

# Hospital Survival Guide

Last Updated Tuesday, 15 April 2014

This Page has been compiled by people who have been there. The information is not intended to rock your faith in hospitals, but to help you be prepared for almost anything that could go wrong, as well as how to be as comfortable as possible. The advice shared here is mainly intended for those facing major surgery with lengthy hospital stays, rather than TUR surgeries for superficial tumors which are usually done on an out-patient basis or overnight admittance.

## Ani's advice

1. If you don't have a will get over it and get one - now.
2. If surgery is your lot, ask that the surgeon and anesthesiologist remain in the OR for the duration. Who thought they might not? Don't even bother to get into the argument phase. You need your strength for other things. Say these words: "I'm going to fax a letter to my lawyer about having made this request. You all can do whatever you want." Bingo.
3. Find out exactly how you are going to feel when you come to and how long it is likely to take before the morphine does its work. This information will be hard to come by. Ask if you should count to 100 or 1000 or something in between. Deep breathing does not hurt.
4. Do not rely on the kitchen to feed you what you should have and exclude what you should not have.
5. The week before your surgery ask for the names of all the medications you will be taking or given and look them up in the PDR to find out what their side effects are and their side effects in relation to other drugs you may be on. In the hospital find out the names and quantities of the drugs they are giving you and keep your own clock on when you get these. Every time a drug is administered ask what it is and what the dose is. This could save your life.
6. Take someone with you for pre- and post- op appointments. Devote a notebook to this event. One with pockets will give you a place to put the many documents the hospital gives you to sign. Create a section for your questions and allow enough space for the answers. The people who accompany you should do the writing. This is the only way you will know the answers to your questions and have a written record of what was said.
7. Don't leave the hospital without finding out when you come back for suture removal. Infected sutures is one alternative to not knowing.
8. Take your own pillow (don't laugh till you've been there), a shawl to wear for the required walks escorting your IV, and

light cotton or linen slacks to wear under hospital non-fashion. Flax summer pants were great.

9. Inquire about the possibility of giving your own blood pre-op.

10. Make sure the public TV channel works at your bed. It's the little things that are colossal.

11. Prepare for the worst, expect the best.

12. Bless those who are good to you.

13. Get a massage, go to your acupuncturist, get your chiropractor to work your bones and see your healer as frequently as you can in the week before you check in. If you're a girl, get a pedicure. Take a little makeup and use it. Lipstick, mascara, blush and a small mirror is all you need. Don't bother to take the entire Macy's cosmetic counter.

14. Have your surgery during the playoff season of your favorite sport; i.e. if you have surgery in December you can watch football games 9 hours a day.

15. Be nice to the nurses. The doctor/surgeon may have saved your life, it's the nurse who will keep you alive.

16. Take your own favorite entertainment whatever it is; tapes, CDs, puzzles, reading material etc.

17. If your veins are uncooperative, ask for pediatric needles. "The thinnest needles I have" isn't what you want. As I understand it, there are regular needles, thin needles and pediatric needles. Pediatric needles are often on another floor-as in the nursery. Avoid getting multiple jabs.

18. If your incision is of any length, dry the area thoroughly with a blow dryer. Warm moisture is an outstanding breeding ground for all sorts of unwelcome guests. You may want to do this for at least six months.

Seth's advice

1. If you take any medications on a regular basis, do NOT assume that the hospital will supply what you need when you need it, especially in the day or two after your admission. So bring your own supply, at least TWICE as much as you think you might ordinarily need, and keep it in a place that's readily available. If the gods are kind and your medicine arrives on time and in the correct dosage, count yourself lucky. If, as is more likely, it doesn't show up, it won't matter.

Important: It is imperative you tell physicians and nurses what medication (and dosages) you are taking regularly (allergy, blood pressure) as some may conflict with or have serious consequences when combined with medications you may receive during your recovery. This includes over the counter medicines such as aspirins, antacids and stool softeners.

