

Surgery Tips

Here are some tips for preparing for and recovering from surgery prepared by Naomi Herzfeld.

PREPARATION FOR HOSPITALIZATION

While I don't mean to scare anyone, it is important to prepare for hospitalization. I naively assumed that I would be told anything I needed to know and that people would do their best for me. It didn't happen that way.

The renal clinic staff didn't tell me much about the hospital, and the hospital staff didn't tell me much either! Although I had no real complications, I had a horrible hospital experience with a lot of unnecessary pain. It prolonged my recovery time and left me very angry. On the other hand, a co-worker of mine was in the same hospital at the same time, in a unit adjacent to mine for gall bladder surgery, and he got incredibly good, attentive care. I've been doing some research, and apparently, this unevenness of care is very common.

I KNOW IT SEEMS EASIER NOW NOT TO WORRY ABOUT IT -- BUT PLEASE TRUST ME ON THIS, YOU NEED TO FIND OUT AS MUCH AS YOU CAN. I recommend a book (out of print but available at libraries and used bookstores) called How to Survive in the Hospital by Joan Hass-Unger, R.N. None of the other guides I looked at contained as much usable information. And seriously consider getting a private duty nurse for your first 24 hours post-op.

Again, I don't mean to scare anyone, but all donors are doing a wonderful thing and deserve the best hospital experience possible. But in order to make that happen, you need to be at least as knowledgeable as if you were going on a camping trip or buying a new car. It is not enough to trust that the hospital will take care of you just because you are doing one of the most life-affirming things it is possible to do.

I've covered the areas I found most important -- hospital environment tips, pain management, food and sleep, and recovery.

HOSPITAL

Many donors are very healthy people who may not have been really sick and may not have been in the hospital ever, or since they were kids. These days, hospitals tend to be minimally staffed. Care varies from hospital to hospital, unit to unit, and even bed to bed, so you may have a great experience or not. Nurses may or may not have the time or inclination to explain how things work in the hospital...so in case you're not one of the lucky ones who gets great care without having ask for it, here's what I wished I'd known:

(1) Have a friend/family member with you 24/7 especially while you are stuck in bed -- or hire a private-duty nurse. This does not mean "visitors" -- this means someone who will get you ice chips, adjust your shade, talk to you if you need to talk or stay quiet if you don't, and talk to the staff about your needs when your brain is fuzzy post-op.

(2) If you need something, ring as far in advance as possible. Holding back from ringing will not

get you a faster response when you do ring. Be clear and factual when you describe the problem and how urgent it is -- the clerk answering your call button can't see you.

(3) Take staff promises with a grain of salt. They mean well, but they're busy and things fall through the cracks. Always ask when something will be done and who is going to do it. If you don't get a response after this time, follow up and keep following up. If someone tries to leave in the middle of a task, make sure to ask when they'll be back.

(4) If you want to be sure your doctor is aware of an issue, leave a message at his/her office or ask the nurse or resident to put a note on the front of your chart.

(5) LAST RESORT ONLY: Ask to speak to the charge nurse or nursing supervisor. Finally, you can call your doctor's office or answering service, using your bedside phone -- have your doctor's phone number with you.

(6) Ask your doctor or nurse as soon as possible (even before surgery) what medications have been ordered for you -- both mandatory and "on request". You may find you can ask for "comfort" measures you didn't know about -- sleep and digestive aids, for example.

(7) If you're stuck in bed, get into the habit of checking that everything you need (call bell, water, food, book, phone, etc.) is within reach BEFORE you let people leave you alone in the room!

(8) Find out how to move your bed rails up and down. Sounds stupid, but even in the same hospital, different beds work differently. My first morning post-op, ravenous after 30 hours of fasting, I spent a half hour staring at my out-of-reach breakfast tray-- because the aide who left it didn't know how to lower the rails and get the table close, and then told me she'd be back soon -- and never returned. It can also be difficult to get out of bed post-op if the rails are up.

(9) Ask how TV and phone service works at the hospital. You may need to request the service and/or pay cash. Depending on how you feel, you may want to unplug the phone at times -- hospital switchboards usually have a cutoff but it may be quite late or you may just not feel good enough to receive phone calls.

(10) Don't bring anything valuable to the hospital. If you receive gifts, send them home with friends and family -- also saves effort when packing to go home.

PAIN MANAGEMENT

Before going into the hospital, talk with the surgeon about having a plan for pain relief in place ahead of time, with contingencies for "What my pain relief method doesn't work? Who can help me? When are they available? What if they are busy? How can I contact them?" Get details. If necessary, ask to speak to someone on the hospital's pain management staff.

Don't settle for, "They'll take care of that in the hospital." Once you are already in the hospital, it is

much harder to get a cohesive pain management plan, since the hospital environment has a lot of people who are very busy, see you only briefly, and go on and off shift. I found there was not a lot of communication among my caregivers. For example, several nurses were unclear about which department was responsible for maintaining epidurals and were leaving messages with the wrong one, resulting in long and painful delays.

