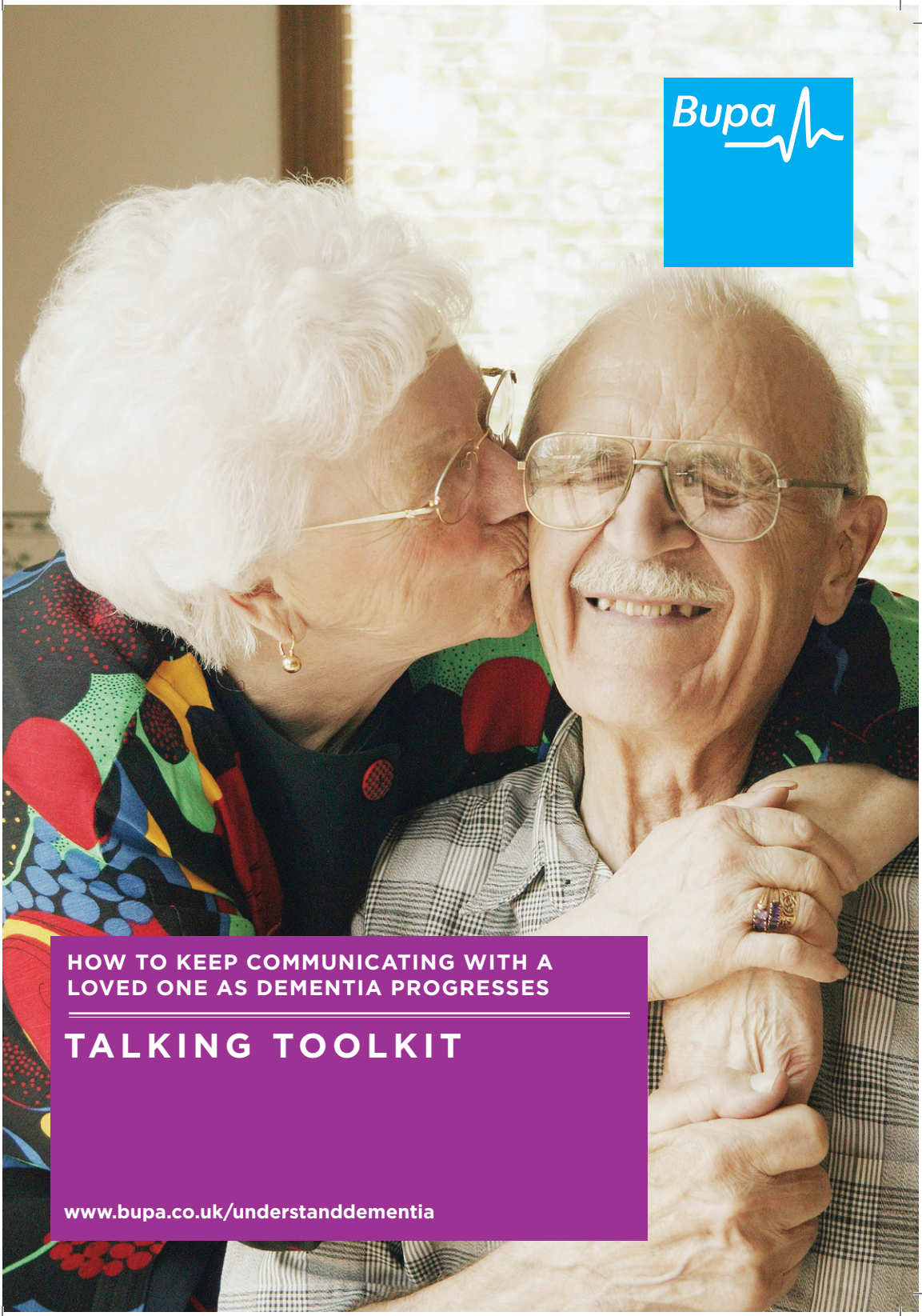


HOW TO KEEP COMMUNICATING WITH A LOVED ONE AS DEMENTIA PROGRESSES

TALKING TOOLKIT

www.bupa.co.uk/understanddementia

CONTENTS

ABOUT DEMENTIA

There are about 800,000 people in the UK with dementia and this is expected to double over the next 40 years.

Dementia is a broad term which describes a set of symptoms that develop as a result of damage to the brain. The symptoms typically include memory loss, difficulty communicating and changes in mood. Dementia is a progressive condition, which means it gets worse over time.

There are many different forms of dementia, including Alzheimer's disease, vascular dementia, and Pick's Disease. It is more likely to affect people over 65, but can affect younger people too. In the later stages, people with dementia become unable to do everyday things and will need increasing amounts of support.

Early diagnosis of dementia is important as it can help you or a loved one to access drugs that slow down the progression of the condition, receive counselling, advice and support, and importantly it can give you the time to plan and make important decisions about the future. If you're worried about a loved one and their memory loss, it's important to see a GP as soon as possible.

Bupa is the UK's leading provider of dementia care. We combine experience and expertise to care for over 8,000 residents living with dementia, providing a safe, comfortable and stimulating environment in care homes across the UK.

Bupa's expertise in dementia care includes an innovative 'person first' approach. Our care revolves around each person's own needs, not fixed rules and routines.

