## I Am Empowered for TNBC

## My Triple Negative Breast Cancer (TNBC) experience: What I know. What is next for my care?

Your Name $\qquad$ Today's date $\qquad$

Use this handout to learn about your TNBC, understand what you should know, share your understanding with your doctors, family and partner to help you make decisions for your care.

WHAT YOU SHOULD EXPECT:


SIGNS \& SYMPTOMS (check all that apply and date)

|  | My Left breast | My Right Breast | Date of Change |
| :---: | :---: | :---: | :---: |
| New Lump |  |  |  |
| Swelling on all or part of breast |  |  |  |
| Breast or nipple pain |  |  | - |
| Skin dimpling |  |  | - |
| Nipple turning inward. |  |  | - |
| Red, Dry Flaking or thickened skin |  |  |  |
| Liquid leaking from nipple |  |  |  |
| Swollen Lymph nodes |  |  | - |

## DIAGNOSIS OF TNBC

1. 6 SUBTYPES of TNBC (may be found on your pathology report, check the one that applies to you)

Basal-like 1 (BL1)
Basal-like 2 (BL2)
Immunomodulatory (IM)
Mesenchymal-like (M)
Mesenchymal stem-like (MSL)
Luminal androgen receptor (LAR)
$\square$
$\square$
$\square$

2. STAGE (check the one that applies to you)
0 $\square$
1 $\square$
2 $\square$
3 $\square$ 4 $\square$
$\square$
3. GRADE (check the one that applies to you)
1 $\square$
2 $\square$
3 $\square$
4. CANCER BIOMARKERS (check ALL that apply to you)

| ER negative | $\square$ | PR | $\square$ | PARP1 $\square$ |
| :--- | :--- | :--- | :--- | :--- |
| PR negative | $\square$ | HER2 | $\square$ | PD-L1 $\square$ |
| HER2 negative or low | $\square$ | BRCA1 | $\square$ |  |
| ER | $\square$ | BRCA2 | $\square$ |  |

Other $\qquad$
Other $\qquad$
Other $\qquad$
Gene changes called MSI (microsatellite instability) $\square$
Gene changes called MMR (mismatch repair) genes (MLH1, MSH2, MSH6, PMS2) $\square$

1. IMAGING TEST

2D Mammogram
3D Mammogram
Ultrasound
MRI
DXA SCAN (BONE SCAN)
CT Scan
PET Scan
Molecular Breast Imaging (MBI) $\qquad$
2. BLOOD TESTS

Notes and Date(s)
$\qquad$
3. BIOPSY - taking tissue samples to look for cancer cells under a microscope

Note type if known (i.e. fine needle aspiration, core needle, stereotactic, MRI guided)

LYMPH NODE BIOPSY - taking some lymph nodes (small bean-shaped organs) under the arm to check for cancer spread
Date completed $\qquad$
4. BIOMARKER TESTS - taking tissue or fluid samples to test for special features of the cancer

Date completed $\qquad$
5. FERTILITY PRESERVATION - cancer and cancer treatment can affect your ability to get pregnant.

Date to meet with a reproductive endocrine \& infertility specialist.

## 1. SURGERY (NOTES)

Lumpectomy - removing the lump or mass
Mastectomy - removing one or both breasts
Lymph node surgery - removing the lymph nodes from under the arm (or collarbone)
Plan for a nipple sparing approach $\qquad$
Plan for breast reconstruction
2. RADIATION THERAPY - machine that uses high energy rays to kill cancer cells.
Note number $\qquad$ of treatments over $\qquad$ time
$\qquad$
3. CHEMOTHERAPY - medicines to stop the growth of cancer cells but also may affect normal cells

Note number $\qquad$ of treatments over $\qquad$ time $\qquad$
CHEMOTHERAPY BEFORE Surgery - called Neoadjuvant Circle Yes/No
Chemotherapy AFTER Surgery - called Adjuvant Circle Yes/No
4. TARGETED THERAPY - medicines that attack cancer cells with less harm to normal cells.

Name $\qquad$ Note number $\qquad$ of treatments over $\qquad$ time $\qquad$
5. IMMUNOTHERAPY - medicines that work with your immune system to fight cancer

Name $\qquad$ Note number $\qquad$ of treatments over $\qquad$ time $\qquad$
6. COMBINATION THERAPY - using 2 or more treatments together

Name _ Name $\qquad$
Note number $\qquad$ of treatments over $\qquad$ time $\qquad$
7.

## MAINTENANCE TREATMENT FOR GENE MUTATION

Name $\qquad$ Note number $\qquad$ of treatments over $\qquad$ time $\qquad$
8. CLINICAL TRIAL - a type of research study designed to learn more about how our bodies respond to new drugs or treatments

Offered at time of treatment decision? (Yes/No), Eligibility (Yes/No); Considering? (Yes/No), Started (Yes/No)

## Questions to ask myself

1. While I get treatment, do I:
a. Need to work?
b. Have someone to help me get to treatment?
c. Have someone to help around the house, help care for my children or grandchildren or pets?
2. What does "quality of life" mean to me?
3. Do I need to eat a specific diet or avoid certain foods or beverages?
4. When should I speak to my family and friends?

## Questions to ask my doctor

1. Have you treated other patients with TNBC?
2. What is the cancer stage, grade, and how do they impact my treatment options?
3. Are there long-term effects of the treatment, and how do the risks of the therapy compare to the benefits?
4. Are you going to cure my breast cancer or is the treatment to keep it from getting worse?
5. Am I eligible for a clinical trial?
6. Should I speak with a professional about genetic testing and counseling?
7. Will you speak to \& include my Primary Care doctor or my GYN as a member of my care team?
8. Am I going to lose my nipple? Can my nipple be spared?

## Diagnosis questions

9. Should I get a $2^{\text {nd }}$ opinion and how do I do that?
10. Will you test my cancer for biomarkers?
11. What should I act on or do while I am waiting for biomarker testing results?

Treatment questions
12. What is the goal of my treatment?
13. What are my treatment options?
14. Do I need occupational therapy for my arm swelling after lymph node surgery?
15. What would we do if my treatment doesn't work or if the cancer comes back?
16. How can I learn more about emotional, physical, and medical support services?
17. Will I have a peer navigator or case manager assigned to me?

## Side effect questions

18. What possible effects and side effects might I have from treatment?
19. I'm afraid of what will happen when I have treatment. How will it feel?
20. What can I do to treat side effects?
21. Who do I call if I have severe health challenge outside of your office hours, such as high fever?

Phone $\qquad$
22. Will I need help controlling pain (pain management)?

## Clinical trial question

23. Should I think about taking part in a clinical trial?
24. Where can I learn about clinical trials for TNBC? Visit website(s) $\qquad$

## Financial questions

25. Does my insurance cover this test or treatment?
26. Where can I learn about financial assistance?

## Resource questions

27. Are there local resources that help with rides to and from treatment?
28. Is there a local TNBC support group meeting?
29. Are there additional support resources and educational resources that you recommend? see www.tigerlilyfoundation.org , please search for RAISE, barrier toolkits and the TNBC web page.
30. Can I get connected to others who have survived or are living with TNBC for support?

For questions about your triple negative breast cancer care
Names of Health Care Professionals:
Primary Care Physician $\qquad$
Gynecologist (GYN) $\qquad$
Radiation Oncologist $\qquad$
Surgical Oncologist $\qquad$
Medical Oncologist $\qquad$
Palliative Care Specialist $\qquad$
Navigator $\qquad$
Community Based or Faith Based Organization(s) $\qquad$
Peer Support: Tigerlily Foundation www.tigerlilyfoundation.org
(ANGEL advocates)