2. If you have pain or other problems at night in the hospital, and the nurse can't resolve it, DON'T accept the standard explanation that "nothing can be done until your doctor arrives in the morning." There is always a doctor available (this is a hospital, remember?), but the nurses are often reluctant to disturb him/her. Too bad, that's their job. In my own case, my morphine IV clogged about 36 hours after my nephrectomy. I didn't know that, all I knew was I was in tremendous pain. But I had to go about 10 hours with NO pain medication at all while I waited for the doctor to saunter in around 8 am. the following morning. To add insult to injury, I then had to wait another hour for the hospital pharmacy to open at 9 am, so they could get the morphine. Meanwhile, there was a 24-hour CVS across the street. Makes you wonder.

3. Speaking of pain, don't be a martyr and wait until the pain becomes unbearable to request help. It may take the nurse from 5-15 minutes to answer your call button, and another 30-60 minutes or more to get the doctor to OK the order for the painkiller. Then they have to get the stuff from the hospital pharmacy, and then find another nurse to give it to you. Then you have to wait for it to work. So plan ahead; enough said.

4. Unless you enjoy being nauseous, remember that most painkillers should be taken with food, even if it's just a slice of bread or a cracker or two. And unless you like being constipated, remember that many painkillers (especially codeine) are also constipating, so drink lots of water and perhaps some prune juice. Also, ask for a stool softener like Colace (the liquid version looks and tastes like shoe polish, but the pills are tasteless and seemed to be equally effective).

5. Most hospitals have chaplains on staff. If they do, they usually spend a fair amount of time on the oncology floors, for obvious reasons. Whether you are religious or not, and regardless of what religion you are, it's worth it to request a visit. These people can provide a fair degree of comfort and compassion.

6. If you have a roommate, be considerate, particularly with noise. Hospitals are noisy enough as it is, with people and equipment moving at all hours of the day and night. Keep the volume on your own TV low. If you have guests, try not to disturb your roommate, who may be trying to sleep. If you're lucky, you and your roommate will also watch out for each other, listening for odd or sudden noises, groans, etc.

7. A portable CD player is a wonderful idea. It not only keeps you occupied, but can also help you "zone out" when and if necessary. Keep the player under your pillow or blanket, to prevent it from being seen and perhaps stolen. To eliminate the need for batteries, also bring an AC/DC converter (about \$15 at Radio Shack) and a 6-foot extension cord. That and a dozen of your favorite CD's should solve all your musical problems for a least a week. With "ear bud" headphones (also about \$10 at Radio Shack), you can put one earphone in one ear, sleep on the other ear, and still go to sleep with music. It will only be "mono," but who cares?

8. If you will be making a number of long-distance calls from the hospital, check with AT&T or your long-distance telephone service provider before you're admitted. They probably have a number of different options that you can exercise for a month or two. In my case, for an extra \$5 a month, I was able to make long-distance calls to my home telephone number for 10 cents a minute, the same rate as my usual outgoing calls from home. That \$5 paid for itself very quickly, avoiding the standard long-distance rates, collect calls, etc. I used the option for one month, then deactivated it once I was home from the hospital.

9. In my experience, most nurses are really good and they try their best to be helpful. For that reason, it pays to be nice to your nurses, even if you feel lousy. The main problem is that there just aren't enough of them (more "managed care"), and often they can't really do everything they're supposed to be doing. So it also pays to have a friend or relative with you as much as possible during the first 2-3 days of a hospital stay, to make sure that things are running smoothly, and to set things right if they aren't. You as a patient aren't in a condition to pay attention to all the little details right after surgery, and certainly in no condition to argue about them if there's a problem.

And Hildegard reminds us:

If you are allergic to anything such as latex, silk or paper tape, any antibiotics, analgesics, etc, make a poster, write or print in large letters ALLERGIC TO \_\_\_\_\_ and hang it over your bed.

What kind of hospital stay can you expect before, during, and after your radical cystectomy and urinary diversion? Nurse Sharon McMullen has written an informative page for WebCafe, 'Hospitalization for a Radical Cystectomy and Diversion'. [Click here for the article.](#)