

**NEW!**



HELPING CARERS COPE

# DEMENTIA HELP

ISSUE 1

## COPING WITH CHALLENGING BEHAVIOUR

ESSENTIAL TIPS ON MANAGING MOOD SWINGS

**KEEPING YOUR LOVED ONE SAFE AT HOME**  
THE DOS AND DON'TS OF FINDING THE BEST SUPPORT



## '8 THINGS I WISH I'D KNOWN ABOUT DEMENTIA'

WHAT THE EXPERTS DON'T ALWAYS TELL YOU AT THE START



## 'I DREADED THE FIRST TIME BARBARA WOULDN'T KNOW ME'

SCOTT MITCHELL ON CARING FOR DAME BARBARA WINDSOR

## HOW TO PREPARE FOR THE FUTURE

YOUR HANDY GUIDE TO LASTING POWER OF ATTORNEY

## DEMENTIA AND SUGAR CRAVINGS

HOW TO STOP YOUR LOVED ONE FROM OVEREATING

## You're Not Alone

**Am I doing enough? Is Mum OK on her own? Should I be visiting more regularly? Has she eaten properly? What will I do about paying for her future care?**

All of these questions and more raced through my mind regularly when caring for my late mum, Hazel, who had vascular dementia. I was her main carer – I managed her daily needs, ensuring she had her medication, keeping her cupboards fully stocked with nutritious foods (while disposing of the out-of-date ones) and taking care of her paperwork. I was also juggling a busy job as a magazine editor.

### Knowledge is power

It was exhausting, rewarding, heartbreaking, exhilarating and draining. There were so many things I wish I had been told at the start of Mum's diagnosis. That's why I have chosen to launch *Dementia Help* magazine. Being a carer is isn't easy, but the more you know about dementia, the better placed you are to provide the best possible care. I genuinely believe there is a real need for a trusted source of advice and information written by those with first-hand experience of being a carer. I hope this magazine is it!

### Much-needed support

Speaking of support, I'm hugely grateful to Scott Mitchell, widower of Dame Barbara Windsor, for taking the time to give *Dementia Help* an exclusive interview. Read about Scott's life with Barbara as her carer on page 18. His support has been invaluable.

I hope you find the magazine useful and would love to hear from you. Please feel free to share it with anyone else who would benefit.

Sending you love and best wishes...

*Christina*

**Christina Neal**

Founder & Editor  
Dementia Help

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*The mind may not remember, but the heart will never forget*

Issue 1



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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 MORSE**

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**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. In this issue (page 40), Jeff writes about the importance of organising Lasting Power of Attorney (LPA) early on. Visit [mbassociates.net](http://mbassociates.net)

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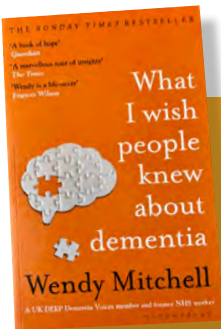
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# Updates

The latest news, facts and stats about dementia



## Our Recommended Read: *What I Wish People Knew About Dementia*

This book is a unique insight into what it's like to live with dementia

by Wendy Mitchell, who spent 20 years as a non-clinical team leader in the NHS before being diagnosed with young-onset dementia in 2014, at the age of 58. Wendy campaigns to raise awareness of dementia and is keen to show there is life after diagnosis. [Available on Amazon.](#)



## 700,000

The number of informal carers for people with dementia in the UK.

Source: Alzheimer's Research UK

## Reducing your risk of dementia

If you're looking after a close relative with dementia, you may be worried about developing the condition yourself. However, there are things you can do to reduce your risk. According to Alzheimer's Research UK, up to 40% of dementia cases could be prevented if certain risk factors could be eliminated, such as smoking, high blood pressure, inactivity, excessive alcohol consumption, diabetes and limited social interaction. However, only a third of people realise there are steps they can take to reduce their risk of dementia.



## Be positive, stay sharp

Our beliefs about ageing may play a key role in our cognition as we get older, according to a study published in

*JAMA Network Open*. The study found that those with positive ageing beliefs were more likely to recover from mild cognitive impairment compared to those with negative ageing beliefs.

## Hearing aids can help cut dementia risk

Hearing loss can increase the risk of dementia, but having a hearing aid may help to alleviate the problem, according to *The Lancet Public Health*. A study followed more than 437,000 people and looked at their risk of dementia. It was confirmed that hearing loss has a link with dementia. Hearing aids may help to cut risk, as they reduce cognitive effort involved in hearing.

## 143

The number of drugs in trials for Alzheimer's disease. 117 of them are intended to slow down the progression of the condition.

Source: Alzheimer's Society



# Updates

The latest news, facts and stats about dementia

## FOOD FOR THOUGHT

**'A lack of stimulation is harmful for a person with dementia'**

Bob DeMarco, *AlzheimersReadingRoom.com*

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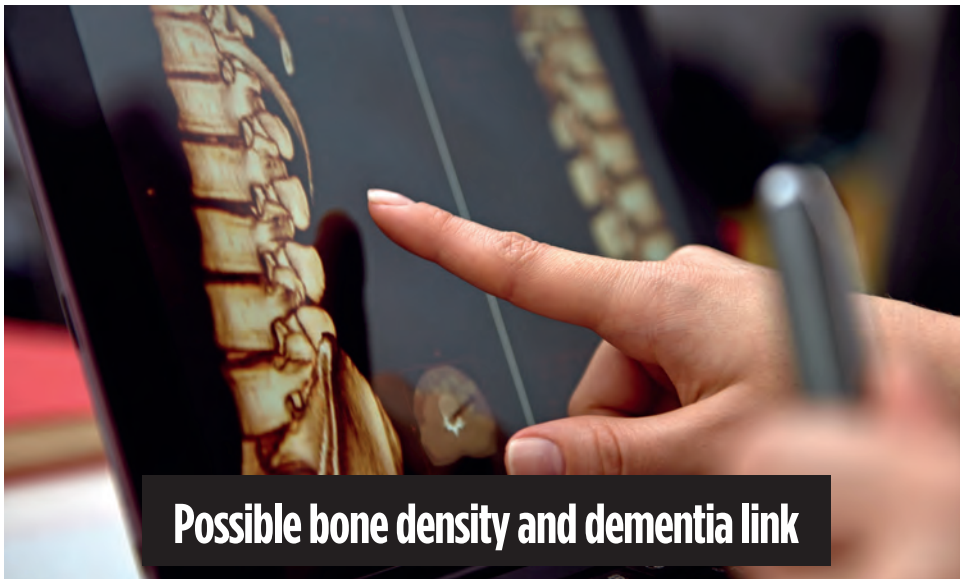
The percentage of carers who have a long-standing illness or disability.

Source: *Alzheimer's Society*



## Praise for Bruce Willis' family

Angela Rippon has praised Bruce Willis' family for speaking about the actor's dementia diagnosis. The former newsreader added that more people are talking about dementia now and said that a higher profile could mean more money put into research to mitigate the effects of the condition. Willis, aged 68, was diagnosed with frontotemporal dementia (FTD) in March last year. Symptoms can include unusual or antisocial behaviour, loss of speech and, later on, movement disorders, such as being unsteady, twitching and muscle weakness. Alzheimer's Society saw visits to its website increase by 12,000% in the days after his diagnosis.



## Possible bone density and dementia link

People with low bone density may have a higher risk of developing dementia, according to a study published in the medical journal, *Neurology*.

The study involved 3,651 people in the Netherlands with an average age of 72 who didn't have dementia at the start.

Over 11 years, 19% developed dementia. Researchers looked

at X-rays to study bone density. Participants were interviewed and tested every five years.

Of the 1,211 people with the lowest total body bone density, 90 people developed dementia within ten years, compared to 57 of the 1,211 people with the highest bone density. However, the study is not conclusive and more research may be needed.

63.5

The percentage of carers who say they have received insufficient or no support.

Source: *Alzheimer's Society*



## FOOD FOR THOUGHT

**'It's like getting up in the morning and your cell phone is only on 30%'**

Former All Blacks rugby player, Carl Hayman, on having early onset dementia



# Updates

The latest news, facts and stats about dementia



## Struggling with your loved one's mood swings?

Take it one day at a time where moods and behaviour are concerned. Plan ahead for the future by all means, but take a flexible approach. Don't try to force your loved one to do something they don't want to do, even if they previously agreed to do it. Anger can develop in the mid stages of dementia, but there will still be good days. Cherish them. (See page 22 for advice on coping with challenging behaviour.)



### Be aware

A person with dementia may lose the ability to remember things and articulate themselves, but it's important to note that they will still feel things. This means that if you're in a bad mood or you're fed up, they will pick up on how you are feeling.



### Dementia myth:

*'You have to wrap the person in cotton wool'*

Dementia is a progressive condition so, over time, your loved one will need more support. Yet, while the person is still able to be active and mobile, and interact with others, avoid the temptation to take over.

When you visit a loved one with dementia, it's easy to spend all your time tackling household tasks and organising medication. However, your loved one will benefit from social interaction so make sure you spend some time with them.



