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A Guide to Help You Through The Journey

As you go through this journey, you will be inundated with so much information most of it will likely escape your memory. I have put together information which I hope will be of help to you.

HELPFUL HINTS

- 1) As soon as you can after being diagnosed get two NOTEBOOKS. Take one with you to all of your appointments. Jot down any questions that pop in your head, any comments you do not understand, or to make notes about what is being said. Keep the other one beside your phone to make notes from the calls that will be coming your way.
- 2) DO NOT make any quick decisions. Remember the doctors work **FOR** you and they can wait for your decisions. Get two opinions if you feel the need.
- 3) If you have not seen a Patient Navigator, ask for one. Every hospital now has them. They will help with coordinating all the different doctors you will be told to see. If you feel you do not need to see a particular type doctor, say so. YOU are in charge!!
- 4) Be careful with your internet searches. Look for what you really do not know, but you can get some misinformation that will not be to your benefit.
- 5) Post Surgical garments will make your recovery more comfortable. Your doctor can send a prescription for these items if you do not have one. Most insurances pay for at least two of them. While you are here, check out a breast prosthesis and a mastectomy bra. This might help you with your decision concerning reconstruction.
- 6) You will have drain tubes in your chest wall when you leave the hospital. They have a collection bulb on them for the fluid to drain into, so if you are a bit squeamish, ask your surgeon about a home health nurse. They can come check on you and empty the drain bulb. For a single mastectomy there will be 2 drain lines connected to 1 bulb. With a bilateral mastectomy there will be 4 drain lines with 2 drain bulbs on each side.
- 7) Do not listen to other people's depressing stories. For some reason those are the stories you will hear the most. DO NOT LISTEN to them. Put your hand up to stop the discussion the minute it starts, saying "I am sorry, but I am only listening to positive statements, so if you have something positive to say I would appreciate hearing it."

BE PROACTIVE

If you know you will be having lymph node(s) removed, ask about lymphedema. I have a pamphlet on it, so ask for one if I forget! You can order a compression sleeve before your surgery so you will have it when you come home from the hospital. Most insurances pay for a portion of the cost with a prescription, call and ask them about your benefits for the sleeve and a gauntlet for your hand, if needed.

If you find out post-surgery that lymph nodes were removed, ask your surgeon for a prescription for a compression sleeve before leaving the hospital, call me and I will come to your home and measure you.

Once you know you have had lymph nodes removed here are a few tips: (This is now up for debate.)

- 1) **NO** needle sticks or blood pressure should be done on that side: **EVER AGAIN**
- 2) **DO NOT** carry your purse on that side
- 3) **DO NOT** carry or lift anything heavy on that side
- 4) **Exercise** your arm(s) **for life** to keep the fluid moving
- 5) **Wear** a compression sleeve when doing housework, gardening, golfing, etc.
- 6) **Wear** a compression sleeve if you fly, putting it on 2 hours before and leave it on for 2 hours after.



If you are wearing a sleeve and your hand starts to swell call your doctor. You may need a gauntlet/glove for your hand. We can measure you for them and have it for you in a few days.

Ask your surgeon or the nurse about post-surgery exercises. You need to exercise your arm(s) soon after surgery so scar tissue does not form, will aid in helping to get your arm(s) up over your head, and move the fluid through the lymphatic system. You will not be able to lift your arm(s) over your head for a short time due to the surgery itself and healing time. I have a booklet on lymphedema if you would like one.

SURGERY DAY

1. Take your post-surgical garment and drain pouches with you to the hospital. If you are having bilateral surgery, take both packs of pouches with you.
2. You will be wearing these garments during your recovery time. Do not wear a “regular” bra for at least 4-6 weeks post surgery. The “puffs” given to you are for healing time **only**. You will need to call us for an appointment for a fitting of your mastectomy bras and your long term breast prosthesis.

POST SURGERY

You should have a follow-up appointment with your surgeon about two(2) weeks after surgery. You might want to make this appointment when given your surgery date, that way it is done and you can put it on your calendar.

Once home, if you have discomfort from swelling, fluid build up, or are bleeding call your doctor ASAP.

About 4-6 weeks after surgery you can come in for your first fitting of bras and breast prosthesis. As long as all drains are out and **most** of your tenderness is gone, call for an appointment. If you are still having swelling it is best you wait till it is gone. You may want to wear your prosthesis for only a few hours a day when you first receive it. If your swelling has not gone down tremendously by this time you should call your doctor. The form (puffs) you were given with your post-op items is to wear only during your healing time. You will need a weighted prosthesis to give you balance.

You must have a prescription from your doctor for these items. Call their office and they can fax us.

We look forward to helping you look balanced and symmetrical. With the advances in breast prosthesis technology they are lighter, cooler, and because of the different shapes, we will have you looking and feeling very natural.

If you have reconstruction and are not completely symmetrical or feel unbalanced when completed, we have very thin prostheses for that exact reason. We will gladly let you try them on to see if you look more symmetrical and feel more balanced.

Here a few sites you might want to look into before your surgery or any pre-treatments. Check out our web site, www.victoriousimages.com for more informational sites on our Resources page.

CareCalendar

This is a wonderful site for those who need help from friends or family during this time. You make a calendar and post on it what days you need help and the people **only you** give access to can fill in when they can be your helper. From requesting meals, needing rides to doctor appointments, picking children up from wherever, or just needing a visitor, it is great. No one can see it but those you choose.

CaringBridge.org

This is a great site for letting friends and family know how you or a loved one is doing. Again, no one can see the posts but those you give permission. This is helpful so your phone is not ringing off the hook with well-wishers wanting to know the scoop and you will not have to answer the same questions numerous times.

So, blog away and let everyone know how you are doing!!

*We are only a phone call away,
here to help in anyway we can, so please do not hesitate to call.*

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God bless you and know you are in our prayers.

BE YOUR OWN ADVICATE

*ASK QUESTIONS - NO QUESTION IS A
STUPID QUESTION*

*DO NOT BE AFRAID TO ASK FOR HELP
THAT IS WHAT FAMILY/FRIENDS
ARE ALL ABOUT !!*

