

Personal Reflections

Separate and Yet Together: Living with a Spouse Suffering from Alzheimer's Disease

by Thomas Cassirer

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Our Life Before

Both of us, as children, were torn from our homes in Germany by the Nazi revolution and, via different itineraries, found ourselves by the age of 18 separated from our parents and living in North America. Some years later we met in Montreal and eventually married on the slender funds offered by a graduate fellowship (hers) and an assistantship (mine) in the United States. We each launched careers in higher education, where we introduced students to cultures outside the United States through the teaching of language and literature. Our marriage brought us a daughter, whose assistance was to be invaluable later in our lives during the crisis brought on by Alzheimer's disease.

In 1990 we both retired, triggering changes that gradually undermined our married life. We did not retire for the same reasons. My retirement was voluntary, brought on by the realization that it was time to end my career and explore on my own the potential of the Third Age life cycle. She, on the other hand, had no choice, since she belonged to the last generation subject to mandatory retirement. Consequently, she felt expelled from a career to which she had devoted 40 years, while I felt liberated from a bureaucratic lifestyle and free to do whatever I wanted. I believe this had a definite effect on the course of her Alzheimer's disease, and perhaps the inverse is also true - the early, unrecognized stages of Alzheimer's disease may have narrowed her range of responses to this new challenge. She experienced the loss of her position as a loss of support, almost as being thrust back into the predicament of her youth, when she had to find a "ladder" that would allow her to climb to the level of her intellectual capacity. But now in retirement there was no such ladder, and though she remained physically very vigorous she could not at her age repeat the climb of her youth. She felt herself diminished whereas I felt my life expanding now that I was freed from the limitations imposed by my job. Over the years, this difference in our orientations caused increasing conflict between us, while at the same time she became more and more dependent on me because of what I now recognize as the inroads of Alzheimer's disease.

Our life as a couple collapsed in the fiftieth year of our marriage. In the years since our retirement, I had become involved in ever more strenuous caregiving because she refused all medical intervention with the argument that she was in perfect health (which was true of her physical constitution) and that doctors made you sick in order to make money. In November 1997, I collapsed with severe pneumonia. Since she insisted on treating me herself at home, and the only friend to whom she might have turned for help happened to be out of town, I would probably not have survived if she

had not gone to the post office to collect my mail. The woman behind the counter, who knew us both, suspected that my absence meant that something was wrong and notified her supervisor, who notified the police. The police found me semi-conscious but able to signal that I wanted to go to the hospital. They warded off an attack by my wife, who wanted to keep me home, and took both of us to the hospital. There, my wife was diagnosed as suffering from Alzheimer's disease. The hospital called our daughter, who flew in and took over her parents' lives. Our daughter discovered a newly opened assisted living facility for Alzheimer patients and was able to place her mother there, while I spent more than three weeks in the hospital before I began the slow mend back to health.

Our married life had disintegrated. It was out of the question for us to ever live together again. Now we had to build a new relationship. Each of us had to learn to lead a new life in a new location (I sold the house and moved into a condominium). From now on, we would live separately - but could we also be together?

The New Life

What follows is a brief narrative of the trial-and-error problem-solving process through which we learned, over the course of about a year, how we could lead separate lives and yet also be together to the point where our relationship has become happier and more satisfying than it had been in the later years of our marriage. Or, to say the same in her words: "We used to yell a lot at each other and now we don't any more. How come?"

The word "we" in the preceding paragraph is deliberate because in her own way she has participated in this process and in many ways has set the conditions. Since she has consistently denied that she is suffering from any illness, she has refused all medication, even vitamins, and will not let herself be treated as a patient. When, after weeks of recuperation, I first visited her, she called out, "My Dad has come back!" Since then she usually refers to me as "Dad" and to herself as my daughter. When I told her our daughter would be returning for a visit, she said, "And then you will have two daughters." This is when I started to learn her new language, which frequently expresses her emotions rather than her perception of external reality.

What was she telling me by identifying me as "Dad"? She wasn't confusing me with my father-in-law. She refers to him as "my father," or sometimes as "my other father." What I eventually understood was that by calling me "Dad" she was acknowledging her dependence on me, a radical change from the independent, self-directed professional woman who had been my partner for so many years. She also told me clearly that she relied on me to orient her so she would not get lost and said that I had to act as her memory since hers was no longer so good. As "Dad" of this Alzheimer child in her upper seventies, I had to see to it that she was protected from the world at large in which she could no longer orient herself. It was up to me to find a world "her size" in which we could be together and she could feel at home and safe. But that presented quite a problem: How could I provide such a home when living with her had proved quite literally life-threatening for me? The assisted living residence provided for her need to be safe and taken care of, but it did not offer us a space that was ours and in which we could create a home for ourselves.

