

When Your Parent has Dementia, Is Lying Ever OK?



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Is it ever right to lie to a parent who has dementia*? It's a question nearly all families struggle with during the course of the disease. We'd probably all agree that in most cases, telling the truth is best. But honesty is not a black and white matter in dementia care – it is wrapped in shades of gray.

What counts as lying?

According to ethicist and philosopher Sissela Bok, in her book *Lying: Moral Choice in Private and Public Life*, a statement that is intentionally deceptive is a lie.

A lie has three essential features:

- A lie communicates some information
- The liar intends to deceive or mislead
- The liar believes that what they are 'saying' is not true

Intention matters

When your parent has dementia, intention matters. The purpose of a lie is usually not to create false beliefs. Instead, lying in dementia care is designed to promote wellbeing, distract from upsetting circumstances, or protect a loved one from harm. This small but important distinction makes a difference when determining the best path forward.

Keep in mind that as dementia progresses, your parent's emotional regulation can go haywire. Your mom may become stuck in a world of upsetting thoughts, fears, or anxieties. Providing reassurance and attending to her emotional needs is an act of caring, even if the truth is bent.

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Compromised Autonomy

An argument against lying is that it undermines autonomy because it distorts the information your parent uses to make decisions. Remember that the ability to make decisions becomes harder over time. We tend to think of dementia as a condition that primarily causes memory loss. But another hallmark of the disease is the gradual loss of other cognitive skills such as reasoning, judgement, logic, and insight. Without these abilities, your mom's capacity for decision-making is compromised and so is her perception of the world around her. It becomes more difficult for her to understand information, weigh the pros and cons, and sort through all the various alternatives. Along the disease continuum, her capabilities steadily shift away from independence and move towards a need for compassionate care. It is in this context that we consider how to respond.

Doing Good and Preventing Harm

Lying to someone who has dementia may be justified when it's necessary to promote wellbeing or prevent harm. Medical ethicists call this beneficence and non-maleficence. Beneficence involves the act of "doing good." Non-maleficence, on the other hand, means to "do no harm."

Let's look at a few examples families sometimes encounter.

Picture your mom living at home alone. You start to get worried when you notice she often forgets to eat and rarely takes her medication. Over time you observe that her health deteriorates from self-neglect. You are dismayed to learn that she frequently gives out her credit card number to identity thieves who siphon away her savings. You try talking to her about your concerns but she thinks everything is fine and says she doesn't need any help. Using benevolent deception to protect her may be justified if she lacks insight into the dangers all around her and steadfastly refuses help. If she lacks understanding about what is happening it is critically important to step in to safeguard her health and finances. Closing your eyes to her situation, even when she tells you she is okay, may be considered neglect.

Now imagine that your dad's car had dents and scrapes and he's gotten lost in familiar places. His neighbors call you to describe some near misses and say they are worried he will eventually hit someone. You talk to your dad about the need to retire the car keys. He gets angry and demands you mind your own business. Disabling your dad's car and hauling it off the property to be "fixed", while misleading, can be justified. Doing nothing at all could seriously injure your father and others.

If you find yourself in difficult situations like these, it may be reassuring to learn that studies have shown that both people living with dementia and caregivers endorse the use of lies and deception as long as it is done to promote the person's best interest. Consider applying the Golden Rule when you aren't sure about what to do; ask: "Would I want to be lied to in this situation?"



Are there other options besides lying?

Fibbing should be used cautiously and in consideration of the stage of your parent's condition. Families are often more comfortable first trying a straightforward approach. But candor may get in the way of a productive discussion when a parent loses the ability to reason. There are other techniques that may sometimes work better and feel more satisfying than lying to your parent. These alternatives can take a bit of practice and include using "validation techniques" and limiting how much information you share.

What if she asks, "Where is my mother?" Is it better to tell the truth or lie?

The case for validation – emotional support

A therapeutic approach called validation allows you to be fully present, compassionate, and affirming of your parent, regardless of the reality of the situation. Validating a person's experience addresses their emotional needs without the use of logic, reason or judgement.

How does it work? Let's say your mom lives in a memory care community. She bangs on the door demanding to see your father. Her behavior suggests she is lonely. Telling her that her husband is dead (the truth) or that he is away at work and will come home later (a lie), overlooks her feelings.

Painful feelings that are ignored or suppressed can crescendo. But, if recognized and validated by a trusted listener, they diminish. Try listening empathically acknowledging the concerns she raises. Invite your mom to talk about your father. Notice her emotions and demeanor. If she is distraught, gently steer her to happier memories – reassure her that she is loved, cared for and important to you.

What if she asks, "Where is my mother?" Is it better to tell the truth or lie? The answer is, neither. Answering the question directly doesn't fulfill her emotional needs. Instead of jumping to an answer, curiously ask her to tell you about her mother. Stick to long treasured memories. Try saying something like, "Tell me about that time you and your mother took the train to New York." Doing so gets at the heart of her desire for connection and security.

If your dad believes someone is stealing his money, listen and acknowledge his concerns. Arguing, explaining and telling him he is wrong ignores

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his truth and diminishes him. Reassure him that you'll look into it. After he's been heard, redirect the conversation to something positive.