INTRODUCTION

Communication is vital to our lives and to our relationships. It is so much more than just a way to deliver factual information – it is the way we express what we think and how we feel. Losing the ability to communicate is one of the most debilitating and isolating things that can happen to a person. Watching a loved one lose the ability to communicate can be just as distressing.

Professor Graham Stokes, Director of Dementia Care, Bupa.

For people living with dementia, and for their carers or those close to them, communication can be a daily struggle. Dementia is a progressive condition, and as it progresses, it increasingly affects a person's ability to convey their thoughts and feelings. The inability to communicate can leave carers feeling that there is a great emotional distance between themselves and their loved ones. This booklet has been designed as a practical guide to bridge that gap and help carers cope.

As the changes they see in their loved ones become more acute, carers of people living with dementia need to be adaptable. It is one of the hardest things to accept that what worked for Mum five years, five months, or five days ago, might now be met with a blank expression or a lack of understanding. But to give people with dementia quality of life, it's very important that carers can recognise when change is needed to better support the person they care for; this includes the way they communicate.

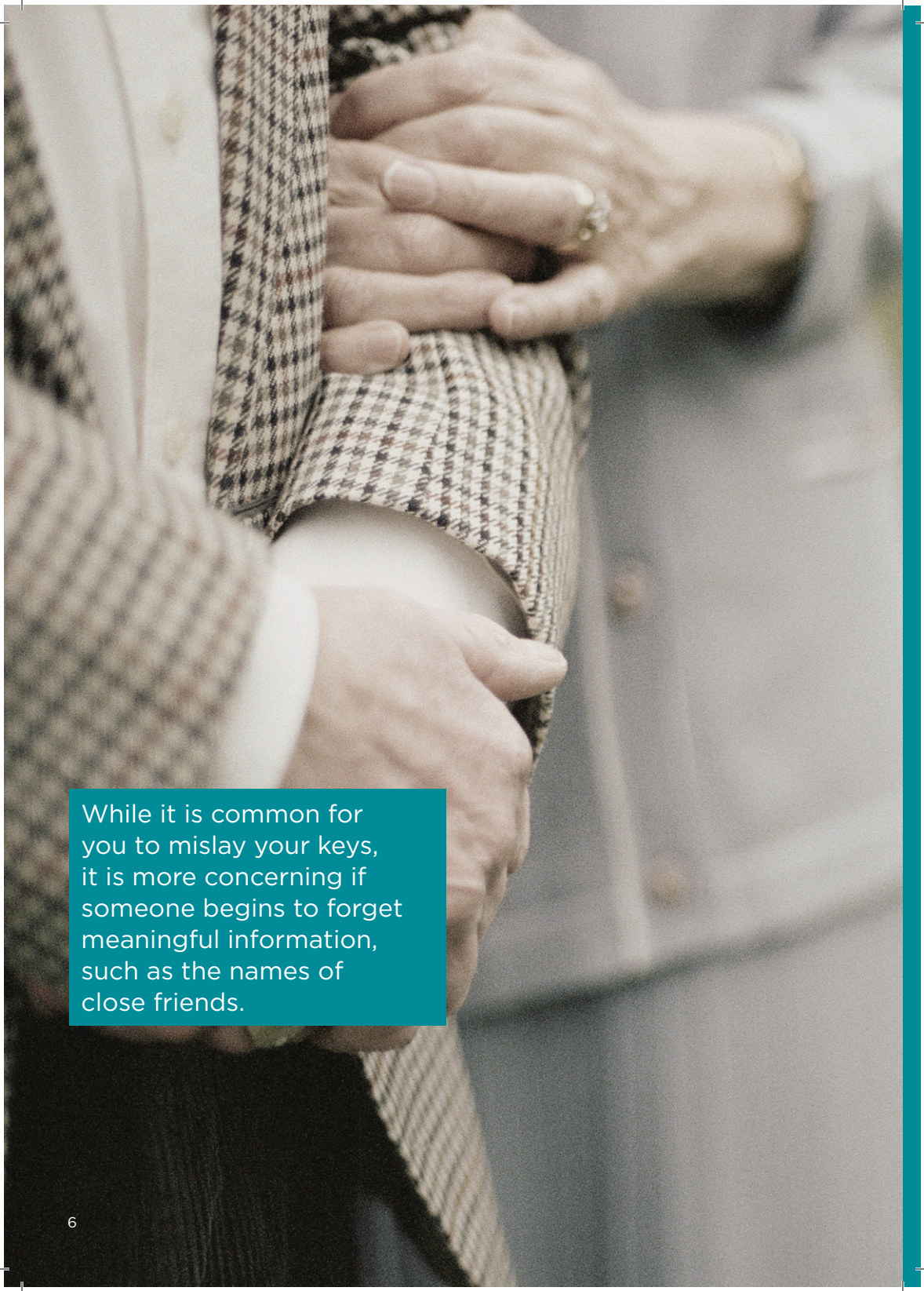
There is no 'silver bullet' to cure people with dementia, but it is a condition which can be managed and, if handled sensitively, it is possible for people with dementia to live well. It is vitally important that as a carer, you have a sense of what to expect. You are then best placed to feel that you are doing all you can.

USING THIS GUIDE

This guide has been developed for the friends and relatives of people with dementia. Whether your loved one is at home, or in a care home, each section of this guide will provide practical tips on how to communicate with them at every stage of dementia, advising carers on steps they can take to connect with their loved ones, and to help them have a good quality of life.

