and stressful for carers – but understanding why dementia affects sleep and how to manage these disturbances is key to improving the quality of life for both the person with dementia and their carer.

CALM ENVIRONMENT

By creating a calm, consistent environment and paying attention to both the person's physical and emotional needs, you can hopefully reduce the frequency of night-time waking. Although this strategy may not eliminate sleep disruptions completely, they can help to improve the quality of life for both the person with dementia and their carer, making bedtime a far less stressful experience for all involved.

Here are five steps you can take to help your loved one sleep better and stay safe...

1. STICK TO A ROUTINE

A steady routine helps reinforce the body's natural sleep-wake cycle and can reduce confusion or anxiety caused by unexpected changes. Aim to keep the person's waking, meal and bedtimes the same each day. By keeping to a predictable routine, you can help your loved one feel more secure and less anxious, which can contribute to better sleep.

2. CREATE A COMFORTABLE SLEEP ENVIRONMENT

A person's sleep environment plays a crucial role in determining the quality of their sleep. Aim to keep the bedroom at a comfortable temperature that's conducive to restful sleep. Minimise distractions and make the bedroom as dark as possible. While complete darkness is ideal for inducing sleep, you could consider using a soft nightlight to prevent disorientation or falls if your loved one wakes up to use the loo in the night.

3. LIMIT DAYTIME NAPPING AND STIMULATING ACTIVITIES IN THE EVENING

Daytime napping can disrupt sleep, so try to limit naps to no more than 20-30 minutes, preferably earlier in the day, so that your loved one will be more tired at night. Engaging in light physical activity, such as a short walk or simple exercises, can also help promote better sleep – but it's important to avoid overstimulation in the evening. TV, loud conversations or exposure to bright lights all make it harder to wind down. Establishing a calming night-time routine can signal to your loved one that it's time for bed, so try to engage in soothing activities – listen to calming music, read a familiar book or run them a warm bath.

4. MONITOR DIET AND LIMIT STIMULANTS

Certain food and drink can interfere with sleep, especially in the afternoon or evening. Energy-boosting caffeine, found in coffee, tea and chocolate, should be avoided after midday, and the same goes for sugary snacks or heavy meals close to bedtime, which can induce discomfort caused through indigestion or acid reflux. Instead, offer a light snack, such as a banana (packed with magnesium and potassium) or a small glass of warm milk (which contains the amino acid tryptophan), both of which are recommended to beat insomnia. Encouraging proper hydration throughout the day, while limiting fluids a few hours before bed, can also reduce the urge for night-time trips to the bathroom.

> **'Certain food and drink can interfere with sleep, especially in the afternoon or evening'**

