

# What is Truth?

An Inquiry about Truth and Lying in Dementia Care



Mental Health  
Foundation



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# Foreword



Caring for people living with dementia has been described as living the 36-hour day. This refers to the demands created by helping someone with their daily living but also to needing to respond to frustrations and behaviours that can be distressing and challenging to the person caring and person living with dementia. Never is this more apparent than when their perceived realities clash and conflict.

There are currently around 850,000 people living with dementia in the UK. Around half may be living with different realities and beliefs at any one time. The experience of perceiving different realities becomes more frequent and persistent as dementia progresses. It can cause considerable distress to the person themselves and to those around them, especially family and friends (even if not distressing to the person themselves).

The challenge when caring for someone living or reporting a reality different to our own is often summarised in the questions: "How should I respond; what do I say; do I agree; do I contradict"?

Commissioned by the Joseph Rowntree Foundation, in 2014 the Mental Health Foundation began an inquiry into our understanding of one of the most challenging aspects of living with dementia, when people with dementia experience a reality or set of beliefs

different to those around them. We are now publishing the findings of this major inquiry.

Unsurprisingly, there is uncertainty about the best response to these experiences. Practitioners and carers are often desperate for advice and guidance. 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?" The inquiry took evidence from people with diverse experiences of grappling with this issue and the ethics behind the question "What is Truth"? We are addressing these issues in this report and the accompanying supplement which presents the evidence presented.

The inquiry took us through a fascinating journey of clinical, philosophical, social and structural debates, informed both by academic and practice evidence, as well as the evidence of experts by personal background and experience. Having sat on the panel of experts, I am delighted to see this report published and to it becoming an indispensable resource to people living with dementia and those caring for them in family or professional capacity.

*Jenny Edwards CBE*



*“What I hope that this project serves to do...is that we give the professionals food for thought and that we challenge some of their thinking. [...] Ultimately what you are after is the well being of the people you are looking after and you want to do that as truthfully as you possibly can for that person and their perception of truth is where you are working from...”*

Inquiry Panel member with dementia

# Summary



"98% of professional carers admit to using untruths on a regular basis. Therefore this is a topic that can no longer be ignored. Carers are seeking guidance on what to do in challenging conditions. Simple, realistic and meaningful guidelines are essential."

Panel member and Researcher on Communication in dementia

The Mental Health Foundation has led an inquiry into our understanding of some of the most challenging aspects of living with dementia, in which people with dementia experience a reality or set of beliefs different from those around them.

The **key questions of the inquiry** were:

- What might these experiences of different realities and beliefs mean?
- Is "non-truth" telling justified in supporting the wellbeing of the person with dementia with these experiences?

It was firmly the panel's view that perceiving different realities and beliefs only as symptoms of dementia, while occasionally appropriate, is not sufficient

to address the range of complex experiences people living with dementia are having.

The inquiry panel found that there are three **common ways to understand the experiences of different realities and beliefs**:

1. The use of memory to make sense of the situation one is in
2. An expression of unmet (physical, psychological, social or emotional) needs
3. Creative solutions or coping strategies

The meaning of these experiences can be very different for practitioners and family carers, who may not easily



understand or wish to share a person's meaning of their different reality/belief for a number of reasons, especially in advanced stages of dementia. The inquiry heard many examples of the confusion, distress and difficult situations that these experiences could cause others, especially close family members and friends. The panel agreed that it is extremely important for services and support to be available to enable family carers to have respite breaks in order to maintain their own health and wellbeing (and in turn, sustain the best care possible to their relative with dementia).

While 'truth' is a difficult concept to define, **it is agreed that 'truth-telling' is hugely important, and something most people wish to give and receive by way of communication.** In the context of this report, "lies" refers to blatant untruths initiated by a carer, whereas "untruths" refers to any situation or utterance which, in an attempt to meet the person with dementia in their reality, conveys

less than the full or whole truth.

It is important to view the concept of untruths within the wider context of person-centred communication. Using this perspective, untruths can be seen as strategic therapeutic interventions. Their use is sometimes compared to use of psychotropic drugs in this area; for example, they should be employed with caution and only in situations where other approaches have been trialled first. The context in which they should and should not be used are explored in this report.

The panel agreed **five terms that encompass types of caring interventions and responses** to people living with dementia experiencing different realities and beliefs. They can be represented as part of a truth-lies axis in the following continuum in which as you move to the right the use of untruths increases as well as the level of deception, but also inner discomfort:

Whole- truth telling	Looking for alternative meaning	Distracting	Going along with	Lying
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The panel felt that **one should always start from a point as close to whole-truth-telling as possible – always underpinned by respect and kindness towards the person with dementia – and if this is causing unnecessary distress, move on to a response that might include an untruth.**

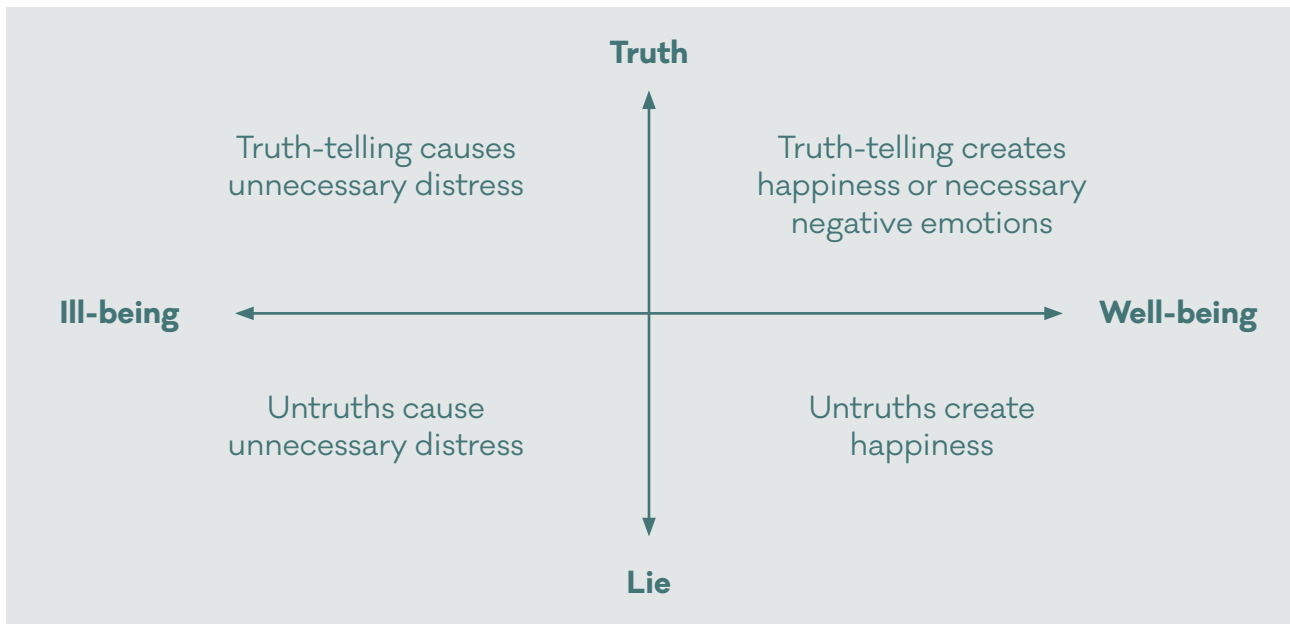
Judging what is 'unnecessary distress' is no easy task. It will depend on the person and their history, the carer(s) or practitioner(s), and the exact circumstances of the situation.



The panel found six underlying principles of all responses and interventions that are critical in supporting the person living with dementia to have wellbeing:

1. Experiences of different realities and beliefs are meaningful to a person living with dementia. A key role of any carer or practitioner is to find out what this meaning is. This is a fundamental aspect of good quality care, and should not be considered a luxury agenda item, "if there is time".
2. Finding out what experiences of different realities and beliefs mean must be done with an open mind; a flexible, tailored approach; and with kindness. The more a carer or practitioner knows about the life story, personality and values of the person with dementia, the more likely they will be able to understand the meaning behind these experiences.
3. Responses and interventions start as close to whole-truth-telling as possible. In other words, there may be situations where it is known from the start that whole-truth-telling will not be possible. But moves away from whole-truth-telling should only occur if it would cause unnecessary distress. 'Lies' (as in blatant untruths initiated by a carer or practitioner – as opposed to meeting a person with dementia in their reality) may only be used in extreme circumstances to avoid physical or psychological harm.
4. Environmental lies should be avoided. These are artificial spaces designed to deceive, such as a painted shop front (as opposed to a real small shop within a care setting).
5. Responses and interventions should be kept consistent across family carers or staff teams.
6. What does and does not work should be documented and shared.

As demonstrated in the above principles, owing to the complexity involved in the employment of untruths within clinical settings, it is beneficial to provide guidance and training in their use; training would also be appropriate for families. Such training would be best presented within the broader context of 'effective communication strategies in dementia care'.



*The Truth vs. Wellbeing Graph for a person with dementia (adapted from Caiazza and James, 2016)*

The choice to use an untruth in dementia care should not be taken lightly. There is always a balancing act between wanting to try to stay as close to whole-truth-telling as possible and ensuring one is not causing unnecessary distress. The Inquiry identified six key moral and practical issues in dementia care that can make giving a response outside of 'whole-truth-telling' particularly challenging:

1. The highly charged nature of the words "truth" and "lies"
2. Maintaining trusting relationships while telling untruths
3. Supporting wellbeing; not simply happiness
4. Balancing the wellbeing of the person with dementia, their carer(s) and practitioners

5. The pressures of 'too little time'
6. Fluctuating realities implying fluctuating response types

Family members may struggle with telling untruths as it may feel as if they are doing something wrong. Within families response-types often differ from one family member to the next, according to the type of relationship they have with the person living with dementia.

The panel found that paid staff often find it simpler to cope with experiences of different realities and beliefs in relation to their own emotional investment, which is bound to be less.



# Introduction



“These experiences are part and parcel of the worldview she has now. I understand these experiences to mean that she has ‘gone back in time’ in her own mind, or is reinterpreting the people and the world around her through an older ‘lens’. I can’t know what exactly is going on for her but the experiences have a clear meaning for her and it is important I don’t belittle that.’

Survey Participant, Family member/friend

## What is this report about?

In 2014 the Mental Health Foundation began an inquiry into our understanding of some of the most challenging aspects of living with dementia, in which people with dementia experience a reality or set of beliefs different from those around them.

