



# COPING WITH CHALLENGING BEHAVIOUR

*A guide for families and carers*

A note from the author...

## **'Her mood changes were rapid and often out of the blue'**

I cared for my late mother Hazel, who had vascular dementia, for five years until finally accepting that she needed 24-hour nursing care in 2014. I learned a great deal about how to care for and communicate with a loved one who has dementia. I did everything I could to make mum feel safe and happy, so I was upset when she sometimes became angry or aggressive. Her mood changes were rapid and out of the blue. One minute she was happy, the next she would become angry or tearful.

At the time, I didn't consider how much the dementia was affecting mum's brain. I also didn't understand that there were underlying reasons for her mood changes. Once I realised the mood swings had a pattern and usually occurred at around the same time (often at 4pm

when mum knew I would be going home), I used key strategies to manage her behaviour. Sometimes her anger was borne out of anxiety and fear. She feared being on her own later in the day. Reassuring her I would be back the next day and making sure she knew that friends would be popping in to see her later on (which meant leaving reminder notes) made things much easier.

This exclusive Alzheimer's Show guide contains practical tips on coping with challenging behaviour that I wish I'd known at the time. I hope you find it useful and you're able to apply some of the advice here to your own situation.

## The challenges we face as carers

Caring for a person with dementia can be extremely challenging and stressful – emotionally as well as physically. If the person with dementia is your partner or parent, you may have relied on them in the past and now you have to accept that your roles are reversed and they are relying on you. While there is help available for domestic tasks, like washing, dressing, shopping and cleaning, there is one unpredictable element of dementia that can strike at any moment and often without warning – mood swings. Sudden changes in mood can be one of the most difficult challenges we face as carers. Moods can be unpredictable and can change swiftly. One minute the person can seem happy and content, the next they may be shouting, swearing, crying or even threatening someone. Although clearly upsetting for carers and relatives, it's important to understand that dementia is a disease of the brain, so mood changes are likely and in some cases the person with dementia can become angry. But of course it's difficult for an often tired and stressed carer to cope with sudden mood swings.

## Shouting and screaming

What if the person is shouting or screaming at you for no reason, or they suddenly lash out when you are trying to help them get washed and dressed, or move them from a chair to the bed?



What if they suddenly burst into tears? What's the best way to deal with the situation and not cause further upset to both parties?

## Reasons why they may be angry

Firstly, it's important to think about why the

person might have suddenly become angry or upset rather than just trying to deal with their mood, (which is a bit like taking a headache tablet rather than working out why you keep getting headaches). Here are some points to consider that may be causing the anger so that you can either manage their moods or avoid the situation from arising altogether...

## Find out if pain is the cause

If the person is unable to explain that they are in pain, then shouting can be their way of defending themselves or it may be they are unable to express their needs. 'Establish if the person is in pain because often when people have dementia they are not able to explain they are in pain. They are trying to make it better for themselves but actually they are making it worse, because all you get as the carer is the behaviour,' says Vivien Ziwocha, Head of Care at Red & Yellow Care (<http://www.redandyellowcare.com>). 'Is the person walking with some discomfort or holding their head or their stomach? General analgesia (medication for mild to moderate pain) can help somebody if the doctor is comfortable prescribing it so that you can administer it when the person says they are not well.'

## Acknowledge that there is a reason for the behaviour

Although it may seem completely unwarranted (especially if it occurs out of the blue), the person with dementia is behaving in an aggressive manner for a reason. If they are not in pain, they may be too hot or too cold, or they may be hungry or thirsty. How about the room temperature? Is it too cold or too hot? Even if you feel warm the person with dementia may be cold if they are sitting around doing nothing while you're on the move doing chores. Check to see if they feel warm or cold.

## Food and drink

Think about their dietary needs – have they had enough to eat or drink? Have their eating habits changed recently?

## Increased confusion

If they seem more confused than usual then lack of hydration could be the reason. 'If the person is not hydrated then that's likely to



cause an increase in confusion,' says Barry Sweetbaum, founder of SweetTree Home Care in London (<http://www.sweettree.co.uk/>). 'A urinary tract infection is another very frequent cause of increased confusion,' adds Barry. 'And if someone has vascular dementia, they may have had a small stroke, which is what happens with vascular dementia.'

## If in doubt, check it out

If you are concerned then visit the GP and if the person with dementia refuses to go, then make an appointment and see the GP on your own to discuss the situation.

Other reasons for random mood changes can include a change of environment or a sudden change of routine. Have you moved them to a different room? If they normally feel safe and comfortable in their lounge and they've been moved somewhere else then it could have an

impact. Have they finished reading a newspaper or book and need something else to keep them occupied? Try to see if there is a pattern to their behaviour.