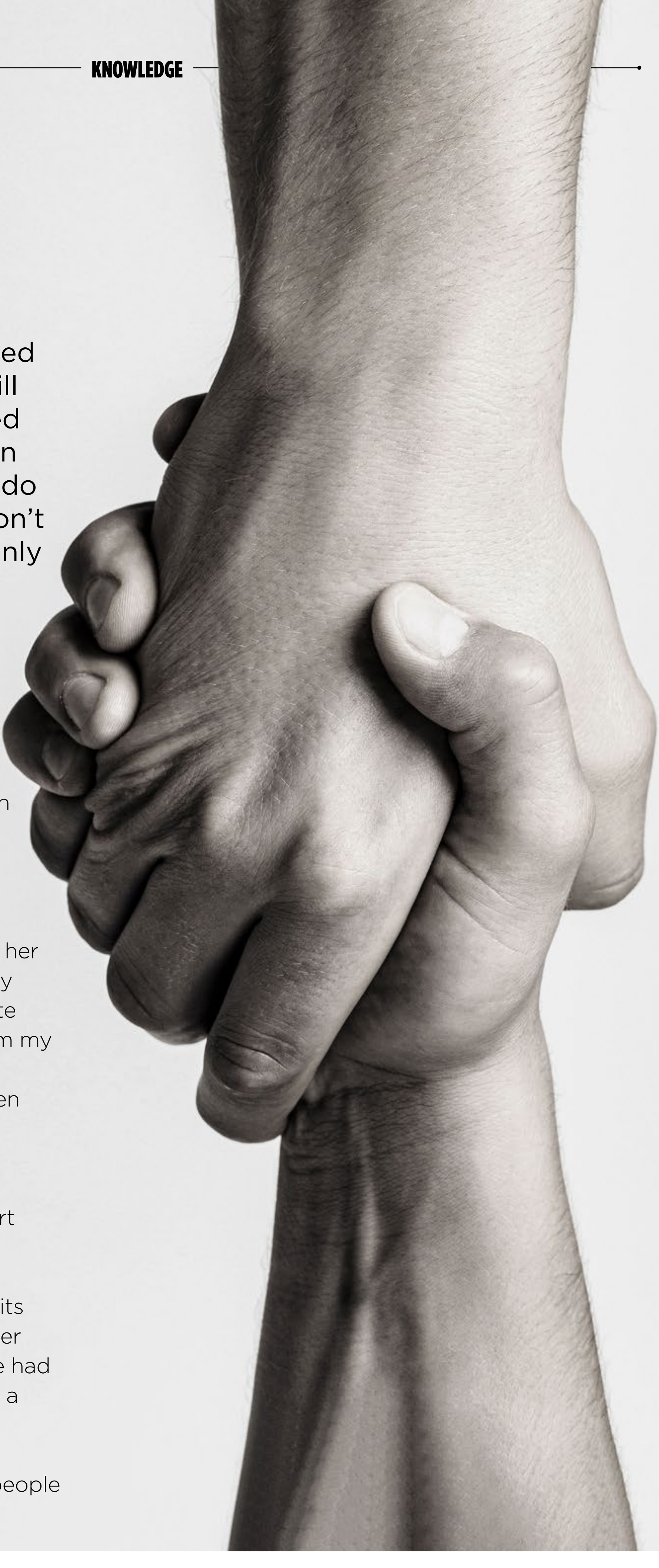
5. TRY MOTION SENSOR NIGHTLIGHTS

Despite all your best efforts, your loved one may still wake up during the night. For their safety, take steps to minimise the risk of wandering and falls. Motion-sensor nightlights in hallways or in bathrooms can provide enough light for them to navigate, without becoming overstimulated. Door and window alarms can alert you if they try to leave bed or the room unexpectedly, and consider using safety locks on exterior doors if wandering is a concern. Installing bed rails and removing any trip hazards, such as rugs or clutter, from their path will also reduce the risk of falls and injury. DH

Find your support crew

Struggling to care for a loved one on your own? There will come a time when you need more help and support than before – but what can you do if other family members won't do their bit, or you're the only family member?

Words: **Christina Collison**



It took me a long time to admit that I couldn't do it all on my own. Caring for my mum was mentally and physically draining, and as her needs grew, the situation became more challenging. There came a point when what I could offer was simply not enough. What Mum needed and what I could give were two different things. Juggling her care with working full-time in a busy job with a three-hour daily commute (while Mum lived an hour away from my home) was impossible to sustain in the long-term. Even more so when Mum's needs increased.

LACK OF SUPPORT

Unfortunately, I had minimal support from family members. One relative proved to be unreliable and self-motivated. Mum had occasional visits from another relative and my partner helped out sometimes. However, he had other tasks and priorities, including a busy work schedule of his own.

I felt alone at the time, but I also knew that there were many other people out there facing similar challenges.

‘Many carers find themselves trying to cope with caring duties alone’

WHY DO SOME PEOPLE BACK OFF?

‘Some friends can back away,’ says Scott Mitchell. ‘We had some friends who suddenly weren’t around and at first you think, “What’s wrong with them?” But it can be anything. It can be a trigger of something they may have gone through themselves that they can’t face seeing again with somebody else, or the fear of not knowing how to react, what to say, what to do, because they may know nothing about the illness. So, they think avoiding contact is most likely the easiest way.’

Many carers find themselves trying to cope with caring duties alone, which leads to feelings of isolation, as well as practical challenges.

According to Carers UK, some 50 per cent of carers in the UK feel lonely. A 2020 survey by the University of Exeter showed that 44 per cent of dementia carers reported moderate loneliness, while 18 per cent said they felt extremely lonely.

GOOD INTENTIONS, BAD IDEA

One of the reasons why it can be lonely as a carer is that friends don’t always know how to help. Some of my friends kept encouraging me to go out and have a few drinks, telling me it would make me ‘feel better’. It wasn’t what I needed to hear and certainly wasn’t a solution. I really needed practical help.

However, I realised that some friends genuinely didn’t know how to help or what to say. Scott Mitchell, who cared for his wife Dame Barbara Windsor, encourages carers to maintain their own social life to avoid feeling isolated, but acknowledges the challenges.

‘Making sure that you keep social contact with other people, so you don’t become isolated, is very important,’ he says. ‘Of course, that can be difficult because, apart from not being able to go out as often, some people deal with it better than others.

For me, exercise became very important. You can become quite housebound with the person.'

BUILD A RELIABLE SUPPORT CREW

The key is to start building a reliable support crew around you. If you don't have the support and help you need from family members, then it's time to look further afield and speak to people you know who have a proven track record of being reliable. Who could you turn to for help? Who is in your life who turns up on time and historically has done what they say they'd do? Who lets you down at the last minute or regularly cancels arrangements? It's not difficult to know who to trust when you look at people's past behaviour.

When caring for my mum, I had two close friends whom I'd known for many years. My mum knew them, too. One of them would visit her every few weeks for a coffee and a chat while I was working. The other would ring Mum when I went away for work, just to keep her company.

