"Going Along With It":

Considerations of Truth-telling and Deception in the Care of Persons with Dementia

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Faculty/Presenter Disclosure

I have nothing to disclose

LEARNING OBJECTIVES

At the end of this session, participants will be able to

1. Define and illustrate common examples of deception and “therapeutic” lying in the care of persons with dementia

2. Explore the potential benefits and adverse effects of truth-telling vs. deception in the care of persons with dementia

3. Consider guidelines on whether and when to employ various forms of deception in the care of persons with dementia

Two Questions

- Have you lied to patients who lacked capacity when the lie has been judged to be in their best interests?

- Have you sanctioned the use of lies by caregivers when the lies have been judged to be in the person's best interests?

Complaints of a Dutiful Daughter

USA, 1994. Director: Deborah Hoffmann

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IMPORTANCE OF TOPIC

- Challenging behaviours are **COMMON**
- Challenging behaviours are **IMPORTANT TO TREAT**
- Pharmacologic Interventions are **OFTEN INEFFECTIVE and DANGEROUS**
- Deception is **COMMON** – even if caregivers may not acknowledge it
- Topic remains **CONTROVERSIAL**
- Caregivers are looking for simple, realistic and meaningful **GUIDANCE**

Challenging behaviours are <u>Common</u>

- Also referred to Behavioural and Psychological Symptoms of Dementia (BPSD) or – in DSM*5* - the specifier “with Behavioural Disturbances” for those with a Neurocognitive Disorder – or better yet – ”experiences of different realities and beliefs”

- Estimated that more than 90% of people with dementia develop at least one challenging behavior during the course of their illness

- Metaanalysis: prevalence of BPSD was 78% among individuals with dementia in long-term care facilities

Examples of Behaviours that Challenge

Ongoing belief that a deceased parent or partner is alive

Continuously asking to ‘go home’ when home no longer exists or is unavailable

Challenging behaviours are <u>important to treat</u>

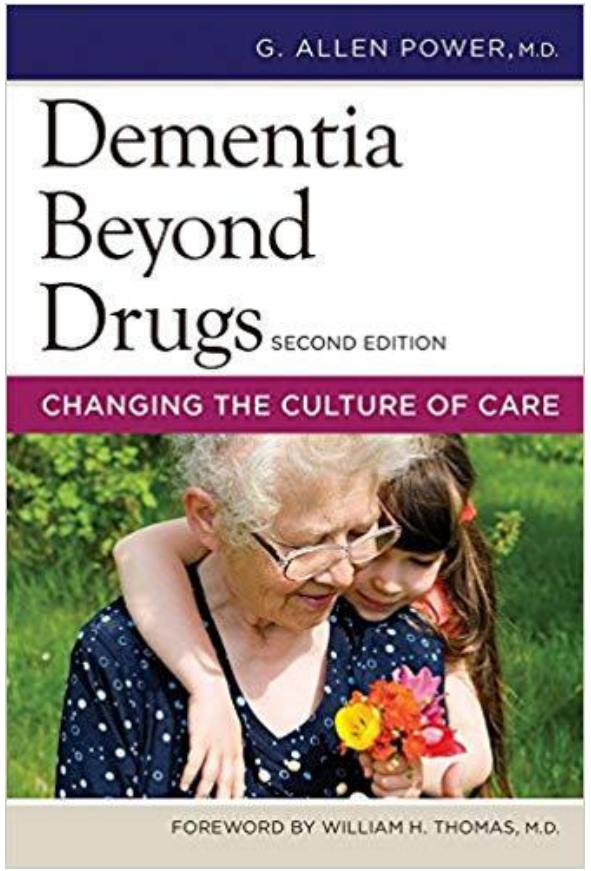
- Alleviate subjective distress (and distress of the caregiver)
- Preserve the physical and psychological safety of the Person with Dementia (PwD) or others
- Family and professional caregiver burnout is otherwise at risk
- Strong predictor of premature institutionalization

Gaugier JE et al (2009) Predictors of Nursing Home Admission for Persons with Dementia Medical Care 47: 191-198.

