

https://pilotonline.com/news/local/health/article_20acd98b-e3d2-54fb-b825-9de3efff7e89.html

I took a tour simulating dementia and here's what I learned

By Arleen Spenceley
Correspondent
Apr 27, 2017



Courtesy photo

Pilot correspondent Arleen Spenceley gets ready to take a Virtual Dementia Tour at Churchland House. Spenceley's grandmother has dementia.



My grandmother likes to talk to strangers. She also likes to eat.

She smiles a lot, counts in Italian, and stands while she watches TV. When I call her, she asks about my daughter.

I don't have one, but I play along. She has dementia.

We first saw signs a decade ago.

She frequently repeated herself. She got lost between the bathroom and our table at a restaurant. She forgot my birthday.

And it got progressively worse.

Now, she can't follow basic instructions. She often insists that she's eaten when she hasn't, and wants to eat when she already has. She folds laundry. Then she folds it again.

She resists changing her clothes. She asks if we've heard from her mother, who died in 1999. She doesn't have a filter.

"You're old — what do you want me to do?" she said, when I told her I'm 31.

She rummages through cabinets and drawers, her own and other people's. She empties her purse and refills it, over and over. She wanders and she mumbles.

I don't remember the last time we had a real conversation. She doesn't remember me.

My grandfather is her primary caregiver, but my parents, my aunt and I stepped in last summer when he broke a hip. We only stayed with her for 10 days — but it exhausted and frustrated us.

So, when Commonwealth Senior Living invited the Pilot to participate in a Virtual Dementia Tour at its Churchland House community, I decided to do it.

The tour was created by Second Wind Dreams, an international nonprofit aimed at changing people's perceptions of aging, and is designed to simulate dementia.

I didn't know what to expect when I showed up, but I wanted to be surprised.

And I was.

When I showed up, Commonwealth's vice president of resident programs, Bernie Cavis, briefed me.

She told me that during the tour, I'd have to find a task list and complete the items on it.

She put plastic inserts in my shoes and gloves on my hands, to simulate neuropathy and arthritis. She covered my eyes with glasses that limited my sight. She covered my ears with a headset that played static and voices, sirens and door slams.

She led me into one of the assisted living facility's bedrooms, totally dark except for a strobe light. She gave me further instructions, but I couldn't hear her — all I caught was "task list," "sweater" and "socks."

I asked if she'd talk louder. Instead, she left the room. I had no idea what to do.

But I looked for and found a sweater and socks. Then I searched through a stack of papers for the task list. When I couldn't find it, I rummaged through nearby dresser drawers.

One had socks in it.

Maybe I'm supposed to put the socks away, I thought. So I did. Then I looked again for the list.

I never found it.

I quit looking and folded a pile of towels I found on the bed. Maybe that's what I was supposed to do.

That's when I realized: the tour is brilliant.

It created conditions in which I knew I needed to do something specific but had no way to know what it is — which is exactly how my grandma will spend the rest of her life.

After eight minutes, Cavis retrieved me from the room. Before I left, I sent texts to my family to say what I've said to several other people since that day.

Find a Virtual Dementia Tour and take it.

It won't take away the exhaustion or frustration we feel after interacting with loved ones who have the disease. But it can bolster something important: compassion.

For information about the Virtual Dementia Tour, visit secondwind.org. For dates of future local tours, contact any Commonwealth Senior Living facility in Hampton Roads.

Arleen Spenceley, arleenwrites@gmail.com

 65

 8

 4


 5

 0



83
Shares

arleen spenceley

 Click to comment