HELPING CARERS COPE

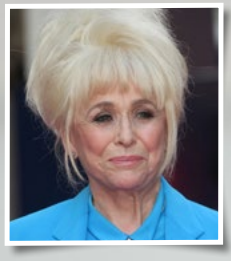
DEMENTIA HELP

ISSUE 7

In partnership with DementiaNet

Keeping your loved one safe

- Changes at home to prevent falls
- One key way to manage wandering
- Safety products for peace of mind



‘It’s about learning and adapting’

Scott Mitchell on how he cared for Dame Barbara Windsor

Coping with mood swings

Helpful strategies to bring calm

What to do when help is refused

Ramping up support without conflict

Young onset dementia

Why needs are different and planning future care

When life feels out of control

Mindset shifts that really work

6 reasons for appetite loss

What to do about them

‘We celebrate the small wins’

One daughter’s story of making her dad feel truly valued



When resilience is needed

There's a saying: *you never know how strong you are until being strong is the only choice you have*. That phrase came to mind when I spoke recently with Sue Strachan, who lives with vascular dementia.

Sue has faced an extraordinary amount of stress in the past year – the devastating loss of her partner of 32 years, followed by a house move to begin a new chapter of her life alone. These events would test anyone, but with dementia in the mix, her resilience is truly inspiring.

Sue generously shared her story with us for this issue. She's also an ambassador for Alzheimer's Research UK, campaigning for faster diagnosis so that people can access the right support sooner. I'm deeply grateful to her for speaking so openly.

We're also honoured to feature Scott Mitchell, widower of the late Dame Barbara Windsor. Scott cared for Barbara and continues to be a passionate advocate for dementia awareness. In this issue, he shares some of the practical changes he made at home to keep Barbara safe – advice that I know many carers will find valuable.

This edition also shines a spotlight on young onset dementia – how to recognise the signs, where to seek help and why support needs can be so different for younger people.

Thank you to our friends at DementiaNet, MedicAlert and Dementia Forward for supporting the magazine. I truly hope you find it helpful and, as always, I'd love to hear your feedback.

Take care,

Christina x

Christina Collison
Founder

christina@dementiahelpuk.com

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'My dementia hasn't just affected me – it's affected my friends and family too'
Gerry Anderson

Issue 7



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



NICOLA BOOTON

Nicola is a dementia adviser for Alzheimer's Society, Warwickshire, and a carer for her dad with Alzheimer's. She has supported her nan and mother-in-law, and worked in care homes with people living with advanced dementia. Nicola joins the Memory Walk annually and is passionate about supporting families living with dementia.



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 funding of £120 million.



LYNDSEY MITCHINSON

Lyndsey is our Contributing Editor and Content Manager at DementiaNet, a digital platform helping people manage life with dementia. She oversees the creation and delivery of web content, drawing on her own experience caring for her father. She is passionate about supporting dementia carers.



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.



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.



KAREN THOMAS

Karen is Head of Young Onset at Dementia Forward, North Yorkshire and York's leading dementia support charity. She helped to develop the charity's young onset model, championing age-appropriate services. Dementia Forward also created Young Onset Dementia Awareness Day and hosts an annual Young Onset Conference.



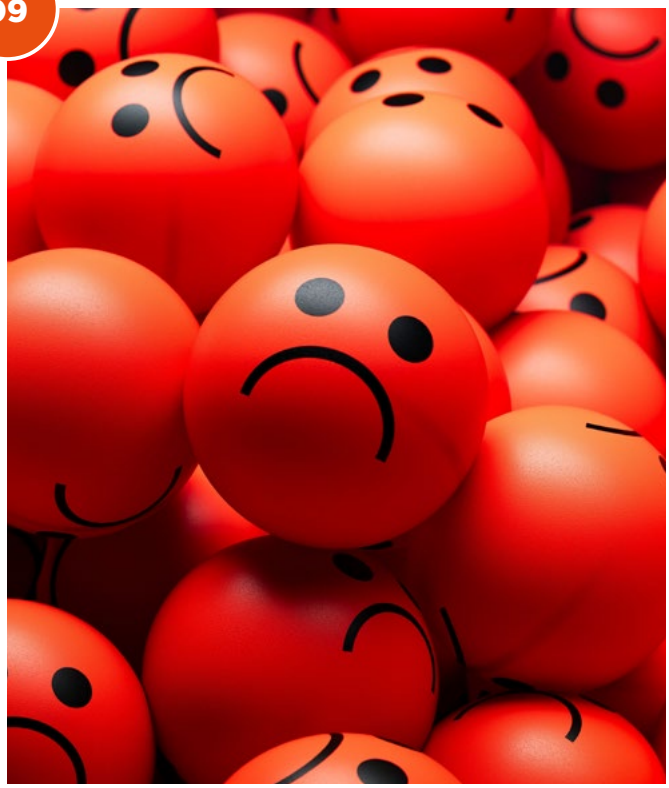
FRAN VANDELLI

Fran is a Dementia Lead for Bupa Care Services Richmond Villages. She has worked for Dementia Voice, The Dementia Care Trust and was an Alzheimer's Approved freelance trainer. She also previously worked for Bristol City Council as an Advanced Dementia Care Mapper, working in the Adult Social Care team.

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For more information,
visit DementiaNet.com

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Updates

The latest news from the world of dementia care

Recommended Read: *Remember When* Fiona Phillips



Former GMTV presenter Fiona was diagnosed with Alzheimer's at 61 after caring for both her parents with dementia. Her book details her journey as a carer to experiencing her own symptoms, which she first mistook for menopause. With contributions from her husband, Martin Frizell, it offers an unflinching look at life with dementia, including the couple's decision to eventually go public with her diagnosis. A few days after giving an interview about her diagnosis, Fiona was asked how she felt now that her news was out in the open. 'Oh, I don't think anyone knows,' Fiona replied calmly. That's the sad reality of dementia. Her husband makes a good point in the book that, unlike other serious illnesses, there is no care pathway for dementia. A compelling, honest read.

Cats offer clues to tackling Alzheimer's



Cats can develop dementia in a similar way to people with Alzheimer's, scientists have discovered. A University of Edinburgh study examined the brains of 25 cats that had shown signs such as confusion and sleep problems. They found a build-up of amyloid-beta – the toxic protein linked to Alzheimer's disease in humans.



UK trials blood test for dementia diagnosis

A major UK study is testing whether blood tests can speed up diagnosis of Alzheimer's and other dementias. Researchers hope earlier detection will give more people access to vital support and treatments.

Be a part of Dementia Forward's
3rd annual **U&ME Conference**



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Shaping the Future of Young Onset Dementia Support

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For more information:
Visit: www.dementiaforward.org.uk
Call: 01765 601224



Meeting the needs of younger people with dementia



Dementia Forward is a charity supporting people with dementia in York and North Yorkshire. **Karen Thomas**, Head of Young Onset at the organisation, explains how the needs of younger people with dementia are different

Karen Thomas talks about the challenges faced by younger people with dementia and how Dementia Forward is leading the way in providing specialist support for people with young onset dementia (people under 65). The charity makes a point of tailoring its services to meet the unique needs of younger people with dementia.

Tell us about your organisation.

KT: We support people of all ages with dementia across North Yorkshire and York – currently 4924 families in total. Some 434 of those families are affected by young onset. My role is head of young onset, so my focus is all those clients, both locally but I also feel a responsibility nationally because we are learning so much from the contact we have that clear and bigger changes need to be made on a national level.

Firstly, tell us a bit about how Dementia Forward was started.

KT: We had seven founder members, who left jobs at a national charity on a Friday and then started the organisation on the Monday.



‘With young onset, needs are different’

They wanted to create something local for local people. They had desks from skips and computers from a closed school. After 18 months, Dementia Forward won three of North Yorkshire’s six health lots. Around that time, one of our carers, supporting a husband with young onset in his late 50s, told our CEO she feared losing the only service for young onset in the area. He was in a hospital room with no windows, doing word searches. Our CEO thought, ‘We could do that better.’ We got a Red Cross bus, a driver, and started taking people out. That group became the Time Out Together group. The idea was just having time out, together – clients and staff alike.

How did your role evolve?

KT: At that time, I was a support adviser. When a referral comes in, we allocate a local support adviser. They get a snapshot of what’s going on and build a relationship to help as things change. With young onset, needs are different. We found the usual signposting wasn’t appropriate. Carers’ respite volunteers might usually take someone to a garden centre but we needed volunteers who could run or cycle. We asked other charities to adapt their models. My role now is to ensure our services are age appropriate and to help build the infrastructure around young onset.

Tell us about your wider work outside North Yorkshire.

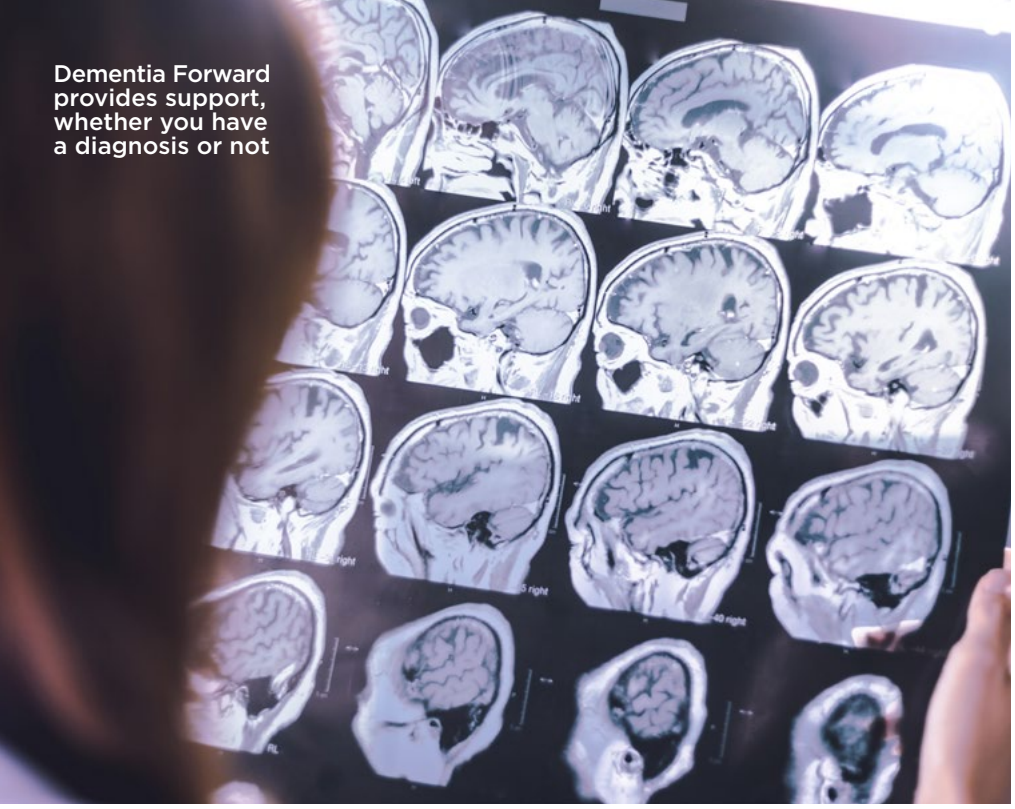
KT: On a national level, we’ve realised the postcode lottery people face. So we started the U&Me Campaign. It started after a referral from a man in his early 60s with young onset dementia called Jonathan Beardsworth. His friend was in marketing, and they wanted to raise awareness. The relationship inspired the campaign because it aligned with our aim to make our voice heard. We now have Young Onset Dementia Awareness Day on 24th October, which is his birthday. Jonathan is featured in our campaign branding. We’ve created a music track called You & Me (search U & Me Y.O.D.A).

