Key Terms

**Confabulation**: a memory disturbance, defined as the production of fabricated, distorted or misinterpreted memories about oneself or the world, without the conscious intention to deceive.

**Conflation**: when two or more distinct pieces of information are combined to create a new “fact,” which can be caused by or result in confabulation.

**Hallucination**: a sensory experience of something that does not exist outside the mind.

**Delusion**: a fixed false belief that is resistant to reason or confrontation with actual fact.

**Validation Therapy**: (preferred) an approach in which we listen carefully, validate what we hear, and are empathetic.

**Reality Orientation**: (discouraged) asks us to tell the person why she’s wrong and use reason and logic to explain why we’re right.

**Therapeutic Fiblet**: telling a lie for the greater good; often used to answer the question “What’s the kindest, most loving thing I can do for my parent/partner in this moment?”

**Reason**: the capacity for consciously making sense of things, and applying logic.

**Logic**: establishing and verifying facts, and changing or justifying practices, institutions, and beliefs based on new or existing information.

**Perseveration**: to repeat or prolong an action, thought, or utterance after the stimulus that prompted it has ceased.
General Ideas & Best Practices

- Listen for emotion behind the words; don’t focus solely on the words.
- Allow time for a response, then take your cue from the response. This isn’t an argument, or a debate, or a fact-finding mission. Your aim is to provide loving comfort, a feeling of safety, a sense of “it’s going to be okay.”
  - Pro Tip: you cannot provide those feelings by saying things like, “Calm down,” “You’re fine,” “Settle down,” “You’re confused,” “You’re just imagining it,” “It’s all in your head.”
- Some families can use humor to their advantage, although it may sound snarky to ‘outsiders.’ You know the difference in your own family.
- Use physical contact to create a connection.
- Before diving in, take a deep breath, consciously pull in all the love you have, and take a moment to connect. Then try any of the suggestions below. Know it’s probably not going to go perfectly straight out of the gate, practice will make you better, and you’re doing the very best you can. The aim is to jump into the moment with your loved one and offer a calming anchor...in this moment. That is success.

Common situations almost all families experience at some point in the disease process are on the following pages. Where a story is included, it’s true and drawn from either my experience in working with over 1,100 people living with dementia as a memory care director and Certified Dementia Practitioner, or from someone in my own family. Identifying details have been changed.

I hope you find this helpful for situations you’re dealing with! If you need further support or ideas, contact me at christy@dementiasherpa.com.
**Situation:** I want to go home!

**True Story:** A woman in her late 60s followed her adult children from China to the United States. She was diagnosed with Alzheimer’s disease and placed in memory care about 20 years later. She frequently stated she wanted to “go home.”

Her family decided that meant her previous home in China, and against the advice of the memory care staff, took her to China to see her old home. The first thing she said upon seeing it? “I want to go home.”

Far from an isolated incident, this is the most frequent outcome when families try to accommodate the request. “Home” is actually more of a feeling than a physical place.

**Don’t Do This:**
- Say, “You are home!”
- Use reality orientation: “You’ve lived here since 1984, this is your home.”
- Say, “I moved you in with me three years ago. Don’t you remember?”

**Try This** instead of grueling travel (which is confusing and physically draining):
- “Tell me about home.”
- “What’s your favorite thing about your home?”
- “What does home remind you of?”
- Recall a common memory: “I remember that Christmas when I was 10 years old and you made it so special by…..”
- Recall a common story: “I’m thinking of that time Dad walked in the door when you threw him a surprise party and when everyone yelled ‘Surprise!’ he was so startled that he…..”

**Situation:** Confusion, disorientation, sounding anxious (“Where’s your [deceased] dad?”)

**Try This:**
- “What has you thinking about Dad?”
- “Isn’t this when he’s usually at work?”
- “I’ve been thinking about Dad, too.”
- “He’s running errands.”
- “I don’t think I’ve ever seen two people as in love as you and Dad.”

**Consider Ruling Out Possible Causes of Confusion:**
- Urinary tract infection
- Dehydration
- Constipation
Situation: Confabulation, delusion, disorientation ("I need to get to the rendezvous point!")

True story: As a memory care director, I had a resident who’d escaped Nazi Germany with her family as a young girl. The family of four had been separated during the day, but met at the pre-planned rendezvous point later that night to begin the start of a journey to successfully escaping with their lives.

Late every afternoon, Renate would start to get anxious, stating she needed to make it to the rendezvous point. Sometimes she accepted it when the staff told her that the rendezvous time had been changed to the following morning and that her parents wanted her stay the night with us in order to stay safe. She would have a calm rest of the evening and wake the next morning with no memory of the previous afternoon’s anxiety.