## Are they likely to be bored or tired?

Mood swings can also be caused by boredom or fatigue. Is the person tired from an earlier walk? Or has the person been indoors all day and been doing very little? Could they be bored or restless and in need of stimulation? If their routine has been different on the day they exhibit challenging behaviour then think about what has changed. For instance, if they normally have a morning walk and they didn't go out for a walk on a given day, this could explain the sudden change of mood. Maybe a short walk will do you both good and help to calm them down. If they have already had a walk, give them some space and let them calm down in their own time.



Has the person's sleeping habits changed? Did they have a bad night that involved lots of waking? If they are struggling to sleep then have a chat with their GP.

## Are you doing too much for them?

This may sound like an insensitive question if you've been doing your best to care for a person with dementia, especially if you've made huge sacrifices to care for them. However, in your role as a carer, it's important to make sure that you allow the person to retain some of their independence if possible and reduce the risk of destroying their confidence by doing everything for them. Imagine how you would feel if your partner or loved one did everything for you because they felt you weren't capable of doing anything. You might feel helpless or even

frustrated, not to mention judged by the person supposedly supporting you. Get them involved in household tasks that give them a sense of purpose and make them feel like they are doing something useful. This will help to maintain their confidence and focus.

## A sense of purpose

And it doesn't need to be much. Asking them to help you fold the laundry or wash a few plates will make them feel like they have a useful role to play and help maintain their confidence.

You can even turn frustrating situations around. When my mother was living at home, she would frequently lose things. I would help her look for an item, such as her keys, and five minutes later she would forget she had lost them and ask what I was looking for. I would pretend I was the one who had lost something. 'I've lost some keys,' I would tell her. 'Can you help me look for them?'

Even if she couldn't find them, it involved her in a task and I felt this was better for her, rather than simply saying to her: 'Sit down while I find the keys you've lost.'



Incidentally, it didn't matter in the end that she confused the TV remote control with the keys and thought she'd found them. Sometimes, if I'd already found the keys, I'd go along with it and thank her for finding them, to help restore her self-esteem.

## Consider whether there is a pattern to the behaviour

Does the anger or frustration occur at a similar time of day? Is there any reason why that time of day might be difficult for them? I used to visit my mum at lunchtime and leave at 4pm. When she needed to go into a nursing home, staff reported she became angry and sad at 4pm. When I explained that this was the time she associated with me leaving her, they created other ways of distracting her, like starting a conversation about something she liked or giving her something to do, such as looking at pictures of animals (she's an animal lover so this was pretty much guaranteed to boost her mood!)

## Separation anxiety

Separation anxiety can be an issue for both the person with dementia and the carer. 'The difficulty is that you can't not part with the person,' says Vivien Ziwocha. 'Say you will see them later and reassure them and don't feel any guilt. Don't tell the person you are going to be leaving in about 15 minutes. You might think you are preparing them but in fact all they are doing is getting more and more anxious. Enjoy talking to them until the last minute and then say: "I am going to go now, I will see you tomorrow". It makes it a lot easier for them because they haven't had a long time to mull over the fact that you are leaving. Give them as little time as possible to ruminate over it.'

## When the sun goes down

Sundowning is a term that refers to a sudden change of mood that usually affects a person with mid or late-stage dementia. It usually occurs late in the afternoon or early evening when the sun goes down. Some people believe that it is caused by chemical changes in the brain but there is no scientific evidence to support this and experts aren't sure what the exact cause is. It

could be because the person is tired or feeling restless. A long walk may have worn them out, or conversely, they may be restless if they've not been out of the house and may need to go for a walk to work off any excess energy. See if you can find any activities to distract them. Put on their favourite CD or talk to them about something they like.

## What could you put off for a few hours?

A person with dementia may become angry when you tell them it's time to have a wash or get dressed. While you may want them to shower because that's what most of us are used to doing every day, it may be a traumatic or tiring experience for them and they may simply lack the energy, even if you are helping them. A wash may be more appropriate and comfortable for them, but consider the timing of your request too. If they don't want to wash right away, how important it is to complete the task at that moment? Do they need to get dressed right now?

If they are staying indoors, then it can wait for a while. Maybe they need more time to wake up, or want to eat something first. Try again later if there's no urgency for them to get dressed. If they don't have to be dressed for an appointment, then don't worry about it now.

## See the person's point of view

If they still refuse to get washed or dressed, then try to put yourself in their shoes. 'You have to start from the perspective of why the person is taking the view that they may not want to eat or get dressed,' says Barry Sweetbaum. 'It's their home and it's their life. Most of the challenging situations occur because we create them. I think

we need to turn the whole situation around and speak to the person and understand what they would like.'

An example might include sending another carer in to help them get washed and dressed. Are they familiar with the carer? Do they recognise them? Consider how you would feel if you were asked to get washed in front of a complete stranger.

If you are using a home care agency then encourage the carer to get to know the person and insist that the agency sends in the same carer, with the exception of sickness and holidays.