The inquiry sought to investigate what these experiences might mean for people living with dementia, carers and family members, and practitioners, and

if, why, when and how “non-truth” telling is justified in supporting the wellbeing of the person with dementia with these experiences. The inquiry aimed to take as its starting point the perspective of the person with dementia who is having these experiences.

This inquiry was commissioned by the Joseph Rowntree Foundation (JRF) as part of their programme of work Reframing dementia in the 21st Century: challenging thinking and stimulating debate



Examples of experiences of 'different realities and beliefs' include:

- believing that a deceased parent is alive;
- gaining comfort by holding a doll, appearing to believe it to be a real baby;
- asking to 'go home' and believing home to be elsewhere;
- being convinced that a family member or friend is an imposter, someone different, or constantly deceiving them;
- believing one is engaged in a task that relates to a previous occupation or role that is no longer part of one's life;
- stating an intention to do something seemingly unrelated to any prior life experience e.g. stating that they were going to mend the motor on the boat – the person never had a boat or had been known to mend anything;
- believing fictional TV dramas are real;
- believing oneself to be living in a previous or new phase of their life and

for example, reverting to a language spoken in their place of origin, wanting to do things that their religion or beliefs forbid, or developing a new intimate relationship with another resident in a care home despite still having a partner;

- encountering visual difficulties such as problems with depth perception, double vision, seeing things that aren't there

This report is a summary of the key themes that emerged from the inquiry, especially in relation to practical examples and guidance. It aims to be particularly of use to family and paid carers of people living with dementia. It includes different perspectives, understandings and responses in relation to experiencing different realities and beliefs when living with dementia. This may sometimes prove frustrating, as it does not offer simple answers. Yet the panel hopes that it will help people to have more insight and understanding about what is going on for people with dementia experiencing different realities or beliefs, and how one can support the wellbeing of those living with dementia and these experiences.

This report draws upon a source document called the Dementia Truth Inquiry Panel: Review of Evidence, available to read here: xxxxxx. It is a detailed, comprehensive write-up of the very wide range of issues the Inquiry investigated, from philosophical to practical, and includes all of the references, quotes, data and evidence involved. Please refer to the Dementia Truth Inquiry Panel: Review of Evidence should you wish to learn more information about any of the points raised here in the Report



## Why is this issue important?

There are currently around 850,000 people with dementia in the UK. People living with dementia commonly experience different realities and beliefs from those around them, although estimates of prevalence vary from around 20% to 70%, depending partly on the type of dementia a person has. They usually become more frequent and persistent as the condition progresses. These experiences can cause considerable distress to the person themselves and those around them, especially family and friends (even when not distressing the person themselves).

There is confusion and uncertainty about the best response to these experiences, and practitioners and carers who frequently deal with this are often desperate for advice and guidance. While responses need to be individualised, there are a variety of more general approaches and available guidelines. Some approaches may involve considerable investment in training or resources to try and help people feel comfortable in supporting wellbeing for people experiencing different realities and beliefs, as well as being compliant with legislation affecting health and social care practice for people with dementia (including legislation covering Mental Capacity, Equality, Care and human rights).

## What was the process behind the inquiry?

The main method used to gather information was through an inquiry panel of 21 people with experience and expertise in dementia, who met

ten times between 2014 and 2016. There were two co-chairs and a vice co-chair, one of whom has dementia. Two members of the panel were people with dementia and two were carers (although other panel members also had caring experience). The rest of the panel were experts such as professionals and academics.

As well as discussing the issues themselves, the panel members also invited 18 'expert witnesses' to come and discuss the topic with them. Expert witnesses came from different fields including: people with dementia, psychiatry, psychology, philosophy, family caring, research, the third sector, frontline practitioners, an artist and poet, and the police.

A full list of panel members and expert witnesses can be found in the Appendix.

In addition to the inquiry panel, information was also gathered through: a review of the published literature (available online [here](#)), an online survey open to the general public, three consultation groups (one with family carers, one with people with dementia and one with day centre and care home staff), and an informal consultation before the inquiry began with the Mental Health Foundation's Views on Growing Old online panel.

## Note on language

Language and terminology was an important theme that emerged from the start of the inquiry. Initially, clinical language and medical definitions were used. These included 'delusions' (also referred to as false beliefs),



'hallucinations', 'disorientation' and 'confusion.' However, there were consistent concerns that these terms could be: rather limited in meaning; too medically focused to help understand what people with dementia might be experiencing; too negative; or might not be understood. The inquiry panel therefore concluded that the phrase "experiences of different realities and beliefs" was most helpful in allowing for a variety of possible meanings and responses to be expressed and explored.

The term "response" is used to refer to care given by someone reacting (responding) to an experience of a different reality/belief expressed by a person living with dementia. By contrast, an "intervention" in care is proactive by the carer/practitioner, trying to initiate or encourage a particular activity - most commonly to eat, drink, wash (stay clean), or stay safe in a particular location.

The panel agreed that "wellbeing" is preferable to "happiness" because the latter can be short term and is only one aspect of good emotional health. Of course, one must experience lots of feeling of happiness in life in order to have wellbeing. Yet there are also emotions such as doubt, anxiety, and sadness which are part of the human experience. Wellbeing involves an ability to manage (independently and with support) these more negative feelings, experiencing a range of emotions in a

healthy balance, and having a sense of autonomy.

People with a diagnosis of dementia are referred to as either "a person/people with dementia", or "a person/people living with dementia". "Carers" refers only to family and friends of people with dementia. Those providing care, support or treatment for people with dementia in a paid or formal volunteer capacity are referred to as "professionals", "practitioners", or their specific role is named.

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia. The report does discuss some differences between the most common forms of dementia but for the sake of brevity the term "dementia" is used.

The inquiry panel spent considerable time discussing the terms involving "truth" and "lies". This discussion forms part of the report but the inquiry preferred not to use the term "lie" when describing something that was not entirely truthful such as 'going along with the person's different reality', because the negative moral baggage associated with "lies" created obstacles to a non-judgemental, open discussion.

# What do these experiences of different realities and beliefs mean?



"I think my answer is still pretty much the same as it always is whenever I'm running an education session and somebody asks me... 'how do you deal with somebody who wants to go home and their home is no longer there?' And my answer is always, 'it's complicated'. It's a very straightforward question but it's a very complicated answer".

Expert Witness, Professional

The inquiry explored what different realities and beliefs mean to people with dementia who experience them, and how important these meanings are. The inquiry also explored how far these experiences are shaped by the dementia versus the person who is having them, and therefore how far a person with dementia may be able to control and shape the experiences they have. This is called a person's 'agency'.

It is important not to assume automatically that an unusual experience or belief that a person with dementia describes having is untrue because the person has dementia. Beyond this, below are the three most common themes that emerged from the inquiry as the driving forces behind these experiences

of different realities and beliefs: using memory to make sense of the situation they are in; expressing unmet needs; and creative solutions or coping strategies. An explanation may involve a combination of meanings.

## **The role of time, memory and emotion in constructing reality**

For many people living with dementia, short-term memory is affected and long term, historical memories dominate. Furthermore, a person with dementia can retain their emotional memory (the ability to have feelings and emotion) even if they are confused or their short-term factual memory no longer works properly.



Therefore, often people with dementia use memories from their past to understand their present and navigate their future. Unfortunately, this may mean people with dementia become 'time-shifted', often believing they are living in the past.

For example a lady living with dementia who worked as a school teacher may well address the practitioners in the care home she now lives in, as though they are her pupils. This is because her lack of short-term memory has resulted in a time-shift to many years earlier, further triggered by the friendly, eager attitude of the young people (her practitioners) around her who carry notebooks and wear uniforms.

Some different realities or beliefs can be positive for the person with dementia. A person may get enjoyment, reassurance or comfort from believing they are a younger version of themselves, or enjoy talking to a loved one who is deceased.

Conversely, a person may connect with a very traumatic memory; for example, an accident, crime or wartime memory, or a fear they have always harboured (forgetting to collect their children from the school gate).

The inquiry heard of a lady who had a leg ulcer and was living with dementia, and believed that there were men in her loft and that they were putting worms in her veins. After some consultation, a professional working with her and her family discovered that that her house had previously been flooded and that workman had come and spent a long time fixing her ceiling. It emerged that her reality in the present day was

constructed using old memories and a need to feel more physically well. When she was coping well with her ulcer, she believed the men were there to help her. At other times the same men were causing her 'disease'.

Emotions such as fundamental feelings of affection or safety may become very influential in shaping a person's reality. This may explain why, as per one example the panel heard, a man who no longer recognised his wife formed a new intimate relationship with a lady in the care home he was living in.

### **The role of (unmet) physical and psychological needs in constructing reality**

Some experiences of different realities and beliefs are expressions of physical, psychological, social or emotional need. This requires a carer to interpret at a deeper level than the immediate words and behaviours, in order to try and meet the underlying need.

For example, a person who is asking to see someone who is no longer alive may be expressing a need for comfort (feeling safe and secure) and attachment (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). And a person shouting at their carer that they are hurting them and they will report them, when the carer has just knocked at and opened their door (so not touching the person), may be expressing an underlying chronic pain or discomfort such as dehydration.



## **The role of creative solutions or coping strategies in constructing reality**

Self-management strategies for health conditions require memory, knowledge, skill and application, all of which become increasingly compromised by dementia. Different realities and beliefs may sometimes represent (subconscious) coping strategies or creative solutions to the situations people find themselves in. This may be to cope with the effects of the dementia, whether or not the person knows they have the condition, and/or to find explanations of reality that maintain autonomy, self-esteem and identity. The significant aspect of this explanation is the emphasis it places on the person's agency: they may be actively seeking ways to manage in often confusing situations, even though their cognitive ability to do this may be impaired.

One example the inquiry heard about was a man required to give up his driving licence some time after his dementia diagnosis. However, his own explanation involved being stopped by the police, who had removed it from him for no good reason. There is the possibility that this story was for him a more positive explanation than having the license removed because of the dementia: a form of coping strategy used to maintain self-esteem and personhood.

There are many different types of coping strategies, such as avoidance, confrontation, or reappraisal of a problem. It may be that a person with dementia is attempting to use these but with limited or confused information. The brain can compensate in some way for the loss of information by "filling in the gaps".

'Editing' autobiographical memory, and having exaggerated self-confidence or optimism, are behaviours most people use at times to maintain self-esteem or deal with challenging situations. Like anyone else, a person with dementia desires a sense of wellbeing and self. Time-shifting to important memories may be an important way of achieving this and trying to retain information about themselves – even if to others these memories appear "false" or "distorted."