### Get fit for a good cause

Alzheimer's Research UK is seeking fundraisers to take part in its new event, Walk For A Cure, a brand new series of 5K walks for everyone affected by dementia. The walks are taking place in London, Harrogate and Edinburgh in July. For more information, visit [walk.alzheimersresearchuk.org/](http://walk.alzheimersresearchuk.org/)

FOOD FOR THOUGHT

***'To the world,  
you may be one  
person, but to one  
person, you may  
be the world'***



# 8 things to know about dementia

Whether you're dealing with difficult behaviour or trying to figure out how to provide ongoing care, **Christina Neal** reveals some key things you need to know about dementia

## 1 DEMENTIA AFFECTS MORE THAN MEMORY

Memory loss is a common and early sign that a person may have dementia, but it's not the only symptom. It's often the most recognised, but there are many other challenges faced by a person living with the condition. Dementia affects moods, a person's judgement and ability to make decisions, and spatial awareness. A person's ability to judge gaps between spaces or items of furniture may be impaired. Over time, dementia will also affect a person's mobility and their ability to recognise objects and people. My mum used to confuse her TV remote control with her purse.

The more you know about dementia, the better placed you are to care for a loved one



## 2 SOCIAL CONTACT CAN MAKE A DIFFERENCE

It's not uncommon for a person with dementia to forget that a loved one has visited, and families can often, therefore, pull back and stop going to see the person. This will have a negative effect on the person's wellbeing. My mum used to forget I had been to see her or when I had last been to see her, but the staff at the nursing home where she lived in the later stages reported that her mood had vastly improved after I'd been to visit.

## 3 MOOD SWINGS CAN OCCUR

A person with dementia can seem happy one minute and tearful or sad the next, apparently for no reason. This can occur for a variety of reasons. The person may be frustrated that they are unable to articulate what they want to say, or they might be in pain and unable to communicate this to you. There can be a whole host of reasons for sudden outbursts or rapid mood swings. Try to work out what is causing the behaviour. Signs of pain can include grimacing, a change of stance or gait, or gripping a certain part of the body, like the stomach.

A person with dementia can struggle to recognise objects





If you think pain could be the cause of the problem, arrange for the person to see their GP.

#### **4 THINGS CAN SEEM BLACK AND WHITE WHEN YOU HAVE DEMENTIA**

A person with dementia may, over time, lose the ability to recognise jokes. Although humour can be a good thing for the wellbeing of you as a carer and the person with dementia sometimes, they may not always know when you're joking.

#### **5 YOUR LOVED ONE MAY NOT KNOW THEY HAVE DEMENTIA**

A person with dementia may not understand they have the condition, or may forget about the diagnosis. My mum forgot she had dementia five minutes after the diagnosis was confirmed by her GP.

#### **6 DEMENTIA CAN CAUSE LOW MOOD**

A person with dementia can suffer from depression and it's understandable, as the person can feel frustrated at not being able to do all of the thing they used to do. According to Alzheimer's Society, depression is often diagnosed in the early stages of dementia, but may come and go. Symptoms can include feeling sad, irritable and a loss of interest in hobbies the person used to enjoy. Talk to your loved



***'A person with dementia can lose interest in hobbies that used to bring them pleasure'***

one's GP if you think they are suffering from depression.

#### **7 DEMENTIA AFFECTS A PERSON'S ABILITY TO EDIT THEIR THOUGHTS**

A person with dementia may say or do things that may sound rude, inappropriate, offensive or even hurtful, such as negatively commenting on someone's appearance. This is usually the disease talking.

#### **8 PLAN AHEAD**

Dementia is a disease of the brain and there is no cure,

so there will, unfortunately, come a time when your loved one is likely to need full-time care. The condition will progress, so it's essential to plan ahead now and talk about the type of care they would like to receive in the long term. It's also important to arrange for the person to make a Lasting Power of Attorney (LPA). There are two types of LPA - Property & Financial and Health & Welfare. See page 36 for more information on how to organise LPA. **DH**

# How to manage carer's guilt

Do you feel bad when you're not with your loved one or when you do something that's purely for you? Christina Neal speaks to CBT therapist **Louise Morse** about how to cope with negative emotions

Carer's guilt is common when you're looking after a loved one. When caring for my mum, I felt guilty when I wasn't with her, guilty when I did something nice for myself, guilty when I had to leave her. You get the picture. And maybe you feel the same whenever you take time out to go away, have a night off or even go for a short walk around the block.

According to Carers UK, these feelings are normal – it's natural to miss having your own independence and freedom. Louise Morse is a CBT therapist who believes we can improve the way we deal with carer's guilt and manage our emotions. We asked for her advice...

## HOW CAN WE COPE WITH CARER'S GUILT?

One of the first things to do is to actually write down the things that you are glad you've been able to do. Because carers are so caught up in the stress of things, they fail to see what they achieve. You would be surprised by how much you achieve. The next thing is to ask yourself, if you didn't look after your

mother, your father, your husband, or whoever it is, who would look after them? Who knows them as well as you? Knowing the person is the key to good emotional care. And since when have you decided

you were perfect anyway? Nobody's perfect.

## HOW CAN WE DEAL WITH FEELING LIKE WE SHOULD DO MORE OR MANAGE THE SITUATION OF SEEING OUR LOVED ONE GET WORSE?

In CBT, we would say: 'What you're saying is, I'm a bad person because there was nothing I could do. Nothing I could do to stop it'. So we look at the evidence. Did the dementia progress because of you? There's no evidence for that at all. On the other hand, there is evidence that, by giving them the love you do, and giving them all of you, you actually held it back. So what we're looking at is a very heightened feeling that distorts the facts. Feelings are so high in people with dementia, but they're equally high in their caregivers. So it's helpful to reframe it in light of the facts. You could say: 'I did my best'. But the disease is inexorable. It's progressive. Nobody can hold it back completely. They can hold it back temporarily. You can keep the person content. But you can't prevent the continuing decline.

*'You would be surprised by how much you achieve'*



CBT can help manage stress and make you feel better



## *‘She was actually able to have a relationship with her mother’*

### **CAN CBT HELP DEMENTIA CARERS MANAGE THEIR STRESSES AND EMOTIONS?**

It could definitely help. CBT helps people see the difference between their feelings and facts. Many people believe things are true based on what they feel. But when you gradually get to the facts, you can see that feelings often spring from other things that happened earlier in your life.

### **WHAT ABOUT SOMEONE WHO HAS TO TAKE CARE OF A PERSON THEY DIDN'T GET ALONG WITH?**

It's very difficult. The trailblazer in dementia care and in understanding dementia is Tom Kitwood.



**Louise Morse** is an experienced Cognitive Behaviour Therapist and has a Master's degree examining the effects of dementia on family carers. She works for the Pilgrims' Friend Society, caring for older people. Visit [pilgrimsfriend.org.uk](http://pilgrimsfriend.org.uk)

He wrote a book called *Dementia Reconsidered, Revisited*. He blew apart the medical-orientated thinking at the time. He said, 'There's a person in there; let's help the person. It's the person who's suffering'.

If you have a difficult relationship, it makes it very hard for the carer. That person deserves a gold bar because they're putting aside their internal struggles to care for the person.

### **A BETTER RELATIONSHIP**

Let me give you an example. I met a lady at a conference. Her mother had dementia. The lady was the youngest of eight children. None of them visited her mother. None of them had had a good relationship with the father or the mother, and the mother was a very introverted person. But as her mother's dementia progressed, and as her inhibitions fell away, the daughter learned more about her mother. She was actually able to have a relationship with her mother, as her mother began to tell her about her own upbringing, reminiscing and storytelling. For the first time in their lives, they actually hugged. **DH**

# Choosing a good home care agency

Does your loved one need more help at home? Or are you no longer able to manage key tasks? Here's how to choose the right home care agency

**T**aking care of a loved one who needs support can be overwhelming, so you may need extra help. But before choosing an agency, there are some key things to consider.

Firstly, you want to find an agency that understands the person's unique situation and can provide the necessary care and support.

## SEEK FINANCIAL ADVICE

Contact the person's local authority (council) and ask for an assessment of their care

needs. They could be eligible for Attendance Allowance or NHS Continuing Care. Attendance Allowance is funded by the Department of Work & Pensions. Google 'Attendance Allowance' for more information.

NHS Continuing Care is a package of care funded by the NHS if a person is assessed as having a primary health need. For information on NHS Continuing Care in England, simply Google 'NHS Continuing Healthcare' to

reach the relevant part of the government's website.

## KNOW THE CARE NEEDED

Make a list of all the tasks your loved one needs help with, so you can discuss them with a home care provider, and you're prepared. Consider how your loved one's needs may change and ask if they have the capacity to increase the amount of care in the future. At first, they might need help with meal preparation and cleaning.



*'The key to receiving good care is to enjoy a consistent relationship with a care team'*

Over time, they may require personal care, such as help with getting out of bed, washing and dressing.

**GAIN INPUT FROM OTHERS**

If you have friends or relatives who have employed a home care provider, talk to them about their experiences. Find out what home care really looks like in your community to discover where the best services are.

**SEEK ADVICE**

If you don't know anyone who has used a home care provider, seek advice and support from local healthcare professionals. Talk to the person's GP or district nurse for advice, as they will have had experiences with home care providers and will know who to recommend.

**DO YOUR HOMEWORK**

Every home care provider will have regular inspections of its services or facilities from the Care Quality Commission (also known as CQC).

'I always advise people to check the Care Quality Commission's rating for the homecare agency you have in mind,' says Cath Magee, Regional Head of Operations from Making Space, an organisation that supports adults with care needs. The Care Quality Commission produces a report (called a CQC Report), which rates the

***'Tell them discreetly that you noticed they might need a bit of help'***



quality of the service in terms of whether it is safe, effective, caring, responsive and well-led. Choose a home care provider with a positive rating in all five categories. 'Read the last CQC report to find out how long the manager has been in the position,' adds Cath. 'Changes of manager less frequently can be a good sign.'