Pharmacologic Interventions are Often Ineffective and Dangerous

- Until relatively recently, a biomedical perspective dominated the treatment of BPSD, and thus, the treatments chiefly involved the use of psychotropic medication

- Empirical evidence now suggests that such treatments are largely ineffective, highly problematic (sedation, movement disorders, gait imbalance, risk of stroke, ….) and can be lethal.



Deception is <u>common</u> - even if caregivers may not acknowledge it

- 96% of care staff used lies in their work with dementia
  James et al. (2006) Lying to People with Dementia Int J of Ger Psychiatry 21:800-801

- Numerous surveys have shown judicious use of lying and deception when less controversial interventions fail is common

Two Questions

Have you lied to patients who lacked capacity when **the lie has been judged to be in their best interests?**

Yes – 69%

Have you sanctioned the use of lies by caregivers when when the lies have been judged to be in the person's best interests?

Yes – 66%

Electronic survey of 76 old age psychiatrists in north east England
29 (38% respondents): 19 consultants, 6 specialty doctors, 4 higher trainees
Cully et al. (2013) *Therapeutic Lying in Dementia Care* Nursing Standard. 28: 35-39.

Views of people living with dementia and their informal/unpaid carers

- Qualitative study using focus groups: people with memory problems (n=14); and informal/unpaid carers (n=18)
- Results: **most** informal /unpaid carers and people with memory problems considered lying along a continuum, from not acceptable when the intention is to deceive and harm, to acceptable when the intention is to benefit and minimize harm.

"No matter what you do he's gone away or she's gone(died), right, so if it's going to help her or help me, do you know what good is making her suffer because she'll forget all about it again…"

Casey et al. (2019) *Telling a 'good or white lie': The views of people living with dementia and their carers.* Dementia

Topic remains <u>controversial</u>

What constitutes a deception or lie?

Should caregivers be trained to lie effectively?

Is lying against a health care professional's code of conduct?

Topic remains <u>controversial</u>

A person with dementia's distress **does not** justify lying

A person with dementia's distress **does** justify lying

Lying is not justified under any circumstances!

The judicious use of person-centered lying when other alternatives have failed is justifiable!

Caregivers are looking for simple, realistic and meaningful <u>GUIDANCE</u>

The Most Challenging Question

Can a “lie” ever be justified in supporting the well-being of a person with dementia?

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What terminology should we use?

