

## It's All About Me: My Life, My Care, My Choices

Entry Questions:

- 1) What are the kinds of choices you should be able to make in your daily lives?
- 2) What factors contribute to the quality of life in your nursing home or facility (or in your care at home)?
- 3) What do you think it will take to bring about good quality care in nursing homes and other facilities?

My name is Joan Ziebarth and I died in a nursing home on August 12, 2016. I know this essay should come from me, but I trust my daughter, Jane Overby, to tell my story. Jane was a journalist and is very good at asking questions and is always writing down facts. I was in the care of a nursing home that was not too far from my home of 52 years in Minneapolis. My husband, Mel, and I raised three children in that home and I cried when I had to leave. I was strapped into a van with a lift for my wheel chair, and driven away. My family did their best to decorate my room in assisted living, but it still felt like a dirty motel room. I've already said I cried about this frightening change in my life, but I also got angry with my family. It's hard for me to say why, but a little part of me felt that they no longer loved me. The staff at the nursing home didn't understand why I was so angry sometimes and they got frustrated with me. You asked what factors contribute to the quality of my life in a nursing home. **My answer: I couldn't be the first nursing home resident to have such intense feelings; I wish they would have been more understanding, or had a counselor on-site who would let me talk without judging me.**

I was in that place for 2 ½ years. One month after I moved in, my daughter got breast cancer. I begged her to let me take her to her chemotherapy sessions. She was a single mom with two little boys and needed my help. *What was I thinking?* I couldn't drive. She would have to help me navigate the building from my wheelchair. I would be more of a burden than anything. I thought about how I nurtured her, my first child and only daughter, for so many years, and when she needed me most, I was trapped in that place. You asked what kinds of choices I should be able to make in my daily life. **My answer: If one of my loved ones was facing a deadly illness, or if anything important was happening in my family, they should have helped me with transportation.** They have several wheelchair vans, but they were reserved for residents who had doctor's appointments. Often, those vans sat idle for days.

Let me jump ahead to the care I received my last week in the nursing home, where I was then in long-term care. On Sunday, August 7, 2016, my husband noticed a rash on my arms and legs. He asked the nurses what it was and they said they didn't know, but that they would monitor it. My husband called Jane, as he always did when something happened to me or my treatment changed. Jane came to the nursing home the next day, after lunchtime, so we could talk. She couldn't find me in my room, and she couldn't find me in the cafeteria. A member of the staff told her to look in a different cafeteria.

Jane told me she found me, alone in that large room, asleep in my wheelchair at the lunch table, where I hadn't touched my lunch. Jane took me back to my room where she looked at my rash. She said it looked more like I was bleeding under my skin, so she took pictures of my arms and legs. Then she gave my caregivers three clues: I had unusual fatigue, loss of appetite and a hemorrhagic rash on my body. In the coming days, the rash spread even more, and my husband kept asking the nurses "why?" By that

time, I also had vomiting and bloody diarrhea for three days. That place called in a special nurse practitioner to see me. She had 30 years of experience working with the elderly. She determined my situation was not an emergency. One day later, I was sent to the Emergency Room in full septic shock. Jane and Mel were there, but I didn't even know it because I think my brain had died by then, as had all the other vital organs in my body. There was one exception: a barely beating heart. I must have known I was dying, though, because my family saw me pull my IV out of my arm, and seconds later, I went limp. My life was over.

They say in the movies that when you die, you can see your life behind you as you float from this life to whatever comes next. If that's true, this is what I would have seen: my daughter and my husband crying. Then I saw more of my family come into the room, also crying. They asked "why?" My death certificate said I died of sepsis.

You also asked: What do you think it will take to bring about good quality care in nursing homes and other facilities? **My answer: make sure the caregivers are trained. Make sure they are compassionate. Make sure they pay attention.** How was a nurse practitioner with decades of experience working with the elderly unable to diagnose sepsis? The rash was the first change in my condition and yet no one reported it to my doctor; no one thought it was important. My family and I were ignored for a week until I had only a few hours of my life left. I still had so many things to say. So many things that no one will ever hear. My daughter is now my voice.

**Footnote from Jane Overby:** The Minnesota Department of Health determined my mother's death due to nursing home negligence was "unsubstantiated." I appealed their decision, with medical proof of how my mother died and why the nursing home was at fault. Again, "unsubstantiated," according to the Minnesota Department of Health. I met with a representative of the Department in person to ask for further information about the lack of care she received the last week of her life. Still "unsubstantiated." You asked: What do you think it will take to bring about good quality care in nursing homes and other facilities? My answer, on behalf of my mom: **Clearly the State of Minnesota has a greater interest in protecting the nursing homes than it does in protecting their residents. This has got to change.**