## **Different realities and beliefs interpreted as neurological symptoms (with no apparent meaning)**

The inquiry also heard evidence that described different realities and beliefs primarily as symptoms of a disease, and meaning being of secondary importance, at most.

There is clear evidence that visual and auditory hallucinations are a common feature of Lewy body dementia. One panel member who has been diagnosed with Lewy body dementia described the frightening hallucinations that he experienced, for which he found no explanation or meaning.

The impact of other health conditions such as sensory impairments can combine with the confusion associated with dementia to cause misperceptions, such as believing a shiny floor surface is water or that a dark mat is a hole. Another common cause of these experiences can be delirium. When the cause of the delirium (e.g. an infection or reaction to medications) is treated, the reality or belief goes away.



The inquiry recognised that many carers and practitioners who viewed different realities and beliefs primarily as neurological symptoms were also interested in the meaning of these experiences. However it was firmly the panel's view that perceiving different realities and beliefs only as symptoms of dementia, while occasionally appropriate, is not sufficient to address the range of complex experiences people living with dementia are having.

### **Meaning and meaningfulness for others**

The meaning of these experiences can be very different for practitioners and family carers, who may not easily understand or wish to share a person's meaning of their different reality/belief for a number of reasons, including:

- not knowing that the person has dementia or that it is causing the different realities or beliefs;
- a lack of understanding of dementia;
- initially thinking the belief to be true;
- a belief that different realities and beliefs are purely symptoms of dementia;
- the person's different reality or belief involving suspicion, disbelief, hostility or rejection of those around them and/or their beliefs (especially family members);
- a reluctance to engage, 'step into' or collude with the different realities and beliefs.

The inquiry heard many examples of the confusion, distress and difficult situations that these experiences could cause others, especially close family members and friends.

One inquiry witness described receiving a phone call from her mother who had dementia in a state of distress saying that her husband had abused her and begging to be taken away to safety. Allowing herself some time to think the situation through, as well as phoning her father, resulted in her concluding that her mother was particularly unwell and needed a doctor. Although it transpired there was no evidence of abuse, the meaning of the situation was interpreted differently by the mother and daughter, and was very distressing for both. In addition, initially not knowing that her mother had dementia had made it impossible for the daughter to understand what was happening or what her mother's behaviour and beliefs could mean.

Often most heart-breaking for close family members or friends are situations where they are no longer recognised or are even believed to be an imposter. For the carer, something that is very meaningful, a lifelong relationship, is being lost.

The panel agreed that it is extremely important for family carers to take the breaks and get the support they need, in order to maintain their own health and wellbeing (and in turn, sustain the best care possible to their relative with dementia).





As one expert witness describes (the “other person” refers to the person with dementia – emphasis added by the expert witness):

*“If, as the carer, you feel constantly told by everyone that your reality does not matter (it does not exist, you must always defer to the other person) it can be seen tantamount to being told that you don’t matter – your sole purpose in life is to support the person you care for, you have no other worth; and any distress, frustration, grief, or resentment you may feel is selfish, ignoble, and to be stifled, because it is “bad for” the person with dementia. I can say from personal experience that this can be hugely destructive to the carer’s mental (and indeed physical) health.*

*It can lead to the carer effectively living under similar conditions to those of domestic abuse: e.g. always subservient, walking on eggshells for fear of upsetting the other person, constantly censoring or modifying their own words or behaviour, denying their own needs, isolated from other family and friends (of whom the other person may be jealous or mistrustful) and trapped in the house (by the other person’s separation anxiety or paranoid fears).*

**A constant negation of the carer’s factual reality can lead to their feeling that they have been “erased” from the outside world.** *This can be mitigated to some extent by other family and friends supporting the carer’s “real” life; but for a sole carer in a domestic setting the long-term effect can be catastrophic.”*

# Are untruths ever justified in supporting the wellbeing of people experiencing different realities or beliefs?



“When somebody has dementia it maybe muddies the water a bit more, but I think the waters of truth and truth-telling are pretty muddy anyway.”

Expert Witness, Professional

While ‘truth’ is a difficult concept to define, it is agreed that ‘truth-telling’ is hugely important, and something most people wish to give and receive by way of communication.

However, there are particular circumstances – both within and outside of the world of dementia care – that one may choose something other than the oath of the truth, the whole truth and nothing but the truth.

In many situations, not hurting feelings is found to be more important than ‘the truth’. An everyday example is how people tend to respond to the question ‘does my bum look big in this?’, where a respectful answer may be both desired and given, even if it’s untruthful. Examples of ‘untruths’ reported to the panel include not telling someone that their loved one was dead when they

were asking for them, or colluding with delusions to reduce distress and avoid aggression.

Untruths can of course be used deliberately for ill gain, but this inquiry explores responses and interventions solely in relation to good intentions: of supporting wellbeing, avoiding unnecessary distress, and seeking to give the best care and support one can provide.

**Ultimately the panel agreed that there are times when untruths are justified in order to avoid unnecessary distress and to support the wellbeing of a person living with dementia.**

This is under no circumstances meant as a green light for ‘lying as default practice’ (i.e. making it an “easy option”) in dementia care. Rather, the intention of



the carer or practitioner and the specifics of each care scenario are to be carefully considered in the process of choosing which response/intervention best supports wellbeing for the person with dementia.

### **Truth-telling and interventions**

An “intervention” in care is proactive by the carer/practitioner, trying to initiate or encourage a particular activity. [This is in contrast to a “response,” used to refer to care given by a family carer or practitioner reacting (responding) to an experience of a different reality/belief expressed by a person living with dementia].

Some people living with more severe dementia routinely resist their carers’ efforts to support them in eating, drinking, washing (staying clean), or keeping safe in a particular location. Often this is because they are experiencing a different reality or belief. This undoubtedly places the person’s wellbeing in jeopardy. Yet these situations seem to be less complex to deal with, primarily because by their nature interventions are not in the ‘heat of the moment’. The first time a person declines to do something, a carer/practitioner can simply note when and why. It is only if this persists that the carer/practitioner will need to consider what intervention(s) may encourage the person to engage with the activity.

The panel heard about an example where care home staff requested that a lady who refused to get out of bed most mornings and was hearing several voices of what she described as ‘gangsters’ be detained against her wishes under mental

health law. During analysis with the family, it emerged that years before the lady had been burned out of her house by youths living in the flat above, selling drugs. Often because the staff found caring for the lady so difficult, they would stand outside her room and discuss the best approach to personal care – in her eyes replicating the behaviour of the gang. The new intervention encouraged staff not to stand in a group, but to enter the room individually and spend time with her one-to-one before asking her to do something. Eventually the voices diminished, her medication was successfully withdrawn, and the lady started to be able to do things that previously had required 3-4 staff members causing her much distress.

The first step in deciding upon an intervention is to understand whether the person with dementia has capacity at that time to make the decision; for example, to have a shower.

If the person has capacity, then carers must respect their wishes and very simply a person will not have a shower that day. It is unethical to force, coerce, and use anything other than truth-telling by way of communication to try and change the person’s mind. [If a situation persists whereby the person is placing themselves at considerable risk, it is worth re-confirming the person understands the ramifications of their choice (i.e. has capacity in respect to this situation) and worth facilitating a review of the person’s mental state to establish perhaps whether depression or other underlying causes are affecting the person’s decision-making ability. If the person is in pain (e.g. because they are refusing medication) it is still important



to ensure they are made comfortable as possible.]

If, however, the person lacks capacity to make that decision at the time, then in order to justify still going ahead with the activity:

- all other options to achieve the same outcome must first be explored and declined, i.e. with this example the outcome is to have clean, healthy skin therefore a bath or bodywash could be offered instead;
- it must be done in their best interests, in accordance with the Mental Capacity Act 2005 in England and Wales (and equivalent legislation in Scotland and Northern Ireland). A Best Interests Meeting could be convened, involving family and staff if possible to understand what the different reality or belief means and how best to respond (see Box on Rights);
- it must be evident that not engaging in the activity would do the person with dementia considerable harm, i.e. the person declining to wash is at high risk of developing a pressure sore.

At this point a carer/practitioner's intervention might now use an incentive that includes an untruth. For example, the carer might tell the person "your friend is coming to tea later [knowing this is false] and it would be nice if you had a wash before his visit."

This should be agreed upon with key family members, other staff and professionals, and in line as much as possible with the person's values, beliefs and ideas. Ideally, this intervention

would also be discussed with the person with dementia during times they feel calm, happy and able to comprehend the carer/practitioner's reality, but the panel acknowledged that this is often not possible. As with all interventions & responses, the more these situations can be explored with the person early on in their journey with dementia, the more likely it is that carers/practitioners will choose interventions that respect their identity.

Just as in any other situation, the impact of an intervention on the person can then be assessed. With the example above, did the person have a wash, forget about his friend coming to visit, and carry on to have a good day? Or did s/he spend time angry and confused after washing in relation to where their friend was, and end up having a bad day?

There will always be an element of trial and error associated with finding the right intervention. However, if time and effort is taken to co-create the right intervention, this increases the chances of averting future distress, and the strategy of using an untruth to maintain a person's self-worth, dignity and wellbeing can be confidently defended.

