HELPING CARERS COPE

DEMENTIA HELP

ISSUE 4

In partnership with
DementiaNet

PLAN AHEAD FOR FUTURE CARE

Key things to implement early on: your how-to guide

Applying for financial help | Organising paperwork | Making the right decisions | Securing your loved one's future

How to plan for a peaceful Christmas
Best ways to ease festive-season pressure

'My life with vascular dementia'
Sue Strachan shares her unique insights

Managing mood swings
Top tips from a professional carer

'I worried I would lose my job'
Your rights as a working carer

Coping with food refusal
What to do about appetite changes

How to plan ahead

When I first began caring for my mum back in 2009, I had no idea of the gravity of the situation. I knew that her memory wasn't good, and I'd got used to repeating things, but nothing prepared me for the challenges in store for us. Mum's GP confirmed her diagnosis of vascular dementia, then turned to me and said, 'Don't let her live alone for too long. Start planning for the future.'

I had no idea how to plan, what help was available or how to access it. My actions were well-intentioned, but sometimes ill-informed. Had I known back then what I know now, I would have done some things differently.

Help and support

Not only that, but the help and support we were eventually able to access would have been available sooner. For instance, I found out from Age UK that Mum was entitled to Attendance Allowance, which I applied for on her behalf, and she received. It covered the cost of a cleaner. She was also eligible for Meals On Wheels, which ensured that she got a hot nutritious meal every day.

Simple yet practical support like this made a big difference and enabled her to stay in her own home for as long as possible.

The more you know about dementia, the better placed you are to be a good carer. *Dementia Help* magazine is about helping carers cope, and this issue focuses on planning ahead for your loved one's future care. It covers what support is available when you need more of it, how to plan for future care and making a will and Lasting Power of Attorney. See page 36 and start planning now for your loved one's future wellbeing.

Carers rights

We look at what rights you have as a carer if you're also working (page 28), and share valuable insights from professional carer Caroline Savage (page 24), as well as Sue Strachan (page 18), who has vascular dementia.

Finally, I'd like to express my heartfelt gratitude to the wonderful team at DementiaNet for partnering with *Dementia Help*. Without their support, you wouldn't be reading this magazine now.

Christina x

Christina Collison
Editor
Dementia Help

christina@dementiahelpuk.com

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'The more you know about dementia, the better placed you are to be a good carer'

Issue 4

Editor
Christina Collison

Art Editor
Xavier Robleda

Sub-Editor
Claire Chamberlain

Website Manager
Dave Collison

Advertising Sales
Christina Collison
07957 360242

Cover photograph
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Published by
Healthy Content Ltd
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Photography:
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Next issue out on 6/2/25

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

JILL ECKERSLEY

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

DR EMER MACSWEENEY

Dr MacSweeney is Founder and CEO of Re:Cognition Health, a pioneering brain and mind clinic specialising in the diagnosis, treatment and care of people with symptoms of cognitive impairment. She's renowned for contributing to groundbreaking research in clinical trials for Alzheimer's.

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*.

LOUISE MORSE

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

DR CAROL SARGENT

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

CAROLINE SAVAGE

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

JAYNE SIBLEY

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

SUE STRACHAN

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

In partnership with **DementiaNet**
For more information,
visit DementiaNet.com

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Getting the right documents in order will ensure your loved one's wishes are met

Updates

The latest news, facts and stats about dementia

Did you know?

Dementia is not a disease in itself. Instead, it's an umbrella term used to describe a group of symptoms that occur when brain cells stop functioning correctly. Symptoms include memory loss, personality or behaviour changes, difficulty concentrating and confusion.

Brothers run the UK

Two brothers have recently run the length of the UK from John O'Groats to Lands' End in 31 days to raise money for Alzheimer's Research UK, raising over £228,000 so far. Jordan and Cian Adams both carry a faulty gene that can cause frontotemporal dementia (FTD). Their mother Geraldine passed away from the condition in 2016 aged 52. Jordan previously ran seven marathons in seven days in 2022, and the pair hope to raise £1 million for Alzheimer's Research UK to help find a cure. The pair have been supported on their challenge by Sue Strachan, an ambassador for the charity who has vascular dementia. Read our interview with Sue on page 18. To donate to the Adams Brothers' amazing fundraising challenge, visit https://www.justgiving.com/fundraising/ftdbrothers

Support for carers

According to a Dementia Carers Count survey, 81 per cent of family carers feel like they had no choice in becoming a carer, while a fifth of family carers reach crisis point on a regular basis. If you're struggling to cope, Dementia Carers Count offers free practical and emotional support: call them on 0800 652 1102 Monday to Friday from 9am to 5pm, or text CARE to 85258 for 24-hour support. DementiaNet also offers helpful information for carers on its website.

DID YOU KNOW?

People living with undiagnosed dementia are three times more likely to have to visit A&E, according to Alzheimer's Society. Making your loved one's home safe could help to reduce the risk of falls. Remove any trip hazards, such as worn or frayed rugs, and declutter as much as possible.

700,000

The number of family carers of people with dementia in the UK.
Source: dementiacarers.org.uk

6 key things to know about dementia

Knowledge is power, and learning more about dementia will make you a better carer. Here are some key things to know that will make your caring role less stressful...

1. EDUCATE YOURSELF

Lack of knowledge around available support can mean you and your loved one don't always get the help you could be entitled to. Some people don't want to apply for a needs assessment because they think they won't qualify for help, but you may be surprised. For instance, Attendance Allowance can be paid to people over the age of 65 if they have a physical or mental disability that means they need help with personal care. There are two levels of financial assistance depending on the care required, ranging from £72 to £108 per week (these amounts usually change over time). Attendance Allowance is not means-tested. For further information, visit www.gov.uk/attendance-allowance.

2. ACT ON EARLY ON

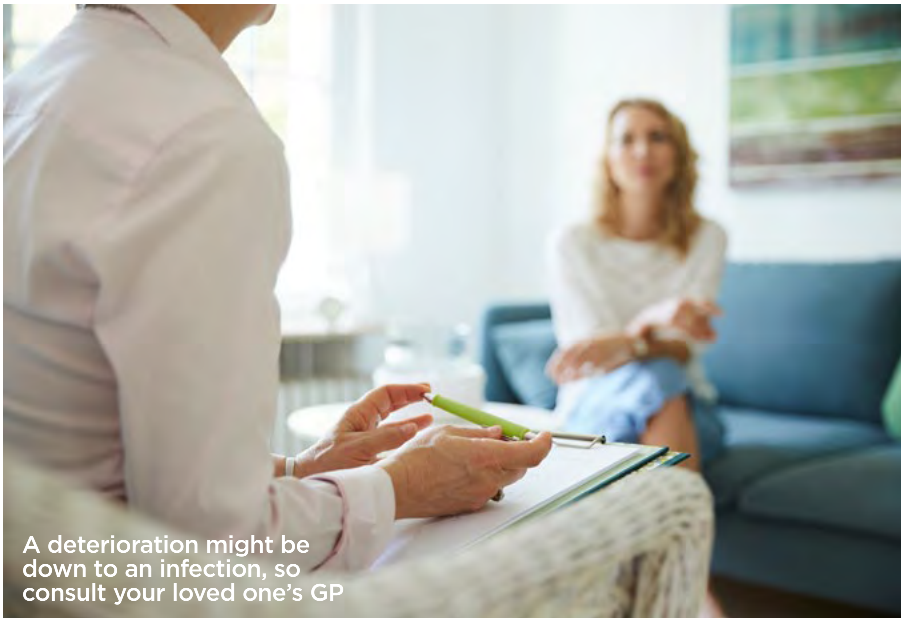
Your loved one is entitled to a needs assessment from their local authority. It is arranged by the local council in the person's area and carried out by social services. The assessment will determine whether your loved one is eligible for funding to pay towards their care. You can arrange an assessment on their behalf by contacting their local council by phone or online at www.gov.uk/apply-needs-assessment-social-services. It could take some time to get an assessment, so it's wise to start the process as soon as possible.

3. UNDERSTAND THAT YOUR LOVED ONE WILL NEED MORE SUPPORT

In the early stages of dementia, your loved one may need just a bit of help with housework and shopping. Over time, they will become increasingly reliant on you for help with getting out and about, personal hygiene, household chores and managing their paperwork. Organise Lasting Power of Attorney as soon as possible and plan ahead for their future care (see page 36).

4. ENLIST A SUPPORT CREW

Whether it's your friends, family or other carers, physical and emotional support can be enormously helpful. It's not only about managing practical tasks, but also having someone to talk to who understands how you feel, especially if it's your partner who has dementia. You would normally rely on them for emotional support in life, but this may no longer be possible. Think about who else can support you and, if need be, join a local group.


A deterioration might be down to an infection, so consult your loved one's GP

5. LEARN HOW TO MANAGE MOODS

Your loved one may have mood swings, even if they were laid back in the past. This can be due to changes in the brain and, although it's not the person's fault, it can be hard to deal with. Here are some useful ways to deal with mood swings:

- Use distraction techniques. If the person is becoming agitated, change the subject, offer a cup of a tea or suggest a walk.
- Don't mention bereavements. If the person asks where a deceased relative is, don't say they've died, or they will grieve all over again. Instead, if they ask why a loved one hasn't returned from work, for example, comment on the traffic being busy and then change the subject.
- Stick to the same routine. A change of routine can cause confusion, so try to follow a consistent routine where possible.

> 'Your loved one may have mood swings, even if they were laid back in the past'

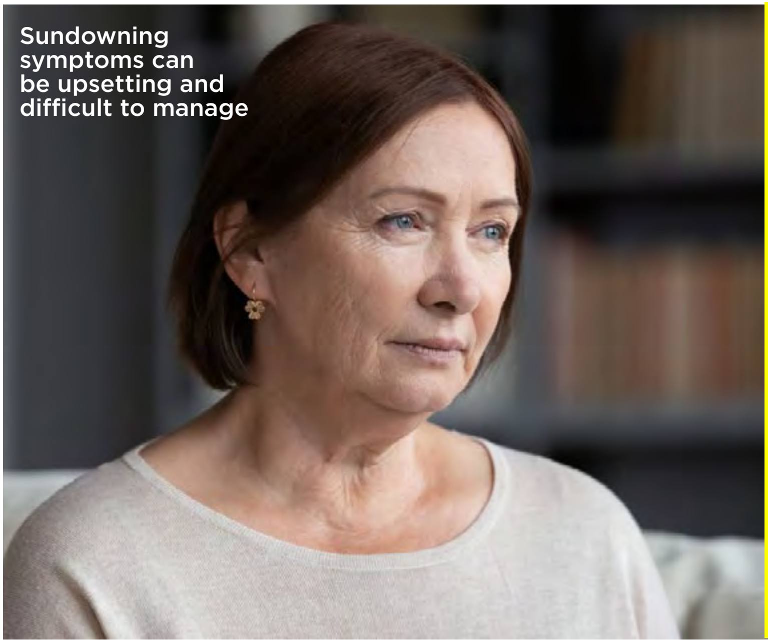

Joining a local group for carers can provide essential emotional support

6. MONITOR YOUR LOVED ONE'S GENERAL HEALTH

While the focus can often be on the person's dementia, it's important to remain alert to other changes. If you notice a sudden deterioration, seek medical help straight away. Sudden confusion can be caused by a urinary tract infection (UTI) – a bacterial infection that can spread, sometimes causing delirium or hallucinations. It should not be left untreated. DH

How to deal with **sundowning**

Does your loved one suddenly become more frustrated, irritable or even angry in the afternoon? They may be experiencing sundowning symptoms. Author and dementia expert **Mary Jordan** explains what it is and how to cope


Sundowning symptoms can be upsetting and difficult to manage

> **‘Most people with dementia can’t just be given something to do like a crossword and left to get on with it’**

Sometimes people with dementia become more anxious and restless in the late afternoon. This pattern of behaviour is often referred to as ‘sundowning’ by health professionals. Behaviour may involve becoming very restless, walking about, becoming more confused than usual and sometimes bouts of frustrated aggression.

Coming, as it does, towards the end of the day, at a time when the carer is likely to be tired and wanting to ‘wind down’, these symptoms can be very upsetting and difficult to manage.

WHY DOES SUNDOWNING OCCUR?

In common with many aspects of dementia, there is no certainty about the causes of sundowning. However, some research suggests that the agitation may be related to changes in the brain’s circadian ‘pacemaker’ – a cluster of nerve cells that normally keeps the body on a 24-hour clock. Sundowning may also be connected to night wakefulness, when a person who has dementia becomes unable to distinguish between day and night, and consequently may become very active at night and unable to accept that they should rest in bed. No amount of reasoning or pointing out that it is night-time seems to help with night wakefulness, and the difference between darkness and light seems to have no significance.

WHAT CAN BE DONE TO MINIMISE SYMPTOMS OF SUNDOWNING?

