HELPING CARERS COPE

DEMENTIA HELP

ISSUE 2

‘EVERY TIME I GO ON STAGE IT’S HELPING ME’

TONY CHRISTIE ON LIVING WITH DEMENTIA

8

KEY THINGS TO DO IN THE EARLY STAGES OF DEMENTIA

‘EMBRACE MY REALITY’

ONE WOMAN’S UNIQUE INSIGHT ON DEALING WITH DEMENTIA

WHAT TO DO IF YOUR LOVED ONE CAN’T LIVE ALONE

YOUR ESSENTIAL GUIDE TO THE OPTIONS AVAILABLE

COPING WITH INCONTINENCE

PRACTICAL SOLUTIONS THAT MAY HELP

THE AMAZING BENEFITS OF MUSIC FOR A BETTER MINDSET

SHOULD YOU LIE TO YOUR LOVED ONE?

THE ANSWER MAY JUST SURPRISE YOU

‘I needed help and support’

Being a dementia carer is an emotional journey. I often felt isolated and alone when looking after my mum. Few of my friends understood. Only two realised how stressful it was and that was because they were also carers. Other well-meaning friends told me to go out and ‘have a few drinks’. That was the last thing I wanted to do.

Practical advice

I’m sure you can relate when I say that what I really needed was help and support in managing Mum’s care. I know many other carers feel the same way, so my goal is to try to tackle some of the practical issues we face as carers. In this issue, we look at what to do if your loved one can no longer live alone (page 40). We also look at key things to do in the early stages of a person’s dementia (page 8) and whether you should tell a white lie, in order to protect your loved one (page 24).

Better knowledge

Aside from practical advice, I also believe the more you know about dementia, the better. So I’m pleased that Sue Strachan and Tommy Dunne agreed to speak to us and share their insights on living with dementia (page 12 and page 16).

Music can be a positive way to manage dementia symptoms, as it’s known to improve mood and reignite memories. I’m therefore delighted that singer Tony Christie agreed to talk to us, and I’m inspired by the fact he’s still performing, despite his dementia diagnosis. Read our exclusive interview with Tony (page 18).

I hope you find this magazine useful and would welcome your feedback. Until next time.

Christina x

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‘What keeps me going during those foggy days is hope’

Wendy Mitchell, best-selling author living with dementia

Issue 2

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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

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

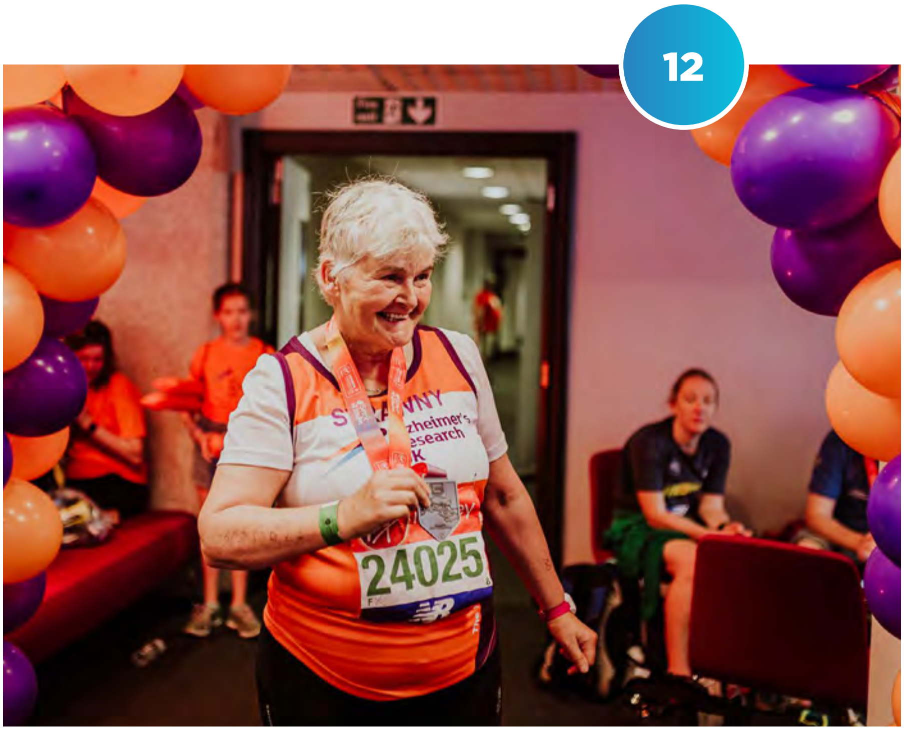
DR CAROL SARGENT

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

JEFF SMITH

Jeff is an estate planning consultant and will writer for MB Associates, who believes that it's important to make plans for the future as soon as possible, so that a person can receive the care and support they would like. Jeff offers support and guidance for creating a Lasting Power of Attorney (LPA). Visit mbassociates.net for more details.

Contents



REGULARS

GOOD TO KNOW

INTERVIEWS

NUTRITION

HEALTH

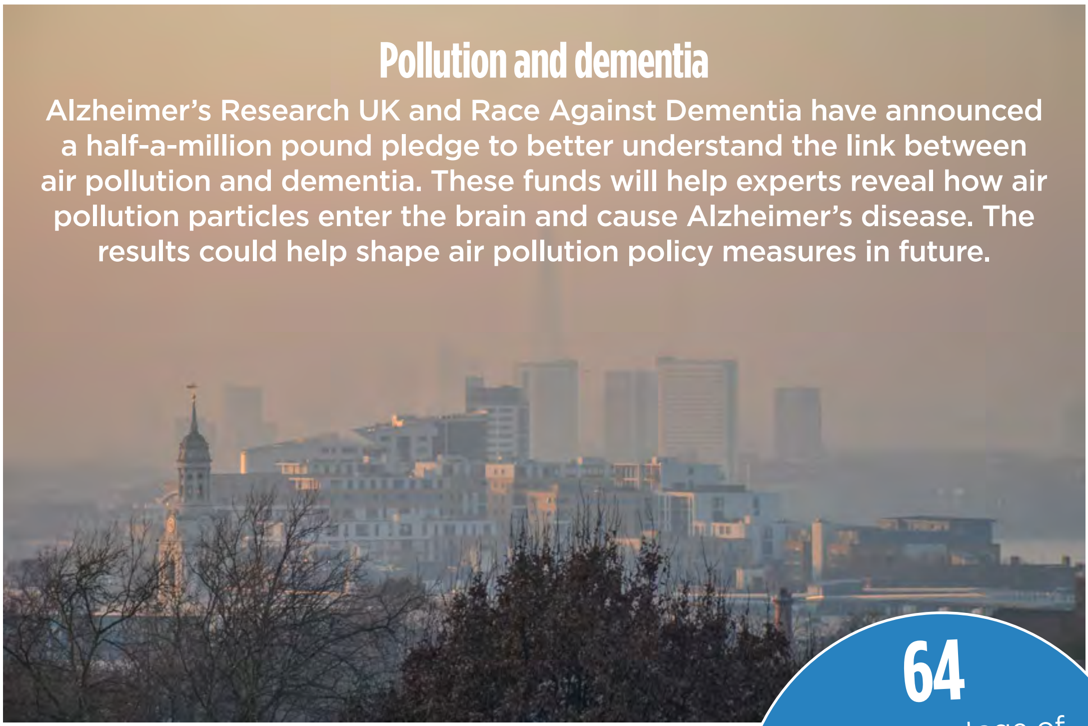
PLANNING AHEAD

Updates

The latest news, facts and stats about dementia

Arlene asks for early and accurate diagnosis

Dame Arlene Phillips spoke out during Dementia Action Week in May, urging the government to act on giving access to an accurate dementia diagnosis. The former dancer, whose father had dementia and who is an ambassador for Alzheimer's Society, said that an earlier, more accurate diagnosis is essential for people to be eligible for new treatments for dementia.



Pollution and dementia

Alzheimer's Research UK and Race Against Dementia have announced a half-a-million pound pledge to better understand the link between air pollution and dementia. These funds will help experts reveal how air pollution particles enter the brain and cause Alzheimer's disease. The results could help shape air pollution policy measures in future.

FOOD FOR THOUGHT

'A third of us will go on to develop dementia in our lifetimes. We need to change the idea that getting dementia is inevitable as we age – it's not called getting old, it's called getting ill.'

Dr Amir Khan from Good Morning Britain

64

The percentage of people who mistook dementia symptoms with getting older and therefore stayed silent about their fears

Source: Alzheimer's Society

Wembley to be dementia friendly

Wembley Stadium is the first national stadium to become dementia friendly. The Football Association is working with Alzheimer's Society to make improvements, including bespoke staff training and increased visibility of current services available, such as lifts. Alzheimer's Society CEO, Kate Lee, says: 'Passion for sport stays with people long after a dementia diagnosis, so these improvements to one of the world's most iconic football stadiums, in a national first, is set to be another legacy of our fantastic partnership with The FA and will make a massive difference to thousands of fans up and down the country.'

Updates

The latest news, facts and stats about dementia

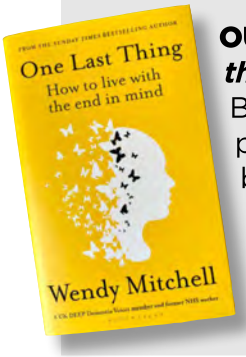
Not a disease of the elderly

Many people mistakenly think that dementia only affects older people. While it's true that your risk of developing the condition increases with age, it also affects younger people. According to Alzheimer's Research UK, there are an estimated 70,800 people in the UK living with young-onset dementia, which is defined as being diagnosed when you are under the age of 65. Some 50 per cent of people with Down's syndrome will develop dementia and are likely to have started developing signs of Alzheimer's disease by the age of 40.

DID YOU KNOW?

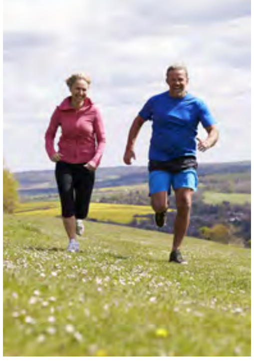
There are estimated to be over 55 million people in the world living with dementia.

Source: Alzheimer's Disease International



OUR RECOMMENDED READ: *One Last Thing: How to live with the end in mind,* Wendy Mitchell

Best-selling author Wendy Mitchell's latest book has just been published in hardback format. Former NHS clinician Wendy has been living with a diagnosis of early-onset dementia since 2014, when she was diagnosed at the age of 58. Wendy has already written several books, including *What I Wish People Knew About Dementia*, and her latest book talks about having hope after diagnosis of a terminal or progressive illness. A fascinating and touching read. Available on Amazon.



GOOD TO KNOW

According to Dementia UK, regular exercise can improve self-confidence and cognition in a person with dementia.

