

The Caregiver Experience at the Hospital, Part 1: The Emergency Room

Editor's Note: This article is based on an actual experience of a middle aged working caregiver, written in the first person "I" that represents a common experience for caregivers.

"I need you. I just don't feel right," said my mom on the phone call at 10:30 am on a Tuesday morning. It took me until 12:30 pm to cover the rest of my day, re-arranging a busy schedule. When I got to my mother's home it was obvious that my 77 year old widowed mother was very ill.

My mother has diabetes, high blood pressure, and chronic pain. She was complaining of her stomach hurting and dizziness and general overall fatigue. She had not wanted to get out over the weekend as we usually do so I knew she had not been well for several days.

She seemed to have a fever but she did not know where the thermometer was. Her blood sugar levels were extremely high. She had not gotten a flu shot because she said that last year it made her sick.

I suggested we call the doctor but she had not been real happy with the doctor she had been using. I suggested that we go to the emergency room but she said she felt too bad to go and sit in a hospital ER waiting room which was what happened the last we had to go. I suggested we call 9-1-1 and at least have the fire department paramedics check her out. She did not want to do that either.

She told me that maybe she would start feeling better but needed me to be there so she was not so scared and alone. She drank some water but did not want lunch. I continued to talk to her about my concerns that she was ill. I felt helpless, frustrated and angry that nothing I suggested was working.

And hour and a half after I arrived I said, "I have an appointment in two hours but I don't feel right leaving you alone feeling this way. I don't know if I can reach someone to re-schedule. Will you at least agree for me to call 9-1-1 so someone can tell us what may be going on?" Reluctantly she agreed but asked me to tell them not to come with the sirens running although the dispatcher could not guarantee that.

Within minutes I met 3 members of the fire department and told them her symptoms. Compassionate, professional, and efficient, within minutes of checking her vital signs the lead paramedic said, "You need to go to the hospital. You have a fever, your blood sugar is extremely high and you need help we cannot give you." She agreed and within minutes she was on the way to the local hospital in her first ambulance ride. We agreed that I needed to follow her after gathering up important papers, insurance cards, and shutting the house.

Because she arrived in an ambulance she bypassed the ER waiting room. However, due to an over-crowded ER center she has placed into a cubicle separated by curtains from other cubicles at a 'crossroads' of activity around the corner from the nurse's station. I arrived soon after she was placed here and ER staff were putting in an IV and so began all of the testing – EKG for her heart, blood work, urine samples and other testing. Tests had to be done before she was given pain medication.

But mostly what we did was wait. And wait. Under those bright lights that are good for staff and terrible for patients and families. We would buzz for water, to know what was going on, and help and frequently it was several minutes before anyone even responded on the call button and then several more minutes before any help came. What was striking is that few of the staff ever introduced themselves by name. Their task was the mechanics of evaluation and giving medications. Unfortunately this was our choice or hospital and we would go again as it is one of the best! I have heard similar stories or worse from others. Too many patients, too little staff, too few resources.

After an hour and a half of constant traffic, staff talking, a screaming child in pain placed in the next cubicle followed by a young woman experiencing a miss-carriage with a lot of family and friends coming and going, I asked staff to move my 77 year old very ill mother. After another 30 minutes they came and got her and wheeled her to a private ER room. Unfortunately it was another 30 minutes before staff came in because in the transfer to another area she was somehow forgotten.

Some of the staff was great and some of there were awful. They may all be different people off the job but they were not all great health care providers. What was painfully obvious is that their major role was to do their paperwork: verifying that she was the person that they needed to treat, getting information into a computer. It often felt that the chart and paperwork were more important than the patient.

We still did not know what was going to happen but finally my mother was hungry. The hospital cafeteria had closed so staff recommended that I go get her something to eat so. I left the hospital and drove through a fast food restaurant close by and brought her back a chicken sandwich.

The doctor came in around 9:00 pm and told us that her diagnosis was Nephritis, a serious kidney infection. She had probably had a urinary tract infection for a while which she is prone to have. The doctor recommended that she be admitted into the hospital for treatment. Having arrived at the hospital ER at 2:00 pm she was taken to a hospital room at 12:30 am.

Me? I was the advocate: on constant alert to ask questions, ask for help, go find staff, ask for her to be moved, ask about food, and a dozen different details. Unfortunately my only other sibling, an older brother was ill himself so I kept him and his wife updated via phone. I don't know what would have happened if she had been alone.

Lessons Learned, Part 1:

- Ask what your ill family member wants you to do but be willing to get tough, expressing your fears and concerns about their health.
- Use 9-1-1 when needed.
- At the hospital emergency room, be assertive and take an active role. Let hospital staff do their job but ask questions and expect answers. Understand that the answers may be that they need more time for testing to be done or treatment to begin.
- If a call button is not answered or staff does not respond within five minutes, go to the nurse's station and ask for an update or for someone to come to the room as soon as they can.

Edited by Zanda Hilger

Next time: The Caregiver Experience at the Hospital, Part 2: The Hospital Stay and Home Care