



WHEN YOU FIRST HEAR YOU HAVE BREAST CANCER: ADVICE from BREAST CANCER SURVIVORS

When you first learn of your diagnosis, it is natural to feel fearful, threatened and out of control. The truth is that you are not alone, nor are you powerless.

There are many things you can do to help yourself, and in the practical things, you will find that you are taking control of your life. The fight against your breast cancer is a process, not a quick fix, and this guide will help you navigate with comfort, ease and peace of mind.



ATLANTA *Breast Care*

WHEN YOU FIRST LEARN OF YOUR DIAGNOSIS

- ONE** Assemble two teams: one for medical support and one for spiritual/social support. Women who have strong medical and spiritual /social support tend to do better in their recovery.
- TWO** Your medical team will first consist of your oncology doctors (a breast surgeon, a plastic surgeon, a medical oncologist, and radiation oncologist), their nurses, P.As and a Nurse Navigator. Your surgeon can recommend members for your team for you to consider. Get their office telephone numbers, cell numbers, and FAX numbers. and put all this information in your notebook (see the section on how to make the notebook).

Talk to your doctors about any concerns you have, make a list of questions and ask them, ask for explanations when you don't fully understand, ask for information to be repeated if you need to do so—and then listen and write (or have someone do it for you) down the answers. Check to make sure you have the correct information and full understanding. Don't worry about asking too many questions; your doctors want you to be well-informed. They are your partners in getting you well.

If possible, take someone with you to your medical appointments. They can be responsible for taking notes so that you review later and reflect on the information. They can also act as a resource to check your memory of what was explained, advised and counseled.

The second part of your medical team is your internist, gynecologist, cardiologist, or any other doctor you feel needs to be kept in the loop. Include them in the lab results and any materials related to your tests, etc. They will be your long-term support and will weigh measures taken by the surgeons and oncologist against your pre-existing medical background in advising and treating you in the future.

The Nurse Navigator will walk with you through the tests you may have done and is available to answer any questions. She is a wonderful, strong support and the source of many kinds of information such as getting you plugged in to the other services Piedmont will supply for you as a breast cancer patient: a cancer nutritionist, exercise, massage, cooking classes and many others.

Incredibly good advice to pass on to you at the very beginning is:

- Don't read about your cancer on the internet. There are over 15 types of breast cancer and they are complex and treated very differently in different patients.
- Don't listen to the "tales" even well-intentioned friends want to tell you. Your cancer may be very different and your processes and outcomes different as well.
- Do listen to your doctors, trust them and do what they tell you to do. They are weighing you, your individual needs and circumstances and formulating the best outcome just tailor-made for you and your health.
- Do read Breast Cancer, Treatment Handbook, 7th edition, by Judy C. Kneece, RN, OCN. This available through the Nurse Navigator.

THREE Your spiritual/social team is more personal (but no less important) to help you stay balanced, positive and peaceful through the process.

- Contact your spiritual advisor, priest, minister, rabbi for prayers and support.
- Put together a prayer support team with whom you be transparent and share your deepest needs.
- Send out general email blasts or Caring Bridge updates for everyone who cares for you and wants to be in touch. This way you can be certain of the accuracy of the information you wish to share, and your friends feel valued and connected.
- Have someone else maintain the communication for you if it becomes too cumbersome. However, I found it therapeutic, writing on my iPhone on the way home from each appointment (I was not driving) and reading it back to my husband to check our memories of what had really happened. It was a great way for us to process together. Our friends began letting us know that they depended on those emails, and my husband took over after each surgery. Your friends will be grateful to know how you are! Allow them to love you.
- Compile a list of telephone numbers of those friends who don't use email and contact them with updates as well. You can appoint a contact person who will call them for you and relay the information in the emails.

EVERYDAY MATTERS WITH A MASTECTOMY *Having breast cancer did not mean we were no longer feminine, and we intentionally made everything we prepared to use after surgery and beyond pretty and attractive. It made us smile and lifted our spirits.*

PILLOWS *can provide basic comfort following surgery as aids for sitting, sleeping and riding in a car*

- If you have mastectomy, single or bilateral, you will benefit from having one (for a single mastectomy) or two (for a bilateral) baby pillows to rest and support under your arms until reconstruction is over. These pillows will help you in riding in a car, with your drains, and when you sleep.
- Should you have the latissimus dorsi flap (back muscle) reconstruction, your baby pillow will be your best friend wherever you go during the first month after your surgery. While sitting or lying down, the pillow is a great support for your back. While sleeping, you can tuck the pillow under your arm on the side of the mastectomy (if you had a single mastectomy).
- You can buy these pillows at any linen store, department store, or Amazon.com.
- These pillows will protect and cushion you. They will make you more comfortable while you have your drains.
- Be certain to get more than one pillow case so that you can wash them.

RIDING IN A CAR

- When you travel in a car following surgery, one pillow can be placed between your breasts and the seatbelt as a cushion and for protection while you are healing. Another small pillow can be placed under your arm while you rest the other on the arm rest. You will be most comfortable staying as still as possible and not “jiggled” around while riding.
- If you have the back muscle reconstruction, tucking an additional baby pillow on your back against the incision has been helpful.

