

Jean and Gene

Finding humor and acceptance in the most unlikely places.

by Nancy

Jean and Gene shared a one bedroom apartment in a senior living facility. I knocked and entered a dark cave. The window blinds were not only closed, but curtains

smothered even the slightest glow of the bright spring sunshine. I stood just inside the door and sensed that the small kitchenette was to my right. As my eyes adjusted to the semi-darkness from that vantage, I could take in a general layout of the entire apartment.

My gaze came to rest on a figure lying in the gloom on a twin sized mattress on the floor up against the living room wall, which divided itself from the bedroom. There was a stirring of bedclothes, so I guessed that my entry was probably felt, but there was no welcoming, "come in". My gaze roved slowly to the left and rested on a figure bending over another twin bed in the deep corner of the darkened bedroom. I assumed it was the other member of the couple. The bending figure straightened and turned to me, so I walked into the bedroom first to introduce myself. It was the caregiver. This was my first introduction to the manner and lifestyle Jean and Gene found themselves. They had entered that stage of complete acceptance of their lives and relationship, just as they were.

Fortunately they had 24 hour caregiving so managing their care needs went fairly seamlessly. The fact that the daughters made the sacrifice of paying for this extremely expensive care was the first indication of how much they loved their parents and accepted who they were. Gene got the bedroom; Jean had the living room. They had been married for sixty-seven years, yet now they never saw each other. In fact I can't ever remember them ever speaking to one another. No "x" "Hey honey, how are you doing in there" or "I'm watching a good TV show. Come on in" even though they lived less than twenty feet from each other, literally. Each had a hospital bed, but Gene was no longer ambulatory so he had a commode next to his bed and also used a wheelchair to get into the bathroom for showering. Jean could still walk but needed standby assistance to use her walker safely as her balance was very poor. She was impulsive, and in her attempts to maintain her independence, she had fallen so many times that the mattress had been placed on the floor. And she didn't have the strength to stand. This then required her to call out for help when she wanted to walk. The caregiver could then assist so she wouldn't hurt herself. She was still fully alert mentally and railed against this "prison". Yet even despite her being fully alert she had settled in. It was like a time warp of sameness, a purgatory of waiting before death.

It took me a long time to get used to this when I came to hospice care. I would often suggest and coax, "My it's a gorgeous day, shall I get you in the wheelchair to go out and get some fresh air?" "Do you listen to books on tape now that you can't see to read as well?" I finally came to realize that at the end of life, people have been there and done that, and the place of least resistance, of just staying as comfortable as possible,

is the very best place to be.

Gene was the first admitted to Hospice, but Jean wasn't far behind. I don't remember their illnesses. What I do remember was that I visited the apartment probably four times a week, twice for each of them. The view was always the same--darkened, quiet, no conversation. Caregivers and I found ourselves drawn into the cocoon of silence, and to break it felt jarring, so generally there was very little conversation except for clinical questions about their progress and needs. It felt oppressive and cloaked. As in the Story *The Night Before Christmas*, I always wanted to "throw open the shutters and throw up the sash!"

At least once a week, I would force myself to bring in the light of day. I'd ask, "Hey, Gene, how about I get you in the wheelchair and we can go in the living room and visit Jean. Perhaps you'd like to see her and then watch some TV with her." Or "Jean, I'd like to see how well you are walking today. Let me help you get up with your walker and we'll take a short stroll. We could go into Gene's room and you could visit by sitting in his wheelchair next to his bed."

Never, not once, did either of them desire to visit the other. There was absolutely no animosity, no noted discord, no irritation, no negative response whenever I asked each of them. They had a history of a warm family life, and as each was able to share more about their earlier lives, all seemed well.

I came to believe that just seeing the other in the declined state was more distressing than just knowing the other was still there, and that was good enough. Neither offered any explanation to me as to why they had no interest in seeing the other. It was just the way it was, and I stopped offering and accepted their relationship the way it was.

Gene's life spiraled down faster than Jean's. He was verbally unresponsive, so my attention was given to his physical needs. But Jean could still be conversational, and we became closer and more friendly. We slowly began to break through the clinical issues to a deeper and more personal connection. Also they had two daughters who would sometimes visit. I scheduled visits with them because their presence allowed more animation and social engagement with Jean while I was there. What a relief to have some outside help in the conversation!

In that way I could experience Jean as she had been in her younger self, learn more

about her so I could have more material to talk about when the girls weren't there. During those visits, one of the girls, without asking permission, the curtains would be opened and in the natural light allowed. Only then could I see the colors of her life--as told by the artifacts and pictures displayed in her room, the living room. A curio cabinet on the wall across from her bed held lovely delicate figurines she had collected. Pictures of a rich and happy family life going back three generations were arranged all around the blackened screen of the TV. On the wall above Jean's bed were two shelves with a variety of standing picture frames and collectibles. Keep in mind, that Jean's mattress was on the floor, so we caregivers had to be careful not to bump our heads on the shelves. There was no bed frame to keep us safely away from the wall.

The daughters also had no ability to coax their parents together, and Jean never wanted to talk about --or to--Gene even while they were present.

"Hi mom, how are things going with you and dad today?"

"Oh hello, Linda. Everything is fine." "But have you seen dad? How's he doing?"

No response to those questions, or Jean would change the subject: "Has Riley chosen his college yet?"--a question to Linda about her grandson in hopes of veering the subject of the conversation away from Gene.

As expected, Gene died first, and I clearly remember making my next visit to Jean after his death. Of course I offered my condolences and wondered how she was taking his loss. Our conversation went something like this.

Nancy: "Jean, I'm so sorry for your loss of Gene, this must be hard for you now to be alone in the apartment."

Jean: "No, I talk to him every day. I'm not alone. He's right here."

Nancy: (Knowing that they *never* talked on a daily basis--or ever--in the months I had known and cared for them.)

"Oh, you talk to him about how you're feeling? You sense him still in your heart?"

Jean: "He's right here. I just talk to him when something comes up."

Now, something seemed a bit odd. Talking to him? Every day? "He's right here?" I was confused. She had never really alluded to a clear and defined belief in the spiritual afterlife either. I paused and waited, trying to think of my next inroad.

Nancy: "Oh, do you still sense his spirit here in the apartment?" I'm sure my voice was hesitant, and I was looking directly at her face which was completely neutral and matter of fact--not demonstrating any overt grief.

Jean: "No! Not his spirit, he's right here."

I could sense she was becoming impatient with me. Her statements were succinct and clear, yet now I was really confused. Always curious about my patient's spiritual experiences, I tried one last time to get her to reveal more of her thoughts. Perhaps if I was lucky she would tell me something of her beliefs. I poked a bit further.

Nancy: "Jean, can you tell me more? More about what you mean by saying he's right here?"

She now seems obviously irritated with this dense younger person, even a nurse, who is not understanding what she has been saying three times over and is still driving at her to say more.

Jean: "He's right here! He's right there!, Right up there!" She raises her weak and frail arm and gestures strongly above, jabbing her index finger above her head to those shelves filled with knickknacks.

"He's in that silver jar right up there!"

Yes, there he was, his ashes in an urn right above her head. "Duh!!", I began laughing. And then she too broke into laughter. We just sat there laughing at each other and together for quite awhile. I have told that Hospice story many times over.

Yes, Gene was right there