As we don’t know the cause of sundowning, it is difficult to suggest what can be done to help minimise or alleviate the symptoms. We have to use trial and error to see what might work in each individual case. Here are some things you can try...

Increase activity or stimulation

Sometimes, this pattern of behaviour can be put down to a lack of exercise and stimulation during the day. Some carers have reported that on days when their cared-for person has been attending a day centre or memory group, no sundowning occurs. If you think this might apply, you can encourage extra stimulation during the day by providing activities or going out to meet other people in social situations. It’s important to remember that most people with dementia can’t just be given something to do like a crossword and left to get on with it. They need active encouragement and the participation of another person.

Active exercise can be encouraged by doing something as simple as taking a daily walk together. There are also many exercise classes – balance classes, chair exercise classes and activities suitable for older people usually available in most areas. Enquire at your local leisure centre or through your local council, to see what is available.

HOW TO MANAGE AGGRESSION

Aggression is usually due to frustration when the person with dementia feels there is no other way to get their feelings across. It can be hard to cope with, as the normal reaction from carers is to try to either reason with their loved one or ask them to explain what the problem is. But some people with dementia are unable to explain or understand reasoning. Try to remain calm. Often, staying seated and not reacting can help dissipate anger and aggression. Don't ask what the problem is – your loved one cannot explain. Don't try to reason – use soothing platitudes ('You're upset'/'Shall we sit quietly for a while?'). If you know what has upset your loved one, try to solve the problem without fuss. If all else fails, remove yourself from the situation. Make an excuse to leave the room and keep out of the way for a while. Often the person will calm down. Remember, you can dial 999 in an emergency – and that includes if you're scared for your own safety.

Turn on the lights

Sometimes people with dementia become anxious as the light changes in the early evening. It's worth remembering that most dementia causes some visual problems, so the person who has dementia can be upset by shadows, or by early evening gloom. Closing the curtains as soon as the light begins to fade, switching on lights and having some distraction available at this time can all be helpful. Serving the evening meal around this time can also be a suitable distraction.

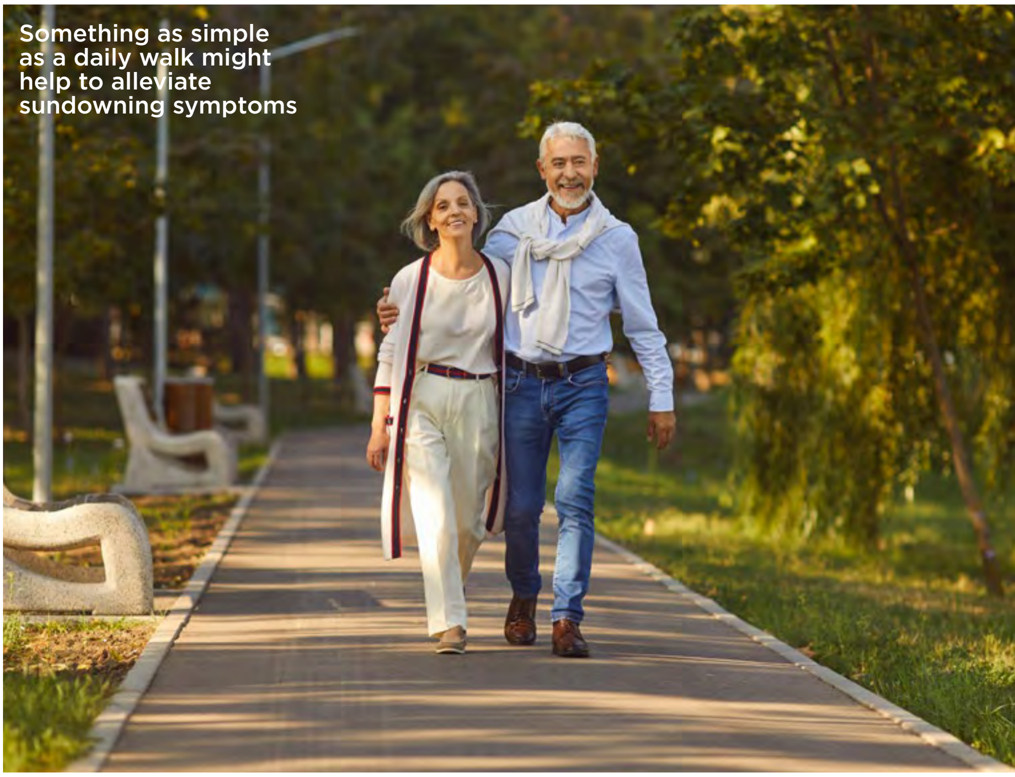
Try distraction methods

TV can help as a distraction if suitable programmes are available, but be aware that early evening news programmes may be upsetting, because people with dementia are not always able to distinguish reality or to understand that unpleasant scenes, such as reports from a war zone, are not immediately threatening to them personally.

Some people respond well to music being played as a distraction, while others find external sounds confusing and upsetting.

Experiment with lighting changes

Some of the most promising recent research indicates that lighting changes may be very effective. It was found that when the lighting in the main rooms in residential care homes was changed to full spectrum daylight lighting, many residents who had previously been agitated in the evening and at night became calmer and more relaxed.



Something as simple as a daily walk might help to alleviate sundowning symptoms

Consider replacing all the bulbs in main rooms with full spectrum daylight bulbs

> **‘Not enough thought is given to the question of lighting in connection with dementia’**

Not enough thought is given to the question of lighting in connection with dementia. If we remember that vision is often affected and then couple this with the disruption to the body clock, it should be obvious that adequate bright and clear light in the daytime is of vital importance in order to address the issue of sundowning.

The lighting should simulate daylight as much as possible. In this instance, we should not be distracted by ecological concerns or suggestions of saving the planet, but must have the wellbeing of the person we are caring for foremost in our mind.

Replace the light bulbs in main rooms

It is best to replace light bulbs in all the main rooms of the house which are used during daylight hours (i.e. not bedrooms) with full spectrum daylight bulbs. It is not so easy to find these in shops any longer, but they are available online. You'll notice the difference immediately, especially if you need to switch on the lights on a dull and overcast day. Full-spectrum daylight bulbs look like daylight. It can seem like having an extra window in the room. A person who has dementia is unlikely to mention the lighting specifically, but you will probably notice they are less apathetic or anxious. You will probably even notice a change in your own mood! DH

More information
Mary Jordan is the author of several books on dementia, including *The Essential Carer's Guide To Dementia* and *Dodging Dementia* (both published by Hammersmith Health Books). Mary is experienced in both aspects of dementia care, as a carer to friends and relatives and professionally. She runs her own business, Adaptdementia, supporting people living with dementia and their carers.

Coping with Christmas and dementia

The festive season can be a testing time for many families, but when your loved one has dementia and needs ongoing care, it can be increasingly difficult. **Christina Collison** reveals how to cope and whether you need to tone down the arrangements...

Christmas is meant to be a time for family, joy and togetherness, but it can also be a challenging period if you're caring for a loved one with dementia. Dealing with extra arrangements for the festive season on top of your current caring duties can seem daunting when you already have enough on your plate. Let's face it, Christmas can cause upheaval, stress and the need for additional organisation, all of which will take up even more of your limited spare time.

So, what can you do? First, it's important to realise that you don't have to overdo it. You may not need to go to town with all the festive trimmings and put yourself under even more pressure.

Start by considering what type of arrangements may best suit your loved one and how much they can reasonably manage. Parties, noisy celebrations, lots of people and a busy environment may all be too much.

BEING AWAY FROM HOME

When I was caring for my mum, she came to my house for Christmas dinner, but being away from home was too much for her. She struggled. She was confused and upset. I soon realised I'd made a mistake.

In my personal experience, too much travel, eating and drinking, noise and upheaval can be overwhelming for a person with dementia. So think about where your loved one is in their dementia journey and whether they are up to staying with you or another relative, or whether they should stay home. If this is the case, there may not be too much for you to organise.

Here's some practical advice on dealing with Christmas when your loved one has dementia...

> 'Too much travel, eating and drinking, noise and upheaval can be overwhelming for a person with dementia'

THINK ABOUT YOUR LOVED ONE'S NEEDS

You can ask your loved one what sort of Christmas they would like, but they may not be able to tell you. My mum used to want company and companionship more than anything else. Presents didn't mean much to her by this point. Work with what you know. How important has Christmas been to your loved one in the past?

Dealing with festive arrangements on top of your caring duties can be overwhelming

'MY MUM'S FESTIVE STRUGGLE'

My mum struggled when she stayed with me one Christmas, and it was a learning curve for me. Despite my best efforts to make her feel comfortable, including putting up signs around the house to help her find her way, she became disorientated and anxious. She couldn't make sense of the signs and got lost frequently. She had trouble finding the bathroom at night despite me putting a nightlight on the landing. The nightlight didn't help at all. In fact, it seemed to bother her. Each time she got up and went to the bathroom, she turned it off before going back to bed.

The following year was better, when I visited her at her home and took her out for Christmas dinner. She enjoyed the outing, but was happy to return to familiar surroundings afterwards. If possible, keeping the person in their own home can significantly reduce stress.

What have they enjoyed doing to celebrate Christmas in the past? You probably know them better than anyone. Think about activities outside the home, too. For example, would they normally go to church and sing carols?

CONSIDER THE PERSON'S LEVEL OF AWARENESS

If the person is in the early stages of dementia, they may want to celebrate in their usual way and keep things as normal as possible. If not, Christmas may no longer have any significance for them. They may not realise it's the festive season. To them, it might be just another day. And it could be a day where they spend it with you and enjoy your company. It may not need to be much more than that.


Ensure presents are easy to open, so your loved one doesn't become frustrated or embarrassed

BE REALISTIC ABOUT HOW MUCH THEY CAN EAT

How important is it to them to have a huge Christmas dinner with all the trimmings? Dementia can affect a person's appetite, so even if they would have polished off a large Christmas dinner in the past, things may have changed. How is their appetite these days? They may prefer to have a smaller meal, or even eat what they normally have most days. Remember that change can be unsettling for a person with dementia at times. They don't have to be confronted with a huge turkey dinner if it's not likely to appeal to them anymore.


Delegate tasks if possible, so you don't burn out over the festive period

CONSIDER KEEPING THE PERSON AT HOME

The holiday season often brings a change in routine, which can be particularly difficult for a person with dementia. A regular schedule is beneficial for your loved one, providing much-needed structure and familiarity. Any disruption can cause confusion and distress.

MANAGE VISITORS

If you plan to visit your loved one with other relatives, aim to keep the number of visitors small. Large gatherings can be overwhelming for someone with dementia. During celebrations, be mindful of noise levels. Remember, loud music, multiple conversations and a bustling environment can become very confusing and tiring for them.

IS ALCOHOL OK FOR A PERSON WITH DEMENTIA?

Christmas is a time for celebration, and for many, this includes enjoying a festive tipple. But is it safe for your loved one to drink alcohol?

For some people, it's not necessarily a problem, as long as it doesn't conflict with any medication. For instance, my mum was never a heavy drinker. She enjoyed an occasional small glass of wine with a meal, but rarely finished it.

However, if you notice your loved one drinking more frequently, then maybe you need to keep an eye on their intake.

Alcohol can interact with certain medications, making them less effective or causing adverse reactions. Review the medication leaflets before offering alcohol.

See if they can switch to zero or low-alcohol alternatives, or dilute alcoholic drinks as much as possible.

On a general note, if you are concerned about how much the person is drinking, speak to their GP.

Hold off the alcohol, in case you need to unexpectedly drive your loved one home

Create a quiet space where your loved one can retreat if they get overwhelmed, or try activities like a gentle walk to provide breaks from noise.

GIVE GIFTS SENSIBLY

Wrap presents in a way that makes them easy to open. Struggling with wrapping can be frustrating and embarrassing for your loved one. The most valuable gift you can give is your time, creating a comforting presence during the holidays. On that note, if your loved one is likely to forget to buy gifts or is unable to do so, you may have to take care of this for them. Try to do what the person would want.

BE PREPARED FOR CHANGES

If you bring your loved one to your home, accept that they might want to go home earlier than planned. Ensure someone is available to drive them home at short notice and hold off the alcohol if you usually enjoy a festive tipple, so that you can drive them home if needed.

