A collection of stories about people with dementia the author has known, loved, and worked with. Every story teaches family caregivers how to better care for, and interact with, their loved one with any type of dementia such as Alzheimer's.

LOVE, LAUGHTER & MAYHEM: Caregiver Survival Manual For Living With A Person With Dementia

LOVE, LAUGHTER, & MAYHEM

Cindy Keith, RN, BS, CDP

"A Wealth of Wisdom! How I wish I'd had Cindy's practical and crucial advice during the most horrific year of my life as the sole caregiver to my challenging elderly father and sweet but ailing mother, both with early Alzheimer's which went undiagnosed by professionals for over a year!"

> --Jacqueline Marcell, author of *Elder Rage* and host of the *Coping with Caregiving* radio show

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Reach For The Sun, Alice

It’s 3:40 a.m. and I catch a movement out of the corner of my eye and turn to see Alice slowly ambling down the hallway toward the nurses’ station. Her white, wispy hair is pressed flat on one side of her head, and in wild disarray on the other side. She’s cold, and has her arms clutched across her chest, no slippers and no housecoat. I rise with a smile and hurry toward her: *“Alice! What woke you up at 3:30 in the morning?”*

“Oh, it’s not 3:30, is it? I thought it was time to get up and get ready for work!”

I put my arm around her and slowly begin to turn her back toward her room. *“Yes, it’s almost 4 a.m., and you really look cold. Let me help you find something to keep warm.”*

“Yes, I’m cold. How do I turn up the heat? But now that I’m up, I might just as well get ready for work. I don’t think I’ll get back to sleep.”

“Oh my! What I wouldn’t give some mornings for an extra hour or two of sleep! What time do you need to be ready for work?”

“Oh--I don’t know. I guess I’m usually ready by--by--Oh, I don’t know. I get ready early.”

"I'll tell you what, Alice. You climb back into this nice warm bed. Here's an extra blanket for you, and try to get a little more sleep, and I promise I'll get you up in plenty of time to get ready, PLUS, I'll make sure you get your favorite oatmeal with raisins and brown sugar for breakfast. How does that sound?"

"Well, I don't feel very tired right now. I don't think I'll be able to go back to sleep."

"I understand, and that's fine if you can't. We'll find something to occupy your time if you're up early, but let me put your music on and maybe that will help you. I wouldn't want you to be sleepy all day tomorrow at work."

I tuck her in, put soft, relaxing music on, dim the lights, and sit on the edge of her bed.

"Alice, here's a good way to relax enough to get back to sleep. Tell me about a vacation you once took. Where did you go?"

"Oh--there were so many. You know we always liked to go to Barbados every year. The children just loved it."

"Okay--Alice, close your eyes, and picture yourself on the beach with the children. Feel the hot sun, how your feet feel in the sand, and hear the waves. Can you see all of that?"

Alice smiles and closes her eyes*. "Yes, that sun was pretty hot so I always wore a hat on the beach."*

"What a smart idea that was. Now, I'm going to leave you here to think about Barbados and what a wonderful time you had. Remember the warm sun, and the laughter of the children playing on the beach."

I gently kiss her forehead and quietly leave the room. Alice is snoring softly when I check on her twenty minutes later.

What could I have done if Alice had not been able to go back to sleep or had resisted my redirection back to her bed? Read on.

"I'LL WHUP YOU!"

Bea was always such a little dynamo around the facility. When she was first admitted, she constantly wanted to be busy, so we would often give her "chores" to do such as pushing a non-electric floor broom down the hallways, or folding aprons or towels from the special basket of items we kept for residents to fold.

You will recall the story earlier when I told you about how Bea reacted to an employee attempting to vacuum a hallway where she had just run the non-electric floor broom. In Bea's mind, she certainly knew how to vacuum the floor, and she had done a good job, so this employee was clearly doing something wrong and needed to stop. If my employee had not stopped at Bea's request, then Bea would have interpreted that as a direct reflection on her capability to properly vacuum a floor, and she would have reacted in anger. In order to preserve Bea's dignity in that instance, the employee reacted appropriately by stopping her vacuuming and apologizing to Bea.

As most people with dementia are, Bea was quite astute at reading body language and interpreting the tone of voice used when speaking to her. She was standing just outside my office one day talking to an employee about doing some activity and I heard this employee respond to her in a patronizing voice: *"Now Bea, you know you can't do that anymore at your age."* I looked up in time to see Bea draw herself up to her full four foot height, glare up at the employee with her jaw locked, as she shook her finger beneath the employee's nose and said in a furious tone: *"Don't you talk to me that way. Just 'cause you're bigger than me doesn't mean I can't whup you when you need it!"* And as she stalked away, she smacked this employee on the behind to drive her point home. Bea recognized she was being treated like a child, and she didn't like it one bit.

I often use this story of Bea when training staff on dementia care because it illustrates so clearly how crucial it is for staff and families to be aware at all times of what their body language is saying, and what the tone of their voice conveys. Because of the brain damage, the person with dementia can no longer figure out what all the spoken words mean. Just as you and I do without even thinking about it, just as infants, and animals do, we all read body language. Body language and tone of voice speak louder to a person with dementia than the spoken words do, always, always, always!

Something else to consider on this topic is that when a person with dementia can no longer express their anger or frustration at someone with words (because their brain just can't find those words anymore) they will often resort to using their fists to get the point across. If Bea had lost the ability to say those words in anger, she would still feel the anger, and not being able to verbalize it would have resulted in her using her fists to make her point.