

Karen

How 3 fellow hospice nurses, danced our dance of death.

by Nancy and Brenda

Karen: Through Nancy's
eyes:

In the fourteen years that I have been a hospice nurse, I'd never taken care of another hospice nurse--until Karen. We shared our profession, and because she was sixty-eight, only two years older than I am, we shared a generational connection as well. As I get older, I continue to think of my age as younger. Sixty-eight just feels too young to die.

She had uterine or endometrial cancer. I can't remember which right in the moment and I'm not going to go look at her chart. The diagnosis really isn't all that important in these last couple of weeks. If Karen was painful or nauseated, we don't care where it's coming from; we just want to fix it. The cancer filled her abdomen and pushed on her intestines causing it to be obstructed, basically causing a blockage in the tunnel not allowing food, fluid, and stool to pass. Brenda had actually admitted Karen to hospice care in another part of the valley. However, when I met Karen, she was just being discharged from the hospital where she had three to four days getting her severe pain under control and where they tried to open up her gut with medications.

She arrived at our local hospice house. It's a beautiful old estate that has been revamped into a twelve bed hospice house. It sits on a lovely hilltop surrounded by established luxuriant gardens and the views of our beloved Mt. Ashland to the south.

The opening ritual at the hospice house is the "quilting ceremony." Either the patient or a family member (if the patient is unable) is taken to an upstairs room that holds a lovely armoire. It is filled with handmade quilts donated by local volunteer quilters. Each is about the size of a crib blanket and is a work of art. The patient gets to choose their favorite, and it is placed on their bed for the remainder of their stay and life.

My first experience with the quilting ritual was with Karen. There were two that caught her eye--both with the colors of autumn-- but the winning choice was with views of her beloved out of doors. She had lived in Alaska, and the quilt was covered with fir trees and wolves.

Karen was absolutely not ready to die when she reached the hospice house. In fact, she planned on having a nice long "vacation" with her needs being met so she could settle in and have time to experience her grief. As a hospice nurse, she knew the importance of this. She told me many times, "There has been too much to do! I haven't had time to let myself be sad." Unfortunately, her body would not allow it, and the symptoms took almost all of her attention. When we met, she hadn't had a bowel movement for ten days. But she was a trooper every day and every night attempting to get her intestines to open up. We tried every possible tool in our toolbox so the blockage in her gut would move along. We literally tried from the top (swallowing medication) to the bottom (inserting suppositories in her rectum.) Nothing worked.

She would take sips of water, juice, broth--all mixed with a laxative--and she ate a lot of popsicles. For a couple days she even tried soft food because she was hungry, and hungry for the taste and satisfaction that food brings. However, most of it came back up. She was never without a vomit bag, and the dry heaves came on if she coughed or laughed. She had hiccoughs quite often that also led to retching. Nausea was with her much of the time, but the medications used to treat it caused her to be sleepy, which she didn't like, so she held off until she couldn't stand it. We held acupressure points on her wrists for nausea. She even had her private therapist come and provide acupuncture. Pain in her left flank area came and went. Her belly was large, and made her look four to five months pregnant. Fortunately, from my point of view as the nurse, it wasn't as bad as it could have been. Her belly was not so large that her skin was stretched to taut and shiny, or that it pressed upward on her diaphragm to hinder her breathing.

We didn't have much time for me to get to know her or talk about her hospice practice, as I had hoped she could teach me something as we went along together. No, her time and energy needed to be spent separating from her friends and life. Karen had lived and worked in eighteen different states and had collected close friends from around the country. She had no family, but during her last week, friends flew in from three different directions and stayed with her twenty-four hours a day. This to me was a testament of how special a person and friend she had been in her life.

As a hospice nurse and a woman of action, she wanted to control everything around her--to be involved in all decisions regarding her care. I wrote everything down for her so when she became forgetful she could look over at the bedside table and read her own plan of care. I get it. I am a control freak, too; most nurses are. I expect I will do the same thing.

I'm writing this remembrance today of Karen, the day she left this earthly plane, August 31, 2018 at 4a.m. Her best friends, Robyn and Mina were with her. I was informed at about 7:30 and immediately went to the hospice house hoping I would catch her before the mortuary had her removed. She was beautiful in death with clear, pale alabaster smooth skin, her short Peter Pan haircut just the right style for her and just a skim of a gentle smile on her slightly parted lips.