Some might suggest that validation techniques are just another type of lie – a lie of omission. People wonder, "If I just go along with my parent's stories, even if aspects are not accurate, isn't that a form of deception?" Keep in mind that your dad's reality is different when he lives with dementia. His perceptions are his truth in that moment; disputing his understanding does neither of you any good. Focus on the goal of your interaction. When your objective is to support your dad, using validation techniques can be enormously helpful for both of you.

Validating a loved one's emotions establishes respect. More importantly, though, validation helps fulfill your parent's deep emotional needs and avoids debating the details of his understanding.

Overzealous candor

In dementia care, it is not deceptive to hold back information when it is not called for. Sharing more than your dad can remember, process and understand can frustrate both of you. It often leads to a tug of war; you feeling the need to explain in more detail, rationalizing your position and decisions – he resisting fiercely and becoming more confused and frustrated every step of the way.

Ask yourself, does your dad actually need to know every detail about the costs of his care? Maybe he used to manage the checkbook and balance it to the exact penny. But, his abilities have changed now. Your approach should adjust to his current needs and capabilities.

Let's consider a time when you are scheduled to attend an appointment together. Prior to your parent's diagnosis, it was natural to discuss detailed plans ahead of time. Now, however, providing too much information can be overwhelming and anxiety provoking. Share only what is necessary: "Let's go for a ride." When you reach the destination, speak in an upbeat tone and say, "Let's go inside." Breaking things down step-by-step makes the process easier for both of you.

What about discussing unpleasant information such as the news a family member has died? If your dad passes away, it may be acceptable to compassionately let your mom know what happened, the decision depends on her individual circumstances. But, if you tell her once, confronting your mom again and again with that agonizing truth should be avoided. If she forgets, focus on reminiscing about fond memories and reassuring her that they shared a special bond. Bringing up the reality of his death over and over serves no purpose.

Learning to edit yourself and the information you share is a gift for both of you.



Doing your Best

The stress and anxiety of trying to figure out how to respond to someone living with dementia can be paralyzing sometimes. Things can be made easier if you give yourself room to be imperfect. After all, this is a journey of discovery and an opportunity to learn to relate in new ways. It takes time, practice, and flexibility.

Accepting help from an expert – Aging Life Care Professionals®

The reassuring news is that you don't have to figure everything out alone. Asking for and accepting help are wise and brave ways to successfully navigate the many challenges you encounter when your parent has dementia. Aging Life Care Professionals (sometimes called geriatric care managers) are trusted advisors who can be an enormous resource. They provide specific tips, techniques and creative ideas to address your family's unique situation. With the help of a care manager you and your family will feel less like you are floating around in a challenge that can be personal and painful for everyone. Because you are reading this guide, it's a sign you may benefit by finding a care manager. Go to the Aging Life Care Association at www.aginglifecare.com to search for your own trusted advisor.



** Dementia is an umbrella term used to describe various symptoms of cognitive decline, such as forgetfulness. It is a symptom of several underlying diseases and brain disorders, including the most common types, such as Alzheimer's disease, vascular dementia, and Lewy Body dementia.*



Bio | Jullie Gray is a Fellow of the Leadership Academy, and has over 30 years of experience in healthcare and aging. She is a Principal at Aging Wisdom in Seattle, WA. Jullie is the President of the National Academy of Certified Care Managers and the Past President of the Aging Life Care Association. Follow her on LinkedIn and Twitter, or email her at jgray@agingwisdom.com. Aging Wisdom has a presence on Facebook – we invite you to like our page.

Sources

Compassionate Deception: Lying to Patients with Dementia. Butkus, M.A. Philosophical Practice, July 2014, 9.2: 1388-96. Accessed at: http://www.academia.edu/8905087/Compassionate_Deception_Lying_to_Dementia_Patients

Lying & Truth Telling. Accessed at: http://www.bbc.co.uk/ethics/lying/lying_1.shtml BBC.

The Law and Ethics of Dementia. Telling the Truth: The Ethics of Deception and White Lies in Dementia Care. Schermer, M. Hart. Publishing (2014)

Validation Training Institute. Accessed at: <https://vfvalidation.org/what-is-validation/>

Communication Quiz for the Family Caregiver

Good communication skills are the foundation for managing a myriad of challenges when you care for someone who has dementia. Take this communication quiz to see how your skills stack up.

TRUE, this often happens! FALSE, not the case in my situation.

1. I never know how to respond when my parent gets upset.
2. I find myself getting frustrated when my parent believes something that isn't true.
3. I argue with my parent when he or she refuses much needed help.
4. When my parent needs to stop doing something dangerous, I either quarrel with my parent or I just ignore the problem to avoid a fight.
5. When my parent is refusing to take a shower or change his or her clothes, my suggestions always seem to lead to a heated argument.
6. My parent repeats the same stories and I am at my wits end!
7. I notice things start to heat up when my parent and/or my siblings disagree about what to do to resolve a problem.
8. I frequently find myself getting annoyed or upset with my parent.
9. I don't know who to reach out to for help about our situation.

The more items you answered "TRUE" to on the Communication Quiz, the higher the likelihood you will benefit from the help of an expert like an Aging Life Care Professional! Even if you responded "TRUE" to just one question, you may want to seek additional help in your caretaking responsibilities. Go to the Aging Life Care Association at www.aginglifecare.com to find for your own trusted advisor.

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