Things you need to know before mastectomy surgery:

What most people don't realize is that while mastectomy surgery sounds horrendous—especially a double mastectomy—it's really not so terrible after reconstruction. How many other surgical procedures are there where you lose a part of your body and can then rebuild it? *Jan Jessup*

What to do before you go to the hospital:

- Ask your doctor(s) for any <u>post-surgery prescriptions</u> (i.e. for pain medication) and fill them. Also have Extra-Strength Tylenol on hand.
- If a <u>blood test</u> has been ordered before surgery, have it done several days ahead.
- Ask your doctor about any <u>vitamins or other medications that should be discontinued</u> before surgery—and how far in advance.
- Sterile dressings that are 5" x 9" were helpful as they cover the entire breast area. One box should be sufficient.
- Smaller gauze pads (3" x 3") and paper tape may also be needed.
- Buy <u>pajamas</u> if you don't have them; you should not raise your arms to put on nightgowns.
- Buy yourself a pretty <u>new robe and slippers</u> for when you return home.
- A <u>camisole</u> with a shelf <u>bra</u> will be comfortable after you've graduated from the surgical bra that may have been put on by your surgeon. <u>Amoena</u> makes great camisoles that you may find at hospital boutiques (they also design scarves, headwear, clothing, lingerie and swimwear). *Note: most athletic bras fit too tightly and you can't step into them*.
- Spanx makes a great wireless *Bra-llelujah* bra that fastens in front, has a comfortable hosiery back and molded cups to give you some shape post-mastectomy without a prosthesis. You can even wear it over the surgical bra. Read the reviews at www.spanx.com as this bra doesn't fit all women.
- Be sure you have some <u>shirts that button up the front</u> for ease of entry and to disguise the presence of drains.
- Compile a list of <u>email addresses and/or telephone numbers</u> for friends and family members you want informed of your progress after surgery—and send it in advance to the person you appoint to take care of these communications.
- It should not be needed, but you and your family will have greater peace of mind if you complete a <u>Power of Attorney for Health Care and Advanced</u> <u>Directives</u>. This is something you should do in any case, so why not now?

What to bring to the hospital:

You will probably be in the hospital for only one night—a "23-hour stay", even for a bilateral mastectomy. That's okay, because you'll get very little rest in the hospital with monitors beeping and a nurse checking vital signs every couple of hours. Ask in advance if you will have a private room with a private bathroom. There may also be a recliner chair in the room if someone wants to spend the night with you (not really necessary as the nurses will visit frequently).

- Bring a <u>small overnight bag</u> with a combination lock. Remember your <u>photo</u> i.d. and insurance card.
- Your <u>arrival and departure clothes</u> will be the same outfit—be sure the top zips or buttons up the front. Pants with an elastic waist (or yoga pants) will accommodate drains more easily.
- If you have lost your hair: bring your wig, if you wear one; you'll look better coming and going. During surgery, you can wear a knit cap to keep your head warm.
- It's okay to bring your <u>cell phone and charger</u>. Some people may also want an iPod for music; the nurses will secure these during your surgery.
- Bring a notepad and pen to write down nurses' instructions or notes.
- Bring <u>reading material</u>—your room comes with a TV, but there may not be anything you want to watch.
- If you wear eyeglasses, bring them and a case. Leave contact lenses at home.
- Bring <u>face soap</u> or you'll have to wash with anti-bacterial hospital hand soap.
- If desired, bring a small <u>makeup kit</u> with moisturizer and blush, lipstick or lip balm, and a small mirror. You'll look better to visitors and feel better going home with some color on your face.
- You'll prefer your own <u>toothbrush and toothpaste</u> to hospital issue.
- Bring <u>earplugs</u> or ask the nurse for a pair—hospitals can be noisy.

Will you need a visiting nurse? After surgery, you'll be dealing with dressings and drains, but this is manageable. You won't really need a visiting nurse unless you have other health complications. There will be a steri-strip over the incision that will stay in place for 2-3 weeks (until it falls off naturally). Just put a clean sterile pad over it each day, which will be held in place by the surgical bra. The hospital nurses will educate you in drain management before you check out.

What NOT to bring to the hospital:

- Pajamas and a robe—you won't be in the hospital long enough to need them. Nurses will need to access your drains and dressings through the lovely one-size-fits-all hospital gown that fits no one. It's only for one night.
- Slippers—the hospital will give you socks with gripper soles.
- Jewelry, watch, wallet and other valuables. You won't need any money.
- Plastic gloves and antibacterial soap. They're everywhere.
- Deodorant—you won't be wearing it for a while.
- Prescribed pain medication or any daily medication that has been approved for you to continue while away from home—the hospital will dispense what you need while you're there.