Visiting a person with dementia

How often should you visit a person with dementia? Aim for regular visits – ideally between three to five times a week if you can. There are ways you can make the most of your visits for the benefit of both of you. Firstly, try to keep visits limited to just one or two people. A bigger crowd of people can be too much. Try to visit the person when they are usually at their best. First thing in the morning, if your loved one has never been a morning person, is best avoided.

Greater financial security

Jayne Sibley had an idea to help manage spending and prevent fraud

Jayne is keen to help those with dementia maintain independence

We report on Sibstar, a new spending card and app for those living with dementia

Busy mum Jayne Sibley has parents with dementia and hit upon a new idea to help those living with the condition manage their money safely, while still retaining as much independence as possible.

After seeing her mum struggle to manage her spending habits, Jayne launched Sibstar, a new flexible debit card and app to help families with dementia manage their spending and avoid fraud.

‘My mum would overspend on things like cleaning products and would forget she’d bought items,’ says Jayne. ‘She’d also take money out of the cash point two or three times a day and give it to the homeless person outside the supermarket. I'd often have to report or try to reverse phone scams because she was being called three times a day by diffent fraudsters.'

Jayne pictured with her mum

Motivated to help other carers and families like hers, Jayne launched Sibstar, a debit card that people living with dementia can use assisted by their carer. Through the Sibstar app, you can choose where and how the money is spent as well as set daily or weekly limits. Jayne says: 'The beauty of this service is that all the limits and protections can adapt instantly to the person with dementia's needs.'

Carers can choose to receive notifications about how the card is being used, and enhanced security protections look for behaviour common to people with dementia to prevent problems escalating. You can set auto-top up so the card never gets declined from small transactions, set detailed cash withdrawal rules and freeze it at any time.

Jayne adds: 'As far as I know, we are the only service delivering a debit card that enables people living with dementia to spend their money by themselves, for themselves.'

For more information, visit **sibstar.co.uk**

8 key things to do in the early stages of dementia

If someone you care about has recently been diagnosed with early stage dementia, it's natural for them to feel overwhelmed. However, it's crucial to take care of certain responsibilities without delay

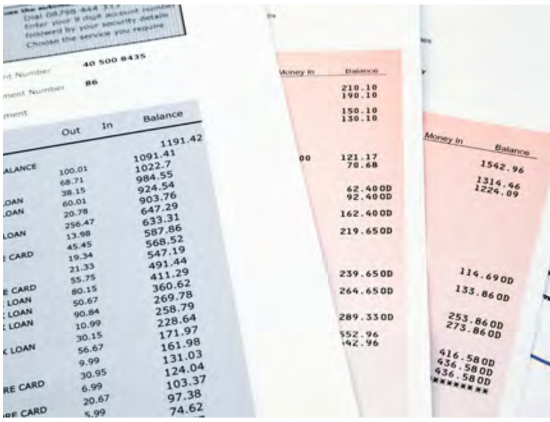
Get the basics organised early on, to give you and your loved one greater peace of mind

Receiving a diagnosis of dementia can be overwhelming. The important thing at this stage is to reassure the person that they have your support and that they are not alone.

Once you have both had some time to come to terms with the diagnosis, it's essential to act quickly and start planning for the future. We have created a useful checklist, which outlines key things to organise in the early stages of a loved one's dementia...

1. SET UP DIRECT DEBITS OR STANDING ORDERS FOR REGULAR BILLS

This is a great way to ensure payments are made on time and alleviates the risk of the person forgetting to pay bills. It's also reassuring for your loved one to know that household bills will be automatically debited from their account, eliminating the possibility of their gas or electricity being disconnected.



2. LOCATE IMPORTANT DOCUMENTS

If the person doesn't mind, take key documents, such as insurance policies, home with you and keep track of key renewal dates in your diary. Alternatively, keep all the documents together in a clearly marked file and store them safely. That way, you can ensure that these important documents are safe and easily accessible when needed.

3. FILE BANK STATEMENTS CAREFULLY

By creating a clearly labelled folder, you will be able to stay on top of your loved one's finances more easily.

Plus, if the person is comfortable with it, you can keep the statements on hand to help keep track of everything. With careful storage, you can ensure that financial records are stored safely.

4. GET SPARE HOUSE KEYS CUT

The person may get locked out of the house on occasion, so get a spare set for you and a neighbour that you trust. You might also want to consider installing a key safe at the front of the house (a box on which you need an entry code to open), which can store a spare key.

5. LET THE DVLA KNOW ABOUT THE PERSON'S DIAGNOSIS

The person has a legal obligation to let the DVLA know they have dementia, but may not have to stop driving straight away.

6. ENCOURAGE THE PERSON TO MAKE AN ADVANCE DECISION

This is a legally binding document, which outlines what treatment the person would like to receive in the future, as and when the condition deteriorates.

You must contact the DVLA, but the person may not have to stop driving immediately

Get legal matters sorted swiftly

7. ENCOURAGE THE PERSON TO MAKE A POWER OF ATTORNEY

This will enable you to make decisions about their health and welfare or their finances when they are no longer able to do so. It needs to be done early on, while the person with dementia still has capacity. There are two types of LPA – Health & Welfare and Property & Financial. Both need to be done. It's also important to make or update a will – not because anything is going to happen in the short term, as this is not likely to be the case, but to ensure this has been taken care of before the person's condition progresses.

> *'The person has a legal obligation to let the DVLA know they have dementia'*

8. OBTAIN THIRD-PARTY AUTHORITY ON THE PERSON'S BANK ACCOUNTS

This will allow you to access and manage the person's bank accounts. You will be able to check the person's bank balances, transfer funds, make online payments for them and order cheque books on their behalf. To do this, you will need to go into the bank with the person, and you will both need to take identification with you, including passports and proof of address. For some banks, Lasting Power of Attorney may give you this authority, but the situation can vary depending on the bank, so be sure to check. DH

The Bookcase Analogy

Being a dementia carer can be hugely stressful, especially when you begin to notice significant changes in the person’s condition. The more you know about dementia, the better placed you are to cope with changes. The Bookcase Model can be a useful way of understanding dementia, as **Christina Neal** explains

When a person is in the earlier stages of dementia, their short-term memory will suffer first. This means the person will struggle to remember recent events or conversations, including what they had for breakfast that day, or whether or not they went to the shops. Long-term memory will deteriorate in the later stages of the disease.

The Bookcase Model is an analogy that is used to describe how dementia might affect a person as the condition develops. The explanation was devised by Dr Gemma Jones.

It's a good way to explain dementia and can help you understand it more clearly. Picture a bookcase filled with books. Each of those books represents a skill or a memory that a person has gained. On the top shelf are the most recent memories (what the person had for lunch, for example); the next shelf down may contain less recent memories, such as events in the past few months or year, such as where they went on holiday. On the third shelf would be earlier decades of memories, of their earlier life.

BOOKS FALLING OUT

When the person has dementia, the bookcase starts to move. Books begin to fall out. The ones that tend to fall off first are the ones on the top that relate to short-term memory. As the condition progresses, the person may begin to lose books on the subsequent shelves and may end up with what they think are the most recent memories, which are actually from an earlier decade or life stage. As the condition gets worse, more books will fall off the shelf. The person will begin to think they are much younger and living their life in their forties, fifties or sixties.

COMMUNICATION

The best way to communicate with a person in the later stages of dementia is to do it in an emotional way. Scott Mitchell, who cared for his late wife, Barbara Windsor, spoke in our previous issue about speaking to her heart. The person will naturally want to feel loved and safe. Tell them you're there for them, hold their hand or hug them if they are happy for you to do this and reassure them regularly. Try to avoid conversations that involve the person having to recall what they did that day, what they had for lunch or when you told them about something else. Invite the person to give their opinion on something. When my mum's dementia became fairly advanced, I avoided asking her questions about her day. Instead, we'd look at fashion magazines, and I'd ask her to tell me which outfit she liked or which pair of jeans would suit me best. I'd thank her for her opinion and tell her she'd helped me decide which clothing items to buy.

THINGS NOT TO DO WITH A PERSON WITH DEMENTIA

Don't wrap them up in cotton wool and make them feel helpless.

Don't talk to them like they are a child – this is called 'infantilisation'.

Don't outpace the person – this means talking to them at a pace that is too fast.

Avoid too much information – keep the information short and to the point.

‘I take it one day at a time’

Many people wrongly think dementia is a disease of the elderly, but **Sue Strachan** was diagnosed with vascular dementia in her 50s. Despite this, she’s gone on to achieve goals and lives a full life

Sue Strachan is 67 and was diagnosed with vascular dementia at the age of 56, after suffering a TGA (transient global amnesia) – an episode of confusion that comes on suddenly in a person who is otherwise alert. She lives in Herefordshire with her partner, Sheila, and is an ambassador for Alzheimer’s Research UK.

An inspirational and driven lady, Sue took up running when diagnosed with vascular dementia, and went on to run the London Marathon and two half marathons.

She talks to *Dementia Help* about her positive outlook and what she wants people to know about dementia.

When did you first realise something was wrong?

SS: I’d been a sales rep, driving around 25,000 miles a year for a publishing company. And it all got too much. So I stopped doing it. And I started to work with Sheila doing her admin, which I loved. Sheila was teaching various courses. And I was liaising with the students. We were living in Woking, in Surrey, and we did an “escape to the country”, which we’d been planning for a long time.

Sue ran the London Marathon in 2018

photography: Tim Parry

In December 2012, we drove back to Surrey, and I helped a friend cut down a holly tree in her garden with my chainsaw. And I have no recollection of driving from Herefordshire or staying at the friend’s house to cut down the holly tree. I’d had something called a TGA – transient global amnesia [where you experience sudden memory loss] – which basically meant that I had lost 24 hours completely.

It became clear that there was something wrong. I was struggling for words. I was repeating myself constantly.

How do people respond when you say you have dementia?

SS: People will say to me all the time, 'You seem fine', which actually isn't helpful. It starts to make me question, do people think I'm making it up? I wouldn't make up dementia. They're trying to be kind, but it's not helpful. Also, when people say: 'You don't look like you've got dementia'. Well, you know, what does someone with dementia look like? It could be any one of us. People also say: 'I'm always forgetting things'. Well, I'm not always forgetting things. I do forget some things. I struggle with what I did yesterday.

How long did it take to get a vascular dementia diagnosis?

SS: It took 18 months to get a diagnosis, because I was only 56 at the time. I went through all the various tests. It never crossed my mind that it was dementia because, at that point back in 2013, I was part of the brigade who thought, 'Oh, dementia. Yeah, that's old people, and they forget everything'. Part of my own campaign is to rid people of that thinking. People as young as their 30s and 40s can be affected.

