

Living with Alzheimer's

By Lori Shearn

We live too long, perhaps. Medicine has performed such miracles in our day, but when an illness such as Alzheimer's strikes, there is little to be done but wait.

Martin and I have been married for over 50 years. We have been partners, filling various roles in each other's lives and in society. Now, however, we have had to adopt new roles.

Who are we? He is a husband, father, grandfather, a physician, an honored teacher, a professor, and a mentor for a generation of rheumatologists. He has written myriad learned articles for the medical literature as well as books and a number of lighthearted, joyous celebrations of special and often-entertaining observations.

I am a wife, mother, grandmother, an immigrant from Hitler's Europe, and a college graduate. I have been the financial officer for the Oakland Symphony, a docent at the California Academy of Science, a counselor for Planned Parenthood, and a speaker for the Holocaust Center. But my new role is that of "caregiver" for my beloved's new role of Alzheimer's patient.

The word "caregiver" feels ambiguous. It does not begin to describe the magical life that Martin and I shared, the adventures we experienced, the occupations and professions we pursued, or the encomiums we earned—together and individually. A

caregiver? Surely that cannot be the only thing I am. Being a caregiver is a long-lingering collection of greater and greater burdens. I miss having a life outside of Martin's illness; but more than that, I miss my best friend and confidant. My other friendships and interests have been eroded. The insidious disappearance of my own life is an incalculable loss, and the cost of energy and of strength is truly overwhelming. The emotional drain is never replenished and leaves a vast hole. I know the negative balance must be replenished or this organism will die. Where will the energy come from? I know Martin will not get better, and I must find my way back to some sort of equilibrium.

"Some forgetting happens to everyone as we get older," we said because it felt reassuring.

Martin made his own diagnosis about ten years ago, when he became aware of failures in his memory. Memory had been his proudest gift. Suddenly, he discovered a glitch in this retrieval process, and it was terrifying to him. "Some forgetting happens to everyone as we get older," we said because it felt reassuring.

For him, the first defense was secrecy: No one must know of this "shameful" loss. But a very few were quietly asked for their impressions: Medical friends and doctors who were not friends were invited to do a clinical evaluation. The favorite explanation was "it's definitely not serious; it's pseudodementia and can



Dr and Mrs Shearn, 1998

be cured by an antidepressant. Start today, and in two weeks you will be better." We wanted to believe. He wanted to believe. As soon as the first dose was taken, he was "better" and happier. But, of course, the gains were not sustained. More testing was needed. And more. And more. We finally decided to do complete psychological testing because "he feels so bad about retiring from medicine."

The results pointed to early dementia, and, for the first time, the "A word" was mentioned. This prospect was grim, but initially we were able to make adaptive changes in our life. We worked diligently to introduce some new activities: Teaching medicine to laymen, presenting workshops on poetry, and discussing biographies at senior centers. It made us both feel better. But the memory



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Remembering Martin Shearn, MD

problem was clearly getting worse. He would get angry, even with me—a totally new phenomenon. He didn't want to talk about it. He began living an insular existence.

And then, a fabulous gift was unwrapped. He discovered within himself a passion for painting. He created remarkable images and was lauded by all for the amazing range of his talent and for the beauty of his colors, his composition, and his imagery. The pictures depicted large, fantastic skylines of great intensity or nostalgic reminders of another time with life-sized nickelodeons featuring some of the songs of our youth, and ice cream sodas of enormous size, recalling happier days without worries about cholesterol.

Years passed. Martin continued to be athletically active, involved with family matters, and creative. Sadly, his fervent passion for medicine had vanished.

Relentlessly the mental deterioration became more debilitating—clearly more widespread, more pronounced and noticeable. He had ways of coping. While reading, he took notes. When he couldn't understand his notes, he became angry. He blamed others—a distinct change in personality.

We went back for more testing, this time to a research center for Alzheimer's; the deficits were documented. By the end of that visit, we acknowledged the diagnosis we had known for a long time. The certainty required a new attitude. Privately, Martin accepted the diagnosis, but he did not feel comfortable discussing it with anyone. He withdrew from old friends for fear of what they might think. We saw no colleagues, avoided medical meetings, rounds, and most friends; only a few who pursued us succeeded in reaching him.

There were legal issues to be attended to, and Martin clearly expressed his wishes in writing that he did not wish to live if his brain ceased to function. He contemplated a life with greater and greater losses.

My personal loneliness was exacerbated by his unwillingness to discuss our fate with friends or with family. Of course, our children knew, but he didn't want to talk about it with them either. I needed to tell those who love us—our friends and relatives—but he did not want to burden them. Also, I guess, he was embarrassed.

Eventually, my insistence brought us to the Alzheimer's Association, and we joined a support program, but still Martin was not willing to share his feelings. I continued alone and found a most supportive group. Aside from that, we were alone.