I had seen Karen yesterday, about twenty hours prior to her death. At the time she had been mostly comatose--unable to respond except for the slightest flutter of her eyelids one time as I was addressing her and holding her hand. Her breathing was beautifully clear, regular, and actually quite deep and relaxed. But even at that her blood oxygen level was only ranging from 72 - 78 (normal is 90 - 100). A dropping of oxygen level is a very normal part of dying, and I always check it because it helps me know where the client is on their path to death. Families tend to find comfort in the numbers because they're something concrete to hold onto. And I can give them a better guesstimate of how much time is left, which they always want to know, yet feel guilty asking.

Karen's had been ninety-two just the day before (two days before her death) when she was sitting on the side of the bed groggily telling me she wasn't having any more nausea! She had stopped trying to put fluids into her body. Her heart rate was quite rapid at an irregular rate and rhythm of 115 - 140, indicating the work her heart was doing to get that blood pumped to the lungs for the needed oxygen. Again a normal change. Looking at Karen, you would never have seen any of these underlying changes in her body; she remained beautifully peaceful. Robyn shared that this had continued all day and right to the end. I was so happy for Karen. She had a peaceful, gracious, and dignified death. With all of the loving, supportive, nurturing, and skilled professional care she had given to others through her life as a hospice nurse, it only felt fair and deserving for her to have a perfect death.

Robyn and I were standing at the end of Karen's bed with our arms around each other's

waists gazing at Karen and honoring her body. The room was beautifully fragrant with lavender. Two candles were lit and Karen's personal dream catcher was hung right where she would have seen it. Flowers in vases graced the dresser. Robyn said she wanted to share with me a very special gift she had received from Karen: About an hour prior to Karen's death, she and Mina had been quietly talking about Karen, and Robyn was looking away from Karen towards Mina. When Robyn turned her head back to look at Karen's breathing body in the bed, she heard Karen's clear, strong, happy voice say into her left ear, "I'm not there!" Robyn immediately knew she had heard Karen celebrating the release of her spirit, yet her body was still alive. She could feel Karen's life energy encircling and dancing around the room.

Another hour passed, and Robyn and Mina had called another good friend on the east coast who was reading poetry to them and to Karen. She came upon a selection with a humorous finish. As the three of them dissolved into giggles, they watched Karen take a final sighing breath and her body let go. Robyn is sure she felt the swish of Karen's spirit pass her as she opened the french doors to the garden to let in the morning breeze.

With Karen, I also was able to experience the hospice house closing ceremony for the first time. After the patient's body has been prepared, the family is given permission for the mortuary to be called and they arrive to take the body. The patient is placed on a gurney with the head and face open to be seen. The special quilt is placed over the remainder of the patient's body. As Karen was wheeled to a special port of departure, which is a lovely circular patio surrounded by gardens on the back of the building for privacy and ceremony, we all gathered around her. The Alaskan scene quilt was over her, and her beautiful dream catcher laid right over that pesky uncooperative belly of hers. Everyone present was invited to speak what Karen had meant to them, from just her ten-day stay at hospice house to the many, many years as a dear friend.

One of the caregivers present said, "Karen told me how much numerology was important to her. Did you know that her favorite and special number was four?" A beat passed and someone else noted, "She died at four a.m.!" We all looked at her and laughed. She seemed to have gone at the perfect time. We sprinkled the flower petals we had over her, pictures were taken, and then the quilt was folded in upon itself in thirds and presented to Robyn.

As I walked through the halls a little later, I was feeling so blessed to be alive and healthy, and impressed by the work the hospice house has done in designing sacred ways to celebrate their residents. I said out loud, "I want to die right here someday."

Then I added but, “not for a long, long, long, long, long time!”

Karen though Brenda’s eyes:

When the email appeared on my phone this morning telling me that Karen had died, I had a pang of sadness. I had admitted Karen a week before she entered the hospital. On my way to her home, I knew she was a hospice nurse and I had a number of feelings. First, I felt the desire to want to do the best job I could for a fellow hospice nurse. You can describe our work to others and they call you an angel (which makes me cringe). There is a sisterhood (and brotherhood) that only doing this work for years you can understand. I also felt grateful to be a member of the highly compassionate and skilled group of people working in hospice care.