You also hold conferences to raise awareness. Tell us a bit about those please.

KT: We’ve held two conferences. The first two were at Bowcliffe Hall where the venue was very kindly given to us free of charge. This year, it’s at Elland Road in Leeds, in partnership with Care England. We can host at least 300 delegates. By being in Leeds, it’s more accessible by train. We’re not making money from the conference – it’s £50 per ticket, which is cost price. We expect a small loss, but it’s important to raise awareness.

What topics will be covered at the conference?

KT: There will be people with lived experience speaking. One of the big themes is people with young onset so often experiencing sectioning. We see a pattern of people hitting crisis, being misunderstood and ending up in mental health wards. We’re arguing that good care – even if it’s expensive – is cheaper than inappropriate care followed by crisis.



Dementia Forward provides support, whether you have a diagnosis or not

Why should people attend?
KT: To help them feel part of a community. It can be isolating having symptoms of dementia, especially with young onset. But there are people working for change. There'll be learning opportunities. Professionals, carers and people with lived experience to connect with. We want people to feel that they're not alone – and also that they can help make change happen. Last year, a man came to our conference and now he's set up a group in his own area. It's like a spark.

What else does the charity help with?
KT: We provide signposting and emotional support as our core service. People don't need a diagnosis to contact us. Anyone can refer, with permission – online or by phone. We also have a helpline. We run activities: hub clubs, cafes, singing groups and carers groups.

'We want people to feel that they're not alone – and also that they can help make change happen'

Do you have an example of the kind of support you offer?
KT: We supported a man who lost his job after 30 years, became separated from his wife, lost his mum and was diagnosed with dementia – all within five months. We built a new routine for him. He found a peer group through Time Out Together, and later our hub clubs. As things progressed, we advocated with social workers to ensure he received appropriate care. His financial situation was also very complicated – no pension, inherited money and separated but still married. We supported him and his ex-wife. Now he's in care and we're still involved.

Who is the youngest person you've supported?
KT: The youngest we currently support is 46. We often see people in their 50s and early 60s. One man, aged 48, has frontotemporal dementia. Social workers initially didn't understand – he seemed very able, but couldn't cross a road safely. He went into age-appropriate care and started speaking in sentences again.

Do you see many genetic cases in young onset dementia?
KT: In most cases, it appears random. Sometimes, it's linked to head injuries from sports. There are some forms of dementia with genetic links and we signpost people affected by these conditions to counselling to explore whether they want to know their risk.

Is there anything else you want carers to know?
KT: People cope for so long, but can then hit crisis. We want to help them manage as things change, so they don't hit that wall. It's always going to be difficult, we want to be there, listening, helping and connecting them with what they need. DH

More information
You can ring the Dementia Forward Helpline on 03300 578592. For further details about the Dementia Forward Conference, including how to attend, visit www.dementiaforward.org.uk



Managing anger and low moods

Mood swings, anger and depression can be common in a person with dementia. Here's why this can happen and how to cope.

Words: **Christina Collison**

I remember the day well. There was a party in my mum's care home and everyone was enjoying themselves. Except for Mum. She was sitting in her wheelchair, staring into space, not engaging. Without warning, she reached out and punched me in the back.

'I know your game', she said angrily. 'I know what you're up to'.

Mum and I had a good relationship, and she would have known on a good day that I wasn't up to anything. My only intention was to care for her, and she usually understood that. But on this particular day, she was angry and paranoid.

I stepped away from her for my own safety and left the home shortly afterwards. When I went back an hour later, she was fine – it was like nothing had happened. She would have forgotten the incident and her mood was normal again. It was upsetting, but I knew by then how unpredictable dementia could be.

According to a study published on the website, BioMedcentral, up to 60 per cent of people with dementia will experience agitation and aggressive symptoms. The website, Medical News Today, also says that changes in personality are common in a person with dementia, alongside angry outbursts.

If you notice emotional changes in your loved one, it can be upsetting, challenging and difficult to manage. But these changes often stem from an underlying reason – whether that's physical discomfort, emotional distress or confusion.



‘Behaviour that seems aggressive may actually be a sign of pain, fear or frustration’

By exploring what may be causing the change, you can often help the person feel safer and more settled.

WHAT CAUSES ANGER OR MOOD SWINGS?

Mood swings and sudden outbursts can feel overwhelming, but it’s important to remember that the person is not doing this deliberately. Dementia can affect how a person processes emotions and communicates their needs, so behaviour that seems aggressive may actually be a sign of pain, fear or frustration. Here are some physical causes to consider:

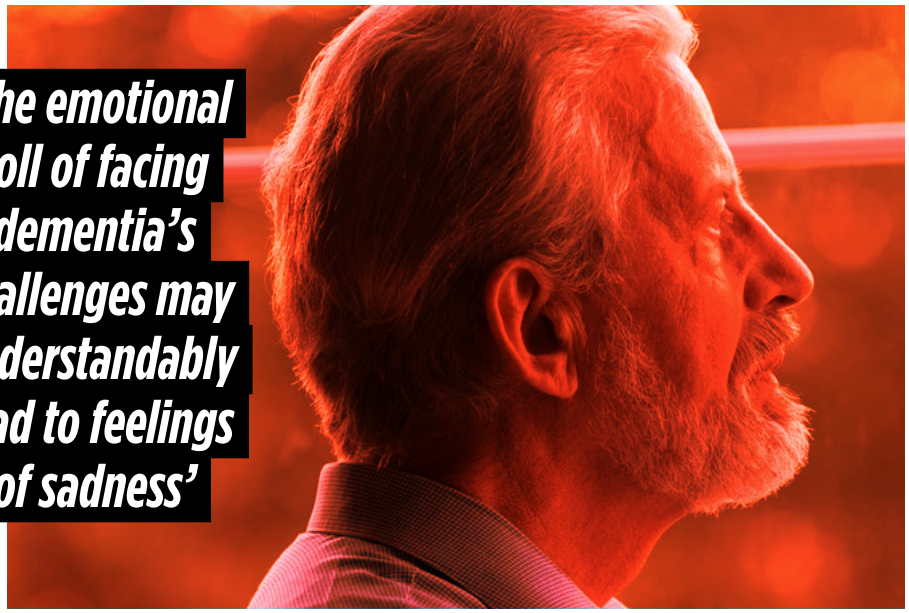
- Fatigue – the person may have had a poor night’s sleep and is simply overtired.
- Boredom or loneliness – a lack of stimulation or company can cause restlessness or frustration. Try inviting the person to go for a walk or help with a household task that gives them a sense of purpose.
- Pain – they may be experiencing discomfort, but can’t explain it. Look for signs such as limping, grimacing, clutching their stomach, appearing pale or sweaty, or running a temperature. Speak to their GP if you’re at all concerned.
- Discomfort – have they been sitting too long in one position? Or are they feeling too warm or too cold?
- Thirst or hunger – check when they last ate or drank. Offer water or a snack if they may be hungry or thirsty.
- An infection – something like a urinary tract infection (UTI) can cause confusion and behaviour changes.

DEPRESSION AND DEMENTIA

Depression is common in people with dementia. According to the National Center for Biotechnology Information, around 30 per cent of those with Alzheimer’s, and over 40 per cent with Parkinson’s or Huntington’s disease, may experience depression. It can be hard to diagnose, because dementia symptoms can mimic those of depression, and sometimes the conditions overlap. Some people are even misdiagnosed with depression before receiving a dementia diagnosis. The emotional toll of facing dementia’s challenges may understandably lead to feelings of sadness and frustration. Signs of depression may include:

- **Fidgeting**
- **Agitation or restlessness**
- **A constant need for reassurance**
- **Irritability**
- **Tearfulness or emotional outbursts**

Because some of these symptoms are also signs of dementia, it’s not always easy to spot depression. If you suspect the person may be feeling low, speak to any other carers involved and encourage them to see their GP. The GP will ask questions about their mood, how long they’ve felt this way, and what might be triggering it.



'The emotional toll of facing dementia's challenges may understandably lead to feelings of sadness'

UTIs should be treated promptly to avoid escalation.

- Medication side effects – if new medication has been introduced or the dosage has changed recently, it may be affecting their mood. Talk to the person's GP if needed.

DEALING WITH ANGER

- Accept that the person can't always control how they react. You are the one who can adapt and remain calm.
- Try to get to the root cause. If there's no obvious physical cause, the anger might be emotional – perhaps they're scared, confused or feel they're losing control.
- Don't do too much. Frustration can come from feeling helpless. Encourage the person to do what they can, rather than doing everything for them.
- Speak respectfully. Avoid talking loudly or in a patronising tone. Shouting rarely helps, unless the person has hearing problems. My mum's hearing was fine, and she got frustrated with care home staff when they assumed it wasn't and raised their voices.
- Use distraction techniques. Change the subject, offer a cup of tea, or play music to shift their focus and lift their mood.
- Look for patterns. Does the aggression occur at a certain time or after a particular trigger, such as a relative's visit?
- In persistent cases, medication may be an option. Again, talk to the person's GP if needed.

PROTECT YOURSELF

If the person's behaviour is aggressive:

- Speak calmly and assertively. Explain that it's not okay for them to hit or swear at you.
- Step away if needed. If you feel unsafe, remove yourself from the situation.
- Consider safety precautions. Hide car keys or sharp objects if there's a risk they might hurt themselves or others.
- If the person has frequent delusions or you believe someone is in danger, seek urgent medical help. Call 999 if necessary and say the person has dementia. DH

SUPPORTING SOMEONE THROUGH LOW MOOD

While medical advice is always recommended, there are things you can do to help support the person emotionally:

- **Keep them engaged in activities they enjoy. Walking, dancing, gardening, listening to music or being in nature can help lift their spirits.**
- **Offer a sense of purpose. Include them in tasks like laying the table, folding washing or light gardening. Feeling useful can be incredibly uplifting.**
- **Provide companionship. Sometimes, they may just want your presence. Sit with them, watch TV together or hold their hand if they want that.**
- **Stick to familiar routines. Predictability can help reduce anxiety and promote calm.**
- **Listen if they want to talk. Even just being there quietly can be enough.**

Coping when things feel out of control

The unpredictable challenges of being a dementia carer can often make you feel like life is out of your control. **Lyndsey Mitchinson** from **DementiaNet** shares her previous caring experiences and explains why a more flexible approach can work

The day hasn't started properly yet, but already you might be wondering what lies ahead. Will your loved one smile and say your name, or look at you like a stranger? Will they take medication willingly, or will it be a battle? Can you both make it through that hospital appointment without any upset?

You may be familiar with thoughts like these. It's like living with a weather system you can't predict – one moment it's calm, the next there's a storm appearing from nowhere.

'I remember those mornings so clearly,' says Lyndsey, who cared for her father through his dementia journey. 'I'd wake up feeling anxious, wondering what the day would bring. While Dad never stopped recognising us, I lived in constant fear that one day he wouldn't know me.'

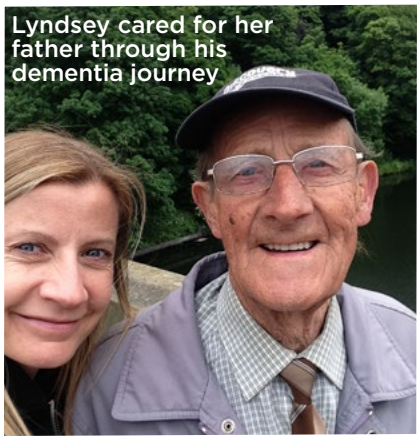
Lyndsey adds: 'He'd ring me at work several times a day – he'd forgotten I had a job – and was hoping I could take him out. It was so hard, as he was feeling lonely and I had to work. I'd rush back to make his meals during my lunch break, only to find he didn't want to eat.'

