

“When We Hear Music, Memories Fill Our Minds”: Living With Dementia

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When I walked into the chapel at Saint Peter's Church in New York City, there were about a dozen pairs of people sitting in an open area in front of the pews on folding metal chairs; each couple shared a music stand. They were mostly older adults, though a few were middle-aged. For a group of people waiting for an audience to take their seats for the concert they were about to give, they seemed remarkably calm.

They call themselves the Unforgettables -- a chorus of couples that include a person with dementia, mostly Alzheimer's, and a caregiver, usually a spouse. This was their third concert.

Tania Papayannapoulou, a smiling, vivacious young woman who leads the chorus along with Dale Lamb, a wonderfully energetic and engaging man with a great sense of rhythm, stepped to the front, made a few comments about the program, and introduced Lin Jacobson, the spouse of one of the people with dementia. Ms. Jacobson read a poem she had written in memory of a chorus member who had recently died, which included the lines: "When we hear music, we come alive... and memories fill our mind."

Then the singing began. The singers -- and the audience -- swayed in their seats, tapped their feet, clapped their hands, and patted their legs in time to the music. The chorus sang songs about love, happiness, and hope. "Que Sera Sera," "Put on a Happy Face," "Accentuate the Positive," "I Love You," "High Hopes," and more. The message was clear in each song. "Smile," they sang, "What's the use of crying? You'll find that life is still worthwhile if you just smile."

That's the major message: "Life is still worthwhile." Not what most people believe about "suffering" from dementia -- as we usually say. It would be better, the chorus showed, to say "living with dementia."

No one knows better than [Mary Mittelman](#) -- the founder of the chorus -- that living with dementia can be terribly hard, for both the people with dementia and their caregivers. Dr. Mittelman, a researcher at the NYU Comprehensive Center on Brain Aging, is one of the nation's leading developers of effective ways to provide support for family members of people with Alzheimer's. She and her team have devised a method of family support and shown that it results in the reduction of stress, depression, and physical illness among family caregivers, and in the

delay in placement in nursing homes for about 18 months. She founded the chorus as a research project to see whether the music and getting together with people with dementia and caregivers would improve quality of life for participants. The data aren't all in; but the results are plain to anyone who attends one of the Unforgettables' concerts. They "come alive" when they sing together.

The woman to whom Ms. Jacobson's poem was dedicated was a great example, Dr. Mittelman told me. She was the most clearly disabled person to attend the first meeting, and she was disengaged -- seemingly lost in her own mind. At the end of the session, the music director asked members of the chorus what songs they would like to sing. The older woman, who was leaving, turned around and said, "Bei mir bis du schein." "I don't know it," the music director said. The seemingly lost woman sang the first verse all the way through. At the second concert, she sang it as a solo -- the whole song, not just the first verse.

Coming alive also happened in front of my eyes at the concert. An older man with a white beard sat in the back row of the chorus with a much younger woman (his wife, as I learned later). He looked very sad and completely disconnected from the singing -- the only person in the chorus who looked that way. About three-quarters of the way through the concert, he stood up and delivered a wonderfully lively solo, backed by the chorus, of "Get Me to the Church on Time." I couldn't believe it was the same man.

After the concert I spoke with him (his name is Chester Rogalski) and his wife, Monica, a doctor of osteopathic medicine. I was wondering why he had seemed so disengaged and then given such a terrific performance, so I asked him if he had been nervous waiting to perform (as I would have been). He gave me a bewildered look. His wife said, "He certainly wasn't nervous, because he didn't remember that he was going to solo until I reminded him. He said to me the other day," she continued, "I have no yesterdays and no tomorrows." He then added, "I live in the moment. That's the most important part, the moment."

After the concert, refreshments were served. The room was filled with lively talk and a good deal of laughter -- like most good parties. I chatted with several caregivers, all of whom told me how wonderful the chorus has been for their spouse, partner, or friend. For example, Howard Smith -- a painter -- said, "The music provides camaraderie for people who would otherwise be alone." When I said that I believe that music and other forms of art have healing power, he agreed and said "Making art allows me to find the center of myself. It also helps me deal with never being able to be alone, which is what happens when you are a caregiver."

The view of dementia in our society is grim. We see it as an illness from which people suffer and as the end of meaningful life. A concert of the Unforgettables makes it clear that there can be a life worth living for people with dementia and their caregivers, and that music and other forms of art have much to contribute to making it so.

The Unforgettables is a project of the Fund for the City of New York. Contributions will help to sustain it. If you would like to contribute send a check to Fund for the City of New York with "Unforgettables" noted in the memo line, 121 Avenue of the Americas, 6th Floor, New York, NY 10013, Attn: Jill Borrero.