

What is truth? Dilemmas when two realities meet

Should we always tell people with dementia the truth, the whole truth and nothing but the truth? **Graham Stokes** and **Antonis Kousoulis** report on the findings of an inquiry set up to find some answers



Professor Graham Stokes is global director of dementia care at Bupa and was co-chair of the Dementia Truth Inquiry Panel. Dr Antonis Kousoulis is assistant director of the Mental Health Foundation.

Caring for people with dementia can be demanding at the best of times. The intensity of support required gives rise to what is often described as the 36-hour day, which refers not only to the sheer hard work of helping someone with their activities of daily living but also to the need to respond to frustrations, upset and behaviours that can be distressing and challenging to both the person who is caring and the one living with dementia.

Never is this more apparent than when the realities of the carer and the person cared for clash. Our response can be to say that the person with dementia is confused, living or reporting a reality different from our own (Stokes 2002). The refrain of both family carers and practitioners is often: "How should I respond, what do I say, do I agree, do I contradict?"

Take the example of Caroline, a woman aged 53, living with young onset Alzheimer's disease who returned to the school she used to work at as a teacher. Sheila, a colleague who saw her there, asked:

"Caroline, what are you doing here?"

"The same as you Sheila. Just another day."

"The same as me? What do you mean Caroline?", and then, with a resigned sigh, Sheila said, "Caroline, you don't work here anymore."

Caroline just stood there as if appreciating something was wrong but having no idea what it could be. Sheila didn't know what to say. Or more accurately, what not to say. Aren't you supposed to agree with people with dementia who are confused? Here was Caroline standing in the staff

room clearly thinking she had arrived at work (Stokes 2017).*

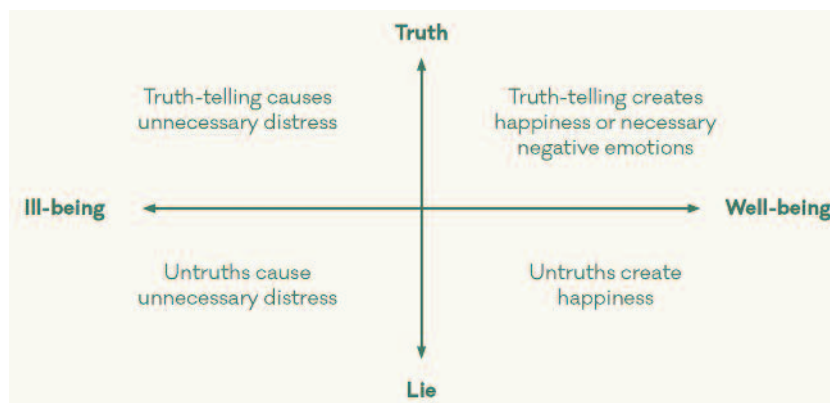
Commissioned by the Joseph Rowntree Foundation in 2014, the Mental Health Foundation began an inquiry into our understanding of the acute dilemmas arising when people with dementia experience a reality or set of beliefs different from those around them (Williamson & Kirtley 2016).

Truth-telling/lying continuum

Among people with dementia the prevalence of those living with different realities and beliefs varies greatly from around 20% to 70%, in small part depending on the type of dementia a person has. The experience of different realities becomes more frequent and persistent as dementia progresses and can cause considerable distress to the person themselves and those around them, especially family and friends. Family and friends may be upset even when the person is not.

Unsurprisingly, there is uncertainty about the best response to these experiences, and practitioners and carers are often desperate for advice and guidance (Wood-Mitchell *et al* 2006). And one of the commonly asked questions is can "non-truth" telling be justified in supporting the wellbeing of a person with dementia with these experiences?

While truth-telling is hugely important and something most people wish to give and receive, when supporting and caring for people with dementia the dilemma carers face is the risk of heightened distress and anger if they pursue the path of truth and challenge a person with dementia's own reality (for nearly 40 years referred to as "reality confrontation"). As a result, good practice guidance needs to make a distinction between "lies" and "untruths". In dementia care "lies" refer to deliberate and blatant falsehoods initiated by a carer, whereas "untruths" refer to any situation or utterance which, in an attempt to meet the person with dementia in their reality, conveys less than the whole truth. "Untruths" can be seen as carefully considered therapeutic interventions to alleviate distress and avoid traumatic confrontation, embarked upon with caution and skill (Culley *et al* 2013).