Moreover, she had not merely lost her home; the crisis had also reduced to a shadowy memory the substance of her 40 years as a teacher and scholar. What remained were the two vital resources, walking and music, that have propelled her since adolescence and that brought us together in 1945, well before it became evident that she was headed for the academic career she has now forgotten. Any space that might be "ours," that could hold us together even while we lived separately, had to

be a space that allowed her access to these two vital resources. But what did she mean by "walking" and "music"? Everyone walks, and almost everyone appreciates some form of music, but that was not what she meant.

Walking gave expression to the freedom of her body as it relied on its inherent strength and perfect functioning to carry her wherever she wished to go. Her walking was at its high point during our annual summer vacations in the Swiss and Austrian Alps when we used our bodies to the fullest, hiking day after day from one mountain shelter to the next. On these occasions she used to say, "When I am above two thousand meters I could walk to the end of the world." Not being as good a walker as she, I was often secretly afraid that one day she might do just that. Walking energized her entire body and her mind as well. She much preferred to talk with friends while walking, rather than sitting down. Walking by herself - and, in later years driving - was her favorite way of relieving tension. In her present condition she still had her physical energy, but she had lost her sense of orientation and no longer felt free to walk by herself. Could I help her regain that sense of freedom?

For the meaning of "music," she also returned to her youth. She rejected the musical activity at the assisted living residence because it consisted mainly of American popular music from the youth of the great majority of residents who grew up in New England during the 1930's and 1940's. In her mind, she returned to the classical music to which she had been introduced at the conservatory during her adolescence in Germany. Above all, she returned to Johann Sebastian Bach, whose music she discovered largely on her own and which has inspired her throughout her entire life.

This needs some explanation: She was sent to the conservatory on the recommendation of her teachers. Her father was proud to have such a gifted child but would not let her play when he was home because he did not care for music. Her mother, a native Viennese who felt exiled in "provincial" Germany, welcomed the opportunity to have her daughter play tunes from the Viennese operettas of her youth, but did not want to hear music that was too serious. Outside the apartment, in the streets of Nazi Germany, the air resounded with the songs and military music of the Nazi movement. In that atmosphere of confusion and hostility she discovered in the music of Johann Sebastian Bach a world of order and beauty. It became her lifetime inspiration and, in a sense, her shield against the outside world.

When she was a girl this situation was rendered even more difficult by the fact that in order to hear Bach she had to go into Protestant churches. But she was brought up a Catholic, and at that time it was a sin for a Catholic girl to go to a Protestant place of worship. It took her mother's reassurance to convince her that she did not need to confess this "sin."

Now she again felt imprisoned, as she used to feel in Nazi Germany; to the point that during the first difficult months in assisted living, she sometimes referred to the personnel as "jailers," even though the facility offers as much freedom as is compatible with the need to keep the residents from wandering. When she managed to escape (she can move with amazing speed) and was brought back by the police, she described this to me as an attack by a group of storm troopers. She again turned to the music of Bach to sustain her, which helped her get over periods of depression, especially when the more rhythmic compositions set her off into energetic dancing. However, I did not understand the full meaning of "music" to her until I took her, on a Sunday afternoon in October 1998, to a performance of two Bach cantatas on the town green. She was in constant motion in her seat as the music flowed through her body; she was moved emotionally as well as physically, as I have seldom seen her, both by the performance and by the feeling of oneness with the very appreciative audience. Suddenly I became aware of something I should have realized long ago: This music put her in touch

with a harmonious social order and lifted her above the many conflicts in her life. Six months later she is still asking me for another such performance on "the Green" (she does not remember the name of the town).

Out of all these elements I had to construct a space that was "ours," where we could be together, as one is in a home, but not confined as one is in a house. I eventually found the space at the Quabbin, a 22-mile-long reservoir that supplies much of Boston's water. It is surrounded by densely forested hills and at its southern end is open to the public, with a network of trails for hiking and a lookout tower on the highest hill from which one can view the entire vast space of water and forest.

We have been going regularly to the Quabbin for more than eight months. During that period, I have built up a routine that is now so familiar to her that it would be more appropriate to call these occasions our "homings" rather than our "outings."

