

On My Mind: Room for love and loss at Windemere



In “Being Mortal,” Atul Gawande says that a good geriatrician “always looks at the person’s feet.” We would add that a good geriatrician always looks at a person’s room. At Windemere and perhaps everywhere else, the qualities of one’s room are a product of their state of mind. At Windemere, like every mind, each room is different. Each room is like a stage set for a one-woman or -man show. Some rooms have framed sepia photos depicting handsome husbands in uniform. Others contain framed puzzles that the occupant has painstakingly completed and painted with glue. Whether it contains Starburst candies, an orange, or half-eaten chocolate chip cookies, there is a story about day-to-day life to be found on their snack shelf. What is the smell in the room? Urine? Chanel No. 5? Is the bedspread hand-crocheted, or does it depict a favorite sports team? One good look at the room tells a story, a first act inviting more to unfold.

As a person ages, friends die, senses dim, and memory often fades. While qualities like wisdom often grow, by and large an elderly person’s world becomes

smaller. In nursing homes such as Windemere, it might be that a resident's room becomes their whole world — a spatial representation of everything that they have lived for, and continue to live for.

A psychiatric interview often contains personal questions such as “What makes life worth living?” or “Do you feel useful?” Some Windemere residents gesture to the props that adorn their rooms. One man handed over a dancing cow that sang “Bésame Mucho” in Spanish, saying “My grandson gave me this, and it makes me laugh!” A woman vaguely waved to a rosary draped across her lampshade, saying, “Oh, I believe God will take care of everything.” Another pulled out a photo album from her bedside table with a toothless grin, wordlessly pointing to the small black-and-white images of her and her siblings as children. At times being at Windemere feels like stepping into a living autobiography, frozen in time.

A person's room indicates what they are living for, but also what they are living without. Many people allude to big losses in their life. “My sons have gone missing, and I am afraid I will never see them again,” one resident implored behind sad eyes. “Maybe if you look over there at their picture, you could tell me if you've seen them.” When asked about what made life worth living, one woman replied tearfully, “I had a good man once. He was a good husband. Such a good husband.” Her husband's portrait hung on the wall, smiling kindly down at her, as if he knew it was true. A man had a painting of the Vineyard Haven Harbor behind a powder-blue house with a white porch. “This is where I used to live,” he explained wistfully. A woman with end-stage dementia hugged a picture of her five children, but could not recall their names. Over time she became distressed by the pictures she did not recognize, and for comfort had them removed. The increasing bareness of her room indicated not only lost husbands, sons, or houses, but a lost memory.

If walls could talk, what would they say? The answer is, they already do. Residents' rooms contain not only the photos, but the soundtracks to their lives. On the dementia unit at Windemere, there is always music playing. In the morning you'll hear the snappy doo-wop tunes of the Del-Vikings, getting everyone ready to start the day with a spring in their step. In the afternoons there will be a musical on the big-screen TV, something to sing along to, like “Singing in the Rain” or “The Sound of Music.” The staff at Windemere know how to expertly wield music to reinvigorate a resident who has withdrawn from the world, bound by depression or dementia. They take it upon themselves to know individuals' favorite artists, to call upon as an instant pick-me-up for the challenges of the day. One resident with a tendency to fall clings fearfully to her

personal aide when it is time for her shower. To soothe her, the aide sings “Take Me Out to the Ball Game,” which lightens the mood. Another resident, muted by a stroke, cracks a lopsided grin when you sing “Respect” by Aretha Franklin. A resident losing her ability to speak will hum nervously to herself between bits of gibberish. And yet, when you sing to her the spirituals of her childhood, like “Amazing Grace” or “Down by the Riverside,” she remembers each verse with astounding clarity. For Windemere residents, music is not merely a form of entertainment, but a window to a joyful past.

When we talk to friends about Windemere, they will often say that they hope to die before needing a nursing home. Even if they were integral in helping their parents or friends move into one, they would rather avoid it themselves. “How can you stand working there?” they inquire. “It’s so sad.” The answer might be surprising.

It is true that every person living at Windemere seems to be in some stage of loss. In most cases, their previous lives included owning a home, driving, and having unlimited privacy. Perhaps they have since lost their hearing or sight. Or, they are mourning lost loved ones. And yet, with all of these losses, most are not drowning in sadness. Research suggests that as we grow older, most of us become less neurotic. That is, we stop sweating the small stuff so much. In fact, it is amazing how much joy, love, romance, spirituality, music, and connection is maintained throughout the lives of the elderly, even into the later stages of dementia. Those empty walls and forgotten names belie a love and passion remembered. A man lights up when hearing Louis Armstrong. A woman caresses a hand and says, “I love you.” Others, who are unable to remember the names of any politician, somehow are disturbed or delighted by our president.

Responses to the question, “Are there moments in your life where you were frightened after something bad happened?” are often astounding. Even when it is easy to think of several horrific things that outside sources have reported, the most common response is “Oh, I don’t really think much about the bad times. The past is in the past.” Their loss has not consumed them in the way that might be expected. Their resiliency often allows them to achieve a new normal, where loss is assimilated seamlessly into their identity. Like a framed picture on the wall, it gives them character and uniqueness, but does not completely define them.

One woman, whom we will call Pam, recently moved to Windemere after becoming unable to live independently in Elder Housing. She showed particular resilience in light of the freshness of her loss. When we asked her if she felt sad

about her circumstances, she paused thoughtfully and shrugged. “It’s one thing if you can change it. But I can’t.” Pam has redefined what gives her meaning, taking this loss as an opportunity to build a rich relationship with a volunteer she was assigned through Resident Activities. “There are two types of people,” Pam says. “The people who sleep in chairs, and the people who do things. And I want to be the type of person who does things.” And she certainly does embrace the opportunity to get out and do, whether it’s dinner dates with her volunteer, trips on a catamaran in Menemsha with Windemere staff, or sampling a platter of Chilmark chocolates. The more you get to know her, the clearer it becomes that Pam’s life has been full of loss as well as love, and that she, like many of our other patients, has found room for both at Windemere.

Maegan Pollard is a senior medical student at the University of Massachusetts. She has been researching issues related to aging on Martha’s Vineyard for the past three years. See her paper on dementia treatment on the Vineyard here: bit.ly/DementiaOnMV. She spent the month of July working with Charles Silberstein, M.D., a psychiatrist at Martha’s Vineyard Hospital who is board-certified in general and geriatric psychiatry. In the stories above, personal details have been changed in order to maintain the privacy of Windemere residents.