How truths and untruths can impact on well-being (source: Williamson & Kirtley)

*Caroline's story is told in Graham Stokes' new book *Watching the Leaves Dance* (see p27).

Respect and compassion

The therapeutic starting point should always be as close to whole-truth-telling as possible – always underpinned by respect and compassion towards the person with dementia. In other words, there may be situations where it is known from the start that whole-truth-telling will not be possible.

However, only if whole-truth-telling (or close to it) causes distress do we move onto a response that might include an “untruth”. At the far end of the spectrum, telling “lies” may only be used in extreme circumstances to avoid physical or psychological harm.

“Distraction” is an example of an intervention that contains an element of “untruth” for it doesn’t dispute the falsehood of the person with dementia’s reality but deflects them on to an activity designed to engage and reassure. By introducing something new into the moment, such as a topic of conversation, pastime or object, comfort and happiness are restored so that later, in a calmer, more positive emotional environment, carers and practitioners can think about a proactive response that may prevent the individual from expressing and experiencing a different reality. There is no doubt that understanding the individual’s personality and life story will increase the chances that the conversation, pastime, setting or object chosen by the carer as a distractive intervention will be meaningful and comforting.

Similarly, “going along with” someone, sometimes referred to as collusion, is more likely to be successful the more you know the person. Here you “meet a person in the place they are in” and a carer neither tries to confirm nor deny the reality the person is expressing, but rather “steps into their world” and explores it by asking questions and on occasions behaving as if this reality is understood – which is the objective. For example, someone who visits a day centre may refer to it from the outset as “going to work”. She does not understand the concept of day centres and gets puzzled and upset upon hearing the term, so staff also go along with this reality and refer to it as “being at work” because they feel it is more important to support her feelings than to “correct” her.

It is rarely correct to see a different reality as a symptom of disease. More accurately it can be understood as the use of memory to make sense of a situation or possibly as a way of coping with life or a set of feelings. However, expressing a different reality – asking for parents, seeking small children, wanting to go home - may also be an articulation of an unmet physical, psychological, social or emotional need. So before moving from truth-telling to distraction and “going along” we need to look for alternative meanings behind an expressed different reality.

We should accept that if there is any group of people who say what they don’t mean, and mean what they don’t say, it is people with dementia. Through observing and using questions, we need to be the “detective” who searches for and finds the underlying meaning that could signify an unmet need. For example, if a woman with

The Inquiry about Truth and Lying in Dementia Care

The inquiry, commissioned by the Joseph Rowntree Foundation in 2014 and conducted by the Mental Health Foundation, set out to shed light on the dilemmas faced by professional and family carers about whether to tell the whole truth to people with dementia experiencing “different realities.”

The main method used to gather information was an inquiry panel of people with experience and expertise in dementia. There were two co-chairs and a vice-chair, one of whom had dementia. Two other panel members also had dementia and two further members were carers (although other panel members had also had caring experience). The rest of the panel were experts such as professionals and academics.

As well as discussing the issues themselves, panel members invited expert witnesses to come and discuss the topic with them. In addition, information was gathered through a review of the published literature, an online survey, and three consultation groups.

Co-chairs were Professor Graham Stokes and Dr Daphne Wallace while the vice-chair was Professor Murna Downs. The *Journal of Dementia Care* was represented on the panel. In late 2016 the inquiry published a report, “*What is Truth?*” – *An Inquiry about Truth and Lying in Dementia Care*, which is available free on the Mental Health Foundation website www.mentalhealth.org.uk



dementia asks where her deceased husband is, she may be expressing a need for comfort (feeling safe and secure) or affection (feeling a close bond to someone).

A person who believes they are still in a role or job they did earlier in their lives may be expressing a need for identity (a sense of self), occupation (a sense of purpose) and independence (agency). Again, the more a practitioner is truly person-centred and takes the time to know the person and their history, the more likely they are to understand the meaning that lies behind the different realities; people with dementia communicate by their deeds and words.

What the evidence shows

Over the course of this inquiry, we gathered evidence that there are five fundamental principles that apply regardless of which response a carer chooses to use when trying to support the wellbeing of a person with dementia experiencing a different reality or belief:

Take a flexible, tailored approach: person first, strategy second

Knowing the person with dementia is important to understanding what the experiences of different realities and beliefs mean, and how best to respond to them. This means a carer will need to spend time with the person with dementia (and ideally their family and friends). There is no one-size-fits-all approach. ➤

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► Explore each experience with the person

The key role of any carer, in a situation where someone with dementia is experiencing different realities or beliefs from them, is to find out why. With this understanding, a carer can give the most helpful and effective response to support the person's wellbeing. Carers have reported that the best time to explore the meaning of different realities and beliefs is when they are not actually occurring, i.e. when everyone is calm and relaxed (James *et al* 2006).

