

A Family's Breast Cancer Experience

Louise Miller, R.T.(R)(M)(ARRT), CRT(M), FSBI, FNCBC
Director of Education, Mammography Educators



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1

Chronology of Events

- | | | |
|-----------------------|-------------|--------|
| • Sarah Marcy - niece | Dx IDC TNBC | age 31 |
| • Louise | Dx IDC TNBC | age 67 |
| • Joan - sister | Dx IDC | age 65 |
| • Alexa - niece* | Dx IDC | age 36 |
| • Louise | Dx DCIS | age 73 |
| • Jean - sister | Dx IDC | age 72 |



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2

For **3** Sisters
VICKY
PENNY
VALEESA

YOU WILL NEVER FIGHT BREAST CANCER ALONE



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3

Breast Cancer "Schedule of Events"

- Mammogram
- Add views/US
- Bx (stereo, US, MRI)
- Bx results
- Meet with surgeon - discuss options
- Surgery
- Treatment



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4

Breast Cancer “Schedule of Events”

- **Mammogram**
- **Add views/US**
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- Bx results
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- Treatment



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5



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6

Breast Cancer “Schedule of Events”

- Mammogram
- Add views/US
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- **Meet with surgeon - discuss options**
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- **Treatment**



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Other Considerations

- Age at diagnosis
- Access to good medical care
- Options/second opinions
- Support system



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8

Other Considerations

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Age at Diagnosis



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Sally's Story

- Lump found on clinical exam required for change in insurance
- Mammo and US bx
- TNBC
- Lumpectomy
- Recurrence
- Mastectomy
- Reconstruction and augmentation contralateral breast



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11

Alexa's Story

- 2 maternal aunts with breast cancer
- Mammo showed extremely dense breast tissue
- Genetic testing - Check 2 gene
- MRI - multifocal IDC and DCIS
- Mastectomy
- Reconstruction
- Plan for prophylactic mastectomy contralateral breast



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12

Breast Care

Review Article

Breast Care
DOI: 10.1159/000531136

Received: March 23, 2023
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Published online: May 19, 2023

The Role of Social Media in Breast Cancer Care and Survivorship: A Narrative Review

Iliana Aristokleous^{a,b} Andreas Karakatsanis^{a,b} Yazan A. Masannat^{c,d,e}
Stavroula L. Kastora^{c,f}

Breast Care
18 | 3 | 23

Breast Care
Multidisciplinary Journal for Research, Diagnosis and Therapy

Focus I
Efficacy and Role of Hormonal Therapy before and after BC Therapy
Editor
S. Konec (Munich)

Focus II
Role of New Media in Surgical Surgery Education
Editors
T. Maassner (Bonn), A. Karakatsanis (Sapporo)

RESEARCH Karger

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13

Background:
Female breast cancer (BC) is the most diagnosed cancer and the leading cause of malignancy-related death worldwide. With the widespread utilisation of the Internet, social media has presented an invaluable yet underemployed tool in the context of BC medical information dissemination, support hub formation, and patient empowerment.

Summary:
In this narrative review, we explore the untapped potential of social media in this context, caveats, and future directions that may aid in formulating a new era of patient led, in addition to patient-centered care.

The Role of Social Media in Breast Cancer Care and Survivorship: A Narrative Review
May 2023 | Breast Care 18(3):1-7 | DOI: [10.1159/000531136](https://doi.org/10.1159/000531136)
https://www.researchgate.net/publication/371743247_The_Role_of_Social_Media_in_Breast_Cancer_Care_and_Survivorship_A_Narrative_Review

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14

Key messages:
Social media represents a powerful tool with significant potential to enable the seeking and sharing of BC-related information, and enhance patient education, communication, engagement, and empowerment. However, its use is associated with a number of limitations, including confidentiality and addiction issues, excessive and inaccurate information, and a possibility of jeopardising the patient-doctor relationship. Further research is needed to shed more light on this topic.

The Role of Social Media in Breast Cancer Care and Survivorship: A Narrative Review
May 2023 | Breast Care 18(3):1-7 | DOI: [10.1159/000531136](https://doi.org/10.1159/000531136)
https://www.researchgate.net/publication/371743247_The_Role_of_Social_Media_in_Breast_Cancer_Care_and_Survivorship_A_Narrative_Review