For ease of use, and to help carers navigate the dementia journey, we have divided this guide into four stages, at each stage giving examples of how the condition changes as it progresses. It's important to realise that the speed at which people progress through these stages can vary considerably and that the condition will manifest itself in different ways for different individuals.

The four stages of dementia are:



While it is common for you to mislay your keys, it is more concerning if someone begins to forget meaningful information, such as the names of close friends.

MEMORY LOSS AND CONFUSION

Memory loss, and the subsequent 'not knowing' and confusion it causes, is usually one of the first signs of dementia. At this stage, forgetfulness and disorientation can often lead to anxiety and frustration, where the person with dementia is aware something is wrong, causing them to begin to feel they are no longer in control of their own actions.

It is important to note the difference between common moments of forgetfulness which happen to everyone, and more concerning signs of 'extraordinary forgetfulness', which could be indicative of the earliest stages of dementia. For example, while it is common for you to mislay your keys, it is more concerning if someone begins to forget meaningful information, such as the names of close friends. Common characteristics of people who are experiencing this early memory loss include confusing everyday tasks, such as storing food in the cooker instead of in the fridge, as well as muddled language, such as using the wrong word at the wrong time.

While you may find that conversations still flow relatively well in this early stage of dementia, there are some simple things you can do to help the person with dementia feel that they are in control and to reduce any anxiety they may feel when they confuse words or forget simple things.

Here are some tips on communicating, which you may find helpful:

Keep it simple and focused on what's important
Dementia isn't just about memory. It can also affect a person's ability to reason, to process information, and to learn. This means the person with dementia may not only have problems recalling words, they may also take longer to understand.

- Try to speak slowly and distinctly, using clear and simple words.
- Where possible, keep conversation brief, as it's very easy for people with dementia to lose the thread of the discussion if you talk for too long, and this can lead to frustration for both of you.
- Try not to ask open questions, as this can be confusing for someone with dementia. All questions should have a direct yes or no answer, or lead them to the answer. For example, instead of asking "What would you like for lunch?" ask "Would you like a cheese sandwich?"
- Speak as clearly as possible and use 'real names' for people and objects rather than words like 'it', 'she' or 'them'. This will help the person with dementia to keep a hold of the thread of conversation. For example, instead of asking "Do you like it?" ask "Do you like the cake?"

Try not to ask open questions, as this can be confusing for someone with dementia.

Be patient

- Try not to finish the person's sentences for them. If you can sense they are struggling to find a word, you could ask a question which might provide a helpful prompt. For example, if they are saying "I want to go... I want to go...", you could ask "Do you want to buy something?" The prompt should always take into account the context. Has the person put their coat on, or are they hovering by a door? Is it a time of day when they usually do something?
- Never say "I've told you this before." It's important to remember that if the person starts repeating themselves or asking you the same question, it's likely they have simply forgotten they have asked you before, due to the memory issues associated with their condition.
- Give the person time to respond, and while it may be hard at times, try not to get angry or frustrated if they don't understand.

EVEN SIMPLE THINGS CAN MAKE A BIG DIFFERENCE

- Try to remove distractions such as TV or radio when you are trying to communicate.
- Face the person and use their name, to ensure you have their attention.
- One-to-one conversations will be easier, but if you can't avoid a group situation, try to ensure only one person speaks at a time.

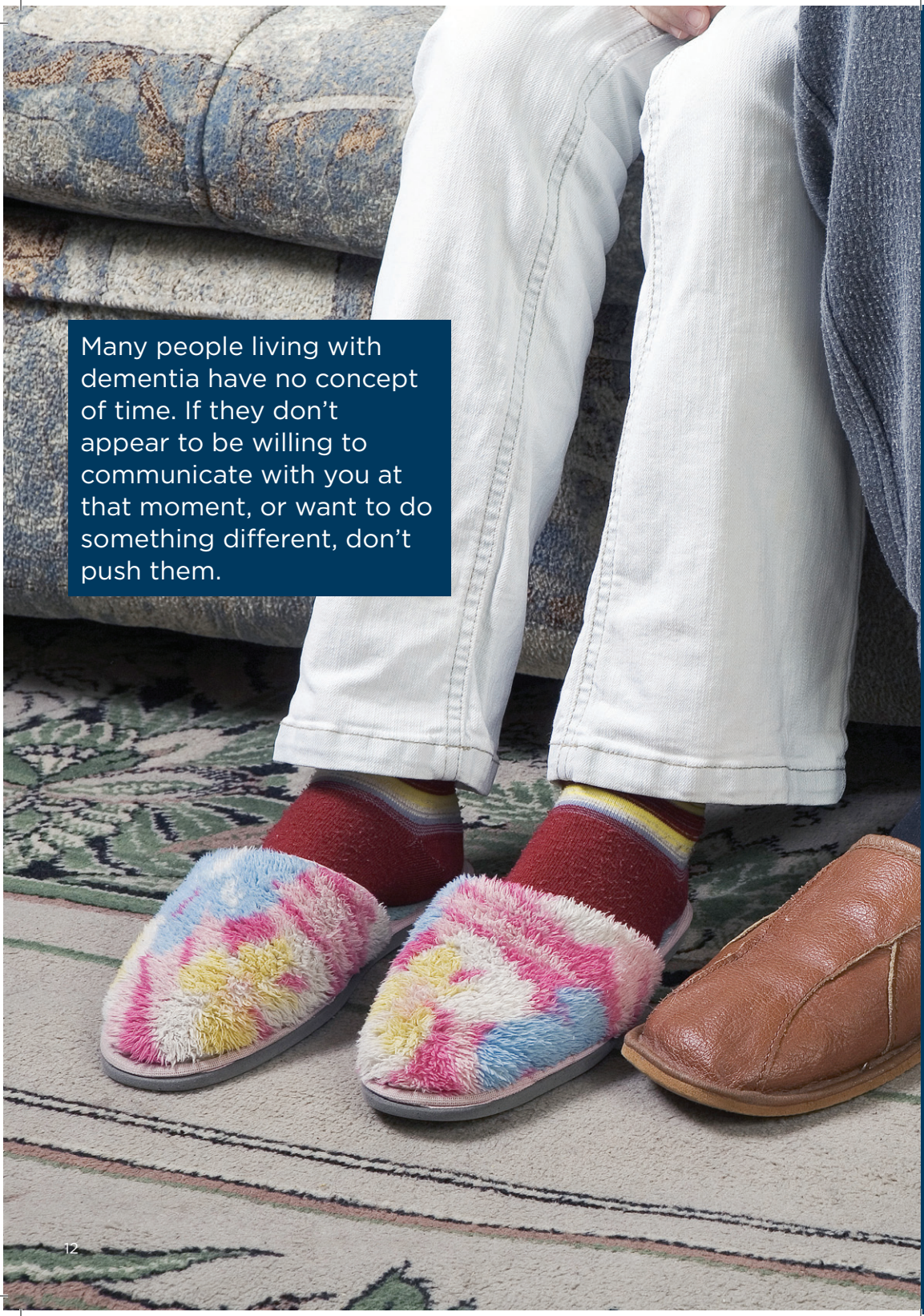
If they get muddled, or begin to say things you know to be incorrect, try not to directly contradict them.