SUPPORT FROM THE LOCAL COMMUNITY

Mum also had caring neighbours. One couple who lived opposite would look out for her, especially in the winter, even bringing her groceries one day when it had snowed. Another neighbour would pop round for a chat. She had good support from people who didn't even know her all that well. One of them told me one day he had been through the same thing with his mum, and he could see mum and me both struggling, and wanted to help. I was amazed at how caring and generous people could be with their time for someone they didn't even know very well.

> *'I was amazed at how caring and generous people could be with their time'*

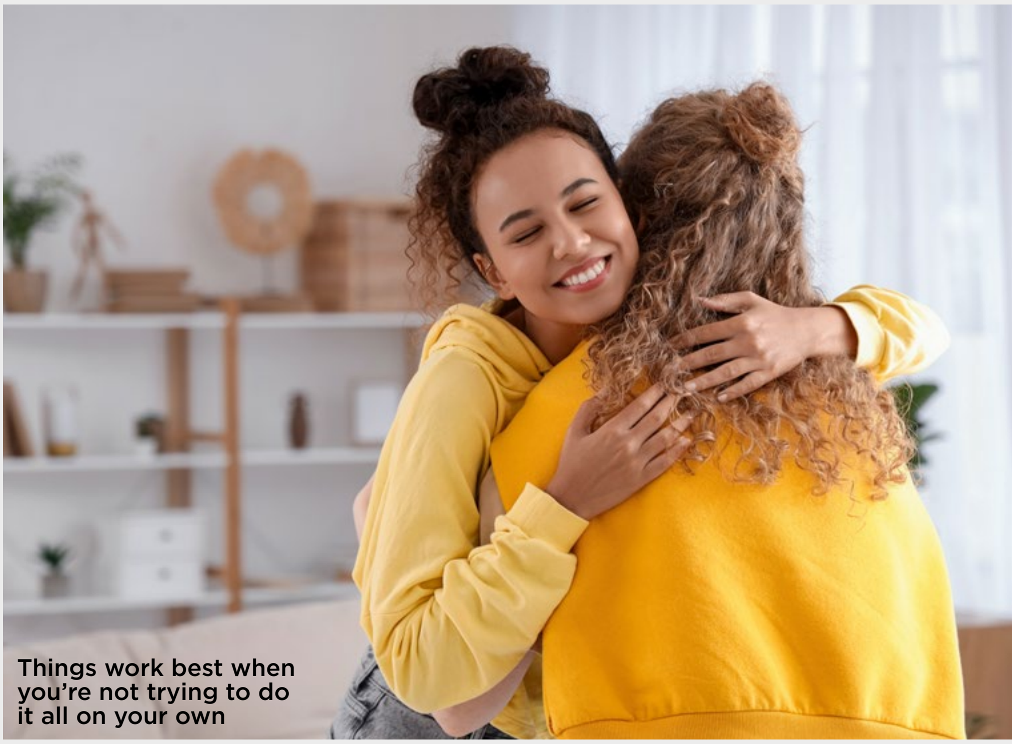
Call on your trusted friends for moral and practical support

COPING WHEN YOUR LOVED ONE REFUSES HELP

It can be a challenge if your loved one clearly needs help and won't accept it. You can find all the help you need, but if they don't think they need it then this presents an entirely separate challenge.

Being overly bossy by telling them they need it and pointing out why will most likely only make the person defensive.

Instead, be diplomatic. Gently suggest that they might benefit from a bit of help, framing it as giving them a break. My mum initially resisted, but I managed to persuade her gently. When she struggled with carrying the hoover downstairs, I used it as an opportunity to suggest getting someone in to help with cleaning, highlighting the risk of a fall. I reminded her that, living in a big house, a little help could give her more time to do things she enjoyed. I emphasised that having someone clean once a week could also provide some company, especially as she often mentioned feeling lonely.



Things work best when you're not trying to do it all on your own

Is there anyone in your community who can help with your loved one? Even if it's an hour a week, so that you can take some time out.

My advice is to look at the level of help and support the person needs right now. Is it mainly company they need, alongside a bit of help with shopping, or are they struggling to prepare meals, do the housework or go out safely on their own?

PLUG THE GAPS

Look at what the person needs, then work out how you can plug the gaps and who can help. Decide what's realistic for you to commit to – if it's just one or two visits each week then don't feel bad. You're doing your best in difficult circumstances. Don't try to overcommit if it's unrealistic. Be honest with yourself about how much you can do on your own. With my mum, for instance, I could only visit her twice a week, and it reached a stage where I knew she would need someone physically checking on her every day. So, I arranged for her cleaner to go in twice a week, professional carers to go in on the days when the cleaner wasn't there and for me to cover the other days. It worked for a time. When her needs grew, so did the level of care. Mum didn't always appreciate people coming in, but ultimately I knew it would help keep her safe.