FEELING THE UNKNOWN

The hardest part isn't just the practical challenges – it's not knowing what's coming next.



The unpredictability of dementia can be exhausting for carers



Lyndsey cared for her father through his dementia journey

You try to plan ahead, but dementia is unpredictable.

'It's completely normal to feel overwhelmed,' Lyndsey explains. 'Our brain likes to know what's happening next and when it can't predict things, it stays on high alert. That's exhausting. I used to think I was failing him, but I learned this is just what caring feels like. Looking back, I have so much more empathy for both of us.'

Maybe you've noticed yourself getting anxious about small things that wouldn't have bothered you before. Perhaps you lie awake at night running through all the 'what if' scenarios that may never happen.

GOING WITH THE FLOW

Even though you can't control dementia, you have more power than you think.

Learning to go with the flow may sound flippant, but it can help calm your busy head.

'Realising I didn't have to control everything saved my sanity,' says Lyndsey. 'I just needed to focus on the things I could influence. There were more of those than I realised.'

Taking action helps: think about how good it feels to tick something off your to-do list. Taking action reminds your brain you're not helpless. This feeling comes from getting organised. You might not be able to stop the condition, but you can usually make each day run more smoothly and change your perspective. Sometimes, the difference between a good day and a bad one isn't what happens – it's how you frame it in your mind.

When you catch yourself thinking, 'Nothing I do matters,' or, 'I'm powerless against this disease,' try switching to thoughts like these:

- Change, 'I can't stop Dad's confusion,' to, 'I can't stop the confusion, but I can make him feel safer.'
- Change, 'Every day is unpredictable,' to, 'I can't predict everything, but I can get his pills organised so I'm ready.'
- Change, 'This disease controls everything,' to, 'I can't cure this, but I can find people who understand what we're going through.'

It's not about pretending everything is OK. It's about noticing where you have choices, even small ones. Each time you organise something or learn something new, you're taking back control. These small acts can make you feel calmer. You'll feel better knowing you're doing something constructive, rather than anticipating the next problem.

HELPFUL TOOLS

Resources like DementiaNet aren't just websites – they're like having a knowledgeable friend who's been through the same thing. DementiaNet breaks down complicated tasks into simple steps, such as:

- How to organise paperwork.
- What to do in a crisis.
- How to talk to doctors.
- Where to find local support.

Each time you use the tools to plan and prepare, you're building a safety net that you can rely on when life gets unpredictable.

You'll never have perfect control over life, never mind dementia. But you don't need complete control. Just enough to feel secure. Every contact list you make, every routine you establish, every time you reach out for help, you're taking charge and helping your loved one. DH

More information
DementiaNet is a helpful website offering information and a supportive community for everyone affected by dementia. Visit dementianet.com

DementiaNet

'It's not about pretending everything is OK. It's about noticing where you have choices'

THREE SIMPLE WAYS TO FEEL MORE IN CONTROL



Start small

Pick one thing that's been bothering you – maybe it's keeping track of appointments or knowing what tablets to give when. Use a simple system or use the tools in DementiaNet to help you get organised.

Find your people

Connect with other carers, either locally or online. They will understand your challenges and how you feel better than anyone.

Be prepared

Keep important phone numbers handy and know where important documents are located. Have a plan for emergencies.

Grief, moving forward and living with dementia

Sue Strachan reveals how she is coping with the loss of her partner and starting a new chapter of her life in a new area

Sue Strachan is 69 and was diagnosed with vascular dementia at the age of 56. A year ago, she tragically lost her life partner of 32 years, Sheila, who she lived with in Herefordshire. Sue has recently moved to be closer to family. Here, she shares her insights about her new chapter in life and how she is managing grief.

It's been almost a year since you lost your partner Sheila. How have you been coping emotionally?

SS: Very up and down. I've discovered how very physical grief can be. I went to the doctor a few months ago, because I couldn't believe how ill I felt. I had no stamina, no energy. They ran blood tests – I was desperate for it to be anaemia. But it wasn't. It's grief.

How are you managing the grief?

SS: I'm doing the best I can, and I think she would be very proud. Somebody once said to me that you don't realise how strong you are until that's all you can do. I talk to Sheila a lot when I'm dog walking.




Sue with her nephew, Gareth

I explain what I'm doing. I think she would absolutely be supporting me, as she did when she was here. It's been a roller coaster. I had grief counselling almost straight after she passed, and it was really helpful. I learned a lot about emotional truth.

Now, when people say, 'I know how you feel,' I say, 'I know you're trying to empathise, but your relationship isn't the same as my 32-year partnership.' Only a couple have been offended. Most people just don't know what to say. And my response is – then don't say anything. Someone in the village also lost a partner, and I bumped into them while we were walking our dogs. We'd both been crying. I said, 'I'm not going to say anything because there's nothing to say.' And they said, 'No, you're absolutely right.' I felt quite liberated by being emotionally truthful.

I hear you recently went to Bali to commemorate Sheila's life.

SS: We took Sheila's ashes to Bali. I went with two close friends. Sheila and I had been going to Bali every other year for 20 years. We became close to a family there and they wanted to do something to mark Sheila's passing. We went to the family's village and they had a beautiful altar with a huge photo of Sheila, which I hadn't expected. The ashes go out to sea and, symbolically, when the rain clouds pick up water from the sea and it rains, that's the person returning. There was a real sense of calm. I just felt I had done such a good thing for her. She would have thoroughly approved.

'It's refreshing to have people around me. I don't have the countryside on my doorstep anymore, but I'm not lonely'

What kind of support are you getting now?

SS: I've signed up with a counsellor in Lewes. I'm being very honest with friends and family. I've given myself permission to be this way. Some people message, 'Thinking of you – how are you?' And when I reply, I never hear back. It felt like a tick-box thing. So, I stopped replying. I'd rather they didn't say anything than come out with something unhelpful. Several friends have been amazingly supportive. Scott Mitchell [widower of the late Dame Barbara Windsor] has been particularly attentive. He checks in every week. He's a dear person. There are so many people who've been helpful.

And your dog Saffy helps?

SS: Absolutely. She's the reason I get out of bed some mornings. I owe it to Sheila and the dog to treat her properly.

Who else has supported you?

SS: There's a private Facebook running group linked to Alzheimer's Research UK. They've been amazing. And my family. One of my nieces has Lasting Power of Attorney for me. I'd urge everyone to create one. So many friends have said they wouldn't know what to do if something happened to their partner.



	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	Meds	Meds	Meds	Meds	Meds	Meds	Meds
	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy
	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast	Breakfast
	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy
ernoon	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch	Lunch
	Rest	Rest	Rest	Rest	Rest	Rest	Rest
	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy	Walk Saffy
	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy	Feed Saffy
	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner	Dinner

Sue's wipe-off chart with daily schedule

What prompted your move?
SS: At first, I thought I'd stay. But I realised I was becoming isolated. We lived rurally and Sheila had been part of everything in the village. But I was lonely and the place needed maintenance. My friend Angie suggested I move to Lewes. I put my house on the market in January and came to Lewes. It has a lovely vibe. We found this retirement flat. I was overwhelmed by the process – Sheila used to handle all that. I'd cry every time the solicitor emailed me. But I had help from Angie and my niece, Lara.

How did you find moving?
SS: Moving is highly stressful. I do worry that once the dust settles, my dementia might dip. But I've told friends to keep an eye out. I've got an appointment with a new GP to see what support is available.

I hope I continue as I am. Yes, I've deteriorated, but I'm still functioning well. One reason I left the village was the painful reminders – Sheila was everywhere. I find it hard to picture her. That's possibly dementia, but also a coping mechanism. I've decided not to have any photos of her up, for now. On good days I think, 'We had 32 amazing years'. On bad days, I still can't believe she's gone.

How are you finding the new environment?
SS: I'm really pleased. It's refreshing to have people around me. I don't have the countryside on my doorstep anymore, but I'm not lonely. In Hereford, I'd walk the dog for an hour and not see anyone. Here, I step out and there are people. A friend said, 'Just because it's the right thing doesn't mean it will be easy.' She was right. Having people nearby makes a difference. And friends now come for the day – before they had to stay overnight and I couldn't always cope.

Lewes is lovely. I have a ground floor flat, so I can access the garden easily with the dog without disturbing anyone. It's starting to feel like home.


Sue with some friends from Alzheimer's Research UK, including Scott Mitchell


Sue in Bali commemorating Sheila's life

What's helping you adjust?
SS: Taking it slowly. I'm usually tough on myself, but my grief counsellor said, 'Prioritise and pace'. That's been really helpful. Sheila used to do so much for me. Now, I'm learning to do things for myself and it's tiring. Sometimes, I need to say to people, 'It's been lovely to see you, but actually I'm exhausted', because just talking to people is incredibly tiring.

Who's supporting you now?
SS: My nephew Gareth, my niece Lara, my dear friend Angie and the rest of my family. They've gone above and beyond. Lara works hard and still makes time for me. I don't know what I'd do without them.

Some friends check in daily. I do word games online with three friends, and I know if I didn't respond, they'd worry.

Do you have happier days?
SS: I have what my grief counsellor called 'glimmers'. I haven't had real joy since Sheila passed, but I strive for it. I've had moments of, 'This is okay,' and moments of, 'I can't take any more.' But I've got people I can reach out to. I think Sheila would be proud.

You're an ambassador for Alzheimer's Research UK. How important is that work?
SS: Sheila and I became ambassadors together. She never got to do anything in the role [due to her passing]. I carry on in tribute to her. It's not just about fundraising – it's about awareness. The Perfume Shop has supported Alzheimer's Research UK for 11 years. They had a campaign called "Be More Sue," which embarrassed me at first, but I now accept it helps others. I've done talks to their managers and I've been to their head office. They've continued the campaign this year and I do videos for them.

What do you want people to know about dementia?
SS: When I say I have dementia, people often say, 'You'd never know.' I used to take that as an insult. What does someone with dementia look like? Not everyone is sitting in a care home, unable to function. A lot of us still contribute. I try to take it as a compliment now. Knowledge is power.

I stopped going to the memory clinic, because they were never going to tell me I'm going to get better. My diagnosis took 18 months. Some say, 'I wouldn't want to know.' But it's not just about you – it's about your loved ones.

What advice do you have for anyone recently diagnosed?
SS: Ask for help and take help whenever it's offered, if it's appropriate. When I lived in Hereford, I was on panels with healthcare professionals discussing why diagnosis rates were so low there. One issue was that people were terrified they'd lose their driving licence. I still get my licence renewed every year. So I say to people, it doesn't necessarily mean you won't be able to drive. But equally if you're not safe to drive, you shouldn't be driving. DH



More information
Sue is an ambassador for Alzheimer's Research UK and previously completed the London Marathon to fundraise. She is working with the charity to raise awareness of the need for early diagnosis.

‘How I manage my dad’s dementia’

Nicola Booton is a dementia adviser for Alzheimer’s Society in Warwickshire, as well as being a carer for her father, who has Alzheimer’s. She talks about how she manages his care and how he remains active and mostly positive

My dad, John, was diagnosed with Alzheimer’s last year, but looking back, I think he’d been showing signs for at least a year before that. The challenge was that he also has cancer, and some of the cancer medication caused confusion and other side effects. At first, the doctors thought the memory problems were just part of the treatment.

We kept adjusting his meds, but I kept saying, ‘Something’s not right.’ Eventually, the consultant suggested stopping the cancer treatment for a month to see if things improved. When they didn’t, we knew it was something more. I was certain it was Alzheimer’s.