### **Advanced Statements and Lasting Powers of Attorney**

In the ideal situation, a person will have formally made known their beliefs and values, wishes and feelings in advance to guide carers and practitioners when they are no longer able to express them. This can be captured in an advance statement. In some cases a person may choose a family member to become their Lasting Power of Attorney and

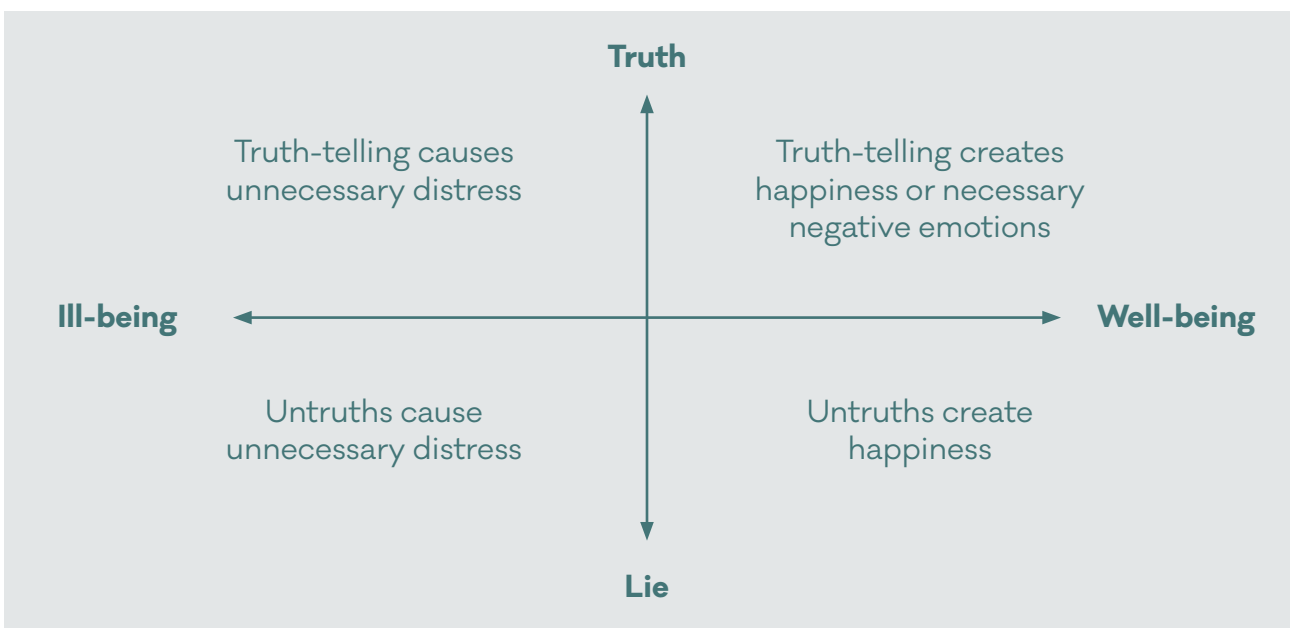


implement these decisions on their behalf. However, the panel heard many examples where a person's opinions and resultant behaviours changed substantially in later years, whether due to dementia or simply personal development. Therefore getting the person with dementia's view on flexibility

of response, truth telling and wellbeing in advance would also be helpful, treating untruths as therapeutic tools.

### Truth versus Wellbeing

One may imagine truth and wellbeing intersecting like so:



*The Truth vs. Wellbeing Graph for a person with dementia (adapted from Caiazza and James, 2016)*

One can conclude that:

- a person with dementia never wants to be in the left-hand-side quadrants where untruths or whole-truth-telling are causing them unnecessary distress;
- ideally a person with dementia wants to always be in the top right quadrant, mostly whereby whole-truth-telling creates wellbeing. However, for a short time whole-truth-telling may be needed in order to support a person with dementia to work through

negative emotions that are part of life and being human;

- in the aim of supporting wellbeing and avoiding unnecessary distress, carers or practitioners may need to interact with the person with dementia in the bottom right quadrant, whereby untruths create wellbeing

An entirely separate (yet intrinsically linked) graph would exist for a carer or practitioner, whose wellbeing is affected by which of the responses and



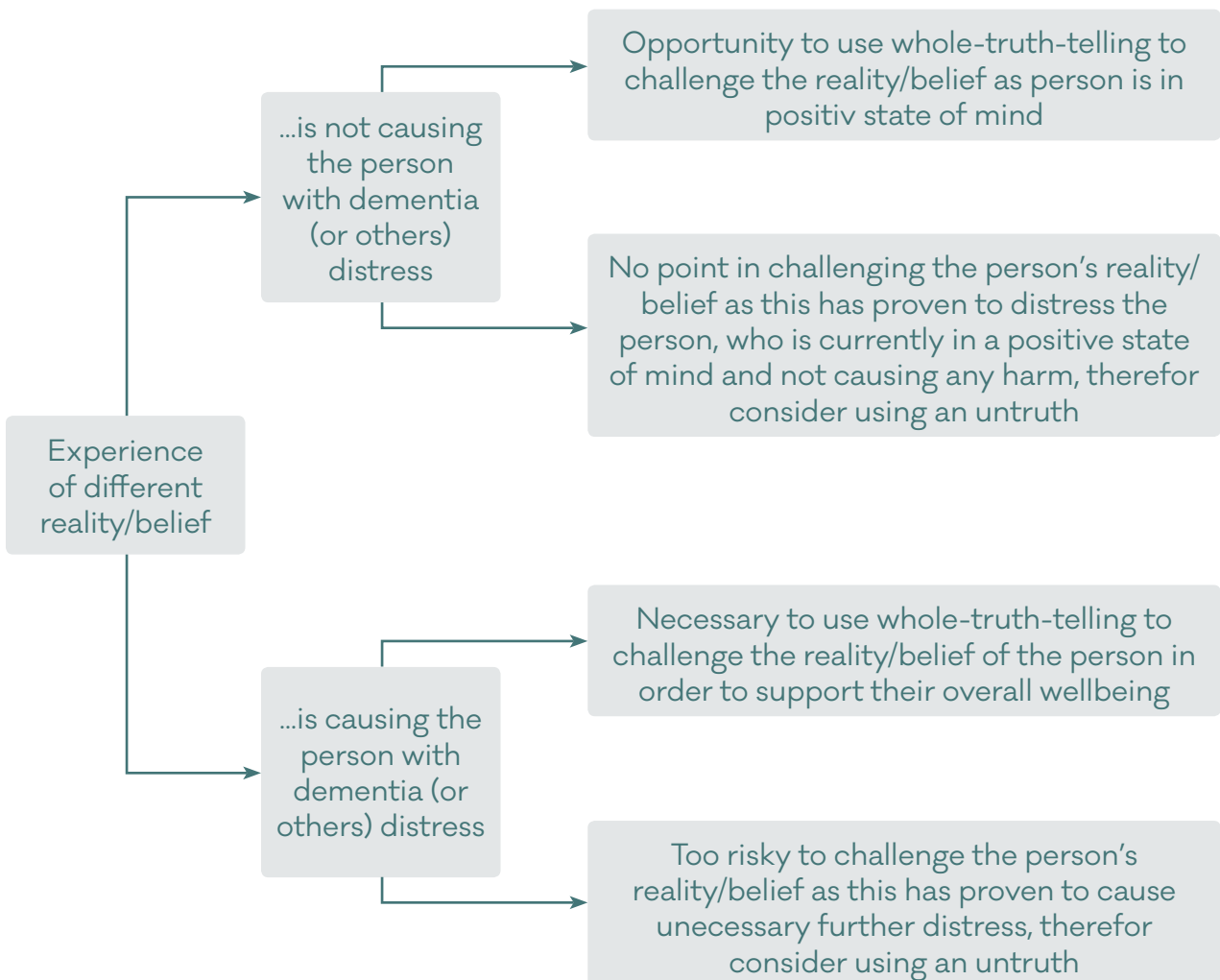
interventions they offer along the vertical truth/lying axis. The panel heard several examples of family members struggling to balance their own wellbeing with that of the person they are caring for. Carers report feeling guilty and anxious about telling untruths, even if it is clearly alleviating unnecessary distress for the person with dementia. This is discussed more below in the challenges to telling untruths.

### Judging what is 'unnecessary distress' when responding to a

### person experiencing a different reality or belief

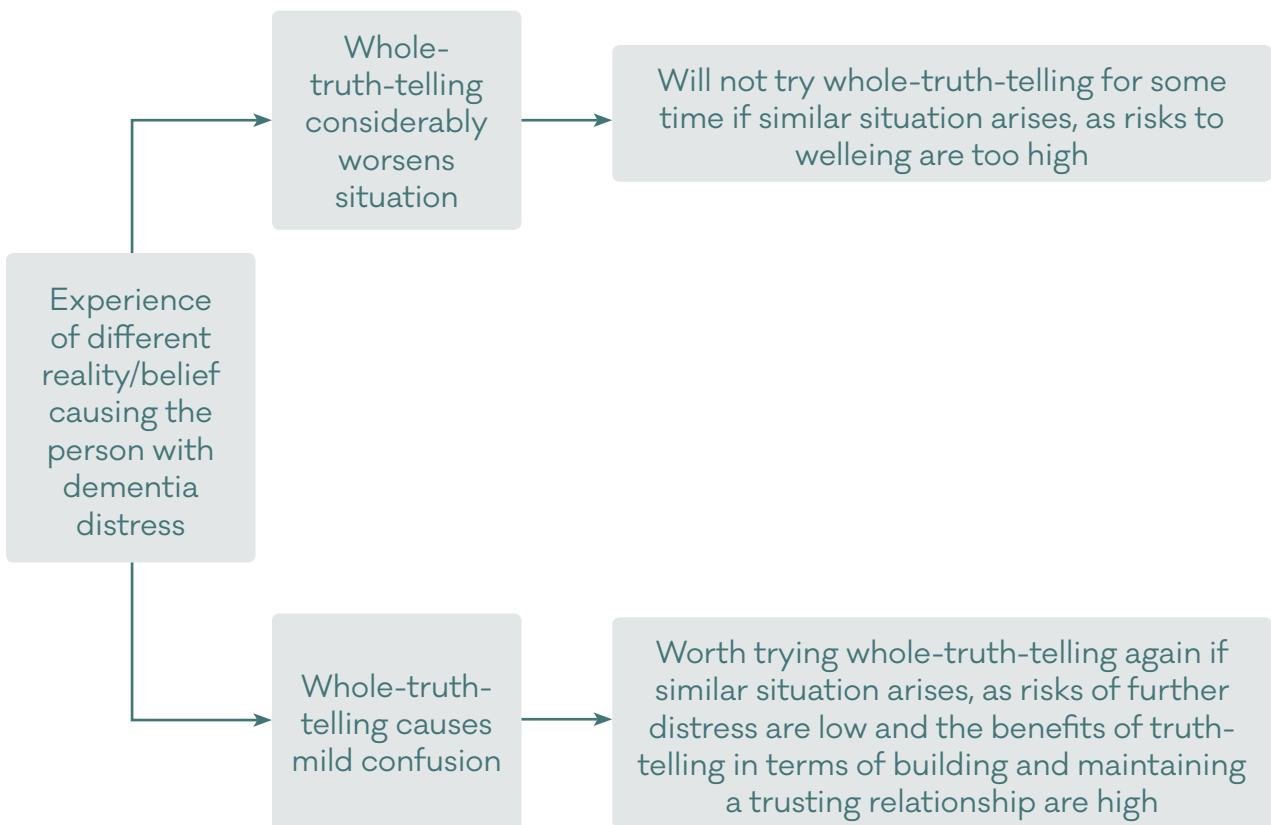
Judging what is 'unnecessary distress' is no easy task. It will depend on the person and their history, the carer(s), and the exact circumstances of the situation.