One friend gave me great advice: 'It's not your job to make your mum happy, it's your job to try and keep her safe.' I can honestly say I did my best, and it worked best when I wasn't trying to do it all on my own. DH

Coping when swallowing becomes a problem

What is dysphagia – and is your loved one at risk? We investigate the signs and symptoms, and explain what can be done to help the person with dementia. Words: **Claire Chamberlain**

A diagnosis of dementia can bring with it many expected – and some unexpected – symptoms. You might be aware of, and prepared for, confusion, forgetfulness and mood changes, but there are some other symptoms of dementia that might come as more of a shock. Dysphagia – or difficulty swallowing – is one such symptom. Here, we'll explore what it is, why and when it occurs, and what you can do to help alleviate any distress and difficulty.

WHAT IS DYSPHAGIA?

The term 'dysphagia' refers to difficulty swallowing. In people with dementia, it can be caused by damage to the area of the brain that's responsible for coordinating the muscles used for swallowing. It's quite common and, while symptoms can be present fairly early on, it's a problem that tends to worsen as the dementia progresses. In fact, a 2022 systematic review into dysphagia in Alzheimer's disease, published in the journal *Dementia & Neuropsychologia*, found that the prevalence of dysphagia in people with moderate to severe Alzheimer's disease was as high as 84 to 93 per cent. However, despite this, the problem can often be overlooked.

'Ironically, dysphagia remains an overlooked symptom, even when its complications can lead to longer hospitalisations and increased healthcare costs,' said reviewers in their report.

DYSPHAGIA SIGNS AND SYMPTOMS

If you're concerned that your loved one might be suffering from dysphagia, there are a number of signs and symptoms to watch out for. These include:

- Drooling saliva, food or drink
- Poor lip closure
- Taking a long time to chew food, or continual chewing with no swallowing at all
- Pouching food in cheeks
- A delay in swallowing
- Coughing, throat clearing or choking when eating or drinking
- A wet sound when eating or drinking
- Refusal to eat or drink

DYSPHAGIA: THE RISKS

Because dysphagia is associated with being unable to swallow food or drink effectively, one of the most common risks associated with the condition is weight loss, alongside malnutrition and dehydration. However, there are other risks as well. These include choking and aspiration (food going down the wrong way into the lungs), which can in turn lead to repeated chest infections. Both of these risks can be extremely serious. And of course, ultimately all of these side effects can result in the person becoming fearful of eating or drinking, which can lead to food refusal, perpetuating any weight-loss issues even further.

A common symptom of dysphagia is drooling food

'Dysphagia remains an overlooked symptom, even when its complications can lead to longer hospitalisations'

OFFERING SUPPORT FOR DYSPHAGIA

Dysphagia can be highly distressing, both for the person experiencing it and for carers. But there are things you can do to help support your loved one.

'Through our work in the senior care industry, we've gained insights into the challenges faced by dementia patients, including issues like dysphagia,' says Dharam Khalsa, CEO and founder of Mirador Living (miradorliving.com). 'We have learned from our care providers that patience and careful observation are crucial. Carers should watch for signs of difficulty swallowing and adjust mealtimes accordingly.

KEY FACTS ABOUT DYSPHAGIA

Six key points...

1. In people with dementia, dysphagia (difficulty swallowing) can be caused by damage to the area of the brain associated with swallowing.

2. Risks of dysphagia include weight loss, dehydration, choking and aspiration (food making its way into the lungs), which can cause serious infection.

3. Signs of dysphagia include drooling, pouching food in cheeks, coughing or choking while eating, and food refusal.

4. Support the person with dysphagia by offering smaller meals more frequently (think 'little and often'), creating a calm environment, gently reminding the person to swallow, and offering adaptive utensils.

5. Smooth, sticky foods will be easier for the person to swallow. These include pureed foods, scrambled eggs, mashed potato, thick custard and yogurt, and shakes and smoothies.

6. A speech and language therapist will be able to offer support and advice, including swallowing therapy exercises. Speak to the person's GP to get a referral.

Creating calm, distraction-free environments during meals helps people focus on eating and swallowing safely, while encouraging upright posture during and after meals aids in swallowing and digestion.'

OFFER VERBAL PROMPTS

If the person still seems distracted or becomes confused about what they should be doing at mealtimes, you can offer verbal prompts that it's time to swallow, or talk to them about the food they're eating while they're chewing, to keep their mind focused on their meal.

While it's important to let the person be as independent as possible during mealtimes, if they are struggling to feed themselves, you could try hand-over-hand feeding – placing your hand over their hand that's holding the utensil and helping to guide it to their mouth.

'Adaptive utensils and cups designed for people with dysphagia can promote independence and safety,' suggests Dharam.

As well as considering environment and posture, Dharam says there are other measures you can take when preparing food, to ensure mealtimes are safe.