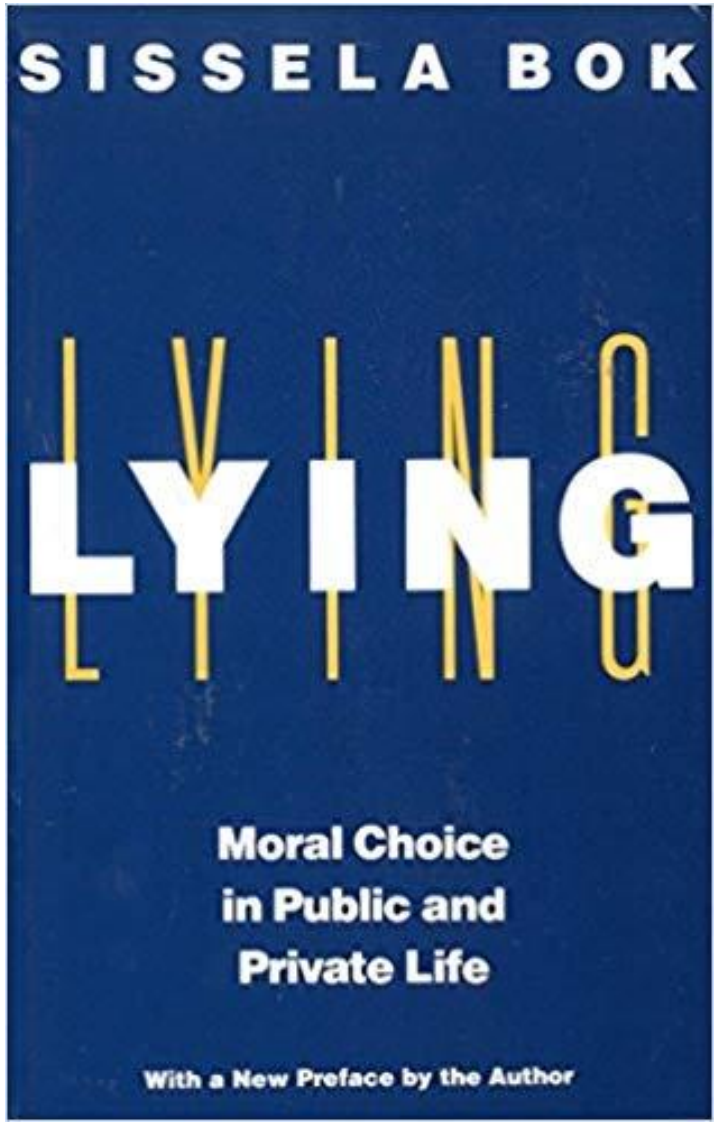
Cambridge English Dictionary

- Truth - the real facts about a situation, event, or person
- Lie - something you say that you know is not true:
- Deception - the act of hiding the truth, especially to get an advantage:

Deception – “When we undertake to deceive others intentionally, we communicate messages meant to mislead them, **meant to make them believe what we do ourselves do not believe**. We can do so through gesture, through disguise, by means of action or inaction, even through silence.”

Lie - “an intentionally deceptive message in the form of a statement.”

Truth - communicate messages consistent with what we ourselves believe



Lies require a reason

- Can be person-centered: the “therapeutic” lie

- Or “mean and culpable”: the “blatant” lie

There’s a difference between “meeting a person in the place they are in” and deliberately setting out to deceive them

Types of Caring Interventions and Responses

Whole-truth telling	Lying

Mental Health Foundation (2016). *What is truth? An inquiry about truth and lying in dementia care* [online]. Available at: http://www.mentalhealth.org.uk/publications/what-truth-inquiry-about-truth-and-lying-dementia-care

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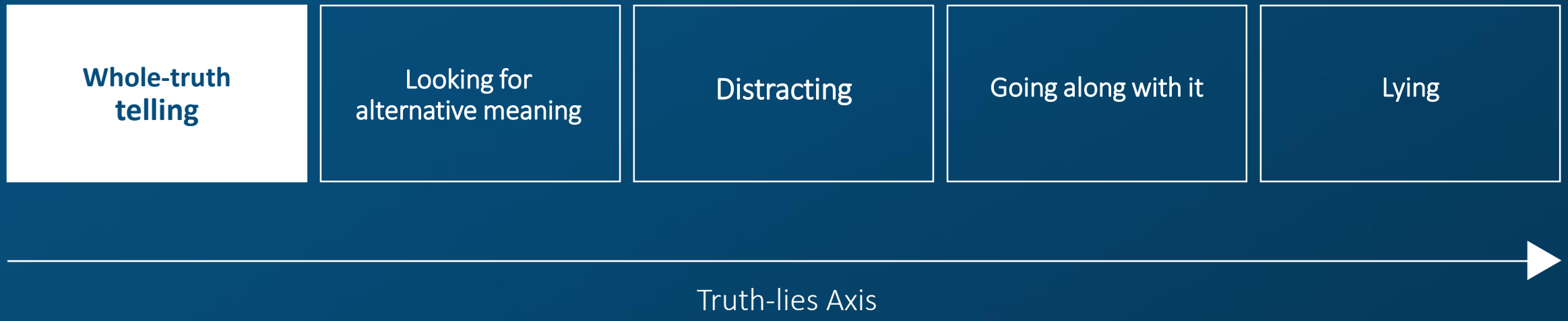

"As you move to the right the use of deception increases, but also inner discomfort"

"An enquiry about *Truth and Lying in Dementia Care* by the Mental Health foundation (2016) utilizes five terms of caring interventions and responses that can be represented as part of truth-lies axis in the above continuum"

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First Principles – Before Intervening

What do different realities and beliefs mean to people with dementia who experience them?

