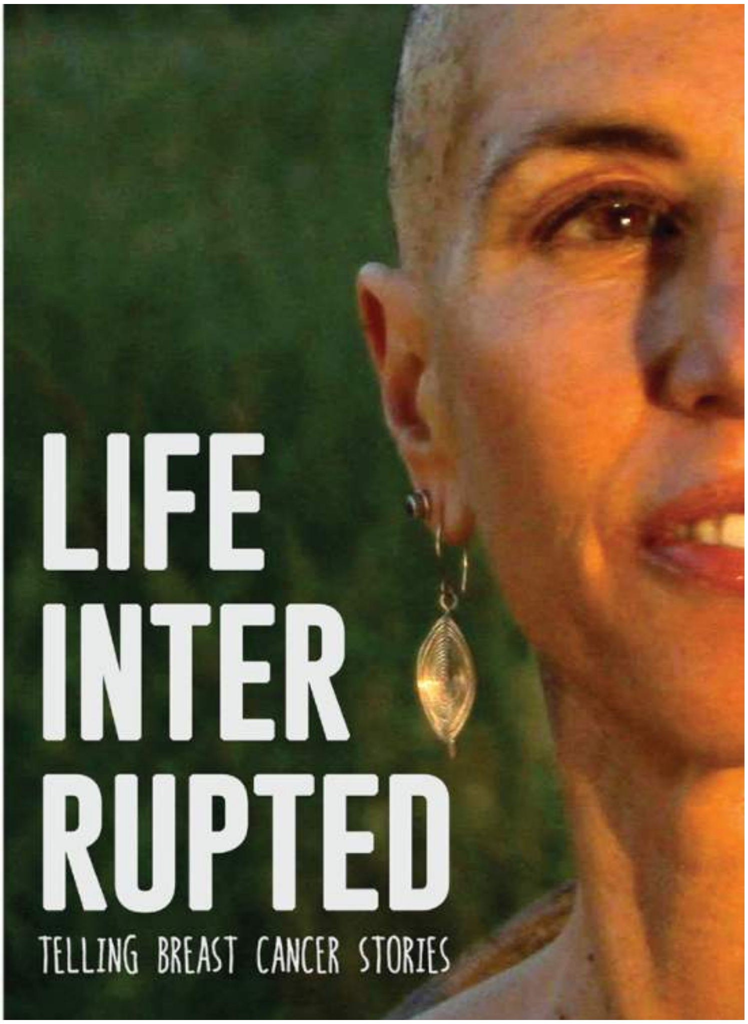
Life Interrupted

Facilitator's Guide

National Library of Medicine
Network of the National Library of Medicine

All of Us RESEARCH PROGRAM

TABLE OF CONTENTS



HOW TO USE THIS GUIDE

KNOWLEDGE IS POWER.

The successful prevention and treatment of breast cancer depends on this.

What is special about this film is that resilient women from various ages, stages of breast cancer, ethnic, geographic and socio economic backgrounds share their journeys as they cross into and return from, the world of Breast Cancer. Breast cancer is not only an epidemic but also a culturally specific phenomenon. “One size does not fit all” when looking at each individual’s circumstances and cultural context.

This Facilitator's Film & Program Guide includes film notes, discussion questions, research ideas and valuable resources for further information to engage with and accompany screening of the documentary film **LIFE INTERRUPTED.**

AUDIENCE

Anyone touched by Breast Cancer including newly diagnosed patients, their families, friends, and co-workers. Healthcare advocates and caregivers will use the film as a guide for client support. The film will be made available to health programs at Universities, Medical Institutions, Community Health, Cancer Wellness and Treatment Centers. Doctors and healthcare providers now have a resource for treating their patients holistically as a critical part of their curricula.

DESCRIPTION OF THE FILM

“I AM SORRY, BUT YOU HAVE BREAST CANCER.”

In the United States, one in eight women will hear these shattering words in her lifetime.

LIFE INTERRUPTED, a film of great intimacy, features empowering stories of breast cancer survivors told through unflinching graphic imagery from the survivor’s perspective. These women are confronting a life-altering diagnosis, and respond to their disease process and the rebuilding of their lives with honesty, dignity, humor and grace. Each woman sheds light on the emotional and physical roadblocks they overcame and what we can learn today from their persistence.