Other times, though, she thought the staff was mistaken and would become more anxious and insistent she needed to leave immediately. On those occasions, we would call her daughter, who would pose as her own grandmother and instruct Renate to stay put, that the rendezvous time had changed to the morning and that they would come pick her up in the morning but needed her to stay there for her safety.

Either way, the result was the same: Renate would visibly relax, confident she was safe and would ultimately be reunited with her parents. This story is the perfect illustration of the value of a therapeutic fiblet. You can see how trying to use reason and logic with someone who is in fear for her life (and those of her family) would lead to an escalation of anxiety rather than creating calm.

Situation: Visual hallucinations ("I can’t get to my bed")

True Story: Ilsa was exhausted but couldn’t go to bed because of the snakes on the floor around her bed. A quick-thinking nurse grabbed a can of rose air freshener and sprayed the floor, explaining snakes can’t handle that smell...but he didn’t try to convince Ilsa they were gone. He just waited for her response. She hugged him, thanked him, and then got in bed and slept through the night.

Try This:
- Ask questions about the hallucinations so you can gain information to help
- Rule out medications/infection as the cause of hallucinations
- Make sure rooms are well-lit to reduce the chance of visual hallucinations
- Reduce high-glare surfaces
**Situation:** Disorientation, confusion, confabulation, sounds matter-of-fact (Mom says she’s at Grandma’s house, but Grandma died a long time ago)

**Try This:**
- “Oh?”
- “Oh? What’s going on?”
- Mentally shrug and move on
- Stay low-key; Mom is just reporting information that she doesn’t find distressful

**Situation:** Confabulation, conflation, sounds upset (Convinced Dad’s having an affair)

**Don’t Do This:**
Succumb to a natural knee-jerk reaction of expressing shock by using reason and logic and saying things like “No, he’s not!” or “How could you say such a thing?” Although completely understandable, it’s not helpful.

**Try This:**
- “I can see how upset you are!”
- “Oh my goodness!”
- “Do you want to tell me more?”
- “Do you want to talk about it?”
- “What can I do to help you feel better?”

**Situation:** Confabulation (“I know you’re going to dump me in an old folks’ home!”)

**Don’t Do This:**
- Argue: “That’s not true!”
- Use reason and logic: “Mom, you’re living with me so I can take care of you. Why would I move you?”
- Make promises you may not be able to keep: “We’d never do that! Ever!”

**Try This:**
- Validation therapy: “I can see how upset you are! [Hug] I love you so much.”
- Validation therapy: “That sounds scary! I don’t want to scare you; I love you.”
- Humor: “Naw, we’d never waste money like that!”
Situation: Confusion, delusions ("My daughter’s caught in the riots!")

True Story: Genevieve, diagnosed with Dementia with Lewy Bodies, suffered from delusions and hallucinations from time to time. She neared hysteria one afternoon when she reported her daughter was “caught in the riots” and was begging staff for help. Important note: many people are under the impression delusions and hallucinations are best treated with antipsychotic medication, but in fact this class of drug is contraindicated for people over age 65, especially contraindicated for people living with dementia (of any kind), and even one dose can be lethal for a person diagnosed with Dementia with Lewy Bodies. An Exelon patch, on the other hand, can be extremely helpful for people with DLB or Parkinson’s Disease Dementia.

Don’t Do This:
- Use reason and logic: “There aren’t any riots happening near here.”
- Be dismissive: “It’s just in your head.”

Try This:
- “You and I are safe right now, and I am going to do everything in my power to keep you safe.”
- “I’m right here with you. I love you, and your safety is my number one priority.”
- If you’re not the daughter: “Let’s call your daughter now.”
- Ask: “Can you tell me more?” with the goal of gathering as much information as possible about what’s going on so you can best help. That said, don’t turn it into a Jeopardy!-style assault.
- For later: Consider getting a specific diagnosis (other than ‘dementia’) if not already done.

Situation: Confusion, conflation (“I’m waiting for Mom to pick me up from school”)

True story: Viola was sitting by the window all day, waiting for her son to arrive from out of town. When she saw him walking down the path, her face split in a wide grin and she started wriggling with excitement. He walked through the door and said, “Hi, Mom! What are you up to?”

Viola excitedly said, “I’ve been waiting for my Mom to pick me up from school!”

Son, frowning: “That’s ridiculous. You’re 86, that would make your mom about 115. Grandma died a long time ago.”

Viola, sobbing: “Who’s going to take care of me?”

As staff, we understood Viola was waiting for her son to show up. Viola herself had told us this, although she was confused in the excitement of the actual arrival. Her son could’ve responded to her greeting by saying, “I’m so happy to see you!” or “I’m here now!” or pretty much anything other than what he said. The likelihood is Viola’s momentary confusion would’ve passed, and the joyful reunion could’ve continued.
Instead, Viola’s son created an awful and scary moment for Viola. Again, look for the emotion behind the words with your loved one, and respond to that.