Reduce anxiety

- Remember that as the person with dementia's short term memory worsens, they are likely to feel anxious, confused and self-conscious. If they get muddled, or begin to say things you know to be incorrect, try not to directly contradict them – this will only increase their feelings of confusion.
- Instead of contradicting or directly correcting what they say, it is more productive to accept what they say as their idea of the truth, and move the conversation along. Being told they are wrong is likely to confuse them further, and will do little to soothe their anxiety.

  For example, if your mother is convinced she has passed on a message or given you a letter to post, but you know she has definitely not, don't make a big issue of this. Instead, make light of it and move the conversation on: "Do you know I'm so scatter brained nowadays I can't remember. I must be doing too much. Do you know, only yesterday..."

> **"One of my residents regularly believes he has left his wallet at the pub. Rather than distressing him further by telling him he is wrong, I simply let him know I'll call in at the pub and collect his wallet for him. This reduces his anxiety at that moment – and he soon forgets that he has asked the question."**
>
> Annie James, home manager, St George's Nursing Home


Many people living with dementia have no concept of time. If they don't appear to be willing to communicate with you at that moment, or want to do something different, don't push them.

BEHAVIOUR WHICH CHALLENGES US

As dementia progresses, the changes in the person living with the condition become more marked. This may manifest itself in obvious physical signs, such as an unkempt appearance or weight loss (people with dementia often forget to eat). It could also become evident in behavioural changes, such as becoming verbally or even physically aggressive – often as a result of feeling frightened or frustrated. The person with dementia may need more support to help them manage their day-to-day living, for example, needing reminders to eat or wash.

People living with someone with dementia may also notice more subtle changes, such as walking about in the middle of the night or erratic eating habits.

It can be distressing to see such changes in the behaviour of a loved one, and feelings of frustration are not uncommon for those caring for someone with dementia. It can be very hard, but understanding that their behaviour is the result of upset, insecurity or an attempt to tell you what they want, is the key to communication.

Here are some tips that may help to deal with communication at this stage of dementia:

- **Help the person retain control** – Think about tasks and activities they could do which will help them to feel valuable, such as everyday jobs they used to do and enjoy. Are there tasks they could help with around the house? Peeling vegetables before dinner, or doing some dusting?
- **Give clear and helpful instructions** – When a person with dementia is becoming more deeply affected by the condition, consider how you can help them to maintain control through simple, effective, communication. You may find that seemingly straightforward requests, such as "Please make me a cup of tea" can cause significant frustration for the person with dementia, whereas making the tea together, with clear instructions, can give back a sense of control. For example, "Fill the kettle with water", "Boil the kettle", "Get a tea bag from the cupboard" etc.
- **Be flexible to their world** – Many people living with dementia have no concept of time. If they don't appear to be willing to communicate with you at that moment, consider whether they have just woken up, or have been awake all night. Perhaps they are simply tired, and not in the mood to converse, or want to do something different such as sleep or watch TV. It's also worth remembering that even if you get no response from the person with dementia, it's important not to speak as though they weren't there as this can make them feel frustrated and ignored.

Seemingly straightforward requests, such as “Please make me a cup of tea”, can cause significant frustration for the person with dementia.

- **Know when to walk away** – If someone is physically or verbally aggressive, take a deep breath and walk away. Remember it isn't easy to live with dementia. You can always go back and try again another time.
- **Have someone to support you** – In all stages, as the person with dementia's condition starts to change, it's important to have someone to share your concerns with. Having someone to share the burden of caring and give you a break from time to time is incredibly valuable.