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15

My Story

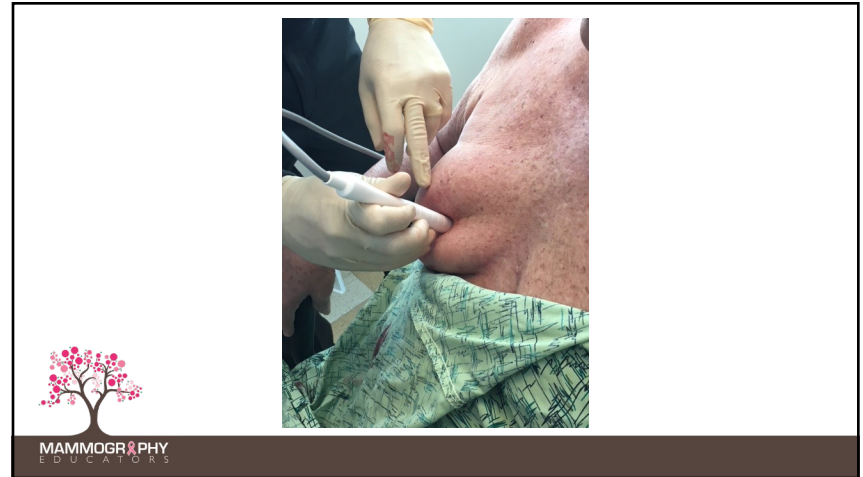
- Screening mammo - August 2017
- Dx mammo, US
- US and stereo bx
- Bx results - Stage 2 TNBC
- Adjuvant chemo - September 2017 - February 2018
- Lumpectomy - March 2018
- Rad tx - March - June 2018

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16



17



18



19

Screening in Women over 70

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[Home](#) > [News & Events](#) > [Cancer Currents Blog](#) > Study Adds to Debate about Mammography in Older Women

Study Adds to Debate about Mammography in Older Women

Subtotal

September 15, 2013, by Sherryl Reynolds

It has become widely accepted that it's always best to find breast cancer as early as possible, when the cancer is less likely to have spread elsewhere in the body and less aggressive treatment may be needed.

And studies have shown that routine screening mammography does reduce breast cancer deaths in women aged 40 to 75.

But screening also comes with downsides, which include the risk of overdiagnosis and overtreatment. **A new study suggests that the risk of overdiagnosis with routine screening mammography is substantial for women in their 70s and older.**

And this overdiagnosis risk escalates with increasing age and other health problems, according to findings published August 8 in the *Annals of Internal Medicine*.

The concept of overdiagnosis is a tricky one. It doesn't refer to false positives—test results that indicate that a suspicious mass is cancer when further tests show that it actually isn't. Instead, in overdiagnosis, a screening test does find a true cancer. But it's a cancer that will grow very slowly—or not at all—and would never cause problems during someone's lifetime.

A mammogram with a white arrow pointing to an asymmetry that was found to be an invasive ductal carcinoma.

20

RSNA

Women 75 Years Old or Older: To Screen or Not to Screen?

Benefits of screening mammography in women aged 75 years or older

- 1 Early detection of smaller lower-stage tumors
- 2 Less invasive treatment
- 3 Better prognosis
- 4 Lower morbidity and mortality rates

MLO view: mass with calcifications in the left breast

CC view: mass with calcifications in the left breast

Spot compression magnification: spiculated mass with fine pleomorphic calcifications

US: irregular hypoechoic mass with calcifications

Biopsy: moderately differentiated invasive carcinoma and DCIS

CC = cranial/caudal; MLO = medial/lateral oblique

Lee CS et al. Published online: April 13, 2023
<https://doi.org/10.1148/rg.220166>

RadioGraphics

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21

Other Considerations

- Age at diagnosis
- **Access to good medical care**
- Options/second opinions
- Support system

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22

Access to Good Health Care

Jackson Hole, WY

San Francisco, CA

Aberdeen, NC

San Diego, CA

Covington, LA

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23

Other Considerations

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24

Options/Second Opinions

- Diagnosis
- Surgical options
- Treatment options



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25

Options/Second Opinions

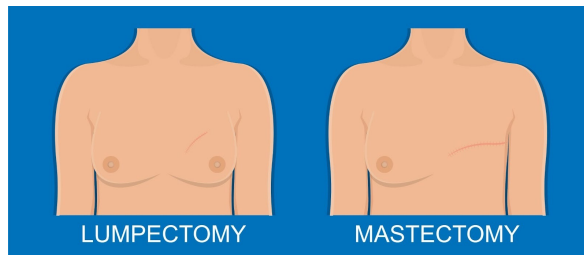
- **Surgical options: lumpectomy, mastectomy, prophylactic mastectomy on contralateral breast**
- Treatment options: adjuvant chemotherapy, surgery, radiation therapy
- Reconstruction/prosthesis



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26

Lumpectomy vs Mastectomy



<https://www.mybcteam.com/resources/lumpectomy-vs-mastectomy-side-by-side-comparison>



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27

Options/Second Opinions

- Surgical options: lumpectomy, mastectomy, prophylactic mastectomy on contralateral breast
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28

Chemotherapy

- Types of chemo depend on stage and grade
- Rounds - how many, how often



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29



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30

Physical Side Effects of Chemotherapy

- Mouth/throat/nose sores and changes
- Nerve changes (neuropathy)
- Pain
- Sexual changes
- Swelling
- Urinary changes
- Memory changes