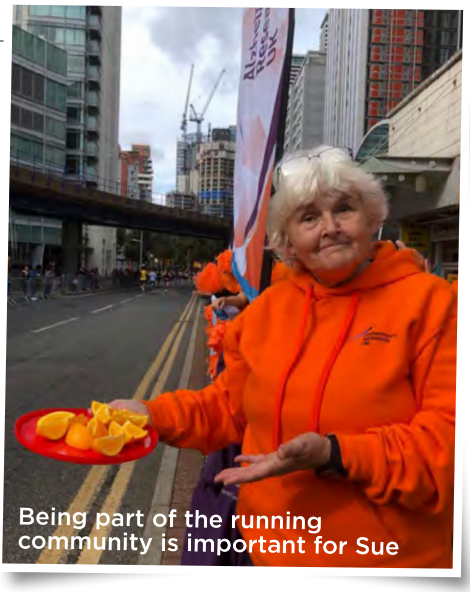
A proud moment: showing off her marathon medal

How did you react when you received the diagnosis?

SS: My initial reaction was that they'd made a mistake. It was, 'I can't have dementia', coupled with, 'Thank goodness, they know that it is something'.

How did you cope with it?

SS: I struggled, but I did start running, because the GP said it was the best thing you can do because it can help to manage cardiovascular risk. The more you can get blood flow to increase, the better. I ran the London Marathon in 2018. I felt amazing – the serotonin levels were off the scale. The emotions tied up with that marathon, I've got videos, I've got a photo book with photos in, and it brings back those feelings so strongly. I often look back at it if I'm having a bad day. I will look back and think, 'Gosh, I did that. That's just amazing.' I've also run two half marathons.



Being part of the running community is important for Sue

> ***'I spent the first 18 months waking up every morning thinking, "Do I feel any different?"'***

You ran for Alzheimer's Research UK. How much did you raise?

SS: About £13,500. My target was £2,000, and I thought, 'I'll see if I can raise £3,000. Somebody sent me £2. And a friend of mine said, 'Oh, why did they bother?' And I said, 'Because that's all they could afford. And they wanted to do it'. It's lovely. Things like that made me very emotional.

You're an ambassador for Alzheimer's Research UK. Tell us about that.

SS: I cannot sing the praises of the charity highly enough.

‘One of my nephews described it as a ticking time bomb that might never go off’

photography: Alex Wallace

Research is the way forward. Community care is necessary, but research is vital.

I understand you were in the programme,* The Restaurant That Makes Mistakes*, featuring people with dementia serving the customers. How was that?

SS: What the programme showed was that we can still do things, given the right circumstances. All of us were working age – I was the only one who actually wasn’t still working. There was a gynaecologist who could no longer work, there was a lawyer. She’s now registered blind and in a care home. There were people from all backgrounds, and some of them thrived in that environment. You could see the change in them.

How do you and Sheila cope with the challenges of dementia?

SS: I’m short-tempered when I’m struggling for words. I still know if I behave badly. Many people with dementia don’t know. They don’t know that they’ve bitten the head off their partner or their carer. And so, afterwards, I would feel really bad because I’d shouted at Sheila about something really silly. It took a long time for her to be able to deal with it, but I just can’t help it. The sudden outbursts of temper, or when I’m tired or hungry – they’re not excusable, but they are due to my dementia. I know people who’ve had to let their partner go into care, because they just couldn’t cope physically or emotionally with those outbursts, those mood swings.

What would your advice be to dementia carers?

SS: Embrace our reality. It’s not going to change anything. You don’t even have to have a conversation with us. You could change the subject.

What do you want people to know about how you’d like to be treated?

SS: I don’t want sympathy. If I’m with Sheila somewhere, don’t talk to Sheila about my condition. Talk to me about it.

Have you planned ahead?

SS: Sheila and I have made all sorts of plans. Knowledge is power, which was what you said in your magazine [in the first issue]. I use that in my talks a lot, because so many people say, ‘Oh, I don’t think I’d want to know about the future’. Well, if you don’t find out, then it’s actually rather selfish. Because your partner is going to be affected, they will see the change in you but not know how to help. If you know you have dementia, it doesn’t mean you’re going to die tomorrow. I spent the first 18 months waking up every morning thinking, ‘Do I feel any different?’ Well, for me, it’s very gradual. And yeah, I am changing.

Do you worry about what will happen in the future?

SS: I worry much more about Sheila than I do myself, because she is the one who will be seeing it. And I may well be completely unaware of how I have deteriorated.

Are you living in the now?

SS: Definitely – one day at a time. None of us knows what’s going to happen tomorrow. Although I’ve got this diagnosis, one of my nephews described it as a ticking time bomb that might never go off. Because I may stay like this and be run over by a bus, or I may stay like this and die from something else. And worrying about it would only add to my isolation. My family are wonderfully supportive. DH

Keep your loved one safe... and found

Worried about the risk of wandering? Keep your loved one safe and gain peace of mind, with MedicAlert's Safe & Found programme

This programme is kindly sponsored by The McLay Dementia Trust, and match-funded by MedicAlert to support people living with dementia in the UK. This sponsorship supports those living with all types of dementia to access the MedicAlert Safe and Found programme.

For more information, please scan the QR code or visit www.medicalert.org.uk/mclay-dementia-trust

If your loved one lives alone and wants to remain independent for as long as possible, you may respect their wishes but worry about them. Getting lost can be a common occurrence when the person's dementia takes hold.

MedicAlert, the leading charity dedicated to ensuring the safety and wellbeing of a person with medical conditions and memory loss, is proud to introduce the Safe & Found programme, a much-needed solution designed to assist those living with dementia and cognitive impairments to reunite with their families safely. With approximately 40,000 reported missing every year, this initiative is of utmost importance.

FREE MEMBERSHIP TO SAFE & FOUND

To support the launch of Safe & Found, MedicAlert can now offer first-year MedicAlert membership FREE. Thanks to the generous sponsorship from The McLay Dementia Trust and match funding by MedicAlert, a person with dementia can experience enhanced safety, increased independence and a fuller life, while gaining invaluable peace of mind for both themselves and their caregivers. The programme helps to ensure a quick and safe return home, should they wander. Membership to the the programme offers 24/7 emergency support and the peace of mind this provides.

HOW DOES IT WORK?

On becoming a member of MedicAlert, you can complete and store your loved one's Herbert Protocol – the form used by police to narrow down a search for a missing person. Information includes the person's appearance, where they may go, details of previous wanderings and other vital details. With a Herbert Protocol saved by MedicAlert, police can access and circulate this information as soon as they are notified your loved one is missing.

PEACE OF MIND

The Herbert Protocol also provides peace of mind for your loved one if they become scared or confused when lost, because they won't need to recall any of their vital information to strangers. Simply wearing their MedicAlert bracelet, engraved with their vital information, offers helpers information to keep them calm – and their full details (including their Herbert Protocol) will be just a phone call away.

With the emergency helpline open 24/7, you can rest easy knowing MedicAlert is on hand to support you and your loved one should an emergency situation arise.

For more information, or to set up your MedicAlert membership, please 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/safe-and-found

'It's not the end of your life – it's the start of a new life'

Tommy Dunne was diagnosed with young onset dementia in 2011. Here, he tells us about his diagnosis, living for the present and how MedicAlert has given him back his freedom...

Music is an important part of Tommy's life

What were the first indications that you might have had dementia?

TD: Well, I was initially misdiagnosed with bipolar disorder. It took nine months to get a second opinion. During that time, I was on lithium tablets, which killed me, because you sleep for 15 hours a day – I changed into a zombie. We eventually got to see a top psychologist and, after numerous scans, he said I didn't have bipolar disorder, I had young onset dementia – Alzheimer's. I'd just turned 58.

It was presumably a shock. How did you cope?

TD: It took me about three years to get over it. You know, I was doing things differently by then. But then I thought, 'Sitting in the armchair is not good. I've got to do something.'

Tell us about Dementia Diaries – encouraging those affected by dementia to record their diaries. You've really started something that's taken off and inspired a lot of people.

TD: Yeah. I think the only people who can truly tell you what it's like to live with dementia are people who actually live it. It wouldn't make sense if you tried to describe what it's like to be cared for as someone with dementia, if you had no understanding of it. Some people think it's just caring for someone when you're making tea or something like that, but it's 24 hours a day, 365 days a year.

What would you like people to know about dementia?

TD: It's not the end of your life – it's the start of a new life. You don't go from being diagnosed with dementia one day straight into the latter stages of dementia. I want to take the fear out of it. I do grieve for the person I used to be, but the only thing I can do anything about now is the present. If I can help people who are newly diagnosed, that's going to make life better for them.

You mentioned you're not the same. How have you changed?

TD: It's like lockdown.

Lockdown gave everyone a taste of what social isolation is like. That's what it's like having dementia. You can't do the things that other people do every day.

You're writing music – that's great.

TD: Music is a great thing for people who have dementia, because it goes into the parts of the brain that are not affected by the dementia.

You're an ambassador for MedicAlert. Tell us a bit about that.

TD: MedicAlert promotes the use of Herbert Protocol which gives people more freedom, because it gives peace of mind (see page 15 for info). When people with dementia go out, they could get lost and not remember how to get home. Having our ID on file is great. It saves time and saves the expense of the police looking for you and getting a helicopter out. It's such a simple thing, yet a great idea. It gives me a feeling of safety.

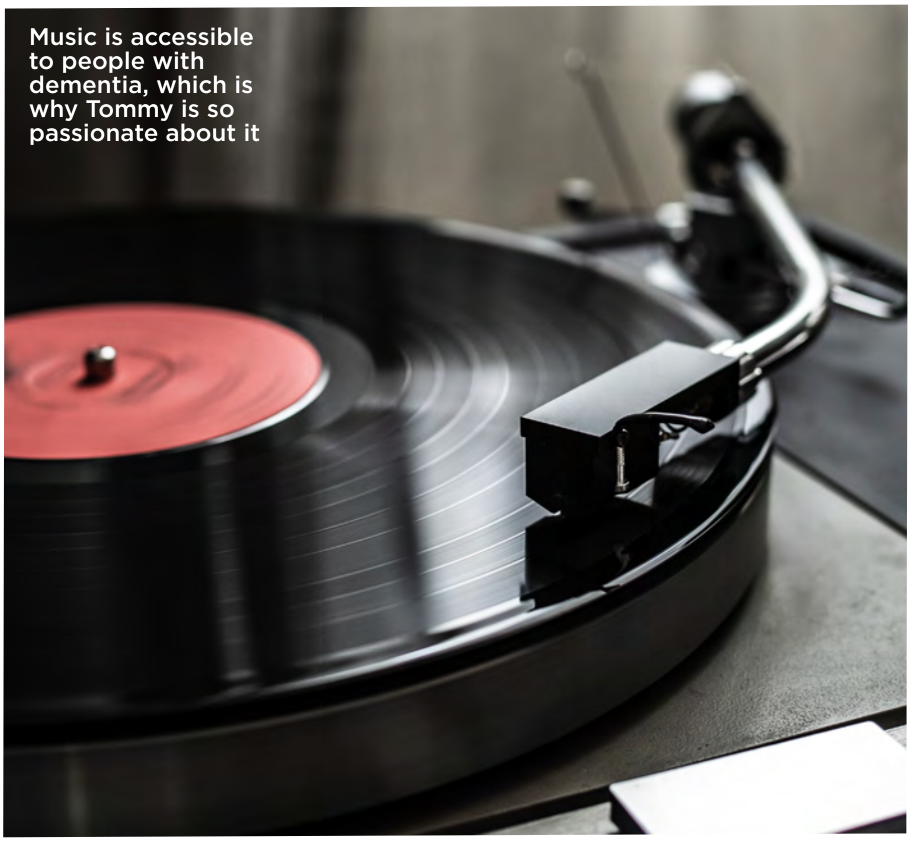
Are there any negative judgments or situations you've encountered?