> Make sure you have a family member or friend who you can confide in. You need to look after yourself.

- **Don't hide the dementia** – You may find it helps to keep friends, colleagues or other family members regularly updated about the person with dementia's condition, so they make allowances and are more accepting of behaviour which appears to be unusual or strange.

“We look after a lady with dementia who sometimes becomes confused, thinking that our care home is her previous house. She becomes verbally very aggressive to other residents and staff, demanding that they leave. We know that telling her the truth only exacerbates the problem, so instead we divert her attention by taking her on memory walks around the home, stopping off at various points of interest along the way. These could include anything from old photos to pictures of historical events, to items of personal meaning to her.

She was actually a recorded soprano in her younger days, so we play music to her. And very quickly, she forgets what upset her, and can be returned to her fellow residents with a smile and no mention of her previous outbursts at all.”

Sandra Holt, home manager,
Maes-y-wennol Residential Home

Remember that no solution is a permanent solution, so while one approach might work one day, a different approach may be required the next time.

LOSING GRIP ON THE PRESENT

During the third stage of dementia, the person living with the condition may start to lose their grip on the present, or even on reality as you know it. As they become more confused in their day-to-day lives, the person with dementia may begin to retreat into the safety of established memories. They may also become confused by familiar faces or places, mistaking their daughter for their wife, or thinking they are in another place or time.

This stage can feel particularly hard for carers as the person with dementia becomes more dependent, and loses awareness of the world and people around them, as well as any understanding of their condition. The burden increasingly falls on the carer, and it's common to feel very isolated at this stage. You may feel you have 'lost' your loved one, however communication at this time remains more important than ever. Relatives of people living with dementia can often feel real distress when their loved ones ask difficult questions, such as asking to see a mother who has passed away or believing they need to go to work or collect children from school.

Dealing with such issues can be difficult, so here are some techniques you can use to help deal with such situations.

Join their world

- Firstly, try not to contradict the person with dementia as this could increase their anxiety. Remember that, at that moment, what they are saying is what they believe to be true.
- Join their world. Focus on how you can put them at ease, thus reducing their anxiety. For example, if they constantly ask for their mother, who you know is deceased, rather than correcting them, you could simply respond "Tell me about your Mum, what was she like?"
- Do not feel guilty that you are lying to them or encouraging what may seem to you a fantasy. If you can make the person with dementia feel content, relaxed and at ease rather than anxious, sad or distressed, you are simply doing the best thing for them. This is known as 'collusion'; not barefaced lying, but a way to give someone what they do not possess, peace of mind.

> **"I knew an 84 year old woman who thought her son was seven years old. She reacted with fury when she was told that he was much older. Instead the carer could have said, 'Have you any photographs of him. I'd like to see. I bet he was a handful', or simply, 'Your son. You must be really proud of him'. These are feelings which are untainted by the passage of time."**
>
> Professor Graham Stokes

- Always try to focus on the emotion, rather than the actual communication. If they say they need to go to work, why could this be? Is it that they are remembering a time when they felt useful?
- Try to put them at ease by looking at some familiar photographs or talking about something you know they love.

> When you understand the meaning behind their behaviour, you'll be more able to find solutions to help them cope.

"I remember a resident who used to wake up at 4 o'clock in the morning and try to leave the home through the front door. We realised that this was because she used to live on a small holding, and she was heading out to collect the eggs. So we left her coat on a hook by the door, and put some boiled eggs in a safe place nearby. Once she picked them up, she felt like she'd done her job for the morning, and we could bring her inside for a cup of tea."

Dawn Harbour, home manager, The Gables Specialist Nursing Home

Creating connections

It is a common misconception that when someone has dementia, they lose their personality. However this condition does not change someone's personality, rather, it affects their ability to recall memories, process and recall language, or differentiate between past and present. The result is that their behavior and how they express their emotions changes, giving the impression their personality has changed.