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31




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32

If I had a dollar for everytime I got distracted, I wish I had some ice cream.



someecards
user card




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Radiation Therapy

- Usually begins 1 month after surgery to allow the surgical site to heal properly
- Usually once a day, 5 days per week, x ___ weeks
- Boost to the surgical bed is usually done during the last 5 treatments
- Side effects include: erythema, sensitivity, pain, itching, peeling
- RIF can last up to 6 months post tx



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34



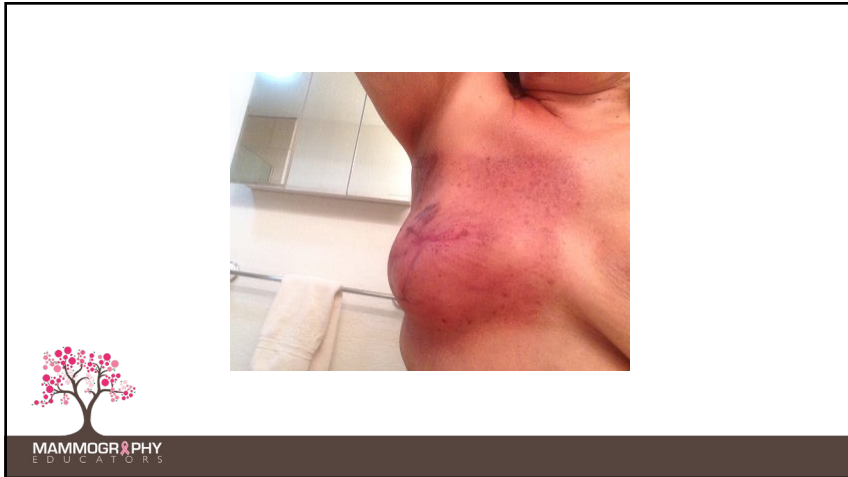
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35



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36



37


If you're getting radiation therapy to the breast
 If you have [radiation to the breast](#), it can affect your heart or lungs as well causing other side effects.

Short-term side effects
 Radiation to the breast can cause:

- Skin irritation, dryness, and color changes
- Breast soreness
- Breast swelling from fluid build-up (lymphedema)

To avoid irritating the skin around the breasts, try to go without wearing a bra. If this isn't possible, wear a soft cotton bra without underwires. If your shoulders feel stiff, ask your cancer care team about exercises to keep your shoulder moving freely. Breast soreness, color changes, and fluid build-up (lymphedema) will most likely go away a month or 2 after you finish radiation therapy. If fluid build-up continues to be a problem, ask your cancer care team what steps you can take. See [Lymphedema](#) for more information.

Long-term changes to the breast
 Radiation therapy may cause long-term changes in the breast. Your skin may be slightly darker, and pores may be larger and more noticeable. The skin may be more or less sensitive and feel thicker and firmer than it was before treatment. Sometimes the size of your breast changes – it may become larger because of fluid build-up or smaller because of scar tissue. These side effects may last long after treatment. After about a year, you shouldn't have any new changes. If you do see changes in breast size, shape, appearance, or texture after this time, tell your cancer care team about them right away.



<https://www.cancerresearchuk.org/about-cancer/treatment/radiotherapy/side-effects/general/tiredness>

38

Less common side effects in nearby areas

Although it's rare, radiation to the breast can affect organs in the chest, including the heart and lungs. This is not as common today as it was in the past, because modern radiation therapy equipment allows doctors to better focus the radiation beams on the area with cancer, with less affect to other areas.


Rib fractures: In rare cases, radiation therapy may weaken the ribs, which could lead to a fracture. Be sure you understand what to look for and tell your cancer care team if you notice any of these side effects.

Heart complications: Radiation to the breast can also affect the heart. It can cause hardening of the arteries (which can make you more likely to have a heart attack later on), heart valve damage, or irregular heartbeats.

Lung damage (radiation pneumonitis): Getting radiation to the breast can sometimes cause an inflammation of the lungs, which is called radiation pneumonitis. See "If you're getting radiation to the chest" below for more details.

Damage to the nerves in the shoulder and arm: Radiation to the breast can sometimes damage some of the nerves to the arm. This is called brachial plexopathy and can lead to numbness, tingling, pain, and weakness in the shoulder, arm, and hand.

Side effects of brachytherapy
 If your treatment includes brachytherapy (internal radiation implants), you might notice breast tenderness, tightness, redness, and bruising. You may also have some of the same side effects that happen with external radiation treatment. Let your cancer care team know about any problems you notice.