TD: A few. Once, I was in a supermarket buying bread. At the till, I held up a card that says I have dementia and need help with money. The girl at the checkout looked at the card, then looked at me, and then got on the tannoy and said, 'Can you help, this man has dementia?' So the whole store heard it. Another time, I was on the bus and went to sit in a disabled seat. A man said to me, 'You can't sit there – it's for disabled people'. I said, 'I am disabled'. He said I didn't look it. People tell me I don't look as if I've got dementia. But what does a person with dementia look like? The media portrays it as an old person on a couch.

> 'I do grieve for the person I used to be, but the only thing I can do anything about now is the present'

Is there anything you would like to say to carers?

TD: I'd say please don't take anything we say personally. We may say some horrible things to you, but that's the dementia talking, not the person. We do love you, even though we don't say it. We think it – we might not say. And also, I want people – both those with dementia and carers – to know that they're not alone. Please don't try to go through dementia on your own. We need to talk about it and give each other hope. DH


Music is accessible to people with dementia, which is why Tommy is so passionate about it

More information

To learn more about MedicAlert and how it can offer peace of mind, please visit medicalert.org.uk/safe-and-found.

Dementia Diaries gives a voice to people with dementia, through audio and video diaries. To find out more, or to get involved, please visit dementiadiaries.org.

'I want everyone to appreciate what carers do'

Singer **Tony Christie** was diagnosed with dementia in January, but hasn't let it stop him from singing and remaining positive – he's also very appreciative of all carers. In this *Dementia Help* exclusive interview, Tony talks to **Jill Eckersley** about his life and his involvement in the campaign Music for Dementia

To celebrate Thank You Day earlier this month, Yorkshire-born singer Tony Christie released a special single called *Thank You for Being a Friend*. Some of Tony's own friends, including Sting, Nile Rodgers and former 10cc stalwart Graham Gouldman, joined him on the recording. The idea was to raise awareness of a campaign called Music for Dementia, and all proceeds from the sales of the single will support organisations celebrating and promoting the healing powers of music, especially for those living with dementia and their carers. Tony Christie himself – best known, of course, for his mega-hit, *(Is this the way to) Amarillo*, was diagnosed with dementia earlier this year, so this is a cause very close to his heart.

'If anyone deserves a Thank You, it's the country's unseen army of carers,' he says. 'So, this one's for you – all of you!'

NOT STOPPING SINGING

Music, Tony explains to me, has been his whole life, and he sees no reason why being diagnosed with dementia should stop him from doing something he has always loved. As a small boy, he would stand on a stool in his grandad's house and sing a song for sixpence!

'My grandparents came from Ireland,' he says. 'My grandma was a well-known fiddler and we still have my grandad's old squeezebox, which dates from about 1918. My dad played the piano and two of my granddaughters are studying drama, so performing is in the genes!'

Tony's musical career began in the Sixties, when he sang in working-men's clubs and later formed his own band. One of his early singles actually featured Led Zeppelin's Jimmy Page on guitar, and in the Seventies, his first big hit was *I did what I did for Maria*.


Tony with producer Graeme Pleeth and Andrew Gold

> **'At first, it was hard to accept that I had dementia, but I carried on doing everything I had always done – and that includes singing'**

EUROPEAN SUCCESS

Then came *Amarillo*, before the rise of punk made singers like Tony unfashionable in Britain, though he was hugely successful in Europe. He now has more than 40 albums, 70 singles and countless performances to his credit, including collaborations with fellow Yorkshiremen Jarvis Cocker and Richard Hawley.

CALMING EFFECT OF MUSIC

'When I was diagnosed earlier this year, the doctor told me I was lucky to be in the music business as it's known music can calm people down and help them cope, which is what the Music for Dementia campaign is all about. I have music playing in my kitchen, in my car and, of course, I am still making music myself. My diagnosis hasn't affected my voice – I'm still singing!' he says.

I asked Tony what made him feel there was something not quite right earlier this year.

'For years, I have been a fan of cryptic crosswords,' he says. 'Suddenly, I found I was having much more difficulty with the clues. And I also started to forget people's names – even people that I had known for donkey's years, so my wife talked me into going to the doctor. I was put on a strong medication called Memantine. At first, it was very hard to accept that I had dementia.

The team behind the charity single, *Thank You For Being a Friend*

But I carried on doing everything I had always done – and that includes singing. Every time I step onto a stage, it helps me. And I like the idea that something I love and have done all my life can one day be part of a cure for dementia.'

NO PLANS TO RETIRE

Tony celebrated his 80th birthday in April at a jazz club in London with some of his fans. He says that the idea of 'retirement' doesn't interest him one bit. In fact, when we spoke, he had just returned from Nashville, Tennessee, where he recorded not one, but two albums at the famous Blackbird Studios – where everyone from Taylor Swift and Dolly Parton to Pearl Jam and Neil Young have recorded.

> 'Some music is so beautiful, it takes you away from your problems – or it can just make you want to get up and dance!'

'American musicians are just incredible and I loved working with them,' he says. 'I am a workaholic anyway; I much prefer doing what I do to sitting around watching TV. One of the albums I've just recorded has my old hits, re-examined by the musicians I worked with who wanted to do the songs their way. For instance, *Amarillo* has become a blues number and one or two of the others have a gospel feel, which worked very well. My voice and my physical presence haven't changed, I have a TV screen onstage with the song lyrics on, as many performers do, so there's nothing to spoil a performance.'

MAKING A DIFFERENCE

I asked Tony how he had become involved with the *Thank you for Being a Friend* single.

'Music for Dementia had heard about my diagnosis and they approached me to ask if I would help,' he says. 'Of course, I said I would do whatever they wanted and anything they thought that would make a difference. The single was made to help those caring for people with dementia. I have met some of them now and can't tell you how much I admire them. They don't complain or brag about what they do, they are just wonderful people. If anyone deserves a "thank you", it's this country's unseen army of carers!'

Thank you for Being a Friend was written by the late guitarist and songwriter Andrew Gold, who sadly died in 2011. Andrew had been a friend of Tony's since working with him back in the 1970s, as has 10cc's Graham Gouldman. Tony says: 'We're all just hoping that it will raise awareness of what carers do, and also stop people being afraid to talk about dementia or even mention it!

ABOUT MUSIC FOR DEMENTIA

The aim of the campaign is to make music – both listening to it and playing it – an integral part of dementia care. MfD was started in 2018 and is supported by a private charitable trust called The Utley Foundation. A review of relevant research had looked at 22 trials, which showed that music-based treatments could improve symptoms such as depression and anxiety in people with dementia, as well as helping with behaviour problems, offering both patients and carers a better quality of life. Singing in a choir, playing a musical instrument and listening to familiar music from the past can all be beneficial. Find out more from musicfordementia.org.uk

I'm not thinking about "living well" with dementia. I am just carrying on doing what I've always done. I don't know why music is so uplifting. Some music is so beautiful it takes you away from your problems – or it can just make you want to get up and dance!'


Producer Graeme Pleeth with Sting

POSITIVE SUPPORT

Tony says it's the support of his wife and family that have kept him positive. He's been married to Sue for 56 years, and they have three children and seven grandchildren.

'Sue comes with me everywhere, and when we're at home, we often have the kids and grandkids staying,' he says. 'Sue and I are mates, always have been. She is a wonderful woman, and the family know they are always welcome. I don't think about what might happen, because I know they'll always be there for me.'

Tony says he is living proof of the power of music to help people living with dementia.


Tony with dementia carers who collaborated on the single

'I don't feel any different,' he says. 'So I am going to go on doing what I've always done until I feel my work is affected. I would say to anyone – if you can do it, then do it! I have had strangers stopping me in the street and thanking me for going public. I want people to know that dementia is not something to be ashamed of or something that can't be talked about. And I also want everyone to appreciate the amazing job that carers do. As for those cryptic crosswords, I have to admit I do struggle with them these days, and they are more of a challenge than they used to be – but I still try to give them a go!' DH

To see Tony live, go to www.tonychristie.com for his tour dates.

Taking part in a clinical trial

Do you wonder whether your loved one might benefit from new medication offered during a clinical trial, but feel unsure what the process involves? We spoke with **George Robinson,** global patient enrolment advisor at Re:Cognition Health, about what to expect...

Are your trials just for people with a formal diagnosis?

GR: Yes. However, we do have many patients who approach us without a diagnosis – people with suspected memory changes. We can diagnose them via our formal screening process, working alongside their GP or memory clinic.

Could you explain the screening process?

GR: Initially, you'll have a 20-minute pre-screening call with me or one of my team members, where we'll discuss the patient's eligibility. So, that will be any medication they're using and any other medical history that may be relevant. We also go through the information about the trial. After that, we arrange a screening visit, so the patient can come in and have a chat with our doctor, plus a blood test and sometimes an ECG. We also need absolute proof that the patient has Alzheimer's – that there's not perhaps a misdiagnosis. This may involve having a PET scan or, very rarely, a lumbar puncture to confirm the presence of plaque.

Besides a misdiagnosis, is there anything else that could mean the patient may not be eligible?

GR: The only big ones usually are things like an active cancer. A pacemaker may be incompatible with an MRI, so we just check everything's suitable to take part in a trial. Also, if patients are on blood thinners, such as warfarin, that can sometimes raise an issue, depending on the trial. The other thing, though, that affects which trial someone's suitable for, is the person's cognition level. If they are mild or moderate, then we have a range of studies, and we do have a trial for those who are more severe. So during screening, we're just trying to understand where that patient will fit.

Do you need consent from a partner or next of kin for the person to take part?

GR: The majority of the patients we bring onto trials have capacity to consent themselves. However, a study partner is always required.

This could be a relative, friend or neighbour – somebody who knows the patient well. For scientific research reasons, the study partner provides information on the person's daily activities. If the patient is more severe and does not have capacity to consent, then yes, we'd need the study partner to consent for them. But everybody, even if they are mild and can consent themselves, needs to have a study partner.

You have clinics across the UK – can people choose where they go?
GR: Of course – as long as the study is running there. We have no restriction on where patients can go – it's always their choice. It would only be if there was an eligibility reason that we might recommend a different clinic to their preference, but there's certainly no restriction on location.