Talking to Dad about it was hard. He was willing to accept his cancer diagnosis, but the idea of having Alzheimer’s really shook him. I tried to frame it gently, like, ‘If we know what’s going on, we can get you some help, maybe some medication like we did with the cancer.’ But the stigma around dementia really affected him. Getting him to the GP involved a bit of a red herring.

Thankfully, he’s more open about it now. He’ll tell people, ‘I’ve got Alzheimer’s and cancer, but I’m doing okay.’ He even says, ‘The cancer doesn’t bother me – it’s the Alzheimer’s that does.’

My dad’s an educated man.



Nicola’s relationship with her dad, John, has changed since his diagnosis



Nicola reminds John of his daily achievements when he's feeling frustrated

We both worked in care homes, so he knows exactly what dementia can look like. And sometimes that knowledge makes it scarier.

THE LITTLE WINS MATTER

Dad still lives on his own and is doing well. I see him every day and so do others – my daughter, his carer, my mum, or kind neighbours. He's surrounded by support.

We make sure we celebrate the small things. If he's put a microwave dinner on, shaved, or tidied up a bit, we tell him, 'That's brilliant, well done.' Because sometimes he'll say, 'I haven't done anything today – everyone does everything for me.' And I remind him, 'No, look what you've done. You've achieved something.' It helps him feel valued and important.

Even something like paying for his newspaper can be a big task now. He finds coins confusing, so we sort them together and pop them in an envelope. I let him do as much of it as he can. Then I say, 'You did that, great job.' It might seem small, but for him, it's a huge win.

A CHANGING RELATIONSHIP

Dad will be 82 this year. He's doing so well, but I can see the journey changing. Just this morning, he said, 'You make me feel safe.' That meant so much. He told me, 'I don't need to worry because you'll help me sort things.' He gets overwhelmed easily now – even small things can become big worries. We've made a daily diary for him, so he knows who's visiting and when, and even where to find his lunch. I wrote in today's entry: 'Lunch is in the fridge.' He knows I'll be back later to do his dinner. The diary helps ease his anxiety, but it's also comforting to know he trusts me so deeply. Our roles have completely reversed. I'm the daughter, but now I'm also his carer. He's still my dad in many ways, but in other ways, he's not. There's a vulnerability now. He says things that just aren't him.

> *'Even something like paying for his newspaper can be a big task now'*

NO FILTER

One of the biggest changes in my dad is that he's lost his filter. Sometimes it's funny, but sometimes it's shocking. He swears now, which he never did before. He uses expletives like its everyday language.

He'll say anything that pops into his head, including comments about someone's appearance – it just comes out. It can be embarrassing, but he has no idea it's inappropriate. He would be mortified.

But that's the illness. It changes how the brain works, how people express themselves, how they interact with the world. It's not who he really is – it's the dementia. DH



Nicola supports John with daily tasks like paying for items

Keeping your loved one safe

When a loved one is living with dementia, the person's safety is always on your mind. The **Herbert Protocol** is a simple but powerful way to help protect them if they ever go missing.

Caring for someone living with dementia and keeping them safe can be a huge challenge. With around one million people in the UK living with dementia, and 70 per cent of them likely to go missing at least once, it's understandable that carers can feel anxious. Every year, over 40,000 people with dementia go missing for the first time. The Herbert Protocol is here to help bring peace of mind.



'If someone goes missing, the details you've prepared can be accessed immediately by officers'

WHAT IS THE HERBERT PROTOCOL?

The Herbert Protocol is a free safeguarding programme designed to help find people living with dementia quickly if they go missing. Provided by MedicAlert, it involves preparing a set of essential details in advance, such as recent photographs, medical information, favourite places and routines, which can be given to the police if needed. Having this information ready saves precious time in an emergency, increasing the chances of a safe return.

WORKING ALONGSIDE THE POLICE

Police forces across the UK – including The Metropolitan Police and Thames Valley Police – have signed up to use the Herbert Protocol. This partnership means that if someone goes missing, the details you've prepared can be accessed immediately by officers, allowing them to begin their search without any delay.

ABOUT MEDICALERT

MedicAlert is the UK's first and only medical ID charity. Its mission is to give people living with medical conditions or any allergies greater confidence, independence and peace of mind.

REASSURING MESSAGE

Rob Burley, CEO of MedicAlert, says: 'We're thrilled to bring the Herbert Protocol safeguarding scheme to those living with dementia in the UK. Making this tool accessible for families, with the support of police forces across the country, offers real peace of mind. It helps ensure that if a loved one does go missing, critical information is immediately on hand to help bring them home safely.'

BE PREPARED

Taking the time to prepare now could make a difference later, knowing you've done everything possible to keep your loved one safe. DH

More information
Visit herbertprotocol.com
Email info@medicalert.org.uk
Call 01908 951045

HERBERT PROTOCOL

Provided by MedicAlert



Do you know someone living with dementia?

The Herbert Protocol helps police find people living with dementia when they go **missing**.

www.herbertprotocol.com

Scan me!

‘It’s about learning and adapting’

The more you understand about dementia, the better placed you are to keep your loved one safe and well. **Scott Mitchell** shares some of the changes he made indoors to keep his late wife **Dame Barbara Windsor** safe at home

Caring for a loved one with dementia means constantly adapting to new challenges and learning as you go along. Scott Mitchell, husband of the late Dame Barbara Windsor, who had Alzheimer’s disease, shares the practical changes he made around their home to keep her safe.

Scott, an ambassador for Alzheimer’s Research UK, is also the People’s Champion of the government-funded Dame Barbara Windsor Dementia Goals Programme – a national mission to help beat dementia – for which he helped to campaign. He remains keen to share his experiences to help others looking after a loved one with dementia. In this candid chat, he reflects on what worked, what he learned as a carer and why safety starts with understanding dementia’s unpredictable nature.



Scott began caring for Barbara when her symptoms first started in 2009

You looked after Barbara at home for as long as you could. What changes did you make to your home to keep her safe?

SM: One of the first things I did was put up a whiteboard to help with her early confusion. Barbara would often think we were in her childhood home in Stoke Newington, even though we lived in central London. She would also ask how we knew each other. So, I created a board with photos of us from over the years, labelled with dates and messages such as, “This is our home now.” Sometimes it helped and sometimes it didn’t, but it was a start.



Installing a gate at the top of the stairs gave Scott peace of mind

As her condition progressed, mobility and perception became big issues. She'd walk into furniture because her peripheral vision wasn't working properly. I learned to put things in her line of sight to help avoid accidents, such as a footstool near a table she kept bumping into.

One key change I made was in the bathroom. We had white tiles and a white toilet with a white seat – all of which blended into one another. I added black tape to the seat and edges, to give visual contrast, which helped her see where to sit.

Were there any key concerns about the layout of the house?

SM: The top of the stairs really worried me. Barbara was unsteady and sometimes I'd find her hovering at the top looking uncertain. She had a floor mat by her bed that triggered an alarm when she stepped on it, and I put in a gate at the top of the stairs – something that blended in with the decor but gave me peace of mind. It wasn't high or restrictive, so she didn't feel trapped.

'It's all about adapting continuously and asking for advice where you can'

Moving to a bungalow is often suggested for people with mobility issues, but for someone with dementia, a move can cause even more confusion.

SM: Absolutely. A change of environment really unsettled Barbara. If she had a hospital stay, it could take two weeks for her to readjust at home. That's why I focused on making our existing space safer instead of moving. I also added a sensor light outside her bathroom, which switched on when she got up at night, reducing the risk of wandering in the dark. Those lights are a great idea; they're not on all night, just when movement is detected.

Over time, you notice dangers specific to your own home and your loved one's behaviour. For example, the kitchen – what do you do about sharp knives? How do you make drawers harder to open without stripping away independence? It really depends on whether the person is left alone, even for short periods. It's all about adapting continuously and asking for advice where you can.



It took time for Barbara to accept the presence of a carer



'Forget about appearance – the goal is clarity. Anything that reduces confusion is worth doing'

Was there any advice that helped you early on?

SM: The whiteboard idea came from Barbara's neurologist. I told him that she was getting confused about where we lived and how we knew each other. He suggested using visual cues. That worked well in the early stages.

Most other changes I figured out myself – just by being in the situation or reading things. Barbara didn't want to talk about her diagnosis for the first four years, so I wasn't able to open up about it or connect with support groups early on.

How did you get Barbara to accept outside help?

SM: It was hard. I initially tried to do everything myself, but eventually it became too much. You need space just to live your own life, do the shopping, go to work and protect your own wellbeing.

When I first brought in a carer, Barbara didn't take to it. She wasn't rude, but clearly didn't want them there. I had to appeal to her heart, her emotions. I told her, "Barbara, I need help, too." That emotional appeal made a difference. She eventually accepted them and, over time, the carers became part of the family. She would even joke with them.

It helped that we had a small, consistent team. Familiarity builds trust. I know that's not always possible, but in our case, it made a huge difference, especially when it came to personal care.

What about signage around the house?

SM: Yes, I used large signs with bold writing – especially for toilets. Forget about appearances – the goal is clarity. Anything that reduces confusion is worth doing. Towards the end, Barbara was rarely without one-to-one support, but not everyone has access to that, so signage becomes essential.



Simple adaptations to the home can help to prevent falls

Did you have to start locking away knives and other sharp utensils or objects?

SM: In Barbara's case, no. She wasn't engaging with utensils much. She'd come into the kitchen and sit at the table, and I'd help with her food. I'd do the cooking anyway – it had been like that in the 27 years we lived together. But others might be different. Some people with dementia were the main cooks and might still try to use the oven or kettle. That's when accidents can happen.

You do your best to anticipate things, but dementia is unpredictable. You can't always foresee how someone will behave from one moment to the next. It can be overwhelming. But that's the nature of caring – you have to constantly react to the moment and adjust as needed.



Be aware that someone who enjoys using the kitchen could be at risk of accidents

Did you use any technology to help care for Barbara?

SM: Yes, the sensor light and the floor mat were both vital. I have indoor cameras – not in private areas, but in places like the hallway and stairs. In the early stages, if I went out, I could check in to make sure Barbara was okay and hadn't had an accident or fallen.