**ASK FOR AN ASSESSMENT**

Before taking on new a client, the home care agency should make every effort to get to know your loved one and their needs. There should be a comprehensive assessment. The home care agency should be asking questions – not just about medical needs or care needs or about moving, handling and risk assessments, but should be looking at what will benefit the person receiving care.

**AIM FOR A BETTER LIFE**

View the extra help as an opportunity to improve your loved one's quality of life and not just take the pressure off. Look for a home care provider that offers a chance for them to socialise, engage with the local community and pursue interests they might be unable to pursue on their own.

**MEET THE CARER FIRST**

If you are going to have a regular carer for your loved one, then you need to be sure they will get along. Ideally, it's best if they have some common interests so that they can talk. Both parties need to consider if they can have a good conversation. For instance, if your loved one has a cat or a dog and loves animals, it would be helpful if their carer feels the same way. Immediately, this will establish some common ground.



A carer who can encourage your loved one to pursue their hobbies and enhance quality of life could be ideal

**CHECK THE CARER IS SUITABLY TRAINED**

Find a carer with a specialism and extensive knowledge base within dementia. Ask if the care team are specially trained in dementia.

**ASK IF THE CARE TEAM WILL BE CONSISTENT**

While everyone needs to have holidays, the key to receiving good care is to enjoy a consistent relationship with a care team your loved one knows and likes. Ask the home care agency if they can provide the same care team with the exception of sickness or holidays, so that your loved one isn't answering the door (or refusing to answer the door) to a stranger, which could be daunting and potentially upsetting. [DH](#)



**What if your loved one refuses to accept help? Christina Neal has some advice...**

My mum refused to accept that she needed any help, so I had to be persuasive.

Bring in help gradually and be diplomatic. Tell the person you noticed they might need a bit of help with housework, so they can have a break sometimes. I told mum that it wouldn't be a good idea for her to carry the Hoover upstairs, as it was heavy.

I didn't mention the fact that the house wasn't clean. I reminded her that having someone come in twice a week would be good company.

I knew mum didn't like cooking, so instead of telling her she wasn't eating properly, I said it would be nice for her not to have to cook her own meals. She eventually agreed to have Meals On Wheels.

Fortunately, she got used to the idea of having help and even became friends with the cleaner. In time, she grew to appreciate the company. A gradual approach is best, and you may have to be gently persuasive. If you know it's the right thing for your loved one, then be persistent without being abrupt. Don't give up.

# Keep your loved one safe... and found

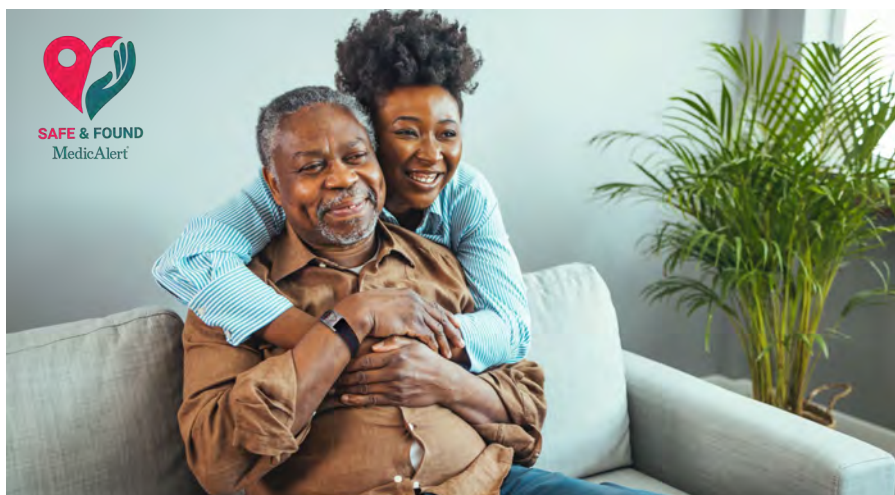
Worried about the risk of wandering? Keep your loved one safe and gain peace of mind with MedicAlert's Safe & Found programme

**W**hen caring for a loved one with dementia, there are so many things to consider to keep them safe. High on a carer's list of worries is the fear of their loved one going out and getting lost. And with an estimated six out of ten people living with dementia being reported missing at least once, this is a big concern.

While sometimes the person might only go a short distance, it's not uncommon for a person with dementia to walk much further afield, where they are less likely to be recognised. So what can you do to minimise the risks and ensure they are found and returned safely home as swiftly as possible?

## MINIMISING RISKS

MedicAlert has partnered with Thames Valley Police to launch the Safe & Found programme. The programme supports people living with dementia and other cognitive or memory-loss conditions, to ensure a quick and safe return home if the person is reported missing. Membership to the programme costs less than 10p a day, offering you 24/7 emergency support and peace of mind.



## 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 on the form includes the person's appearance, details of previous places they have gone to and other places of importance..

With a Herbert Protocol saved by MedicAlert, police can access and circulate this information as soon as they are notified that your loved one has gone missing.

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.

Wearing their MedicAlert ID bracelet, engraved with their most 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 your loved one.



For more information, or to set up your MedicAlert membership, call **01908 951045** (lines are open Monday to Friday, 8am to 3.30pm, and Saturday 9am to 3pm); email [enquiries@medicalert.org.uk](mailto:enquiries@medicalert.org.uk); or visit [medicalert.org.uk/safe-and-found](http://medicalert.org.uk/safe-and-found)

# Go with the flow

Being organised is a good thing, but being flexible and not trying to control every situation is also important. **Christina Neal** explains why

**B**efore I began caring for my mum, I used to plan everything in life. I was a control freak. Everything had to be scheduled and every goal had a deadline. I enjoyed having control over my routine and achieving goals. It felt rewarding. I was making progress.

When my mum was first diagnosed with dementia, I grew frustrated by the lack of flexibility and the fact that her dementia was so unpredictable it couldn't be controlled. I tried to plan mum's care the way I planned everything else in life. I booked her appointments and arranged for her care in the same rigid way. Sometimes it

By all means, be an organised carer, but be flexible too



worked, as being organised would help ensure mum's needs were met.

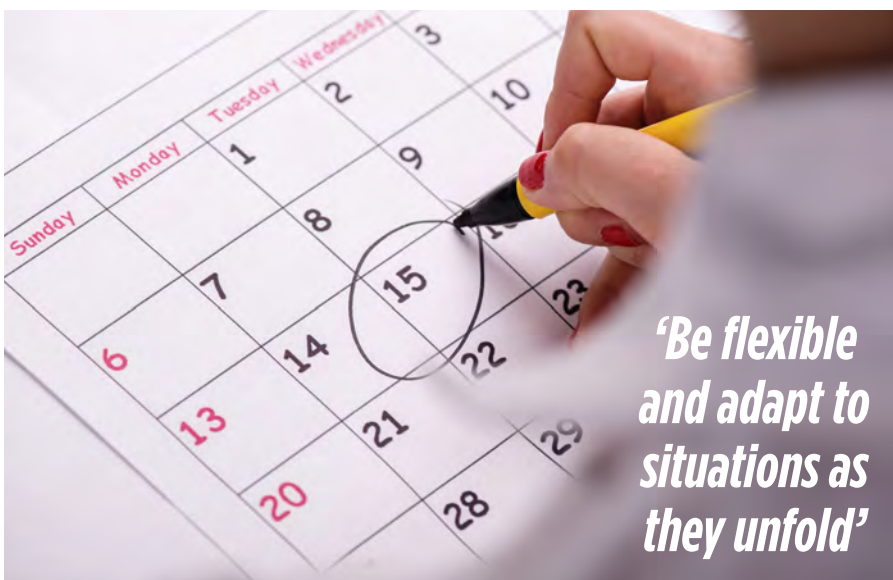
On the other hand, my inflexible approach meant I grew frustrated when things went wrong. Sometimes I'd make an appointment for

mum to see the optician or go to the hairdresser and I'd arrive at her house after a long drive and she would refuse to go.

I learned you have to be flexible when caring for a loved one with dementia. I'm a strong advocate of planning for the person's future care. Planning ahead is not a bad thing as such. But as every dementia carer knows, there are good days and bad days, and you have to be patient and flexible on the bad days.

## GO WITH THE FLOW

Even if you've got a busy day, if the person refuses to get up, go out or get ready, you can't force them. Give them space and go with the flow.



*'Be flexible and adapt to situations as they unfold'*



There will be times when the person agrees to do something and then changes their mind at very short notice without any real logic. There's no point saying to them: 'You said you wanted to get your hair cut', or, 'You asked me to take you out and I've come all this way to do it'. The person may not even remember they asked you to do something for them in the first place.

Be flexible and adapt to situations as they unfold. If you're visiting a loved one to take them out for an appointment, here's how you can make the process as stress-free as possible...

### **REMINDE THE PERSON ABOUT YOUR VISIT**

Call the person just before you arrive to remind them you're visiting - it used to take me over an hour to get to mum's house and I knew that if I called before I left home, she'd forget what time I said I was arriving, or might even forget I was visiting at



all. I would pull over in the car and call her five minutes before I was due to get to her house. Even then, she didn't always remember I was coming, but mostly she would.

### **ARRIVE EARLY**

Allow plenty of time to help the person get ready. I used to allow an extra hour so that if mum was having a bad day and was slow to get dressed or had lost something, we still had plenty of time.

### **DON'T RUSH THE PERSON**

If they are having a hard time getting ready, telling them to hurry up will only make them more stressed and could lead to angry exchanges. Be calm and patient. If they can't find something, help them look for it but don't take over completely. Be prepared to help the person get washed and dressed if they need you to, but don't be bossy or overbearing.

