

Musical Encounters with Dying

Stories and Lessons



ISLENE+RUNNINGDEER

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Jean was a middle-aged piano student of mine when we first met. She had studied piano as a child and adolescent, then given it up, as many young people do, to follow other interests. In Jean's case, she eventually became an accomplished equestrian. She enjoyed classical music and vintage songs, such as Hoagy Carmichael's "Stardust," and hoped to reclaim some of her rusty and nearly-forgotten piano skills. Before I practiced music therapy in medicine, I taught piano privately for many years, focusing not only on musicianship, but also personal and emotional growth for the student. I often found myself working with adults, such as Jean, who had had somewhat negative and unsatisfying experiences with childhood piano teachers, and hoped to bring music back into their later lives in a more joyful way. So, in a sense, my teaching involved a certain kind of therapy that used the musical experience as a vehicle for self-growth.

Life is full of surprises. It was through my relationship with Jean that I was introduced to the world of end of life care. Neither of us knew it at the time of our meeting, but Jean was soon to be diagnosed with glioblastoma, a fast-growing brain cancer that so often leads to death within a relatively short period of time. This was terrible and startling news for this otherwise very healthy woman, who decided that she still wanted to carry on with piano lessons as planned. As the universe would have it, I had recently completed a training in volunteer hospice work, learning the basics of end of life care. But I hadn't followed up with doing any actual volunteering with the local hospice. Perhaps I was subconsciously waiting for Jean to show up.

Several weeks into piano lessons, both Jean and I noticed that her left hand was weakening. The tumor was located on the right side of her brain, and this was only the beginning of the gradual loss of much of her left-sided mobility. The specific location of the mass eventually affected both motor and cognitive strength, and within a few months it became clear that Jean needed daily care and support. Lessons in my studio could no longer continue, but Jean had begun to trust me as a teacher and friend. And my interest and caring for her as both a student and a woman of my age who was dealing with a very serious life-threatening disease led me to take on the role of part-time "companion," which Jean and her husband offered as a

paid position in their home. Jean and I agreed that we'd keep music alive in this new arrangement, which we could easily do, given the baby grand piano in her den. Her husband, already quietly grieving and at a loss as to what to do to help her, immediately went to work building a sunroom addition onto their old country house, a place that included a fine sound system where Jean could listen to music and rest, and, sadly, eventually die.

I had ten months to learn, from Jean, how to build a caring relationship with one who is dying. It was one of the longer therapeutic relationships I've experienced with a person, and perhaps the most intense because I spent five mornings every week with her. I got to know her as a very private, lonely individual, who had spent much of her lifetime trying to fulfill the expectations of others. She seemed to have no close friendships. During those ten months, I recall only one friend coming to visit her, and only once. Several family members paid visits, especially during her final weeks, but Jean did not seem to share very intimate connections with any of them. Indeed, even her husband spent most of his time working outdoors, constantly mowing fields and lawns, repairing equipment, clearly avoiding close contact with the daily losses his wife was facing with me inside the house. No blame. He channeled all his fear and grief into working outdoors, the best way he knew how to cope with such a devastating change in his life. Occasionally, Jean and I would venture out for a little walk, waving to Jim in the field as he drove the tractor, before her initial minor stumbling led to the need for a cane, and then a wheelchair.

I accompanied Jean through two brain surgeries, followed by two cycles of chemotherapy, all the while watching her clutching onto shreds of hope and not able to yet give up on what even her doctors knew was a futile attempt to save her life. After chemo treatments, we'd return home and Jean would immediately go to the couch in the den. I would play gentle piano music while she slept. Several days of deep fatigue, nausea and vomiting would follow. We used music to calm and soothe her. She would sometimes cry as I played. But for the most part, she was reluctant to speak in words what her deepest fears were. I let her take her time with this, until

one morning when I saw that her panic and desperation could be contained no more.

Jean had just seen the results of the latest MRI showing no reduction in the size of the tumor. In fact, even with chemotherapy and all the distress she had undergone to get through it, the mass had continued to grow. I was with her when her kind doctor shared these results, and gently let her know that he was running out of ways to help her. Even then, Jean believed that she was “expected” to continue therapy, expected by her family to fight for her life. I doubt that this expectation was ever clearly verbalized by those who cared about her, since this family was not very openly communicative. These may have been expectations that Jean had created in her own mind, based on past experiences and what she may have believed the world at large expected of her. Or perhaps some in her family did have these attitudes, spoken or not. In that moment of panic and desperation, Jean cried out: “I don’t think I can keep doing this!” I took her hands and said, “You don’t have to keep doing this. You can stop fighting. You can decide to stop chemotherapy, to find some peace before you die.” She looked at me incredulously, as if the idea were totally new to her (as I’m certain it was). She answered: “I can stop?” I took her hands, smiled, and said: “It’s all up to you, no one else.”

The relationship we had forged made it possible for us finally to speak honestly about what *she* needed to do. I helped her get hospice services in place, she said farewell to the oncologists who had tried to save her life, and Jean spent the next few months at home, enjoying small pleasures, listening to beautiful music and saying goodbye to those she loved. I sang and breathed with her at her bedside as she drifted into a deep coma and died on her own terms.