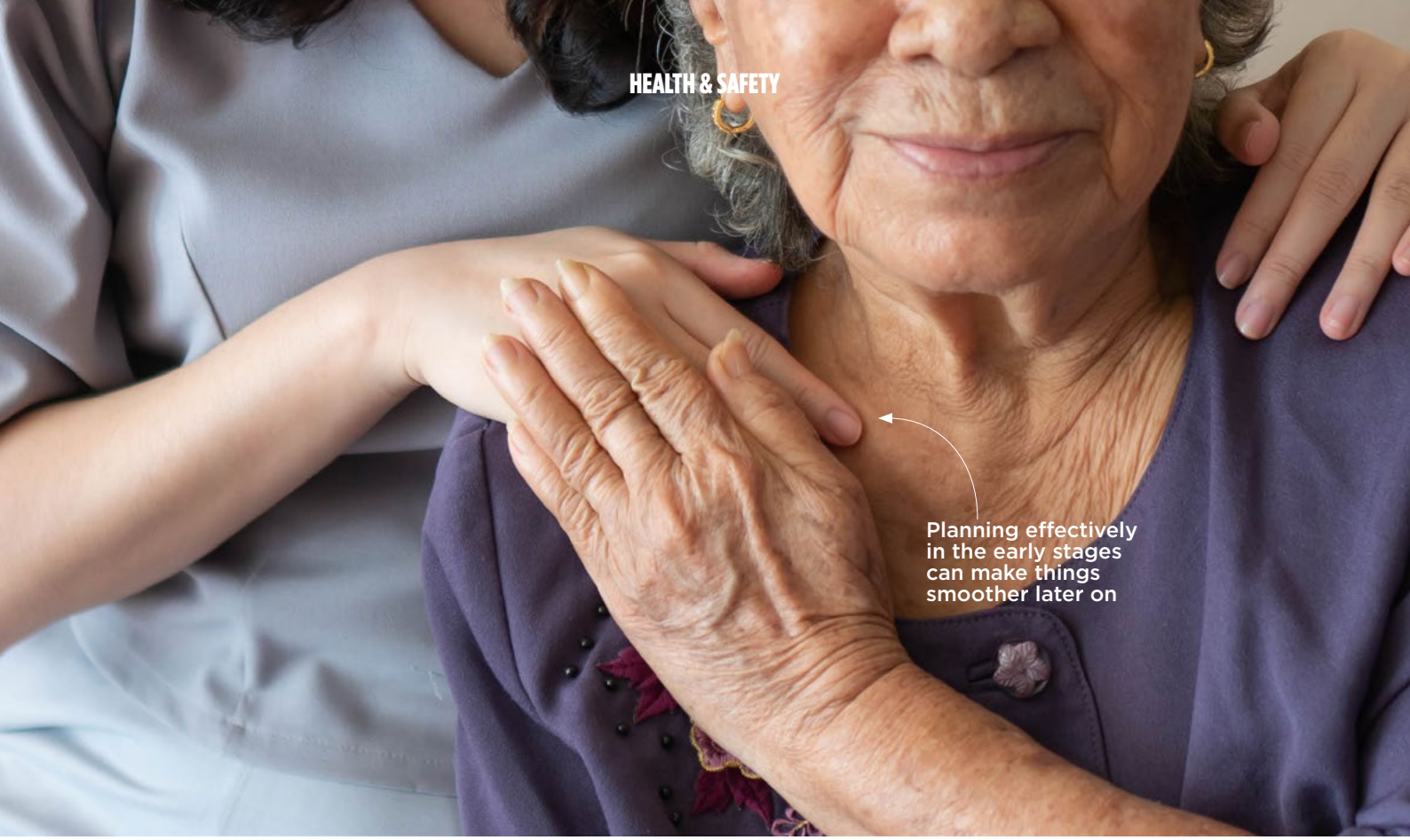
But there came a point where I couldn't leave her alone at all. The first time she got lost was the turning point. She wandered off and I got a call from the local dry cleaner – thankfully, she was recognised, and they phoned me. Barbara later said, 'I'm so sorry, love. I suddenly didn't know where I was.' That was when I knew I couldn't leave her by herself anymore.

Of course, you can't just lock someone in. You have to think about safety without making someone feel imprisoned. After that, if I had to go out for a few hours, I'd arrange for someone to be with her – friends, carers, anyone who could step in. DH

More information

Scott is an ambassador for Alzheimer's Research UK and is supporting the charity's current campaign to support people's rights to an early diagnosis, so that they can access medications promptly. For more information about the charity's work and to sign the petition, visit: www.alzheimersresearchuk.org

For more details about Scott's role as the People's Champion of the government-funded Dame Barbara Windsor Dementia Goals Programme to beat dementia, visit the Dementia Goals website.



Planning effectively in the early stages can make things smoother later on

Keeping a person with dementia safe at home

Key things to think about and why it's important to make changes as the person's care needs begin to increase.
Words: **Christina Collison**

Keeping a person with dementia safe at home takes planning, foresight and a willingness to adapt as their needs change. They may still be fairly independent now, but their abilities will shift over time. Putting the right support in place early can help them remain at home for as long as possible and give you peace of mind.

DON'T TRY TO DO IT ALL

Even if you can take on much of the care yourself for the time being, there will come a time when the person cannot be left alone. Accept early on that you can't do it all yourself. If you have other family members, ensure the whole family understands the situation, so the caring responsibility can be shared. If not, think about reliable friends who could help. You can also check whether there's an Admiral Nurse in your area. Admiral Nurses specialise in supporting families affected by dementia, offering practical strategies and emotional guidance. Visit www.dementiauk.org for further information.

WHERE ARE YOU NOW?

Think about the level of care the person needs right now. For example, in the early stages, my mum could go out alone and live fairly independently. She mostly needed help being prompted to take her medication and I'd drive her to appointments.

However, as the person's dementia progresses, they may forget their house keys, leave the door unlocked or go out and get lost. Identifying potential risks now helps you put safeguards in place before they become urgent problems.


A pendant alarm can be reassuring

If you are worried about wandering, you can register your loved one's details with The Herbert Protocol, a free online register that records a person's details and ensures they can be found more easily if they go out and get lost.

WHEN TO STEP IN

Sometimes, it's obvious when to take charge – other times, it's not so straightforward. One of the hardest things for me was knowing when to take control of parts of Mum's life – when to take away the car keys, start doing her washing, buy her food, or switch off the oven at the mains. Each decision came with sadness, but you have to trust your instincts.

My mum began losing weight and also had regular stomach upsets. I found her fridge full of expired or inappropriately stored foods. She had frozen foods stored in the fridge and meats left uncovered and out of date. I arranged for her to have Meals on Wheels through social services, so that she could have a nutritious hot meal every day. At first, she was reluctant to have the meals, but after a week, she began to enjoy them, especially the puddings. Another key benefit of having Meals on Wheels delivered was that it meant someone would knock at her door every day. One day, she forgot they were coming and went out – and the Meals on Wheels office rang me to say she hadn't answered the door. Mum was fine, but I was impressed that they'd gone to the trouble of alerting me to the situation.

'An occupational therapist can recommend adaptations, such as stair rails, bath seats and shower stools'

OVERCOMING RESISTANCE

Many people with dementia will resist help at first. Negotiation, gentle persistence and compromise can work wonders. Take things slowly and don't present solutions as a permanent thing. Sometimes, you can present changes as 'just trying it for a week'. Other times, you simply need to make the decision and hope they adapt.

CAREFUL OBSERVATION

Discreet observation is key. Look for signs the person is struggling – dirty clothes, laundry piling up, broken appliances. Remember, written instructions for appliances might not help if they can't process them.


Meals on Wheels can give you peace of mind that the person is eating well



Rugs can be a trip hazard, so you could consider removing them

TOP 10 SAFETY CHECKS FOR A DEMENTIA-FRIENDLY HOME



1. Remove trip hazards Clear clutter, fix loose carpets and remove small rugs.

2. Improve lighting Add nightlights to hallways, bathrooms and bedrooms.

3. Secure appliances Fit automatic shut-off devices on ovens, hobs and irons.

4. Label rooms and cupboards Use clear signs to help with orientation.

5. Simplify controls Replace remotes, phones and radios with easy-to-use versions.

6. Store medication safely Use a locked box and supervised administration if needed.

7. Install a key safe Provide secure access for carers and emergency services.

8. Consider a pendant alarm For 24-hour help if they fall or need urgent assistance.

9. Adapt the bathroom Add grab rails, a shower stool and non-slip mats.

10. Maintain outdoor safety Keep paths clear, fit a secure garden gate and remove hazards.

If they can no longer manage certain tasks safely, arrange help, whether from family, neighbours or care workers.

If the person enjoyed activities such as walking, consider whether they can still do them safely. My mum liked walking around her village, but eventually couldn't find her way home. I would take her out as much as I could, so she still had fresh air and stimulation.

Is the person's home safe? Safety hazards can appear in everyday routines. Will the person remember to lock up at night, turn off the oven or switch off the TV? Spend the night occasionally, to observe unprompted routines.

Consider whether it's safe for the person to cook. If not, disconnect the oven or replace it with an automatic shut-off model. Look into helpful items, such as pendant alarms or monitoring systems if needed – these can provide peace of mind, even if they feel like a big step.

PREVENTING FALLS

As mobility declines, the risk of falls increases. An occupational therapist can recommend adaptations, such as stair rails, bath seats, shower stools, raised toilet seats and mobility aids. Nightlights can also help prevent confusion in the dark.

Here are some things you can try:

- Remove trip hazards, such as loose rugs and clutter.
- Encourage gentle exercise to improve balance.
- Look after foot health with regular chiropody.
- Check eyesight regularly.
- Keep frequently used objects within easy reach.

MEDICATION MANAGEMENT

Medication can be a safety issue. Early on, a reminder call may be enough. Later, you might use a dosette box to separate pills by day, but in time even this can become confusing. I eventually locked my mum's medication in a small safe and arranged for a care worker to administer it, as I was worried Mum was at risk of taking her tablets incorrectly. If in doubt, lock medication away.

FOOD AND NUTRITION

If they're not eating, Meals on Wheels can be a lifeline.



In the early stages, a dosette box can be helpful for medication

They deliver hot meals daily at a low cost, with the added reassurance of a regular visitor.

ALARM SYSTEMS AND KEY SAFES

Key safes (lockable boxes fixed outside the home to store a spare key) and pendant alarms (worn as a necklace or wristband to call for help after a fall) are both useful options. Social services can often arrange installation, or they can be bought privately.

ASSISTIVE TECHNOLOGY

Simple devices can remove daily frustrations. Phones with fewer buttons (Doro products are useful), like easy-to-use TV remotes, one-button radios or familiar-style appliances can make life less confusing.

'Look into helpful items, such as pendant alarms or monitoring systems if needed'

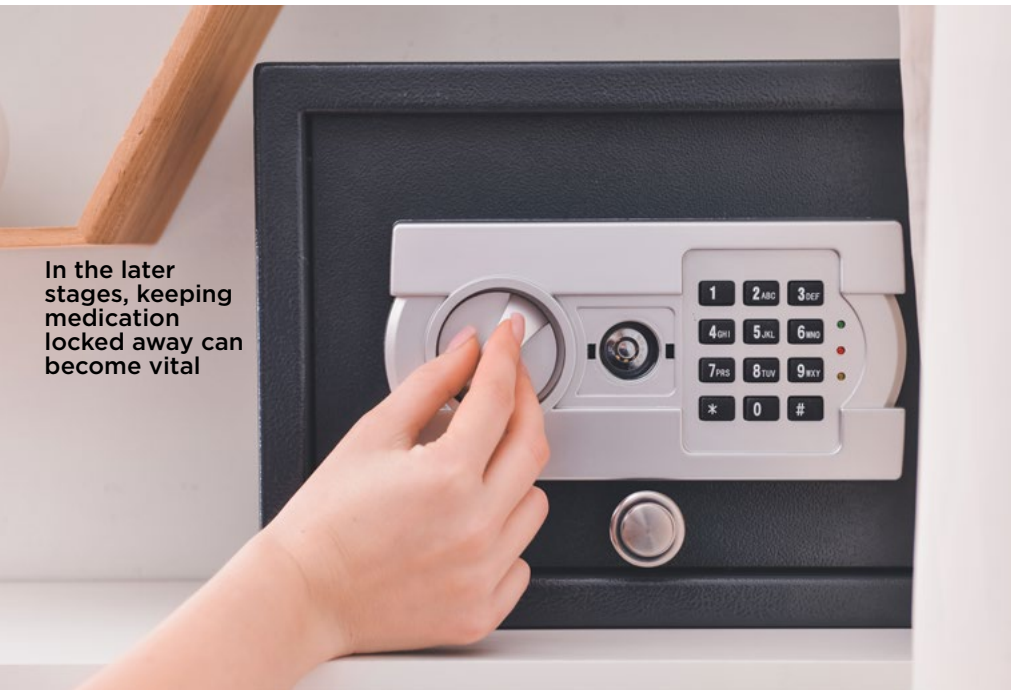
REGULAR VISITS AND A SUPPORT NETWORK

Regular visits can keep your loved one safe and socially engaged. But if you work or live far away, visits may be less frequent than you'd like. That's when extra support is vital.