Sunday is the day when classical music is most likely to be performed in the afternoon. (I cannot take her to an evening concert because it frightens her when we drive in the dark.) That may have been the superficial reason why I chose Sunday as our regular day, but after a while I came to realize that it had become our day of communion - not with any particular faith or congregation, but a day of communion with the universe, with the sky and the water and the woods that rise from the shore and reach up toward the horizon, a day when in warmer weather we can walk barefoot in the grass and find a quiet spot on a meadow or in the woods where we can rest or even snooze. It is a day of solitude because we often are the only people walking the trails, yet also a day when she can mingle with the families out for a stroll and enjoy the feeling of being in a "normal" social setting with many children and teenagers - and can do so without the fear that she might run into an acquaintance or friend from former times who might greet her and unintentionally remind her that she had forgotten those who still remembered her.

Here again it was she who made me aware of the deeper meaning of the Quabbin, as she drew my attention to the sky and the water, and to the woods in which no human habitation could be seen. She got to know the trails and could tell me which trail she wanted to take. She felt particularly drawn to the lookout tower on the highest hill, because from there she could "see the whole world." This was also the time when I turned the car into a "moving home": While sitting in the car and looking out over the reservoir, we would have a picnic lunch consisting primarily of the kind of bread she liked and "Deutschmacher" frankfurters that really taste like German "wurst." The lunch was consumed to the accompaniment of a cassette of music by Bach and she got many a laugh out of this German combination of sausage and Bach.

Through comedy of this type and by introducing "interesting questions" into our conversation, I would see to it that she also got some "mental exercise." I recall one day when I used her father's expressions which were somewhat off-color and very funny - the type he would use over beer with his business colleagues. I started a discussion on the difference between German and American joking. She got so interested that she urged me to look for literature on the subject and said she would love to help me write this up. (The next week, she had of course forgotten all about this.) Recently, she discovered the memorial stone to the chief engineer who directed the building of the Quabbin; she gave me, in a somewhat confused way, a feminist critique of this memorial, and last Sunday she said she needed to look at this memorial again and see this man who took all the credit for the Quabbin.

On days when there is no suitable concert, we usually wind up driving to a nearby town for a visit to

an Italian café. She does not drink coffee and is not particularly interested in sweet pastries, but the café represents for her the epitome of urban life, especially on the days when we also have time to stroll along Main Street, with its many shops. After such a Sunday, she usually concludes, "This is the best yet," and is quite ready to return to the assisted living residence, as long as I assure her that I will come again soon.

One final remark on these "homings" and the new relationship we have developed: While her face lights up immediately when I show up at the assisted living residence, and she is always very happy and affectionate, she wavers in her identification of exactly who I am. At times I am one of a group of "Thomases," and she tells me about another Thomas who visited her the previous week. At other times, when we arrive back at the residence she acts as though we had been out on a very enjoyable date, hopes that I will come again soon to take her out, reminds me of her name, and adds, "But I don't know your name." It is evident that she feels there are at least two of me: The one who is with her and the other who is out somewhere, who is leading a life that she cannot imagine but who is likely to turn up at some other time. Again she is right, though her language is not what we who are "on the outside" consider normal, because I do lead two lives, one together with her on Sundays, and the other on my own in another world, yet with her tucked away in my mind just as the "other Thomases" are tucked away in her mind.

Some Final Comments

First, a comment on the economic context that has allowed us to find a solution to our problem. We very probably could not afford this life if we had not married in 1948 with the explicit understanding that we would both have professional careers in order to insure us against unforeseen emergencies and give us freedom to lead the life we wanted. In the setting of that time, with its conventions that were so different from today's American life, our decision was viewed as contrary to what an American marriage should be. My wife was frequently penalized for her refusal to conform. But if we had done things differently, where would we be today? My hope is that for younger generations this solution of "separate, yet together" will be available to more couples because they will arrive at our age with the earnings of two individuals.

My other comment concerns the responsibilities of the "parent" of a spouse suffering from Alzheimer's. When I brought up my daughter, I was familiar with the adult world and therefore qualified to guide her toward her life as an adult. But my wife and I belong to the same generation. How can I be sure that as "Dad" I give her the right guidance toward a future that is as unknown to me as it is to her? I don't have a ready answer, and probably never will, but I am confident that a sequence of happy Sundays will strengthen her for whatever is in store, just as it strengthens both of us right now. I also believe that the weekly communion with the basic elements of our existence - the water, the earth, the vegetation nourished by water and earth, and the sky that opens our eyes to the universe - that all this orients us toward what transcends our individual lives. And finally, I believe that the strong rhythm of Johann Sebastian Bach, which she has always identified as the rhythm of a "walking man," will keep us in touch with the human spirit, even when words can no longer do so.

Editor's Note: Sidonie Cassirer died on March 14, 2001.