

HARRY HAS DEMENTIA

A quest for harmonious
interaction with my
disoriented father

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Content

Part 1
At Home

Part 2
Assisted Living

What I learned About
Dementia

Epilogue

Avoiding the Truth

“You don't lie to your own father,” I thought when my sister-in-law, who also spent years caring for her disoriented father, told me that you have to lie to people with dementia. And now I do. I lie to my father. It doesn't feel right, but I don't want to confront him with the truth. It makes him sad. In his world, he isn't ill. My challenge is to let him float around in his own foggy bubble.

Avoiding the truth is a way for me to cope. Most of the time, it's easy for me to avoid the facts. Even when he suddenly wants to go to work at the age of 72. My father retired eight years ago.

“I have to go to work,” he says enthusiastically.

“Today is your day off. You don't have to go. Isn't that nice?”

“Oh, is it? That's great!”

I'm not lying when I say he is off today. I'm just avoiding the truth. With time, I develop a knack for finding the sentences that work.

My mother calls.

“Your father has lost it. He doesn't remember that I have cancer, and I just tried to explain it to him. I told him the treatment will

cure me. It calms him down, but by the time I crawl back into bed, he doesn't remember."

"Why tell dad that you have cancer? It makes him so sad."

"He needs to know that I'm ill. Maybe it helps to keep repeating it. It will stick at some point, I'm sure."

"I know it's a harsh thing to say, mom, but he's ill in his head. Wiring in his brain has ruptured and it's not going to heal. He freaks out the second he hears that you're incurably ill. He doesn't want to lose you."

"I know. I just can't lie to him."

"You don't have to lie. You can just avoid the truth. If you don't want to lie, just find the right words." My mother says she'll try, and later confirms that it works. He's sweet whenever she says she's tired; asks whether he can bring her a glass of water or a book and leaves her be so she can stay in bed.

I'm Not Crazy!

The phone rings. My father answers: "Yes doctor, I will tell her you called. Elsa has to come in for a scan on Wednesday. I'll pass it on. Have a nice day!"

At dinner time when my mother has arrived home, I ask him about it. "I heard you say on the phone this afternoon that Mom has a scan this Wednesday and you would pass on the message?" "No way. I would've told your mother." "I heard you say it too, Grandpa," my daughter tries.

"There's no way. I didn't speak to a doctor. Maybe you need to have your ears checked," my father jokingly says.

"You did say it on the phone, that Grandma has to go on Wednesday and that you would tell her," she cheekily tries once again.

"Enough! I'm not crazy, am I?" My father suddenly pushes his chair back. I try to salvage the situation: "I'm sure we just misheard." As my father walks out of the room, my daughter looks at her grandmother. "I really heard Grandpa say it." The next morning, I call the hospital. Sure enough, a scan has been scheduled for Wednesday. I give them my mother's cellphone number and have their landline number removed from the file, just to make sure no appointments will be missed.

Abandonment

We arrive at the assisted living home. My brother is waiting in the parking lot. My father sees him and gets out of the car, smiling.

“How nice, you’re here too. Come, let’s have some coffee.” We ring the bell and our father’s caregiver walks us down a long glass corridor that surrounds a courtyard garden. On the way to my father’s room, we see some of the other residents.

My father looks at me and says, “These people are not well. You can tell.”

We enter his room. It seems like my father feels right at home. He looks around and takes a seat at the dining table. My brother and I each sit on one side of him.

“Look, they’ve got the same furniture here as we have at home, what a coincidence,” my father says. Meanwhile, he’s wondering where he is exactly. My brother and I tell him this is our room. It’s easier since Elsa has to go to the hospital for tests all the time. He nods and asks, “We bought this, right?”

“Yes Dad, this apartment is ours.” We avoid the truth. We’re renting the room. My father hates renting. He thinks it’s a waste of money. We drink coffee with my father at his new home and have lunch with him, hoping he’ll feel good about the place.

After lunch, my father gets up. "Let's go. I'll settle the bill."

"We've paid."

"Oh, really? I'll pay you back then."

"Don't worry about it, Dad." "Let's go."

"No, we'll stay for some more coffee."

My father always wants to pay for everything. He doesn't want to become dependent on others. He certainly doesn't want to owe anything to anyone. My brother and I suddenly realize that his wallet is particularly important to him. We decide to leave the wallet with him, and put money in it so that my father will always feel like he has enough money with him. That wallet will turn out to be of enormous value. After every meal he is offered at the nursing home, my father wants to pay for it. The caregivers respond, "It's already been paid. We enjoy having you eat with us."

We discuss with the caregiver how best to say goodbye to my father. We agree that I will try to get him to read the newspaper, and my brother and I will leave on the pretext that we have some errands to run. My father starts to read the newspaper and we put on our coats.

"Where are you going?"