'Modified food textures, such as pureed foods or thickened liquids, can make swallowing easier,' he says.

> 'Modified food textures, such as pureed foods or thickened liquids, can make swallowing easier'

Offering pureed foods and thick soups can make swallowing easier

Good foods to offer can include:

- Scrambled eggs
- Mashed potato
- Pureed fruits and veg
- Thick soups
- Yogurt
- Thick custard
- Porridge
- Shakes and smoothies

Dharam suggests thinking about meal size, too, as large meals can be daunting for a person struggling with dysphagia and can take them a considerable time to eat.

'Smaller, more frequent meals can help prevent fatigue during eating,' he advises.

CHECK FOR OTHER UNDERLYING CAUSES

If the person you are caring for is struggling with dysphagia, there may be other underlying causes, so it's important to investigate these. For example, are they suffering from dental pain, which is making them reluctant to eat? An appointment with a dentist could rule out any potential discomfort. If they have dentures, are they well-fitting and comfortable? This should also be checked.

TREATMENT OPTIONS FOR DYSPHAGIA

If you have implemented changes to support your loved one to swallow more easily, including creating a calm environment, offering them adapted utensils and providing food that's easier for them to swallow, and they're still struggling or their dysphagia is getting worse, there are therapy options that can help.

'It's important to remember that each person's experience with dementia and dysphagia is unique,' says Dharam, 'so a personalised approach that is developed in consultation with healthcare professionals is key to providing effective support.'

One option is to consider speech and language therapy – speak to the person's GP about whether this is appropriate and to get a referral. A speech and language therapist will be able to assess and treat a person's ability to swallow. They are best placed to advise on the most appropriate food and drink consistency, and will also offer other strategies to assist with swallowing.

'Speech and language therapists play a crucial role in managing dysphagia in dementia patients,' says Dharam, 'and swallowing therapy exercises can often form part of comprehensive care plans.' DH

'What I wish I'd known about dementia'

Scott Mitchell is the widower of Dame Barbara Windsor, who passed away five years ago after a battle with Alzheimer's disease. He shares what he wishes he knew at the start of her diagnosis. Interview: **Christina Collison**

Scott and Barbara were together for 27 years and married for 20 years. Dame Barbara was diagnosed with Alzheimer's in 2014 and passed away in December 2020, aged 83. Scott says Barbara became more anxious and less confident as the disease progressed.

What kind of assumptions or initial thoughts or understanding did you have about dementia when Barbara was first diagnosed?

My knowledge of dementia was very little. I knew it was to do with bad memory. I had no idea about the other ways that it can affect people once it starts progressing. I went to the darkest place straight away. Although there were symptoms, Barbara was still able to function and she was still able to do certain types of work. But I went into this instant place of grieving. I was told, 'Look, it could be years down the line before all these things that you're worried about may happen.' It was quite a few years later before I faced some of those things. I wish I would have been able to rationalise it a bit more, but when it's our loved ones, it's an emotional reaction more than anything.

Supporting Alzheimer's Research UK

We have to live every day that we have them. Me worrying back then about the fact that one day she might not recognise me, and spending days feeling sad about that, was a waste of the time I had with her. We worry about the future, but it's totally beyond our control.

Was there anything in terms of resources or information you wish that you had known at the start?

Barbara went through a stage of being really emotional, sobbing uncontrollably at times, and I just couldn't figure it out. I thought, 'Is this her reaction to it?' It was all part of the illness and the meds that she was on. I didn't know that it was going to affect mobility. I suddenly noticed she was getting unsteady on her feet – tripping up more and not being aware of certain objects.

Did the change in mobility occur quickly or was it gradual?

Barbara always used to say that from a little girl she always used to fall over, so it was part of her makeup. It wasn't unusual for me to have witnessed this during our 27 years together, but suddenly it was starting to become more regular. Her walking pattern had changed. There would be more of a shuffle of the feet and also her posture as well, certainly towards the end, started to go. She would lean forward. Her balance had gone. We had a stairlift put into the house, which at first she didn't want to use, but it was an important adjustment, because as things progressed it was a Godsend.

Scott with the late Dame Barbara Windsor at the British Comedy Awards

> **'Everyone with dementia has a different journey and you will have to adapt to your own journey'**

'DEMENTIA CAN'T BE SWEPT UNDER THE CARPET'

Scott is an ambassador for Alzheimer's Research UK and is the People's Champion for the Dame Barbara Windsor Dementia Goals Programme, a government programme which aims to speed up the development of new treatments for dementia.

Scott's aim is to encourage the government and medical organisations to interact and start planning for dementia care in future. He says: 'We're pushing the government to get the NHS, the pharmaceutical companies, NICE – the body that decides on the regulation of what's available on the NHS – all in the same room, to start planning now for what's coming down the line. It was a little bit disappointing that at this point in time, the new drug treatments won't be available on the NHS, but the ongoing work that we'll be doing, both for ARUK and with the Dame Barbara Windsor Dementia Goals Programme will continue. Dementia can't be swept under the carpet anymore. It's still the UK's number one killer and something must be done. People need help.'