One way to judge distress is relative to the psychological place from which a person is starting. Here are two opposite ways of considering how one may choose whether to use an untruth or not in relation to distress:





Another way to judge distress is relative to how the person living with dementia reacted in the past to a response the carer/practitioner used:



**Even if in the past whole-truth-telling caused distress, it is important for carers not to be afraid to try whole-truth-telling again at some time in the future, in case the person with dementia's memory or perception has changed.**

Distress may sometimes also be necessary, in the context of supporting wellbeing (which includes a range of emotions), not just happiness. This is discussed further below.

# The inevitable challenges of using untruths



"It often seems more helpful to step into the person's shoes to decide how best to respond, rather than attempting reality orientation. This is not without ethical issues though.. We need to make sure we have consistent ethically-informed care plans to help people feel safe and secure. We need to spend more time debating ways of responding and the ethics surrounding this."

Expert Witness, Professional

The choice to use an untruth in dementia care should not be taken lightly. The Inquiry identified six key moral and practical issues in dementia care that can make giving a response outside of 'whole-truth-telling' particularly challenging.

## **The highly charged nature of the words "truth" and "lies"**

The words 'truth' and 'lie' in our language tend to instinctively connect with feelings of 'good' and 'bad.' In most settings language has been polarised and simplified: truth-telling is translated as 'right' and lying as 'wrong' across all circumstances and with nothing in between. Consequently, carers or practitioners are left to feel their

way in the dark, testing and learning responses and interventions in real time, discovering for themselves the 'areas of grey' within the truth-lies spectrum. The fear of being accused of poor practice or the guilt of feeling one might be 'a bad person', plus the lack of language to describe interventions that sit within this grey area, mean that often responses go undocumented and unshared, i.e. covertly. This might include compassionate, insightful and successful responses through to those that turn out to be ineffective or distressing. In either event, this impacts unnecessarily on the quality of life for the person living with dementia, who could be receiving more effective care, more of the time. Similarly, the quality of life of a carer or practitioner whose desire is to improve a





person's wellbeing will increase if given evidence of how best to achieve this.

### **Maintaining trusting relationships while telling untruths**

Good quality care relies on a good quality relationship between the person being cared for and their carer or practitioner. A carer may feel that not being wholly truthful can undermine trust, and therefore the quality of a relationship. Yet there are difficult situations in which a carer has to decide whether maintaining a good quality relationship relies more on avoiding distress or avoiding untruths. Indeed the panel heard many examples whereby carefully constructed untruths, consistent with a person's reality, in fact enhance the relationship between carer and person with dementia.

For example: a woman living with dementia accuses their daughter of taking their shoes. The daughter's reality is that she did not do this, and they have simply been mislaid somewhere. But she knows that - in the spirit of repairing the relationship in the moment - if she finds and returns them with an apology, her mother will 'forgive' and relax, and express that she feels better. If on the other hand she defends her personal truth, there will be an argument and the relationship in the moment will suffer.

### **Supporting wellbeing; not simply happiness**

If someone living with dementia is experiencing a different reality or belief that is causing them distress, it is tempting for a carer to want to help or protect the person by making them

feel 'happy'. Yet the panel heard several examples whereby carers had instead chosen to support the person to work through their distress, in the hope of supporting the person's overall sense of wellbeing, as opposed to achieving short-term happiness. In other words, being able to 'live well' with dementia does not necessarily equate to being 'wrapped in cotton wool' and denied the truth, however upsetting. Stress and distress are part of being human, so in order to accord people with dementia dignity and respect and as much autonomy as they can exercise, one must also allow them to experience the full range of adult emotions including doubt, uncertainty, sadness and change, and to participate in adult relationships that include disagreement, disappointment and conflict.

The death of a loved one was a common example. Just as with trying to help someone without dementia coping with a bereavement, it would be inappropriate to constantly remind the person of their loss knowing it caused them distress, but there are times where the person would need to be listened to and supported to grieve, and other times where it may be desirable to try and move the person on to a topic or activity that helps them to feel happier in the moment. The type of response would depend very much on who was involved, what had happened to trigger those feelings of grief.

There are also occasions when helping someone with dementia to explore their negative emotions can reveal underlying unmet needs. For example, if someone asks anxiously where their deceased mother is, rather than their carer simply trying to avoid distress with a response



such as “I’m not sure, but your mum isn’t coming today”, they could instead explore the anxiety by asking “is there something you want to tell her, or that is worrying you? Can you tell it to me?”

## **Balancing the wellbeing of the person with dementia, their carer(s) and practitioners**

### *Carers*

Dementia is a diagnosis noted as a “life changing condition for everyone.” A family member’s decision of whether to respond to a relative with either whole-truth-telling or otherwise often had a direct impact on their own level of wellbeing. In connection with the highly charged nature of the words ‘truth’ and ‘lies’ (see above), carers report they agonise over “am I doing something that is morally wrong or unethical?” The wellbeing of carers is of real importance not only because of the impact on the carer, but also because the evidence shows that if carers are stressed, their ability to give good quality care is diminished. Indeed an increasing number of care home and hospital admissions directly correlate to family carer burnout.

Carers want to give as much support as possible to their relative with dementia, but as the dementia progresses and support moves towards a 24-hour role, some carers report that if they do not value their right to express their own reality when different from their relative’s, it had a negative impact on their wellbeing. For example, one carer explained how always ‘going along’ with the reality/beliefs experienced by her

mother was the only way to help her mother feel less anxious and distressed, but to the great detriment of her own mental health and wellbeing. “It denies everything that is true for you. So all of your life becomes untrue.”

### *Practitioners*

While practitioners can undoubtedly form strong attachments to the people they care for, wellbeing is a different issue for paid staff who do not share the same history with the person living with dementia, and therefore do not have as much emotional investment as family carers.

Yet paid carers also report feeling anxious or guilty about using untruths to support wellbeing, with concerns such as “is this something I’ll get told off for, or a violation of my professional code of conduct?” Judging what is good practice in relation to whole-truth-telling or otherwise will be in the context of best practice guidelines, models of care, skills and knowledge, and organisational policy. A lack of support for staff by the organisation in such a complex area of care can easily lead to poor staff morale and/or poor practice.

## **The pressures of ‘too little time’**

Dementia care involves working with each person’s unique beliefs, values, wishes, feelings, life history, family, lifestyle, and culture. In a sense the only real expert can be the person with dementia themselves, with family and paid staff doing their best to catch up. Spending time with the person with dementia is therefore essential. Yet time is often in short supply in dementia care.



Paid staff who are trying to balance the needs of many people living with dementia at the same time report finding themselves in a situation where the primary needs being met are purely physical – ensuring people are washed, have eaten, slept and so on. Meeting the more complex and time consuming emotional and psychological needs, so important for good quality of life, can unintentionally fall behind.

Family carers on the other hand, who may find themselves in a 24/7 caring role especially as the dementia progresses, report trying to balance the time spent on the needs of their relative with dementia, with their own.

The risk arises that a continual feeling of a lack of time can create an environment whereby decisions as to whether to whole-truth-tell or otherwise are always made in the 'heat of the moment'. This is in effect a culture of so-called 'fire fighting' involving little opportunity to make the deeply considered, collaboratively agreed decisions the panel feel are salient to supporting the long-term wellbeing of a person with dementia.

### **Fluctuating realities imply fluctuating response types**

For many people living with dementia, their sense of reality can fluctuate over time. There is always going to be a limit to being able to predict how someone's experience of reality might fluctuate. This implies that while a particular response may be helpful one moment, it may upset or confuse the next.

An example from a panel member was of a lady who sometimes expressed she was living in a time from her past and felt quite distressed, but who at other times would be experiencing life in present day and feel much less anxious. While the lady was experiencing life as time-shifted to the past, responses that were based on whole-truth were found to cause further distress, whereas when the lady's sense of reality coincided with her carer's sense of present day, it was far easier and more effective to talk in terms of the whole-truth they were both sharing at the time.



## **Dementia Care, Wellbeing and Human Rights**

A proliferation of recent legislation affects health and social care practice for people with dementia, including the Mental Capacity Act 2005 (MCA), the Equality Act 2010, and the Care Act 2014. UK legislation and the delivery of public services also have to be compliant with international human rights law and conventions.

The wellbeing principle is central to the Care Act in England. Wellbeing is a broad concept. It is described as relating to the following areas in particular:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over their day-to-day life
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal domains
- suitability of the individual's living accommodation

Taking the approach of ensuring people's rights are respected and upheld can help guide responses/interventions to experiences of different realities and beliefs by carers and practitioners. According to the UK's Human Rights Act 'inhuman or degrading treatment' is prohibited – which could include repeatedly telling the person the full truth and causing unnecessary distress, or repeatedly lying to them.

'Best interests' decisions making under the Mental Capacity Act 2005 can be helpful to guide appropriate responses.

The social model of disability, which underpins legislation such as the UK's Equality Act 2010 and international disability rights' conventions, can also shape our responses. The legal definition includes a 'mental impairment' that has a 'substantial' and 'long-term' negative effect on a person's ability to do normal daily activities. The impairments caused by more severe dementia therefore would usually meet this definition. Two expert witnesses referred to the social model of disability, and how environmental factors and the response of others can potentially have the greatest negative impact upon the person with the disability's wellbeing. Thus, rather than trying to 'fix' the person, it is society which needs to change in both its attitudes and behaviours.

# How can people respond to these experiences of different realities and beliefs?



“My feeling is ‘horses for courses’, and depending on the situation that you are in depends on how people are to deal with it and sometimes to go along with what the person is thinking at that time is the best way forward, not always to stay there but at that moment to calm the situation down... so you are not lying in the big word ‘lie’, you are not telling the truth, you are just floating sometimes in the middle area to help make the person feel more comfortable”

Expert Witness, Family Carer

## **What happens in the ‘heat of the moment’ and/or the first time these experiences occur, might be different from the ideal, co-created strategy**

In the ‘heat of the moment’ it is often not appropriate or there is simply not enough time to consult care plans and other carers, or sit down with the person and have a calm and rational conversation about which response might be the most helpful for them. Much of the deeper relationship-building and care-planning decisions will therefore progress outside of the times the person is having those experiences.