<https://www.cancer.org/cancer/managing-cancer/treatment-types/radiation/effects-on-different-parts-of-body.html>


39

Tiredness

You might feel tired during your radiotherapy treatment. This could be because:

- of the cancer
- your body is using energy to repair damage to healthy cells from the radiation
- you are in pain
- you are having to travel quite a way for your radiotherapy appointments
- you're feeling anxious and stressed - this might affect the quality of your sleep at night

Radiotherapy side effects tend to get worse as you progress through your treatment. So you might not feel tired at the beginning of your course but might do towards the end. And for a few weeks afterwards. It's hard to say who will feel tired during treatment as some do and others don't.



<https://www.cancerresearchuk.org/about-cancer/treatment/radiotherapy/side-effects/general/tiredness>

40

Why Does Radiation Cause Fatigue?

Radiation causes fatigue by damaging healthy cells, even though it targets tumors. It can kill red blood cells, making it harder for blood to carry oxygen throughout the body. Radiation may also damage the power plant inside cells, effectively making them run on a low battery. For many patients, these changes can be temporary, but fatigue may persist long-term for others.



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<https://www.mesothelioma.com/blog/radiation-fatigue-causes-duration/>

41

Breast Care (Basel). 2021 Jun; 16(3): 236-242.
Published online 2020 Aug 14. doi: [10.1159/000509410](https://doi.org/10.1159/000509410)

Radiotherapy-Induced Fatigue in Breast Cancer Patients

Lita Kewerová*¹, Christian Reuschmann², Barbara Cerezo³, Taha Kocak⁴, Christian F. Simeu⁵, and Alex Fera⁶*

Abstract

Background A large proportion of breast cancer patients who undergo adjuvant radiotherapy suffer from radiotherapy-induced fatigue. The possible causative factors of this specific side effect are diverse.

Summary Prevalence, duration, and severity of radiotherapy-induced fatigue are dependent on the type of radiotherapy, as well as on the irradiated volume, dose scheme, on the number of radiation fields, the combination with other treatments, diurnal rhythm, smoking, and time-to-hospitalization. Recommended treatments include non-pharmacologic interventions, such as physical and psychosocial interventions. Pharmacologic therapies include treatment with methylphenidate and modafinil. In addition to its early detection with standardized instruments, adequate education to breast cancer patients about risks and predisposing factors of radiotherapy-induced fatigue is essential. Multidimensional strategies help to maintain the patients' quality of life and therefore guarantee treatment adherence and efficacy.

Key Messages

Radiotherapy-induced fatigue is an underreported, underdiagnosed, and undertreated side effect. This review provides an overview of radiotherapy-induced fatigue in breast cancer patients receiving adjuvant radiotherapy.



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42

Options/Second Options

- Surgical options: lumpectomy, mastectomy, prophylactic mastectomy on contralateral breast
- Treatment options: adjuvant chemotherapy, surgery, radiation therapy
- **Reconstruction/prosthesis**



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43

- When can I have a reconstruction?
- Who will do the reconstruction
- Types of breast reconstruction
- Implant reconstruction
- Flap reconstruction
- Re-creating the nipple
- Surgery to the other breast
- What to expect after surgery
- Taking care of yourself after a reconstruction
- Costs and financial assistance



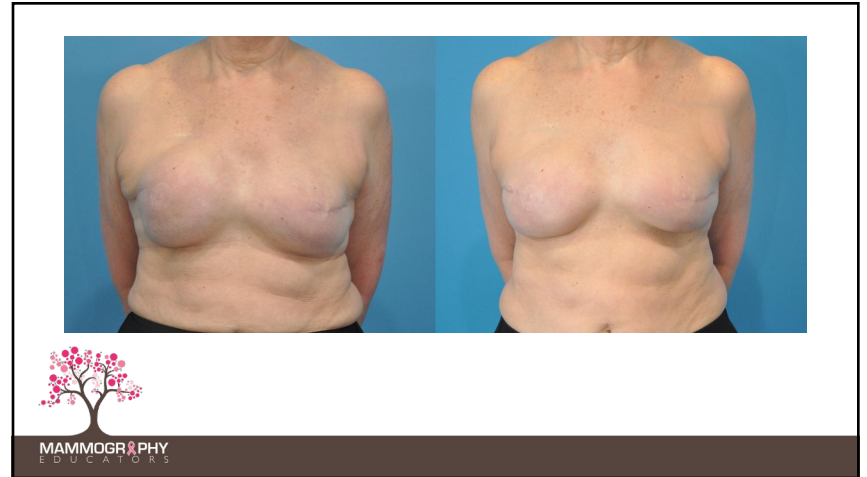
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<https://www.cancerouncil.com.au/cancer-information/managing-cancer-side-effects/breast-prostheses-and-reconstruction/breast-reconstruction/>