Notes on drain management:

- For sponge baths or showers, you'll need to support the drains while you're undressed. A one-inch cotton web belt around the waist worked perfectly for this. The safety pins holding the drains fit right over the belt (or can be pinned to it) and the belt didn't suffer from getting wet.
- Drains cannot be removed until you are down to fluid output of 20-30 ml per day (doctors differ). If you have had lymph nodes removed, this may take 2+ weeks. It's a temporary nuisance.
- If you have any concern about infection, swelling or redness near the drains, call your breast surgeon or see your plastic surgeon if having reconstruction.
- A Physician's Assistant recommends that you coil the drain tubing once around the exit port in your torso and secure with paper tape; this takes some of the weight off the sutures and makes it more comfortable. Then follow the drain tubing about 3-inches further down and tape that to your side above the waist. In case you catch the remaining tubing on a doorknob (it happens), it will pull at the lower tape and not at the upper sutures and entry port.
- An American Cancer Society catalog and other sources sell special camisoles, vests or belts with pockets for drains. They may be helpful, but they're really not necessary. Knit tops held my drains in place during the day. At night, keep the knit top on or pin the drains to your pajama top.

Physical therapy post-surgery can be very helpful, especially if lymph nodes have been removed. Look for a facility with female therapists certified in mastectomy treatment*. They deal with recovery of range of motion, cording, lymphedema, scar massage and other possible side effects of surgery. A doctor needs to write a prescription for physical therapy in order for it to be covered by insurance; an initial prescription may cover 12 sessions.

*Specialty Rehabilitation has several such therapists, all are very simpatico. They are located on the 4th floor of the Helen Graham Center at Christiana and their telephone number is (302) 709-3411.

Recommended books

The following were particularly helpful in preparing for surgery and recovery:

Now What? A Patient's Guide to Recovery After Mastectomy by Amy Curran Baker, c. 2012, published by Demos Health, New York. This paperback book is sold at hospital boutiques or can be found in their libraries (and is also available through Amazon or Barnes & Noble). This book was written by three sisters: Amy is an Occupational Therapist who helps patients with post-surgical recovery; she underwent a mastectomy with reconstruction. Sister Linda Curran is an Advanced Practice Registered Nurse specializing in women's health, and she had a prophylactic mastectomy; sister Marybeth Curran Brown is an RN with an interest in oncology nursing and wound care. This book also contains a list of many resources, websites, organizations and other books that will be useful in your reading and research. It also has great charts for tracking the output of your drains—much better than what comes with the drain literature.

The Breast Reconstruction Guidebook: Issues and Answers from Research to Recovery by Kathy Steligo, Third Edition c. 2012, <u>published by Johns Hopkins Press</u>, <u>Baltimore</u>. This book deals with the mastectomy decision, every possible reconstruction procedure, preparing for surgery, what to expect in the hospital, recovery and beyond. It also has useful lists of questions to ask doctors as you're investigating reconstruction options.

Recovery and Activity

Every patient's pace of recovery is different. Within a couple of days, I went to a movie, and the first week of recovery, I was out visiting museums, shopping, having a facial or dining with friends. For me, this activity was therapeutic and not overly fatiguing. Just watch out for your incisions and your drains. I didn't spend hours in bed, aside from sleeping. From personal accounts in the books above, other patients were more affected by their surgeries and didn't feel like doing much at all. Listen to your body and it will tell you how much activity it can tolerate.

Nipple Reconstruction & Tattooing

Plastic surgeons can create a realistic looking nipple and areola. The real art is in tattooing these to look real. Many breast cancer patients skip nipple reconstruction, especially if we have had radiation treatments, but still want *the look* of a nipple, an important focal point for your body. Nipple tattoos are the answer—and the best in the business is Vinnie Myers, located right outside Baltimore. Vinnie and his team have tattooed 8,000+ women, creating a realistic looking nipple and areola perfect for your skin tone, combining eight different shades like fine *trompe l'oeil* artists. They perform most of the work for the breast surgeons at Johns Hopkins and at the Breast Center for Reconstruction in New Orleans. The video link below shows the entire process: http://www.today.com/health/meet-tattoo-artist-making-breast-cancer-survivors-feel-whole-again-t48276