LIFE INTERRUPTED is distinguished for its diversity and inclusiveness, representing survivors of widely diverging ages from 27 to 68; ethnicities including, African American, Native American and Jewish American with a wide range of socio-economic and geographic backgrounds.

RELEVANT SUBJECT AREAS

Medicine, Nursing, Allied Health, Public Health, Health Policy

TECHNICAL INFORMATION

Copyright 2018 TRT 60 minutes
Exhibition Format: Blu Ray DVD, DCP
Aspect Ratio 16:9 English Language

This film is closed captioned in English.

Learn more about the film at **lifeinterruptedfilm.com**

FROM THE FILMMAKER

I was a filmmaker long before becoming a breast cancer survivor so I knew the power of storytelling and how transformative it could be for an audience to experience.

Testing positive for the big "C" was a shocking experience. When first diagnosed, I wanted to take care of it and move on. The last thing I wanted to do was to make a film about it, a project that I knew would take several years to fundraise and complete. Time passed and I got perspective on my own situation, I realized I was NOT alone; there are hundreds of thousands of us out here. In the United States, one-in-eight women will get breast cancer in her lifetime. In 2020, an estimated 330,000 new cases will be diagnosed.

Breast Cancer is indeed an epidemic. It can be found across all age, gender, socio-economic, ethnic, and geographic groups. It does not discriminate. Holding these truths together plus having the inside track to my own experience, I decided to make the film I wish I could have seen when I was diagnosed, both times. I wanted LIFE INTERRUPTED to put a FACE to the statistics and tell meaningful stories in order to inspire change. Today, Breast cancer patients are often asked to make their own choices in terms of treatments available. The moment the diagnosis is received, each person must gather information and make life-altering decisions under extreme emotional duress, all in a relatively short period of time. Individual circumstances are unique and yet, hearing stories from articulate women who have traveled this road before is invaluable for navigating the treatments and keeping hope alive. Knowledge is power, the successful prevention and treatment of breast cancer depends on this.

- Paula Mozen, Director/Producer of LIFE INTERRUPTED

TOPICS

The following Breast Cancer specific topics (emotional, physical and scientific) are covered chronologically in LIFE INTERRUPTED.

WELCOME TO THE DREADED SISTERHOOD

Film opens with introductions to Pat Bear from Fort Belknap Reservation in Montana, Debi Wood from Philadelphia, and Paula Mozen (Director) from Berkeley, California and Bozeman, Montana. Each woman describes her childhood and we get to see three diverse backgrounds.

DIAGNOSED

Each woman describes why and how she was diagnosed and her immediate reactions. Paula attends young survivor's conference in Philadelphia to speak with other young survivors who briefly tell their diagnosis story.

RESEARCHING TREATMENT

Interviewing doctor's, getting referrals from trusted providers, getting second and third opinions.

TREATMENTS & SIDE EFFECTS

Mozen gets a Biopsy and lumpectomy while learning about radiation.

CANCER RETURNS

Uh Oh. Time to make new decisions and what about fertility? Experiencing Chemotherapy and its Side Effects, More Research and discovering Cryopreservation.

WHAT HAPPENS NOW? LIFE AFTER TREATMENTS

Fear of recurrence and experiencing depression. Debi gets pregnant and later has cancer recurrence, turning to the church for support. Pat Bear helps others in her community.

MASTECTOMY

Paula chooses mastectomy getting surgery and reconstruction. Problematic infections cause implant removal. Paula tries fat transfer surgery.

WRAP UP/MOVING ON

Debi, Pat and Paula do their best to put cancer in the rearview mirror.

THEMES

ONE SIZE DOES NOT FIT ALL

- Breast cancer does not discriminate.
  (However access to healthcare can and does discriminate)

PUT A FACE TO THE STATISTICS

- 1 in 8 women will get bc in her lifetime (in the U.S.).
- 325,000 will be diagnosed with breast cancer in 2020.