> *'The most valuable gift you can give is your time, creating a comforting presence during the holidays'*

TAKE CARE OF YOURSELF

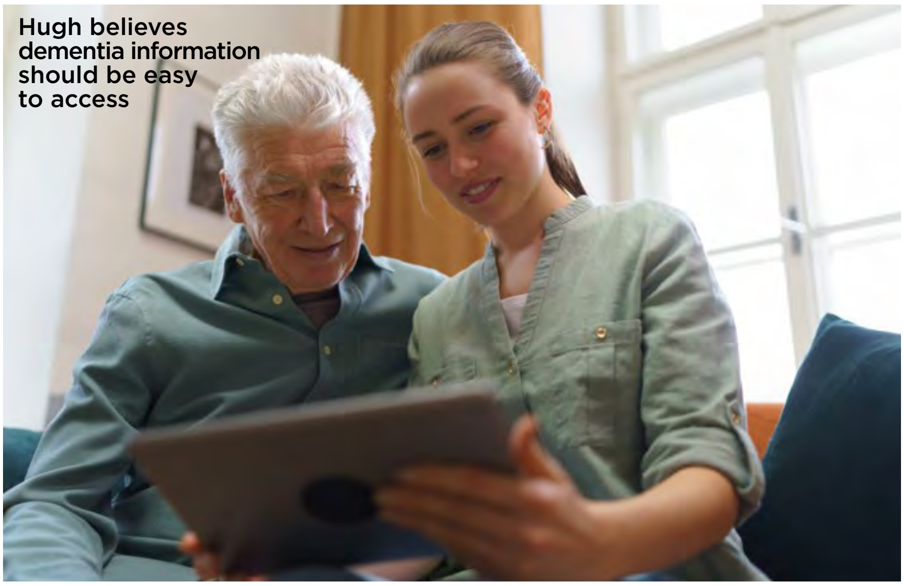
It's not always an easy thing to do, but it's important that you get a break at some point, too. Self-care is vital – remember, if you burn out, you'll be no use to yourself or anyone else. If possible, delegate responsibilities and ask other family members for support. Whether it's sitting with your loved one so you can take a break or accompanying them on a gentle walk, sharing the caring duties can help you enjoy the holiday season as well. DH

'We were given 48 hours to find mum a new home'

DementiaNet co-founder, **Hugh McGouran**, reveals his personal experience of caring for parents with dementia, as well as the inspiration behind the launch of DementiaNet

Hugh McGouran isn't a stranger to the devastating effects dementia can have on a family. Both his father, Dennis, and mother, Molly, had the disease – a fact that threw him into the deep end of dementia care, along with his sister, Shelagh.

'After retiring, my dad quickly went downhill,' he remembers. 'Mood-wise, he was changing, and there were other things, too – an inability to tell the time, for instance. I remember one time being at my parents' house with my girlfriend. Dad had always been keen on his appearance. He was upstairs getting ready to go out and he heard chatting downstairs, so he came thundering down with enthusiasm. He had on a tweed jacket, shirt and tie... and nothing on the bottom. It was a very awkward moment and he was blissfully unaware. That hit like a stone, but then we saw a rapid decline.


Hugh believes dementia information should be easy to access


Hugh's parents both had dementia

'My mum refused to accept it. Christmas 2000 was the crucial time, because he lost the ability to use a knife and fork, and because my mum was in denial, she was determined to stick with a traditional dinner. She snapped at him about which fork to use while he was weeping. He was 68.'

After diagnosis, Hugh and his mum arranged for his dad to spend time in a local care home for a week, for respite, but sadly he fell and suffered a head injury, passing away at 73.

HEARTBREAK AGAIN

Hugh's mum gradually pieced her life back together, even socialising at a theatre-based club. But after being mugged while walking home one night, she lost all her confidence and stopped going out. After a series of falls, she was admitted to hospital and then transferred to a respite hospital, where Hugh and Shelagh got a shock.

'We were told she wasn't poorly enough to stay, but not well enough to go home. We were given 48 hours to organise a care home for her.'

Thankfully they managed it, but at the home his mum was diagnosed with vascular dementia. She lived there until she died in 2014, aged 92.

Hugh's parents, Molly and Dennis, in happier times

However, the time they had spent getting to grips with funding and future care planning had been a steep learning curve – one Hugh wouldn't forget.

DIGITAL SOLUTIONS

As chief executive of a community foundation and chairman of Dementia Action Teesside, Hugh began thinking about the role of digitalisation in dementia care. At a dementia conference in Teesside two years ago, he talked to keynote speakers and exhibitors about their approach to digital.

'They simply said they didn't do it,' he recalls, 'including some of the big organisations. But my view was that if I was the 50-year-old son of someone recently diagnosed with dementia, would I get into my car to drive somewhere to get a leaflet, or would I simply Google, "Alzheimer's"?

'I was with my colleague, Angela Walton, and we had a flash of inspiration that, in most cases, it's not the person diagnosed who's going to be looking for information online. It's the person with responsibility to care for them. An idea was bouncing around in my head. We sat down to watch the keynote speaker at the conference, but this idea wouldn't go away, so I started making notes – "no digital information", "contact", "network". Angela was sitting behind me, and she looked over my shoulder and whispered, "It's like Mumsnet for dementia". And we both looked up and said, "DementiaNet!"'

> 'In most cases, it's not the person diagnosed who's going to be looking for information online. It's the person with responsibility to care for them'

SUPPORTING OTHERS

The idea grew quickly and, following input from digital wizard, Brian Schur, and investment from Dementia Action Teesside for research, the DementiaNet website was recently launched.

'DementiaNet offers support, information and guidance, as well as a secure online vault so users can store all their information about a loved one, including care plans and property, together,' explains Hugh. 'The website offers clean, intelligible information in bite-sized pieces. One of the most common things that we discovered during our research was that carers were feeling utterly overwhelmed by not only the dementia, but the sheer weight of information that was out there and how to navigate it.

'In contrast, DementiaNet is accessible and clear. We have achieved a calm, informative online environment where you can ask a question and be given a clear answer, and then you have the ability to ask another question and build from there. The vault enables you to put all your personal information into one place, so you can find it easily again.' DH

More information
DementiaNet proudly sponsors *Dementia Help* magazine. For more information, please visit DementiaNet.com

‘We need to educate people about dementia’

Sharing her insights about what it’s like to live with dementia gives **Sue Strachan** a purpose and is also hugely beneficial to anyone else living with dementia. **Christina Collison** spoke to Sue about her life with dementia

Sue Strachan, 68, was diagnosed with vascular dementia aged 56, after suffering a TGA (transient global amnesia) – a sudden episode of confusion. She lives in Herefordshire and is an ambassador for Alzheimer’s Research UK. Tragically, at the start of August, Sue’s partner of 32 years, Sheila, passed away from a pulmonary embolism. At the time of our interview, Sue had just lost Sheila, and was trying to keep busy. She now realises that being too busy is not always the best solution for her.

I’m so sorry about your sad news. How are you coping?
I’m incredibly up and down. I don’t believe she’s gone. I’ve got people staying – my nieces and nephews are amazing. Other people are learning what Sheila was putting up with. I have hyperacusis, which is oversensitivity to sound. One friend who’d been staying had no idea until she banged a saucepan and I leapt six feet in the air.

The people with me are close friends and family, and it’s OK to an extent if I ‘lose it’ with them. It’s not great. But they get it, and because I still know how to behave to a certain extent, I still worry about shouting at people.

Sue's dog Saffy is a huge help in managing her grief as Sue has to get up and take her for walks every day

I did a talk last week [about dementia] and people said, ‘Oh, how could you do it?’ But continuing my support of the charity is what Sheila would want me to be doing.

How has life changed in the last 12 months in terms of your health?

A big positive is that for the London Marathon in April, I talked to Alzheimer’s Research UK and we put a team of runners together called ‘Sue’s Crew’, which was very flattering. We had more applicants than the charity could cope with, which was lovely.

I think it was 14 who ran on the day – we raised £73,000. Some £30,000 of that was raised by Jordan and Cian Adams, known as the FTD Brothers. Jordan and I were in the TV show, *The Restaurant That Makes Mistakes*, back in 2019. Jordan had only just then discovered he has a faulty gene that means he will get frontotemporal dementia. Jordan and his brother Cian, who has just been diagnosed with the same faulty gene, are both in their 20s and will get frontotemporal in some form, probably in their 40s.

‘Vascular dementia is a stepped progression’

When you give talks about dementia, what are the key things from your perspective you like to share?

It’s about educating people. I was in hospital in June with ulcerative colitis, which I’ve had for 14 years, and one of the doctors came to see me. He looked at my notes and said, ‘Oh, you don’t look like you’ve got dementia’. I absolutely went for him. I said, ‘I can’t believe that someone with your education has come out with such a crass, stupid comment.’ He was really taken aback, but I was angry. If the medical profession is so naive, what hope have we got for the public?

‘Sue’s Crew’ raised £73,000 for Alzheimer’s Research UK at the London Marathon in April

Sue congratulating The FTD Brothers on their amazing multiple marathon challenge for Alzheimer’s Research UK

When I talk about dementia, sometimes I can see people in the audience thinking, ‘Oh, it’s all right for her’. Well, no, it isn’t. I do understand how awful it is.

When you were first diagnosed, what information would have been useful for you to know from the start?

One of the key things was the understanding that vascular dementia is a stepped progression. I didn’t find that out until a year after I’d been diagnosed, and so I used to wake up every morning for quite some time thinking, ‘Well, is today the day I am going to deteriorate suddenly?’ So, the more understanding of the different types of dementia the better. It needs to be simple, clear advice.

As an ambassador for Alzheimer's Research UK, Sue campaigns for funding for research

What other support would you like for those living with dementia?

There needs to be signposting to local support. We were sent to the memory clinic. I only went three times, and on the third time I said to the woman, 'I really don't know what I'm doing here, because you're not going to tell me I'm getting better. It's not like I've got a broken leg and, you know, the bones are healing. All you're going to tell me is that I'm deteriorating.' So I stopped going. I'm sure the memory clinics are helpful to some people, but they weren't to me.

Signposting to places and people that can help would be really useful. I was in denial for a while. During those first 18 months, I kept thinking they had got it wrong. But it was obvious to Sheila that I had it due to the repetition, because I'm reasonably articulate and sometimes I couldn't find the right words.

What sort of information would have been useful to you at the very start in financial terms?

Trying to get Personal Independence Payment should be made an awful lot easier for people with dementia. I was very resistant to apply for it, partly because I thought that I wasn't entitled to it, because I was functioning OK. What I hadn't realised was that it was a real worry for Sheila because I lost my ability to do my finances. Eventually, we applied and the first application was refused completely. So, we then went down a different route and somebody came to the house to interview me. She arrived and she was late, and she said, 'We'll have to hurry through this. I've got another appointment that I need to get to after you'.

I offered her a cup of tea or coffee. When she reported back later, she said part of the reason that I didn't score well enough was because I'd offered her a cup of tea or coffee. What she didn't recall was that I had to ask her three times, 'Did you say it was tea?' There was no compassion there at all.

PIP should be easier to get for people who are entitled to it. There shouldn't be so many barriers.

> 'It's about continuing to raise awareness. It's what Sheila would want me to do'

Can I ask you about the noise sensitivity you experience. To what extent does it affect you?

Sheila would go to the cutlery drawer and I would leap six feet in the air and say, 'What the f*** are you doing?'

Celebrating after running the London Marathon in 2018

We used to have rows about it, because she would say, 'For goodness' sake, I've just got a knife and fork out of the drawer'. That's not to say that she wasn't a brilliantly caring person. She just didn't understand the issue at first.

We'd go out for a meal and I'd be seated under a speaker in a restaurant and couldn't concentrate on the conversation because of the music. I went to see an audiologist at the hospital who said that with vascular dementia, hyperacusis is quite a common symptom. Again, it's about educating people, not to say you will definitely get it, but to say it is a possibility and this is how it may affect you.

You're an incredibly resilient person. How does it feel for you to know that you're playing a part in giving hope to people?

Thank you. People call me inspiring a lot and I get a bit embarrassed about it, because I'm just being me.

Sue with her late partner, Sheila

Being in loud environments is difficult for Sue

But weirdly, the diagnosis has changed me in a positive way. I wasn't glass half empty before the diagnosis, I was no glass. I wasn't constantly depressed, but I would always be anxious about things and worrying, 'Have I done this right?' Getting the diagnosis somehow changed me and gave me a mission to really be me. Do you know the Perfume Shop? They are a corporate sponsor for Alzheimer's Research UK. I've done talks to their managers and I've been to their head office, which is called Scent Quarters. They have a campaign running this year called, 'Be More Sue', which is incredibly flattering. I like the fact that I am making a difference. Everybody needs a purpose, don't they? I live in this huge world, but if I can do something in the little corner I live in that makes a bit of a difference to people, then that's great. DH

'With vascular dementia, hyperacusis is quite a common symptom'

Peace of mind your loved one can wear *anywhere*

In an emergency, every second matters. Leave nothing to chance with MedicAlert's medical ID, to help keep your loved one safe

When your loved one has a medical condition, such as dementia, you'll know there are so many factors that need to be taken into consideration when it comes to supporting them and improving their wellbeing.

Something that's likely to be front and foremost of your mind is the person's safety. Fears that your loved one might become unwell while out and about, or gets reported missing, are sadly all too real. This is where MedicAlert can help, offering you true peace of mind when it matters most.

THE MEDICAL ID THAT SPEAKS VOLUMES

MedicAlert's wearable medical ID range is the perfect way to help keep your loved one safe if they ever get lost or experience a medical emergency while they are out and about.

