

Joan's Family Bill of Rights

Hospital staff are the greatest people on earth. They take our sick, wounded and worried and most often heal them. Every day thousands of people walk out of hospitals as a result of doctors' knowledge and treatment, nurses' loving care and unsung assistants' toil to keep patients clean and happy. In a supporting role are the legions of social workers, secretaries, housekeepers, food staff, clergy and volunteers, who selflessly devote their time and energy to help the patients, families and friends cope with the sick, as well as the complicated hospital system.



Throughout hospitals are posted "Patients' Bill of Rights and Responsibilities," which outline the expectations of patients. Nowhere are there rights of families, who spend long hours every day at the bedsides of loved ones, sometimes watching them endure a heartbreaking death. After spending two weeks, most of which in the intensive care unit with my sister Joan, here are my suggestions for hospital staff when dealing with families:

1. Don't say, "I suck at IVs." That information doesn't inspire confidence in your abilities as a nurse. You are our lifeline to the doctors and we expect that you are great at what you do.
2. When you enter the patient's room, announce yourself, so the patient isn't startled by your actions in a situation that is already scary and unfamiliar. Introduce yourself to the family, so they can greet you. Don't make the family invisible by not making eye contact with them and ignoring them.
3. Before you raise the bed or begin a procedure, describe it to the patient, so there are no surprises. Some patients want to be involved in every decision and others are in such pain that they need to prepare themselves for the least bit of movement or the next dreaded procedure. Every single thing you do to the patient is felt by the family.
4. Don't question the doctor's orders as in, "I don't know why the doctor did that, ordered those meds, took so much fluid, etc." We are clinging to the doctors' orders that everything, which is being done, is appropriate and correct. Your questions raise red flags and bust our confidence. If you don't agree, please consult the doctor privately. We are not in a position to make judgments on the doctors' orders.
5. Don't complain about anything – the computer doesn't work, there are no shelves, etc. Family members of gravely ill patients don't want to hear your petty complaints. We want the room filled with as much positive energy as possible.
6. Don't dismiss the family's involvement as meddling in your work. Some people can only cope with a sick family member by trying to feel in control of a world that is eons away from everyday reality.
7. Determine the patient's energy level before you make a high energy entrance that feels chaotic to a patient, who is finally calm after enduring the high mark pain scale for two

hours. Your rushing around the bed causes accidents (like spilling the urine bottle). Your energy level should match the patient's and if it's calm and relaxed, you should mimic that emotion, so you're in tune with the patient and the family.

8. Know that every word you say in the room, despite the appearance that the patient is sleeping, may be understood by the patient. So when the patient is resting with closed eyes, step outside the room to talk with family members.
9. Comfort the patient like a loving family member. Every small action that you take may ease the patient's final days and alleviate the family's nightmare when they see your caring attitude.
10. Read the research posted in the ICU waiting room that discusses the importance of sleep. Don't carry on conversations as if you're in the cafeteria. Use your quiet voice at all times. Families hear all the gossip, confidential patient information and inconsiderate remarks such as "I'm just waiting for my two patients to die," unless you're whispering.
11. Don't arrange janitorial duties at 10 PM when the patient is trying to sleep. Any noise upsets the family who has been keeping vigil over a sleepless patient for many hours.
12. Use a checklist for a room, so when you start your shift, you check all the machines, equipment, medicine, catheters, etc. to ensure that they are operational and working properly. Family members need to be confident in your professionalism as soon as they meet you. If a family member notices equipment that doesn't look right or sound right, don't brush them off, only to be reprimanded by the doctor when he discovers the malfunctioning equipment which didn't monitor the critical condition of the patient.
13. Demonstrate concern for the patient's family, who might have flown across the country at a moment's notice, to be with a loved one. Their devastating pain is internal and there is no cure. Your kind words can save a breaking heart.

Thank you to the doctor who always answered my many questions and hugged me the last night.

Thank you to several nurses whose kind actions spoke volumes about their love for their job.

Thank you to the social worker who toiled tirelessly to move mountains.

Thank you to the final night nurse who asked me a number of times if I needed anything.

Thank you to the two nurses and the social worker who talked to me about dying.

To you, I owe my heartfelt and everlasting gratitude.

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