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# COMMENTARY

## Creating the Truth with Persons Living with Advanced Dementia

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**Keywords:** Dementia, Advanced, Caregiving, Deception, Truth Telling, Ethics

**Abstract:** Truth telling to persons living with dementia is a nuanced problem that demands negotiating between the hazards of principlism and the loving deceiver's demand to lie as needed. To ban deception, as we do restraints, would be misguided and cruel. So too to demand we always tell the truth. We ought to adopt a practice called "creative care." It begins with the premise that persons living with dementia are capable of creativity. Creative care breaks down the mysterious fourth wall we build around persons living with dementia, especially persons with advanced dementia. It invites us to see a person living with dementia as a person who is capable of creating something beautiful. They need our time and words, not our lies and sedatives.

One Saturday afternoon, several years ago, when I was on call for the geriatric medicine practice, I received a call from a nurse at a residential care facility I was covering. The nurse was overseeing the readmission of a resident following the person's stay in hospital. The nurse wanted to review admission orders with me. This meant a recitation of the person's dietary, activity, and medication orders.

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Twenty-nine times out of thirty, this is dull ritual, a routine. Nurse recites, I agree. Call over.

This one was number 30.

The nurse asked for an as-needed order for Ativan, one-half milligram, a form of a sedative in the family of sedatives such as Valium and Xanax.

"Why?" I asked.

"In case she gets riled up. We like to have something to calm 'em down."

"Why not ask her why she's riled up?"

The nurse did not like that. "Do you know what it's like caring for these people?"

The problem with Ativan and other sedatives isn't simply the risks they heighten, risks of falling, sedation and a dulling of the senses (think of a martini in a pill). The problem with Ativan is the intention in the decision to prescribe the pill. It sets aside discerning why the person is riled up. The list of orders didn't include deception as needed to calm him down, but I bet that, as needed, this nurse was telling this resident that "father would soon be coming home" or whatever lie was needed to calm him down.

My point is that prescribing Ativan to care for persons living with dementia is like using deception. Both can work, but they have risks and costs that ought to make such interventions one among those in our set of last desperate options. Use them occasionally, only in emergencies, and regret that they had to be prescribed. Why?

In this issue of the *Journal of Law, Medicine & Ethics*, Rebecca Dresser offers answers that are sensible and ethically sound.<sup>1</sup> She presents a thoughtful analysis of the nature and scope of the conundrum of truth telling to persons living with dementia. The treatment

of the issues is thoughtful and appropriately nuanced. It recognizes the hazards of principlism, both the reality therapist's command "never lie," and the loving deceiver's demand to lie as needed.

I agree with Dresser. It would be misguided and cruel to ban deception, as we do restraints, and mandate truth-telling. A rule against deception would also be pointless. Caregivers, sometimes at the end of their wits from repetitious questions, will occasionally need to break the glass and deceive, just as sometimes I do write a prescription for a few doses of Ativan.

I'd like to develop what I call "the third way" that Dresser gestures to. That way begins with the premise that persons living with dementia are capable of creativity.

"If father was here, what would we say to him?"

The possible answers are up to the person living with dementia. They might include "get to work," "I don't know," or perhaps "He's not here. He's in Heaven" (or Hell, depending on the relationship). The point is the answer inaugurates the next question such as "What kind of work would he do?" Or perhaps, the answer might be the truth, "Father passed on in the early 1990s." In time, a story takes shape. It might be true. It might be fiction. Or, it might be a bit of both, or "faction," a term coined by Truman Capote to explain the genre that was *In Cold Blood*. The point of creative care is to invite the person living with dementia to create, or not to.

The value of adopting a stance of creative care is

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Some readers might be perplexed by this. The production of art is an act of higher cortical function. How is it possible that a person who can no longer manage money, cook, or organize a day, who needs assistance to pick out clothes and put them on, who asks for long-ago deceased relatives, how it is possible that such a person can engage in creativity?

In her book, *Creative Care: A Revolutionary Approach to Dementia and Elder Care*, Anne Basting explains how definitions of creativity converge on two common features.<sup>2</sup> Creativity generates something new that has value. Creativity is novelty and worth. Her work using theater arts with persons living with dementia and their caregivers, both formal and informal (the paid and the unpaid, respectively), shows how with persons living with dementia, even advanced dementia, are capable of creativity. Consider the following common case of the person who asks after a long-ago deceased family member.

*When's Father coming home?*

Truth tellers suggest we reply kindly and truthfully, "He's been dead for 32 years." Loving deceivers urge us to occupy the person's reality and reply, "In about an hour." Creative carers reply not with a statement but instead, with a question.

that it breaks down the mysterious fourth wall we build around persons living with dementia, especially persons with advanced dementia. The term is from theater arts. Performances of theater are grand deceptions set on a stage, a space created by three walls. The fourth wall is the invisible one that separates the actors from the audience.

In the care of persons with advanced dementia (the audience), the loving deceivers (the caregivers) take to that stage. I'm not exaggerating. There are whole communities built to resemble past lives: the town of New Canaan, Connecticut as it was some 50 years ago, San Diego circa 1950s complete with a portrait of President Eisenhower in the library above the wooden card catalogue. There's nothing fundamentally wrong with such spaces. Their builders and the staff who run them have the best of intentions, but there is something weird about working there. Over time, the experience leads to a kind of othering, a beneficent stigma.

In sharp distinction, the reality therapists shut the theater down.

Creative care changes how the theater operates and the very script the actors follow. Breaking the fourth wall down means the actors ask the audience, the per-

sons living with dementia, to join them on stage and create today's performance.

A wife asks her husband of some fifty years,  
"We ought to get married."

**Loving deceiver:** "Yes, that would be lovely."

**Truth teller:** "We are. Fifty years this August."

**Creative carer:** "Where would we have a wedding?"

A man stands in the den of his home of many years and asks to go home.

**Truth teller:** "This is your home."

**Loving deceiver:** "We'll be leaving in about an hour to go there."

**Creative carer:** "What do you treasure about home?"

I do empathize with the nurse who wanted the Ativan. In the lives of persons living with dementia, the truth seems up for grabs. I have long-retired patients tell me how they're busy at work, how their daughter is in the waiting room (in fact, she's his wife), and so

on. Some persons with dementia live in a world that's neither real nor unreal. It's surreal. Being with such a person can be morally challenging and sometimes exhausting.

The heart of the matter is to see a person living with dementia as a person who is capable of creating something beautiful. To do that, they need our time and words, not our lies and sedatives.

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#### References

1. R. Dresser, "A Tangled Web: Deception in Everyday Dementia Care," *Journal of Law, Medicine & Ethics* 49, no. 2 (2021): 257-262.
2. A. Basting, *Creative Care: A Revolutionary Approach to Dementia and Elder Care* (New York, NY: HarperOne, 2021).