Make sense of the world together with kindness

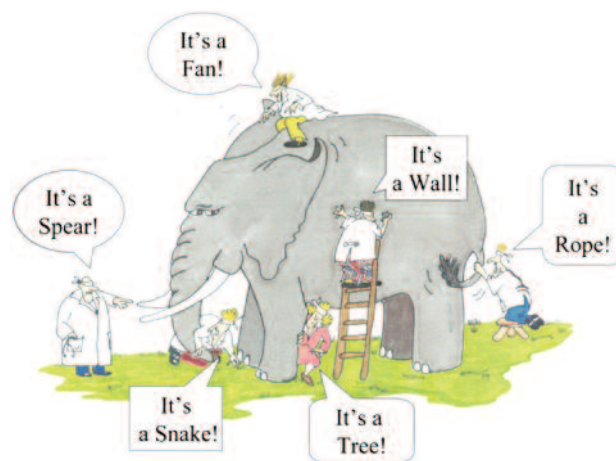
Effective dementia care often involves making sense of what is being experienced together, rather than one person imposing their reality or truth on another. Many people living with dementia said during the project that kindness and compassion were the qualities that mattered most to them in how a person responded to them. Yet this means different things to different people regarding whole-truth telling. People living with dementia told our inquiry in interviews that they did not want their carers to feel overly protective. So even though people may be experiencing different realities and beliefs, a carer's responses should not eliminate the chances of supporting the person with dementia to carry on with what they wish to do.

Some people with dementia also expressed a wish not to be protected from understanding someone has died, despite the distress this may cause (Day *et al* 2011). Our evidence concluded that finding out and understanding the meaning of a different reality or belief must be guided by the person with dementia, and so too must deciding which response will best support their long-term wellbeing. Ideally, these issues will be discussed by the person and their carer soon after diagnosis when they are best placed to choose the most appropriate response together.

Document and share what does and doesn't work

The best way for carers to learn the wishes of those they care for is by writing the individual's wishes and experiences down, so they can be thought about and discussed later. Documenting care in this way is often called a care plan, which can be a formal document or an informal diary. The information in a care plan is led by the person with dementia, and includes their choices and preferences about all aspects of daily life, their life story, and information on physical and mental health. It can also include wishes involving truth-telling and how others should respond if they are experiencing a different reality or belief.

A care plan allows carers to reflect on experiences and learn from them, while several carers of the same individual can learn from one another's experiences to ensure that they give support that is as consistent, compassionate and effective as possible. Sometimes there may be a need for professionals and family members to discuss the care of a person with dementia on their behalf, to ensure they are kept safe and well. This can include "best interests" meetings, and having



Elephant in the room? Practitioners need a considered response to "different realities" (source: Williamson & Kirtley 2016)

documents that represent the person's own voice and articulate their own choices in these meetings is important.

Patient confidentiality can make it difficult for professionals to discuss some issues with family carers. Some GPs and consultants will speak to the person with dementia first and then to the carer about how they feel, before explaining the situation to both parties. This is a helpful approach because it puts the person with dementia first. Having a Lasting Power of Attorney (LPA) for health and welfare decisions, under the Mental Capacity Act 2005, can also make things easier by authorising someone else to make decisions on behalf of the person.

Question one's own intent

It is worth always checking one's own motivation as a professional or family carer. In particular, if a person with dementia is experiencing a different reality, a carer should think about whether their response is really to make their own life easier or to try and support the wellbeing of the person they care for. Sometimes family carers may need to put their own wellbeing first. Whichever it is, it is always best to be open and honest about one's own motivation to make sure the wellbeing of the person with dementia is uppermost as much as is possible (Caiazza *et al* 2016).

Bringing it all together

The inquiry panel, comprising people with experience and expertise in dementia, has been on a fascinating journey. Pulling the findings together from our discussions among ourselves and from interviews with expert witnesses, among other things, and agreeing on common messages was not a straightforward process, especially as not everyone was in direct agreement on the best approach to be followed.

But our methods did embody the principles underlined above. Dementia care essentially needs to be underpinned by a person-centred approach driven by the desire to improve or sustain the wellbeing of people with dementia and their carers. ■