The person may also refuse to take their medication. Again, don't force the issue. The more of a fuss you make the more they are likely to dig their

heels in and say no. Do they need to take tablets right away? If they are in a bad mood then leave it until they are feeling happier.

## Don't challenge or contradict when it comes to memories

Having dementia can cause a person to lose their confidence. They may be struggling to remember things and a normal conversation that most of us would take for granted can be a difficult challenge. A person with dementia will have to work harder to complete normal daily tasks, which is why frustration or anger can arise sometimes. So if the person is describing a past experience and they get their facts wrong, don't correct them. If they say: 'That holiday last year was fantastic', there's nothing to be gained by saying: 'Actually it was in 2010'. Let them have their memories and tell stories the way they want to remember them. Interestingly, using past experiences to modify and reduce anxiety has been used in residential environments and should be encouraged within the home as a basis for



discussion. When discussing something, always encourage the person's opinion, rather than fact. Seek the person's views.

## When it comes to bereavement, distract and deflect

When a person with dementia asks where their late husband or wife is, I personally believe it's best to change the subject or tell a white lie rather than point out that their loved one is dead. I learned this from personal experience. My mother once asked where my father was and I told her he had passed away, then said: 'Don't you remember we went to the funeral?' I had a lot to learn about dementia at that stage. Mum was not only upset at losing her husband of 50 years but very distressed that she would forget something so significant. I felt terrible as I listened to her grieve all over again, as though he had only just died.



Now, if she asks where her parents or husband are, I will either change the subject or deflect the situation by saying: 'Where would they normally be at this time?' and then offer her a cup of tea. The distraction of the tea will usually work and we can soon move on to talk about something else.

If the person keeps referring to a dead relative, it may be that you need to offer reassurance and make them feel safe. 'They may not be searching for their husband or parent in particular,' says Vivien Ziwocha. 'It's the familiarity and security that this person represented. If they felt very secure with their mother, that's what they are missing.'

## Conversation could be the key...

Another reason why a person with dementia can get angry could be because they are scared and fearful. 'Because we don't know what is happening in the person's mind, we don't know what they are thinking as night-time approaches,' says Vivien Ziwocha. 'They may be wondering, "Is there going to be anybody to talk to me?" "I don't feel safe", or "I don't feel like there is somebody for me to talk to".'

As carers, it's natural that we will tend to focus on practical tasks like helping the person with shopping, domestic tasks and personal care.

However, don't underestimate the value of conversation and interaction. Regular social contact can make a huge difference. 'Somebody with dementia should be engaged in something,' says Vivien. 'Especially if it's something they are still able to do. If somebody enjoys talking to people, let them talk to people. Let them have conversations. You just have to find different ways of communicating and engaging with them.'

## Has anything changed lately?

Unfortunately dementia is a progressive disease and there will be changes in the person's condition. If you notice any key changes then



don't be afraid to visit their GP and discuss them. I distinctly remember the first time my mother called me and asked where her deceased parents

had gone. The first time it happened was a shock, but then it became a regular occurrence. When there are sudden dips in cognitive abilities or memory gets noticeably worse, it's worth letting the GP know and seeking advice on managing the situation. 'Always seek help even if it's a small change,' says Vivien Ziwocha. 'When the person deteriorates, do not be alarmed. Take it within your stride and just understand what it is that the person has lost this time, because they are going to do it in small steps or big steps, but as soon as you identify a change, go to the doctor or nurse and try and identify what they have lost so that you can compensate and try to make their life a lot easier.'

## Accept that you are the one who has to change

Dementia is a disease of the brain, so the person with dementia is unable to change their behaviour, even if their behaviour seems unreasonable at times. 'Remember that the person has changed,' says Vivien. 'They are no longer the person you knew before. Adapting to this can be very difficult but if people allow themselves to transition slowly, then it makes it a lot easier for them. But the environment should meet the person with dementia's needs, not the other way round. I would also advise carers to take care of themselves. Without them being well and having time to themselves they will not be able to provide care for a person with dementia. Carers also need to realise they are doing a fantastic job and that's something they need to continually remind themselves.'



Rikki Lorenti, an Admiral Nurse for SweetTree Homecare Services, has some good advice: 'Carers need to have the time and space to build up resilience, so that they are in a position to continue the caring role, while acknowledging that it was never in their life plan. Carers and families need support, and that "listening ear", so find someone who understands. This can be a friend, relative, professional, carers group or an Admiral Nurse.'



## Come to The Alzheimer's Show and meet our experts in person!

The Alzheimer's Show takes place at London's Olympia on 5-6 June 2020 and brings the dementia community together under one roof, offering support, information and practical advice for families, carers and healthcare professionals. Come along and meet our team of experts, take part in practical workshops, ask Admiral Nurses for advice on coping with dementia and learn more about how you can best care for your loved ones.

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