I lived over an hour away from my mum and worked full-time. I visited at weekends and phoned Mum several times a day, but as her needs increased, I realised that what she needed and what I could give weren't the same thing. So, I arranged for the following:

- A weekly cleaner, later increased to several visits a week.
- Carers to prompt medication and help with washing and dressing.
- A gardener who also handled odd jobs and kept an eye on Mum.

I can only stress the importance of people you can count on: if someone proves unreliable, don't make them part of the care plan.


In the later stages, keeping medication locked away can become vital

THE BIGGER PICTURE

Keeping someone with dementia safe at home is not just about preventing accidents — it's about preserving dignity, comfort and a sense of normality. By planning ahead, observing carefully and accepting help, you can create an environment where your loved one can live safely and well for as long as possible. DH

From daughter to campaigner How dementia changed everything

Beth Britton MBE cared for her late father, who had vascular dementia, for 19 years. She now helps other carers as a mentor and dementia awareness campaigner. Here, she shares her story.



When Beth Britton's father, Ray, began showing signs of vascular dementia, she was 12 years old. What followed was nearly two decades of caring, resilience and, ultimately, a platform for change. Beth shares her family's difficult journey, the emotional toll of being a young carer, and the legacy her father left behind.

Can you tell us about your father's dementia journey?

BB: My dad had vascular dementia for 19 years. Looking back, symptoms began when I was about 12 years old. He went 10 years without a diagnosis. This was before memory clinics, and he was having TIAs (transient ischaemic attacks). Eventually, he had a larger stroke and was admitted to hospital. That's when he was diagnosed and declared a danger to himself and others if he returned home.

What happened next?

BB: He started in the first of what would be three care homes. The first lasted six months, but it didn't go well and he returned to hospital. After three more months in hospital, during which we argued over his funding, he entered the care home where he would spend over eight years. It changed hands multiple times. In 2011, it was owned by Southern Cross, the UK's biggest provider, but when they went out of business, another provider took over. The care declined dramatically.


Beth says that small, special moments together carried them through

Dad developed pneumonia and pressure ulcers, and never recovered. We didn't want him to die in hospital, so we found a care home for the final two weeks of his life, where he received outstanding end-of-life care.

What was it like being a young carer?

BB: So much of my teenage and early adult life was shaped by Dad's illness. From age 12 to 22, we noticed things changing but didn't have a label for it. Dad went to the GP on his own by choice, so we weren't aware of the full picture. At meetings after his diagnosis, we discovered professionals had noted concerns, but waited until a crisis occurred – when he collapsed at home.

What was your dad like?

BB: Dad was a farmer and allotment gardener – very active. After selling his cattle, he gradually withdrew: first the allotments, then gardening, then self-care. Strange behaviours followed: storing food in odd places, keeping items around the house in strange spots, hallucinations. He believed people on TV were in the room. There was far less awareness of dementia then. We didn't understand what was happening. Once diagnosed, we were only given a leaflet. We did get some time with a consultant, which helped explain the condition.

Did you have other family around you?

BB: Yes, my mum and I are very close. She's now 85 and I'm starting to see some cognitive changes in her. I also have a half-brother and half-sister from Dad's first marriage, both with disabilities. They weren't involved day-to-day or living nearby. My sister had moved away for university. While there was family support, the day-to-day was mostly down to Mum and me.

How did you cope emotionally?

BB: It was difficult. Friends didn't have this kind of experience. Dementia wasn't talked about; there was a stigma. Some people thought my dad was crazy and that made them think I must be, too. I didn't have many supportive friends. I didn't know about wellbeing or mindfulness. But I loved being outdoors, and walking helped. Looking back, the little moments made the biggest difference. Those cups of tea, sitting outside, singing with Dad – they sustained us. Dad was physically strong, even with all the infections and hospitalisations. When things were calm, we tried to enjoy them. Those moments carried us through. I'd have my dad back in a heartbeat, dementia and all, because he was still my dad. There were still special moments.

'The little moments made the biggest difference. Those cups of tea, sitting outside, singing with Dad – they sustained us'

What inspired your advocacy work?

BB: My dad died in April 2012. Earlier that year, the Prime Minister's Challenge on Dementia was launched – the first time the government had focused seriously on dementia. That inspired me.


Beth treasures those calmer moments



Beth was a young carer from the age of 12

I didn't speak publicly while Dad was alive, as I was worried it might affect his care. I don't believe in only sharing the positives. We had some really bad experiences. I'm convinced poor care led to my father's death.

A few weeks after he died, I began my blog, D4Dementia, during Dementia Awareness Week in May 2012. I wanted to share what had helped us. Music had been amazing for Dad. I never imagined it would lead to a career. Then I was asked by the charity BRACE to speak at events. A care provider CEO told me, 'My staff need to hear this.' That was a turning point.

What work did you do during your caring years?

BB: We chose to spend as much time with Dad as we could. We were told early on that he had a terminal illness. I never did full-time work. I did freelance jobs – for a photographer, as an editor for a football website – but I needed flexibility. Lunchtime was Dad's main meal, and we often made sure one of us was there to support him. In his final years, it took Dad over an hour to eat and the care home staff didn't have time for that.

What support do you wish you'd had?

BB: We had very little. One leaflet. We didn't even know Admiral Nurses existed. More societal awareness would have helped, too – to hear the word 'dementia' and understand it, instead of people just thinking someone had 'gone mad.'

'I love the environmental guidance that's out now, and I wish every newly diagnosed person got that support'

Nowadays, there are podcasts, webinars, online support, events. I love the environmental guidance that's out now, and I wish every newly diagnosed person got that information with proper support from an occupational therapist. Small changes at home can keep someone independent longer and reduce family stress.

I also love the work of Dementia Carers Count and TIDE. They offer online support, carer development programmes and even men's groups. There are brilliant resources now, including from the Royal College of Speech and Language Therapists about safe swallowing, which would have helped us immensely.

Why is music so powerful for people with dementia?

BB: It was amazing for my dad. We made the classic mistake of putting a TV in his care home room. He smashed two of them. We got him a CD player instead. When he couldn't talk anymore, he could still sing a whole song perfectly. It brought words back and gave him a way to communicate.



Music gave Beth's dad a way to communicate

Why did you continue your work after your dad passed?
BB: It wasn't a deliberate plan. The blog was just to share what worked for us. Then it grew. I wanted everything Dad went through to have meaning – a legacy. 19 years is a long time to live with something that eventually strips you of everything. I didn't want that to be in vain. Someone at the 2024 Alzheimer's and Dementia Show asked me how I keep going. They said they would want to walk away after their loved one died. But for me, it's always been about helping others. This work doesn't feel like a job; it's my happy place, because I get to make a difference.

What should dementia messaging look like?
BB: Always involve people with lived experience. When I design training or workshops, I include people living with dementia as much as I can.

Messaging must be balanced. Dementia can be incredibly hard – the distress, incontinence, confusion. We can't ignore that. But we also need to highlight how people can live well. Use language that respects everyone's experience.

Can you give an example.
BB: Campaigns should show both the problem and the solution. I liked the Alzheimer's Society advert showing a man struggling to make tea, then managing with simple labelling. Or the Dementia UK campaign with a husband navigating choppy waters to his wife in a lighthouse – helped by an Admiral Nurse. Some campaigns go too far. One said people with dementia 'die and die and die again.' That was deeply offensive. When you've seen someone truly dead, like I did with my dad, you know the difference. Even towards the end, I could hold Dad's hand and he would squeeze back. There's a big difference between someone alive but struggling and someone truly gone.

What's your takeaway message for families?
BB: Treasure the small moments. I put a lot of my life on hold to be with my dad and I don't regret that.

One Christmas, when Dad could barely speak, I was leaving after lunch. He was sitting down to watch *Oklahoma* and said, 'Thank you for everything.' That moment will stay with me forever. So seize those little moments. They are precious and they become the memories that carry you through the harder times. DH



More information
Beth is a consultant, campaigner and speaker, trainer and mentor, specialising in ageing, health and social care. Visit bethbritton.com



What to do when help is refused

Convincing a person with dementia to accept help can feel like an uphill battle. But with the right approach, support can be introduced in a way that protects their dignity and your wellbeing. Words: **Christina Collison**

As a carer, you'll reach a point where you know you need help with your caring role. Your loved one's needs will increase, so you'll spend more time caring for them and, as a result, your energy levels may dip and you may even become ill. Before you get to that stage, it's important for you and your loved one to accept help and support, so that you don't burn out. However, it's very common for a person with dementia to refuse to accept help from outside sources. They may see it as losing their independence, especially if they used to be very self-sufficient. They may dislike the idea of a stranger helping them with personal care. And let's face it, who wouldn't feel that way?

UNAWARE OF THEIR NEEDS

However, they may also be completely unaware that they need help. My mum once told a social worker that she was able to manage housework, gardening and shopping. 'I'm doing all of my own washing and ironing, and all the cleaning,' she told her assertively.

The reality, though, was very different. I was doing all those things for her. In her mind, she genuinely believed she was doing everything herself. She even told me one day that she'd been out for a drive, which I knew wasn't true because she no longer had her car. She wasn't lying to me – she was simply confused and recalling much older memories.

On another occasion when I visited, she told me that she'd been outside in the garden mowing the lawn. I knew that couldn't be true either, because it had been raining heavily all day and, on top of that, I doubted whether she would have remembered how to use the lawn mower.

So, although sometimes people are aware they are having cognitive problems, they may not be fully aware of the extent of it.

For instance, in the book, *Remember When*, TV personality Fiona Phillips' husband talks about Fiona having limited awareness of her tendency to repeat the same questions and have the same conversations.

So, if your loved one refuses help, they're not necessarily trying to be awkward. They may be genuinely unaware of how much they rely on you. And if you try to explain that you are becoming stressed due to your caring role, they may simply tell you they can manage on their own.



Framing care as a temporary solution can help the person accept it

KEY WAYS TO GET THEM TO ACCEPT HELP

Here are some things you can try, to get the ball rolling...

• Gently press on

If they refuse to accept help, going ahead is often the best course of action. This may sound heavy-handed, but may be the only way to ensure their safety and wellbeing. Your loved one may resent your interference at first, but they will usually accept the help after a while.

• Frame it right

How you explain the situation might make a difference. Go with a gradual approach. Say you'll try having someone come in for a few days for a trial. In reality, it may be an ongoing plan, but describe it as a short-term experiment.

• Describe carers as housekeepers or friends

Framing carers as housekeepers or friends may encourage a better response. Age UK had a befriending service and a volunteer rang my mum every week to check on her. I told Mum the volunteer was an old friend of mine. She wouldn't have accepted it if I'd told her it was a stranger from a charity ringing.

'In her mind, she genuinely believed she was doing everything herself'

• Blame it on a temporary issue

Give a specific reason for using outside help. For example, meal deliveries until the cooker is repaired, or to give the person a break from cooking; a cleaner for a few weeks until the person recovers from a bout of flu; or shopping deliveries as your car is being repaired and you can't deliver the shopping.

• Protect self-esteem

No one likes to think they are struggling so offer praise when it's due. When the person completes a task or helps in some way, show gratitude to build up their confidence.

• Don't beat yourself up

When bringing in help, you may feel guilty about saying things that aren't strictly true. However, you're acting in the person's best interests. You know what the person needs. You can't always make them happy, but you can try to make them safe. DH

Supporting younger people with dementia

While dementia is more common in older people, there has been an increase in younger people living with the condition. **Nicola Booton** is a dementia adviser for Alzheimer's Society Warwickshire. Here, she talks about providing support, plus the benefits of CBT

We're seeing more people diagnosed with young-onset dementia. This might be due to greater awareness, thanks to TV storylines and public campaigns, alongside reduced stigma. More people are now seeking help early, which is a good thing. Early diagnosis means earlier access to support, medication and therapies.

