

Question List for Ella's meeting with Dr. Breast Surgeon on [Date]

Prepared by Ekene Obi-Okoye on [Date]

SITUATION (clarifying known facts about my condition)

- I'm at a stage 0 DCIS in breast cancer. How can I be at a stage 0 and having to have a mastectomy?
- What do we know about this type of DCIS and how it works in the body?
- Initially my treatment plan was partial mastectomy with 6-8 weeks of daily radiation and tamoxifen?
 - Why is that changing?
- Calcifications on the left breast but no cancer. Do calcifications turn into DCIS?
- CTC did a surgical biopsy, mammogram and MRI.
- I do not know if I have the BRCA gene.
- I'm a firefighter so my job is physically intensive.

CHOICES (clarifying which options are available)

- Mastectomy?
- Chemo?
- Radiation therapy?
- No treatment?
- Clinical trials?

OBJECTIVES (clarifying my goals and priorities)

- I want to make sure that a mastectomy wouldn't interfere with physical demands of my job.
- I have a daughter. I'm concerned with her health now that I've been diagnosed.
- I want suggestions that would make that recovery time more comfortable.
- I want to avoid recurrence.

PEOPLE (clarifying roles and responsibilities)

- If I choose to do a mastectomy, what does my cancer team look like? Who will I report to? How will it all work? How will they monitor me?
- How do I come out to my children about cancer?
- What is the impact on my children as far as support for them and my immediate family? Friends?

EVALUATION (clarifying how my choices affect my objectives)

- Is there any possibility to saving the right breast? Any other options? Could we treat it instead?
 - If I can't keep it, then is this surgery preventative or life-threatening? What is the correct term?
- What is the predicted outcome of the DCIS if no mastectomy? Will I die if I leave this untreated?
- With a mastectomy, why no radiation or chemo or hormone therapy?
- If I decide to keep my left breast, what will treatment plan be as far as mammograms, radiation, chemo?
- Will I have to say goodbye to left breast if I have DCIS in right and BRCA+? Statistics?
- How much does BRCA gene play into recurrence of breast cancer? How does it affect ovaries/uterus?
- If BRCA negative, what is the likelihood of me getting BRCA in that left breast?
- How does this DCIS affect other areas as well? What needs to be done if I'm BRCA positive?
- Based on my age, what is the recurrence rate for my breast cancer?
- What can I do to change my life to avoid recurrence? Diet? Nutrition? Western Eastern? Medicine?
- When will I be considered a survivor or in safe zone/remission?
- Any recommendations for reconstruction for my body type and job? Both procedure and surgeon-wise?
- If I keep the nipple and didn't get all the DCIS, could I have a recurrence?
- Do we get rid of nipples if it's in the milk ducts or is that where DCIS originates?

DECISIONS (clarifying which choice is best and next steps)

- Leaning toward right side mastectomy with reconstruction (DIEP flap) using own body tissue.
- Can I wait as I'm trying to figure out choices and options?

Summary of Ella's meeting with Dr. Breast Surgeon on [Date]
Prepared by Ekene Obi-Okoye on [Date]

SITUATION (clarifying known facts about my condition)

- You have high grade DCIS that covers a large area—affects short term more than long term outcomes.
- Calcifications are normal in breasts. Don't directly cause cancer, but are caused by cells sloughing off.
- Your lymph nodes may be swollen because of previous operation. No need to worry.

CHOICES (clarifying which options are available)

- Chemo is not generally an option for DCIS
- No clinical trials
- Mastectomy and reconstruction
- Hormone therapy (tamoxifen) after surgery

OBJECTIVES (clarifying my goals and priorities)

- [See answers regarding recurrence and family risk under Evaluation below]

PEOPLE (clarifying roles and responsibilities)

- Your team: surgeon, plastic surgeon, maybe medical oncologist with regards to tamoxifen
 - If you have a mastectomy with DIEP, see plastic surgeon for 6 months as follow-up.
 - Might see surgeon a year after.
 - Might see oncologist every 6mo if you choose to take tamoxifen.
- You see your regular PCP for yearly mammograms for left breast.
- The Cancer Resource Center on first floor can give you more info about sharing diagnosis with others.

EVALUATION (clarifying how my choices affect my objectives)

- Larger area, high grade DCIS means that mastectomy is best, difficult to do lumpectomy.
 - If you leave it, likely to turn into invasive cancer within 6 months to 2 years.
 - If multiple lumpectomies, 23-30% recurrence over 10 years, 50% recurrence will be invasive
 - If it turns invasive, 10% chance you could die within 10 years.
- At the mastectomy, you will also get a sentinel lymph node biopsy just to check again for invasion.
- Chances of DCIS coming back is 0.5% after 10 years. You're pretty much cancer free after that.
- You may not be able to conserve the nipple because of your breast size but talk to a plastic surgeon.
- You can take tamoxifen after surgery to decrease risk of left side breast cancer by 50-60%.
 - Half of women who are offered this don't take this. You can take 6 months to make decision.
- No need for surgery on left breast. Risk of new cancer is 0.5% a year.
- If you were BRCA+, Dr. Breast Surgeon would recommend bilateral mastectomy, but that's unlikely.
 - You would also have to consider removing ovaries if BRCA positive.
- Changing diet to be more well balanced could decrease risk slightly but not much.
- Your daughter has slightly higher lifetime risk of DCIS (13% to 18%ish).
 - She would probably have to start mammograms at 34 but that's 30 years away.
- With the mastectomy, pathology keeps the tissue for up to 7 yrs so it can be requested for research.

DECISIONS (clarifying which choice is best and next steps)

- You should schedule mastectomy within 6-8 weeks.