For more information, visit alzheimersresearchuk.org.

Scott is an ambassador for Alzheimer's Research UK

Is there anything else that helped?

I had a board with photos of us at different points of our lives, or different points of Barbara's life, which I would continually remind her of. I'd have writing on it to say where we were, where we lived. I wasn't aware of any of that stuff at first on diagnosis, but I learned that those things would be helpful. I think it's very important to engage as early as possible with the information that's out there.

What else did you wish you had known right at the start of Barbara's Alzheimer's journey?

One thing I wish I had known right at the beginning was that once Barbara started saying things that didn't quite make sense, I shouldn't contradict her. I went through a phase of trying to explain that the information she just said was not correct, or her memories of something were not correct. That can end up in irritable exchanges between the two of you. So to not stress the person out, go along with their reality in that moment.

> **'I know that everyone will be doing the best they can in what is a very frightening and overwhelming situation'**

Did Barbara have any hallucinations?

She did. There would be people sitting at the kitchen table with us at times, which I just learned to deal with and acknowledge. She'd also ask me many questions about her parents. She would constantly ask, 'Is my mum coming to see me today?' My answer would be, 'She might be later'.

Dame Barbara Windsor and (left) Scott running the London Marathon

It was so much easier, because the distressing part would be to remind her that her mum hadn't been alive for many years.

Did you get any support?

We were contacted by one of the main charities. I was put in touch with someone who advised me. But there is actually quite limited advice. There are certain things you can be told to be aware of, but you have to learn as you go along, because it's ever-changing and because there's no blueprint. Everyone with dementia has a different journey and you will have to adapt to your own journey.

What would you like to share with other carers about your experience of dementia?

As a carer, you will have to care for your loved ones in ways that you would never have thought you needed to, whether that's personal hygiene or helping them go to the bathroom – all of those things will be something you need to prepare yourself for, because that will be very possibly coming down the line for a lot of people.

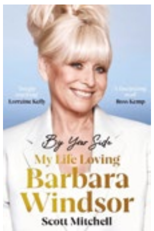
What other advice would you like to share?

The person living with dementia will still want to interact, even if their way of interacting may become a bit different or a bit confused. It's really important to still embrace them and make them a part of everything that's going on.

People can start talking about the person when they're in the room. But they are still very capable of answering for themselves, even if it may be a confused answer. As far as they're concerned, they are communicating their part of it. I think that's so important to remember.

Any final thoughts to share?

As a carer, you will make mistakes and that's only because you don't know what you're dealing with or maybe getting impatient and snappy at times. You have to forgive yourself, because you're doing the best you can. Everyone will be doing the best they can in a very frightening and overwhelming situation. You will be tested in ways you never thought possible. You will find strength you never thought you had. I used to really berate myself when I got things wrong, and I really wish I had been kinder to myself and instead thought, 'OK, you're doing your best throughout this whole journey.'



More information
Scott's book, *By Your Side: My Life Loving Barbara Windsor*, is available on Amazon.

How to deal with challenging behaviour

Professional carer **Caroline Savage** reveals what might cause challenging behaviour and how she manages difficult situations that could escalate

Can you share the most common types of challenging behaviour you've dealt with?
I've experienced aggressive behaviour – both physical and verbal. I've also seen paranoia and accusatory behaviour – for example, when the person believes their family or carer is wanting to cause them harm or is stealing from them.

As well as this, I've seen repetitive behaviour, repeating the same sentence or asking the same question, or it can be a repetitive action, such as constantly washing their hands or, in the case of one of my clients, constantly wiping down the sink.

Restlessness and wandering are also common and, coupled with mixing up daytime with night-time, it can be exceedingly difficult for families to sleep when the person with dementia is pacing around the house in the middle of the night.

How can carers effectively respond to aggressive or agitated behaviour in a person with dementia in a safe way?
Initially, I'd try to establish whether there is another cause of the aggression. Find out if the person is experiencing any discomfort, such as pain, being too hot or too cold, hungry or thirsty. Or they may have a urine infection, which can really escalate aggression and confusion.

I ensure I am as reassuring as possible, letting the person know I am on their side and want to help.

What's the best way to calm the person down?

It can be difficult, but the best approach is to keep all interactions positive, use a gentle voice and avoid any confrontation or a tone of voice that may make the person feel they are being chastised. Give them space – it may help to leave the room and give them time to calm down.

I try distraction methods, too – changing the subject, talking about something that interests them, or make them their favourite drink. You could also ask them if they can help you with something. A change of environment is a great tactic as well, so go into another room or change the mood with some music or television.

Are there any techniques that can prevent challenging behaviour in the first place?