DRAINS AND CAMISOLE: *How to dress after the surgery*

- Following surgery, you will have two drains per side of mastectomy under your arms for a period of at least 5 days and up to a few weeks. You will be instructed on the care of your drains before you leave the hospital, and the plastic surgeon will take them out when your drainage has decreased the required amount.
- While you will be instructed in the care of the drains when you go home, you may need help in measuring the fluid from the drains, although you certainly may do it yourself.
- The drains look like small plastic bulbs at the end of straw-like tubes which come from under your arms. They are secured by stitches so that they will not be pulled out. However, you want to be careful not to tug on them when cleaning the drains. You may find that you are sore under your arms where the drains are attached.
- You will also need to have some method of dealing with the presence of the drains when you dress. Some suggestions would be:
- Choose something as simple as pinning them with a safety pin inside your shirt or pajamas (they have a place in the top for pins) or more specialized as wearing a mastectomy camisole with pockets in the front to hold the drains. For a further list of places to get the camisole, talk with the Nurse Navigator. You will need a prescription for the camisole and that can be obtained from your breast surgeon or plastic surgeon. It is best to shop for these before surgery as you may need to go to more than one place for your size and you may want to wear it home from the hospital.
- While you have the drains, if you need to dress to go out, you will need a shirt large enough to go around the waist area where the drains are being held.
- Drains are your friends, but it is a red letter day when they come out—taking them out may prick, pull or feel tender, but it doesn't hurt—celebrate a milestone!
- After the drains are removed, you will need some kind of support while still recovering from surgery. We used 100% cotton soft camisoles from Old Navy. At under \$10, you can have several! Also, Spanx makes a great snap-in-the-front bra which can be very easy to manage.

HUGS: *Loved ones will want to comfort you during this time; how to accept and give hugs*

- Before surgery, if you have certain tests, i.e., the stereotactic mammogram, and certainly following surgery, you will find that your chest area is tender and sore from the procedure. Any contact that applies pressure to your chest, or to the area of reconstruction, like a hug, can cause some pain and discomfort. The best thing to do is to tell your family and friends how you can be touched and hugged. They want to help you heal, and physical touch is immensely comforting.
- Unfortunately, there are times when you simply do not have the opportunity to verbally stop physical contact.
- By turning your shoulder toward the approaching contact, you can allow a hug that will not press on your surgery.
- Wearing your pocket book in front of your chest will provide a shield against someone pressing into you when you are in public.

PRESCRIPTIONS

- Fill prescriptions given to you in the hospital on your way home (or have someone do it for you) so that you have what you need.
- When you go to the pharmacy, have the medications put in the pop-off top bottles, since you may have trouble applying top-down pressure to twist them open.
- Before surgery, get a prescription from the doctor for the camisoles.
- Let your doctor know if you feel like you need something for anxiety.

BATHING

- If you are allowed to shower after surgery, the drains should be secured so that you can move around. The drains have a hole in the top flap, into which you can place a safety pin. You may use a shoe lace or string (I used a white satin ribbon) to tie around your neck or waist. Then pin the drains to the ribbon so you can move without pulling on them. You will need medium-sized safety pins.
- After your shower, dry the drains carefully and then secure them back in your camisole or pin them to your pajamas.
- If you enjoy tub baths, you may find that bathing in a tub is initially restricted. Ask your doctor when you can resume bathing.
- If you are allowed to bathe in a tub, you may prefer to place drains on the side of the tub instead of hanging them on a ribbon.
- Washing your hair may depend on how high your doctor will let you raise your arms, and you may need help doing so. You may find that you need help lifting or holding the hairdryer when you wash your hair. A light travel hairdryers can be a solution.

SLEEPING: *Pajamas and more pillows*

- After surgery, you will not be able to lift your hands over your head so your night clothes should button down the front.
- Pajamas are perfect for the buttons down the front and modesty in being examined in the hospital.
- You will sleep on your back for a while. In the hospital, you'll sleep with your head at an incline. At home, you may find it more comfortable to sleep "sitting up" to some degree. A recliner works for some, and layering three bed pillows under your back and elevating the neck worked for us. This is especially helpful if you have had a bilateral mastectomy with expanders.
- With some reconstructions (like back muscle reconstruction) you will be sleeping on your side. You can tuck the baby pillow under your arm and prop a regular pillow up against your back.
- Having baby pillows wedged under your arms will allow you to have something to rest them on and take pressure off your chest as you lie down.

HOUSEHOLD CHORES

Ask your doctor what you will not be allowed to do following surgery and how long the restrictions will be in place. Emptying and filling the dishwasher, the washing machine and the dryer, and vacuuming and ironing may be restricted.

MAKING A NOTEBOOK

Having a notebook to keep all our information in one place invaluable. Here are some suggestions on how to put this together.

- Get a three-ring binder. One-inch width is probably adequate.
- Use dividers with blank tabs so that you can write on them. You can change as you go along and determine what you need.
- Different sections we used were:
- Important names, phone numbers, fax numbers, email addresses of doctors' offices, nurses, hospital, pre-op, friends, etc.
- Printed information and notes from doctor visits. Be sure to have extra blank paper in this section.
- Other paperwork including insurance information, handouts, receipts etc. You might also use the side pockets for some of this.
- Information on nutrition and exercises.
- Emails and notes from friends that you want to save...this can be a great source of encouragement!
- Thank you notes to write – remember to get extra thank you note paper.

AN INVITATION *We hope this information is helpful as you go through your mastectomy experience. We would love to hear about any method or suggestion you discover to make living with this process easier – perhaps it would help others and could be included in future editions. Thank you!*