With that said then, there remains the question about what one should do in real time if planning has not (sufficiently) taken place to know which response is best suited for the person experiencing a different reality. This becomes especially pressured in circumstances where the person with dementia is distressed and/or aggressive, or this is the first time a carer or practitioner has been involved with such an experience.



The panel concluded that the most important elements of a response are:

- to show kindness, compassion and respect
- to try understand and acknowledge how the person with dementia is feeling
- to do the best one can do legally and ethically to reduce distress and delicately try and restore feelings associated with wellbeing: safety, reassurance, happiness (if possible), and calmness.

The response chosen first may not always be the ideal one. However, the carer can apologise to the person with dementia that they are still feeling upset, and try again. The panel felt it was important that carers try not to take on feelings of guilt and remorse as they negotiate their way through such difficult and emotional situations.

### **Family carers and practitioners often choose to interact differently (in the same situation)**

Within families there evolves a culture that determines what is appropriate in terms of truth-telling, manners, humour, intimacy, and so on. This often unspoken set of rules will affect a carer's responses to someone experiencing a different reality/belief from them, and also how they will feel about each type of response. Response-types may differ from one family member to the next. For example, children may be more likely to challenge the experiences of different realities or beliefs of their parent living with dementia, compared to a spouse who is more used to negotiating truth in a relationship.

### **If not 'truth', then what?**

Here are five terms that encompass caring interventions and responses to people living with dementia experiencing different realities and beliefs. They can be represented as part of a truth-lies axis in the following manner:

Whole- truth telling	Looking for alternative meaning	Distracting	Going along with	Lying
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The panel felt that one should always start from a point as close to whole-truth-telling as possible, and only when this is causing a person with dementia unnecessary distress, move on to a response that includes an untruth.

All responses and interventions must always be seen within the context of the main objective of supporting the wellbeing of the person with dementia. It is worth remembering also that 'wellbeing' is not simply a good idea which nice people talk about; it is enshrined in legislation, for example, with the new statutory principle of individual wellbeing the driving force behind care and support, underpinning the Care Act 2014 in England.

### **Whole-truth-telling**

'Truth' can be seen as subjective, therefore interacting using 'whole-truth-telling' equates to a carer telling the person living with dementia what they take as being their (the carer's) truth. This runs the risk of causing distress, therefore the way in which a carer's truth is related to the person with dementia is critical: delicately, respectfully, with kindness (as per the principles outlined

above), or put another way, without being patronising, abrupt or imposing. However, the benefits of truth-telling are that there may be greater trust between the person and their carer, which can have a positive impact on wellbeing in a manner of different ways across care practice.

An example the panel heard was of a lady living with dementia in a care home asking where her (deceased) husband was. As we will use this example several times, we will call the lady with dementia Nora and her deceased husband John. The practitioner(s) took Nora to her room (a place of comfort and calm and away from others), and gently prompted her through stories of John's life, using photographs where possible. This included telling the story of Nora attending a beautiful funeral service for John. The staff member(s) spent time with Nora as she grieved, but also felt some relief at things 'falling into place in her mind' and no-longer feeling anxious due to searching for John.

It was acknowledged that as per any type of response, this may not necessarily work at times and for all people.



## **Dementia With Psychosis**

Dementia may cause late-onset psychosis or a person with dementia may have a history of psychosis. Typical symptoms of psychosis are delusions and hallucinations i.e. different realities and beliefs. In general, beliefs involving feelings of suspicion, paranoia or persecution are more likely to be psychotic experiences, whereas other beliefs or realities involving confusion or time-shifts are more likely to be caused by the dementia.

When trying to support people expressing paranoia, whole-truth-telling is particularly complicated. People with these beliefs will often be looking for evidence that they are being lied to. On the one hand using reason and 'truth-telling' can exacerbate the person's paranoia if the person does not believe the carer's/practitioner version of reality. On the other hand, "going along" with the person's reasons for feeling paranoid will not enhance their wellbeing.

## **Looking for alternative meaning**

When a carer is 'looking for alternative meaning' of an experience, they acknowledge the reality a person with dementia is experiencing, and explore it using questions in order to move the person on, to decrease distress, and to find if a more subtle underlying meaning signifies an unmet need.

To continue with the example used above (in whole-truth-telling); if Nora, the lady with dementia, asks where her [deceased] husband John is, a carer may respond with "He seems like such a wonderful man. Can you tell me more about him? How did you meet?"

This would aim to facilitate a positive (reminiscence) discussion and to establish whether Nora wanted John specifically, or some of the feelings/ concepts he symbolised such as 'love' or 'hugs' or 'talking about the children together over dinner' – which the carer

can then work on providing in different ways.

## **Distraction – where validation attempts fail**

A clear separation needs to be drawn between approaches that try to find out more about the reality a person is in, versus those which move a person into a reality that bears no relation to what they are currently experiencing (and runs the risk of confusing them further). The former is about seeking meaning. The other is about distracting, which as the term suggests, will not necessarily solve the underlying causes of distresses, but if successful can alleviate the distress and at its best provide comfort and restore happiness so that the causes can be examined at a later time in a calmer, more positive emotional environment. Distraction would therefore usually be used as a temporary measure. Otherwise it is merely deflecting a reality that is perhaps very important to the person





and that they need a more direct response to in the long term, so as to try and eliminate the source of the distress in the first place. When a carer distracts a person, they do so by introducing something new into the moment, such as a topic of conversation, environment, or object.

An understanding of a person's personality and life story will increase the chances that the conversation, environment, activity or object a carer chooses to distract the person living with dementia with, will be meaningful and comforting.

For example, attempting to distract someone by saying 'shall we have a cup of tea and listen to some lovely classical music' may only exacerbate any distress if the person in fact only drinks coffee and prefers heavy metal music. Whereas if you know a person loves the outdoors and animals, an offer to walk around the garden and see the horses in the next field, will likely be far more appreciated and effective, if a distraction is to work at all.

For this reason, there are several activities that could be seen as meaningful engagement in one context,

and distraction in another. These would include any hobby/interest that the person living with dementia usually enjoys as part of their regular life style). However if any of these activities are used as an opportunity to deflect from distress, this could then be termed a distraction.

The panel felt that empathy / therapy dolls and artificial environments were also forms of distraction. This is discussed more in the box on the next page.

A large proportion of people report that where validation attempts fail, and the person with dementia is highly distressed, distraction is the next preferred method. This was particularly the case if the physical safety of either the person with dementia or their carer is deemed to be at risk.

In the example of Nora and John, a carer may respond to Nora (who the carer knows loves flowers and gardens) when she asks for John with: "I'm not sure Nora, but I've been meaning to show you the new tulips the gardener planted yesterday so I thought we could have a cup of tea and wander round the garden seeing as the sun is shining for a change!"

## **Artificial Environments and Objects**

### *Rooms and spaces*

Artificial environments are spaces that are designed to simulate another place and function altogether – for example a fake bus stop or sweetshop, a 1950's lounge, or a care home corridor that depicts a high street with front doors rather than bedroom doors. The panel felt that in general artificial environments are attempts at 'distracting' and 'going along with' types of intervention.



While there is plenty of anecdotal evidence to suggest that artificial environments can be stimulating and positive places for many people living with dementia, the panel felt that solid research is lacking and overall the quality of relationships is far more important than the environment.

One of the challenges with any artificial environment is that it is limited to a 'one size fits all' approach for everyone there. A lounge made to look like an "English 1950's traditional pub" may not 'ring true' to a migrant who came to the UK post-war, or a person with early onset dementia who didn't go to pubs.

This seems especially risky for people living with dementia who are likely to have confusion as something they struggle with. Furthermore, as artificial environments often apply only to one section of a home, a person is then stepping in and out of that other reality – potentially adding to confusion.

It would be difficult to guarantee that any particular artificial environment will not cause someone distress, for example through triggering unhappy memories. While everyone has their own mementos from the past, and can visit social history museums that take one back in time, this is done through choice and not imposition.

It is important for organisations that use artificial environments not to give mixed messages to staff. The panel heard of several examples where staff were effectively told 'lying is wrong but fake environments for people with dementia is ok'. Clear training as to why and how best to use such environments would help practice remain as person-centred as possible, and alleviate the risk that everyone with dementia is taken into them regardless of their preferences and biography.

In particular, the panel were concerned with what was termed 'environmental lies' – spaces intentionally made to deceive in that they are made to look like they had a particular purpose/function but were just representatives of this. For example, a painted wall depicting the seaside with sound effects of waves crashing. Other common examples include a bus stop where buses will not come, or a painted shop front/fake kiosk that does not offer any real produce.

The panel felt that it would be far more effective – less confusing, more stimulating, no risk of patronisation, more helpful to fostering community-building etc. – to include real versions of what was being artificialised. For example, a care home could include a real shop, or take people out to a shop.

The question that the panel explored was therefore 'why aren't people with dementia afforded the same access and opportunities to everyday, 'real' activities, rather than turning care homes and day centres into social history



museums'? The panel felt that would be hugely beneficial for care homes to open their doors to the wider public as places for positive encounters with older adults including those living with dementia. Furthermore, rather than creating [fake] bus stops and shops in care homes, better to use the same facilities in the local community to normalise the activity and enable people with dementia to participate in ordinary community life rather than be separated from it. Current efforts to raise public awareness about dementia and develop 'dementia friendly communities' provide potential opportunities for communities to be more inclusive of people with dementia including those experiencing a different reality.

Yet clearly this raises the issues of resident dependency and frailty, resources and staff availability.

#### *Empathy Dolls and Soft Toys*

Artificial objects include therapy/empathy dolls and soft toys. There is a growing body of evidence for the therapeutic benefits of dolls for people with dementia, which includes:

- providing comfort, companionship, sensory stimulation and purposeful activity
- positive changes in behaviour, reducing agitation and distress
- facilitating interaction between other residents, relatives and staff in a care home
- helping a person connect to a place in time where they felt a sense of control, in turn increasing self-esteem
- increased verbal and non verbal interaction
- The downsides of using dolls include:
  - the perception by some that it was 'demeaning' and leading to 'infantilisation' of people with dementia
  - a person becoming over-stimulated and fatigued by having a doll
  - an institution using dolls as an alternative to treatment, or distracting people in order to satisfy their social needs of feeling useful/caring for someone

Empathy Dolls, as with anything, should not be used as a blanket measure for all people with a dementia diagnosis. Instead, knowing a person's life history and



personality, and reading body language once the doll is offered (not imposed), will help ensure that empathy dolls as an intervention are as person-centred as possible. If a person's eyes light up when they see a doll and/or they reach out for one, then it is likely to have a positive effect on their well-being at that time.