### **HELP THEM GET PREPARED**

Help the person choose an outfit if they seem confused - they may not know what to wear, or they may choose an outfit that isn't suitable for the weather conditions. Make suggestions for what they can wear and help them do up buttons or zips if you can see they need a hand, but try not to completely take over.

### **TRY TO BE AS CALM AS POSSIBLE (EVEN IF YOU HAVE TO FAKE IT!)**

If you are stressed when you arrive, the person may not understand why - even if you tell them the traffic was terrible - but they will pick up on how you're feeling. If you've had a bad journey, park up for a few minutes outside their house, sit quietly for a moment or two and take some deep breaths. Or stop at a local shop to buy some water and take a few minutes. Be calm when you arrive. [DH](#)



Your loved one will pick up on your moods

# 'I dreaded the first time Barbara wouldn't know me'

Scott Mitchell is the widower of Dame Barbara Windsor, who had Alzheimer's disease. Before she became ill, Barbara was supremely confident, but that changed as her dementia took hold. Scott talks openly to Dementia Help about the impact it had on their lives...

Scott Mitchell was just 29 when he first met Barbara Windsor. The pair married in 2000 and were together for 27 years. Dame Barbara was diagnosed with Alzheimer's in 2014 and passed away in December 2020, at the age of 83. Scott cared for Barbara in their London home until she had to go into full-time care.

## A GOOD CAUSE

Since losing his wife, Scott has continued to support Alzheimer's Research UK as an ambassador. His book, *By Your Side: My Life Loving Barbara Windsor*, is out now in paperback and is a candid account of their life together.

Now 60, Scott completed the London Marathon this year to fundraise for Alzheimer's Research UK with various members of the EastEnders cast, running under the team name Babs' Army. So far, they have raised over £65,000 (and counting). Scott says he won't run more marathons, but will still help Alzheimer's Research UK.

**DH:** *It took some time for Barbara to be given a diagnosis, even though you knew something was wrong. Why did it take so long?*

**SM:** I think he [the doctor] wanted to be absolutely



Scott and Barbara were together for 27 years

positive. His gut reaction was that something wasn't right, but he didn't want to jump to the diagnosis. The majority of the time, Barbara was still absolutely fine. It was only because I spent so much time with her that I saw the repetitiveness and

forgetfulness. It was like something had happened to her personality. I felt like she had slightly withdrawn. There was this distant look in her eyes at times. There were other things, like objects being in the wrong place, like the television remote control in the fridge. Eventually, I thought, 'No, this is more than old age'. It wasn't until 18 months later that Barbara had the lumbar puncture when it was defined as Alzheimer's.

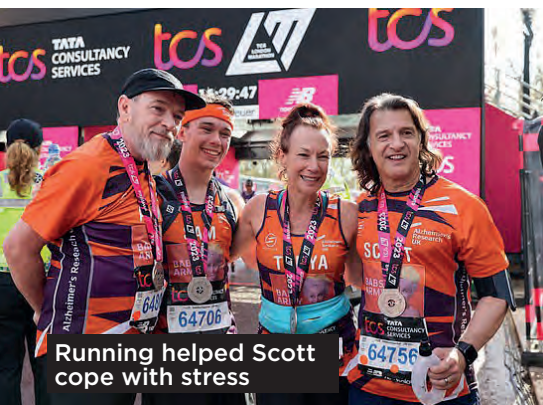
**DH:** *I understand you were encouraged to keep making plans and doing things.*

**SM:** Definitely. In the earlier stages, it's very easy to jump straight ahead, especially at the time of diagnosis, to put our minds in the darkest place. I know I did. In my mind I just went straight to a place where I thought she was not going to know me; and she was not going to know who she was or what she had achieved in her life. I found that frightening and heartbreaking.

And then I had really good advice. I was told: 'This could take years, and you're going to miss out on all the fun times, the good times'. There were still lots of good times and bad times. I was told to keep Barbara active and keep her working. That was what Barbara was most familiar with. Barbara had worked as an actress since she was a young girl. We were told she would be on autopilot and would know what to do.

**DH: It's important not to wrap a person with dementia up in cotton wool, isn't it?**

**SM:** You've got to let it progress in its own time and not make the person feel that something is wrong. Unfortunately, as we all know, it becomes very evident as it's progressing. But we still went out for dinner and still went to the theatre and did lots of things up until quite late. But it eventually became more evident to our friends.



**DH: What changes did you notice as the condition began to take hold?**

**SM:** She was a bit more anxious when we went out. Barbara had always been an incredibly confident lady, but did become very withdrawn at times. But with the public, she reverted back to being Barbara Windsor, the actress, and that was very familiar to her as well. But as it went on, it became harder to hide.

**DH: You kept the diagnosis quiet for four years. Was it a relief when you announced it to the media?**

**SM:** Oh, it was a massive sense of relief. I felt like there had been dark clouds hanging over my shoulder for a long time, trying to protect her, trying to control the whole situation. For the first four years, Barbara didn't want to really talk about it or accept it. So that made it a lot harder for me as well. So I'd have to be betting what she could and couldn't do as far as work was concerned.



In restaurants, she would be relying on me and asking me, 'What do I eat?'

**DH: Do you think, over time, you became more adept at going with the flow?**

**SM:** Definitely. At first, it used to really frighten me. It used to frustrate me. I had to learn

not to contradict her or not argue with her when she said something that I knew was wrong. When Barbara said something that was obviously wrong, I would look at her and think, 'No, you're such an intelligent, incredible lady who has always been on top of everything. Please don't start disappearing on me'.

**'She looked scared and said, "I'm sorry, who are you?"'**

I didn't want to accept it myself at that point, but as I learned more about it, I began to relax and go with the stories.

**DH: Do you feel it was beneficial that Barbara worked for as long as she did?**

**SM:** I do, actually. It did hold it off a little bit in the first couple of years. I think her still focusing on what she had to do made her concentrate and use that brain as much as she could, until it absolutely started letting her down.

**DH: In your book, you said Jonathan Ross came to visit Barbara for two hours, even though he didn't know her very well, whereas some friends stayed away. It seems that some people don't know how to handle dementia.**

**SM:** I think a lot of people have fear and anxiety around people with dementia. If they've never experienced it, they don't know what to expect. They don't know what they're supposed to say or how the person will react. What I would say to people is, think about the person doing the caring. It's a very isolating situation for them; their social life will become smaller. They will spend more time with the

person who has dementia and will need support.

**DH: What were some of the biggest challenges for you?**

**SM:** I always dreaded the first time Barbara wouldn't know me, and I remember when it happened. I was helping to get her out of the bath, and she looked scared and said, 'I'm sorry, who are you?' My heart just felt like it broke in two. I said very gently, 'It's me, Barbara. Scott, your husband'. And she apologised to me. She would look at photos of us and say, 'So how long have we known each other?' Or she'd say to me, 'Sir, have you got someone special in your life?' I'd say, 'Yeah, she's a really cute blonde. Her name

is Barbara'. And she'd say, 'Is it me?' She'd propose to me. I'd say yes every time.

**DH: How did you adapt?**

**SM:** I learned that smiling was a good thing, but sometimes that went against me because she thought I was laughing at her. I'd always try and talk gently. If you say something to a person with dementia and your tone is a bit abrupt, it might come through. Barbara would say to me, 'I can see I'm pissing you off'. I'd say, 'No, it's just that we've had this conversation 12 times this evening'. I tried to bring her into the moment of what it was like. If you can speak to their heart, that's a really important thing.





***‘What I would say to people is to think about the person doing the caring’***

**DH: Did you ever imagine you could be so strong?**

**SM:** No, absolutely not. I didn't know I had that kind of strength to dig into. When you're put into a certain situation, you find out a lot about yourself.

**DH: Tell us about the work you're doing for Alzheimer's Research UK.**

**SM:** I first came into contact with Alzheimer's Research UK in 2019, with the first marathon I did. It was under an umbrella called The Dementia Revolution. Barbara became the face of it. She was campaigning for it, doing videos. Our team raised £250,000. When Barbara passed, they got in touch with me again and I became an ambassador.

**DH: I believe you and Barbara both campaigned together.**

**SM:** Barbara and I went to Downing Street in 2019 to talk to the prime minister, then Boris Johnson. On the way, she asked me about six times, 'Where are we going?' Once she was there, she knew why she was there, and I can remember her holding Boris' hand and saying, 'It's not good; you've got to look after people'.

I wrote to him again after Barbara passed and kept the

pressure on about funding. Boris promised to double dementia research to £160 million per year. After he left, I wrote to Rishi Sunak, who wrote back and said, 'We are sticking to what you asked for'. I continue to talk about dementia. When I talk to people about it, I always say, 'I want you to think of the person you love, the person you hold dearest in this world, and whatever I say about Barbara, think about that person saying it to you.' **DH**



**More Information**

Scott's book, *By Your Side: My Life Loving Barbara Windsor*, is available in **paperback on Amazon**. You can still donate to Babs' Army, to raise funds for Alzheimer's Research UK. To access the link, simply Google 'Babs' Army Enthuse'.

# Coping with challenging behaviour

Mood swings can be common in a person with dementia. It can be scary to see someone you care about transforming from calm to angry in an instant. **Christina Neal** has some tips on how to cope



Caring for someone with dementia can be physically and emotionally exhausting. If you're caring for a loved one, it's even harder to accept that, over time they'll become increasingly dependent on you. But don't forget that dementia is a disease of the brain, and it's not always possible for your loved one to control their behaviour or express their feelings.