With a wide range of medical ID on offer to suit everyone's personal style and needs, your loved one's medical ID will be engraved with their most vital medical details, as well as their unique membership number and MedicAlert's 24/7 emergency phone number.

‘MedicAlert’s wearable medical ID range is the perfect way to help keep your loved one safe’

This means that when a first responder finds them when they’re lost in a medical emergency, they can instantly see your loved one has additional needs and can call to access their details. In this way, MedicAlert ensures your loved one will receive the quickest, most effective support and care when it’s needed most.

WHAT TO DO IF YOU COME ACROSS SOMEONE WITH A MEDICALERT ID

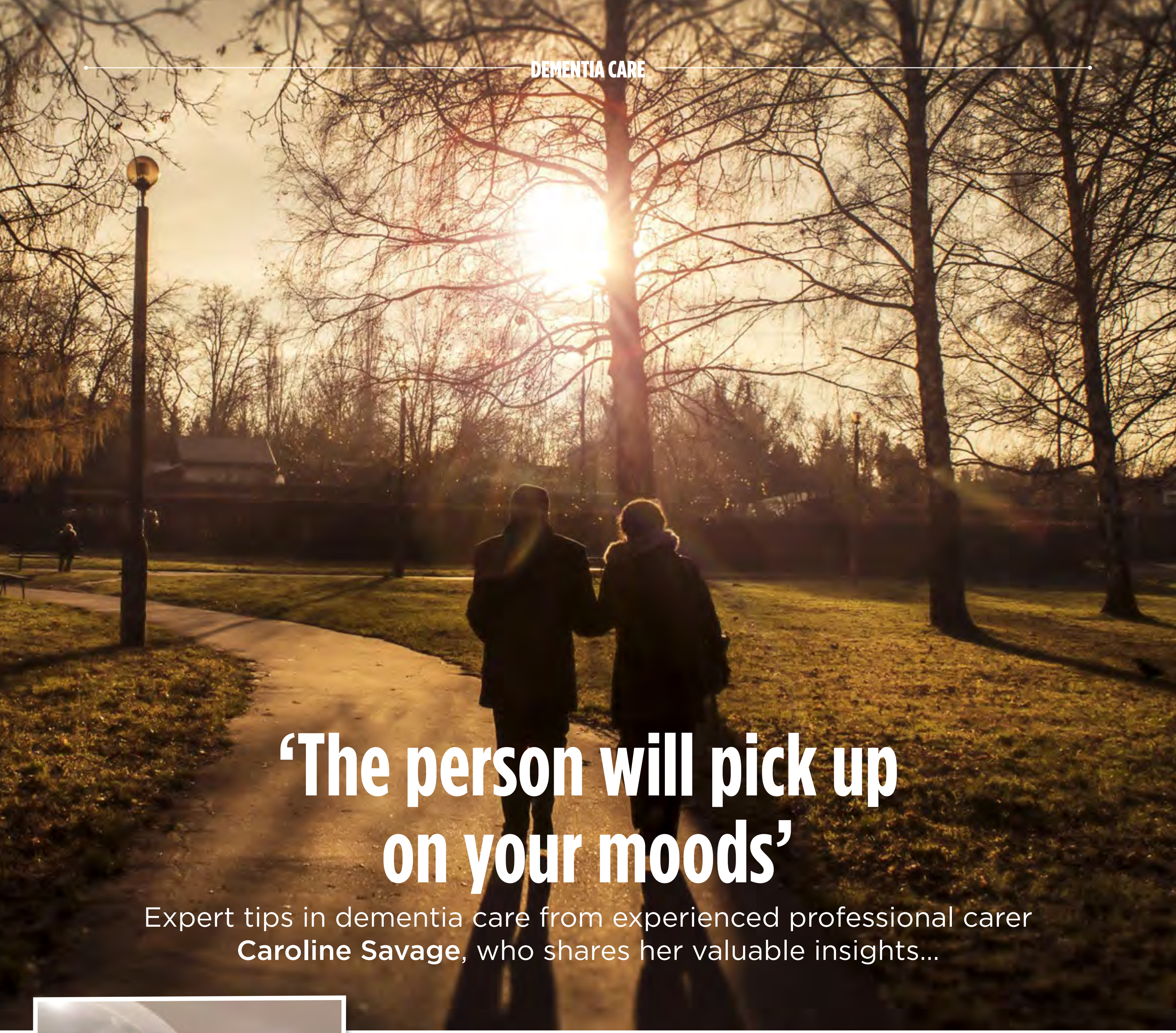
If you come across someone in an emergency and they are wearing a MedicAlert ID, the solution is quick, effective and straightforward, saving valuable time when every second counts: simply call the emergency number engraved on their medical ID (usually a bracelet or necklace), then quote their unique membership number, so that medical services can gain access to their details.

TRUSTED WORLDWIDE

Founded in California in 1956, MedicAlert then launched in the UK in 1964 and is celebrating 60 years of providing life-saving medical ID services here this year. As the pioneers of medical IDs, and still the only charity provider of life-saving medical ID services worldwide, MedicAlert is trusted and recognised internationally.

Its team, based in Buckinghamshire, comprises a production unit creating the bespoke medical ID, as well as registered nurses to support its members. On signing up to MedicAlert, one of these nurses will walk you through every step of the process, and will check your loved one’s full record is up to date and medically sound. Carers IDs are available for additional peace of mind, and carers can help manage a person’s record and store their own emergency care plan. For clients with dementia, MedicAlert can also store their Herbert Protocol (vital information to help track down a person should they go missing) digitally within their MedicAlert record, which can save time in an emergency. DH

For more information
Join MedicAlert today with The McLay Dementia Trust and your first year of MedicAlert membership and an ID is free! Call 01908 951045 (lines are open Monday to Friday, 8am to 3.30pm, and Saturday 9am to 3pm); email enquiries@medicalert.org.uk; or visit medicalert.org.uk



‘The person will pick up on your moods’

Expert tips in dementia care from experienced professional carer **Caroline Savage**, who shares her valuable insights...

Caroline Savage lives in a coastal village and has been working in the care industry for 12 years. She came into it purely by accident. Previously, she ran her own business from home, making and selling fudge into the local tourist shops. However, this was very much a seasonal business, so she started being a carer during the winter months to tide her over, working at a small care home. When the time came to go back to her summer business, she found she didn’t want to leave her clients, as she had become so attached to them. So, she decided to set up on her own, in order to provide the level of care required and have more time to spend with each client.

In addition to being a full-time carer, Caroline is an ambassador for Alzheimer’s Research UK. She raised £25,000 for the charity this year by completing the London Marathon, spurred on to the finish line by her passion to help find a cure.

Here, she shares her valuable experience to help other carers deal with mood swings, personal hygiene and nutrition...

PEOPLE WILL NEED MORE SUPPORT OVER TIME

A lot of the people I visit don't have advanced dementia – instead, it's normally in the early stages, where they just need a bit of support. Over a period of time, the person will need more support. We build the support according to their needs. By that time, I've normally built a very good relationship.

When I go in, I can pretty much tell if they're off colour, or if they are extra muddled – urine infections are a really common problem, especially in hot weather. It's just not drinking enough water. So, I put glasses of water all around the house with little notes saying, 'Please drink me'.

MAKING A NOTE OF WHAT'S GOING ON IS HELPFUL

Always having the lines of communication open is a really important issue. I document absolutely everything. I keep a notebook in all my clients' houses, and I will write even the simplest thing down, because sometimes that becomes important later on.

> 'I document absolutely everything. I write even the simplest thing down'

I encourage families to also write notes in that book. If it's something that really needs attention, I ring them up to discuss it.

PROBLEMS CAN BE CAUSED BY FAMILY MEMBERS UNINTENTIONALLY

I had a situation a few years ago with a family member. She meant well, but she really put my client on edge because she was very bossy, and she would take charge and my poor client was starting to lose confidence anyway. When she came in, it took my client days to get over it. I had a meeting with other family members and discussed that I picked up that this lady's behaviour was changing after this family member came in. I asked them to have a chat with her and ask if she was aware that this client was a sensitive person, and explain that her behaviour was having a direct impact.


Keeping a log of moods, meals and behaviours can be really helpful

The family was so supportive. I gave them some examples of what I meant, and thankfully it got resolved.

HOW TO DEAL WITH YOUR LOVED ONE REFUSING PERSONAL CARE

I have had people who don't want to wash, so I've used distraction methods. I have said, 'That's fine. Can you help me with something? I'm going to get a bowl of water. Can you help me wash my hands?' And they will look at me. They see me putting my hands in the water and then I've got their hands in water. Then I will say, 'Can you put some soap on my hands for me?' So, they're putting soap on my hands, but I'm then also putting soap on their hands. So, we start off with that, and then I'll say, 'Do your hands feel better? I think it's your day to have a pamper! How about we soak your feet?'

If they don't want to shower, no amount of you saying you've got to have a shower is going to work, but sometimes you can soak their feet, and then while they've got their feet in the water, you can wash their legs, and say, 'While you're sat there soaking your feet, should we take your vest off and just do your back a moment?' It doesn't always work, but that's my way. If it's really bad and they're shouting and agitated, I won't push it. I'll simply try again another time.

A keen runner, Caroline completed the London Marathon in April this year

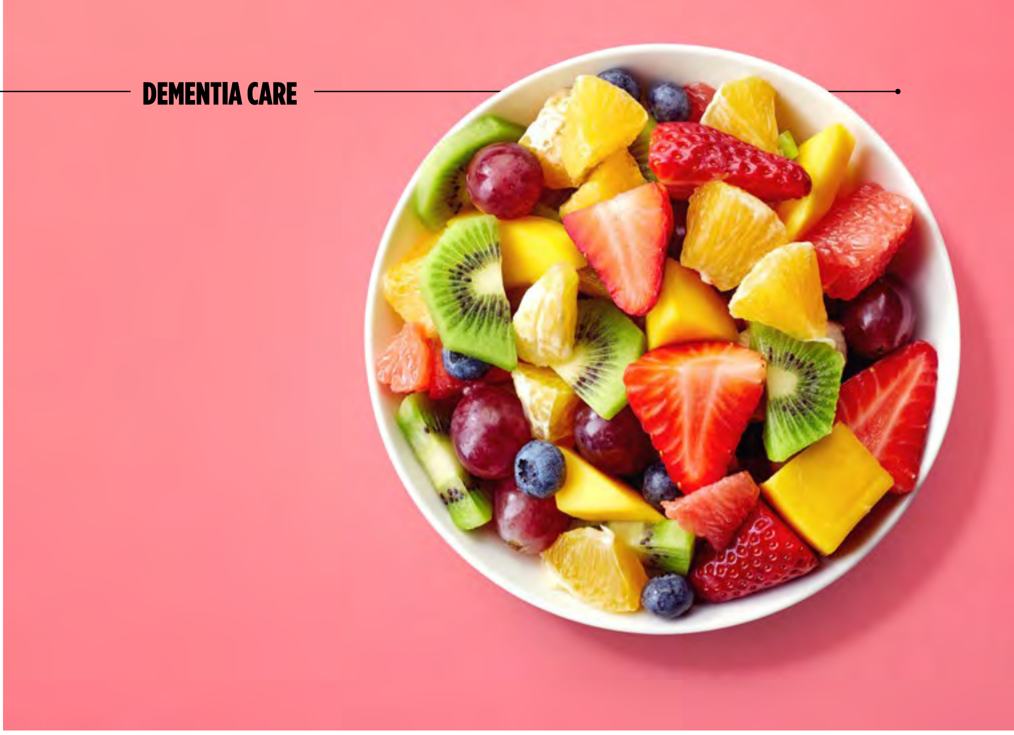
HOW TO IMPROVE A PERSON'S MOOD

Music helps. If there's a genre of music they like or any sort of singalong music – anything that's quite uplifting – before you know it, they'll be humming along! Music is underrated.

Also, open the curtains, let a little sunshine in, a bit of fresh air, and get them outside if you can. If they don't walk, get them in the wheelchair, take them out in the garden, or walk them up the road for social interaction.

HELP THE PERSON CREATE A LIFE WITH MEANING

It's so important to make the person feel like they are still living a life. Sometimes, people can be stuck in a chair all day and they won't get visitors, because sometimes people don't know what to say. So, if you can get them out, that will be a definite mood lifter. Social interaction is always a big thing, even if it's simply taking them up the road or even just to the end of their drive.



DEALING WITH APPETITE CHANGES

I know families worry about the person if their loved one is not eating a proper meal, but sometimes they just don't want it. It's almost like they lose that ability to sit and have a full meal. So instead, I offer a little bowl with a few chopped strawberries and grapes, a bit of banana, and I'll put it beside their chair.

If they see it, sometimes they will nibble at it. If you've got somebody that's not eating well at all, just having small bowls left around, as well as gently prompting them, can help.