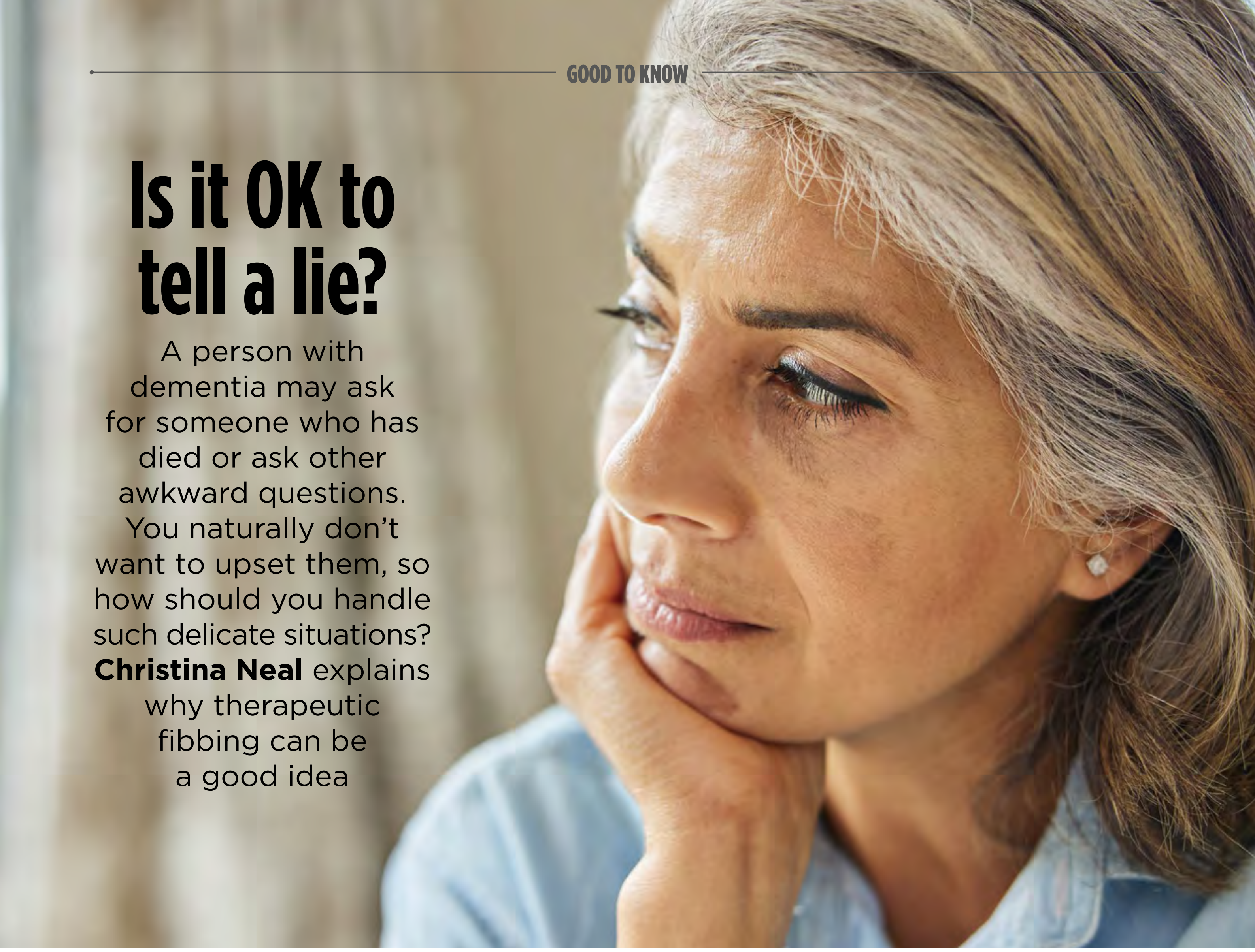
Do you cover travel costs?
GR: Yes – there should be no restriction on finances for a patient. Every UK patient has expenses completely reimbursed, so no patient should be out of pocket.

During a trial, will some people be on placebo drugs?
GR: Yes. All clinical trials the world over must have a placebo arm, simply to avoid the placebo effect. However, all our trials have what's referred to as an 'open label extension', which means that people will get access to the medication afterwards. A person on the trial can continue to take any prescribed medication.

> ***'The recruitment team, who do the pre-screening, have all had a close family relative with dementia, so everyone's compassionate and understanding'***

What if a person changes their mind once the trial has started?
GR: Everything involved in the clinical trials is completely voluntary. So, anyone can withdraw consent at any stage. You can drop out at any point – it's never a contract and never anything you're held to. Patients can have one visit, where they meet the doctor and figure out if it's the right thing for them, and then they never have to come back again. I think there's always a worry that the first visit means they're signing up to something. Or they may be worried that it might be a very clinical environment. However, I find so many patients email me after they have had their first visit to say they'd put it off for too long and they're so happy they've come in. The recruitment team, who do the pre-screening, have all had a close family relative with dementia, so everyone's compassionate and understanding. DH

New study information
Re:Cognition Health is launching a Lewy Body Dementia study, which is opening in July/August and is assessing the medication Neflamapimod to target the inflammatory response seen in Lewy Body Dementia. It would be an oral medication, with visits to the London clinic once every one to two months. If you would like further information about this, or any other trial, please call 0800 802 1030 to speak to a member of the friendly, compassionate team. For more information, please visit recognitionhealth.com.



Is it OK to tell a lie?

A person with dementia may ask for someone who has died or ask other awkward questions. You naturally don't want to upset them, so how should you handle such delicate situations? **Christina Neal** explains why therapeutic fibbing can be a good idea

Telling white lies can be an alien concept to anyone with a sense of honesty and decency. We're brought up to tell the truth, after all. Yet there are occasions when looking after a loved one with dementia that a small white lie can benefit the person.

Your loved one may forget that their spouse, pet or another close relative has died. They may ask about them. If you tell them that the person is dead, they will grieve all over again.

My dad had been dead for a number of years when Mum started asking where he was. The first time she asked, I made the wrong choice. I reminded her gently that he had passed away. She asked if she'd been to his funeral. I told her she had. She was very upset that she didn't remember losing him or being at his funeral. She cried and I felt awful.

NEVER AGAIN

I vowed never again to tell her that Dad was no longer with us. But what can you say when your loved one asks about someone who has died?

I got better at dealing with it. On another occasion, Mum rang me one day and said she was worried that Dad hadn't come home from work. I told her the traffic was terrible and then distracted her by changing the subject. Mum's concern was short-lived. The distraction worked.

'She asked where her cat was. Sadly, her beloved cat had died a few years ago'

On another occasion, I ran the London Marathon and went to visit Mum and show her my medal. She understood what I'd achieved, as she'd always loved watching the marathon on TV. She admired my medal and then asked if I'd told my dad about my achievement.

'Not yet', I told her. 'Make sure you do tell him,' she replied. 'He'll be ever so proud'. By then, my dad had been gone for eight years.

One day, she asked where her cat was. Sadly, her cat had died a few years ago. I pointed to the back garden and said: 'Look at the weather. Cats love the sun'. I'd try to avoid telling a direct lie, and would aim to distract her instead.

'Many professional carers will tell you there's no benefit in telling your loved one a person has died'

MINIMISE DISTRESS

Many professional carers will tell you there's no benefit in telling your loved one a person has died. Your goal is to minimise distress. If this means you have to distract the person or tell a white lie to spare their feelings, then it's worth doing. It even has a name – therapeutic lying or fibbing. It means telling someone something that isn't true or avoiding telling them something for their benefit.

DIFFERENT REALITY

The website, Daily Caring, points out that honesty isn't always the best policy when caring for a person with dementia. It goes on to say that the person's brain may experience a different version of reality.

'It depends hugely on the condition of the person,' says Sheila Marsh, who cares for her partner Sue, who has vascular dementia. 'It's really hard to make hard and fast rules about it, because every person is completely different. But the famous example of "don't tell someone that a loved one is dead if they forget they've died", which will make the person grieve all over again... it's better to say they've just popped out or they're not here at the moment. That is better than the person having the emotional turmoil of experiencing loss again.' DH

TIPS FOR DEALING WITH DIFFICULT QUESTIONS

- If your loved one asks to see or speak to someone who has died, give a response such as, 'Let's have a snack before we go,' or, 'they may have been delayed by traffic'.
- Distract the person. Answer their question and then move on quickly to another subject. Offer them a cup of tea or talk about something else.
- Remember, it's likely to be just a moment that will pass. A short while later, the person may forget they even asked the question.
- Don't feel bad about fibbing if it's the right thing to do for your loved one.

Coping with a loss of interest in food

It's a challenging situation – a person with dementia needs a proper diet for their wellbeing, but may have lost their appetite or only be interested in eating the same meals. **Christina Neal** has some valuable suggestions

Where dementia is concerned, taste buds diminish over time and food preferences can change. In her book, *What I Wish People Knew About Dementia*, author Wendy Mitchell talks about how dementia has changed her relationship with food. Wendy, who has early onset dementia, says decision making can be complicated when you have dementia. This, of course, means choosing what to eat can be a challenge. Wendy says that she often chooses the same meals, as it's easier.

'I don't get sick of meals like others might,' she says in her book, 'simply because I don't remember that it is the same one I had the night before.'

So if your loved one wants the same food, or you are worried that their diet is limited in variety, it's easy to see why.

It's estimated that 50 per cent of people with dementia will have problems with eating, drinking or swallowing. As the condition progresses, this becomes more common. Here are some reasons why your loved one might have lost their appetite...

DEPRESSION

Depression is fairly common in those with dementia, and loss of appetite can be a symptom. If you suspect your loved one is depressed, speak to their GP, who may be able to prescribe medication or offer an alternative talking therapy.

COMMUNICATION PROBLEMS

Your loved one may no longer be able to communicate that they are hungry, that they don't like the food they have been given, or that it is too hot or cold. Be patient.

Offer a simple choice of foods, or use pictures to explain the meal.

TIREDNESS

If a person becomes tired, they may give up on a meal halfway through. If you suspect this may be the case, monitor their patterns and behaviour, and attempt to serve meals or snacks when they are most alert.

PAIN

Could the person be refusing food because they are experiencing dental pain? Could they have a problem with their dentures, or are they experiencing sore gums?

CONSTIPATION

Constipation can make someone feel bloated, meaning their appetite dwindles. If you suspect this is the case, encourage them to drink plenty of water and offer fibre-rich foods. If the problem persists, consult their GP.

LACK OF PHYSICAL ACTIVITY

If your loved one has become accustomed to a more sedentary lifestyle, they simply may not be using enough energy to become hungry. An exercise routine doesn't need to be challenging. Encourage them to go on some gentle walks if they can or, if this isn't possible, see if they would like to take up a hobby, to help them burn some mental energy instead.