## MOOD SWINGS

Try to understand what's causing their actions. It takes patience, but it's worth it to provide the best care possible for someone you love.

I know first-hand how quickly mood swings can occur. My mum could be happy one minute and tearful the next, seemingly for no reason. She could get angry very quickly. One day, I went

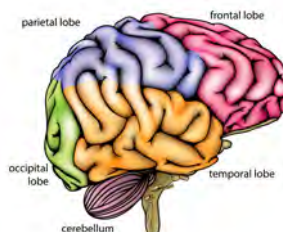
to see her at the nursing home where they were having a party. Everyone was enjoying the celebrations except for my mum. To my horror, she got angry and starting hitting me and shouting at me in front of everyone.

Five minutes later, she had calmed down and was singing along to the music. She had forgotten the incident and therefore couldn't explain or apologise. In fact, shortly afterwards, she was telling the staff at the home that I was her 'lovely daughter'. It was upsetting, but I learned more about why sudden mood changes can occur in a person with dementia, and it made me more understanding.

## THE BRAIN AND DEMENTIA

To understand more about the causes of challenging behaviour, it helps to learn a bit about the brain. The brain is divided into four sections, called 'lobes':

- ⊗ The frontal lobe controls thinking, memory, behaviour and movement;
- ⊗ The occipital lobe controls sight;
- ⊗ The parietal lobe controls language and touch;
- ⊗ The temporal lobe controls hearing, learning and feelings;
- ⊗ Other areas of the brain affected by dementia include the hippocampus (which logs memories) and the amygdala (which processes emotions and records reactions).



When you see how the different lobes influence our abilities, it's easier to understand why dementia can have such an impact on a person's behaviour and mood.

There could be other reasons why your loved one gets angry. They may be hungry, thirsty or in pain and unable to communicate how they are feeling.

## POSSIBLE CAUSES OF MOOD SWINGS...

### Pain

If someone can't verbally tell you what's wrong, they might try to communicate through other means, like shouting. Keep an eye out for changes in behaviour, like a change in walking pattern, grimacing, or becoming protective of a certain area. Even if they can tell you they are in pain, they might not be able to say what hurts. You might find it helpful to give them a general analgesia (if prescribed by

Ensure the person has smaller meals or regular snacks



their GP), in order to make them more comfortable.

### Thirst or hunger

Has the person eaten or had a drink recently? Dehydration is a source of confusion, so ensure they have plenty to drink and offer easy-to-manage snacks.

### Boredom

Your loved one may have been active and sociable in

the past, and this may have changed recently. They could be frustrated by a lack of stimulation. Invite the person to join you on walks if they can, or look into other activities you think they might enjoy.

### Fatigue

Dementia can affect a person's sleep patterns and make them more prone to waking at night, meaning they don't get proper rest. A short nap can help to refresh them, but preferably not too late in the day or else they may not sleep at night. Speak to the person's GP if their sleeping habits have changed.

### Sundowning

As the day winds down, a person with mid- to late-stage dementia can experience a shift in their mood known as sundowning.



*“Dehydration is a common source of confusion, so ensure they have plenty to drink”*



*‘She had also forgotten the incident and therefore couldn’t explain or apologise’*

## HOW TO COPE WITH DIFFICULT DAYS...

### Accept that you are the one that needs to change

A person with dementia cannot control their emotions or reactions in the same way as you – so you need to be the one to change your behaviour. Accepting this fact is the first and most important step to being able to handle challenging behaviour.

### Look after yourself

Caring for a loved one is both physically and emotionally draining, which is why it’s important to take care of yourself, too. Make sure you have time for yourself each day to do something you enjoy, even if it’s just a 20-minute walk around the block or an exercise class.

### Seek help

Have a support team. Even if other family members don’t do their bit, you may find that friends and neighbours may step in and help out. I had several close friends who went above and beyond the call of duty to help. The neighbours were wonderful, too – one told me he’d been through the same thing with his parents and he felt that no one should have to cope alone. Support can come from unexpected sources sometimes. [DH](#)

The cause is still uncertain, but it may be due to changes in brain chemistry. If you suspect your loved one might be experiencing sundowning, try to engage them in activities they enjoy during this time, such as taking a walk or listening to their favourite music. Conversation and company can be very reassuring for them.

### Feeling anxious

A person with dementia may lose their confidence, especially if they were very independent before. If you have to go out or leave your loved one home alone, do they get angry when you tell them you will have to leave soon? Don’t warn the person you’ll be leaving soon. This will give them time to ruminate and get stressed out. Chat to them until you

are about to leave, then announce you are going and leave swiftly. This will ease any prolonged anxiety. On your departure, say you will see them tomorrow, or remind them a friend or neighbour will be dropping in soon.

### Being contradicted

A person with dementia could feel frustrated that they are unable to recall certain words or memories. If they have struggled to formulate what they want to say and you contradict them, it could make them angry. Don’t correct the person, even if they say something that isn’t accurate. Let them recount stories or experiences in their own way.





# A helping hand

The lowdown on useful products, books and resources to help you support your loved one

## FARMER'S MARKET JIGSAW PUZZLE

A 63-piece puzzle perfect for a person in the early stages of dementia. This beautiful illustration has been created with vibrant colours, to help the user complete the puzzle and to spark conversations.

£16.99 including VAT

£14.16 with VAT relief (for people with a disability)

Visit [relish-life.com](http://relish-life.com)



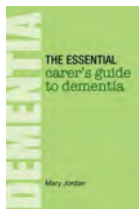
## RELISH DEMENTIA RADIO FM / DAB+

Accessible for all abilities, this radio has clear separate on and off buttons, with audio feedback when pressed and an easy volume control that cannot be turned to zero. Simple to use – the memory buttons allow for three favourite DAB or FM radio stations. It can be set up by the carer, with an interface neatly hidden behind the battery door at the back.

£119.99 including VAT or £99.99 with VAT relief (for people with a disability)

Visit [relish-life.com](http://relish-life.com)

## Boost your knowledge...



### **The Essential Carer's Guide To Dementia**

By Mary Jordan  
If you want to have a better understanding of dementia, this book

is an ideal read. Dementia expert Mary Jordan explains what to expect at each stage of a person's dementia, how to help your loved one maintain independence and how to make the most of available help.

Available on Amazon



### **50 Things Every Carer Should Know About Dementia**

By Christina Neal  
Our Founder and Editor, Christina, has packed a wealth of

information about dementia, including advice on coping with challenging behaviour, arranging care, organising paperwork and understanding more about the condition, into this concise and easily digestible book.

Available on Amazon

## DID YOU KNOW?

*There is a wealth of support and advice available on our Dementia Help website – go online to download more free resources and read our blogs on taking care of a loved one with dementia at [dementiahelpuk.com](http://dementiahelpuk.com)*



# Making progress with dementia drugs

Medication for dementia has improved significantly in recent years, with new drugs showing promising signs of a breakthrough. We spoke to **Dr Emer MacSweeney** from Re:Cognition Health to find out more...

New medications can slow down the progression of the condition



new generation medications to treat the underlying cause of Alzheimer's disease, not just its symptoms. Finally, two new medications have been approved by FDA and a third is scheduled for accelerated approval this summer. Unlike current medications available from your doctor today, these new medications are designed to actually slow down the progression of Alzheimer's disease and its symptoms; they protect the brain cells from being destroyed by removing the toxic amyloid protein in the brain, which is the hallmark for Alzheimer's disease. Current medications can't stop destruction of our brain cells, but just help the dying brain cells to function a bit better for a little longer.

**DH: What results are we seeing from Leqembi, the new medication approved by the FDA in January this year?**

EM: Leqembi, a monoclonal antibody which removes the toxic amyloid protein from the brain, demonstrated a 27 per cent reduction in the rate of progression of Alzheimer's disease symptoms at 18 months of treatment.

**P**rogress is being made with dementia medication. Last November, the BBC reported a 'momentous breakthrough' when referring to an Alzheimer's drug called Lecanemab which was reported to slow down the destruction of the brain in Alzheimer's disease. In addition, Alzheimer's Society recently mentioned another drug called Donanemab, stating that it appeared to slow progression of Alzheimer's symptoms by 36 per cent. A trial also demonstrated a 40 per cent slowing in decline of activities, such as driving, hobbies and managing finances.

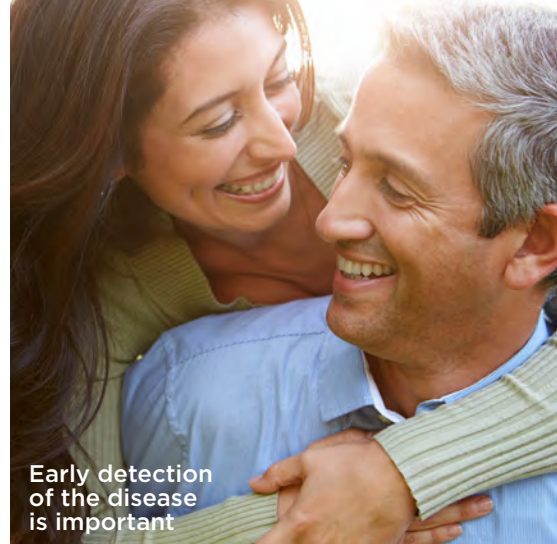
Current prescription medications only treat the symptoms and don't slow

down the progression.

