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English 207

# Someone I Can't Say I Knew

The first time a close member of my family passed away, I was fourteen years old. It was the spring of my ninth grade year, and my maternal grandmother was seven hundred miles away in Missouri. My mother traveled, staying in her childhood home and spending the days with Nana at the hospital, while the rest of my family was at home in Pennsylvania. That summer, long after the small funeral, was the first time I was able to go back, when my younger sibling, parents, and I emptied the vast trove of "storage" in the basement (afflicted by severe arthritis, Nana had not gone down the stairs for years) and prepared the house for sale.

My experience of that loss did not feel like it took full form until I was in nursing assistant training, a full two and a half years later, in the fall of my senior year of high school. I had been assigned to one of the residents in the long-term care unit whose condition had declined the most, Elaine.[1] Around November, she contracted pneumonia and began losing weight, and the physician and her family decided it was time to officially place her in "comfort care" status. As a trainee nursing assistant, I was a bit out of a job, at least in the usual sense. While my classmates honed their skills in all the other kinds of active care that we would be tested on at the end of the year, I was now to simply sit with Elaine, and help moisten her lips when they became dry, hold her hand, position her in the most comfortable way, and let the doctor know about any changes that were taking place in her condition.

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[1] This is a pseudonym, a name with similar popularity at the time of her birth.

She was a short, curly-haired Jewish lady, born in the same decade as my maternal grandmother had been; other than that, there was very little overlap in their biographies. They were not even very much alike in their last months. For one, I had sat by Elaine's side through breakfast for many weeks, always a small cup of fruit, a soft-cooked egg, and a mug of warm, thick chocolate nutrition drink, with her medications crushed and stirred in by a kind LPN. Even with my efforts to gently wake her from a doze so that she could take another bite—she would generally fall asleep in the time it took to chew the previous one—this small breakfast took her nearly an hour to eat. My grandmother had a very different experience; during her brief stay in a rehab facility, she kept her signature sarcasm despite pain and illness. As my mother tells it, when their oatmeal failed to meet her high standards, she asked a staff member wryly "if she could have the recipe" for her breakfast. Still, as I sat by Elaine's bed on each clinical day, I remembered the few mornings when she had been less sleepy and more able to express her slight, quiet displeasure at an egg over- or under-cooked, and thought of Nana.

I never met Elaine's family, and indeed my most direct contact with them was when I noticed that her son had dropped off the toiletries that Elaine preferred, over the standard-issue ones that most of the residents in the community accepted from the nursing staff when toothpaste or deodorant ran out. They certainly never knew that I was sitting there a few days each week, mourning my own grandmother's loss, but feeling an unidentifiable joy that I could be here now, if I could not have been there then. Nana's spirit had always been overwhelmingly present in every room when I had visited her as a child, but I had only known Elaine's as it was, diminished by age and illness. Now, I found that in feeling Elaine's spirit claim kinship with mine in the

quiet of that room, I finally felt able to make up for not having been present for Nana's last few weeks.

I have no idea what Elaine's family would have actually told me, of course. Just because staff didn't tell a seventeen-year-old CNA trainee about strife in the family, about disagreements over her DNR order or her "Comfort Care" designation, doesn't mean that none occurred. I also cannot begin to know what they would have thought about the spiritual experience I had while I was sitting with her. That is, I know that I felt myself to be sitting *in prayer*, rather than any way of simply "saying prayers," for the first time in my quasi-adult life while I sat quietly with Elaine. I do not know whether her family would find that admission offensive, given that I don't identify spiritually with the Jewish heritage that I had then only recently learned of. At the level of tangible experience, I am equally clueless about what it would have been like to hear my own relative drift into a Cheyne-Stokes respirations, the uneven breath pattern of accelerating small breaths, alternating with apnea, that often precedes the end of life. It was alarming enough to wait through each short absence of breath, before I heard the cycle start again. Perhaps it would have left me hushed with fear, to have listened through those silences with my hand on Nana's shoulder, rather than that of someone I couldn't really say I knew.

I have considered this experience at some length, of finding fulfillment of some spiritual need (I might even venture to say, of finding closure, though the word is tricky) in caring for Elaine. The *Faith and Practice* book of Philadelphia Yearly Meeting contains among its "Extracts from the Writings of Friends" a quotation from John Woolman, a famous eighteenth-century Quaker, to which I have referred many times: "[Dig] deep,… carefully cast forth the loose matter and get down to the rock, the sure foundation, and there hearken to the divine voice

which gives a clear and certain sound."[2] I can begin to understand how "casting forth the loose matter" of the day-to-day practice allowed a kind of listening, both to and with Elaine, that was more communion than "caregiving" per se. It was, in retrospect, quite close to the expectant silence of a Friends meetinghouse. "Skilled nursing" was distilled into only the most forgiving and necessary of rituals. We were together, and that was all.

