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A man depicts the often grim atmosphere in assisted living facilities

By Martin Bayne, Published: July 9

People my age — I'm now 62 — might go to an assisted living facility every now and then to visit an older family member. But few people in my age group actually live in an assisted living facility. I do.

Eight years ago, in a wheelchair and after nearly a decade of living at home with young-onset Parkinson's disease, I decided to move into an assisted living facility. I knew what my decision meant. I'd be moving into a place where the average resident was 32 years older than I was, and the average levels of disability, depression, dementia and death were dramatically higher than in the general population.

What I hadn't calculated was what it's like to watch a friend — someone you've eaten breakfast with every morning for several years — waste away and die. And just as you're recovering from that friend's death, another friend begins to waste away. I can say with certainty that the prospect of watching dozens (at my young age, perhaps hundreds) of my friends and neighbors in assisted living die is a sadness beyond words.

Facilitated aging is a way of life for a growing number of Americans, more than a million of whom now live in roughly 40,000 such facilities across the country.

During my first few weeks in one such place, I requested a meeting with senior management. I've been both a journalist and a Zen monk in my day, and I like to make sure we all understand one another and communicate well.

'Their' facility

The three executives and I met in my room, and the meeting soon turned fractious. I don't remember exactly what the head of the housing board said, but I challenged it.

"That's not fair," I told him. "You get to go home every day at 5 p.m., but this is my home." He stood up, pointed his finger at me, and roared: "This is NOT your home. You just lease an apartment here like everybody else."

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I realized right then that the residents of “their” assisted living facility, among whom I now numbered, didn’t have a voice. We arrive in this, our new society, suddenly disconnected from our past life, possibly ill, often without the comfort and support of a spouse we’d been married to for decades. We eat meals in a dining room filled with strangers and, for perhaps the first time in a half-century, sleep alone in an unfamiliar bed.

We then can find ourselves silenced by, and subjected to, a top-down management team whose initial goal seems to be to strip us of our autonomy. And it is in this environment that most of us will die.

Something else I soon came to realize was that the administrators who make up the management team play a distinct and dramatically different role from that of the staff members.

Administrators represent the whims of those who own the facility. The staff members — the personal care assistants, the certified nursing assistants and so on — are the heroes for those of us living in a facility. Underpaid, overworked and highly susceptible to work-related injuries, they are the glue that holds together most of this country’s facilities for the aging. And just as we residents live in “their” facility, these staff members work in “their” facility.

Glaring issues

I lived in the first facility for eight years before moving to the one I’m in now, and if you didn’t know anything about assisted living, you’d probably be quite impressed by my current location. It’s remarkably clean and attractive; the food is high-quality and abundant; the lawns are manicured. Operationally, it runs smoothly.

There are, however, a few glaring issues, the foremost being accessibility. Shockingly, many assisted living facilities aren’t completely wheelchair-accessible.

Sure, there are lots of ramps in these facilities, but at every facility I’ve ever visited or lived in, the bathroom sink isn’t wheelchair-accessible. Just try to shave or brush your teeth when the sink is way up there. You can’t.

Where I live now, I’m on the first floor and fortunate enough to have a beautiful outdoor patio — but my wheelchair is too wide to negotiate the doors, so I can’t wheel myself out onto it.

Additionally, spaces that residents would like to have access to don’t exist in most facilities. Mine, for instance, has neither an exercise room nor a nondenominational meeting center for meditation or worship. These might be seemingly small concerns, yet they have an oversize effect on residents’ quality of life, especially when you consider that most of us can’t leave easily or often.

But the real problem isn’t operational or structural. It’s emotional.

Most residents show a calm, even peaceful veneer. But beneath the surface, all of us are susceptible to the ambient despair that is a permanent component of life in assisted living. It’s the result of months or years of loneliness and isolation. It’s also the result of burying our feelings and emotions about being surrounded by many demented and disabled neighbors and by frequent death.

The story I’m telling here isn’t just mine. It’s one that will resonate with anyone living in an assisted living facility and anyone visiting family or friends there. Were my experience unique, I wouldn’t be motivated to

write this essay or to pursue the other few, difficult avenues available to those of us working to improve the lives of residents in assistant living facilities. Assisted living can improve life circumstances for many people and their families. But, as these snapshots of some of my compatriots reveal, these circumstances are never easy.

‘I don’t want to die alone’

Eighty-nine years old, with a failing heart and a beatific smile, the retired librarian approached me one evening after dinner.

“I don’t want to die alone,” she said. “Would you stay with me tonight?”

Sitting in separate reclining chairs in her living room, we settled in for the night.

“She was right,” she said, while sitting there, placing her delicate hand in mine.

“Who was right?”

“The Good Witch.”

“I don’t understand,” I said, concerned about her state of mind.

“There’s no place like home,” she said. And still holding my hand, she fell into a deep sleep, dreaming perhaps of the Good Witch, Dorothy and the Land of Oz. We both slept through the night.

She lived for two weeks more. When the end came, her daughter was at her bedside.

Christmas lunch

On the eighth Christmas I spent as an assisted living resident, I shared my table and a festive lunch of canapes and beef stroganoff with a 96-year-old widow. Our conversation, inevitably, drifted to those former residents who wouldn’t be joining us for the meal — or any meal, for that matter.

She brought up one older man. “One day he just announced that he was no longer going to kidney dialysis; he died a week later. Two weeks after that, his wife died,” she recalled.

“Was his wife also a resident?” I asked.

She nodded. “She chose to die, didn’t she? Why the hell would she want to stay here, alone?” Then she stared into space. For some suddenly living alone in an assisted living facility, a willed death — whether it’s called suicide or not — becomes a rational choice.

Later that afternoon, as I left with my younger sister to join her family for the holiday, I asked myself the same question I’ve asked every year since I was 53 years old, “What in the name of God am I doing in an assisted living facility?” I guess you’d call it an existential, rhetorical question. I know the answer, of course — I can’t take care of myself independently — yet sometimes that reality is just too painful to deal with.

‘He just left me’

At 4 feet 10 inches tall and 80 pounds, the 89-year-old great-grandmother could easily get lost in a crowd. And that’s exactly what she did for the first two months after she arrived. She always managed to find a quiet corner to sit, alone, with the paperback she always carried. One evening, as I sat outside with my camera, trying to get a few good shots in the fading light, she suddenly appeared in my viewfinder.

“Can I take your picture?” I asked.

She seemed to ignore me, her eyes focused intently on her book. Then, seconds later, I heard a voice, not of an 89-year-old, but of a young girl. “Sure,” she said, “go ahead and take my picture.”

And then as night descended, we both sat quietly, absorbed in our own thoughts.

“He just left me,” said the tiny voice in the darkness.

“Who just left you?”

“My son,” she answered. “One day he showed up at my home in Maine. He said we were going to spend a few weeks together at his place in Pennsylvania. Then . . .” Her voice trailed off.

“Then what,” I said softly.

She paused, and took a deep breath. “Then he drove me here and left me.”

I felt as though a great tectonic plate had shifted. “It’s okay,” I finally responded. “You’re among friends now.”

She set her book down, and even in the faint light of the new moon, I could see her smile.

Bayne is the publisher of [The Feathered Flounder](#), a literary journal showcasing the work of people in their 60s and older. This story was excerpted from [Narrative Matters](#) in the journal Health Affairs.

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