Re:Cognition Health's clinics specialise in brain and mind health, offering free access to clinical trials for medication to slow down the progression of Alzheimer's, plus treatments for mild cognitive impairment. Doctor Emer MacSweeney is a Consultant Neuroradiologist and the CEO of Re:Cognition Health. We spoke to her about the new medications...

**DH: Medication for dementia has improved. Previously, medication could only help to manage the symptoms and not slow down the progression.**

EM: For many years, huge funding and scientific efforts have focused on developing



It also very successfully removed the toxic amyloid protein from the brain. Many of our patients at Re:Cognition Health have been taking this medication for over 18 months now and are thrilled to be among some of the first people in the world to take one of the first medications ever to slow down the progression, or ideally halt, the progression of the disease.

**DH: That's very encouraging.**

EM: It is an historic moment in the treatment of Alzheimer's disease. A BBC documentary featuring two of our patients on Lecanemab (market name Leqembi) was aired on the national news when the results for Lecanemab were announced in San Francisco at the Global Alzheimer's Disease Conference last November.

**DH: Is the new medication only suitable for those in the early or mid stages of dementia?**

EM: Logically any new medication designed to slow down the progression of a disease should be given as early as possible. The clinical trial for Lecanemab was designed for individuals with mild cognitive impairment (MCI) or mild symptoms of dementia due to

Alzheimer's disease. There are lots of other drugs also in development currently, including for people with more advanced symptoms which are expected to be more effective than current medications available from your doctor. For this study, like many others, you can take medications already on the market to help your symptoms and join a clinical trial to access new medications.

**DH: What else is happening in dementia research?**

EM: New medications are only half of the story. The other key innovation is the development of new biomarkers which enable us to make an accurate diagnosis of Alzheimer's disease when symptoms

**'There are over 100 new medications being developed'**

are very mild and not very specific. Like any condition, for example, diabetes, best treatment and outcome will

be achieved if it is possible to detect the condition (poor sugar control, in the case of diabetes), and then start treatment as soon as possible, ideally before the first symptom even begins. Alzheimer's disease is no different in this respect. So today in clinical trials, we can make a very early and very accurate diagnosis

of the cause of your mild memory symptoms and provide a treatment designed to slow or ideally halt further progression.

There are over 100 new medications being developed and in clinical trials right now. But places on these studies are competitive worldwide and the only criteria for access is you fit the eligibility criteria, which ensures you are on the best study for you.

There is no cost to join the studies or for accessing of all the very expensive diagnostic and monitoring assessments, completely free. These places are taken really quickly across the world. If you want to be considered for this opportunity you just have to contact an expert centre. Re:Cognition Health has six centres in the UK, so we may have a centre near you. You don't need to be referred by your doctor but if you are accepted onto the study, your doctor will be kept fully informed of your progress. **DH**

**More information**

For more information about Re:Cognition Health's clinical trials, visit [recognitionhealth.com](http://recognitionhealth.com) or call 0800 802 1030.



It's thought that sweet taste buds remain the strongest

## Coping with a sugar addiction

A person with dementia may crave sugary treats, even if they didn't particularly like them beforehand. Here are some helpful tips to make sure they can still enjoy a sweet treat without going overboard

**Y**ou may have noticed that your loved one has increased cravings for sweet foods. They may start refusing normal meals and consuming sweet, sugary snacks instead. Or you may have noticed that the person is eating more cakes, chocolates and biscuits in between meals. They may

be showing a lack of restraint and over-indulging.

Unfortunately, this is fairly common in a person with dementia and is due to changes in the brain as the condition progresses. Taste buds can diminish over time. However, it's thought that sweet taste buds remain the

strongest, which can cause cravings for sugary foods.

Recent research indicates that it's not just the pancreas that produces insulin. The brain produces it, too. The amount of insulin the brain produces in a person with Alzheimer's is reduced as the condition progresses.

Other studies have shown that dementia attacks the dorsolateral prefrontal cortex (the frontal lobes of the brain associated with inhibition,

planning and working memory). This part of the brain is thought to be responsible for self-restraint.

So what can you do to ensure your loved one doesn't overindulge and has a balanced diet?

**GIVE THE PERSON FRUIT**

Fruit can help to curb cravings. Fruits with natural

sugars may take away the temptation to eat chocolate. Try putting some berries and bananas in a blender with natural yoghurt.

***'A noisy radio or TV in the background or dinner table conversations could distract your loved one from eating'***

**ADD PROTEIN AND HEALTHY FATS TO MEALS**

Protein can help a person feel fuller for longer, which can help to reduce cravings,

especially those pesky 4pm sugar crashes.

**COMBAT BOREDOM**

Boredom could be a reason the person wants to overeat.



**HOW TO ENCOURAGE HEALTHY EATING**

It's important to entice your loved one to eat a healthy range of foods. When preparing normal healthy meals, you can try these quick tips...

- » Ensure that foods look and smell appealing – foods may need to be stronger or sweeter than usual to appeal.
- » Try smaller portions, so that meals don't look too overwhelming to eat. Little and often can be a good mantra.
- » If chewing is a problem, try offering the person soups or stews, or give them milkshakes to boost their calorie intake. Softer meals, like scrambled eggs, can work well.
- » Cut up food for the person if they are struggling to manage it.
- » Offer finger foods. Your loved one may forget how to use cutlery, so remove the embarrassment by offering foods that don't require a knife and fork.
- » Avoid distractions. A noisy radio or TV in the background or loud dinner table conversations could distract your loved one from eating. Try to keep mealtimes as calm and peaceful as possible.



Boredom could be why the person wants to overeat

*‘Share cakes, puddings and biscuits, so that they don’t overeat’*



Make sure they have plenty of stimulation. Encourage the person to go out for a walk if they can and try to keep their mind occupied.

#### **LIMIT ALCOHOL BEFORE MEALTIMES**

Alcohol can lead to less self-restraint with food choices, and contains sugar. Some wines and drinks have more than two teaspoons of sugar per serving.

#### **DETOX THE PERSON’S HOME**

It’s fine to have some sweet snacks indoors and let the person indulge from time to time, but make sure there’s not too many.

#### **TRY CINNAMON**

It’s thought that a teaspoon of cinnamon a day can reduce cravings by controlling blood glucose levels.

#### **DISTRACT AND DEFLECT**

If your loved one has recently eaten a sweet snack and keeps asking for more, try to offer them a cup of tea instead, or invite them to go out for a walk to take their mind off food for a while.

#### **SHARE CAKES, PUDDINGS AND BISCUITS**

If the person wants a sugary snack or pudding, share it between the two of you, so that they don’t overeat. [DH](#)

## **HOW TO AVOID CHOKING WHEN EATING**

In the later stages of dementia, a person can develop problems chewing or swallowing. Signs of problems swallowing include repeated coughing and throat clearing, grimacing and exaggerated movements of the jaw. Offer moist foods that are easy to chew, like scrambled eggs or stewed apples. Consult the person’s GP immediately if you suspect problems chewing or swallowing.

# 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



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](#)

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

For more information, visit [recognitionhealth.com](https://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/](https://recognitionhealth.com/mentalhealth/privatememory-clinic/)

# Should you take a loved one on holiday?

Are you longing to go on holiday? Is your loved one asking for a break, but you feel apprehensive about taking them away? Holidays can work with the right planning and preparation

Like anyone else, a person with dementia needs stimulation, and social interaction is also beneficial. It's not ideal for the person to stay in all the time if they are in the early or mid stages of the condition. At the same time, you may be wondering whether it's a good idea to take the person out of their familiar environment and comfort zone. Is it worth the risk? Dr Carol Sargent supported her

mother and mother-in-law in their dementia journeys, and is also a scientist who founded MindforYou ([mindforyou.co.uk](http://mindforyou.co.uk)), a UK specialist dementia holiday organisation.

Dr Sargent believes that holidays can suit any person with dementia who is still comfortably living at home. In

fact, she likens the concept of a person living with dementia staying at home all the time to lockdowns.





‘I think we all learned in the pandemic that if you can’t leave your house and you’re surrounded by the same four walls, with the same person all the time, you will suffer from boredom,’ she says. ‘In these situations, people can become very depressed.’

### GETTING FEEDBACK

A person with dementia is just like anybody else. We all need stimulation.

Meeting new people and experiencing new things is something that can give increased self-confidence and enjoyment, not just for the person, but for other people sharing the experiences. Bangor University social scientists analysed evidence

***‘It’s essential to be tuned into things that may irritate your loved one’***

from MindforYou holidays and documented significant wellbeing benefits for both the person living with dementia and their family

carer. Here are some useful tips from Dr Sargent on taking a loved one away...

### PICK THE RIGHT HOLIDAY

Think about what your loved one enjoys now, not simply what you have done in the past. More importantly, think about the things that make

them anxious and avoid them. It’s also about what makes a nice environment for your loved one. What is comfortable for them? What stresses them? Dr Sargent says if your loved one doesn’t like busy noises and places, then you need to consider going away at a quiet time and selecting somewhere that doesn’t get too busy. You know your loved one best, so you can pick the right holiday that you can both enjoy.

### PICK WHO YOU GO WITH

A real concern for a lot of carers going on holiday is how they would cope with stressful situations. You probably don’t want to think about it, but you really need to consider how you would cope with any problems. Dr Sargent says: ‘Ask yourself, “What are the things that could happen and what would I do if they did?”’ Have a contingency plan and do some more research about where you could get help. This might mean you decide to go away with friends.’



