



## **Phillippa, one of the brilliant staff members at Memory Matters, talks about behaviour that challenges us in this insightful piece into what it must be like living with dementia.**

“Many people have misperceptions and misunderstanding about living with dementia that result in behaviours and/or practices that feel diminishing and marginalising to people affected by this disease. And these people, with the very best intentions, then label those that they are misunderstanding as CHALLENGING.

These people? Well, I put my hand up. I have been one of ‘these people’ whose behaviour labelled my friend John's as challenging.

I had known John and his family for two years. He had been diagnosed as having Vascular Dementia and Aphasia caused by a stroke and often became frustrated when he couldn't make his needs known straight away. But every swear word came out very clearly. He was able to live independently, with family or myself spending time helping with household chores and some personal care. A proud man who had designed and built his family home and who had a love of MG cars.

But there came the day when John's family decided that his needs would be better met in a care home. It was a lovely, bright, welcoming home with ten other residents. The care staff were lovely.

But for John, surrounded by a host of things that were unfamiliar and that he did not recognise, some lively personalities that were loud and intruding into his private space, plus living with a disease that impaired his cognitive functioning, it was too much. He felt threatened, panicky and wanted some security.

And he tried to tell me on a day that was particularly chaotic for him.

Two residents were yelling, one gentleman was banging a plastic cup on the table and the team working that day were understaffed.

But what was coming out of John's mouth because of his language difficulties, was a list of expletives.

I could see he was alarmed. I could see he was agitated. So I stood beside him, straight on and in my most concerned, caring voice, told John to ‘calm down’.

He became more stressed. So I said it again. Only this time with hand gestures as well. Maybe my head was tilted to the right for added effect. And oomph! I got punched. Squarely on the chin.

Instantly, two care assistants came to my aid. They told John to calm down too. And he grabbed their uniforms and hung on shouting out his expletives...

John got labelled as having CHALLENGING BEHAVIOUR.

Well, I guess he did challenge me and the care team. But I was a challenge to him, as well as his environment, the noise, the sea of faces he didn't recognise...And when you are upset, panicky or angry, what helps you? Someone saying "calm down"? Or would that make you more frustrated?

John was grabbing because he was frightened and when he grabbed on he was looking for security and safety.

I knew what was driving his behaviour but in my world, I was in control, understood why it was noisy and chaotic. I didn't see it from his world. I needed to see things from his point of view.

Did he need time out? Space? Understanding? Did he need to see me in a confrontational stance in front of him?

In the privacy of my car as I went home that day I reflected on what could have been differently. We hadn't taken into account John's past; that he had lived on his own for several years and although he loved socialising he also liked his own space.

I hadn't considered how my behaviour was impacting on the situation. We certainly hadn't thought about how John was struggling with his environment and his changing function and ability.

John's key worker and I set up a plan. Nothing huge. Just a couple of little changes:

- Noting at an earlier stage signs when John started to become distressed
- Asking if he wants to be helped to a quieter area or to his room.
- Addressing him on his dominant side so he felt more at ease rather than head on.
- Maybe hold his hand if he offered it. (Did you know that pressure in the palm is calming? A small pump like a heartbeat?)

So we had reframed the challenge just by looking at his past and his personal preferences. By thinking about his changed abilities and the environment. By acknowledging what he was experiencing and offering practical solutions to him as well as a comfortable way of helping him to calm and be less stressed.

Did it work? Certainly, John felt more valued and secure. You could see that in his demeanour. I didn't get punched again and the care staff weren't grabbed.

John was doing the best he could to explain how he was feeling. It was up to those around him to make changes. That included me and my sore nose!