



My Family's Struggle With Dementia: Trying to Hit the High Notes

Gloria Kim, MD; Tyler Kim

(Fam Med. 2018;50(4):304-5.)
doi: 10.22454/FamMed.2018.530917

At first, it was a quiet withdrawal in personality. Then came the absentmindedness. However, his loved ones did not acknowledge the dementia until he forgot their names and faces. Now, he wanders and is often agitated, leaving his family to struggle with emotions of sadness, frustration, and helplessness. This is not only the plight of some of my patients, but also of my father.

As every Alzheimer patient and their desperate family knows, there is no cure for dementia, and only a limited number of medications to try to slow its progression. My father was on one such medication, donepezil, for many years. It was hard to notice any tangible benefit during his continued neurologic decline. While I saw many of my patients with Alzheimer's disease were swallowing these medications on a daily basis and I repeatedly told them of the benefits and importance of medication compliance, I inwardly thought, "Is this drug even worth taking?" Frustration and hopelessness always accompanied my father's visits to the neurologist, and I spent hours hunting the internet for the miracle elixir to effectively treat this ravaging disease. While I typically tried to advise my patients against consulting Dr Google too much, I saw myself desperately searching the web for answers I knew intellectually did not exist. I found myself

doubting his doctors and his medical therapy due to the hopelessness of the disease.

One of the most traumatic days came when my father wandered away for the first time. While my mother stepped out, he simply meandered off. Even after the sun had set on a winter's evening, we could not find him. Knowing he was without his diabetes medication only added to our concern. Eventually the police located him, three miles away, physically safe, but confused as usual. The next day, he did not go far, but slipped outside and knocked violently on our neighbor's door demanding to be let in. Fortunately, he caused no harm, but we all knew that he had entered a new phase in his losing fight with dementia. Everyone in the family knew the war was being lost. We felt as though we had to prepare for death even though he was alive. Frustration had given way to a sense of defeat.

In the subsequent weeks, the question of what to do next hung in the air at every family get-together. But in the midst of our agonizing and despair, we made a serendipitous discovery. My oldest son, who is a proficient musician as both a piano and guitar player, started playing songs regularly for his grandfather at these gatherings. Whether it was a classical piece from Bach on the piano, or an old Beatles tune on the guitar, Granddad was noticeably

calmer when listening. He was more engaged, even asking appropriate questions such as "How did you learn that?" He even offered compliments such as "You are a genius!", which obviously was a bit grandiose, but was also a typical proud grandfatherly compliment that made us all rejoice. Even though Granddad did not recognize anyone, interactions became natural rather than forced as a result of these musical notes.

My son also became emotionally closer to his once-lost grandfather. The fear of his grandfather's disease wore off, at least during those musical interludes. He even tried to learn some of Granddad's favorite songs. My spirits were lifted too, as memories of my son's early years with his grandfather were restored ever so briefly. When my son said with optimism once, "Granddad seems better today!" they were the most comforting words I had heard in a long time. Even though he didn't recognize me, he felt more like my father than he had in a long time, simply by becoming more grandfatherly.

Through these musical encounters, I learned that it is the non-pharmaceutical approaches to Alzheimer's dementia that can often have the most meaningful impact.

From the Department of Internal Medicine, David Geffen School of Medicine at the University of California, Los Angeles (Dr Gloria Kim), and Torrance High School, Torrance, CA (Tyler Kim).

In fact, there are studies showing that people with dementia do show positive responses to music.¹ I experienced firsthand that music can potentially reduce problematic behaviors and avoid the need for physical intervention.

An anecdotal experience does not make a landmark study. But watching how my father responded to music gave me a new perspective in dealing with patients with dementia. It was no longer just about referrals to neurology or setting up social work support. Rather, I could also lend a personal story and offer an option that did not require writing anything on a prescription pad. In addition, through my family's experience, I realized that music can provide a way for kids to assist in dementia care, rather than staying aloof or afraid.

Many of my patients and their families responded to my musically-themed recommendations with much more optimism than I had anticipated. They even came back on follow-up visits with positive feedback which, as a physician, is my

gold standard for gauging the effectiveness of any therapy. In addition, the stories that my patients and their families told were therapeutic and healing for me, and helped me think about my personal plight in more hopeful ways. We shared common struggles that helped me understand that my family was doing the best we could in managing this devastating disease; and I hope that they also enabled these families to feel that they, too, were doing their best.

Through music, my father became a dad and grandfather again, not just a lost soul. I anticipate with dread that his decline will progress further, to a point where even stimuli such as music will not be able to reach him. But at least for now, music is an occasional high note in his life—and in ours. The author Oscar Wilde wrote, “Music is the art which is most nigh to tears and memories.” When my son plays and my father responds, our memories of him blossom, and we cry tears of loss and gratitude.

CORRESPONDENCE: Address correspondence to Dr Kim, 3500 Lomita Blvd Suite 300, Torrance, CA 90505. 310-257-0028. Fax: 310-257-0031. gskim@mednet.ucla.edu.

References

1. Brotans M, Koger SM, Pickett-Cooper P. Music and dementias: a review of literature. *J Music Ther.* 1997;34(4):204-245.