> *‘A person with dementia may look at an item of food and no longer recognise it’*

LONELINESS

It could be that mealtimes are a lonely experience.

‘MUM FAILED TO RECOGNISE FOOD’

During the later stages of my mum's dementia, she struggled to eat. I had to cut food up for her and sit with her while she ate to encourage her. She was easily distracted. If anyone made a noise, causing her to stop eating and turn around, it was difficult to get her to resume eating again. One day, I went to visit her and she folded up a napkin into a V-shape, like a small sandwich, and went to eat it. I grabbed it from her hand before she had the chance to bite into it. She told me off for taking her sandwich away. I didn't explain it wasn't food – I simply told her the "sandwich" was out of date and replaced it with some fruit. This highlighted to me that a person with dementia can fail to recognise food, especially in the later stages, so putting a meal in front of them and leaving them to it isn't a good idea. Once a week, I'd take my mum for a pub lunch and she'd enjoy salmon (her favourite food) and a small glass of wine. This seemed to reignite her interest in eating well.

Try to keep non-food items, such as napkins, off plates

This could make your loved one less inclined to want to eat. If they live and eat alone, why not take the time to sit and enjoy a meal with them? It could be all the encouragement they need.

LARGE PORTION SIZES

Your loved one may feel daunted if you put a large plate of food in front of them. They may not recognise certain foods or it may be tiring for them to contemplate eating a large meal. Smaller meals or regular healthy snacks may be a better option.

WHAT CAN YOU DO?

To make eating and drinking easier for a person with dementia, you could try swapping cups and saucers for mugs, or plates for bowls. Wendy Mitchell says this makes eating easier.

During mealtimes, try to limit distractions – avoid noise and allow the person plenty of time to eat. It's also important to understand that your loved one may not recognise the food on the plate in front of them.

> 'Why not take the time to sit and enjoy a meal with your loved one?'

White rice on a white plate can be confusing – so try using a coloured plate. Research from Boston University showed that a person with dementia may eat 25 per cent more food when eating from a red plate than when eating from a white plate. This could be because of how a person with dementia sees food on a plate. Colour may also help to stimulate the person's interest in food. DH

Helping your loved one prepare a meal and eating it with them could reignite their interest in food

PROBLEMS WITH SIGHT

It's important to be aware that dementia can affect a person's sight. This happens because, although we see with our eyes, our brain has to process what we see. When it comes to dementia and food, this can cause all manner of problems. A person with dementia may look at an item of food and no longer recognise it, or they might struggle to identify between food and non-food items, resulting in them trying to eat a napkin, for example, or trying to cut up the pattern on their plate. If they seem unsure as to what they should be eating, offer them gentle guidance. Try to keep all non-food items, such as napkins, off the table, and serve food on plain plates (blue or red can work well), so that they can more easily distinguish the food in front of them.

Better health for your loved one

Brain and mind experts **Re:Cognition Health** are offering free clinical trials to those in the early or mid stages of dementia, which could significantly benefit their quality of life

There is no cure for dementia, and previously medication could only manage the symptoms of the disease. However, new medications coming onto the market have shown promising results, which means getting a diagnosis and access to the right treatment early on could make a real difference.

If your loved one is in the early or mid stages of dementia, they may be eligible to take part in a clinical trial for a drug that could slow down the progression of the disease.

Award-winning brain and mind experts, Re:Cognition Health, offer places on clinical trials for those living with Alzheimer's and mild cognitive impairment.

WHAT'S THE PROCESS?

The first step is to have a quick pre-screening call with a member of the patient engagement team, to check which study would best suit your loved one.

The next step is then to have an on-site screening consultation with an experienced doctor, which can be done in one of several locations, including offices in London's prestigious Harley Street.

If your loved one is eligible to take part in a trial, they will receive new medications and interventions that could be life-changing and lead to a better quality of life.

NEW TREATMENTS

The trials are free, and as a study volunteer, your loved one will gain access to new treatments for memory loss. As an added benefit, they will also receive a thorough health check, including MRI scans and PET scans, at no cost, with their GP kept in the loop. In addition, travel fares will be reimbursed, so that they won't be out of pocket. DH

For more information,
visit recognitionhealth.com
or call 020 4571 8530

MEMORY CLINIC

If your loved one hasn't had a dementia diagnosis and has general concerns about their memory, it's worth considering Re:Cognition Health's Memory Clinic. The clinic is suitable for anyone in mid or later life who is having significant memory problems and keen to understand why. It's also suitable for anyone who wants to find out what their brain health is like and what they can do to reduce their risk of developing dementia. Visit recognitionhealth.com/mentalhealth/privatememory-clinic/

Coping with incontinence

Up to 70 per cent of people living with dementia will experience incontinence issues. Fortunately, there are ways to reduce the risk or cope when it occurs. **Dr Carol Sargent** has some advice

Incontinence is something that many of us worry about, and people living with dementia are no different. If your loved one is suffering from incontinence, you may be wondering how you can raise the subject without embarrassing them.

Firstly, try to mention it as something happening to you or to other people without dementia. Reassure the person that incontinence is not simply an inevitable part of dementia, but is actually something that could happen anyway as you both grow older.

LOOK AT OTHER CAUSES

If an accident happens, the first thing you need to do is identify the cause with the person's doctor. Your loved one could have a urinary tract infection, constipation because of a poor diet, problems with prostrate function in men, or a side effect of certain medications.

Indeed, early in my mum's journey with dementia, she was prescribed Aricept (medication to manage dementia symptoms). She became very anxious and started to go to the toilet frequently. Eventually, I discovered that urinary incontinence can be a side effect of this particular medication. Sure enough, when her prescription was stopped, her anxiety and obsession with going to the toilet disappeared.

HOW DEMENTIA CAN CAUSE INCONTINENCE

If there is no other cause, then dementia is likely to be altering messages from the brain, which can lead to incontinence. These changes can include:

- No longer recognising the feeling of needing to go to the toilet
- Not being able to get to the toilet quickly enough, because the person can't find the loo
- Not being able to judge how long it's going to take to get to the toilet
- Not being able to get their clothes off easily to go to the toilet
- Not having the mobility to get there
- Not being able to communicate that they need the toilet

HOW TO DEAL WITH THE PROBLEM

- Encourage your loved one to eat a healthy balanced diet that contains enough fibre.

> *‘Establish a routine for both of you going to the toilet’*

Consider introducing healthy foods in different ways, such as having prunes in sticky toffee pudding, or barley and lentils in a bowl of soup.

- Ensure the person drinks enough fluid – ideally eight glasses of water daily. If drinking is difficult, then consider giving the person fruits with fluid, ice cream or jelly drops.
- Limit things that can irritate the bladder, such as caffeine, fizzy drinks and alcohol. Switch to decaffeinated tea or coffee after 6pm.
- Limit foods that can irritate bowels, for example, spicy foods or too much fibre.
- Get checked out for any food allergies.
- Establish a routine for both of you going to the toilet after every meal, before you go out, when you arrive somewhere new and before going to bed.

GET THE RIGHT CLOTHES

- Buy the person clothes that are easier to undo or remove.
- Encourage the person to wear pop socks rather than tights.
- Encourage them to wear waists that are elasticated.
- Get the person to wear loose-fitting clothing that is the correct size.

MAKE SURE THE TOILET IS EASY TO FIND

Ask for seats near a toilet when you go out, use night lights at home and consider having a portable urinal or commode at home for nighttime use.

CONTINENCE PRODUCTS

If none of this works, your loved one could use continence products. When you are out together, have a bag with a lightweight change of clothes and wipes.

You may decide to use a waterproof mattress cover. Some pure plastic ones can be noisy and hot for people, making it difficult for them to sleep. On our holidays, we used high-quality waterproof covers with thick terry towelling topping. These were also easier to wash and dry.

Dry Nites is a product that can reduce washing. These disposable, soft mattress toppers come with double-sided sticky tape. For somebody who is not a restless sleeper, they can be stuck on top of the sheet across the bed, and for others, under the sheet, stuck on top of a waterproof mattress cover.

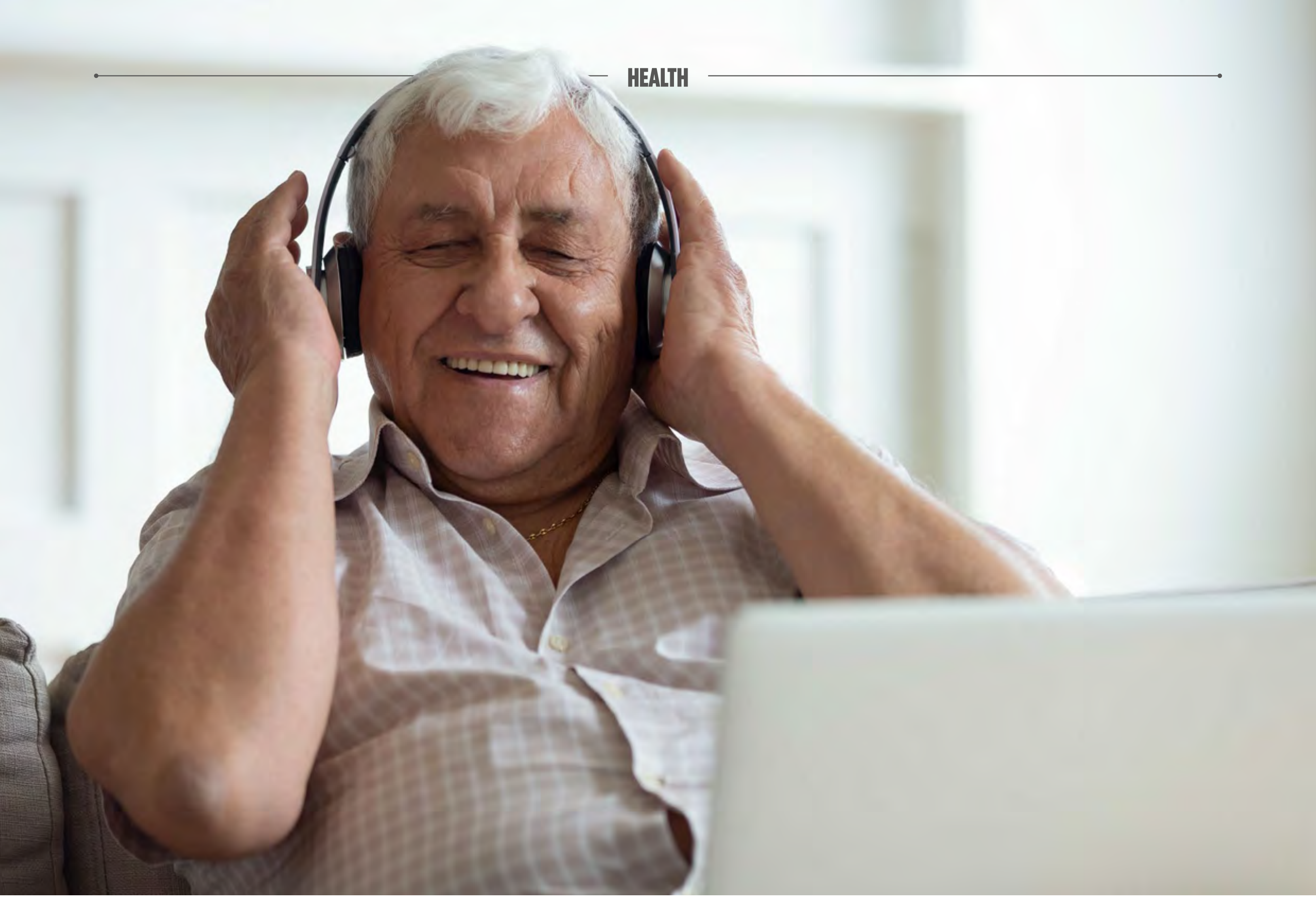
Male continence sheaths can be worn over the penis and attached around the leg. I have seen these revolutionise the lives of some of our male holiday guests, but they aren’t widely provided on the NHS.