VALIDATE SURVIVORS' EXPERIENCE

- Breast cancer is not pretty pink ribbons.
- The treatments are rough, including amputating body parts and taking toxic chemo into system.

EMPOWER PATIENTS

- Learn from those who have gone before us and empower current survivors to be proactive in their treatment decisions.
- Ask questions, get support, make best decisions for your situation.

HELP PROVIDERS TO "TREAT THE PATIENT NOT THE DISEASE

- Survivor/thrivers are real people with real lives.
- Give family members, friends, advocates a sense of what living with a breast cancer diagnosis is truly like.

OUTCOMES/OBJECTIVES (SURVIVORS/LAY PEOPLE)

- Increase Breast Cancer awareness
- Empower patients to be self-advocates
- Provide practical education of diagnosis and treatment
- Increase screenings and breast health interventions
- Provide HOPE, support and resources for quality of life survivorship
- Provide resources for prevention and non-toxic lifestyles

OUTCOMES/OBJECTIVES (HEALTHCARE PROVIDERS)

- Insight and empathy to the cancer experience
- Better cancer patient understanding
- Understanding of different generational reactions and cultural differences
- Increased awareness of the emotional, physical and psychological side effects of breast cancer

- Understanding of cancer psychosocial impacts on family relationships

Life Interrupted

DISCUSSION QUESTIONS

GENERAL QUESTIONS ABOUT THE FILM

- The three women profiled in this documentary—Pat Bear, Debi Wood and Paula Mozen—have different life experiences and grew up in different places. How do you think their varying environments and experiences affected both how they were diagnosed with breast cancer, and what treatment options they pursued?

- Were you surprised by how many types of breast cancer and how many ways there are to treat breast cancer? Why might it be important to know that there is a not a one-fits-all solution?

- Did Paula's struggles with the decision to have a mastectomy, and her years-long struggles following the surgeries resonate with you? If so, why? What did that story mean to you?

QUESTIONS THAT TIE IN WITH

ALL OF US

- Based on what you've learned about the *All of Us* Research Program *(All of Us),* how could participating in a research program like *All of Us* improve health outcomes for people diagnosed with breast cancer?

- Why is it important to ensure that participants in research programs like *All of Us* and clinical trials are diverse?

QUESTIONS THAT TIE IN WITH

PRECISION MEDICINE

> *"Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."*
>
> **— Susan Sontag, Illness as Metaphor**

- What did you learn about the BRCA genes, and how genetic factors contribute to the risk for breast cancer?

- How did Paula's illustration of her family tree, and her ancestry help explain why she might have been prone to breast cancer?

- On that same note, how did Debi's diagnosis seem so improbable?

- Paula highlights that she has been a vegetarian since she was 11, and has always been physically active in both lifestyle choices. Based on the concept of precision medicine, how do environment and biology affect a person's health?

- The three women profiled in this documentary—Pat Bear, Debi Wood, and Paula Mozen—have different life experiences and grew up in different places. How do you think their varying environments and experiences affected both how they were diagnosed with breast cancer, and what treatment options they pursued?

- The three women profiled are of varied ages and ethnicity. How does reflecting on these differences help us understand the vagaries of breast cancer? What were similar experiences between the three women? What were some different experiences?

- Several survivors address hitting a wall in the time period following treatment, then what next? What did the survivors learn about how to proceed, both practically and emotionally, after their treatments end? What is the value of continued tracking and care in healthcare?

QUESTIONS THAT TIE IN WITH

PATIENT AGENCY

- What are some vocabulary words that were new to you, both in the film and/or in your personal experience navigating the medical jargon that comes with disease diagnosis?

- How did Pat's proximity to medical care affect her decisions when choosing a doctor and treatment path?

- What did you make of Debi's advice to not accept that the first doctor you see will be the one who treats you? She advocated interviewing doctors, asking them how they would treat her, how willing they were to work with her. Why was this important to her, and how did it affect her decisions to pursue treatment and possible fertility issues?

- What are some things that Paula did to give her confidence in the care and treatments she ended up receiving?

- Were you surprised by how many types of breast cancer and how many ways there are to treat breast cancer?