CHOOSING THE RIGHT PLATE

A plain plate is better than a patterned one. If there's a pattern on the plate, it's almost like they don't see the food, they see the pattern, and I think it confuses people. When they're eating, they'll eat so much, and then I'll distract them and turn the plate round, and then they'll eat a little bit more. Sometimes, visually, they're not seeing the whole plate of food. I always leave snacks. It depends what stage the person is at, but prompt cards can be helpful. Things like leaving a note on the fridge if they live alone with a smiley face saying, 'Your sandwiches are in here'.

> **'I offer a little bowl with a few chopped strawberries and grapes, a bit of banana, and I'll put it beside their chair'**

MANAGING THE PERSON OVEREATING

Sometimes people are just bored. None of us has all the answers, but if somebody spends an awful lot of time on their own with just television for company, eating is something that becomes a habit and they're not really aware of how much they're eating. I keep a food and drink chart in all my clients' houses. Some will need assistance with eating. Others are absolutely fine.

WHY FAMILY MEMBERS SHOULD ALWAYS COMMUNICATE

Another challenge is sometimes when family members have got differing opinions on how the care should be and how they're going to do things long term. If families are all singing from the same hymn sheet and supporting their loved one the best they can, it makes the whole caring situation easier. If you have families with opposing views all falling out with each other, it makes it even more difficult. Your loved one will pick up on it. They will pick up on moods and tension, and then it makes them feel they've done something wrong.

MAKE THE PERSON WITH DEMENTIA FEEL HELPFUL

Sometimes you find people with dementia want to help you, and getting them involved in tasks can give them a real sense of purpose. For example, when I go in to change somebody's bedding, they will be quite keen to help me if I ask. It might take three times as long, but that really doesn't matter, because I've got the time to do it and it's given them meaning.

Workers' rights for carers

If you're working full time on top of looking after your loved one, you may be struggling to manage everything. What support is your employer obliged to give you and what can you do if you're finding it hard to cope? **Jill Eckersley** reports

There is some light at the end of the tunnel for this country's five million working carers – and that includes carers looking after people with dementia, as well as children with special needs and those with other disabilities. From April this year, both the Carers' Leave Act and the Flexible Working Act came into force, giving more rights to carers in the workplace. The new laws apply in England, Scotland and Wales, while slightly different rules apply in Northern Ireland.

Making life easier for carers who work outside the home, either full- or part-time, is something that the organisation Carers UK (www.carersuk.org) has been campaigning for for some time. It states that combining work with caring can be extremely challenging and therefore it's important to understand just what your rights are.

British law gives 'statutory rights' to everyone.

‘BEING WELL INFORMED ABOUT YOUR RIGHTS IS CRUCIAL’

Jane Norman found it hard to juggle her busy job with looking after her mum. Here, she reveals what she wishes she had known about flexible working…

When caring for my late mum back in 2010, I had very little help from my employer. I’d been with them for two years before her dementia diagnosis, so they knew I was reliable with a strong track record, but they weren’t supportive. When I had to take time off to care for mum, they’d say it was OK, but would then constantly email me with work queries, most of which were not urgent.

I was exhausted and stressed, worrying I’d lose my job. In the end, I had to go part time as I couldn’t deal with the pressure. However, what I didn’t realise at the time was I was legally entitled to ask for flexible working hours, and I could have worked remotely more often. Being well informed about where you stand is crucial.

A year after leaving my job, my former boss rang me and said her dad had been diagnosed with dementia, and it was very stressful. She apologised and said she hadn’t realised how difficult being a carer was until she had to do it herself!

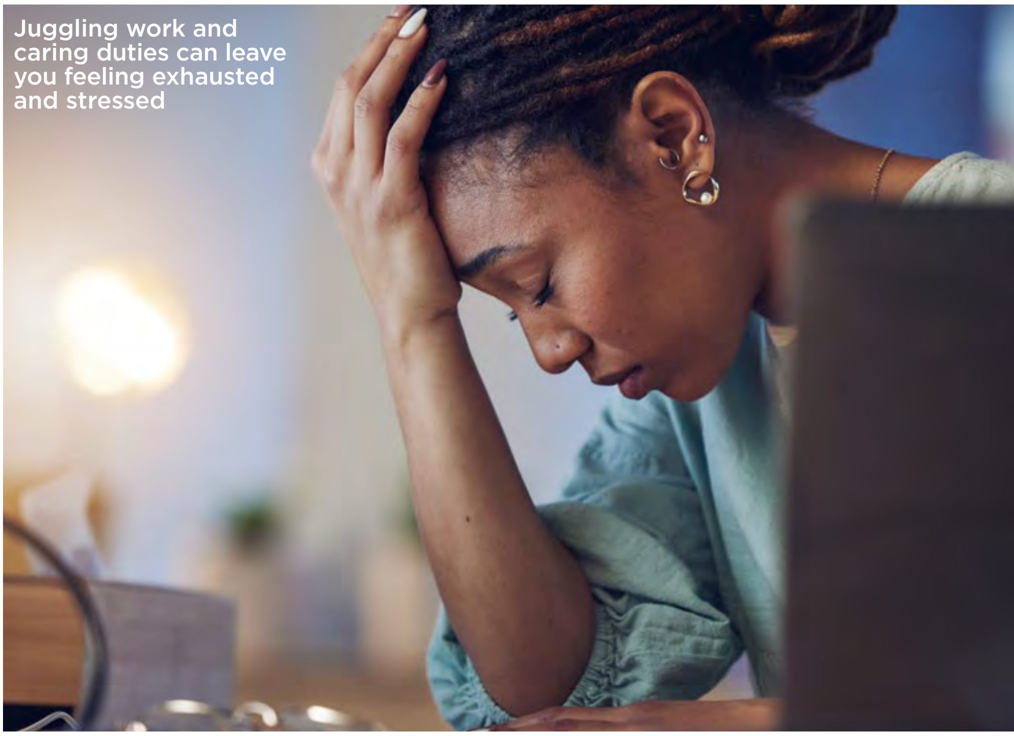
However, a worker’s contract of employment may give him or her ‘contractual rights’ as well – and these may be more generous. You can check yours in your own contract, the staff handbook if you have one, or your employment letter. If you happen to be on a ‘zero hours contract’, you may be either an employee or worker, and your rights will depend upon which of these you are – so do ask your employer to clarify.

> ‘The Act also provides protection from dismissal – in other words, you cannot be discriminated against, or lose your job, just for being a carer’

NEW LAWS FOR WORKING CARERS

So, what are the new laws saying? The Carers’ Leave Act states that employees are entitled to a week’s unpaid leave per year if they are providing or arranging for care for someone with a long-term care need – for example, someone with dementia. This leave can be taken flexibly, in half or full days, and is available from the first day of employment.

You are required to give notice if you want to take advantage of this. The amount of notice will depend on how much time off you believe you need. The Act also provides protection from dismissal – in other words, you cannot be discriminated against, or lose your job, just for being a carer.



Juggling work and caring duties can leave you feeling exhausted and stressed

Some employers offer more protection than this legal minimum, and some even agree to paid rather than unpaid leave.

DEALING WITH UNEXPECTED EMERGENCIES

The Act is mostly concerned with planned commitments, but as all carers know, being a carer can often involve unexpected emergencies. What are your rights in those circumstances?

In fact, employees do have a legal right to time off to deal with an emergency involving a 'dependant' (which could include someone with dementia). This time off could be paid or unpaid, at the employer's discretion.

The Flexible Working Act is also relevant for carers for whom a standard, five-day-a-week, nine-to-five job may not be appropriate. You now have the right to request flexible working from your employer, who must not refuse your request unless there are very good business reasons.

Flexible working covers many different working patterns – flexi-time, home working or a mixture of both, working shorter days, or not working every weekday. Carers UK says it is a good idea to suggest a trial period to your employer, to see how it works for you both. Before considering it, try to work out if the working pattern that suits you might cause problems for the company and how those could be solved if it did. if you are a Trade Union member, ask the Union, or if there are other carers at work, you could ask them how they manage to balance their working and caring obligations.

DOES YOUR FIRM HAVE A CARER'S POLICY?

As well as Carers UK, Alzheimer's Society has information about your rights at work when you are a carer. It says that you don't have to tell your employer your circumstances, but it might help if you do. You should also check what your contract of employment says; for example the company might already have a specific carer's policy, or your employer might be willing to agree to something that matches your needs. Especially good news is that Carers UK has a group called *Employers for Carers*. At the time of writing, this group had more than 230 members, including many major household names, including Asda, Barclays Bank, the John Lewis Partnership and many local councils. Could your employer be one of them?

You now have the right to request flexible working from your employer

Working for a carer-friendly organisation can make your life considerably less stressful

If you are thinking of changing your job, it would certainly be worth looking for a position in a company which was already committed to supporting carers.

The idea of this group is to help make working for these organisations more carer-friendly, so that they – the employers – don't lose valued employees and can also offer appropriate support to new recruits.

If you work for a large organisation, you are unlikely to be the only person with caring responsibilities. Colleagues who understand the issues you face may be willing to form a carers' group with you. According to Carers UK, such groups exist already, offering mutual support in the workplace and helping to deal with any problems that might arise.

> **'Colleagues who understand the issues you face may be willing to form a carers' group with you'**

WHAT TO DO IF YOU DON'T GET SUPPORT

If for some reason you are unable to reach an agreement with your employer about balancing your work commitments with caring, Alzheimer's Society recommends that you contact your Trade Union, if you're a member, or ACAS for help. It is useful to keep a diary of any discussions you had and what the outcome was, plus any related emails or notes from meetings, in case of an appeal from either side. You can also get support from the Carers UK online forum, called Carers Connect, where carers can share their experiences with others who have been through the same issues and, hopefully, found solutions.

Useful contacts
www.carersuk.org
www.alzheimers.org.uk
www.acas.org.uk – offers free, impartial advice on workplace rights to employers and employees.

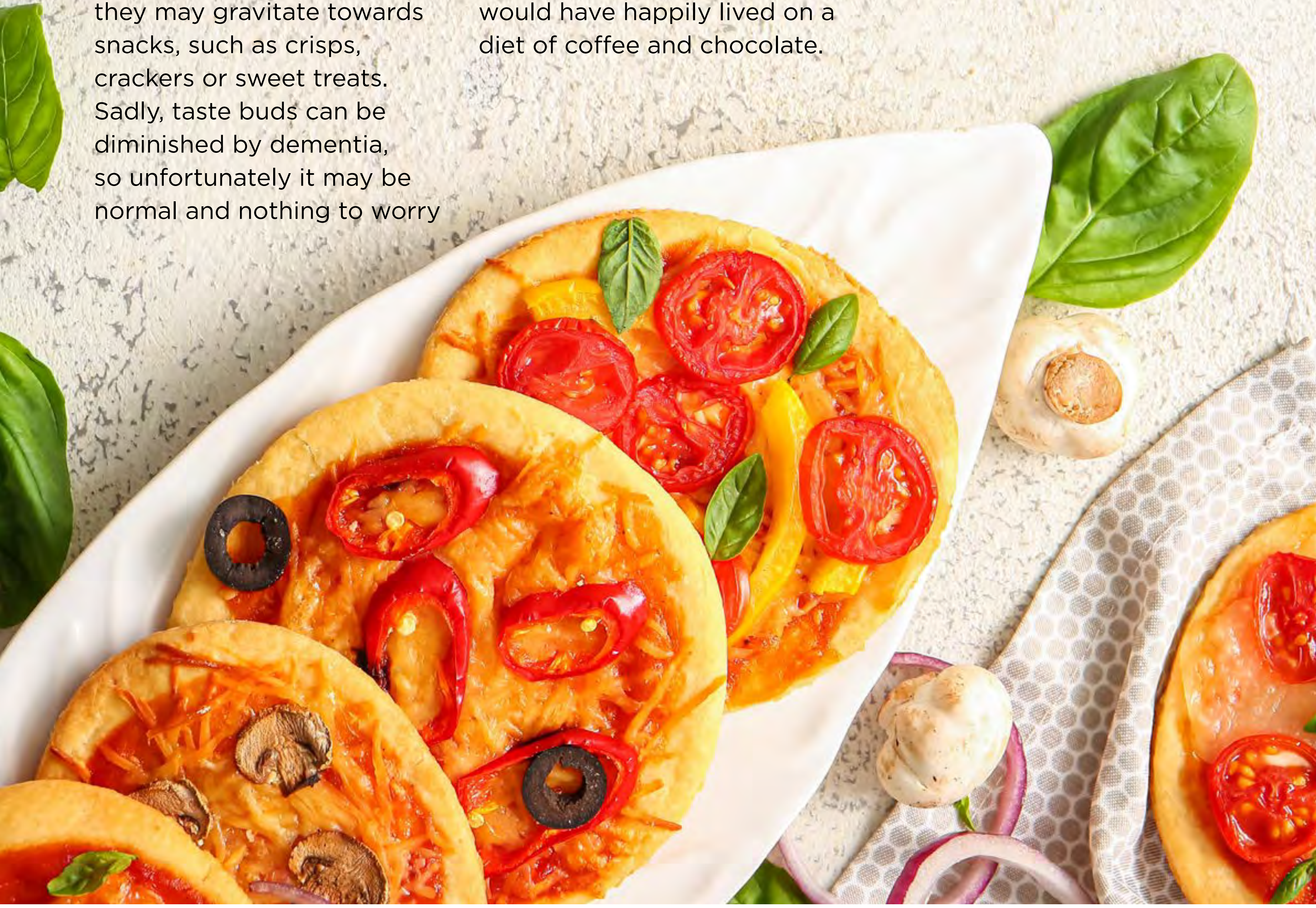
Dealing with appetite changes

Are you worried your loved one is eating less and refusing meals they used to enjoy? A person's appetite can change with dementia, and while it can be worrying, there are reasons why it occurs and things you can do about it. Words: **Christina Collison**

Has your loved one seemingly lost interest in food? You may be putting healthy, home-cooked meals in front of them that they usually love and finding that they barely eat anything. It's not uncommon to see appetite changes in your loved one, or less interest in food than before. Instead, they may gravitate towards snacks, such as crisps, crackers or sweet treats. Sadly, taste buds can be diminished by dementia, so unfortunately it may be normal and nothing to worry about. However, you still want to ensure your loved one is getting all the nutrients they need. So, what can you do?