Our nursing assistant course textbook contained only a short section on care of the dying, and we spent accordingly little class time one it. Indeed, one of the only things I remember being taught about my role when someone passed away was a small expansion of my scope of practice: apparatus that ordinarily only licensed nurses can handle, such as feeding tubes or ileostomy/ colostomy dressings, were no longer off-limits to us as nursing assistants once a patient had died. If we were tasked with preparation of a body, we could remove these without help from a nurse. As it happened, only a few residents that my classmates and I cared for over any substantial duration passed away during our year with them, though to this day I still search my local paper's obituaries every few months or so for the name of the retirement community, in case any of those I knew have been lost since. I never had to use these skills.

The state nurse aide curriculum committee, the textbook authors, and the like all assumed, it seems, that we would each handle the emotional experience of a resident's death our own way, with perhaps the support of our own religious or spiritual leanings. The co-workers I spoke to brought up those recently lost, especially the happy memories of certain residents. Still, I never had the sense that anyone was particularly well-equipped for deaths, except by the equanimity that came with experience. Three scholars of end-of-life care, including one nurse

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[2] Philadelphia Yearly Meeting of the Religious Society of Friends, *Faith and Practice* (Philadelphia: PYM, 2018), 130.

practitioner and minister, one doctor, and one public health specialist, came together in the early 2000s to address this need. They produced the training manual *Improving Nursing Home Care of the Dying*, written for the benefit of staff at all levels in communities like the one in which I worked. They include chapters on care goals, grief, practical matters of care like pain management and nutrition, and spiritual care. However, the final chapter of their book is far more necessary than most give it credit for: "Caring for the Caregiver: Taking Care of Yourself Emotionally."[3] Along with recommendations about how to discuss care for the dying with the other members of your team, and an opportunity to share stories about instances when a resident's death may have been stressful or difficult, they offer examples of how "caring for dying nursing home residents can be deeply rewarding," and even "special," strange as that word may sound.[4] Reading them, three years separated from my last skilled nursing unit shift, brings some more clarity to what I was starting to feel then, and feel now: a call to do the remarkably rewarding work of caring and of helping others through the experience of care.

When I notified my class that Elaine had passed away, my instructor sent the Mary Elizabeth Frye poem, "Do not stand at my grave and weep," to our group chat, and with some kind words from other students, that was that. When I next came to complete clinical hours, I had been assigned to a new resident, a kind and somewhat scattered former university professor. He was constantly embarrassed by the various deficiencies caused by his dementia, and my interactions with him taught me a great deal more about the efficient, task-oriented practice of being a CNA, than had sitting at the breakfast table with Elaine, much less listening to the

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[3] Martha Henderson, Laura Hanson, and Kimberly Reynolds, *Improving Nursing Home Care of the Dying: A Training Manual for Nursing Home Staff* (New York: Springer Publishing Company, 2003), v–viii.

[4] Ibid., 75–79.

irregular breaths of her final illness. I learned about helping this new resident forgive his body, about carrying on extended conversation even if the topic was not quite clear to either one of us, and about the importance he felt in protecting his dignity in his ongoing relationship with his physician. All of these will certainly serve me well in future practice. But there was something special about caring for Elaine, that has informed my reflections about spirituality and vocation more than any other single experience.

Each member of my family handled the combination of grief and work very differently during the time we spent emptying my grandmother's house. My mother and I did most of the crying, even as we sorted through the mundane contents of drawers. We even cried while laughing ruefully about those contents. We cried over a few teal t-shirts, which we suspected Nana only rarely took out of the drawer, as that was more my aunt's color than hers. We were still surrounded by the familiar scent; by the kitchen where I had learned to make meatballs; by the sofa where we had always watched Cardinals baseball games on the muted TV (while the radio, without the TV time-lag, celebrated the home runs as we watched the previous pitch still working itself out); and by the ever-present St. Louis summer heat and mosquito population.

And by the time we flew back home, we had spent enough time in the basement, and in that sadness, and had accomplished what was needed. It was all very real to me, even though I had not been there when Nana had actually passed away: the house was empty, we had been to visit the cemetery where she was buried, and she was gone. Still, merely having experienced loss in the absolute sense—I now only have one grandparent remaining—could not have told me what caring for Elaine told me. I could not have known what it felt like to spend time in that space of the "clear and certain sound," where action was always secondary to presence.

Somehow, I think that is where I am supposed to be, and though only time will tell, I know that Elaine, through Nana (or perhaps Nana, through Elaine) gave me a place to start.