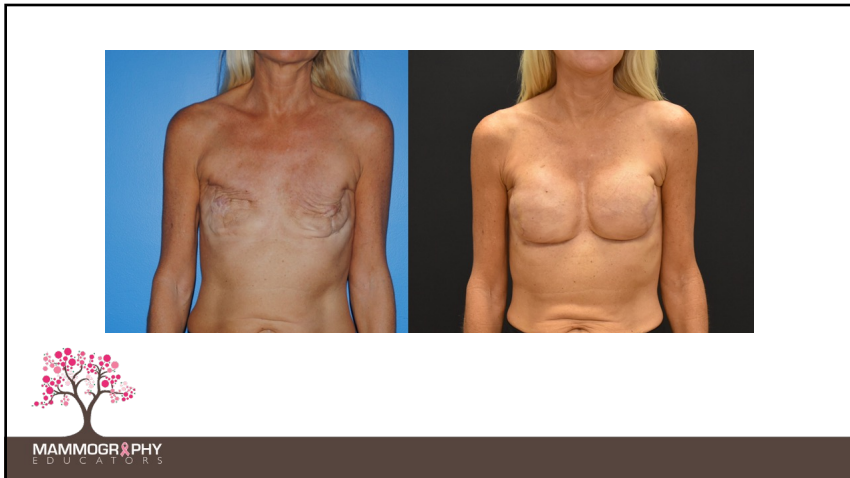
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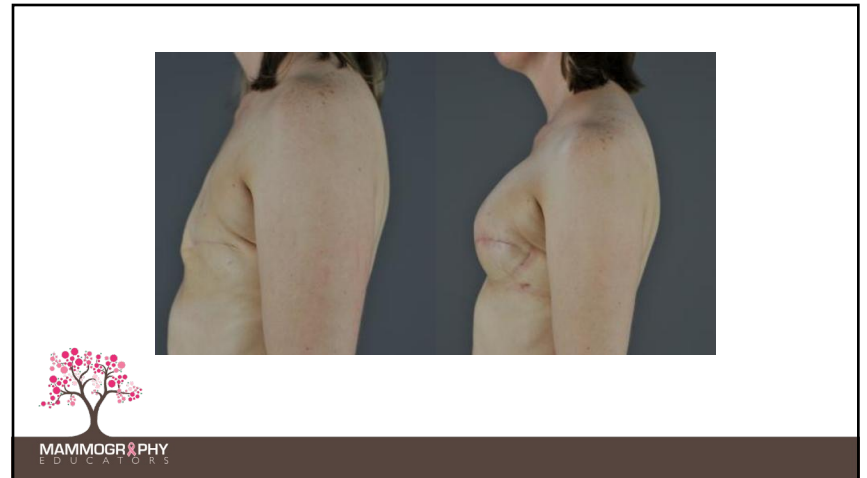
45



46



47



48



49

Prosthetic Considerations

- Type
- Weight
- Temperature
- Comfort
- Cost
- Availability



50

knitted knockers

soft, comfortable, knit prosthetics for breast cancer survivors



51

knitted knockers

soft, comfortable, knit prosthetics for breast cancer survivors



52



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53

In addition to helping enhance a patient's appearance by providing a more natural and balanced look, other reasons to consider a breast prosthesis include:

- Preventing musculoskeletal and posture problems
- Staying warm
- Protecting your chest wall and surgical scars
- Keeping your bra in place



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<https://www.cancerCouncil.com.au/cancer-information/managing-cancer-side-effects/breast-prostheses-and-reconstruction/breast-reconstruction/>

54

5 Types of Breast Prostheses To Know About



<https://www.mybcteam.com/resources/types-of-breast-prostheses-to-know-about>



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55

You may want to work with a certified mastectomy fitter, a trained health care professional who specializes in postmastectomy breast forms — also known as prosthetic breasts. Many shops that sell breast prostheses employ certified fitters. Although a ready-made breast prosthetic may be right for you, custom-made breast forms are also available.

Here are the various types of breast prostheses you may want to consider.

1. Temporary Breast Prosthesis

Soon after you have breast surgery, your breast care nurse will likely give you a temporary breast prosthesis, sometimes called a "softy" or "comfie." This soft, lightweight type of prosthesis can be sewed or pinned into a bra cup while you're healing after surgery.

2. Partial Breast Form

A partial breast prosthesis fills in areas where breast tissue was removed during breast-conserving surgery or a lumpectomy. A partial prosthesis is typically worn inside the bra.

3. Full Prosthesis

A full prosthesis, or standard prosthesis, is used after a mastectomy and is sometimes paired with a postmastectomy bra that has pockets for the breast form. Some research has shown that a properly weighted breast prosthesis can help correct posture after a mastectomy. The surgery has been shown to cause forward-leaning posture disorders.

Full prostheses are available in different skin tones. Some breast forms can be positioned directly on the chest with adhesive strips. A proper fitting for a full prosthesis can help ensure that you are as comfortable as possible.

4. Shell Prosthesis

A shell prosthesis is a hollow form that goes over the breast and gives it a fuller look. Shells are sometimes used when breast shapes aren't symmetrical after breast-conserving surgery or breast reconstruction.