Think about what your loved one enjoys now, not just in the past



## KEY THINGS TO CONSIDER...

- ⊗ Consider whether the journey is feasible for your loved one.
- ⊗ Look at the itinerary before you go, so you have an idea of how your days will be spent.
- ⊗ Be flexible while you're away. Your loved one may not want to do certain things or may change their mind about plans you've made. Accept this may happen.
- ⊗ Don't forget to discuss the trip with your loved one. They have as much right as you to get excited about it.

Plan how you will spend your time on holiday



Having friends and family on holiday with you means extra support. 'It may also be that you just want someone else to chat to, as conversation with your loved one is limited,' says Dr Sargent, who says she has met lots of people from dementia groups who have decided to go away together. 'This has really worked for them,' she says. 'A problem shared is a problem halved.'

### BE TUNED IN

Acknowledge small habits and routines that are important to your loved one. 'I've been away with some people who made sure they went back to their room to watch *Pointless*,' says Dr Sargent. 'That was the thing they enjoyed. So it's about understanding these things.' It's also essential to be tuned into things that may irritate your loved one, even small things. 'If loud noises, like coffee machines, upset your loved one, then it's about finding a seat away from the coffee machine,' says Dr Sargent. 'Or finding places you can visit at certain

times of day when it's quiet. Noisy environments can be a problem. So consider what makes a person anxious.'

Dr Sargent has a great deal of experience in trips with people living with dementia. 'The most impressive person who came on holiday with me was a former Professor,' she recalls. 'Over the course of his dementia he had created his own booklet for people to get to know him. As soon as we met him, he handed it to us and told us about the things he enjoyed, and most importantly, the things he didn't enjoy, which in his case was discussions about Brexit! So it's about recognising those things.'

### NEW EXPERIENCES

With some research, planning and preparation, it can be possible to take your loved one away and create new experiences. Even if they don't remember the holiday or the details, they will feel happier for having had quality time with you. 'To me, dementia is all about

continuing to learn about that person and create those special feelings,' says Dr Sargent. 'Learning how to make life as enjoyable and stimulating as possible is important – nobody likes being in the same place with the same things all the time. Life is all about continuing to experience things.'

It's also about learning. 'Going away helps you learn about the key things at home,' says Dr Sargent. 'But equally, you can learn that certain things in a new environment are much more relaxing, like staying somewhere on one floor and not having to go up the stairs.'

If you're apprehensive, try different things at home to give you confidence in selecting the most suitable type of holiday. [DH](#)



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# Keeping your loved one safe at home

It's understandable your loved one will want to stay at home for as long as possible. **Mary Brown**, team leader of Derby City Dementia Support, explains how to get help and make the person's home safer



**W**hen it comes to helping a loved one at home, the key is to build support around the person and their individual needs, and adapt as their condition changes. Here's what to do...

## ARRANGE A NEEDS ASSESSMENT

If the person hasn't had a needs assessment, ask their local council to arrange one. It's free, and you don't need a dementia diagnosis to apply. The assessment can be face-to-face or online and takes around an hour.

The person will be asked how well they manage tasks,

including getting out of bed and making hot drinks. The results determine what help is available, from home adaptations to access to day centres or meal delivery. Funding is means tested and a financial contribution may be required.

You can apply at [gov.uk/apply-needs-assessment-social-services](https://www.gov.uk/apply-needs-assessment-social-services)

## ACCESS SUPPORT GROUPS

Specialist groups offer tailor-made activities, reduce isolation and help to maintain a positive routine.

Typical groups include dementia cafés; weekly or monthly activities, such as singing, dancing or quizzes; and day centres offering activities and meals.

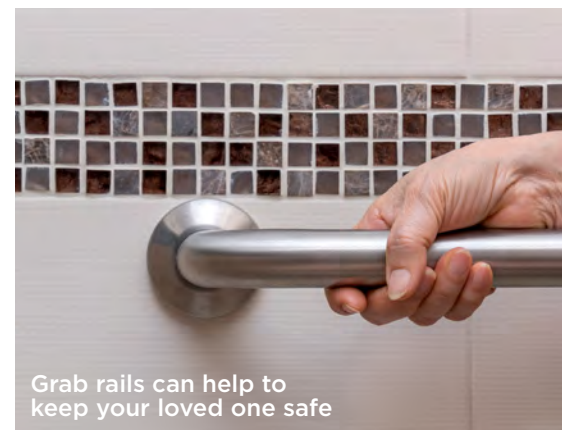
There are also lots of groups offering practical support and advice for carers. Carer breakdown is a common reason for people moving into residential care, so make it a priority to find a group of like-minded people

and professionals for support. Availability depends on where you live – the person's GP or social services should be able to tell you about local groups in the person's area.

## APPLY FOR BENEFITS

Your loved one could be entitled to claim Carer's Allowance, Disability Living Allowance, Personal Independence Payments or Attendance Allowance.

Financial help could pay for home visits from a hairdresser, gardener, chiropodist or cleaner – as well as practical support and company, they're also an extra pair of eyes to look out for any issues.



Grab rails can help to keep your loved one safe

Don't assume the person won't qualify – a few extra pounds in their pocket could mean the difference between taking a taxi to a support group and staying at home.

The website, Carer's UK, has information on different help available. Visit [carersuk.org](http://carersuk.org) for more information.

### MAKE SOME CHANGES

Look around the home to make sure there's good lighting, even flooring with no trip hazards, labels and signs to use as prompts and dementia-friendly technology, such as a single remote control for the TV and any attached devices.

Install grab rails, ramps and personal alarm systems as soon as possible after diagnosis, so the person with dementia can become familiar with them.

Replacing crockery and glassware with brightly coloured melamine has been proven to help maintain an interest in food. As symptoms progress, it can be difficult to recognise plain food, such as chicken or rice, served on a light-coloured plate. They also

reduce the risk of accidents and injuries.

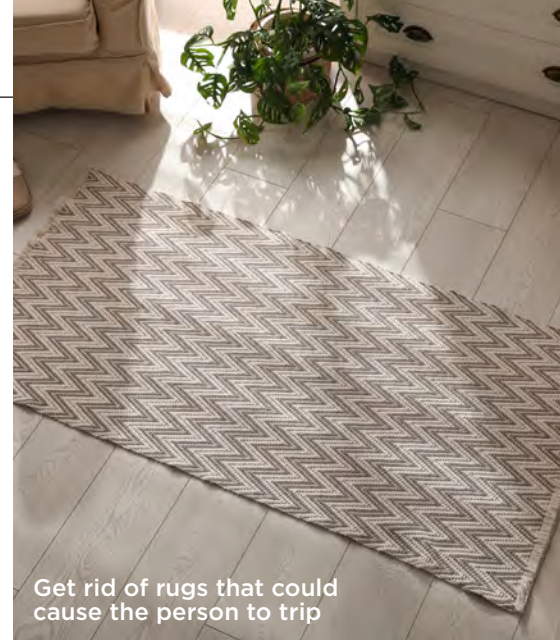
### HOMECARE AGENCIES

Professional help from an agency or live-in carer should be suited to the needs of the person with dementia. For someone struggling with personal grooming, morning and evening visits to help with showering and the evening bedtime routine could help. If weight loss is an issue, one home visit during the day to supervise lunch and prepare dinner could help

the person with dementia to remain healthy and active for longer. See page 12 for advice on choosing the right home care agency for your loved one.

Consistency and familiarity are key. A succession of different people turning up at random times can be unsettling, so it's important to monitor progress and get regular feedback from the agency.

***'Look around the home to make sure there's good lighting and even flooring with no trip hazards'***



Get rid of rugs that could cause the person to trip

### LIVE-IN HELP

A live-in carer isn't necessarily a more expensive option than residential care. Care fees may need to come out of any savings the person with dementia has; if that's the case, it could be more beneficial to pay for someone to live in.

Bear in mind that at least two people are necessary for full-time live-in care, with overlapping time for handovers. As well as sleeping space, they may also need facilities for their own mealtimes, washing and other personal requirements.

Deciding on the best care for a person with dementia is a complex issue, with many factors to consider. It's not an easy decision. But if the decision is based on what's right for the individual and their personal circumstances, it will be the right one. **DH**

**More Information:** Derby City Dementia Support can be contacted at [derbycity.dementia-service@makingspace.co.uk](mailto:derbycity.dementia-service@makingspace.co.uk) or by calling **01332 497640**. The service provides memory assessments, a living well programme, carer support, respite groups and activity sessions for people living in Derby.

# ***‘Mum could only recall old memories’***

Jill Eckersley is a journalist based in London. Her family live in Southport on Merseyside. Jill did the ‘holiday relief’ care for her mother, who was diagnosed with Alzheimer’s in 2013 and died in 2017, aged 97

***When did you notice that all was not well with your mum?***

In the summer of 2013, when I visited. Mum and dad were living in a retirement flat about a mile from my brother and sister-in-law. I noticed mum kept repeating herself and that dad had pinned up reminder notes in the kitchen.

***How long did it take for her to get a diagnosis?***

Dad didn’t tell us he was concerned at first. He took her to their GP and was given an appointment with a local EMI (elderly mentally infirm) consultant. Dad didn’t share the diagnosis of Alzheimer’s with us for some time.

***How challenging was it to get a diagnosis, and did your mum understand it?***

None of us felt that mum was really taking it in, and neither she nor dad discussed it with us. Dad clearly found it very hard to accept and didn’t want to talk about it. My sister-in-law remembers watching a TV programme where dementia was mentioned, and mum said, ‘Well, thank goodness I still have all my faculties!’

***What changes did you notice in your mum over time?***

Mum tired easily and had trouble with the stairs and getting to the loo in time, but as she was in her late 90s, it was hard to tell whether this was a result of dementia or old age.



