I Am Empowered for TNBC

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

Your Name ____________________________________________ Today’s date ________

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:

Testing to find breast cancer
This includes tests to find breast cancer and help to diagnose it.

Diagnosing Breast Cancer
Your diagnosis will include the cancer type, stage and biomarkers present.

Deciding on treatment
There are different types of treatments that you may have 1st, 2nd, and beyond. The type or order of treatment may change. Ask your doctor about availability of clinical trials as a treatment option.

Care during and after treatment
This may include care to relieve symptoms, treat side effects, and have more tests or repeat biopsies to learn if treatment is working.

SIGN & SYMPTOMS (check all that apply and date)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>My Left breast</th>
<th>My Right Breast</th>
<th>Date of Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Lump</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swelling on all or part of breast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast or nipple pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin dimpling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nipple turning inward.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Red, Dry Flaking or thickened skin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liquid leaking from nipple</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swollen Lymph nodes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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)

2. **STAGE** (check the one that applies to you)

   0 1 2 3 4 Recurred (Came back)

3. **GRADE** (check the one that applies to you)

   1 2 3

4. **CANCER BIOMARKERS** (check ALL that apply to you)

   - ER negative
   - PR negative
   - HER2 negative or low
   - ER
   - PR
   - PARP1
   - HER2
   - PD-L1
   - BRCA1
   - BRCA2
   - Other
   - Other
   - Other
   - Gene changes called MSI (microsatellite instability)
   - Gene changes called MMR (mismatch repair) genes (MLH1, MSH2, MSH6, PMS2)
**TESTING** check ALL that apply to you and date

1. **IMAGING TEST**
   - Date completed
     - 2D Mammogram
     - 3D Mammogram
     - Ultrasound
     - MRI
     - DXA SCAN (BONE SCAN)
     - CT Scan
     - PET Scan
     - Molecular Breast Imaging (MBI)

2. **BLOOD TESTS**
   - Notes and Date(s)

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)

4. **LYMPH NODE BIOPSY** – taking some lymph nodes (small bean-shaped organs) under the arm to check for cancer spread
   - Date completed

5. **BIOMARKER TESTS** – taking tissue or fluid samples to test for special features of the cancer
   - Date completed

6. **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

Plan for breast reconstruction

2. **RADIATION THERAPY** – machine that uses high energy rays to kill cancer cells.

Note number ______ of treatments over ______ time ____________________________

3. **CHEMOTHERAPY** – medicines to stop the growth of cancer cells but also may affect normal cells

Note number ______ of treatments over ______ time ____________________________

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 ______ Note number ______ of treatments over ______ time ____________________________

5. **IMMUNOTHERAPY** - medicines that work with your immune system to fight cancer

Name ______ Note number ______ of treatments over ______ time ____________________________

6. **COMBINATION THERAPY** - using 2 or more treatments together

Name ____________________________ Name ____________________________

Note number ______ of treatments over ______ time ____________________________

7. **MAINTENANCE TREATMENT FOR GENE MUTATION**

Name ______ Note number ______ of treatments over ______ time ____________________________

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 DURING MY TNBC CARE EXPERIENCE

**Questions to ask myself**

1. **While I get treatment, do I:**
   - Need to work?
   - Have someone to help me get to treatment?
   - 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 2nd 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 __________________________
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) __________________________

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 __________________________
Gynecologist (GYN)____________________________
Radiation Oncologist ___________________________
Surgical Oncologist _____________________________
Medical Oncologist_____________________________
Palliative Care Specialist ________________________
Navigator ______________________________________
Community Based or Faith Based Organization(s) ___________________________________________

Peer Support: Tigerlily Foundation www.tigerlilyfoundation.org
(ANGEL advocates)