- Why might it be important to know that there is a not a one-fits-all solution?

- Did Paula's struggles with the decision to have a mastectomy, and her years-long struggles following the surgeries resonate with you? If so, why? What did her story mean to you?

- All three main subjects in this film identified men – whether they were a father, son, or partner – who either actively supported them during their cancer treatment or refrained from caregiving at their request. Based on the film, what suggestions would you give to the loved one of a breast cancer patient, regardless of gender?

Life Interrupted

MEDLINEPLUS ARTICLES

Anywhere, anytime, on any device—for free.

MedlinePlus is an online health information resource for patients and their families and friends and is a service of the National Library of Medicine.

The mission of MedlinePlus is to present high-quality, relevant health and wellness information that is trusted, easy to understand, and free of advertising, in both English and Spanish.

MedlinePlus provides a wealth of quality health information on the topic of breast cancer. To get you started, check out the MedlinePlus articles listed below.

medlineplus.gov

BREAST CANCER

medlineplus.gov/breastcancer.html

BREAST CANCER SCREENING

medlineplus.gov/ency/patientinstructions/000837.htm

MALE BREAST CANCER

medlineplus.gov/malebreastcancer.html

GENETIC CONDITIONS: BREAST CANCER

medlineplus.gov/genetics/condition/breast-cancer/

UNDERSTANDING YOUR BREAST CANCER RISK

medlineplus.gov/ency/patientinstructions/000830.htm

Life Interrupted

RESOURCES

American Cancer Society (ACS)

cancer.org

ACS maintains a website with access to information about all types of cancer, news stories, research information, statistics, alternative approaches, and tips for living with cancer. A nice feature of this site is the section on how to tell children about a parent's cancer diagnosis.

FOR THE BREAST OF US
ALL MELANIN. ALL MOXIE. ALL TOGETHER

For the Breast of Us

breastofus.com

A community to uplift women of color affected by breast cancer by sharing stories that educate, inspire and connect.

Living Beyond Breast Cancer

lbbc.org

Offers practical and evidence-based content that is meaningful to those newly diagnosed, in-treatment, post-treatment and living with metastatic disease.

Young Survival Coalition (YSC)

youngsurvival.org

YSC addresses the unique needs, amplifies the voice and improves the quality of life of young adults affected by breast cancer, locally, nationally and internationally.

Rethink Breast Cancer

rethinkbreastcancer.com

A Canadian non-profit who seeks to empower young people worldwide who are concerned about and affected by breast cancer through innovative education, support and advocacy.

Cancer Support Community (CSC)

cancersupportcommunity.org

CSC offers a variety of professionally-led FREE programs designed to assist every age group and families affected by cancer. 170 locations worldwide, programs that include support groups, yoga classes, and educational workshops.

Mercy Medical Angels

mercymedical.org

Provide free transportation to a specialist medical facility at a distant location. On the ground with gas cards, bus and train tickets and in the air with trips flown by volunteer pilots and the commercial airlines.

Surviving Breast Cancer

survivingbreastcancer.org

Provides support, education, and resources to those diagnosed with breast cancer and their caregivers.

Bay Area Cancer Connection

bayareacancer.org

Supports anyone affected by breast or ovarian cancer, FREE OF CHARGE with personalized services that inform and empower. These include pro-bono counseling, medical research services, events and a wig boutique.

Environmental Working Group

ewg.org

(EWG) Empowers people to live healthier lives in a healthier environment. With breakthrough research and education, including consumer guides for cosmetics and skincare, pesticides in produce and healthy home cleaning products.