Try to establish what the triggers are for certain behaviours. Keep a diary of escalations and see if you can work out a pattern of behaviour. For example, some people get stressed about bathing, which can be a trigger for aggression. In this situation, maybe a new routine is needed with a different approach.

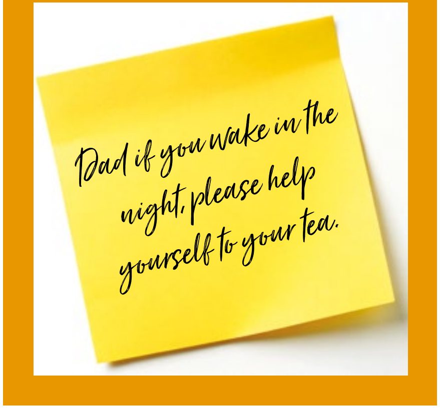
A person's environment can really help to calm some challenging behaviours. Are there any familiar items that could be a source of calm and comfort – perhaps photographs, a favourite item of clothing, a cuddly toy or a particular blanket?

> **'A change of environment is a great tactic, so go into another room or change the mood with some music or television'**

CASE STUDY

'We covered the front door to avoid night-time pacing'

A gentleman I was caring for was pacing the hallway at night-time and his family were exhausted. They were concerned he was going to let himself out of the front door, as most nights he tried to unlock it. We don't know why, but his trigger was the front door. We decided to hang a long curtain over it to disguise it at night. We also made him a thermos of tea and left it beside his bed with a note saying, 'Dad, if you wake in the night, please help yourself to your tea'. We also attached a note to the curtain hiding the door, telling him he had tea waiting next to his bed. The curtains hid the door and the note served as a distraction! He always had a cup of tea before bed, so when he went back to his room and had his tea, he connected this with his bedtime routine. This worked well and cut down the number of hours he was pacing, and the family could cope as they were getting more sleep!



Having items close at hand which are important to them, or that they hold dear and are familiar, can help make a person feel calmer.

Being included and feeling valued is also of great importance. Getting the person involved with some chores can be a distraction and give a sense of purpose.

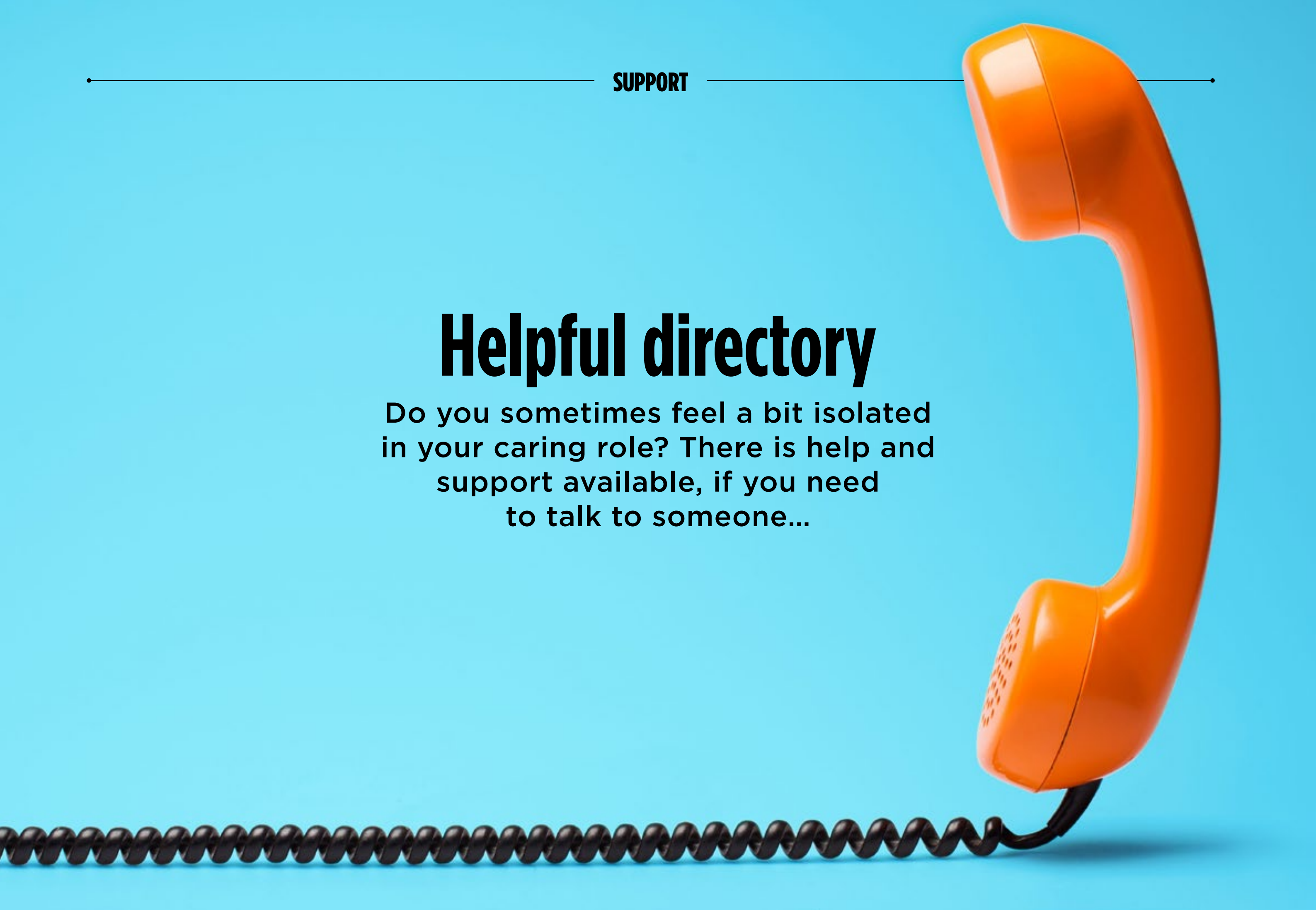
> **'A person's environment can really help calm some challenging behaviours'**