**Situation: Perseveration about money**

True story: This happens more often than I can count on both hands and both feet combined. Rather than using reality orientation and brushing someone’s concerns off with a “Your daughter is taking care of everything for you” response, we would say, “Sure, let’s call the bank!” and hand over the receiver as we dialed our own home number.

Usually, the resident would say, “It’s one of those things!” or “Here, I don’t know what they’re saying” while handing the phone back. We’d say, “You need to leave a message” and then the resident would state his or her concerns. This allowed the person to verbally express whatever anxiety-producing thought was on his mind, releasing it.

Sometimes this was enough. Sometimes the same person would need to make the call 30 times in a day. Sometimes a staffer at the other end of the building would call back the person and say, “Thank you for your call. I’m happy to report, you have plenty of money.” It was very rarely about wanting to know an exact number, but more about needing to know that there wasn’t anything to worry about.

Try This (if you’re in charge of helping with finances):
- Change account addresses to your home so statements and bills come directly to you
- Set up online bill pay so bills get paid without creating anxiety

**Situation: Night terrors**

True story: Stephen got out of bed at midnight, went to the nurses’ station and crawled under the desk. Shaking and crying, he wouldn’t come out, saying he didn’t want the snipers outside the building to find him. He was certain that, as a retired FBI agent, he’d been targeted.

The staff at first thought he’d been having a bad dream and asked him if that was the case. He said no, this was real. They asked if he’d like accompaniment back to his bed so he’d be more comfortable. He said no, that wouldn’t be safe. They asked if he’d like a nightlight, if he’d like a staff member to stand guard, if he’d like someone to sit with him in his room. He said no to all that, none of it would be safe and he didn’t want to endanger staff lives.

What the staff didn’t do was attempt to comfort him by telling him there were no snipers outside the building, or that he had nothing to worry about since he’d actually never been an FBI agent. Instead, the staff assured him throughout the night that they were working to keep him safe. The “stand-off” lasted all night. Stephen would become calmer, but the idea of moving out from under the desk
caused him to become upset all over again. So staff took turns checking in on him, crawling under the
desk next to him to squeeze his hand and reassure him.

When I got to work the next morning, I recruited Jake, the business office manager (who just
happened to wear a suit and tie every day), to come into our memory care neighborhood. I introduced
Jake as the FBI Director to Stephen, telling him the sniper threat had been “eliminated” and that the
Director wanted to personally thank Stephen for his vigilance. My recruit nodded in agreement, shook
Stephen’s hand and thanked him for his time with the Bureau, and walked with us back to Stephen’s
room so he could stretch out and rest.

**Situation:** Conflation, confabulation, hallucination, delusion (“Dwight Yoakam is going to be
my son-in-law!” and “The contest people are watching”)

**True Story:** My grandma Anna lived with Alzheimer’s disease for 19 years. At one point, she was
obsessed with the Country Music Television channel, confiding in my dad that she was so exhausted,
she really wished “the company” would go home so she could get some sleep, gesturing toward the
screen broadcasting the large Grand Ole Opry audience. Dad pulled the plug on the tv and Anna
thanked him profusely for managing the guests who’d overstayed their welcome.

Anna also told us that Dwight Yoakam was going to ask my aunt Karen to marry him. Anna was
adamant, and this phase lasted for several months. It made her happy and didn’t harm anyone, so
there wasn’t any need for intervention.

CMT wasn’t the only thing that had Anna’s attention, though. A long time subscriber of several
magazines, Anna passed them along to us when we came to visit. But she came to the idea that “the
Contest People” (from Publisher’s Clearinghouse, we presumed) were watching her. This lead to
subscribing to over 30 magazines, and refusing to part with them. My grandfather added a shed in the
backyard to house her ever-growing collection.

The expanding magazine collection soon led to ordering items from the Franklin Mint. One completely
full guest room and $30,000 later, my grandfather was finally able to have her credit cards cancelled.

**Try This:**
- If you don’t already have the appropriate documents in place, see an elder law attorney and
  get them drawn up.
- Remove your loved one from accounts, or add another person who can appropriately oversee
  activity.
- Cancel bank cards. Anna wouldn’t have been capable of completing the steps to set up a new
  account by the point she was spending so much money, but companies already had her
  information on file.
- Change the phone number, if necessary.
● Use validation therapy and reassurance: “I can see you’re very concerned about the contest people. Are they bothering you? I’ll help you.”
● Limit tv watching if it’s causing problems. Either remove the tv, or unplug it.