Breast Advocate App for iPhone and Android

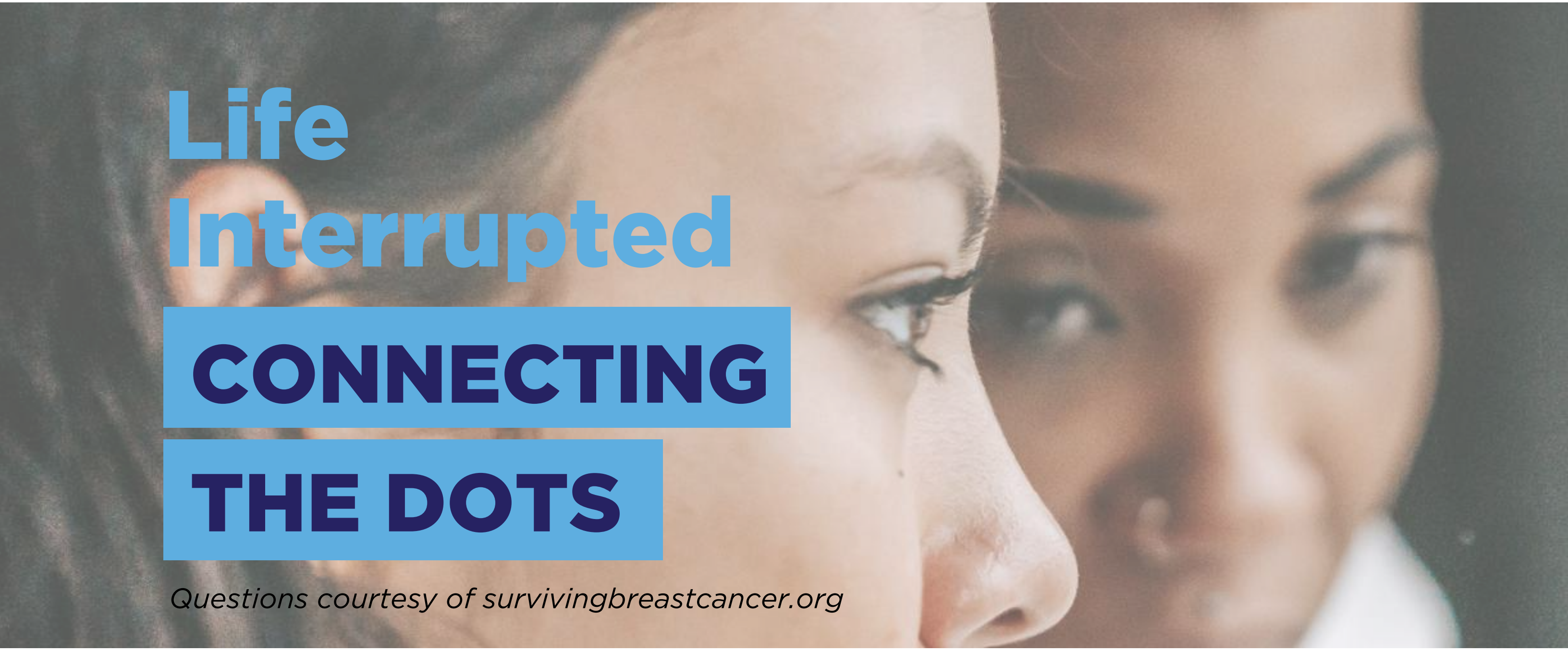
breastadvocateapp.com

A free app, co-created by breast cancer specialists and patient advocates, provides anyone diagnosed with breast cancer or at risk of developing breast cancer a voice in the decisions surrounding surgery. Breast Advocate personalizes information about breast cancer surgery and reconstruction options, and provides access to the latest studies and expert opinions.

Flat Closure Now

flatclosurenow.org

An education and advocacy group created by breast cancer survivors and advocates that is dedicated to ensuring the recognition of and understanding that “going flat” is a valid, beautiful, and healthy breast reconstruction option after a mastectomy or removal of breast implants.



Life Interrupted

CONNECTING THE DOTS

Questions courtesy of survivingbreastcancer.org

The following suggestions and questions have been compiled by previous breast cancer survivors.

KEEPING TRACK

- Get a notebook with pockets and take this to every appointment.
- Be prepared to have records and/or images on discs copied to hand carry to other offices.
- Try to bring someone with you to help take notes if possible. You can also ask them to record the appointment for you. This will allow you to read or listen to the information later and take the time you need to process it.
- If you don’t understand something, ask.