"We need to do some grocery shopping." "Will you be back soon?"

We promise him we'll be back. My brother and I leave. We close

the door of his room behind us and hastily walk down the corridors of the assisted living home. "Don't think, don't think," my brother mumbles. "There is no other way, we're doing the right thing," he continues. I'm choking up.

Alive and Well

I visit my father the day after the funeral. "It's so nice you're here. Your mother will be pleased. She's getting groceries."

"A necessary chore. Look, I brought flowers."

"They're beautiful. Elsa will be pleased." I go along with it, he's so cheerful.

My brothers and I decide to keep up the illusion that my mother is still alive. The location manager disagrees at first and suggests making a photo album with pictures of my mother's deathbed and funeral so they can explain her passing to my father. She even suggests putting a photo on his nightstand, of my father next to the open coffin, to remind him that his wife has died. I don't like the idea; why would we make my father live through the sorrow over and over again? I even regret taking him to the funeral. Why did we do it? Was it for ourselves? For the sake of appearances? Because my mother would've wanted it? It only brought him a great deal of pain that day. The image of my father crying as he walks behind the coffin is etched in my memory. Mourning takes time. And time is something he doesn't have because he keeps forgetting. As soon I tell him once again, the mourning process starts all over. How do I convince the location manager of the assisted living home that we shouldn't be confronting my father

with the passing of his wife all the time?

Suddenly, I recall the dementia coach I met a year and a half ago during her presentation, “Attention for Dementia.” I was impressed with her approach. That night, everything I’d experienced and felt in dealing with my father fell into place. I decide to get in touch with her.

“Your father lives in a world where your mother is still alive,” she says. “Why would you want to hurt him by telling him that his wife has died over and over again? Just go along with it.”

The caretakers tell me that my father is satisfied with the following answer to his question.

“Have you seen Elsa around?”

“No, not today.”

“She should be here soon. She knows I’m here, right?”

“Yes, she likes you being here.”

It works. My father is happy every day. In his world, his sweet Elsa is still alive and well.

We replace my mother’s funeral card on the cabinet in his room with a cheerful black-and-white picture of my young parents dancing with each other. I tell the care team the story of how my father asked my mother out to a dance fifty-six years ago. My father told me the story as well. He beams when he recalls these love-filled memories. Now that the caregivers know the story behind the photo on his cabinet, they will sometimes grab the

picture and ask my father about it. Sometimes, his brain room is closed and he doesn't remember. But when the door to that room is open, my father will enthusiastically share his story.

What I Learned About Dementia

I listed the lessons I've learned, and those shared with me by other loved ones, in the hope that it may help other family caregivers.

Situations

Going Out Alone

Whenever my father had gone out alone, we made sure: to inform whoever he thought he was going to visit, there was a GPS tracker and a note with my contact information in my father's pocket.

It's best to give them a pre-programmed cellphone to bring with them, but we never managed to do it. My father resisted the idea of being reachable all the time.

Home Alone

My mother would put a note on the table saying where she'd be. To avoid writing the same thing over and over again, she kept the written notes in a tin. I'd call my father whenever I knew my mother wasn't home. I'd quickly figure out if he knew where she was or if he was disoriented. If I'd find him disoriented, I'd call again 15 minutes later. This would often have a reassuring effect.

By the time the disease had progressed, we made sure to hire a sitter. My father refused to accept it, until the sitter started cleaning. Whenever she was there, my father was able to do his own thing while the sitter kept an eye on him.

Going out together

I still take my father out a lot. Whenever he needs to go to the bathroom at a restaurant, I'll walk with him. I'll tell him I need to go too, otherwise he won't let me come. I'll wait in front of the men's room. He smiles at me as he comes out of the bathroom, and I know he's happy to see me.

Whenever I leave our table to go pay inside, I give my father the task of keeping a close eye on my handbag. He'll remain seated in his chair with the bag clasped in his hands.

Outsiders don't always notice that my father has dementia, which can be problematic. It can create confusion, for instance in a store. I've carry a note that says, "My father has dementia." I'd hold it up behind his back to help people understand.

Taking Away the Driver's License

I made up a story to get my father to stop driving his car. Emphasizing that his driver's license was gone temporarily because it had expired, worked well. A relative told me that he parked the car out of his father's sight. This was enough to prevent his father from wanting to drive again.

Delusion

At times my father became delusional. Correcting him wasn't helpful. I found that I was able to change the subject quite

quickly, as long as I said that I believe him and will help him find a solution.

Celebrations with Dementia

We noticed that involving my father in everything was becoming increasingly counterproductive. We decided to stop telling him anything about our plans and organized surprise parties and surprise vacations instead. Others have told me that it actually helps to diligently inform their loved ones. One son told me that he writes up a comprehensive document on the upcoming vacation a month in advance, so his father can rejoice over and over again.