Experiential Audit*

- Recognize that dementia shifts a person with dementia's experience of the world around him/her

- Consider three common themes that can be the driving forces behind these experiences
  - Underlying (unmet) psychological and physical needs
  - Time-shifting
  - A coping strategy

*Power GA : Dementia beyond Drugs

First Principles

Medical Audit* – consider a medical evaluation if

- New or different behaviour, prominent physical symptoms, new to your care, less alert
  - Pain, medication side-effects, infections other illnesses
- Impaired reality testing may be intrinsic to the underlying neurophysiology or another health condition
  - Hallucinations of Lewy Body dementia
  - Delirium secondary to infections or medications

Environmental Audit*

- Are there triggers of the behaviour in the person's immediate surroundings
  - Over- or understimulating environments

*Power GA : Dementia beyond Drugs

Whole-truth telling	Looking for alternative meaning	Distracting	Going along with it	Lying

"Telling the person living with dementia what they take as being their – the carer's truth"

“Most would agree 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.”

A focus on ‘Reality Orientation’

Memory for Max, Claire, Ida and Company

Canada, 2005. Director: Allan King

Whole-truth telling	**Looking for alternative meaning**	Distracting	Going along with it	Lying

"When a carer is 'looking for alternative meaning' of an experience, they acknowledge the reality a person with dementia is experiencing, and consider whether a more subtle underlying meaning signifies an unmet need."

"The caregiver focuses on addressing this unmet need or responding to the emotions expressed by the Person with Dementia rather than the factual information that the person may be stating."

A 'Validating' or 'Experiential' approach"

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Whole-truth telling	Looking for alternative meaning	Distracting	Going along with it	Lying

“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.”

“This new reality that bears no relation to what they are currently experiencing (and runs the risk of confusing them further). But if successful can TEMPORARILY alleviate the distress and provide comfort.”

ALZHEIMER'S: THE CAREGIVER'S PERSPECTIVE

Directed by Mason Mills (2016)

--From the 2-episode "Dementia Documentary Series" on PBS

Whole-truth telling	Looking for alternative meaning	Distracting	Going along with it	Lying

Caregivers align their actions with the “reality” of the person with dementia .

“For many people living with dementia, short-term memory is affected and long term, historical memories dominate. This may mean people with dementia become time-shifted, often believing they are living in the past”

HARRY KARLINSKY

Whole-truth telling	Looking for alternative meaning	Distracting	Going along with it	Lying

Lying – the explicit communication of false information

Significant debate as to whether a lie can ever be "therapeutic" (aka "little white lie", "bending the truth")

For those who support "therapeutic" lies, the lies must be
person-centered,
employed with caution
used only in situations where other approaches have been trialed first and failed

What is generally not condoned –

Blatant untruths ("outright lies") : initiated by a caregiver for the caregiver's benefit

"EXTREME LOVE: DEMENTIA"

A 2012 BBC2 Documentary Series

Other Categories of Deceptive Practice*

- **Not Telling:** Omissions of the truth
  - Omitting the truth all-together, withholding key details
  - E.g., Presenting planned outings with an agenda as spontaneous

- **Tricks:** A deceptive action on the part of the caregiver, as opposed to an untrue verbal communication
  - Disabling the stove or car
  - Placing a lock in an unusual location

*Blum N.S.!1994) Deceptive Practices in Managing a Family Member with Alzheimer's Disease. Symbolic Interaction, 17: 21-36.