USING PADS

For women who have had children, you can highlight the need to wear pads when they gave birth and how much easier this was for them.

Incontinence pads and pants can be purchased without VAT or provided free by your doctor. It’s important to get the right style, size and absorbency. Different types of pads and pants can have different degrees of comfort for each individual, so you might need to try a few different types.

More information
Dr Carol Sargent is a scientist and consultant specialising in dementia-friendly holidays.



The power of music

Make life a little better with the healing power of music therapy, says **Angelina Manzano**

If someone told you there was a tried-and-tested way to improve the mental and physical health of your loved one, would you not try it? This is no snake oil. It's easy, it's cheap (or even free) and its healing power is right at your fingertips…

Music is powerful, with research showing it can reduce anxiety, release feel-good hormones and improve cognitive skills. Its popularity as a means of treatment for dementia patients is on the rise, thanks to resources such as Playlist For Life, BBC Music Memories and the Music for Dementia campaign.

'Music is neurologically very unusual, because of the number of parts of the brain it can affect,' explains Sarah Metcalfe of The Utley Foundation, the charitable trust behind the Music for Dementia campaign. 'It means that if you play music, if you sing music, or take part in a musical event or activity, you can actually connect with somebody even though they have dementia. And what we see is that it can bring back memories, affect feelings, manage anxiety and reconnect people.'

Educating clinicians, patients and carers is the first step in mobilising music as an accepted treatment and means of improving the quality of life for those with dementia. Sarah says: 'Once people know that music can help, and they understand why it helps, they become aware of the different things they can try. We know that there are lots of issues facing social care and dementia, but this is one little thing that could make life a bit better on a day-to-day basis.'

BOOSTING MEMORIES AND RECONNECTING

Sarah has insight into one of the most devastating ramifications of dementia. 'Everybody knows that dementia is about memory – but what a lot of people don't realise is that dementia is also an isolating illness. The person becomes more and more withdrawn, and communication becomes a lot more difficult. Music can break down that isolation.'

Although your loved one may become more withdrawn, they are still the same person inside, and no one knows them better than you, so you are best placed to be aware of their musical likes and dislikes. Creating a bespoke playlist featuring their favourite tunes will help you to reach them and overcome that isolation.

Music can break down the sense of isolation

There are plenty of Apps to help you do this, such as Spotify, Amazon Music, YouTube and iTunes, and resources such as Playlist For Life and BBC Music Memories are invaluable, as they also offer advice and support. If you're not technologically savvy, it really doesn't matter. You can achieve the same results through the radio, music channels or your old CD/vinyl collection. The beauty of music is that it's easily accessible, and comes in many shapes and forms. I remember my own mum's final trip down from Aberdeen to visit me in Sussex. She was in the early stages of dementia and the journey had left her disorientated. That first evening, I helped her into the bath and knelt on the floor beside her as we scooped up handfuls of foam and blew it from the palms of our hands as I sang, *I'm Forever Blowing Bubbles*. Her distress melted away. It didn't matter to her that I only knew the chorus. It was magical – and she was filled with joy in that moment.

> **'The beauty of music is that it's easily accessible, and comes in many shapes and forms'**

DON'T DISMISS LIVE MUSIC

Whatever your musical taste, live music is one of life's great pleasures and it brings people together in more ways than one. Phenomenally, musical legend Glen Campbell was able to tour despite his dementia diagnosis. Singer Tony Christie continues to tour and stay positive to this day (see our exclusive interview on page 18).

For someone with dementia, being in a situation where there is live music can be overwhelming.

Music can be a wonderful diversion if you're having a tough day

THE BENEFITS OF MUSIC

Although music cannot magically return your loved one to how they were, research has shown that it does have an undeniable positive effect on physical and mental health...

> It improves cognitive skills (including memory and speech).
> It triggers the release of feel-good endorphins.
> It reduces feelings of anxiety, depression and distress.
> It helps reduce heart rate and blood pressure.
> It engages the person, reducing their isolation.

Crowds of strangers, an unfamiliar environment, and objects and situations which are run of the mill for most people could easily become distressing or hazardous. However, more and more venues and organisations are becoming aware of the importance of music and its ability to help people with special needs and cognitive conditions.

So, if you think that live music is something that your loved one could still enjoy, then do check out your local venues to see if there are any dementia-friendly performances or classes available, or see if your local health service offers any suitable music-based groups.

INTRODUCING MUSIC THERAPY

Sarah Metcalfe, of the Utley Foundation, recommends these three easy steps to integrate music therapy into your daily routine...

> *'Music is neurologically very unusual, because of the number of parts of the brain it can affect'*

1. Singing is good for us. It helps our mood, our breathing and it helps you be in the moment. It's very difficult to think about something else if you are singing. If you're having a tough day, why not sing a line or two from a favourite song, as this can actually divert and start a whole other conversation.

2. A very interesting thing to do is to just get on your phone or laptop and think of one song that you think your loved one would enjoy – or that you would both enjoy! Start with that one song, then think 'What's the next song?' Have a musical browse.

3. We speak a lot about how to use music to help the person with dementia, but music can also be valuable for the person who is living alongside them. It's important to do anything you can to look after yourself. Take time for your own music and enjoy it.

More information
Visit Music for Dementia for further information on the benefits of music for a person with dementia.

COMING NEXT ISSUE...

SELF CARE SPECIAL

- **Key ways to find time for yourself**
- **Easy health hacks to boost your energy**
- **Getting emotional support as a carer**

Is your loved one getting all the financial help they need?
Your essential guide to the support available

What do when your loved one refuses to accept help
Dealing with the situation in a sensitive way

Dementia and hallucinations
What causes them, and how to cope

How to make hospital visits less stressful
(And ways to avoid them in the first place)

ON SALE
29
SEPTEMBER

HELPING CARERS COPE
DEMENTIA HELP

For more advice, visit **dementiahelpuk.com**

What is an Advance Decision?

If your loved one is in the early stages of dementia, they should consider making an advance decision, so you are clear on the type of care they would like to receive in future. **Christina Neal** explains what it is and how to get one done

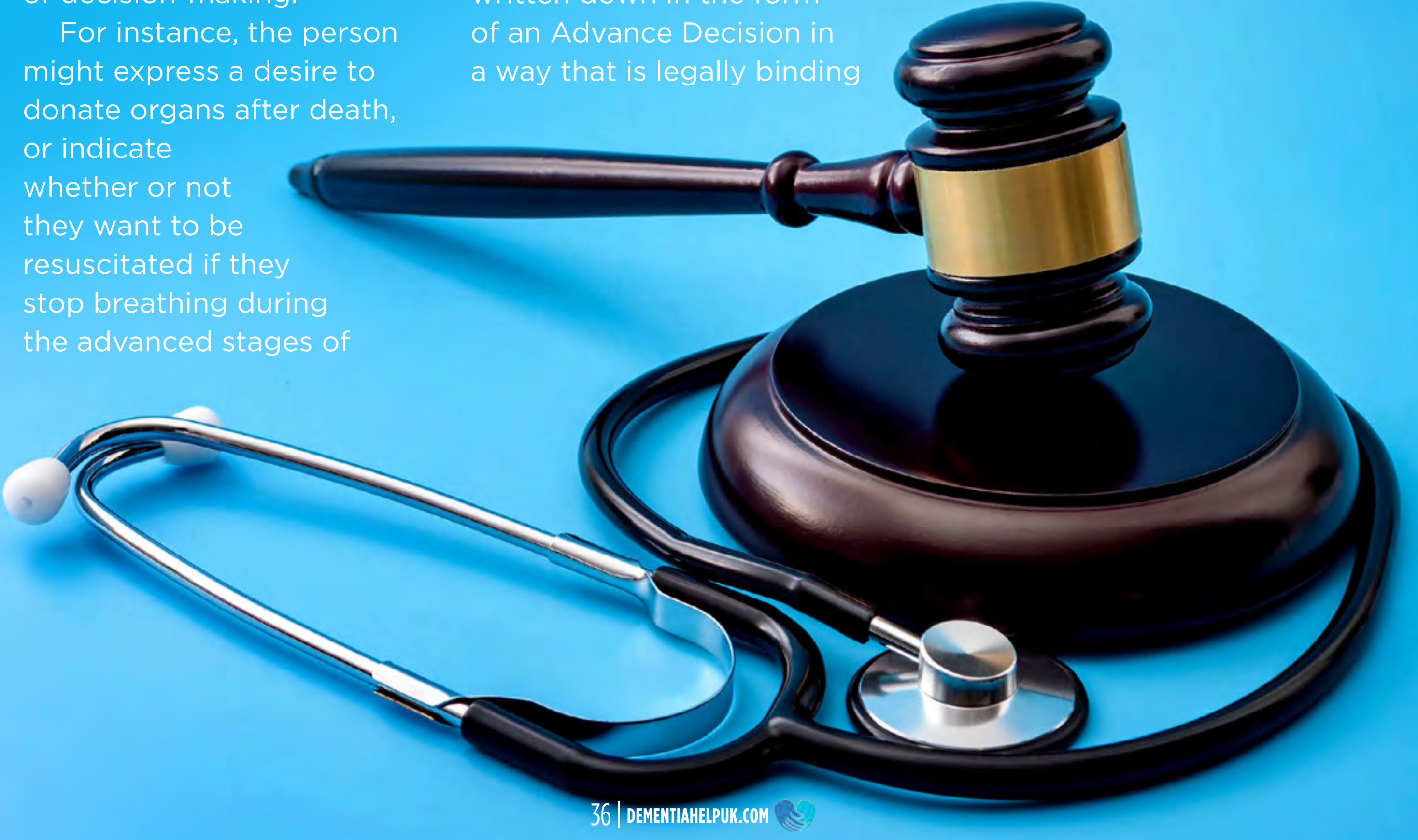
An Advance Decision provides peace of mind that your loved one's wishes will be respected in the future, where care and treatment are concerned. An Advance Decision – also called an Advance Directive – is a legal document that specifies an individual's preferred treatment and end-of-life care, in the event that they become unable to communicate their wishes. It's essential to create an Advance Decision while the person is still capable of decision-making.