How important is routine for preventing challenging behaviour?

Routine can be key to help a person with dementia manage their day. It brings a sense of structure. I have observed with my own clients that if a routine is disturbed, for example, at Christmas or a celebration, it can alter behaviour. Anxiety can also creep in when routine is broken. I once had a lady who needed an early morning blood test and she was a late riser. Feeling she had to be out of the house by a certain time was overwhelming and her anxiety about missing her lunch was high. Getting back home to her environment with her lunch at exactly 12.30pm was the only thing that calmed her.

If you notice that agitation tends to escalate late afternoon and directly impacts the person's ability to cope with tasks, you can work around it by creating distractions to help them cope, such as putting the radio on or getting them to help with a simple task. DH

More information
Caroline Savage cares for people in their own homes and specialises in dementia care. She is also a fundraiser for Alzheimer's Research UK.



Helpful directory

Do you sometimes feel a bit isolated in your caring role? There is help and support available, if you need to talk to someone...

AGE UK
A charity dedicated to helping older people.
ageuk.org.uk

ALZHEIMER'S RESEARCH UK
A charity conducting research into finding treatments for dementia.
Infoline: 0300 111 5555
alzheimersresearchuk.org

ALZHEIMER'S SOCIETY
Help and support.
Support: 0333 150 3456
alzheimers.org.uk

CARERS UK
Information and advice on caring, connecting carers and campaigning with carers for change. Carers UK offers advice on benefits and financial support, and your rights as a carer in the workplace.
Helpline: 0808 808 7777
carersuk.org

DEMENTIA CARERS COUNT
Free online learning about dementia.
Support line: 0800 652 1102
dementiacarers.org.uk

DEMENTIA HELP
Our own website, with articles and free guides on coping with being a carer for your loved one, as well as free resources you can download to make you better informed about dementia, including guides on challenging behaviour and nutrition.
dementiahelpuk.com
Email: christina@dementiahelpuk.com

DEMENTIANET
Our partners, providing a new website offering comprehensive information and support tailored to your personal circumstances. It will enable you to store essential information about your loved one in a secure online portal, ask questions, access helpful advice and make a personal plan to support your day-to-day life as a carer.
dementianet.com

DEMENTIA UK
Specialist support for advice and information on dementia.
Helpline: 0800 888 6678
dementiauk.org

DEMENTIA TALKING POINT
A free online community available 24 hours a day run by Alzheimer's Society.
alzheimers.org.uk/get-support/dementia-talking-point-our-online-community

YOUNG DEMENTIA NETWORK
A community of people keen to improve the lives of those who are affected by young onset dementia.
youngdementianetwork.org
Email: youngdementianetwork@dementiauk.org

DementiaNet
dementianet.com

A NEW online hub to help you manage life with dementia.

If you're caring for a person with dementia, DementiaNet is here to help with information, planning and support.

Designed to make your life easier, this packed platform offers information, a planning tool for the practical things and an online community to get support in caring for your loved one.

It's a place to come together, give and get help, swap tips and take a step-by-step approach to caring.

Read articles on dementia care

Search for topics relevant to your situation

Join our network and take part in discussions

Get your personal affairs and plans in place with a secure, easy access online planner.

The dementia help hub

When life's affected by dementia, it can be tricky finding the right support. DementiaNet aims to provide the information and resources you're looking for.

Dementia & you

Handy tips to help people living with dementia

Dementia & others

Advice and support for those caring for people with dementia

Working with dementia

People with dementia

How can we help you today?

Are you looking for help...

See how our community can help you

DementiaNet is a supporter of **DEMENTIA HELP** HELPING CARERS COPE