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Artificial Environments and Spaces

Artificial Environments and Spaces – “designed to simulate another place and function altogether”

Generally viewed as ”going along with” and “distracting” interventions

Can be stimulating and positive places for many Persons with Dementia

BUT …
Consider the fake bus stop – first introduced in Germany over 10 years ago with the intention of reducing wandering

Harvey Krumpet

Australia 2003. Directed by Adam Elliot

The fake bus stop is an example of an –

> Environmental Lie - “spaces intentionally made to deceive in that they are made to look like they had a particular purpose or function but were just representative facsimiles’.

These environmental lies/deceptions can be extremely elaborate

George G. Glenner Alzheimer's Family Day Care Centers

- The faux town has 14 different storefronts, including a diner, a movie theater, a pet store, a park-like square, and a city hall
- "Participants"- most of them have early-to-moderate-stage Alzheimer's disease -- rotate around with an aide in small groups, usually visiting five or six storefronts in a day and doing tailored activities in each one.
- A Thunderbird is parked next to an old-fashioned filling station.

https://www.citylab.com/design/2018/09/why-a-memory-town-is-coming-to-your-local-strip-mall/569905/

Artificial Environments and Spaces

Benefits are not well-studied and there are significant concerns

- "One size fits all" approach
- Demeaning, stigmatizing
- Potentially confusing

Quality of relationships is far more important than the environment

Why aren't people with dementia afforded the same access and opportunities to everyday 'real' activities – including positive encounters with the wider public?

Hogewyck – a Dementia Village

IN LANGLEY

"The Village”

- A dementia-inclusive community opened recently in Langley, B.C.
- Called The Village, it's billed as "the first memory care community of its kind in Canada," modelled after communities in Holland and the U.S.
- The facility consists of six cottages, each with 12 or 13 private bedrooms tailored to those living with dementia.
- The Village Plaza includes a fully functioning general store, post office, salon, spa, and patio area

Artificial Objects: Empathy Dolls and Soft Toys

Product Description

- **Empathy/Therapy Dolls** are a valuable contribution to health and well-being in dementia care, and our dolls have been specifically designed for people with cognitive loss.
- Our dementia dolls do not cry
- Eyes remain open (research has shown that this is preferred by people with dementia)
- Realistic body size and weight that encourages interaction

Contents

- 1 x Doll
- All of our dolls come supplied with both a pink and blue set of clothes, so you can swap the colours/outfits as required.

£54.95 incl. VAT

https://www.alzproducts.co.uk

Benefits

Reduced agitation and aggression

Reduced tendency to wander

Increased wellbeing

Increased interaction with staff and family members

Reduction in psychotropic meds

Drawbacks

Not every PwD interested

Relative and staff skepticism – infantilizing, demeaning

Increased distress in some individuals - for example. doll misplaced, arguments with other residents over ownership, overstimulation and fatigue

Mithchell G. Use of Doll Therapy for people with Dementia: An Overview. Nursing Older People. May 20014

Dolls Remain a Controversial Intervention

Doll may have been introduced to address and validate a perceived need – loneliness, sense of identity, and usefulness

A potentially useful distraction

BUT

Arouse strong emotions re infantilization

And what do you do if the PwD believes the doll is real? Are you prepared to go along with this belief?

Similar to artificial environments…

Would it not be more beneficial for persons with dementia to interact with real animals, children and adults?