Jill with her mum and brother

***How did you and your family cope with providing help and support for your mum?***

We all felt very strongly that care should be shared and that mum’s money should be spent on providing the best possible care. After dad died in 2014, mum moved to my brother’s, and he and my sister-in-law provided everyday care. I covered their holidays. We also investigated local daycare and found an excellent day centre.



Mum went three days a week at first and enjoyed herself so much she asked if she could go every weekday! She had always been sociable and really enjoyed meeting different people and taking part in activities. At home, we weren't able to provide all-day entertainment.

**How did it affect you on both a practical and emotional level?**

Of course, we were sad to see the mum we had known and loved slowly fading away. But we all had a part to play. My main contribution – both when I was with her and at home in London – was

reminiscing, which she loved. Her short-term memory had gone, but she remembered her childhood in the 1920s and her early married life. I heard the same old stories over and over again. But I knew that when she was no longer with us, I'd be glad I'd listened.

**What were the most challenging moments about being a carer?**

Mum wasn't always able to get to the loo in time, so it was out with the Marigolds and scrubbing brush...

**Were there good moments that you remember?**

Yes, mum and I shared a lot of laughs over her old memories!

**Did your mum always remember you as her condition deteriorated?**

She was only really confused when she woke in the night. She once asked me

where the staff were. I just told her I would sit with her until she fell asleep.

**What advice would you give to carers just embarking on their new role?**

Don't try to do it on your own. We were a family team. But there are also helpful GPs, carers' groups, day centres, Admiral nurses and dementia cafés out there. Alzheimer's Society is a good source of information, too.

**What do you wish you'd known at the start?**

That people with dementia are still the same people underneath. Mum was still sweet-natured and not hard to care for. She longed to help in the house and would say, 'You're doing all the work!' even when I was only making a cup of tea! **DH**

**'People with dementia are still the same people underneath'**

Jill's mum could recall old memories but not recent ones





Planning ahead early on is vital

# A guide to Lasting Power of Attorney

It can be possible for a person with dementia to arrange a Lasting Power of Attorney, but the key is to act swiftly. We speak to **Jeff Smith**, an estate planning consultant and will writer from MB Associates

**H**as a loved one recently been diagnosed with dementia, or are they in the early stages of the condition? Then it's essential to make sure their legal and financial affairs are in order. This will enable them to hand the responsibility over to you or another family member when they are no longer able to cope. The earlier the person can do this, the better - otherwise, it may be too late.

## DEMENTIA AND LASTING POWER OF ATTORNEY

A diagnosis of dementia won't necessarily stop a person from setting up a Lasting Power of Attorney (LPA), but a legal adviser will need to be satisfied that they understand what they are doing and are clear about their intentions. If the person doesn't have the required capacity to sign an LPA, then an application will have to be made to the

Court of Protection. This is an expensive and lengthy process, so it's best avoided by acting quickly.

## 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 medical opinions, and the person's GP may need to act as a Certificate Provider.





It's best to get both types of LPA done

This means they would be the person who confirms that the person with dementia understands the nature of the Lasting Power of Attorney.

**TWO TYPES OF LASTING POWER OF ATTORNEY**

Most people focus on sorting out their finances, but it's also essential to make provision for your long-term health and wellbeing. 'Our experts often find that people don't always realise there are two types of Lasting Power of Attorney - Property & Financial Affairs and Health & Welfare,' says estate planner Jeff Smith from MB Associates.

Jeff adds: 'Property & Financial gives the Attorney the authority to deal with and make decisions about finances, which includes things like investing money, paying the mortgage, paying bills, arranging repairs to the person's property, collecting pensions and benefits, and selling the person's home. Health & Welfare means

that the Attorney can make decisions about the person's medical care, where they should live, who they should have contact with and also make decisions about life-saving treatment. However, you can have a Health & Welfare Power of Attorney that doesn't include instructions about life-saving treatment if you prefer not to give instructions on this.'

**DIFFERENT TYPES OF LPA**

There are different types of Lasting Power of Attorney. 'In addition to Lasting Power of Attorney, there is the older style Enduring Power of Attorney that a person may have set up many years ago. They were phased out in October 2007 but are still valid,' says Jeff.

'However, there can be several issues with this,

because the Attorney or Replacement Attorneys appointed at the time may have died or be in poor health and may be unable to act on your behalf. Or the person with dementia may not want the people they appointed originally to be their Attorneys now. So it's important to check whether an Enduring Power of Attorney is still suitable and what the person would want it to be today.'

Jeff adds: 'The other key point about Enduring Power of Attorney is that it

only relates to financial matters, not to Health & Welfare. So if your loved one made an Enduring Power of Attorney some years ago, I recommend they get it reviewed and

potentially replaced. They should consider updating to a Lasting Power of Attorney for Property & Financial and adding the Health & Welfare.'

***'People don't always realise there are two types of Lasting Power of Attorney'***

**CHOOSING CAREFULLY**

It's important that your loved one thinks very carefully about who they appoint as their Attorney.

Is the person(s) they have in mind completely honest? Are their own finances in good shape? If the person has any doubts, they shouldn't take chances. Fraud is not uncommon, even among family members. The charity, Action on Elder Abuse, reports that 20 per cent of calls to its helpline concern financial abuse.

A report by King's College in London and the National Centre for Social Research in 2007 revealed that 57,000 people aged 66 and over in the UK had suffered financial abuse by a friend, relative or care worker in the past year.

### DIFFERENT METHODS

One way to minimise risk is to appoint more than one Attorney. At least two would be ideal. It's also worth noting that there are different ways of appointing Attorneys when setting up a Lasting Power of Attorney, as follows:

⊕ The first is Jointly – where the Attorneys must make decisions together and must all sign paperwork.

⊕ The second is 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.

⊕ The third option is Jointly in respect of some matters and Jointly & Severally in respect of other

matters. That's a mixture of the two, but you must be very specific as to what decisions are to be jointly made and what decisions are to be made Jointly & Severally.

It's currently taking an average of 22 weeks for the Office Of The Public Guardian to register an LPA, so it's essential to act swiftly.

***'Health & Welfare means that the Attorney can make decisions about the person's medical care'***



A person can have more than one Attorney

### CAN A PERSON REVOKE AN LPA?

Once the person has the Lasting Power of Attorney in place, if they feel 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.

### WORRIED ABOUT FINANCIAL ABUSE?

If you are a carer and have concerns about someone abusing their status as an Attorney, then you can contact the Office of the Public Guardian on [0300 456 0300](tel:03004560300) or by email at [opg.safeguardingunit@publicguardian.gsi.gov.uk](mailto:opg.safeguardingunit@publicguardian.gsi.gov.uk).

If you sense something isn't right, trust your instincts. **DH**



### More Information

Jeff Smith from MB Associates can help with setting up a Lasting Power of Attorney. Call [020 8652 5240](tel:02086525240) or email [info@mbassociates.net](mailto:info@mbassociates.net). Visit the website at [mbassociates.net](http://mbassociates.net). For more general information on Lasting Power of Attorney, visit [gov.uk/power-of-attorney](http://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](http://ageuk.org.uk)

### ALZHEIMER'S RESEARCH UK

*A charity conducting research into finding treatments for dementia.*  
 Infoline: 0300 111 5555  
[alzheimersresearchuk.org](http://alzheimersresearchuk.org)

### ALZHEIMER'S SOCIETY

*Help and support.*  
 Support: 0333 150 3456  
[alzheimers.org.uk](http://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](http://carersuk.org)

### DEMENTIA CARERS COUNT

*Free online learning about dementia.*  
 Support line: 0800 652 1102  
[dementiacarers.org.uk](http://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](http://dementiahelpuk.com)  
 Email: [christina@dementiahelpuk.com](mailto:christina@dementiahelpuk.com)

### DEMENTIA UK

*Specialist support for advice and information on dementia.*  
 Helpline: 0800 888 6678  
[dementiauk.org](http://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](http://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](http://youngdementianetwork.org)  
 Email: [youngdementianetwork@dementiauk.org](mailto:youngdementianetwork@dementiauk.org)

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### Healing

Contact - Telephone - Skype - Zoom  
E: [healingreception@burrowslea.org.uk](mailto:healingreception@burrowslea.org.uk)



### Distant Healing

Email [healing@burrowslea.org.uk](mailto:healing@burrowslea.org.uk) or write to us at: Harry Edwards Healing Sanctuary, Burrows Lea, Shere, Surrey, GU5 9QG



### Support Groups

**Bluebells Cancer Support**  
Bluebells is a friendly, sharing group for anyone with cancer. Please contact Stephanie Beinart on **07795 150731** to find out more.

**Bereavement Support Cafe**  
We run a welcoming and supportive cafe for anyone affected by bereavement. For further information please email Alison McWhinnie at: [alison.mcwhinnie@burrowslea.org.uk](mailto:alison.mcwhinnie@burrowslea.org.uk)

### Retreats

1/4/5 day retreats - Groups - Events  
E: [events@burrowslea.org.uk](mailto:events@burrowslea.org.uk)

### Online Healing Events

Healing Minute - Healing Circle - Healing for You

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[healingreception@burrowslea.org.uk](mailto:healingreception@burrowslea.org.uk)

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## Who Can Healing Help?

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- Healing cannot harm you
- Can often help with mental wellbeing and from the effects of treatments such as chemotherapy and radiation therapy

## Benefits:

- Creates deep relaxation
- Aids the body to release stress and tension
- Aids better sleep
- It may help you to stay well if you care for someone else with a health issue