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A Room With A Grim View: The ‘Ambient Despair’ That Marks Life In Assisted Living

After entering an assisted living facility at age fifty-three because of young-onset Parkinson’s, an observer-advocate contemplates the dire need for long-term care reform.

BY MARTIN BAYNE

People my age—I’m now sixty-two—might go to an assisted living facility every now and then to visit an older family member. Facilitated aging is a way of life for a growing number of Americans, more than one million of whom now live in roughly 40,000 such facilities across the country.

But few people in my age group actually live in an assisted living facility. I do.

Eight years ago, while still in my fifties, 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 thirty-two years older than I was, and the average levels of disability, depression, dementia, and death were dramatically higher than those in the general population.

What I hadn’t calculated, however, 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.

‘Their’ Facility

During the first few weeks in my new surroundings, I requested a meeting with the facility’s senior management. I’ve been both a journalist and a Zen monk in my day, making me someone who likes to make sure we all understand one another and communicate well.

The three executives and I met in my room, and the meeting soon turned fractious. I don’t remember exactly what the chair of the housing board said, but I challenged it. “That’s not fair,” I told him. “You get to go home every day at five o’clock, 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.”

I realized right then that the residents of “their” assisted living facility, among whom I now numbered, didn’t have a voice. Those of us there, and in many other such facilities, arrive in this, our new society, alone, 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 usually 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 the facility owner(s). 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. Grossly underpaid, overworked, and highly susceptible to work-related injuries, they—many of whom are young women of color—are the glue that holds together most of this country’s aging facilities. These are the people whom residents trust and come to rely on. While we live in “their” facility, they 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, most assisted living facilities aren’t completely wheelchair accessible.

Sure, there are lots of ramps. But in 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 non-denominational meeting center for meditation or worship.

These might be seemingly small concerns, yet they have an oversized 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 in assisted living facilities, by necessity, live secret lives. On the outside, there might be 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 this type of facility.

This despair is as real as the landscaping or the food—only more deeply and widely prevalent. It’s the result of months or years of loneliness and isolation and of a lack of true social interaction among residents. It’s also the result of burying our feelings and emotions about the exceptionally high numbers of demented and disabled neighbors around us and being surrounded 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. 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 assisting living facilities.

Here, in a few snapshots, are the experiences of some of my compatriots and cohabitants.

Snapshot 1: ET, Fear Of Dying Alone
ET was eighty-nine years old, a retired librarian with a failing heart and a beatific smile. She 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.

ET lived for two more weeks. When she finally surrendered her body and began the next phase of her journey, her daughter was at her bedside.

Snapshot 2: ER, Christmas Day
On the eighth Christmas I spent as an assisted living resident, I shared my table and a festive lunch of canapés and beef stroganoff with ER, a ninety-six-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.

“You remember B,” she said between mouthfuls of noodles. “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.”

“Was his wife also a resident?” I asked. She nodded. “Well, of course she was a resident,” ER answered. “She chose to die, didn’t she? Why the hell would she want to stay here, alone?” Then she stared into space. For some, like B’s wife, 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 fifty-three 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—and sometimes that reality is just too painful to deal with.
Snapshot 3: B, Just Left

At four feet, ten inches, and eighty pounds, B could easily get lost in a crowd. And that’s exactly what she did for the first two months after she arrived. B 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, B 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 eighty-nine-year-old great grandmother, but of a young girl. “Sure,” she said, “go ahead and take my picture.”

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,” B 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, B, 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.

Hard, Cold, Aging Facts

Yet, in many ways, ER, ET, and I—even B—are the lucky ones. We’re able to afford—or we have others in our lives who can afford—the cost of the long-term, assisted care we require. To date, my care has cost well over $700,000, with the lion’s share of that coming from a long-term care insurance policy I had the foresight to purchase in my early forties. Because of my still relatively young age, the final price tag might well be in excess of $2 million.

In 2009, $2.1 trillion was spent on all US personal health care services, defined as services provided to those whose activities of daily living (using the toilet, bathing, eating, transferring, and so on) are compromised. Often they are provided to an aged, chronically ill, or disabled person. Of that $2.1 trillion, $294.4 billion (14.1 percent) was spent on formal—meaning paid—long-term care. The bulk of those costs, $209 billion (71 percent), were paid for by taxpayers, largely through Medicaid ($126.8 billion) and Medicare ($62.6 billion).

Patients and their families, in addition to being taxpayers, paid a staggering $52.4 billion in out-of-pocket expenses.

To many Americans, these long-term care costs are little more than numbers on a page. But to people I know, these numbers represent a terrifying reality. A friend who cared for his spouse through the terminal ravages of a brain tumor; a woman living in my assisted living facility who nursed her husband through eight long years of Alzheimer’s; my younger sister, who provided more than ten years of in-home care for our mother following a stroke. In retrospect, all of these caregivers would admit that they were unprepared for the physical, emotional, financial, and spiritual toll that protracted care of a loved one exacts.

Then there are other burdens: the constant confusion about Medicaid benefits, and the phantasmagorical complexity of Medicaid estate planning. Despite or perhaps because of, the growing burden of long-term care costs, implementing the Community Living Assistance Services and Supports (CLASS) Act was suspended. Throw in the typical lack of media interest in the daily lives of “seniors,” the advertising industry’s glorification of youth, and the profit-fixation of too many owners of assisted living facilities. These cold, hard facts mean that aging in assisted living can be a disaster, and the situation will not improve without genuine reform.

Changing Long-Term Care

Living with Parkinson’s disease has led me to realize that the quality of my life depends on the future viability of the long-term care system in the United States. So, too, does the quality of life for the millions who are similarly situated—the chronically ill, disabled, frail, and elderly individuals who are unable to accomplish those defined activities of daily living. We need better, more humane places to live in that allow us to preserve whatever health and happiness we have left. We also need to be surrounded with more compassionate, higher-quality, yet still affordable care.

To create genuine long-term care reform, we as a nation need to perform a series of activities. We must understand the full nature and scope of the problem, including knowing the benefits that are and aren’t available under skilled, custodial, and intermediate long-term care. We have to acknowledge the full range of policy options that exist and create a workable way to finance care using a mix of public- and private-sector support. People will also have to acknowledge their personal responsibility for leading purposeful lives, a part of which means considering the costs of long-term care and planning ahead for how to pay for them. In short, we must all be held accountable for ourselves and for the whole.

Until the totality of that approach is under way, we’re in trouble. I’m tackling the part that I can. Difficult as it sometimes is, I’m actively trying to be accountable for myself, my fellow residents, and everyone who lives in assisted living facilities.

Earlier this year, I became the publisher—Paul Soderberg in Arizona is the editor—of the first literary journal to showcase the work of people in their sixties and older. Published online and without charge, it’s named The Feathered Flounder. You can read a copy at http://thefeatheredflounder.com. As I explained in my first publisher’s note, the literary journal “is born in the imagination of those with the benefit of having accepted the unexpectedness of aging.... It is the nature of creativity.”

I hope others—especially policy makers—also will call on the nature of creativity as they wrestle with the realities of assisted living facilities and of aging in general. I’ll keep doing what I can: being active in my community, publishing, and writing about the view from my wheelchair from inside an assisted living facility. Others need to go about tackling the systemic and looming issues for an aging nation.

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