UNDERSTANDING APPETITE CHANGES

My mum, who had vascular dementia, used to enjoy large meals, but over time, she seemed to prefer snacks. She would have happily lived on a diet of coffee and chocolate. If she felt hungrier on a given day, she'd have a bowl of cereal. Meals no longer appealed to her. It was worrying, so I encouraged her to see the doctor. However, her GP ruled out anything being wrong with her, other than her diagnosis of vascular dementia.



DEMENTIA AND DEHYDRATION

Lack of hydration can lead to confusion, increased risk of developing a urinary tract infection (UTI), and can also make the person dizzy and increase the risk of falls. A 2014 Royal Society of Medicine conference revealed that people with dementia are six times more likely to be dehydrated. Encourage your loved one to drink at least six to eight glasses of water daily. You may need to prompt them, as they may not remember.

If the person doesn't like water, try adding a cordial, or offer fruit juices or smoothies. You could also offer drinks in a beaker, which makes it easier for them to hold. If they have mobility issues, make sure they always have a drink next to their chair.

Another option is a sweet product called Jelly Drops, a sugar-free treat made of 95 per cent water with added electrolytes and vitamins. They're designed to increase fluid intake and help a person with dementia stay hydrated.

For more information, visit www.jellydrops.com

When these changes occur, it's crucial to consult a GP to rule out any underlying health issues. If no medical concerns are identified beyond their dementia diagnosis, several factors might be influencing your loved one's appetite...

DEPRESSION

A person can lose interest in food when they are depressed and, unfortunately, depression can be common in a person with dementia. If you suspect depression, seek medical advice straight away.

COMMUNICATION PROBLEMS

Your loved one may not feel well and might not be able to tell you, or they may have gone off certain foods.

> 'If they have mobility issues, make sure they always have a drink next to their chair'

FATIGUE

This may reduce their ability to finish meals. Also, placing a large meal in front of the person may be daunting.

DISCOMFORT

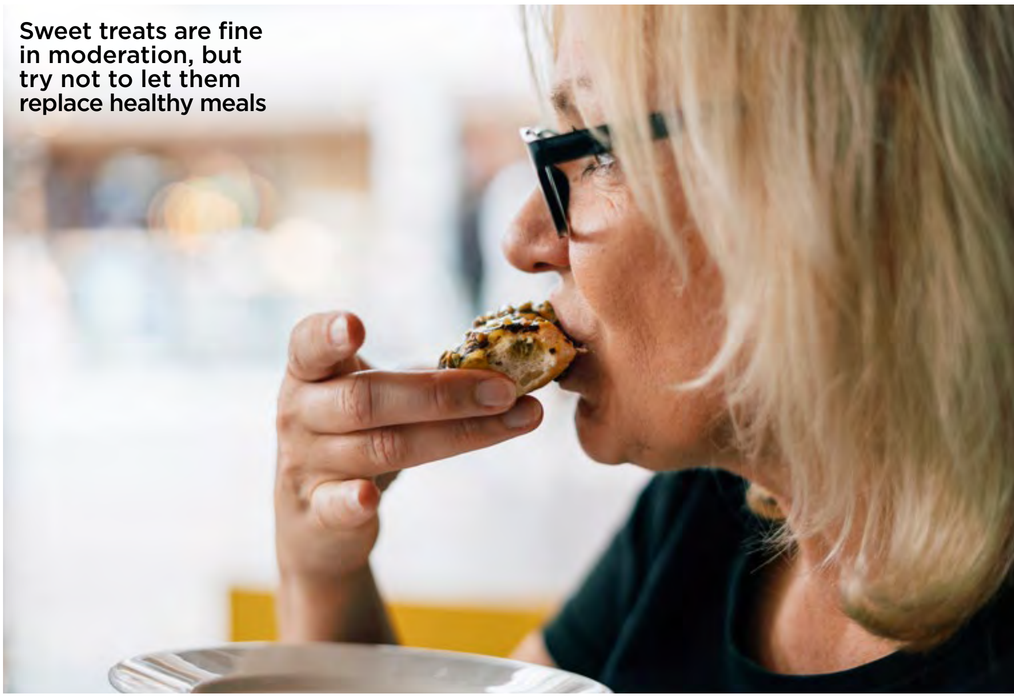
Pain, especially dental pain, may cause food refusal and the person may not be able to tell you something hurts.

CONSTIPATION

This can lead to bloating and disinterest in food. Encourage your loved one to remain hydrated, as this can help to reduce the risk. Speak to the person's GP if this continues.

LACK OF EXERCISE

If your loved one is sitting down all day and not getting much exercise, they may not be building up an appetite.



Sweet treats are fine in moderation, but try not to let them replace healthy meals

CHANGING TASTE BUDS

Your loved one may find that foods they used to enjoy taste bland and are no longer appealing. You might find them liking foods they weren't so keen on before. My mum used to dislike anything hot or spicy, but one day I visited her at her residential home and found her enjoying a hot curry. As taste buds can diminish due to dementia, the person may become more interested in stronger tasting foods.

SERVE SMALLER PORTIONS

If your loved one hasn't been out much or built up much of an appetite, larger meals may be too daunting for a person with dementia. Serve smaller portions more frequently, so that meals aren't too overwhelming. You could try serving several buffet-style foods, such as chicken nuggets, sausage rolls or scotch eggs now and then, instead of a set meal.

SERVE SWEET TREATS NOW AND THEN

Your loved one may be more interested in sweet foods, such as chocolate, cakes and sugary desserts. While too much of these foods isn't healthy, the occasional indulgence is fine from time to time. At the same time, try not to let sugary snacks and treats replace healthy meals.

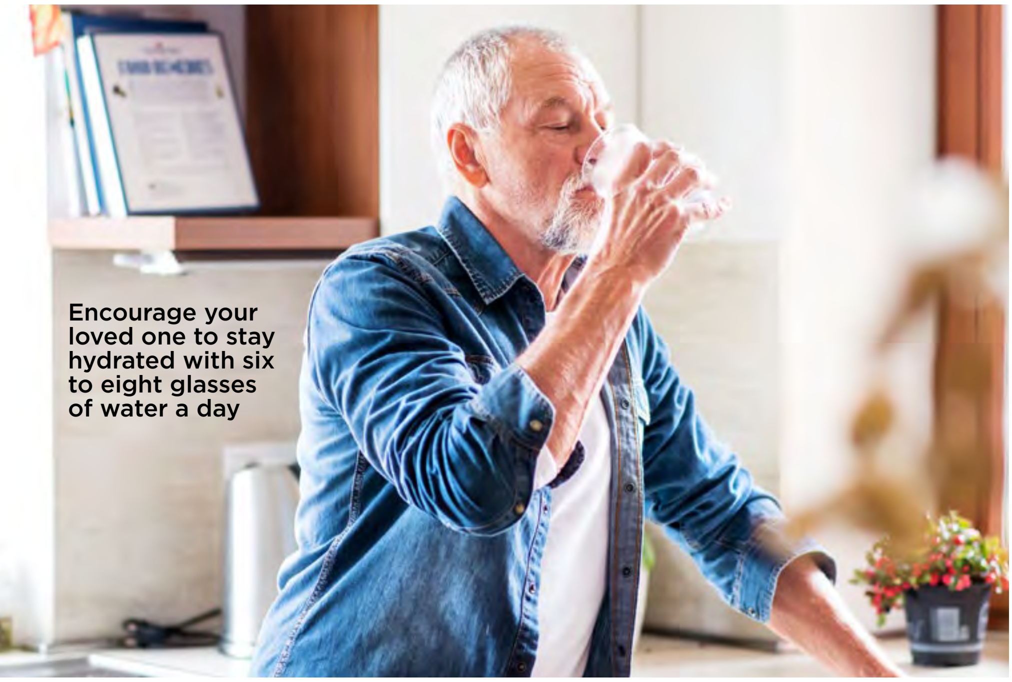
CUT FOOD UP IF THIS HELPS

Your loved one may find it difficult to use cutlery, so cutting up food or serving finger foods may be easier.

MAKE SURE YOUR LOVED ONE CAN IDENTIFY FOOD

In the later stages of dementia, your loved one may find it more challenging to identify the food on their plate.

> **'Serve smaller portions more frequently, so that meals aren't too overwhelming. You could try serving buffet-style foods instead of a set meal'**



Encourage your loved one to stay hydrated with six to eight glasses of water a day

TOP UP CALORIE INTAKE WITH MEALS OUT

Take the person out for meals if you can, which will be a treat for both of you. You may find they eat more when they go to a restaurant and getting them to take in more calories than usual can be a good thing. They may want a starter and a pudding, which of course they wouldn't necessarily normally have at home. My mum used to enjoy going to her favourite pub for Sunday lunch once a week – she would enjoy poached salmon or a Sunday roast and eat more than she would normally have at home. It also meant we got to spend some quality time together, which wasn't just about me caring for her or doing practical tasks. It was good for both of us.

WHAT IF THE PERSON IS OVEREATING?

Your loved one may overeat for several reasons – firstly, they might forget they've already had breakfast or lunch. Secondly, they may be bored or restless, or even depressed. What can you do? Try to keep them occupied and distract them with other activities, such as going out for a walk. Share food portions with them, so they are eating less. It's also important to make sure they are hydrated, as thirst can be mistaken for hunger. If they are eating too much of a certain food, try only having a certain amount of it in the house. 'Fun-sized' bars of chocolate, for instance, might be better than a normal-sized bar and avoid having packets of food like biscuits in the house, as they may get eaten in one sitting.

Buffet-style food can be appealing

My mum once folded a napkin up into a triangle shape so that it looked like a small sandwich, then went to eat it. She genuinely believed she was making a sandwich. The person's brain has to process what's in front of them and this can become increasingly difficult over time.

HAVE SNACKS TO HAND

Make sure there is plenty of fresh fruit and healthy snacks around. Stock up their fridge with healthy options, such as yoghurt and berries.

AVOID DISTRACTIONS AT MEALTIMES

Make sure mealtimes are quiet and relaxed. Turn down the TV or radio if need be and avoid having meals with lots of other people around. Distractions can stop the person from eating and they may not resume eating afterwards.

SEEK HELP IF YOU ARE CONCERNED ABOUT WEIGHT LOSS

While a person's appetite will naturally change with dementia, if you notice the person is eating less and less, and you are worried about their weight, speak to their GP. They may be able to recommend supplementing the person's diet with milkshakes they can have in between meals, to top up their calorie intake. DH

Planning ahead for future care

Your loved one will require full-time care and support at some stage, so don't leave it until the last minute to have a conversation about future care. **Christina Collison** explores the options

Dementia is a progressive disease, which means your loved one will need more help and support as time goes on. Even if they don't need much help at the moment, in the longer-term future, they will require 24-hour care.

It's important to be realistic about the future. While it's not a pleasant thought, it's essential to have difficult conversations early on. Don't put it off, however tempting that might be. Talking about the type of care your loved one would like to receive now will mean you can do all you can in the future to ensure their wishes are met.

