

## NO WAY TO KNOW

Columbia Professor/Mental Health Advocate Michael B. Friedman's short story contemplates how the will to live might be affected by Dementia..



He and his wife were having a drink in the garden of a small neighborhood restaurant. As usual, they talked little, preferring to watch strangers. Three men came shortly after they sat down. One was in a wheel chair. He could have been 80 or 90. He was feeble and wore a plastic ID bracelet from a hospital, or more likely a nursing home. His straight white hair was neatly parted on one side, and he wore an old-fashioned plaid shirt and tan khakis. A man with a white beard and thinning hair who looked about 60 moved a chair away from one side of the table, slid the wheel chair in where it had been, then sat in a chair to the left of the old man. He was dressed in pseudo work clothes, a chambray shirt and baggy jeans. He seemed pained by the old man, looking away from him far more often than at him. The third man, who has handsome and looked about 40, sat on the other side of the old man. He too was dressed casually but his clothes were stylish; he clearly cared about his appearance. He paid careful attention to the old man, tried to engage him in conversation, and stroked his arm gently from time to time.

He took them to be three generations of a family--grandfather, son, and grandson. His wife took them to be a gay couple visiting an old friend, perhaps a former lover, now alone in a nursing home. He looked again and saw that she was right, but it made no difference to him. Three generations of a family or current and old lovers, what did it matter? He found the scene almost unbearably sad. The old man smiled only once that he noticed. For the rest of the time he focused on eating, which he did like a man for whom decent food is a rare treat. His hands shook as he fed himself soup, but he managed to eat it all with not

too much spilled. The young man wiped up after him. Then he had some sort of fried seafood and french fries, which were easier to eat. The pieces he dropped on the table he then picked up and ate.

There was virtually no conversation. The old man had apparently reached that point of cognitive decline where he could say one or two things that had become habits of speech and made him seem himself, but beneath that there was nothing that could be expressed in words. His deteriorated state was obviously very painful to the man who was either his son or former lover, who continued to look away and, frequently left the table to smoke. The younger man stuck with it. His gaze stayed on the old man; he didn't flinch at the dribbled food or the shallowness of the old man's mind. Occasionally he petted his arm affectionately.

"Just shoot me," he said to his wife. "I never want to live like that." But he had thought about taking his own life often enough that he knew that he might change his mind when the time came. He knew that he might want to hang onto the awareness of life around him as long as he could or that having a decent meal or being in the presence of people who cared enough about him to visit might be reasons enough to continue to live.

This, he thought, was the \$64,000 question about old, old age. He was already past 65 --old, no matter what people said about 65 being the new 45. Old, but living well. A few chronic conditions, but he could still have sex; he could still work; he was still respected by people in his field; he could still tell a joke and be enjoyable company. In many ways, his life was better now than it had ever been. He had achieved a level of success, lost his driving ambition, did not have work all the time and did not have to deal with the constant and unpredictable stresses of running his own business. His daughter was doing well, finishing a graduate degree and in a serious relationship that seemed to have a future. Grandchildren were still a way off, but he thought he would live long enough to have one or two. He and his wife lived in peace, with humor about the foibles that they had hated in each other in past years whenever their relationship was strained. Differences between them didn't matter in the way they once did. And he could take time for--well for pretty much anything. Life was good.

But there were intimations of what life might become when he was very old. Already his memory was a bit unreliable. He joked that what stood out were the moments of humiliation and that one day he would write a very long autobiography called "Apologies and Humiliations." At some point, if he lived long enough, he would probably forget even the most distressing moments--so much for memoirs. At some point he might not be able to have a conversation beyond a few familiar riffs. People would know it was him from mannerisms that marked him as himself. They would start conversations with him as if he were not a shell, but he would not be able to do more than repeat these signs of who he had been. Then they would turn away and talk to each other. That, he remembered with a bit of shame, was what he had done with an old friend who had died recently. They would exchange pleasantries; then, when there was nothing to say, he would talk with his friend's wife. He had learned that reminiscing with his friend seemed to give him pleasure; his eyes would have some life in them. But then his friend's eyes would turn inward, and he himself would become bored with the lack of exchange. He could only babble on about what used to be for so long; then he needed to return to the present. He needed feedback. He needed acknowledgement. Stroking his friend's arm, touching his shoulder, brushing crumbs from his shirt were not enough for him. Were they enough for his friend?



