

Being There: Sensory Perception & Caregiving

By Phil Rice

originally published by PBS's [Next Avenue](#), 2016

A few months ago a friend of mine had arranged for his mother to be moved into a memory unit of an assisted living facility. Having been through a similar experience with my own mother, I offered words of encouragement and asked for the address of the facility so I could stop by for a visit. He reluctantly told me the address, adding “It doesn’t really matter though. She won’t know who you are.” I just smiled and said, “Well, maybe she’ll know somebody’s there,” and let it go. I understood the sort of pain and confusion such events can bring into a person’s life, and I wasn’t about to start preaching to my friend in that moment. But I thought about it.

Having found myself in the company of friends and family suffering various stages of dementia over the years, including my mother, I have become keenly aware of the value of sensorial connection—of communicating through tone, touch, scent, images, and sounds. After my fiancée had emergency surgery to remove a massive brain tumor in 2010, I was introduced to an even higher level of sensory communication.

Janice endured about 10 hours of surgery that day, and the report was not good. She had stage four brain cancer. The surgeon said that with treatment, she could live for another 12 to 16 months. He also added that in the process of removing the tumor, damage had occurred that could slow her ability to physically recover well enough to endure the rigors of radiation and chemotherapy. Time would tell. In the meantime she was transferred to the neurological intensive care unit.

The healing was slow; Janice stayed in the ICU for three weeks. For the first several days, she was essentially in a coma. But I drew from the well of my life experiences. I kissed her, held her hand, massaged her feet, read to her, and spoke to her. I also left a favorite book near her bed so that she might see something familiar if she awoke while I was away. My own senses were on high alert during this time, so I was able to be attentive to Janice while also surveying the medical equipment and hearing any input from the attendants. Eventually she did regain consciousness but with limited communicative abilities.

When she was finally moved to a regular hospital room, I was able to add music and visuals from my laptop computer to the mix. Familiar lotions and a daily spray from her favorite perfume offset the ever present hospital scent with something familiar. Pictures of family were set near her bed along with a photo book of her beloved Smoky Mountains. And I consistently spoke to her, caressed her, held her hand, and read her familiar poems, essays, and letters from friends. My goal was to share the experience as sensually and intimately as circumstances would allow—to truly be with her.

As the weeks passed, her ability to verbally communicate improved, but the healing proved too slow to allow for treatment. Finally, after two grueling months in the hospital, I was able to bring her home and take care of her with the help of hospice, my son Paul, and her brother and sisters.

We set up the living room as an infirmary stocked with equipment and supplies provided by hospice (wonderful people). A hospice caregiver and a nurse visited every other day, and I was tending to Janice—being with Janice—fulltime. I performed hygienic chores, kept her clothes and bed linens clean, administered her medications, and made sure nourishment was flowing through her feeding tube properly. There was a desk situated so that I could work while remaining within arm's reach, and an inflatable bed was beside her hospital bed so that I could hold her hand through the night.

This period of hospice caregiving would last for about three weeks. During the first week Janice was at her most communicative. We had conversations. Her ability to express her thoughts was limited but she was able to respond verbally in ways that demonstrated she was aware of the context and the moment. I would carefully stretch out beside her in the hospital bed to watch nature documentaries on television or for me to read to her—or for us to just be together. This was a special week. We were experiencing life at an essential level.

The second week was marked by rapid decline. She was alert but no longer verbally communicative beyond a whispered “I love you.” Sensory perception was now on full power—giving and receiving sights, sounds, scents, and especially touch. The third week saw her slip into unresponsiveness, but I continued—even accelerated—the sensual routines we had established. She knew I was with her until she was no longer with me.

I am by nature an intellectual sort. When something interests me or a perplexing situation develops, I'll dive into reading and research until I exhaust the topic. But there are those moments when I've learned that the intellect won't be able to crack the code. End of life moments top that list. Intuitive perception and sensory communication take the lead, and intellect is replaced by awareness. The answers fall away until all that's left is love. And the awareness says love is enough.