5. Nipple Prosthesis

A prosthetic nipple can be worn if nipples are uneven after breast surgery, with breast reconstruction, or with another type of prosthesis. A nipple prosthesis is attached with an adhesive backing or skin glue that holds it in place for several days at a time.



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<https://www.mybcteam.com/resources/types-of-breast-prostheses-to-know-about>

56

Other Considerations

- Age at diagnosis
- Access to good medical care
- Options/second opinions
- **Support system**



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57

Role of Patient Navigator

- Provide individual guidance and support for the patient
- Getting scheduled for needed tests/procedures
- Understands and can advise on sequence of events
- Assist with increasing access to community and social support services
- Work with community groups to increase breast health awareness and provide breast health education



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58

Familial Breast Cancer

- Roll of genetics
- Environment
- Psychological factors
- Advise/information
- Treatment
- Survivorship
- Ongoing support



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59

Familial Breast Cancer

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60

Genetic Testing

About 5% to 10% of breast cancer cases are thought to be hereditary, meaning that they result directly from gene changes (mutations) passed on from a parent.



61

→ WHAT ARE BRCA1 AND BRCA2?
Genes that fix DNA damage inside your cells to help prevent cancer from developing. If one of your BRCA genes is mutated, your body has one that works and a broken one, meaning not every episode of DNA damage is repaired. This is especially a problem in the cells of your organs like the breast, which are prone to cancer in BRCA mutation carriers.

LITTLE KNOWN FACT:
Everyone has two BRCA1 and BRCA2 genes, but when one gene in a BRCA pair is mutated it can't fix DNA damage in breast cells. This leads to breast cancer.

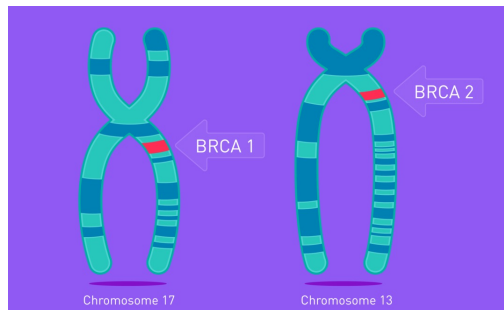
FACT: A woman's lifetime risk of developing breast and/or ovarian cancer is greatly increased if she inherits a harmful mutation in BRCA1 or BRCA2.

HOW IS IT INHERITED? ←
50/50
Each child of a parent who carries a mutation in one of these genes has a 50% chance of inheriting it too.

Cancer happens when DNA is damaged



62



<https://pinkribbon.org.pk/brca-gene-testing-for-breast-cancer-what-you-need-to-know/>



63

Genetic Mutations

- ATM
- BARD1
- CDH1
- CHEK2
- NFI
- PALB2
- PTEN
- RAD51C
- RAD51D
- STK11
- TP53



64

- **PALB2** – After BRCA1 and BRCA2, PALB2 is currently the third most prevalent breast cancer gene. PALB2 is short for “Partner And Localizer of BRCA2.” In other words, it works in partnership with the BRCA2 gene to repair DNA damage and thereby prevent breast cancer from developing. An estimated 35% of women with a mutated PALB2 gene will develop breast cancer by age 70.
- **CHEK2** – “Checkpoint Kinase 2,” or CHEK2, creates a protein that helps suppress **tumor** growth. Having a mutated CHEK2 gene doubles the risk of breast cancer in women. In men, it makes **male breast cancer** 10 times more likely to occur.
- **CDH1 – CDH1**, or “CaDHerin 1,” is a tumor suppression gene that helps groups of cells stick together to form organized tissues. A mutation in the CDH1 gene can increase the risk of forming lobular breast cancer, or cancer that begins in the breast’s milk-producing lobules. Since the gene normally helps cells stick together, a mutation can also make it easier for individual cancer cells to break off from a **breast tumor** and **metastasize**, or spread to other parts of the body.
- **PTEN** – The “Phosphatase and TENsin homolog” (PTEN) gene helps prevent tumor growth by controlling the rate of cell division. It also causes damaged cells to self-destruct before they can become cancerous. Like CDH1, PTEN also plays a role in helping cells stick together, which can help prevent cancer from spreading.
- **STK11** – “Serine/Threonine Kinase 11” is another tumor suppressor. STK11 gene mutations cause Peutz-Jeghers syndrome. **Peutz-Jeghers syndrome** carries an increased risk for multiple types of cancer, including breast cancer.
- **TP53** – Also known as P53 (and nicknamed the “guardian of the genome”), “Tumor Protein p53” recognizes when a cell’s DNA has been damaged. It then either activates a DNA repair gene (like BRCA1) or causes the cell to self-destruct. If TP53 is mutated, the damaged DNA won’t be repaired and the cell will live on, perhaps becoming a cancer cell. Though some TP53 mutations are inherited, most of them occur during a person’s lifetime and are only found in cells that become cancerous.