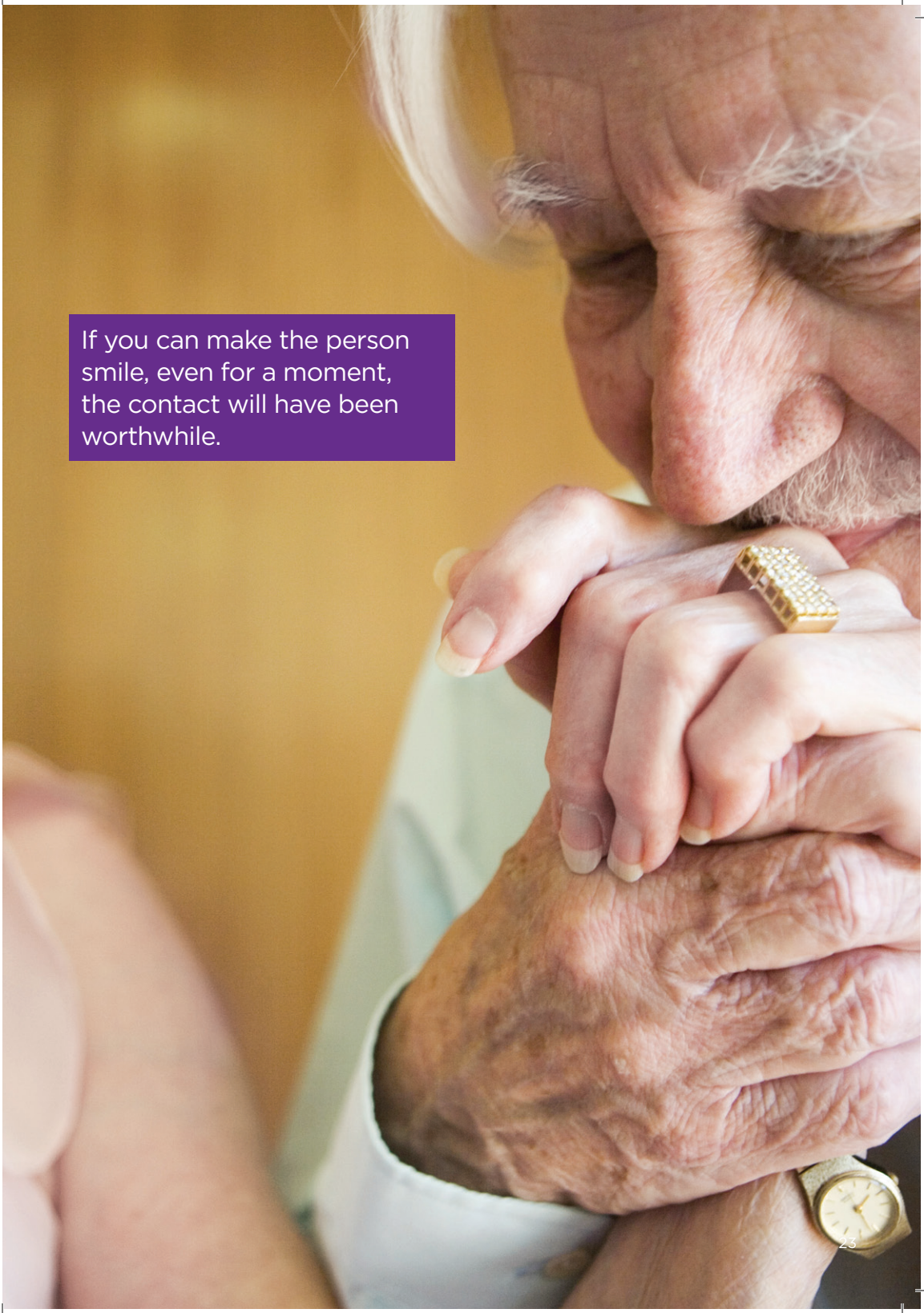
As a result, the most successful connections are the ones that carry deep-seated meaning for the person with dementia.

If you have reached a point where you feel your relationship with your loved one is diminishing, or you feel you are struggling to communicate or make a connection, here are some tips that might help strengthen your relationship.

- If you engage in a conversation with someone with dementia, make sure it is meaningful to them. Talk about things they like talking about, whether this is sport, their family or another hobby or pastime. Flippant conversations and statements can confuse them and increase their anxiety.

INCREASE COMFORT, REDUCE ANXIETY

As dementia progresses, so might anxiety. As the person with dementia begins to lose grip on reality, they no longer have the knowledge of what is happening, where they are or who is around them. At this stage in the journey, it's vitally important to focus on how you as a carer can reduce that anxiety.


If you can make the person smile, even for a moment, the contact will have been worthwhile.

- Use memories to connect with your loved one. While recent memories can be a struggle for people with dementia, they can often recollect times from their youth and early adulthood.
- Another common misconception about dementia is that if the person no longer appears to respond, then there is no point in engaging. However, if you can make the person smile, even for a moment, the contact will have been worthwhile. Think about what would make them 'come alive'. This could be playing a meaningful piece of music that triggers happy memories, or watching an old film from decades ago.
- We all have bad days when we don't feel like talking, or feel irritable. Do remember that this is also true for people living with dementia, so sometimes communication may not be a success. If this happens, try again later.

REMINISCE TOGETHER

Reminiscing can bring back happy memories for our residents and create a sense of wellbeing. So in Bupa Care Homes we encourage family members and loved ones to help residents put together a Memory Box filled with meaningful items such as photographs, keepsakes and other special objects collected over the years. These also can help them recognise their room. This is something simple that anyone could do at home to create connections with their loved ones.

“Looking after our residents means living with them at that moment in time – whatever that moment happens to be for them. Recently the husband of one of our residents passed away, and she often asks us about him. We understand her character, and knowing that she has a lovely sense of humour, when she asks if her husband is out we may say something like “He’s probably spending too much money!” which makes her laugh. Rather than upset her, we know that it’s sometimes kinder to follow on with her reality.”

Dawn Harbour, home manager, The Gables Specialist Nursing Home


“I told Geoffrey it was no longer about supporting, caring, doing, it was about being. Not even talking. Just being close, sitting there, sharing a view, holding hands.”

PHYSICAL FRAILTY AND DEPENDENCY

In the most severe stages of the condition, the person with dementia has now lost the physical capacity to care for themselves. The person may appear to be completely disconnected from the world and people around them, and may be almost totally unable to communicate. Because of their physical frailty and dependency, the person may require more care than is possible to provide single-handedly at home, and may, therefore, be living in a care home.

At this stage of dependency, communication may be possible only through physical contact; however this can make a huge difference to the person with dementia. This section provides some advice on maintaining that important connection with your loved one, without the use of language.