When you're in the hospital, if you're on pain pills or shots, ask your nurse immediately when and how they will be delivered. Is it on schedule or on request? How far in advance should you ask in order to get it on time? Can you take anything between doses for breakthrough pain? Ask about what position would be most comfortable, and if necessary, for help getting into that position.

It's easier to control pain and you'll need less medication if you can stop pain early and not let it get bad. If you are asked to rate your pain, don't underestimate it -- keep in mind that a level of pain that is tolerable at the moment may become pretty unbearable if it doesn't let up for another three hours.

Ask if the nurse has a "Faces" pain rating chart -- it may help you communicate your pain level more accurately. I found the "scale of 1-10" hard to use -- I have a very vivid imagination and was probably rating too low. Also ask if the hospital has set some arbitrary level as a goal for pain relief, or if they will encourage you to determine what your target level is.

The first couple of days post-op, it felt like a really bad "stitch" in my side. It wasn't so bad moment to moment, but not having it let up much was a problem. However, my epidural didn't work properly -- if I could do it over again, I'd take a morphine pump. My recipient had one and was much more comfortable than I was. Since then, I've heard good things about morphine pumps; mixed reviews on epidurals. Epis seem to be either very effective or very ineffective. At my hospital, I also found that the only doctors who could fix a problem with an epidural were unavailable for long periods -- busy in the O.R. or available only during limited daytime hours. I've read that if you do get an epidural, it works better if they actually start it running and test it before the surgery begins.

In either case, keep in mind that the staff may start you at the lowest dose possible and wait for you to ask for more pain relief, instead of starting higher and adjusting it down. I don't know for sure but I think I was undermedicated because they were afraid of giving me very much -- I'm very small and normally have very low blood pressure.

Ask in advance if the surgery will stretch or injure any nerves. Waking after surgery, I had a mysterious numbness in my leg and was convinced the surgical stocking was cutting off my circulation! I kept pulling at it, and it was only later they told me that the surgery stretches the nerve serving the skin of the thigh. The weird thing is that this type of pain or numbness is not right next to the incision -- later, when I was getting some sharp twinges from the nerve, I thought I'd herniated or something awful. The pain and numbness mostly go away over time, but you might want to ask about this issue in advance so you won't worry if and when you experience it.

FOOD AND SLEEP

The first night post-op is filled with vital sign checks, beeping machines, weird boots that inflate and

deflate every few minutes, noises in the corridors, unfamiliar place and unfamiliar sensations. So ask for something to help you sleep. It will make a huge difference in your mental clarity and emotional outlook the next day.

Food varies from hospital to hospital, so if you can't eat the hospital food for any reason, have your loved ones bring you any food that the doctor says is OK. There's a refrigerator in the unit kitchenette, with a few basic food items. Don't let anyone leave your meal out of reach or move your food out of reach when they come in to do something else. Most hospitals will let you "select" from a "menu" -- but your chances of receiving what you chose are probably no higher than 50/50.

RECOVERY

I'm sure this is different for each individual and type of procedure, but here are the things I learned about recovery:

The surgeon said that it would take about 6-8 weeks to get 90% back to normal, and 6-8 months to get that last 10%, and this prediction was absolutely correct. I was tired and somewhat sore for the first few weeks. I went back to work after six weeks, but $\frac{3}{4}$ days. After eight weeks, I was back to the full schedule and to my dance classes. (I believe I might have had a shorter recovery if I'd had better pain control in the hospital.)

Laughing, coughing, sneezing and hiccuping were uncomfortable for 6-8 week -- do not go see extremely funny comedies during recovery. Just sitting bent at the waist for long periods was uncomfortable.

Incisions do weird things as they heal -- I recommend asking in advance so you'll know what's normal -- don't let them get away with just saying "call me if there's pain, redness, swelling, etc." Hospital discharge instructions are VERY minimal. Ask your surgeon "What will the incision be like as it heals?" For an open procedure, it is normal for a large ridge or lump to form under the scar and stay for a few weeks -- there may be little "knots" as well. Numbness around the incision is common and there may be a little numbness and pain nearby as well, if a nerve was cut or stretched during surgery.

I went home with just strips of tape on the scar, and was told to just let the tape fall off when it was ready. When it started peeling up, it got inconvenient and the nurses told me to trim the ends. Some people may be allergic to the antiseptic under the tape or to the adhesive -- if so, call the doctor and ask if it's OK to remove the tape.

I was worried about the scar but it was much neater than I expected -- they didn't use staples -- they did these neat little under-the-skin stitches that healed beautifully. The scar is barely noticeable now after 18 months -- they try to fit the incision along a natural curve of the body so it is less visible. It had faded considerable by 8 months or so.

I could predict the weather by twinges for a few months after, but that's mostly gone, and the numbness is going away too. I feel just as good as before, my creatinine is actually lower.

My recipient (a co-worker) feels great too, now, but it took over a year. The kidney worked really well right away, but she had a lot of complications from the medications and surgery, and for many months, she felt worse than she did before the transplant. It was depressing for both of us -- but she hung in there and now she tells me she hasn't felt this good in years!!

Thoughts and Advice on Donating a Kidney by Naomi B. Herzfeld 7/1/2001