Firstly, think about where the person will live. If they currently live alone, they could explore the following options:

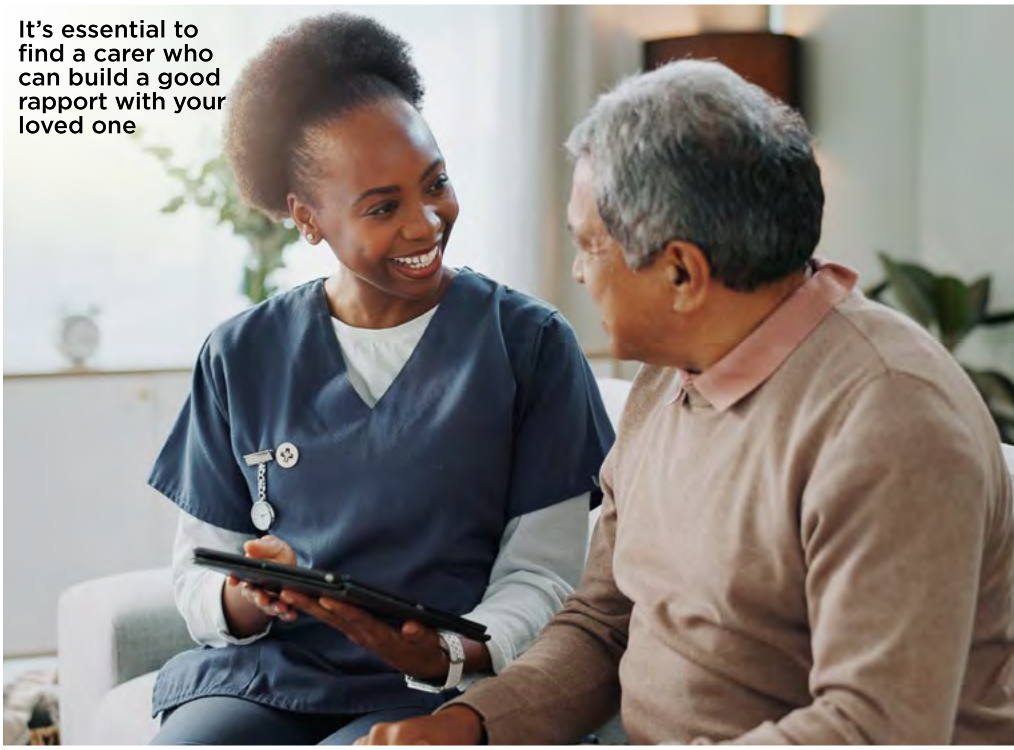
- Having a family member/relative move in with them.
- Having a live-in carer.
- Moving into an assisted living apartment.
- Moving into a residential care or nursing home.

LIVING WITH YOUR LOVED ONE

If you are thinking of moving in with the person, again, it's important to be realistic. While it may seem like a good short-term solution it might not work for you in the long-term. Dementia can interfere with a person's sleep, which means they may wake frequently at night. They can nap and rest during the day, but that may not be an option for you, especially if you have other commitments.

If you have a job, think about how you might juggle work with their care. Is it realistic?

WHO WILL SUPPORT YOU?
Is anyone else available to support you, so that you take it in turns to care for your loved one, or so that you get a break? If so, is the person offering support someone you trust to do it, or do they have a history of letting people down? Or maybe they have health issues of their own? Again, it's about being realistic. Try to take any guilt and emotion out of the situation and focus on what the person really needs, and whether you can provide it. Even if you already live with the person, you may need more support or may not be able to keep things the same – especially if you work.


It's essential to find a carer who can build a good rapport with your loved one

> ‘If you have a home care agency in mind, check their rating on the Care Quality Commission (CQC) website’

HAVING A LIVE-IN CARER
Another option could be to employ a live-in carer through an agency, so that your loved one could stay at home. Live-in care means a professional care worker would move into your loved one's home and provide personal support. The care would be tailored to your loved one's needs, but typically covers personal care, domestic chores, basic admin, running errands and feeding pets.


A residential care or nursing home might be the best option for your loved one

IS A LIVE-IN CARER A GOOD IDEA?
Depending on the circumstances, it might be better for your loved one to remain in their own home, rather than moving to an unfamiliar setting. However, it's essential to find the right carer, who can build a good rapport with your loved one.

It's also important to ensure they are trained in dementia care, so they can adapt to unpredictable or challenging situations. Ask the agency what would happen if the carer became ill or had to go away. If you have a home care agency in mind, check their rating on the Care Quality Commission (CQC) website.

The local authority will offer a list of approved care homes to choose from

WHO PAYS FOR CARE?

To discuss who will finance your loved one's care, a needs assessment is crucial so contact the person's local council. Depending on their financial situation, the person may have to cover all or some of the costs.

- If their capital exceeds £23,250, they may need to fund their care entirely. If they have less that this they will contribute what they can while the local authority may help with fees. For care at home, the value of their property will not be considered. However, if they reside in a care home and own a property, it could be considered in the financial evaluation.

- If they have between £14,250 and £23,250 in savings, the council will provide some financial support and they will pay a contribution from pension income, plus a tariff.

- If they have less than £14,250, the council will provide financial support and they will need to pay something towards their care but no tariff.

In some cases, selling a loved one's home to cover care expenses may be necessary. The property's value is not included for the first 12 weeks in a care facility.

Care home fees vary, but there is typically an upper limit set by the local authority for contributions. They also offer a list of approved care homes.

This rates home care services, care homes and other healthcare providers on whether the service they provide is safe, effective, well-led, responsive and caring. If you know of neighbours using similar services, it's a great idea to ask around, to see if they can recommend anyone or share their experiences. For more information, visit www.cqc.org.uk.

WHAT DOES A LIVE-IN CARER COST?

The cost of live-in care varies significantly depending on where you live in the country, as well as the level of care that's necessary. As a very rough guideline, it can range from around £150 per day for 24-hour personal care to £200 per day for more complex care, which usually involves medical support, such as nursing care.

WHAT ABOUT SHELTERED HOUSING?

Also sometimes known as retirement housing, sheltered housing offers the option to rent accommodation with 24-hour emergency support through an alarm system. It also offers a communal area, as well as social activities. This option may be a good idea for someone who wants to live independently, but it's not necessarily suitable for a person with dementia, who will require considerable care.

COULD ASSISTED LIVING BE AN OPTION?

Assisted living offers more support than sheltered housing. The person lives in a flat, house or bungalow, and staff are available 24 hours a day to provide support. There is a communal lounge area for activities and your loved one may be able to buy extra care.

A warden can provide support, and social activities are often arranged. While this may sound like a great idea, it may not be suitable long-term.

While it's less expensive than residential care, most assisted living housing is leasehold, so there may be restrictions on the lease. It's important to look into this carefully before your loved one makes any decisions. In addition, assisted living is not the same as residential care. It may be a good option for early or mid-stage dementia, but not necessarily later on, when your loved one needs more support. Assisted living locations are rated by the Care Quality Commission, unlike sheltered housing.

> 'Think about the type of care your loved one needs and where they are in their dementia journey'

WHAT ABOUT A CARE HOME?

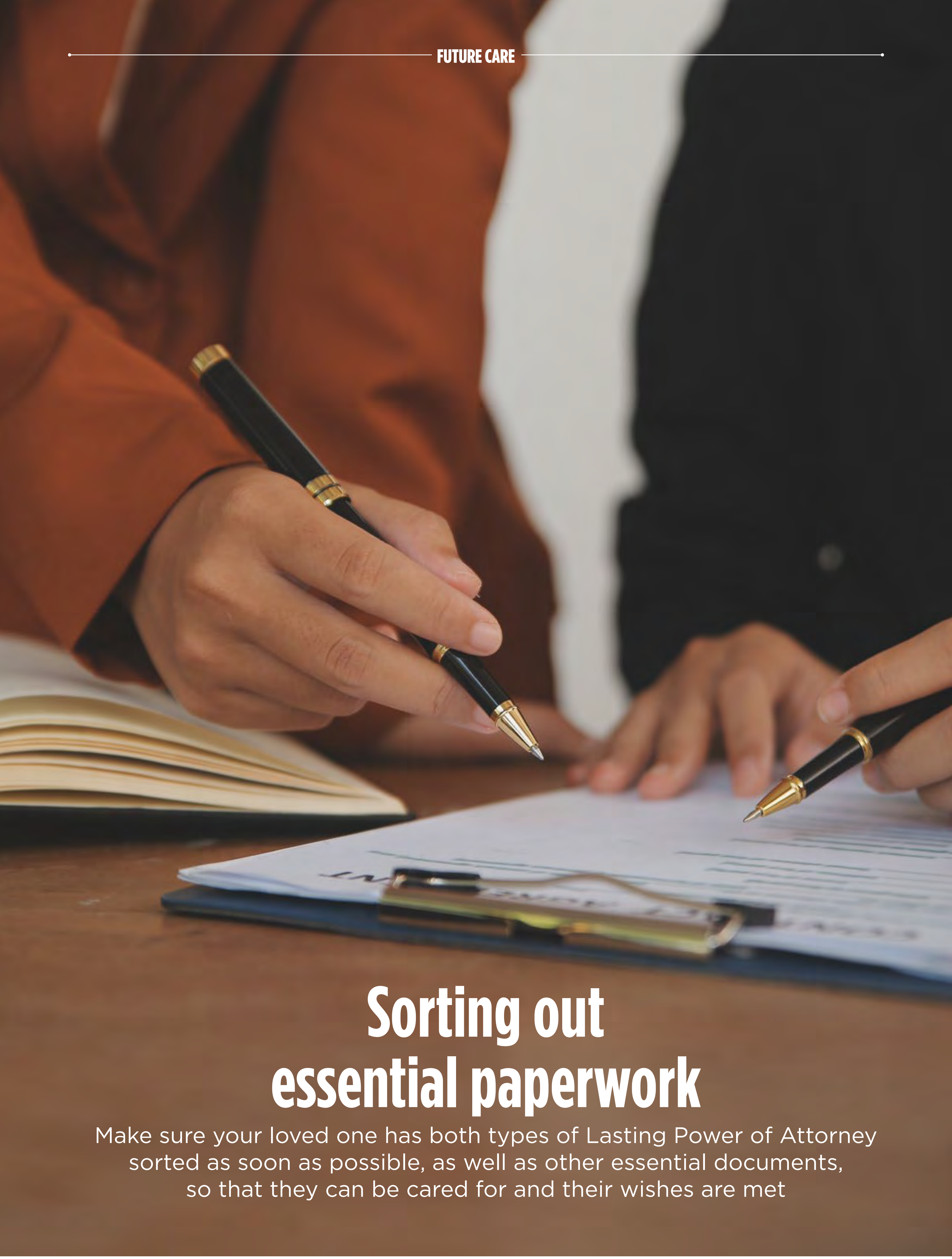
Think about the type of care your loved one needs and where they are in their dementia journey. There are different types of residential care to consider. A care home will offer personal care and social activities, while a nursing home provides registered nursing care for those needing a higher level of support, such as people in the later stages of dementia. For guidance on the best option, consult the person's GP or healthcare provider. When selecting a care home, ask questions and check their rating on the CQC website.

Care home costs vary considerably, depending on the area and type of home. Nursing home care is more expensive. According to the website, carehome.co.uk, the average weekly cost of residential care for a self-funder is £1,160 and £1,410 for nursing care. DH

A care home will offer personal care as well as social activities

WHAT IF YOUR LOVED ONE REFUSES TO DISCUSS THEIR CARE NEEDS?

I know from first-hand experience that it's not always easy to have the conversation. Your loved one may refuse to talk about it or may be in denial about the situation. My mum refused to accept that she needed any help and support. If your loved one refuses to talk about the future, go ahead and do your research anyway, so that you're prepared for when additional support is definitely needed. I researched care homes for my mum about six months before she moved into one. I knew things were heading that way and didn't want to leave it until the last minute.



Sorting out essential paperwork

Make sure your loved one has both types of Lasting Power of Attorney sorted as soon as possible, as well as other essential documents, so that they can be cared for and their wishes are met

Making a will and Lasting Power of Attorney are both essential elements of planning for future care.

Your loved one may not want to think about paperwork, such as making or updating a will or LPA, but both are important.

Making a will is the only way for your loved one to ensure their estate will be distributed as they wish when they pass away. If the person dies without making a will, their estate may not be distributed as they would have liked. They may need to change or update their will. It is possible for them to make a will with a dementia diagnosis, provided their solicitor is happy they understand what they are signing. They have to show they understand what making a will means, what they own, and why they are choosing to leave (or not leave) things to loved ones. They don't have to use a solicitor, but it's worth them speaking to one to ensure that everything is done properly. As your loved one has dementia, it's a good idea for them to get a medical opinion and evidence from their GP confirming that they were able to make a will.

> **'As your loved one has dementia, it's a good idea for them to get a medical opinion'**

Making or updating a will is vital so your loved one's wishes can be met

It's perhaps even more important that the person with dementia makes a Lasting Power of Attorney (LPA). They should organise this as a matter of urgency. Again, the solicitor will need to be confident they understand what it is and its implications.

There are two types of LPA and, while most people tend to focus on the financial one, both are important:

Property & Financial

This means the person appointed to handle your loved one's affairs, known as the attorney, can manage their finances, including their banking, collecting pension or benefits, paying bills and making financial decisions on their behalf. The attorney can also arrange to sell the person's home to pay for future care.

Health & Welfare

This means the attorney can handle arrangements around your loved one's medical and health needs.

