

HAVING A MASTECTOMY OR DIEP RECONSTRUCTIVE SURGERY?

by Ann Nelson - Survivor, Mentor & Volunteer for Carolina Breast Friends



Ann's TOP 10 Suggestions You, Family & Friends may find helpful

1. Call your doctor's offices asking any/all questions.
2. PUT YOURSELF FIRST -- physical and emotional self-care is 1st & foremost right now and in the future.
3. Open up with your loved ones because they might not always know how to help or what to say and do.
4. Keep the laughter coming & find the joy in each day in any way that works for you.
5. If friends offer to help out, let them help. If the shoes were reversed what would you do for them (laundry, errands, cooking, taking the kids to events, walk the dog, etc).
6. Get fresh air & walk when possible, it is good for the body and the soul.
7. When you get a burst of energy, try not to overdo it because it might set recovery back a little bit.
8. Perfectly ok to say, "I am not up for calls or visits today" if the timing doesn't work.
9. When up to it, connect with the Pink House or with other survivors for support. We all understand.
10. Although your body will have changed, think of scars as reminders of the "gift of life" & reducing your chance of recurrence.

ANN'S STORY

DIAGNOSED @AGE 55 ON
8.15.2011: STAGE1, ESTROGEN +
INVASIVE DUCTAL CARCINOMA,
BRCA1

LUMPECTOMY, INTERNAL
MAMMOSITE RADIATION,
RADICAL HYSTERECTOMY
(UTERUS, CERVIX, BOTH
OVARIES & FALLOPIAN TUBES)

DOUBLE MASTECTOMY, DIEP,
REVISION SURGERY, SMALL
SALINE IMPLANT ADDED TO RT
BREAST, ANASTROZOL 5+ YRS

POST SURGERY EXPERIENCING
CHRONIC MODERATE
LYMPHEDEMA AND
NEUROPATHY

*"POST DIAGNOSIS, I TRY
LIVING EACH DAY WITH MORE
PURPOSE GIVING GRATITUDE
FOR HEALTH, FAITH, FAMILY,
FRIENDS & OF COURSE MY
PINK HOUSE FAMILY."*

FOR SUPPORT PLEASE REACH OUT TO
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PRO TIP: GO TO THE PINK HOUSE IN ADVANCE OF SURGERY TO GET A COMFORT BAG, PILLOWS, AND DRAIN BULB BAGS



Hospital Pre/Post Surgery:

- Ask to video hospital staff changing dressings, cleaning and emptying drains, and other things you will need to do when home
- Ask the hospital for a dose of pain medications prior to discharge to help manage pain for the car ride home
- Make sure the hospital calls in your prescriptions to the pharmacy so they are ready for pickup
- Pack comfy clothes and shoes
- Take pillows, blankets, and a rolled towel for under the seatbelt shoulder strap for car rides

General Recovery:

- Follow discharge papers for do's and don't's (exercise, lifting, restrictions, etc)
- Use incentive spirometer (aka "breathing gizmo"), if supplied from the hospital
- Reduce anxiety and relax through yoga breathing techniques
- Pace yourself
- Stay ahead of any pain with proper pain medication schedules



WHEN YOU GET HOME...SUGGESTIONS

Medications

- Create a medicine calendar & drain chart
- Use an alarm to keep track of dose reminders

Drains

- Watch the video from the hospital staff
- Pinch drain line using an alcohol swab between the thumb & pointer finger starting at the top working all the way down to the drain bulb. Swabs will make the process smoother and also keep drains clean.
- Record amounts of fluid in each drain
- Use waterproof drain bulb bags for showering- available from the Pink House

Hygiene

- Antiseptic soap, disposable wipes & extra washcloths – sponge baths save energy in the early weeks
- Dry shampoo
- Rubber gloves for the caregiver (optional)

Comfort

- Rest when you can because healing takes place then
- Your doctor may recommend sleeping elevated and/or on your back
- Extra pillows for sitting in a chair or for bed (prop under each arm, under the knees)
- Use your Pink House pillows – the perfect size for underarms, in the car & at home
- Set up a little side table near chair or bed with things you will want (books, phone charger, drinks, etc)

Clothing

- Lose robe you can step into or wrap around as a cover-up
- Loose-fitting zipper/button-down tops, tee shirts, sweaters, jacket
- Slip-on footwear – ie sandals, slippers, crocs, sneakers
- Camisoles – step into & pull up your body rather than lifting arms

YOUR ARE NOT ALONE

Take advantage of friends, family, programs, and other resources



Other Hints & Thoughts:

- Remember EVERYONE will have an OPINION, they only want to help
- What works for one may not work for another; everyone is different
- Getting up from sitting position, toilet, or chair with help - crisscross wrists with caregiver standing in front of you - count to 3 - on 3 - gently pulled up to the standing position
- A recliner to prop head and shoulders up OR multiple pillows to elevate for sleep in the beginning - you may find pillows under each arm and under your knees that may provide additional comfort.
- As nerve endings regrow post-recovery you might experience strange creepy, crawly, pressure, or sensitive to touch sensations that might startle you.

Caregivers, Family, Friends:

- This is most likely a new experience for them as well
 - They will run the full gamut of emotions
 - Not everyone will show emotions the same way
 - They may try and inject humor to "lighten the mood"
 - **Let them know**, it is ok to show and talk about what they are feeling
- They will want to be "Strong" for you
 - Some hours and days may be better than others
 - They aren't perfect
 - **Let them know**, its ok not to be perfect, nobody is
- They may not always say or do the "right" thing
 - **Let them know**, you appreciate the effort and guide them
 - What worked for you a few hours ago or a day ago may not work now
 - **Let them know**, they are here to help you

YES,
IT IS ALL ABOUT OPEN,
HONEST, FREQUENT
COMMUNICATION