



If dementia comes for me

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“His name is Hunter the Hunter!” The rest of the group clamors with approval. “Why do you think he’s a hunter?” A bright-eyed woman gazes between the picture displayed on a projector and toward the semi-circle of white-haired participants.

“He’s got a rifle,” another calls out.

“What’s he doing?” The woman at the front asks.

“He’s thinking.”

“About what?” She answers curiously.

“About rabbits!”

“He’s thinking I’d rather be home.”

“That’s not what he’s thinking,” a woman interjects.

“He’s wondering, what’s going to be for dinner?”

Hearty agreement from the 12 participants. They sway with laughter. They could have been lifelong friends. The woman giggles and zips around the circle encouraging the participants with questions and jokes to keep coming up with more ideas—first about Hunter the Hunter, but then about imaginary characters who could be near him and about places his next adventure might be.

On large sheets of poster paper, she scribbles a story that blows past the original image they are looking at. The session also conjures up stories about loving dogs and ends with the room singing *Respect* by Aretha Franklin. Every so often the group leader catches my eye and smiles as if to say, “Yes, this energy is real. Yes, all of these people have dementia. And yes, I am loving this as much as it seems.”

This was my first observation of TimeSlips, a type of dementia care program that uses imaginative stories to connect with patients in early stages of dementia through song, laughter, and lots of puns.

Connecting to those with dementia

In 1995, Anne Basting founded TimeSlips as a way to connect to older adults with dementia. She scrapped the concept of having patients remember their past. Instead, she focused on creating spaces and tools to create new ideas. Using historical or silly photos, Basting asked open-ended questions. She found that people with dementia generated stories that sounded like personalized *Mad Libs* comics.

Anyone can become a facilitator by completing an online course. Any room with enough seats can be transformed into a session. Today, TimeSlips operates in 20 countries and all 50 states. The method has been praised for its positive impact on facilitators and participants.

I learned about the organization in my first year of

medical school and now I am leading TimeSlips sessions with my classmates at a nearby assisted-living facility. Researchers have found that participating in or leading, these sessions improves medical students' attitudes toward people with dementia.¹ For the participants it has been shown to boost joy and increase quality of life.^{2,3}

That first day, standing at the back of a beige-gray room at an adult day care center, I thought I had just witnessed a miracle. Did they really have dementia? These people had come up with stories so snappy that they would have made a room of professional writers jealous. My cheeks ached from smiling throughout the entire session. Afterward, I thanked the participants for letting me observe their humor, grief, and joy for nearly two hours. When we hugged goodbye, they urged me to keep coming back. I felt like I had been initiated into a club.

The stranger in the room

When I was 10-years-old, my mom and I went to see the doctor because my grandfather was sick. He had been there for me when I was sick as a kid, and I wanted to be there for him. Pop sat on the exam table crinkling the thin white paper beneath him while my mom and I sat in chairs and looked at framed diagrams of organs on the walls. When the doctor came in, we all stood. He started with a battery of questions I could barely follow. Then he asked my grandfather about me.

"Who came in with you today?"

"I don't know," Pop said with a tilt of his head that made us all smile.

"Who's this?" he nodded toward my mom.

"Karen," he said with a wry grin. "Of course I know who my own daughter is."

"And who's this handsome fellow?" All the eyes in the room turned on me.

"Never seen him before in my life." All four of us laughed for a moment. Then the doctor pressed.

"Joe, is this your son?" My mom rested a hand on the back of my neck. She must have begun to feel nervous.

"No, that's not my son." Good, we all nodded. But then he continued. "He's a stranger." My mother choked out a laugh, but this time she was the only one.

"Come on, Pop," she strained to smile, "I know you know who this is." But he did not.

"He's a stranger and I haven't seen him before." No one was laughing or smiling. My throat burned with shame.

"Pop, it's me."

"Dave," my mother interrupted, "It's okay he's just joking."

"It's me," I stressed. But Pop folded his arms and turned his attention back to the doctor for more questions. Though he was unbothered, I saw fear in my mother's eyes. My legs hung from the hard armchair and as soon as I started to cry my mom scooped me out of the room. Before the door closed behind me, I heard my grandfather say once more, "Never seen him before. Total stranger."