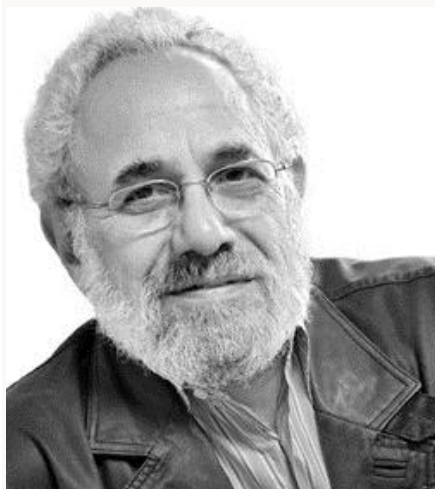
Developmental psychology, he knew, teaches that we are different people at different stages of life. Infancy, toddlerhood, pre-school, school aged, pre-adolescent, adolescent, young adult, grown-up, and old person--each had its own form of consciousness, thought, and way of being. Erik Erikson characterized each stage as having a challenge to be met and a form of character to be achieved. The challenge of old age, Erikson had said, is to avoid "despair" and to achieve "integrity". That seemed right for him at 67. It seemed right for any age while the mind was still working. But what about when it became a mind short of memories, knowledge, and ability to think? What integrity was there in that state of being?

He had gone to a speech once in which the speaker had claimed that, when some cognitive functions decline, others remain intact and are freed from the insistent controls of what Freud's translators called "the ego." (Freud actually said "das Ich", as he liked to point out to show off his erudition.) When the ego defenses against inner desire and feeling break down, the speaker said, people are freed to feel and express emotion in a way they had choked off since childhood. It was that speech that helped him to understand that exchanging a touch with his old friend could be meaningful to both of them. That made it better between them, but only for a time.

He had heard another speaker, a person who liked to care for people with dementia in their final days, say, "When I am with a person who remembers nothing and can provide no care for themselves, I feel I am in the presence of pure being, of the person's soul uncontaminated by the body." He imagined at the time that that would be a powerful spiritual experience and envied it a little, but he thought that it was an experience in the mind of the caregiver and not in the person nearing death without human awareness.

Still he knew that his reaction to what he saw as the loss of mind came from his own stage of development, his own form of consciousness, his own way of being. And he knew as well that his way of being was very much a product of his society--a society in which people whose deaths after long illnesses were notable enough to make the news always "died today after a long battle with cancer," or some other dread disease. Apparently, no one ever died at peace, having accepted the inevitable end of human life. "Do not go gentle into that good night. Old men should... rage against the dying of the light," Dylan Thomas cruelly told his dying father. "Old men should be explorers," says T.S. Eliot after he became religious. "We must be still and still moving/Into another intensity/For a further union, a deeper communion." Thoughts of young men, Western men, ambitious men, men for whom darkness is undesirable, men who want to hold onto the light forever.

Although he himself was old enough to know better, he wondered whether the idea of living in darkness was so horrible to him that he would rather be dead or, to the contrary, when the time came he would want to hold onto whatever life he had. When he was that old man in the wheel chair in the garden restaurant with a grandchild petting his arm and wiping away the food he spilled, when he was that old man whose former admiring lover could no longer stand the pain of looking at him and trying to talk, when he was that old man for whom getting out of a "home" was a great treat, would he still want to live? Would he hold on to the screen of consciousness, however flickering the light? Would he get enough pleasure from a vague sense that someone cared, from the feel of a touch on his arm, from the sight of an almost remembered lover, from the warmth of the sun on his back and the taste of fried seafood in his mouth? Would he want to go on living? There was no way to know.



Michael Friedman, a retired mental health advocate, founded the Geriatric Mental Health Alliance of New York and other coalitions. He teaches health and mental health policy at Columbia University, and writes frequently on mental health and aging issues, including a blog on the *Huffington Post*.