

Go Ask Alice

Category: Stories

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Ellen Rand

In 2010, I became a hospice volunteer.

My mother had died of a brain tumor five years earlier at age eighty-seven. I saw being a hospice volunteer as a way to express my gratitude for my mother's compassionate hospice care and to help other caregivers to weather a loved one's passing. And, as a former reporter and writer, I thought I could help people to write their life stories, if they were interested.

In short, I wanted to act on E.M. Forster's words, which for me sum up the goal of hospice: "Only connect."

I soon realized, though, that by the time most people come to hospice, they're too ill and/or too demented to carry on a conventional conversation, much less to express complex thoughts about the arc and meaning of their lives.

I found this deeply frustrating. I wanted to make a difference to my hospice clients—to connect. How could I do this when it was a challenge just to carry on a simple conversation?

One person who taught me how to meet people where they are, and not where you'd like them to be, was Alice, a woman who lived in a nursing home.

A frail woman in her mid-nineties, she'd been bedridden for years. She was so thin that I could barely see her body under the blankets, and her bedside blinds were always drawn, because the light hurt her eyes.

When we first met, I introduced myself and told her I was a volunteer.

"If you're a volunteer, you better feed me!" she croaked.

"I would if I could," I replied; hospice volunteers are not permitted to give patients food. This answer seemed to annoy her; perhaps not the best start. Still, from then on I came to see her every week.

If Alice was sleeping, I'd just keep her company, sitting in the chair squeezed between her bed and the wall. Afterwards, filling out the activity report that hospice volunteers must file after visits, I'd check the "Providing a calming presence" box.

If Alice was awake, we'd talk. Since she didn't have much to say, I did most of the talking—about my family or the day's news or a recipe that I'd found. If she seemed tired, I'd find *Rhapsody in Blue* on my smartphone's iTunes library and hold the phone up to her good ear so she could hear the music.

I found myself wishing that I knew more about her; I felt it might help me to connect with her better. I would have liked to know the big things—where she grew up, what her childhood was like, her opinions about the changes that she'd seen in the world. I would have liked to know the small things, too: was she a Yankees fan? What were her favorite foods or movies?

Some nursing homes put “get to know me” signs in patients’ rooms—photos and mementos that give doctors, nurses and aides a better sense of the person for whom they’re caring. I often wished that Alice had a sign like that, but she didn’t. And the one time when her niece visited while I was there, the niece told me more about herself than about Alice.

As time went by, I began to wonder whether my presence and efforts made any difference to Alice. Was I making her day better, even a little? I couldn’t tell.

One afternoon, as I approached Alice’s room, a woman sitting nearby told me that Alice had been calling out all day.

“Maybe you can do something,” she said.

Once inside, I barely had time to take off my coat before Alice started talking.

“I’m so sorry that we’re alone here,” she said haltingly, clearly panicked. She grabbed both of my hands. “It’s a dark cave, and we’re trapped. If we try to leave, they can chop your head off.”

Her dark eyes fixed on mine, silently imploring.

I remembered my mother in her final months—terrified, she would imagine herself stuck without her handbag in an unfamiliar subway station, not knowing where she was going or who would take her home. I knew that, to have any hope of providing comfort to Alice, I had to acknowledge her reality but also try to reassure her that she was not in danger.

“We’re safe and comfortable and well taken care of,” I told Alice, trying to sound calm as she clutched my hands tightly, looking up at me. “We’re okay right here.”

Although she continued to warn against trying to escape the cave, she gradually calmed down. After a pause, she asked, “Are you the little boy who visited here a few days ago and said you’d be back?”

“I was here last week,” I said. “I played music for you on my phone.” She gave no sign of hearing this.

“Are your parents here?” she asked, after another quiet pause.

“No, they’re not.”

“We’ll wait until your parents get here to take us home,” she said.

So often, when people near the end of life, they talk about needing to take a trip. Needing to leave.

“Take me home...” These words echo down so many nursing-home hallways. You could see the phrase as a metaphor for dying itself, or as an expression of the basic human wish to return to all that is familiar and welcoming. Either way, it’s haunting.

I stayed with Alice most of that afternoon, holding her hands, offering reassurance and giving her sips of water when she asked. Gradually her grip on my hands loosened, and she dozed off.

Leaving the nursing home, I felt exhausted but also pleased that I had been a comfort to Alice. I felt that I’d given her what she needed: I had traveled with her on this dark and frightening part of her journey. I hadn’t dismissed her fears or tried to convince her that she was imagining things.

And I felt deeply that, despite the barriers, I had managed to connect with her—on a different plane.

About the author:

Ellen Rand has been a journalist for more than forty years, including five years as a weekly Housing columnist for *The New York Times*. “Early on in my work as a hospice volunteer, one question puzzled me: why do people enter hospice care so late in the course of their illness? This question led to others. The best way I knew to answer these questions was to research and report on them, which feels as natural to me as breathing. This piece is adapted from a book I’m writing, whose working title is *Endings: Finding Hope and Comfort at the Close of Life*.” A member of the Hospice Volunteer Association, Ellen is also cofounder and former executive director of the [Teaneck International Film Festival](#) in New Jersey.

Story editor:

Diane Guernsey