When someone starts to lose their memory, there is usually a rush to recover the past. When this fails, as it always does when a person develops dementia, the gap created by a lack of memory can be filled with a lot of things. In my family it was filled with silence. For some families, this silence is not benign.

In the silence, the person with dementia can feel a crushing pressure to remember. It can lead to shame and embarrassment. People in these situations can be marginalized by isolation, stigma, and in more severe cases, by chemical restraints via anti-psychotics. The end of the story so often has patients getting siloed into nursing homes, leading to downward spirals of isolation and dehumanization. These nursing home residents often cling to wisps of autonomy.⁴ In a study designed to target how older adults understand aging and associated stereotypes, researchers showed that negative self-images about aging among the elderly were associated with an average loss of 7.5 years from life expectancy.⁵

I just wanted my grandfather to stay the way that he was. Following that fateful appointment, I was determined to help him get better, which meant finding ways to get his memory back. I thought I could reverse his memory loss by flooding him with more memories. After school, I would go to my grandparents' apartment to comb through photo albums. For years, he would sit at the head of his dining room table with me flipping pages by his side—weddings, babies, wars, and birthdays. Sometimes a memory would flash in his mind and force a big belly laugh. Sometimes he would recall costume parties in his backyard and adventures around the world. When memories burst forth, they felt like breakthroughs.

Over time, I came to recognize these moments as mere blips. I became a stranger in his house. Sometimes he would yell at me to leave and my grandmother would have to calm us both down. After years of trying to preserve his memories, it was clear that I would never again talk to the man I called Pop. He lived like this for 10 excruciating years until he died surrounded by family.

After his death, I began interviewing people with dementia and their caregivers while I was in college. I wanted to learn about communicating with people with dementia

so that others would not have to struggle like I did. I interviewed a man in his 60s in the early stages of dementia who was terrified. He told me about his fears. He knew that his marriage would deteriorate in a few years and that he would become oblivious. He feared for his wife who he knew would have to dress, medicate, and clean him. He was scared about the hurtful things he might say to her. “You live a life together, and by the end it’s just one person dragging the other. And it’s not clear who’s dragging and who has it worse,” he explained.

Living with dementia

Another fear is that lives of people with dementia become meaningless, because people with dementia can lose the circumstantial understanding of what they are doing.⁶ A person may be getting dressed and while they are in the act of putting on a sweater with their arms in the air, they can forget where they are or who is helping them. A person may be walking through their house looking for something, and not only forget what they are looking for, but also entirely forget where they are and how they got there. They lack the short-term memory to know what just happened and are unable to predict what is about to happen.

I asked a patient what she thought it would feel like to not have that type of memory. She took my hand in hers, leaned toward me and whispered, “I’m afraid of Alzheimer’s because I’d rather be dead than lost.”

I thought about her daughter who had brought her to the appointment. How carefully she had helped to take her jacket off. “When you get lost,” I said, “your daughter will bring you back.”

We smiled at each other, but I think she knew that my words rang hollow, because when a person’s mind gets lost to dementia, there is no bringing them back.

Caregivers who are ill-equipped for the search find themselves isolated too.⁷ My grandfather, who was once my mom’s ultimate source of comfort became her biggest source of sadness. The man who I once loved grew to resent me, and the feeling—to my despair—was mutual.

In the TimeSlips sessions I have led as a medical student, I have seen patients and caregivers light up with joy while they got lost in the story. We start every session with the reprise, “There are no right or wrong ideas, only your ideas.”

The participants rush to their seats at the beginning of each session, and linger afterward to chat and enjoy each other’s company. They have redefined what dementia means to me, and have changed how I support people with this disease. When patients do not remember my name or cannot follow along in a conversation, we forge forward

and forget about the pressures of who remembers what. We laugh and make up stories and find new connections.

Today there is no cure for dementia, but TimeSlips offers something unique. It brings meaning to those who give, and receive, care. It offers playfulness to brighten a disease that is so often cloaked in fear.

If I were sitting on Pop’s couch today, I would not pull out any pictures from that old photo album. I would not force old memories out of him, but work to create new ones, together. If dementia comes for me, I know that I will want to find meaning in my life. I will want to have fun, be able to laugh, and find companionship, however fleeting those feelings will be. I will want to be known as more than a disease. I will want to know that there are people doing everything they can to help me enjoy life. I will want someone to share TimeSlips with me.

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