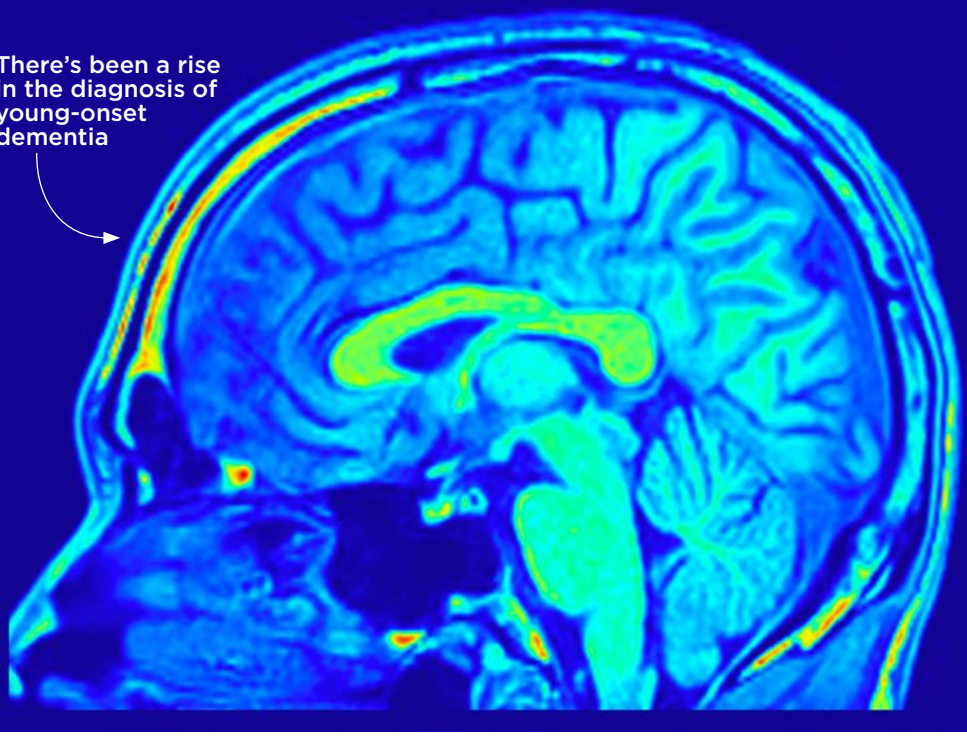
One woman we support is keen to remain at work for as long as possible. She recently started medication and wants to keep her life feeling "normal." I'll be visiting her workplace soon to speak with her employer about simple adjustments, such as a larger monitor and keyboard, and reducing her phone-based tasks, which she finds difficult due to memory and processing issues.

She's also been offered a 14-week CBT course, which she's keen to attend. Her employer is looking at adjusting her working hours to accommodate this. We're also arranging for Dementia Friends training at her workplace, to help colleagues better understand how to support her, without overcompensating or stepping in too much, which she finds frustrating.

Even small moments can highlight the challenges. When I visited her at home, she offered me a coffee but then realised she didn't know how to use the machine. I said a cup of tea would be fine, but she was visibly anxious about making tea, worried she'd forget steps. I simply asked if she wanted me to chat or stay quiet while she focused. She chose quiet, and she made the tea herself. It took longer, but the pride she felt was worth it. These are the little things that matter.

TAILORED SUPPORT MATTERS

Everyone's dementia journey is different. Some struggle with memory, others with planning, daily tasks or social interactions. So, we start by asking: 'What's worrying you most right now?'



There's been a rise in the diagnosis of young-onset dementia



A CBT course can be hugely beneficial

Then, we tailor support. This might include memory cafés, clubs or care assessments for the person and their carers.

We also help with benefits – many don't realise they're eligible for Attendance Allowance. We support them through the application process to ease financial pressure.

HOW CBT CAN HELP

CBT (cognitive behavioural therapy) can be available for people with dementia and their carers, depending on where you live. For people with dementia, the 14-week course helps them understand their diagnosis, symptoms, and how dementia affects their thoughts and actions. For carers, a six-week course covers the emotional and practical sides of caring, from understanding the condition to dealing with behaviour changes and managing day-to-day challenges. The chance to share experiences in a supportive group is hugely valued.

One challenge is that people on the course may be at different stages. Some newly diagnosed may worry when they see others further along the path. But the course also teaches that every journey is unique – dementia types, other health conditions and timing of diagnosis all vary.

'CBT (cognitive behavioural therapy) can be available for people with dementia and their carers'

GETTING A DIAGNOSIS

Sometimes, getting a loved one to the doctor isn't easy. I had to use a "little white lie" to get my dad assessed – we said it was just a routine check-up. Once there, the doctor gently included a memory test. That led to a referral and, eventually, the support he needed.

We also help people pre-diagnosis – those showing memory problems but not yet formally assessed. If someone is reluctant to visit the GP, many surgeries now offer home visits or have dementia nurses who can assess in a familiar environment. The important thing is to start the conversation, even if it means being a bit creative in how you approach it.

There is support out there – for people with dementia as well as for carers. The key is asking for help early. Speak to your loved one's GP about CBT. Talking therapies such as CBT accessed through the NHS are usually free of charge.

Alternatively, the British Association for Behavioural and Cognitive Psychotherapies can provide a list of CBT therapists in your area. Call 0161 705 4304 or visit www.babcp.com. DH

More information

Nicola works as a dementia adviser for Alzheimer's Society Warwickshire. She supports people who are newly diagnosed with Alzheimer's and dementia, working in the community, in their homes, and helping them to access services and support following their diagnosis. Nicola, who has two children, works full-time and is also a carer for her father, who has Alzheimer's. If you need support, you can ring the Alzheimer's Society's support line on 0333 150 3456 or visit www.alzheimers.org.uk/get-support/dementia-support-line



Care options for younger people with dementia

How do you find affordable, age-appropriate care for a younger person with dementia? **Lyndsey Mitchinson** explores some options

Receiving a dementia diagnosis at any age can be deeply overwhelming, but it can feel especially unexpected and life-changing when it happens before the age of 65. Many support systems are designed for older adults, so younger people can feel overlooked. They might still be working, supporting children or managing mortgages when everything suddenly changes.

When care at home is no longer possible, finding an affordable, age-appropriate care home can feel overwhelming. But with the right knowledge and support, it is possible to find a place where the person you love feels understood and well cared for.

WHAT MAKES YOUNGER NEEDS DIFFERENT?

A younger person with dementia is unlikely to see themselves reflected in traditional care homes. They may still have financial responsibilities, be supporting children or elderly parents, or have hopes, plans and aspirations that have been suddenly cut short.

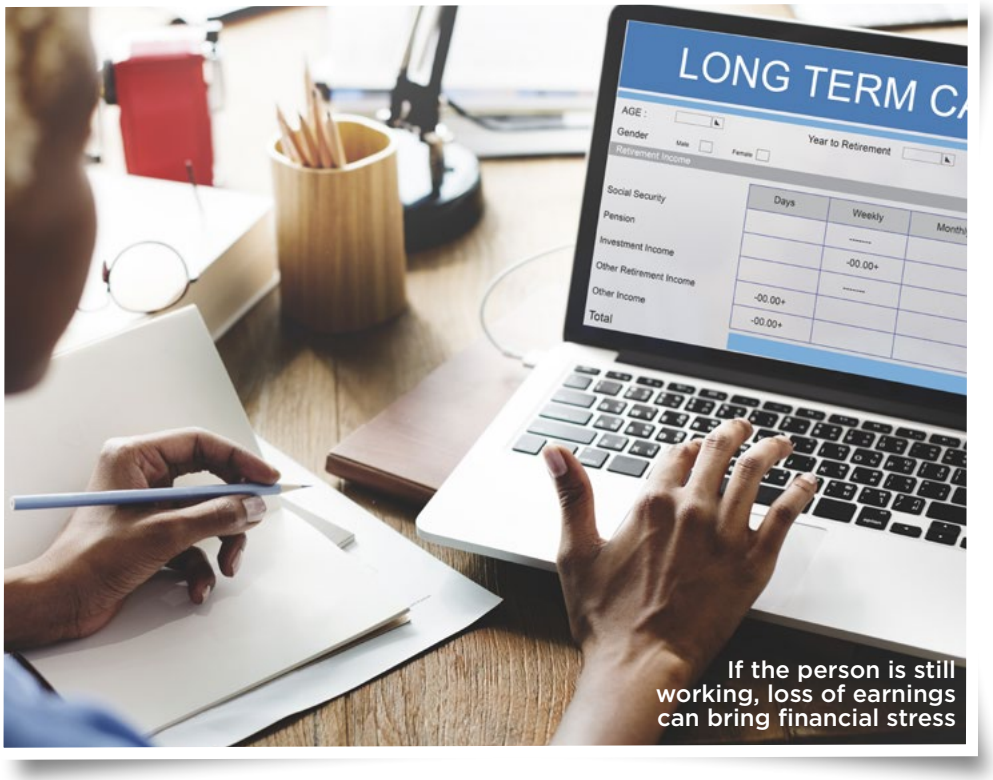
LOSS OF EARNINGS

Loss of earnings combined with growing care needs can bring unexpected financial pressure. Someone who once managed teams or complex projects may now need help with daily tasks, yet still long for purpose, structure and independence. Symptoms can also look different. Memory problems are common, but younger people often experience changes in speech, mood or movement first. They're usually more physically active and may not have other age-related health conditions, which can make traditional care settings feel unsuitable or even isolating.

It's also not uncommon for early signs to be misread, leading to delays in diagnosis. This can leave people feeling confused, frustrated or dismissed. All of this makes it even more important to find the right care and support from the beginning.

FINDING SPECIALIST CARE

Care homes that specialise in young-onset dementia do exist, but they are limited.



If the person is still working, loss of earnings can bring financial stress

Some have dedicated spaces for under-65s. Others cater to all ages, but adapt their approach to meet younger residents' needs.

You may need to widen your search beyond your local area. This can be difficult, but it increases your chances of finding appropriate care.

There are several care providers in the UK that support people with young-onset dementia. B&M Care has a number of homes that offer this type of care. Inspire Neurocare also provides support for people diagnosed at a younger age. St Matthews Healthcare offers services for people with different types of dementia, including those with early-onset.

You can also ask your GP, social worker or dementia nurse if they can suggest homes with experience in young-onset dementia.

ADVICE ON RESEARCHING CARE HOMES

Helpful questions to consider when researching:

- Do they have experience supporting people under 65 with dementia?
- Are there any other younger residents at the home?
- What type of activities and routines do they offer for younger residents?
- Do they support independence?

Where to find more information:

- Your local council or social worker.
- Care Quality Commission (CQC) website and carehome.co.uk.
- Support groups for young-onset dementia.
- GPs, dementia nurses and specialists.

'Even small responsibilities like mentoring others or helping with technology can make a real difference'

Even homes without specific young-onset services may be willing to adapt. Visiting several care homes can really help you get a feel for what matters most. While you're there, take your time to look around and don't be afraid to ask plenty of questions. If the first few don't feel right, don't give up – the right place is out there.

WHAT GOOD CARE LOOKS LIKE

Good care homes recognise that younger people need more than basic support. They need meaningful activity, flexible routines and social connection.