When he could no longer make sense of reading, he took a shocking action. He destroyed some favorite books. He snatched them off the shelf, cut the pages into pieces, and threw them away. "There was nothing in them," he said.

And yet, I am not crying out in anguish; nor am I in a state of denial. It is as if I have gotten used to this disease's huge presence in our life. I can remember what we had. We shared the most amazing and satisfying years. The thrills and excitement of our mutual discovery of each other empowered both of us to considerable accomplishments. His thinking was always original, dependable, and multifaceted. He had found it possible to take an idea, turn it upside down, and then state it in a better way. It has given us both so much delight to write articles on subjects that had never been explored before, or to expand studies to give a new slant on an old issue. So, even

though Martin's memory is gone, I still have mine. And we have his writings, his files, and his pictures. We often look at our past life in this way. Martin's sense of humor remains, though now more like a child's. Although his words are most often clear, comprehension and meaning are no longer there.

We have been so blessed to be together as we raised our children in a medium of love, intellectual stimulation, and the games of the mind. He was always able to translate his role as a serious teacher of medicine to that of a very playful father, joyfully detailing the perversions and contradictions of humanity in a difficult and cruel world. He inspired our son, David, and daughter, Wendy, to become physicians and both are with The Permanente Medical Group (TPMG). Our daughter Bobbi became a physical therapist and is now a musician.

Martin has always been compassionate. His patients adored him because he truly searched for the spot in their lives he could understand—to which he could connect. We sometimes reread their letters of appreciation. I knew that his students would remember too. This, then, became a possibility of return to sociability, I felt. Without his permission, I contacted selected former medical residents and suggested that they visit him and that they pass the word around. His diagnosis was no longer a secret. It was liberating for me. Martin didn't need to talk about it. Many of his admiring ex-residents came to visit, and he basked in their warmth and friendship. They didn't talk medicine. He was interested in their lives and families. There were lots of laughs. It was a marvelous interlude.

As his cognitive skills continued

soul of the healer

to decline, his emotional side came more fully to the fore. His love for me is expressed a thousand times a day, though I detect a desperate dependence—every minute, every day, everywhere.

As language skills have diminished, the brain centers of emotion and whatever controls the arts have expanded. He no longer has the ability to paint on his own. Initiative seems to have dried out. But he still loves art, and he now has an art therapist to help him—one-on-one—create newer, simpler pieces. He is rapt with attention as they work, and he enjoys the process and what he creates. He continues to love listening to music and has expressed an earnest desire to play the piano. He can no longer read music, but he can sing and play all the old songs by ear. He can't remember the words. We have a music therapist who works with him, and he thoroughly enjoys that activity.

He now has caretakers—other than me, who come daily, eight hours a day, and he enjoys their attention, nature walks, the birds and flowers that flourish around us—and he chats with all the dogs and babies in the neighborhood. It is heartbreaking for me to note that, instead of conversations with Nobel Prize winners, he now counts or comments on the caw of the crows. He is extremely sociable with all strangers. He is no longer aware of the diagnosis. He feels lucky that he is healthy, and he agonizes over the dilemma of others who have been afflicted by debilitating diseases. He likes to play and to pun and to laugh.

Fate can be cruel, but this new stage is part of our life—though not together in the old way.



The Shearn Family: Lori, Wendy, David, Martin and Bobbi; 1990.

He seems incredibly happy most of the time—joyful and sweet and kind.

Our grandchildren are amazingly attuned to his abilities and often involve him in their games. But they are noisy and wild, and he feels excluded when conversation does not center directly on him.

I try to concentrate on the pluses and not the minuses. I will continue to do so. I will not allow myself to wallow—not in despair, not in simple pessimism—at least not very much. My mind works. My children are helpful and kind and near and contribute greatly to my day-to-day comfort and pleasure. My grandchildren are a joy and they too are sweet and kind and near. Perhaps I'll get busy with a new project, or I will write, or I will travel.

Somehow I will contribute. My life is not empty. I play the piano. I read. I attend classes. And I address children's classrooms to talk about my Holocaust experience.

Our devoted children are ever-present. Martin seems to know who they are, but maybe he doesn't. They

now worry more about their mother's well-being than their dad's. Perhaps we all have to learn to step away a bit more to save ourselves. They have lives of their own, and they must live them. We are beginning to have family gatherings without dad. The first of these, a few months ago, was most traumatic for me. I felt that a new chapter of my life had begun—without my love. Everyone listened when Bobbi, our daughter, played a song on her violin that she had written. It wailed and throbbed with feeling, and it broke the dam of my self-control. I was dissolved in tears, surrounded by my family, who care so deeply about us both. The full impact of my terrible loss engulfed me.

I have benefited enormously from Martin's loving. We have appreciated so much in each other—strength, athleticism, writing ability, giving to others of our own bounty—that it surely has spurred me on to better performance as a person. Fate can be cruel, but this new stage is part of our life—though not together in the old way. We must go forward toward the unknown abyss, and we will both attempt to be pacific. ❖