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

After a cancer diagnosis, your relationships with your healthcare team is likely to become some of the most important in your life. Because you will be spending so much time with your team throughout treatment and will share the highs and lows of this experience with them, it is important to find an oncologist that you not only feel confident in but also feel comfortable with. The important point to remember is that it is always okay to ask questions of your health care team, and there are support services to help with any language barriers you may face.

ABOUT YOUR BREAST CANCER TREATMENT PLAN

- Should I consider chemotherapy before surgery?
- Will radiation after surgery affect my reconstruction options?
- Will radiation affect the aesthetic outcome of my surgery? (i.e. will my breast change size?)

ABOUT YOUR SURGEON

- Are you board-certified?
- Do you specialize in this type of surgery?
- How many operations like the one I am considering have you performed?

ABOUT YOUR LYMPH NOTDES

- Do the lymph nodes in my underarm need to be removed?
- What is a sentinel lymph node biopsy? What are the benefits and risks? Would you recommend it for me?
- What is the risk of lymphedema with a sentinel lymph node biopsy? What is the risk of lymphedema with axillary lymph node dissection?
- What should I know about taking care of my arm after lymph node dissection?
- What is the benefit of having more lymph nodes removed?
- What are the side effects of these procedures? Can they be prevented or minimized?

ABOUT SURGERY OPTIONS

- When do I need to make a decision about surgery?
- What are the risks if I decide not to have this surgery?
- Will my tumor be saved? Where will it be stored? For how long? How can it be accessed in the future?
- If I need a mastectomy, is reconstruction (plastic surgery) an option for me?
- What are the advantages and disadvantages? What types of breast reconstruction surgery am I eligible for?
- Fat Grafting/ autologous fat transfer vs implants vs. opting for going flat and no reconstruction (aesthetically flat closure)
- If I chose to have implants, are there different types of implants to choose from? How do I decide which implant is best for me?
- What are the potential risks and side effects of this operation?
- Do I need to consult a plastic surgeon about reconstruction options? Can you help me arrange that?
- How many surgeries will be involved?
- Will I need expanders? Can you explain to me what they are and for how long I will have them?
- Am I eligible to have one surgery where you remove the tumor and can go direct to implant? What are the pros and cons?
- If I have a mastectomy without reconstruction, where can I get a prosthesis? Is this covered by my insurance?
- Will there be permanent effects from the surgery?
- Should I get a second opinion? How do I go about doing that?

ABOUT THE SURGERY ITSELF

- How long is the procedure? How long will I stay in the hospital?
- What type of anesthesia will I need for this operation?
- What medications and supplements should I stop taking? Should I stop taking hormone replacement therapy? What about birth control pills?
- What are the possible complications for this type of surgery? How would I know if there is a problem?
- Will my medical insurance cover all charges from you and the hospital?

BEFORE SURGERY

- Do I need any other tests before this surgery?
- Am I a candidate for a lumpectomy?
- Am I a candidate for a nipple sparing surgery
- If I have a choice between a lumpectomy or a mastectomy, what are the pros and cons of each option in my case?
- What is the best possible outcome from my surgery?
- What is the worst case scenario from this type of surgery?

ABOUT THE DAY OF SURGERY

- What should I do to get ready for the operation? Do you have recommendations on how to help me relax before surgery?
- What can I expect as part of the pre-op? Does that happen the same day of the surgery or prior?

ABOUT RECOVERY

- How long will it take me to recover after the surgery? What should I expect the first day, first week, first month?
- What kind of pain will I be in afterwards? How do you help me manage my pain?
- What risks or side effects of this surgery do I need to know about? i.e., pain, tenderness, bruising, scarring, numbness? Which ones do I need to report to you?
- Will any of the side effects be long-term? Is there anything I can do to reduce side effects?
- When should I call your office if I experience any side effects?
- Will the hospital provide a home nurse to help change my bandages? How will this be arranged?
- Will I have stitches, staples, and/or bandages?
- Will I need to have surgical drains? How do I clean the drains? How long will the surgical drains be in?
- What kind of care will my incision need after surgery?
- Is there anything I can do before surgery to help the healing process after surgery?
- When can I shower or bathe?
- Where will the scar be, and what will it look like? Can you draw me a picture so I can better understand?
- What will my breasts look and feel like after surgery?
- What type of clothes should I bring to go home in? Will I need a special type of bra?
- When will I need to return for a follow-up appointment?
- When will I find out the results of the surgery? Who will discuss the pathology report with me? Will it be in person or by phone?
- Will my arm be affected by surgery? For how long? Will I need physical therapy for my arm?
- Are there physical therapy exercises I should do after surgery? When can I start exercising again?
- Are there any activities I should avoid and for how long?
- When can I start to treat my scar on my own? Do you recommend special creams or lotions?
- When can I return to work and other daily activities?