- Firstly, remember that even if the person with dementia is no longer able to communicate with you by talking, your physical presence alone may be enough to reassure them or put them at ease.
- Likewise, even if they cannot respond with words, show them how you feel. Sometimes holding hands, gently touching or hugging will get the person with dementia to respond.
- It may be an obvious point, but maintain eye contact with the person you are communicating with. It's a simple, yet effective way to show you are engaged, and trying to connect.

Visual clues

- Try to observe visual clues from the person with dementia. They may use facial expressions to show they understand, or are content.
- Look out for smiles, looks of confusion or distress as clues to what is being understood, or misunderstood.
- You can also observe their breathing to gauge emotional effect – faster breathing may indicate distress, while slower breathing may show they are calm.
- Likewise, remember that they may be looking for clues too – so if you look angry, frustrated or confused, they are just as likely to read this as you would. A smile can go a long way!

A PICTURE CAN PAINT A THOUSAND WORDS

"A picture can paint a thousand words" – never so true a saying as for people with dementia. Where words fail or you are struggling to get your message across, think about how you could communicate using gestures, pictures, photos or facial expressions. Remember that you're speaking in an attempt to communicate, and there are many different ways to do that.

- If you're trying to get a response from the person with dementia, show them what you mean rather than asking a question repeatedly. For example, if you are asking if they would like a sandwich, or a bowl of pasta, show them the food to reinforce the question.
- Many of us use gestures in our day-to-day lives to make communication easier. Think about how you use hand signals in a restaurant to demonstrate that you would like the bill, or signal that you'd like someone to call you? This is a simple way to make communication clearer and easier for the person with dementia. For example, asking whether they are cold or hungry could be coupled with the appropriate actions to emphasise the question.
- If you are struggling to engage with the person with dementia and feel at a loss as to how to make a connection, you could use prompts such as pictures or old photographs.

> The simple action of sharing a moment together or reminiscing over family photographs may help you to maintain your relationship.

FREQUENTLY ASKED QUESTIONS

Communicating with someone with dementia can be frustrating and tiring, and at times you may wonder whether your efforts are worthwhile. However you are not alone and many of the questions you may want to ask are likely to have been asked before.

Here are some of the common questions, encountered by Bupa dementia care experts on a regular basis, answered by Professor Graham Stokes.

Q: I feel I don't know how to talk to my husband/wife/mother anymore. How can I reconnect?
A: It's normal to feel afraid that you no longer know how to connect with your loved one, particularly if they have reached a stage with their dementia where they no longer appear to understand or seem incoherent. The most important thing to remember is that they are still the same person. Although they may seem to have little understanding or ability to communicate, they may respond to affection and enjoy interests that have always been a part of their life. Think about the things they used to enjoy, whether that was music, sport, watching TV or gardening, and try to engage on that subject. You could also use visual or other sensory stimuli to engage with them, such as sitting in the garden where smells, colours and sounds come alive. Making a happy meaningful moment, even if it is just for a short period of time, is hugely beneficial to the person – even if minutes later it is forgotten.

Q: My mum, who has dementia, keeps asking for my Dad. Should we tell her that he has died?

A: This is not an uncommon question asked by people with dementia and it can be very distressing to have to answer again and again. If a loved one has died recently, you could remind the person with dementia of this fact a few times to see if they remember; however, it is important to use your judgment to avoid causing unnecessary upset.

Consider each response you give as a way to reduce the person's anxiety. If the person genuinely can't remember, repeatedly having to break the news that someone has died can be as painful as the first time they heard it because, to them, it is the first time. Causing such distress and grief isn't necessary, so instead, try to put them at ease. You can avoid the direct question by engaging them with conversation. In this instance you could say, for example "You and Dad used to go walking together didn't you? Where was your favourite place? Let's see if we can find some photos."

Don't feel bad that you have not given the whole truth, as you have the person's best interest at heart and are focusing on what's important – reducing their anxiety.

Q: I feel myself getting angry when I have to repeat myself for the hundredth time and this makes me feel guilty. What can I do?

A: Caring for someone with dementia can be frustrating and tiring, so it's no wonder people feel angry and irritable from time to time. No one should sacrifice themselves entirely for someone else, nor should you feel guilty if you want some space for yourself, or a day off to do something fun. It's so important to make time for you.

Having time away from caring doesn't necessarily have to be physical – it can simply be having some time alone at home to read, relax or even sleep. Many people find that sharing the load of caring for someone with dementia is valuable.

If you don't have friends or relatives available to support you, look for a care home near you which offers short term or day care to support the carers of people living with dementia. If the person with dementia is already in a care home, don't feel that you need to visit every day. Take some time out, do something for yourself, and you'll feel all the better for it. It's also important that you have someone to talk to, so you can share your thoughts and concerns.

A few hours off now and then is the least you deserve; feeling guilty is common, but your health and wellbeing needs to be a priority. Visit www.carewelluk.org for more information on looking after your own health whilst caring for someone else.