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<https://www.nationalbreastcancer.org/other-breast-cancer-genes/>

65

Familial Breast Cancer

- Roll of genetics
- **Risk factors**
- Psychological factors
- Advise/information
- Survivorship
- Ongoing support



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66

Risk Factors You Can Control	Risk Factors You Cannot Control
<ul style="list-style-type: none"> Give up smoking Reduce alcohol consumption Eat a healthy, balanced diet Keep your weight under control Exercise regularly 	<ul style="list-style-type: none"> Age Gender Family History Genetic

<https://twitter.com/Samitivej/status/1182144656231944192>



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67

Familial Breast Cancer

- Roll of genetics
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- **Psychological factors**
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68

Psychological Factors/Reactions

- Fear
- Shock
- Disbelief
- Confusion
- Anger



69

Common Emotions During/After Tx

- Concerns about chronic health problems
- What do I do next?
- Frustration with physical changes or new limitations
- Sense of grief or loss (over others being diagnosed)
- Discomfort or shame when asking for help so long after treatment
- Anger



70

Common Emotions During/After Tx

- Relief that it is finally over
- Cautious optimism
- Fluctuations in emotions
- Concerns about chronic health problems



71

AND THE NUMBER ONE CONCERN

FEAR OF RECURRENCE

- Can interfere with every aspect of life
- Can be triggered by reminders
- Can be masked by effects of treatment



72

Remember: Recovery Takes Time

“When treatment ends, the “warrior” and his/her family often not prepared for the fact that recovery takes time. In general, your recovery will take much longer than your treatment did. People often say that they did not realize how much time they needed to recover.”

Facing Forward



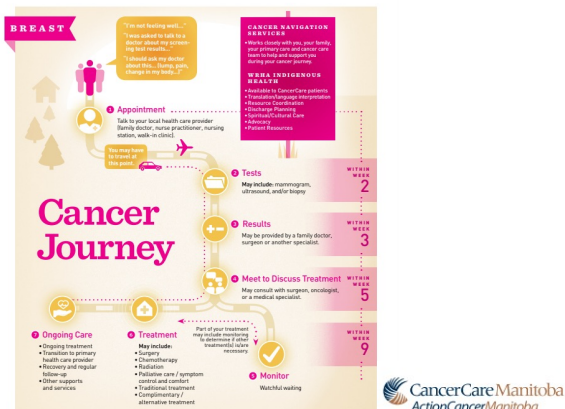
73

Familial Breast Cancer

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74



75

Advice/Information




76



Role of Patient Navigator


- Assist in identifying, applying, and using appropriate social services
- Help identify and obtain financial help for their health care needs
- Help patients arrive on time and prepare for scheduled appointments
- Help reduce patients' fears and anxiety



Role of Patient Navigator

The program grew out of the 1989 ACS national hearings on cancer and the poor which noted:


- Gaps in service that lead to fragmentation of care
- Delayed and/or missed appointments
- Substantial barriers to care, including lack of knowledge of available financial support (insurance) and assistant
- Lack of social support



Role of Patient Navigator

Functions patient navigators do NOT perform:

- Physical assessment, diagnosis or treatment
- Ordering of care, treatments or medications
- Direct patient care
- Physical, occupation, psychological or speech therapy





Lorie Kielley is a registered nurse who works as a cancer patient navigator with Newfoundland and Labrador Health Services. (Paul Daly)

"Having someone to reach out to, to guide them through what to expect, what supports are available to them and guide them through the whole process, is definitely something that can at least take a little bit of stress out of the experience," said Kielley.

<https://www.cbc.ca/radio/whitecoat/cancer-navigator-diagnosis-1.7137874>



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81

Familial Breast Cancer

- Roll of genetics
- Risk factors
- Psychological support
- Advise/information
- **Survivorship**
- Ongoing support



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82

Survivorship

- Relief
- Fear
- Sadness
- Shame
- Anger



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Familial Breast Cancer

- Roll of genetics
- Risk factors
- Psychological support
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- **Ongoing support**



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Ongoing Support

Women of Color
Breast Cancer Survivors' Support Project



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Future Generations

- Genetic testing
- Breast density awareness
- Individualized screening



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Learning and Teaching Points

- Realization that the breast cancer survivor/patient may have different emotional and physical needs
- The effectiveness of good communication skills
- The importance of education



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“Say What?” Things You Should Never Say To A Cancer Patient*

- “What are your odds?”
- “You brought this on yourself.”
- “I know someone with your type of cancer, they _____.”
- “Good luck on your journey.”
- “Forget what your doctor says, you should try x,y,z.”
- Nothing



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*Hutch News: Oct. 30, 2013 By Diane Mapes

90

Importance of Education

- Learn all you can
- Ask questions
- Read, read, read
- Understand the *patient* experience
- Use the information to be compassionate towards those finding their way



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KNOWLEDGE IS POWER!!