AFTER YOUR FIRST SURGERY

- What is the size of the tumor?
- What is the grade and stage of this disease? What are my biomarkers? What do these mean?
- What are the chances that the breast cancer will return?
- Will I need chemotherapy? Am I eligible for the Oncotype DX or Mammoprint?
- Can you explain my pathology report (laboratory test results) to me?
- Can I get a copy of my pathology report?
- Was all of the cancer removed during the surgery? Do I have clear margins?
- How many lymph nodes were removed?
- Has the cancer spread to any of the lymph nodes? If so, how many? Has the cancer spread to anywhere else in my body?
- Do I need additional surgery?
- Are there additional tests you recommend?
- How often do you and I meet for follow ups?

WHAT QUESTIONS DO YOU HAVE?

NOTES FROM NNLM

ABOUT THE NATIONAL LIBRARY OF MEDICINE

Founded in 1836, the National Library of Medicine (NLM) is one of the 27 institutes that make up the National Institutes of Health and is the world's largest biomedical library.NLM maintains and makes available a vast print collection and produces electronic information resources on a wide range of topics that are searched billions of times each year by millions of people around the globe.NLM produces two electronic information resources:MedlinePlus (https://medlineplus.gov/), an online health information resource for patients and their families and friends, and PubMed (https://pubmed.ncbi.nlm.nih.gov/), a free resource containing. supporting the search and retrieval of biomedical and live sciences literature with the aim of improving health – both globally and personally. PubMed contains more than 30 million citations and abstracts of biomedical literature.

ABOUT THE NETWORK OF THE NATIONAL LIBRARY OF MEDICINE

The Network of the National Library of Medicine (NNLM) is the core of NLM's community engagement program. The mission of the NNLM is to advance the progress of medicine and improve the public health by providing all U.S. health professionals with equal access to biomedical information and improving the public's access to information to enable them to make informed decisions about their health. NNLM's membership includes representation from academic health sciences libraries, hospital, pharmaceutical and other special biomedical libraries, public libraries, information centers, and community-based organizations. Through its Regional Medical Libraries, NNLM provides funding, training, and connections to empower members to transform their communities with trusted health information.

Learn more about NNLM at nnlm.gov/about

ALL OF US
RESEARCH PROGRAM

All of Us is a national research program whose mission is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us.The goal of the program is to help researchers understand more about why people get sick or stay healthy. By looking for patterns, researchers may learn more about what affects people's health. *All of Us* aims to build one of the largest, most diverse datasets of its kind for health research, with one million or more volunteers nationwide who will sign up to share their information over time (it is a 10-year program).The program aims to reflect the diversity of the United States through its participants. All people living in the United States—not just citizens—will be eligible to participate. *All of Us* is a bilingual program, with all components of the program available in English and in Spanish. Additional languages will be added in the future. Learn more about *All of Us* at joinallofus.org/nlm (English) or joinallofus.org/bnm (Spanish).

The National Library of Medicine (NLM) has partnered with the NIH *All of Us* Research Program *All of Us* to help public libraries in supporting the health information needs of their users. Through its main outreach initiative, the Network of the National Library of Medicine, NLM provides:

- health information training for public library staff,
- funding and other resources to support health programming and activities, and
- connections to medical libraries and other NNLM members in their area.

The NNLM also supports the program's commu*All of Us*agement activities by leveraging public libraries as community conveners where the public and All of Us consortium partners can find help locating information, meeting spaces, and access to technology.

Learn more about how your public library can participate in the program at nnlm.gov/allofus