For instance, the person might express a desire to donate organs after death, or indicate whether or not they want to be resuscitated if they stop breathing during the advanced stages of dementia. An example of a more specific decision might be declining antibiotics for pneumonia during late-stage dementia. While it might seem morbid, preparing an Advance Decision ensures that the person's wishes are respected.

Solicitor Gary Rycroft, from Joseph A Jones Solicitors, says: 'We are all entitled to refuse medical treatment. If we are lacking capacity, if we can't communicate our wishes to the medical staff, having it written down in the form of an Advance Decision in a way that is legally binding means that the doctors will honour your wishes. We all have our own views of what's important to us, and the Advance Decision is a way of writing down your views for the future, for a time when you can't communicate them yourself.'

WHEN CAN AN ADVANCE DECISION BE USED?

The decision will only apply to the medical situation that caused it, and it can only be put into effect if the person loses decision-making capacity.



The medical profession must follow your Advance Decision, provided it is considered that it was made when you were deemed to have mental capacity and also that the decision is applicable. This means that the wording must be relevant to the medical circumstances that have arisen. The advance decision must be clear and specific. It may not be used when you are still capable of communicating and have capacity. You may wish to discuss your Advance Decision with your GP before you write one, and if you are still unsure or have concerns, then it's worth discussing it with a solicitor. Your loved one can write an Advance Decision to communicate their wishes about medical treatment. To ensure the person's wishes are met, it's best to describe specific scenarios and consult with the person's GP. You can speak with a solicitor, though you don't have to. Once the person has written their Advance Decision, be sure to inform their GP and provide them with a copy.

An Advance Decision should always include the following information:

- The person's name
- Their address
- Their date of birth
- The name, address and phone number of their GP
- The date and signature

To ensure the validity of this document, arrange for someone over 18 to sign and witness it. If you don't use a solicitor, but have previously employed one for other matters, consider giving them a copy for safekeeping. Keep in mind that laws vary in Northern Ireland. Rest assured, taking these steps will help protect your important legal documentation.

Making decisions about life-sustaining treatment can be daunting, but with the right support and planning, your loved one can have peace of mind. DH

'It's essential to create an Advance Decision while the person is still capable of decision-making'

Pet Peace Of Mind

Is your loved one worried about how they might take care of their pet in future? Blue Cross provides a service that aims to match pets with new owners when the need arises. **Christina Neal** speaks to Blue Cross to find out more...

Pets can be a great source of comfort for a person with dementia. My mum loved her tabby cat, Foxy, and enjoyed caring for her. Looking after Foxy gave Mum a sense of purpose. Sadly for Mum, her cat died before she did, but it was some comfort to know that Foxy was well cared for throughout her life. Pet owners with health issues may worry about what might happen to their pets if they have to go into care, become ill or were to pass away.

Animal charity Blue Cross has a service called Pet Peace of Mind where, should you die before your pet, they will do all they can to ensure the animal is safe and loved. The service aims to match pets with new, loving owners and will care for the pet until a new owner is found.

They will accept dogs, cats, horses, rabbits, guinea pigs, chinchillas, degus, mice and rats onto the service, but you need to apply to be on it.

We spoke with Emma Hinds, Assistant Legacy Officer, from Blue Cross, who told us all about it...

Knowing your pet will be cared for is so reassuring

Tell us about the service.

EH: Becoming unwell, ageing, and death are topics that people don't really like talking about, especially when it comes to their pets, because we know how important pets are to people. But it's important to be prepared, so that your pets can be safe when you're gone or unable to take care of them. Pet Peace of Mind is a service through an application process. We ask people to fill out a form.

How many pets are you able to register?

EH: We accept four pets per person per household. If someone had any more than four, it would obviously be very difficult to find homes or space in a centre for so many.

So we have a cap on it. But it's done case by case. So if there were circumstances where someone had five cats and no family, we would look at it.

What information has to be provided?

EH: On the forms, we ask for information about the pet and their medical history, and we need their microchip details. That means we're ahead of the game should they come into our care.

How does the registration process work?

EH: We will review each application. One of the stipulations is that horses, cats and dogs have to be microchipped. That's the legal requirement. Once they're accepted onto the service, we'll send them a welcome pack. They'll receive some cards to go in their purse or wallet, or on display in their home, certificates to keep with their paperwork and some collar tags that they can put on their pets' collars. They will also be given some suggested wording that they can hand to their solicitor or their next of kin, just so that people know what their intentions and plans are, should anything happen to them.

Blue Cross will step in whether your pet is large...

...or small!

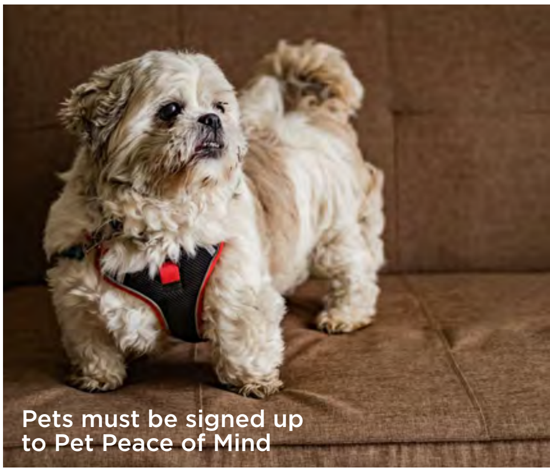
Do you have to pay for the service?

EH: It's completely free. It's not dependent on a legacy or a gift. It's just something we try to encourage, because it's so important. We've had situations where people haven't made plans for pets, and it's left for the family to find someone to care for them. That can be really stressful at an already stressful time. If they want to leave a gift in their will, that would be much appreciated, or if they want to leave a donation, that's completely a matter for them. But it's not essential.

> 'It's important to be prepared, so that your pets can be safe when you're gone or unable to take care of them'

What happens when a pet has been accepted onto the service?

EH: They'll stay on our records. Quite often, we'll have people who have been diagnosed with early onset dementia, and they may have been on the service for a while and will have to go into a care home. The family will make contact with us to say that this is what's happening, and we would step in, take the pets and put them up for re-homing. It can be any sort of situation. So it could be if the owner dies. We've had cases where the person has been terminally ill at home and wanted their pets with them at home until the very end because it's comforting for them. But it gives them that peace of mind to know that when they are no longer around, or can no longer care for their pets, we are there. We will step in and help find them a home.



Pets must be signed up to Pet Peace of Mind

More information

For more details on the Pet Peace of Mind scheme, call 0300 777 1910, email petpeaceofmind@bluecross.org.uk or visit bluecross.org.uk

When your loved one can no longer live alone

Are you looking after a loved one who lives alone? If recent events have made it clear they can no longer safely live on their own, it's time to consider full-time care. Christina Neal has some advice

I remember the day well. It was 10pm, and I decided to give my mum another call before she went to bed. I'd already spoken to her several times that day. She didn't answer the phone. After calling several times, I grew concerned. I lived more than an hour away from her and wondered what to do next. I waited a bit longer and tried again. This time, she answered, sounding angry and frustrated. I asked if she was OK and said she hadn't answered earlier.

She shouted at me for 'checking up' on her. She told me she was a grown woman and didn't have to answer to me. She said she'd gone out, and it was up to her how she led her life. I kept calm. I was used to her mood swings. I told her I was glad she was OK and said goodnight.

The next day, I found out what really happened. Her neighbour rang me and said Mum had been found outside her house by another neighbour at 10pm, locked out, without a coat, while holding an empty tea cup. Mum didn't know why she was outside. The neighbour who found her didn't have my contact details, so they had phoned the police. The police came along and managed to get Mum back inside without breaking her front door down. This happened in December. Mum had no recollection of it the next day.

> ***'Her neighbour rang me and said Mum had been found outside her house by another neighbour at 10pm'***


A live-in care worker is an option, as they'll be with your loved one most of the time

It was the final straw. Mum had been battling with me over this, but I knew things had to change. She could no longer live on her own.

A 'FINAL STRAW' MOMENT

You may have a similar 'final straw' moment with your loved one, when you realise it's inevitable for the person to either move in with you, have a live-in carer or move into a care home. Or you might live with the person and be their carer, but finally reach the stage of being unable to cope with their increasing needs.

You can't always make the person happy, but you have an obligation to keep them safe.

It may take something like a specific event or a fall for you to conclude they can't be alone. Or the person may be in hospital, and you know they can't return home until they have consistent care. There will come a time when what your loved one wants and what is best for them could be two different things. If you want the person to live in a care home, your hands may be tied. If they have made an Advance Decision that clearly states they don't want to go into a care home, then you do have a duty to act on their wishes and do your best to keep them out of one until it's the only safe option.

You may have considered these options:

- Sheltered housing or sheltered accommodation.
- The person coming to live with you.
- A residential care home.
- A nursing home.
- A live-in care worker – this may be an option, as the carer will be with the person most of the time, usually on a rota basis over a weekly, fortnightly or even six-weekly basis, to comply with working time rules for breaks.


Your loved one will adapt to a care home environment

SHELTERED ACCOMMODATION

When it comes to looking for sheltered accommodation, there are two types available – sheltered accommodation and extra care sheltered accommodation.

A sheltered housing facility will provide 24-hour support from a warden on-site or via phone line support.

With extra care sheltered accommodation, there are likely to be additional facilities, such as a communal café or a care scheme that the person would have the option of buying into. For a person with dementia, sheltered accommodation may only be viable as a short-term solution, because their needs are going to increase over time.

LIVING WITH YOU

It's easy to feel that you should be the one to take care of the person, but this may not be practical if you work full time, as you may struggle to take care of the person during the day while you're working.

Remember that the nature and extent of the care will grow. In the early stages, you might only need to do domestic chores, prepare meals and prompt the person to take medication. As things change, however, you will need to be comfortable with personal care, such as bathing and taking the person to the toilet.

A CARE HOME

Moving the person into a care home or a nursing home could be a good solution, but it's essential to do your research and check out as many different homes as you can. Make sure that the home you have in mind has a good rating from the Care Quality Commission (CQC) – visit cqc.org.uk for details. Age UK also has an extensive guide on its website on choosing a good care home.

If you can't care for the person yourself, don't dwell on it. Work on finding a solution and try not to feel guilty. You may want to move the person into a care home. In time, they should adapt to their new environment. Remember, ultimately it's about keeping the person safe and finding the best solution for them – and for you, too. DH

'It may take something like a specific event or a fall for you to conclude they can't be alone'

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

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