The admission process was long--two and a half hours. Karen demonstrated all the classic characteristics of a seasoned hospice nurse--strong, honest, controlling, smart, communicative, and hopeful. It was Karen’s hope that came through the strongest. Appropriately she was anxious and fearful about her rapid decline in status, and she knew that hospice was her best chance of feeling better (and living longer). As she realized I saw her and was on her page and on her side, I could physically see her relax and her hope surfaced. To be honest, so did mine. I thought with a little bit of steroid we could open up her gut and get her bowels moving and she could enjoy a longer stretch of good physical comfort and quality of life.

The other characteristic making itself very present in the room was her honesty. She knew her strengths and weaknesses, she exposed her vulnerabilities. She revealed her childhood scars that were profound and deep. These scars led her on a lifelong journey of spirituality and finding her personal meaning and expression of it.

During my visit it was also clear Karen would need people to care for her as she declined. She had an extensive friend network that was vast in depth and territory. Even during her short time at her apartment complex, she had nurtured friendships and connections with people. Her place was small, humble, meager, and very sweet. It was an extension of who she was and she was grateful for it. When I read Nancy’s story and discovered these friends showed up for her, my heart warmed.

But in the meantime she would need care. I brought up the hospice house. Her first

response was, “well, I am more of a nature person and it’s not quite my era.” I then offered the idea of an adult foster home instead, and this time her response was, “the hospice house sounds great!” I giggled inside. We hospice nurses can be dreamers but we are practical. Don’t get me wrong. I love Adult Foster Homes. I think it’s a much better answer to taking care of our elderly than these huge corporate assisted living homes. But our local Hospice House is kind of the Utopia for dying. I not only explained to Karen her needs would be met in a beautiful manner, but more importantly I explained that her hospice nurse would be Nancy and she would see Karen for who she was and fully take care of her in the way of which she would approve. Karen at that point, did not think she needed care. This is so common. We think we are so much better than we actually are in our decline into dying. It takes an objective eye to see the reality full on.

Every visit and contact I had with Karen in the short week I cared for her (and a lot of care was required), she held hope. Her bowels did not respond to the steroid. Each day she had worsening symptoms of nausea, vomiting, weakness, and escalating anxiety. It was a Friday evening and I was on call and it was no surprise when the call came in that Karen was struggling. I arrived to find her miserable and her neighbor sitting with her. I gave her a combination of medications that would address her nausea, pain, and anxiety, and it was helping, but now she was weaker and unable to care for herself. Karen’s neighbor was willing to stay the night with her but had to go to work the next day. Another Hospice lesson: life goes on around us while we die.

After much discussion with Karen and our hospice doctor, we agreed the best option was for Karen to go into the hospital for symptom management and caregiving needs until we had another plan. I met her in the emergency department and our hospice doctor had called ahead to let them know a hospice patient was coming and to please focus on symptom management--not a lot of diagnostic tests.

A lovely emergency room doctor came in who had a great bedside manner, but within two minutes he was talking about MRIs, CT scans, and possible surgery. Karen looked at me with deer in the headlights look and asked, “what do I do?” Fortunately that very long admission visit paid off. I knew her wishes, and going down that path was not it. By now it was late and I asked if we could just for tonight do a little IV fluids and IV medications to get her symptoms managed? He was agreeable.

With the best intentions in mind, he told Karen to try and avoid using the pain medication because we didn’t want to slow her gut down anymore than it already was. The next morning I met Karen in her room with the hospitalist (MD) on duty. She was

young. In fact she looked twelve years old and couldn't have been out of school very long. But this young bright woman clearly had palliative training and was spot on with Karen's symptom management needs and was open to asking the seasoned hospice nurse any advice I could offer.

You may recall in my introduction I talked about having hope in this younger generation and here it was. I set in motion the process for Karen to move to the hospice house as soon as she could, and I continued to express my trust in Nancy. Two days later Karen moved into the home and met Nancy and the fabulous crew there. I did not see Karen again, partially intentionally, because she needed to let her new team take over her care, and partially because as hospice nurses we are really busy and I knew she was getting the care she needed.

Later in the day (after receiving the news of Karen's death) I was sitting on a patio waiting for my daughter to arrive on a bus and having a glass of wine. I read Nancy's story of Karen and was filled with chills and tears. My morning feeling of sadness came from the fact that I knew Karen had hoped for more time. Reading Nancy's story of Karen, I once again witnessed we die like we live, and my faith in dying was renewed.