

## Excerpt from Joe McDonough's CaringBridge Journal Dated May 22, 2007

### Day 114

**For what it's worth, here are some random thoughts and perspectives from Chris, Ali, and me regarding life in the hospital.**

#### **Observations of one family of a long-term patient:**

1. Regardless of the medical condition, the families of long-term patients ALL share one quality -- fatigue...physical and emotional. You can see it on our faces.
2. Life-threatening illnesses do NOT discriminate...it doesn't matter what you look like, how much money you have, or who you know.
3. You can recognize the long-timers in the cafeteria because they don't mess around. They know what's good, what's not, and they get in and out of there fast.
4. There's a bond between the families...our stories may be different, but we share each other's pain.
5. Just as the doctors and nurses surely talk about the patient's family, the families share notes on the medical staff. Most of the comments are very positive, but you always get warned about an odd doctor or two. And, the nicknames can be entertaining. Honestly, I don't think it's mean-spirited...it's a way to cope. Sometimes, I truly think that we families are too tough on the medical staff but we need to take our anger out on someone. Unfortunately, they take the heat from us.
6. There is absolutely a need to teach "Positive Thinking 101" in medical school. I won't say it's true for all doctors, but many give you the worst case scenario first and hope things improve from there. I don't know if it stems from our litigious society or the "under-promise/over-deliver" philosophy, but it is NOT productive. Someone needs to get this message. And no, I'm not advocating denial but, instead, I want to hear a plan of how we are going to attack the problem, not a statistical prognosis based upon a medical textbook or journal.
7. Faith and science work together...don't ever underestimate the power of prayer!
8. Nurses are underpaid and undervalued in society relative to their contributions.
9. Man, there are a lot of acronyms in the hospital... PICU, PACU, BBMT, IR, NPO...
10. Life isn't fair, but it doesn't really serve much purpose to dwell on this conclusion.
11. To ensure the best care, the family must take a very active role in the care of their loved one in the hospital. We mean no disrespect to the medical staff, but the nature of health care (constantly changing nurses, Residents, therapists, Fellows, Attending docs, etc) requires the family to be the continuity, the watchdog.
12. We never realized how much "art" there is to the practice of medicine. It is absolutely a combination of "art" and "science"!
13. All hospitals are not created equal. You are blessed if you can be at a world-class institution that also espouses a family-centered approach to the care of your loved one. At AI DuPont Hospital, they care about the family almost as much as they do the patient and this approach really helps to reduce the anxiety of a traumatic situation.
14. Healthcare workers (at least at a children's hospital), by and large, really care so genuinely about the patients. It's really impressive. They are passionate about what they do.
15. It is impossible to sleep well at a hospital! And, you lose all track of time. There is not much of a difference between 3am and 3pm, Monday or Saturday.
16. Is there a prize for the Resident that comes to the patient's room earliest in the morning?
17. I want to be the guy that sells and services pagers in the hospital. Does everyone get one on their first day along with your ID badge? I think even the cashier in the cafeteria has one.
18. Suggestion – if you're a doctor visiting a patient and their family, don't enter the room with a 'doom & gloom' face unless you're there to deliver bad news. We've had heart attacks watching doctors come into our room with long faces only to hear them say "No news, I'm just here to see if you have any questions." Hey, I'm a guy that lives on pizza and fast food – I'm not in great shape -- are you trying to put me into cardiac arrest?
19. You want to find heroes? Don't go to the NBA or Hollywood. Come to any children's hospital and meet the kids!!!
20. Your perspective on life will forever change after a long-term hospitalization of your child.