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Different Ethical Frameworks Assess Benefits and Risks Differently

Deontologism (Kant's position)

- Actions have an intrinsic moral value independent of their consequences
- All lies are wrong/treacherous!
- Suffering does not justify unethical actions

Different Ethical Frameworks Assess Benefits and Risks Differently

Utilitarian (Consequentalism)

The morality of the action is determined by the consequences, so lying can be justified if used in a person's best interests

Arguments FOR Lying and Deception are Also Strong

- Ease subjective distress
- Improve compliance
- Save time
- Protect person or another from injury or harm

Arguments AGAINST Lying and Deception are Strong

- Violates the autonomy of the person lied to
- Violates the human dignity of the person lied to
- Undermines trust and the care relationship
- May increase the confusion of the person with dementia
- Can damage public trust in the professional care of persons with dementia
- Damages the human dignity and integrity of the deceiver
- Can be a slippery slope – lying becomes a habit
  "It is easy to tell a lie, but hard to tell only one."

Arguments for Lying and Deception are Also Strong

- Some arguments against lying or deceiving may not be relevant as the intellectual capacity of the Person with Dementia decreases

- Risk of loss of trust or infringement may not be affected

Your Role Also Impacts Your Benefit and Risk Analysis

- Administrator
- Physician
- Front line Staff
- Family Member
- Person with Dementia

What will you do?

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Four-stage Communication Strategy for PwD*

- Identify the resident's need and attempt to meet it
- Simulate/substitute where the need can not be met
- Distract when simulation/substitution fails
- When distraction fails – therapeutically lie

*Wood-Mitchell et al *J Dementia Care* 14:30-31, 2006

Four-stage Communication Strategy for PwD*

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If one opts to lie

A 12-item set of guidelines on the use of therapeutic lies*

- Lies should only be told if in the best interest of the PwD
- Specific areas – such as medication compliance – require individual documented policies
- Clear definition as to to what constitutes a lie
- Residents ability to retain truth must be considered
- Family consent required
- Lies must be used consistently across people and settings

Adapted from James et al. (2006) Lying to People with Dementia Int J of Ger Psychiatry 21:800-801

A 12-item set of guidelines on the use of therapeutic lies*

- All lies must be documented
- Relative costs and benefits for the lie must be established
- Staff instituting agreed upon lies must be supported by management and family
- Circumstances for inappropriate lying must be outlined and documented
- Telling lies should not lead to disrespecting residents
- Staff should receive training and supervision on the potential problems of lying and taught alternative strategies when lies inappropriate

Caveat! Read the Fine Print*

"Legal consequences may arise for those using the guidelines without appropriate consultation and agreement with the relevant authorities."

- The reality is that guidelines and ethical codes of conduct may explicitly preclude deception and lying to patients.

- Failure to comply may bring one's fitness to practice into question and endanger one's registration as well as expose oneself to legal liability

Cully et al. (2013) *Therapeutic Lying in Dementia Care* Nursing Standard. 28: 35-39.

CMA CODE OF ETHICS AND PROFESSIONALISM*

- Articulates the ethical and professional commitments and responsibilities of the medical profession

- Amongst virtues exemplified by the ethical physician:
  Honesty - "An honest physician is forthright, respects the truth, and does their best to seek, preserve, and communicate that truth sensitively and respectfully."

- In the context of the patient–physician relationship:
  "Communicate information accurately and honestly with the patient in a manner that the patient understands and can apply and confirm the patient's understanding."

*https://policybase.cma.ca/documents/Policypdf/PD19-03.pdf

Has the CMPA has ever been involved in complaints or actions brought against physicians in the context of their providing deceptive care to persons with dementia?

“Unfortunately, the CMPA does not capture that type of information and we are unable to help with this request.”

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Next Steps

- Acknowledge that lying and deception are part of the hidden curriculum of dementia care, Begin to openly discuss communication strategies with patients, family members and staff and professional regulatory bodies

- Establish an agreed upon definition of what constitutes a lie including guidelines as to when, where, if at all, lies should be used.

- Continue to study the effects, risks, benefits and ethical implications of all communication and interactive strategies, including therapeutic lying

Next Steps

- Develop and deliver teaching programmes to increase our abilities to engage with people with dementia

- Anticipate further technology-enhanced artificial objects and environments!

The End