MAKING AN ADVANCE DECISION

It's worth having the important conversation with your loved one about creating an advance decision. This legal document, also known as an advance directive, specifies which medical treatments the person doesn't want in the future when they're unable to communicate their wishes.

What should be considered in an advance decision?

- Desire to donate organs after passing away
- Preference not to be resuscitated in later stages of illness if that's what your loved one wants to happen
- Decision against antibiotics for pneumonia during advanced dementia

Why is an advance decision significant?

It may seem daunting, but ensuring the person's wishes are followed is vital. The decision must align with the individual's medical circumstances and can only be invoked if they lack capacity. While a person with dementia can create their own advance decision, clarity and specific scenarios are key. Consulting a GP or solicitor is recommended for added guidance. Don't forget to tell the person's GP about the advance decision and give them a copy for safekeeping.

However, this is only when the person with dementia is no longer able to do so. It can typically cover decisions such as where the person lives, medical care received, moving into a care home and decisions around their daily routine.

Your loved one can choose just one attorney, such as yourself, if they prefer, or they can have up to four people. If they choose to have more than one, they need to decide how decisions will be made.

OPTIONS FOR LPA AND ATTORNEYS

Jointly

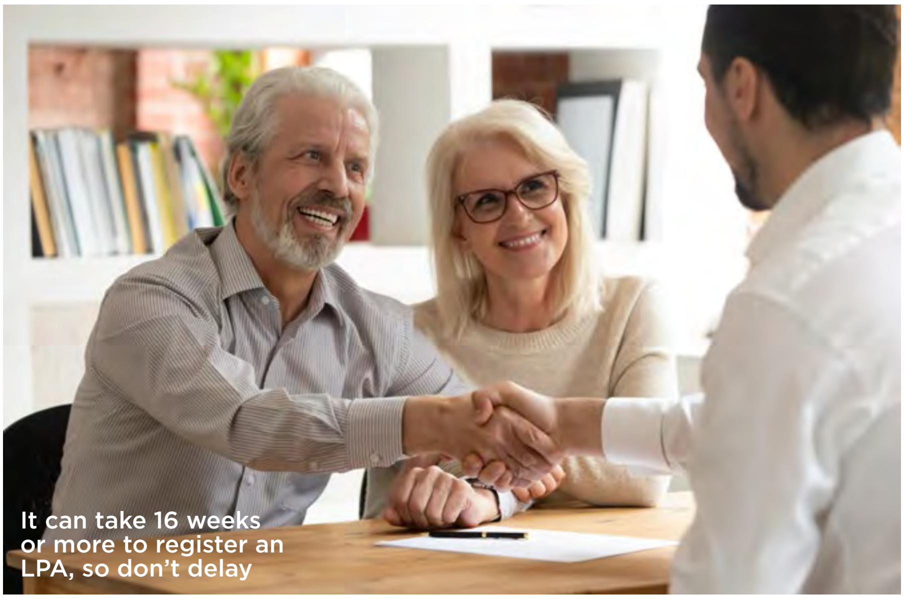
Where the attorneys must make decisions together and must all sign paperwork.

Jointly & Severally

Where one or more person(s) can act on your behalf and that of other attorneys. Most people choose the latter option, simply because of practicalities; people are living all over the country now, so it's easier. This means that one attorney can sign the paperwork and make decisions without the other attorneys present.

A combination

Jointly in respect of some matters and Jointly & Severally in respect of other matters. That's just a mixture of the two, but you must be very specific as to which decisions are to be jointly made and which decisions are to be made Jointly & Severally.


It can take 16 weeks or more to register an LPA, so don't delay

It can take around 16 weeks or more to register an LPA, so don't delay – it's important to get the ball rolling as soon as possible.

WHAT IF THE PERSON HAS LOST CAPACITY?

If there is any doubt about the person's ability to understand what they are signing, they may not be able to proceed without there being medical opinions needed, and the person's GP may need to act as a Certificate Provider (the person who confirms that the person with dementia understands the nature of the Lasting Power of Attorney).

WHAT IF IT'S TOO LATE TO MAKE AN LPA?

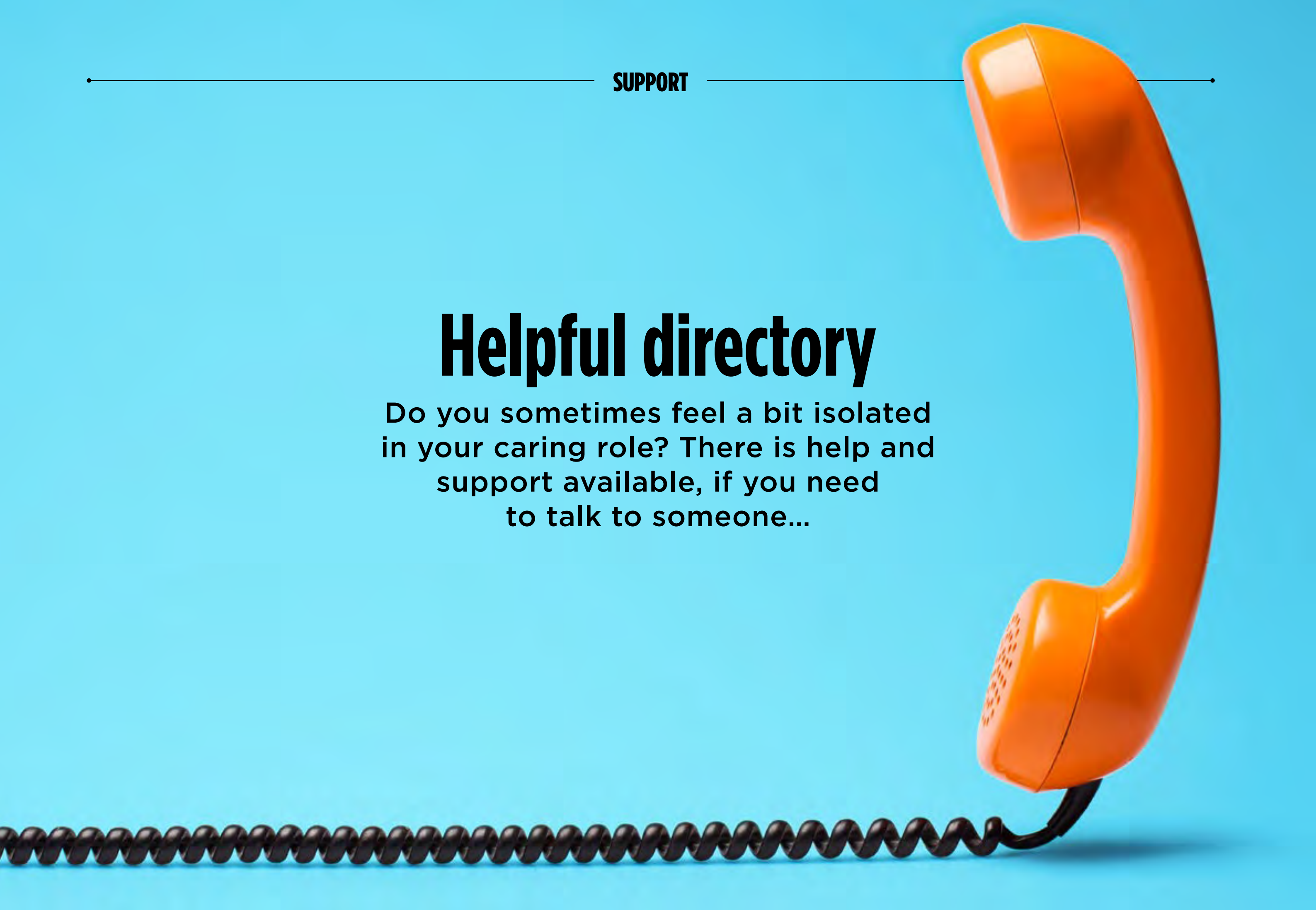
If your loved one is deemed to have lost capacity and can't make an LPA, someone who wants to act on their behalf must apply to the Court of Protection to be what's known as their 'deputy'. This is an expensive and lengthy process and, because the person has lost capacity, they can't choose who their deputy is.

CAN A PERSON REVOKE A LASTING POWER OF ATTORNEY?

Once the person has the Lasting Power of Attorney in place, if they sense that something is not right, then they can still protect themselves. While they still have the capacity, they can revoke the Lasting Power of Attorney at any time.

If you are a carer and have concerns about someone abusing their status as an attorney, you can contact the Office of the Public Guardian on 0300 456 0300 or by email at opg.safeguardingunit@publicguardian.gsi.gov.uk DH

More information
For further details on setting up a Lasting Power of Attorney, visit www.gov.uk/power-of-attorney



Helpful directory

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

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

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

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

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

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

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

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

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

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

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

‘There is so much good out there’

Harriet Thomas recently completed an adventure combining her love of hiking with a personal mission. She walked 900 miles from Lands' End to John O’Groats to raise money for Dementia Adventure’s Support Fund, interviewing others affected by dementia along the way.

Harriet walked 15 to 20 miles every day

After enjoying a hiking holiday which eased her back pain and improved her mood, London-based singer/songwriter Harriet Thomas completed a personal challenge to raise money for Dementia Adventure’s Support Fund. This charity provides life-enhancing supported breaks for people living with dementia and their carers.

Harriet camped in a tiny tent each night. Her journey has also been documented in a new podcast *The D Tour*, and she interviewed people living with dementia along the way, including singer Tony Christie.

Harriet’s epic challenge saw her walk the length of the UK

Braving the rain in Cornwall!

LOSING A LOVED ONE

Harriet’s mum died last year, after battling dementia since 2013. When her mum was first diagnosed, she refused to accept her diagnosis. However, there was no doubt in the family’s mind that she had dementia.

‘She thought that people were getting at her,’ says Harriet. ‘She wanted some work done in the house, but when the builders came in to do the work, it was massively distressing to her. She also wanted to visit my sister, who lives in Canada, and she had a total breakdown. My brother in law’s doctor prescribed some tranquilisers to calm her. We couldn’t leave her alone, because she would descend into a very distressed place.’

WALKING TOGETHER

When the family returned from holiday, Harriet's mum was admitted to a care home and passed away there last year.

Harriet and her mum used to enjoy walking together, so it seemed fitting for Harriet to take on a walking challenge. She covered an average of 15 to 20 miles per day since the start of August.

'My mum loved nature and often went on walks,' Harriet says. 'She also loved gardening. When she had dementia after she had lost her language, she loved going into the garden and finding a brightly coloured flower – those things would elicit a word. It would be like a miracle, because I hadn't heard her speak for a while. Dementia Adventure aims to allow families living with dementia to share precious moments outside. The holidays are supported, so carers can have a break too.'


Catching up with singer Tony Christie in Lichfield

HAPPIER AND AT PEACE

Harriet believes that the joy gained during a walk can make a person happier, even if they don't remember the activity afterwards. 'Peace from nature can filter into your life,' she says. 'Nature is something we can all enjoy.'

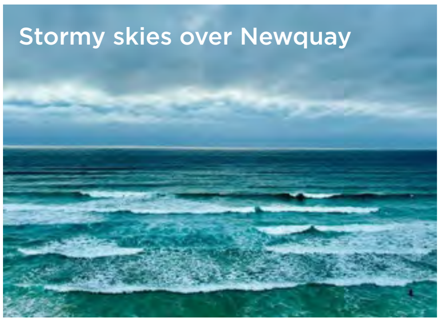
Harriet was inspired by singer Tony Christie's positive outlook on dementia. 'I think his point of view is he still sings,' says Harriet. 'He loves singing. That's his gift. He'll keep doing it as long as he can. Tony loves doing cryptic crosswords, and he realised he couldn't do them anymore, and that's when he went to the doctor. He was very proactive in getting a diagnosis. He probably got diagnosed relatively early, and he's taking medication to slow the progress.'

HELP AND SUPPORT

The amount of people who have been generous enough to donate and offer support during her walk has impressed Harriet. 'There is so much good out there,' she says. 'We hear about the world being such a bad place, and of course, there are lots of bad things happening, but I've been heart-warmed by the generosity of people – total strangers have given me money to put into the pot.'

Harriet also praises the outlook of the team at Dementia Adventure. 'Their attitude is about living in the moment,' she says. 'It doesn't matter if somebody can't remember their activity. If in the moment they were having fun, that's the whole point. We get so worried about what will happen later, today or tomorrow, that we forget to say, 'Where am I now? This is okay. This may be great'.' DH


At the very start of her journey


Stormy skies over Newquay

More information
At the time of writing, Harriet had raised over £17,000 in donations. You can donate to Harriet's fundraising challenge at dementiaadventure.org/dtour


DementiaNet
Home
Dementia & You
Dementia & Others
The dementia help hub
Dementia & you
Dementia & others
Working with dementia
Next →
DementiaNet
How can we help you today?
Are you looking for help...
I have been diagnosed
I might have dementia
I am a family carer
I am a carer
DementiaNet
See how our community can help you
hat's on in my area
Conversations
View conversations →