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What You Can Do as a Family Member/Friend

- Speak from the heart
- Help with specific tasks before they ask
- Remember, even cancer patients get cancered out
- Be there
- Show compassion



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“Cancer brings changes that are not always for the worse and they bring about healthy personal growth. The cancer experience and your emotional responses can become important resources as you face your future.”

LIVESTRONG ©2004



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This is personal!

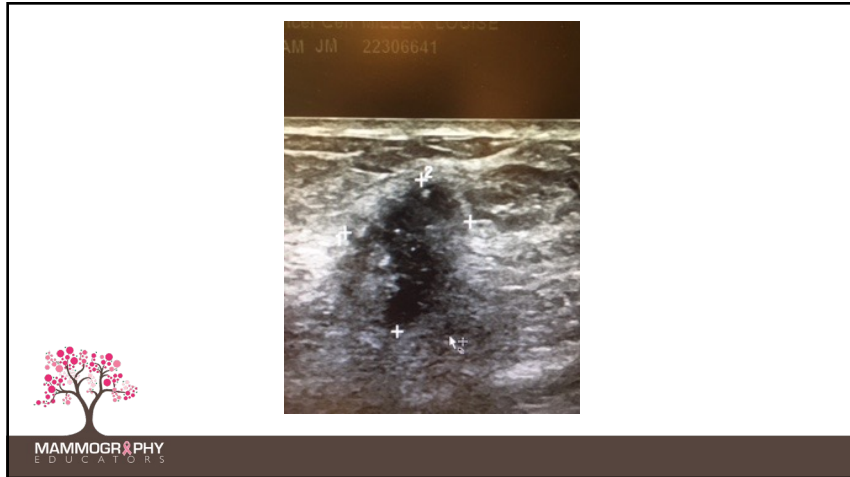
Each and every patient belongs to someone.

Take the time to see them as such.

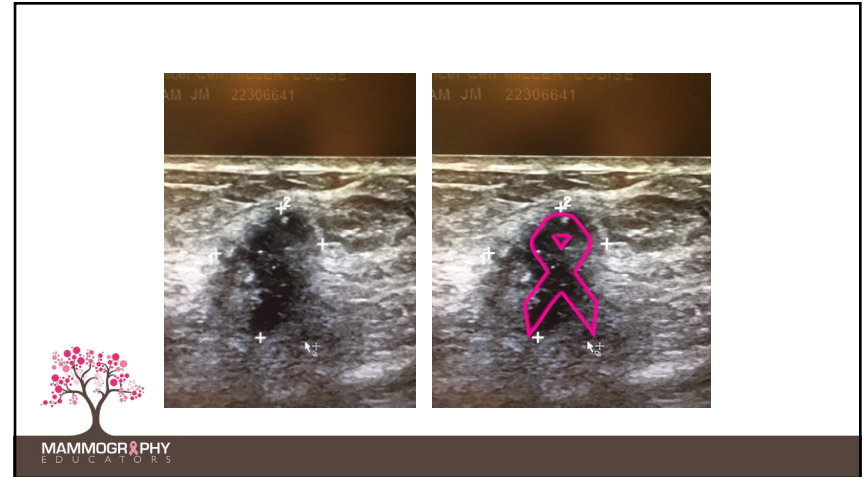


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96



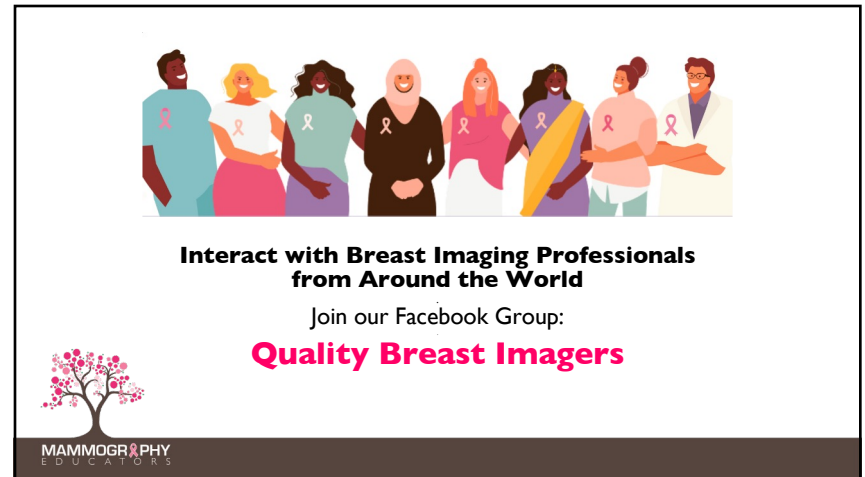
97



98



99



100

For questions or more information:

www.mammographyeducators.com

619-663-8269

info@mammographyeducators.com

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