- Choice matters – not everyone wants breakfast at 7am or the same mealtime every day. Many younger residents benefit from having more freedom in how they spend their time.
- Activities should reflect real interests – beyond bingo and board games, look for options such as music sessions, fitness classes, photography, quizzes, cooking or gaming.
- Make it personal – personalised activity plans will help ensure your loved one stays engaged.



Look for care options that cater to the person's interests and passions

One person might enjoy helping in the kitchen, while another might prefer gardening or art. Fixed schedules rarely suit everyone's preferences.

- Make social interaction suitable – age-appropriate social interaction is essential. Ask whether the home has other under-65s or creates peer connections through smaller groups, community outings or online groups.
- Consider the environment – the environment matters, too. Private rooms, accessible kitchens, reliable Wi-Fi and safe outdoor spaces can all help people feel more at home. Regular outings for walks, shopping or local events can also help to maintain a sense of normal life. The key is daily choice: what to wear, when to eat and how to spend time. These small freedoms all add up, to help preserve identity and confidence.

MAINTAINING PURPOSE AND IDENTITY

Many people diagnosed younger still want to contribute, stay busy and feel like themselves. Their careers, hobbies or interests don't just vanish.

Some care homes support meaningful roles, like event planning, office work or helping run cafés or shared spaces. Creative options might include music production, digital art or building projects. Others offer volunteer opportunities or skill-sharing, sometimes with support from local businesses. Peer-led activities, walking groups or book clubs also help people stay connected.

Even small responsibilities, like mentoring others or helping with technology, can make a real difference. It's not just about staying occupied – it's about feeling valued and purposeful.

Family members can play a vital role here, too. Share what your loved one enjoys or finds comforting. Bring in familiar items from home. If possible, join in with activities. These small touches can ease the transition and help staff tailor support more effectively.

'Creative options might include music production, digital art or building projects'

UNDERSTANDING COSTS AND FUNDING

Care homes typically cost between £700 and £1,500 per week, depending on location and care level. Specialist homes or private rooms may be more expensive. Help is available.

NHS Continuing Healthcare (CHC) covers all costs for people with complex needs. It can be hard to obtain, but worth applying for.

If the person has savings or assets under £23,250, they may be eligible for Local Authority support. This starts with a care needs assessment, then a financial assessment by your local council.



The right care will allow the person to live with purpose, connection and joy

Here's a guide to a step-by-step funding approach:

- Request an NHS CHC assessment.
- Ask your local authority for a care needs assessment.
- Gather financial documents for means testing.
- Seek help from dementia charities.
- Get legal advice for complex situations.

Funding care can feel complicated, but support is out there. Start with these key steps and don't be afraid to ask for help.

If you're struggling with appeals or delays, organisations like Beacon CHC or the Alzheimer's Society helpline can offer advice. Some carers also find it helpful to join online forums or local support groups, to hear how others have navigated the system.

ALTERNATIVE OPTIONS

If a suitable care home isn't available, consider respite care, short-term placements or Shared Lives schemes, where a trained carer invites the person you care for into their home. Supported living or live-in carers with funding support may also be options.

Some families consider adapting their own home or pooling resources with others to create a shared living arrangement. This can offer more control, though requires careful planning and support.

Availability differs across the UK. If you're struggling to find the right place locally, try expanding your search to nearby regions.

KEEP ASKING QUESTIONS

Finding the right care for someone under 65 is about more than ticking boxes. Their needs and experiences are different, but with the right support, they can still live with purpose, connection and joy. Keep asking questions. Talk to other families. Trust your instincts. The right care home won't just support your loved one, it will support you too. DH

Useful contacts

Care Quality Commission (CQC)
Search for care homes and view their inspection reports: www.cqc.org.uk

Carehome.co.uk
Search for care homes and read reviews: www.carehome.co.uk

Beacon CHC
Provides free advice and help for families navigating the NHS Continuing Healthcare process. Visit beaconchc.co.uk

Young Dementia Network
Useful resources and information: youngdementianetwork.org

Alzheimer's Society Dementia Support Line 0333 150 3456

Dementia UK
Search for young-onset dementia support groups in your area:
www.dementiauk.org/information-and-support/young-onset-dementia/find-support/

How does dementia affect the brain?

We know that dementia is a progressive condition and leads to changes in cognitive function, but how exactly does it affect different parts of the brain?

Dementia causes damage to different areas of the brain, leading to a wide range of symptoms, including mood changes, memory loss and confusion. Understanding how dementia affects brain function can help explain these changes.

The cerebral cortex, the brain's outer layer, plays a vital role and is made up of four key lobes:

- Frontal lobes – control thinking, behaviour, movement and motivation. Damage here can affect judgement, cause inappropriate behaviour, and lead to apathy or lack of interest.
- Occipital lobes – handle visual processing. Damage may result in difficulty recognising people or objects and may cause hallucinations. It may explain why your loved one doesn't always recognise people they already know.
- Parietal lobes – responsible for touch and language. When affected, the person may struggle with speech, including an inability to find the right words. Try not to finish words or sentences for them. Be patient.
- Temporal lobes – key for hearing, memory and emotions. Damage can impair understanding and recall. Inside the temporal lobes is the hippocampus, vital for forming new memories – this is often one of the first areas affected in Alzheimer's disease.

'Inside the temporal lobes is the hippocampus, vital for forming new memories'

PROCESSING EMOTIONS

Another important area is the amygdala, which processes emotions and forms memories. Damage here can affect emotional responses and regulation. It is often affected in conditions like Alzheimer's and Lewy body dementia.

Dementia can also impact the vascular system, which supplies oxygen-rich blood to the brain. In vascular dementia, blood vessels are damaged – often due to strokes – which leads to the death of brain cells in the affected areas. This results in symptoms specific to the part of the brain impacted.

Over time, many types of dementia lead to brain shrinkage, which worsens cognitive and emotional symptoms as more brain tissue is lost.

When you understand that these brain changes occur, it can make it slightly easier to understand why there can be changes in a person's mood or behaviour. DH

6 key reasons for a loss of appetite

Loss of interest in food is common in people living with dementia, and it can be caused by a range of physical, emotional and environmental issues. Here's a quick round-up of some common reasons why it can happen

1. FORGETTING TO EAT OR CONFUSION

Memory issues can mean the person simply forgets to eat. They may believe they've already had a meal or be too distracted to finish one – especially in noisy or busy environments, like communal lounges or restaurants. A calm, quiet setting can make a big difference, and gently prompting or eating with the person can help.

2. DIFFICULTY RECOGNISING FOOD

Visual and cognitive changes may affect a person's ability to eat. They might not recognise the food on their plate or not understand how to use cutlery. Eating from a coloured plate on a contrasting table can help food stand out, while gentle guidance can offer reassurance.

3. DISCOMFORT

Physical health issues, such as tummy upsets from eating out-of-date food, can cause discomfort and lead to food avoidance. Check the person's fridge and cupboards regularly, to make sure food is safely stored and still in date.

4. LOW MOOD

Depression is common in dementia and can reduce appetite significantly. If the person seems low or withdrawn, speak to their GP.

5. TROUBLE COMMUNICATING

Communication difficulties can also play a part. The person may not be able to tell you they're hungry, dislike a certain food, or are in pain – especially in the mid to later stages. It helps to speak about food preferences and watch for signs of discomfort, such as grimacing.



6. SWALLOWING PROBLEMS

In the later stages, swallowing can become difficult. Look for signs, such as coughing, fear when eating or grimacing when swallowing. Offer soft, moist foods and ensure the person is upright, unhurried and well supported.

Other common causes of loss of appetite include:

- Fatigue, which may prevent them from finishing meals. Eating can be tiring for a person with dementia, especially if it's a large meal.
- Pain, particularly dental issues. When did they last have a dental check?
- Constipation, which can cause bloating and discomfort.
- Lack of physical activity, which can lower appetite. DH

DementiaNet

dementianet.com

Want to help us build a supportive community for carers?

At DementiaNet, we know that the people who understand best are the ones who've been there

If you've ever found yourself juggling care information with tricky websites, confusing forms or the feeling that you're doing it all alone – we'd love to hear from you.

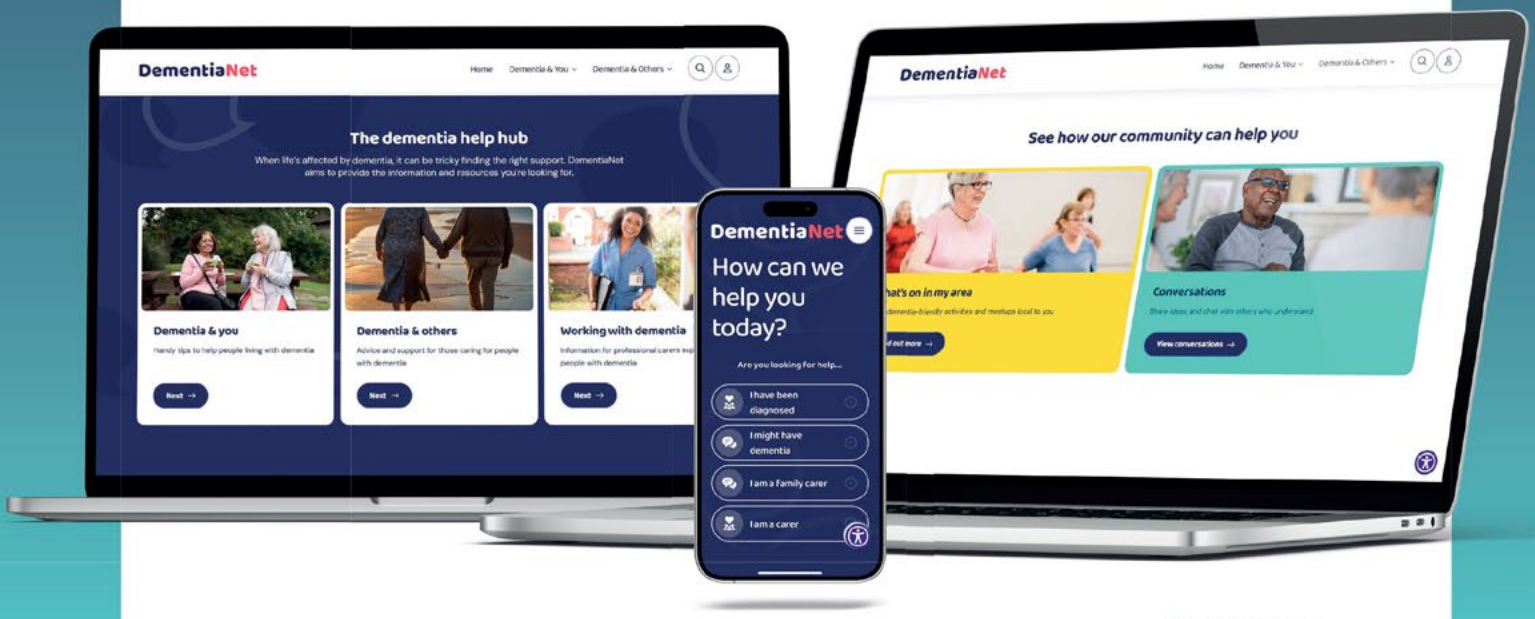
We're building an online community shaped by carers, for carers – a place to share stories, swap tips and make sure no one has to figure this out on their own. You can get involved by:

- Sharing your experience – your story could be the lifeline someone else needs
- Helping us improve – try out new features and tell us what actually works
- Connecting with others – meet people who truly understand what you're going through

Whether you've got five minutes or five years of experience, you can make a difference by offering a response to someone else's question. If you can help, it's free to create an account and we'd love to see you in the active conversations.

Together, we can build something that makes life a little clearer, a little easier and a lot less lonely...

Visit dementianet.com



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