Similarly to conclusions in relation to artificial environments, the panel felt that rather than having dolls or robot seals, there would be more benefit (and less risk) in having real animals and children around to spend time with (with acknowledgement that this is no simple matter and issues such as child/animal welfare need to be considered).

### **'Going Along With'**

There is a difference between 'meeting a person in the place they are in' - that is a different reality / belief to one's own - and deliberately setting out to deceive them. When 'going along with' a person with dementia, a carer is neither trying to confirm or deny the reality that person is expressing, but rather 'stepping into their world' and exploring it by asking questions and on occasion behaving as if this reality is understood (which is the objective). The panel felt that this response was seen to provide a mechanism by which to engage and communicate with the person, even if the reality was not shared, and an opportunity to gain important information about the person as an individual.

Some carers and practitioners feel it is often essential not to contradict or actively challenge a person with dementia's beliefs - a basic form of "going along with" - as this can cause further distress and confusion, and damage the potential for future communication. They describe "going along with" as their most used, most effective, and most compassionate response.

For example, the panel heard about one lady who visited a day centre and referred to it from the outset as "school". As the lady did not apparently understand the concept of day centres and got confused upon hearing the term, the family too took to 'going along with' this reality and also calling it school - they felt it was more important to support the feelings of their relative than to 'correct' her. The family's acceptance of her perceived reality was enormously helpful in constructing a concept that gave meaning to what she was experiencing each week.

There are very challenging scenarios however within which going along with the person's reality can jeopardise other people's wellbeing. For example, the panel heard about a gentleman who believed himself to be in his 20s and was expressing sexual desire for staff members. The staff were trying to change their behaviour so as to avoid provoking his behaviour, but were also trying to acknowledge and work with the needs and desires of the person.

Continuing the example of Nora and John; if Nora asked a carer where John was in this way: "I can't find John. Is he at



work still?" A carer who was 'going along with' may answer with "well it's only 2.30 in the afternoon Nora, so that does make sense. He's a hard worker your John!"

## Lying

Overall, the evidence presented to the inquiry concludes that 'lying' – which is where a carer initiates purposeful deception (as opposed to a carer meeting a person living with dementia in their reality) – is only felt to be appropriate to protect the psychological or physical safety of the person living with dementia or that of others. The panel heard evidence that this occurs mainly in two circumstances.

The first is at times of extreme risk. Witnesses said that in cases of high risk to the person or carer, a lie might be appropriately used 'on the spot'. For example, if the person was taking an action that could be physically and psychologically dangerous, a falsehood that prevented them taking this action may be appropriate. Following the incident the episode would need to be reported and assessed. But the lie would have to be in the person's best interest. Using the example of Nora and John a final time, it may be that a carer sees Nora shouting at another resident in the home "where have you put John? I know you've hidden him from me, tell me where he is." In this moment, to protect the other resident and try and help Nora who is massively distressed, the carer may say "Nora it's only 2.30pm, John will still be at work just now. Don't worry, everything is ok, he's not hidden, he's just not here, he's at work."

The second is during care 'interventions' (as opposed to 'responses') – where a carer/practitioner tries to initiate or encourage a particular activity (e.g. washing) – as a last resort. Using the example from the 'truth-telling and interventions' section above, a carer/practitioner may decide (ideally following a best interests meeting) to tell a person with dementia "your friend is coming to tea later (knowing this is false) and it would be nice if you had a wash before his visit," in order to support their wellbeing. This is the use of a lie ('a blatant untruth') in an intervention. However, in a different scenario, if the person with dementia began talking about a friend coming to visit them later which the carer/practitioner knew to be incorrect, they may choose to 'go along with' this story in the moment to avoid causing the person unnecessary distress. The carer/practitioner may 'meet the person in their reality', not contradict, but listen and explore the person's thoughts/concerns/feelings about their friend's visit, before probably moving on (through possibly distracting/reframing) to a different topic which sat within both persons' shared reality. The subtle but important difference here is that people reported to the panel that this was not 'lying.' Only if the carer/practitioner then pretended that they agreed that the friend was visiting, by building on the story themselves and adding facts - e.g. "oh yes I'm looking forward to seeing them too, they'll come around 3pm and we can all have tea together" [knowing this all to be false] – did this become lying, which was felt to be unnecessary, and in most cases morally wrong.

# The underlying principles to all responses and interventions



The panel acknowledged just how much skill, energy, empathy and compassion are required in maintaining a positive, supportive relationship between a person living with dementia and their carer/practitioner, while negotiating the ethics of highly complex situations and deciding what responses and interventions are best in terms of whole-truth-telling or something else.

The table below tries to incorporate: all the challenges explored in choosing whether to use truths or untruths; how a carer or practitioner could attempt to know which is the most relevant explanation for a person with dementia experiencing a different reality or belief; and the critical aspects of all responses to and interventions with a person living with dementia experiencing a different reality or belief, when trying to support their wellbeing.

Principle	Key Points	Practical advice and questions for carers and practitioners to consider
<p>1. Experiences of different realities and beliefs are meaningful to a person living with dementia. A key role of any carer is to find out what this meaning is, with 'positive curiosity'. This is a fundamental aspect of good quality care, and should not be considered a luxury agenda item, "if there is time."</p>	<p>A diagnosis of dementia is not 'the end of the road': people with dementia are people, first and foremost</p> <p>As far as possible the process of finding out and understanding the meaning of a different reality or belief must be guided by the person with dementia</p> <p>Only when there is an understanding of what an experience means to the person can a carer give the most effective response to support the person's long-term wellbeing. By contrast, responses that are simply reactionary without deeper understanding are destined to do little more than try and effect short-term happiness</p>	<p>How can I communicate my underlying respect for and valuing of the identity of the person with dementia, before exploring the meaning behind their different reality or belief?</p> <p>Have I made sure to check that the person's reality is not in fact "accurate" (and nothing to do with dementia)?</p> <p>What is the person seeing, hearing, feeling or thinking?</p> <p>How can I help the person tell me more about their different reality or belief?</p>



Principle	Key Points	Questions for carers and practitioners to ask themselves
<p>1. Experiences of different realities and beliefs are meaningful to a person living with dementia. A key role of any carer is to find out what this meaning is, with 'positive curiosity'. This is a fundamental aspect of good quality care, and should not be considered a luxury agenda item, "if there is time."</p>	<p>What might be the possible meaning to the person of their different reality or belief? Could it involve time, memory and emotion; underlying unmet needs; or creative coping strategies?</p> <p>People living with dementia report that it is important to feel they are taken seriously and given the respect that a carer would give anyone else (ie without a diagnosis) when listening to and investigating that person's concerns. "Don't assume it's the dementia talking"</p>	
<p>2. Finding out what experiences of different realities and beliefs mean must be done with an open mind; a flexible, tailored approach; and with kindness. The more a carer knows about the lifestory, personality and values of the person with dementia, the more likely they will be able to understand the meaning behind these experiences.</p>	<p>There is no 'one-size-fits-all' approach that is effective in dementia care, and no particular response is permanently successful in supporting wellbeing for a person with dementia. It may take a number of attempts to find out the meaning of different realities and beliefs, and it may occasionally not be possible.</p> <p>Finding out the 'why' behind someone's different realities/ beliefs can often progress best during times outside of the experiences themselves, while everyone involved is calm and relaxed'.</p>	<p>Am I putting aside time to spend with the person living with dementia in a relaxed, informal way, to get to know them and how they feel about these experiences and my responses to them?</p> <p>Have I done my best to show kindness and compassion to the person having these experiences by offering reassurance and acknowledging that I recognise they are expressing strong feelings ?</p> <p>Have I explored all the possible explanations for the person's different reality or belief? How do they react to my response in the moment? Is it helping to support the person's wellbeing?</p>



Principle	Key Points	Questions for carers and practitioners to ask themselves
<p>2. Finding out what experiences of different realities and beliefs mean must be done with an open mind; a flexible, tailored approach; and with kindness. The more a carer knows about the lifestory, personality and values of the person with dementia, the more likely they will be able to understand the meaning behind these experiences.</p>	<p>The normal rules of healthy social engagement should apply as when anybody expresses a very different view of the world from oneself: “you offer a respectful, tentative, alternate view for what your perception is of that reality,” (rather than one person imposing their reality/truth onto another).</p> <p>Many people living with dementia feel that kindness and compassion are the qualities that matter most to them in how a person responds to their experiences. One of the first steps to any response is to offer reassurance and acknowledging the strength of feeling expressed</p> <p>Finding out the meaning should not done at the expense of their (or others’) safety</p> <p>Knowing the person is vital – their life history, values, personality, habits, hobbies, interests and lifestyle preferences.</p> <p>Knowing about the person’s dementia is also crucial. Information about the person’s dementia is likely to help provide explanations for the experiences the person is having and the behaviour it causes.</p>	<p>Am I getting the balance right between listening and respecting the person’s views and thinking about their wellbeing and safety? Who can I get advice from about this?</p> <p>Can I find out more about the person to help me understand their different reality or belief? If I need to find out more, who can I talk to?</p> <p>Do I know enough about the person’s dementia to understand the affect it is having? If I need to find out more, who can I talk to?</p> <p>Am I trying to make sense of these different realities and beliefs together with the person experiencing them, by “stepping into their world” and trying to see things from their perspective (rather than simply believing/communicating to the person that they’re wrong)?</p>





Principle	Key Points	Questions for carers and practitioners to ask themselves
<p>3. Responses and interventions start with whole-truth-telling. Move away from this only if it is causing unnecessary distress. 'Lies' (as in blatant untruths initiated by a carer – as opposed to meeting a person with dementia in their reality) may only be used in extreme circumstances to avoid physical or psychological harm.</p>	<p>The mantra of “never lie” may be unhelpful in practice; instead take the approach: “always tell the whole truth (or stay as close to the truth as possible) unless it is going to cause unnecessary distress”</p> <p>Even if in the past whole-truth-telling caused distress, it is important for carers not to be afraid to try whole-truth-telling again at some time in the future, in case attitudes have changed and it is now effective.</p> <p>There are challenges to using untruths that must be carefully considered when deciding which type of response/intervention is most appropriate.</p> <p>It is important to take into account and discuss the impact some responses/interventions may have on carers and practitioners, in terms of their reality, and their beliefs, views and professional expectations regarding truth telling.</p>	<p>When can I best take time – outside of the ‘heat of the moment’ experiences – to discuss and check whether whole-truth-telling is causing unnecessary distress, with the person with dementia?</p> <p>How can I best judge what are necessary negative emotions, from unnecessary distress? Can this be discussed with the person with dementia?</p> <p>How do I feel about moving away from truth-telling? What impact does it have on me, my reality, and my position (if acting in a paid role). Who can I discuss this with, without being judged?</p>