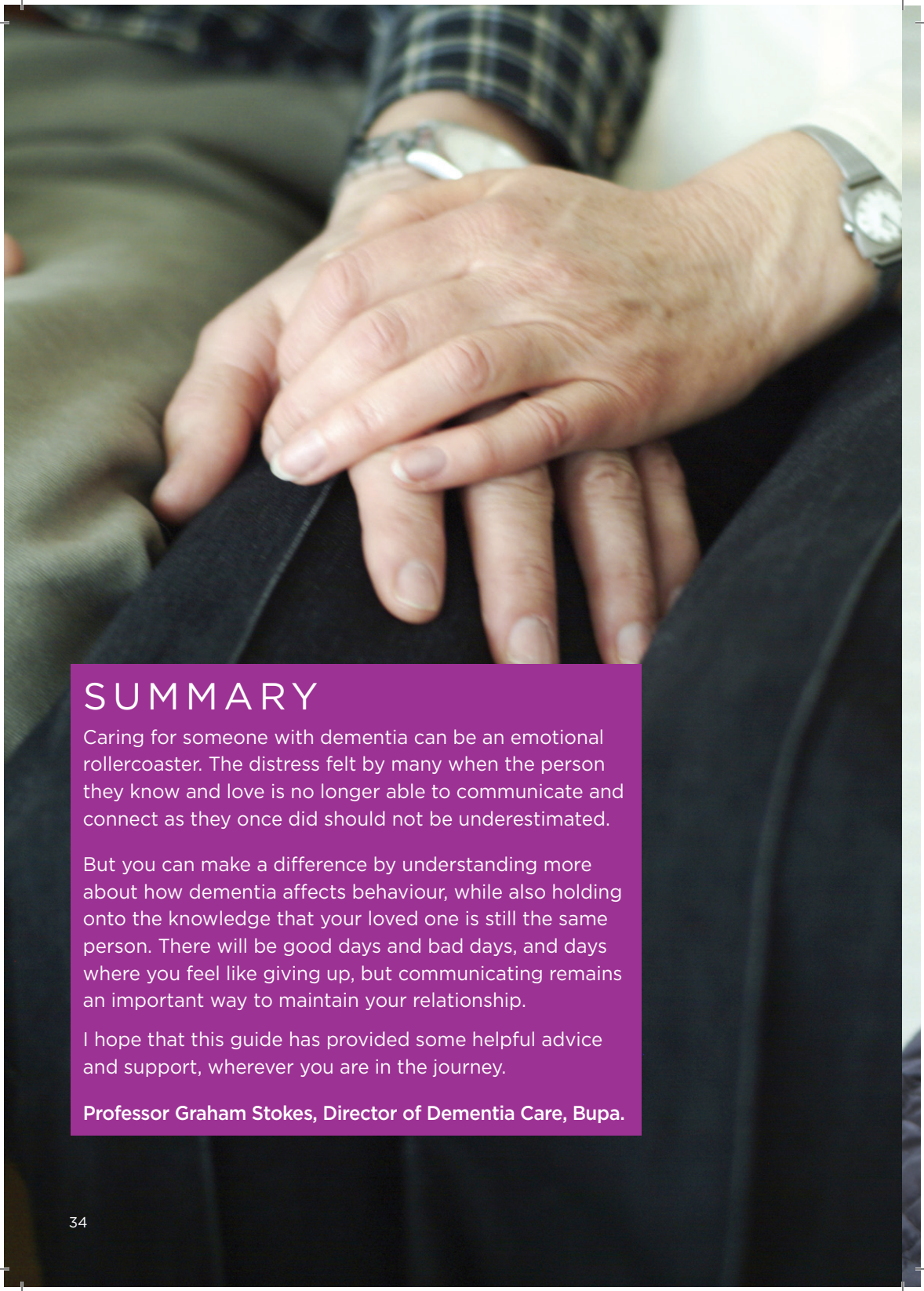
Q: My partner won't let me hug them anymore. I feel as though they don't love me anymore. Why have they changed?

A: It can, understandably, be distressing to see a loved one distance themselves physically and emotionally from you. However it's important to remember that this is not a personal attack on you – it is the dementia affecting their memory. It could be that they are confused about who you are – and it's only natural that you wouldn't welcome affection from someone you don't know well. Or perhaps they are mistaking you for another relative, who they wouldn't usually hug?

It doesn't mean they will never want affection from you, but you may need to judge carefully what is appropriate – depending on how they are, and the stage of their dementia. It's also important to remember that people with dementia have good and bad days, and sometimes they might just feel tired, frustrated or confused.

Q: My Dad won't answer to the name Dad anymore, why is this?

A: If your Dad doesn't recall that he is a father, or believes you are someone else, such as his wife or mother, it may seem strange that you are addressing him by the name Dad. Instead, try using his first name, or a nickname that he is used to others using.



SUMMARY

Caring for someone with dementia can be an emotional rollercoaster. The distress felt by many when the person they know and love is no longer able to communicate and connect as they once did should not be underestimated.

But you can make a difference by understanding more about how dementia affects behaviour, while also holding onto the knowledge that your loved one is still the same person. There will be good days and bad days, and days where you feel like giving up, but communicating remains an important way to maintain your relationship.

I hope that this guide has provided some helpful advice and support, wherever you are in the journey.

Professor Graham Stokes, Director of Dementia Care, Bupa.

CONTACT DETAILS

For other useful sources of information and support, please visit **www.bupa.co.uk/understanddementia**

Call 0800 600 500 for information on all other Bupa services. Lines open 8am–8pm Monday to Friday 9am–5pm on Saturday. Calls may be recorded and may be monitored.

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