Principle	Key Points	Questions for carers and practitioners to ask themselves
<p>4. Environmental lies should also be avoided. These are artificial spaces designed to deceive, such as a painted shop front (as opposed to a real small shop within a care setting)</p>	<p>Knowing or not knowing one has dementia is likely to affect the experience and meaning of different realities and beliefs. People have a right to be told about what is probably the major reason for these experiences. Sometimes this can even alleviate distress that comes from not understanding why the experiences are happening.</p> <p>Solid research to suggest that artificial environments can be positive places for many people living with dementia is lacking and overall the quality of relationships is far more important than the environment.</p> <p>It would be difficult to guarantee that any particular artificial environment will not cause someone distress, for example through triggering unhappy memories. While everyone has their own mementos from the past, and can visit social history museums that take one back in time, this is done through choice and not imposition.</p>	<p>Is it possible to use real versions of what is being artificialised through an artificial environment?</p> <p>How can I support people with dementia the same access and opportunities to everyday, 'real' activities, rather than turning care homes and day centres into social history museums?</p> <p>How can I create an environment in which people with dementia can spend time with real animals or children toward making a positive impact on the formers' well-being?</p>



Principle	Key Points	Questions for carers and practitioners to ask themselves
<p>5. Keeping responses and interventions consistent across family carers or staff teams.</p>	<p>There is a vast range of opinions and education in relation to how to respond to someone experiencing a different reality or belief to one's own. This may occur between family members or family carers and practitioners.</p> <p>Inconsistent responses and interventions can be confusing, distressing and damage relationships. An example is if a person with dementia asks 'where's mum?' and one person says 'at work', another says 'I'm afraid she's passed away', another says 'I don't know' and another says 'why, do you miss her?'</p>	<p>Have I made sure to share the stories of how which responses and interventions worked and didn't work with everyone included in the person's care?</p> <p>Do all the people involved caring for the person living with dementia feel the same about the role of whole-truth-telling or otherwise in supporting wellbeing?</p> <p>How can I ensure that everyone agrees to give the same responses at any one time, and also allow these responses to change over time according to what is working or not?</p>
<p>6. Documenting and sharing what does and doesn't work.</p>	<p>A (dynamic) care plan is most effective as a 'living document' that is referred back to, reflected upon and updated, as people's needs change over time. It is a plan or strategy for giving holistic care to an individual, and the information should be based as much as possible on the person (with dementia)'s own words.</p> <p>It is important to keep a steady record of what does and does not work by way of responses to a person's experiences of different a reality/belief.</p>	<p>Do I have a care plan for the person with dementia that includes detailed, up-to-date information about:</p> <ul style="list-style-type: none"> <li>• life history, personality, hobbies/interests, and lifestyle preferences (eg chosen routines, times of day with more/less energy, etc.)</li> <li>• beliefs, morals, and values (eg religious, humanitarian, dietary, etc.), including the person's views of truth-telling</li> </ul>



Principle	Key Points	Questions for carers and practitioners to ask themselves
<p>6. Documenting and sharing what does and doesn't work.</p>	<p>The term 'care plan' is more frequently used in institutional settings than by family carers in a person's home. It is content of a care plan that is most important, not what it is called or how it is laid out.</p> <p>In organisations there are likely to be a number of templates for care plans relating to different subject areas, alongside 'daily care notes/records' that are added each shift. (The panel would suggest if an area listed above is not covered by any such templates that it be implemented immediately).</p> <p>For family carers this information could be kept in the form of an informal diary, with a few pages at the front outlining personality and so on, while the bulk of the diary is for recording (and, if time, reflecting) on current everyday experiences.</p>	<ul style="list-style-type: none"> <li>• people, places and things that can make or break a person's day</li> <li>• most effective ways of communication (eg verbal, written, pictorial)</li> <li>• physical and mental health, type of dementia and medications</li> </ul> <p>How can I best record what responses and interventions are and are not working to support the person's wellbeing, in relation to their experiences of different realities and beliefs?</p> <p>How can I best meet with others involved in the person's care all together, to share information and expertise?</p>



Principle	Key Points	Questions for carers and practitioners to ask themselves
6. Documenting and sharing what does and doesn't work.	<p>The panel felt that it is paramount for carers and practitioners to find time to share and reflect together upon the person's general wellbeing, and why and how responses were working or not to support the person's wellbeing, with the person with dementia. This could take the form of a multi-disciplinary meeting (including best interests meetings) whereby different experiences and interactions are shared and discussed, so that a range of opinions and expertise can come together</p> <p>In a care home or institutional setting this will involve the resident themselves if possible, their next of kin and other family members, key workers, the resident's GP and any specialists working with them.</p> <p>If the person is living at home, this could be key family members and anyone else involved in the person's care – professional or otherwise.</p>	



## Appendix I: Panel Members And Expert Witnesses

### Panel members

Professor Graham Stokes (Co-Chair)	Mark Ivory
Dr Daphne Wallace (Co-Chair)	Dr Ian James
Professor Murna Downs (Vice-Chair)	Alise Kirtley
Raydene Carver	Simon Kitchen
Janice Clasper	Keith Oliver
Ken Clasper	Catherine Ross
Jenny Edwards CBE	Dr Kate Ross
Kate Emery	Nada Savitch
Philly Hare	Rachel Thompson
Professor Julian Hughes	Toby Williamson

Research and administrative support for the panel was provided by Dr Yulia Kartalova Doherty, Katrina Jenkins, Kirsten Morgan and Holly de las Casas. Some individual panel members had additional support provided by Jess Amos, Rosemary Oliver, Sophie Razzel and Richard Wallace.



## **Expert Witnesses**

Min Stacpoole  
*St Christopher's Hospice*

Dr Maggie Ellis  
*University of St Andrews*

John Killick  
*Writer*

Jane Gilliard  
*Family Carer*

Prof Robert Howard  
*Kings College London*

Penny Garner  
*Contented Dementia Trust*

Cathy Baldwin  
*Alzheimer's Society*

Professor Dawn Brooker  
*University of Worcester*

Professor Lisa Bortolotti  
*University of Birmingham*

Celia Stamper  
*University of Brighton*

David Storm  
*Clinical Lead, Cumbria NHS  
partnership Trust*

Gwyn Grout  
*independent Nurse Consultant*

Roberta Caiazza  
*Clinical Psychologist*

Reinhard Guss  
*Clinical Psychologist*

Paul Baker  
*Hearing Voices Network*

Professor Arlene Astelle  
*University of Sheffield*

Ming Ho  
*Family Carer*

Sergeant Vanessa Rolfe  
*West Yorkshire Police*

## **Focus Groups**

Canterbury Forget Me Nots

Stokesley Carers Group

Staff at Housing & Care 21's Watermill  
Centre in Walsall



## Appendix II : models of caring

**Reality Orientation** involves a carer guiding a person out of the reality or belief they are experiencing and into that which the carer (and presumably other people) hold, particularly in terms of date and time and place. Sometimes this is done with the use of physical evidence, for example a photo album. One of the main criticisms of the Reality Orientation approach is the risk that people are being constantly contradicted and re-educated in order to be brought to the shared reality of practitioners or carers, causing unnecessary distress.

**Namaste Care** is an approach that uses sensory experiences and personal care as meaningful activity, to help both staff and family members communicate better with people in the advanced stages of dementia. It helps the carers to 'slow down', and increases their confidence and self-esteem in helping people who are often no longer using verbal communication.

**Validation Therapy** uses verbal and non-verbal communication to 'validate' or accept the values, beliefs and reality of the person living with dementia. A carer will agree with everything the person with dementia is saying, and echo sections of speech and/or the non-verbal communication back to the person. From there, the person with dementia is supported to feel more calm and secure, but also when appropriate, redirected out of their reality if it is distressing them.

### **The 'Hearing Voices Network'**

challenges the traditional idea of hearing voices purely as a symptom of psychosis. Hearing voices can be a coping mechanism to deal with unresolved emotions, often from past trauma. The approach involves respecting, entering and then deconstructing the experience of that person. People's belief systems are never challenged. There is evidence that this approach is reducing anxiety and distress-reactions in people living with dementia hearing voices; reducing hospital admissions; and beneficial to self-esteem as it acknowledges the reality of the experience for the person. However it is time-intensive and specific training is needed to be confident working with somebody who hears voices.

**Functional Analysis** aims to understand the meaning or function behind a person's distressed behaviour as an unmet need. For example, agitation or aggression can indicate unmet physical, psychological or social needs, such as pain or discomfort, environmental stressors, social isolation, lack of verbal or cognitive stimulation in the person's surroundings.

### **Specialised Early Care for Alzheimer's (SPECAL)**

is based on the following 'golden rules': listen to the experts (the people with dementia) and learn from them; and don't contradict. Although one can argue that the SPECAL approach is person-centred as it relies on the personal histories of people, it has also been heavily criticised by some for suggesting 'a blanket approach to





deception of people with dementia'. SPECAL is a model many family carers have heard about and are drawing upon in practice. However, it has not been adopted in mainstream health and social care policy because of concerns about loss of autonomy for the person with dementia. Many Expert Witnesses were concerned that SPECAL is too rigid, and the panel concluded that the SPECAL approach is too much 'one size fits all' with no room for truth-telling and alternative ways of interacting, which the Panel feel strongly is important in the right situations.

**Dementia Oriented Realities** are untruths used for the person with dementia's benefit. The information given to the person is consistent with his/her 'time-shifted' beliefs, but inconsistent with reality. They build upon the 12-item set of guidelines on the use of therapeutic lies compiled by Dr Ian James (James et al, 2006; Culley et al, 2013). It is worth noting that the set of guidelines was originally designed by Dr James in response to the Mental Capacity Act 2005 as a means of ensuring that the mental capacity of a person was assessed, prior to considering if any form of 'lying' in dementia care was appropriate.

**Adaptive Interaction** involves connecting with the person using non-verbal techniques such as touch, and imitating the sounds the person with dementia is making; "talking in [the person with dementia's] language." The focus of AI is on enabling people to retain communication skills and connect with others when these skills are very limited. It is thought that this kind of interaction will have a positive impact on the person's wellbeing even if the factual memory doesn't last.

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