

# CONQUER™

the patient voice™

## BREAST CANCER SPECIAL ISSUE SERIES

IN THIS ISSUE:  
an interview with  
16-year survivor  
Maimah Karmo of  
Tigerlily Foundation

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**AONN** Official patient magazine of  
Academy of Oncology  
Nurse & Patient Navigators  
—Paid for in part by AONN+ Membership Dues—

For those facing **high-risk early-stage triple-negative breast cancer (TNBC)**,

# START WITH **KEYTRUDA** + CHEMOTHERAPY

**The first and only immunotherapy used with chemotherapy before surgery, then alone after, to treat high-risk early-stage TNBC.**

KEYTRUDA is a prescription medicine used to treat a kind of cancer called triple-negative breast cancer (TNBC). KEYTRUDA may be used with chemotherapy medicines as treatment before surgery and then continued alone after surgery when you have early-stage breast cancer, **and** are at high risk of your breast cancer coming back.

## IMPORTANT SAFETY INFORMATION

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen any time during treatment or even after your treatment has ended.

**Call or see your health care provider right away if you develop any signs or symptoms of the following problems or if they get worse. These are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA:**

- **Lung problems:** cough, shortness of breath, or chest pain.
- **Intestinal problems:** diarrhea (loose stools) or more frequent bowel movements than usual; stools that are black, tarry, sticky, or have blood or mucus; or severe stomach-area (abdomen) pain or tenderness.
- **Liver problems:** yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); dark urine (tea colored); or bleeding or bruising more easily than normal.
- **Hormone gland problems:** headaches that will not go away or unusual headaches; eye sensitivity to light; eye problems; rapid heartbeat; increased sweating; extreme tiredness; weight gain or weight loss; feeling more hungry or thirsty than usual; urinating more often than usual; hair loss; feeling cold; constipation; your voice gets deeper; dizziness or fainting; changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness.
- **Kidney problems:** decrease in the amount of your urine; blood in your urine; swelling of your ankles; loss of appetite.
- **Skin problems:** rash; itching; skin blistering or peeling; painful sores or ulcers in your mouth or in your nose, throat, or genital area; fever or flu-like symptoms; swollen lymph nodes.
- **Problems can also happen in other organs and tissues.** Signs and symptoms of these problems may include: chest pain; irregular heartbeat; shortness of breath; swelling of ankles; confusion; sleepiness; memory problems; changes in mood or behavior; stiff neck; balance problems; tingling or numbness of the arms or legs; double vision; blurry vision; sensitivity to light; eye pain; changes in eyesight; persistent or severe muscle pain or weakness; muscle cramps; low red blood cells; bruising.
- **Infusion reactions that can sometimes be severe or life-threatening.** Signs and symptoms of infusion reactions may include chills or shaking, itching or rash, flushing, shortness of breath or wheezing, dizziness, feeling like passing out, fever, and back pain.
- **Rejection of a transplanted organ.** Your health care provider should tell you what signs and symptoms you should report and they will monitor you, depending on the type of organ transplant that you have had.
- **Complications, including graft-versus-host disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic).** These complications can be serious and can lead to death. These complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your health care provider will monitor you for these complications.





Talk to an oncologist about KEYTRUDA  
**keytruda.com/high-risk-early-stage-TNBC**

If you need help with medication costs,  
**call 855-257-3932 or visit keytruda.com**

### **IMPORTANT SAFETY INFORMATION (continued)**

**Getting medical treatment right away may help keep these problems from becoming more serious.** Your health care provider will check you for these problems during treatment with KEYTRUDA. They may treat you with corticosteroid or hormone replacement medicines. They may also need to delay or completely stop treatment with KEYTRUDA if you have severe side effects.

**Before you receive KEYTRUDA, tell your health care provider if you** have immune system problems such as Crohn's disease, ulcerative colitis, or lupus; have had an organ transplant or have had or plan to have a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic); have had radiation treatment in your chest area; have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome.

If you are pregnant or plan to become pregnant, tell your health care provider. KEYTRUDA can harm your unborn baby. If you are able to become pregnant, you will be given a pregnancy test before you start treatment. Use effective birth control during treatment and for at least 4 months after your final dose of KEYTRUDA. Tell them right away if you think you may be pregnant or you become pregnant during treatment with KEYTRUDA.

Tell your health care provider if you are breastfeeding or plan to breastfeed. It is not known if KEYTRUDA passes into your breast milk. Do not breastfeed during treatment with KEYTRUDA and for 4 months after your final dose of KEYTRUDA.

**Tell your health care provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

Common side effects of KEYTRUDA when used alone include feeling tired; pain, including pain in muscles; rash; diarrhea; fever; cough; decreased appetite; itching; shortness of breath; constipation; bones or joints and stomach-area (abdominal) pain; nausea; and low levels of thyroid hormone.

Common side effects of KEYTRUDA when given with certain chemotherapy medicines include feeling tired or weak; nausea; constipation; diarrhea; decreased appetite; rash; vomiting; cough; trouble breathing; fever; hair loss; inflammation of the nerves that may cause pain, weakness, and paralysis in the arms and legs; swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina; mouth sores; headache; weight loss; stomach-area (abdominal) pain; joint and muscle pain; and trouble sleeping.

These are not all the possible side effects of KEYTRUDA. Talk to your health care provider for medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

**Please read the adjacent Important Information About KEYTRUDA and discuss it with your doctor.**

Having trouble paying for your Merck medicine?

**Merck may be able to help. [www.merckhelps.com](http://www.merckhelps.com)**

**KEYTRUDA<sup>®</sup>**  
(pembrolizumab) Injection 100 mg

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US-0BR-00940 02/22



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**Important Information About KEYTRUDA® (pembrolizumab) injection 100 mg.** Please speak with your healthcare professional regarding KEYTRUDA (pronounced key-true-duh). Only your healthcare professional knows the specifics of your condition and how KEYTRUDA may work with your overall treatment plan. If you have any questions about KEYTRUDA, speak with your healthcare professional. **Rx ONLY**

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**What is the most important information I should know about KEYTRUDA?**

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen anytime during treatment or even after your treatment has ended.

**Call or see your healthcare provider right away if you develop any new or worsening signs or symptoms, including:**

**Lung problems**

- cough
- shortness of breath
- chest pain

**Intestinal problems**

- diarrhea (loose stools) or more frequent bowel movements than usual
- stools that are black, tarry, sticky, or have blood or mucus
- severe stomach-area (abdomen) pain or tenderness

**Liver problems**

- yellowing of your skin or the whites of your eyes
- severe nausea or vomiting
- pain on the right side of your stomach area (abdomen)
- dark urine (tea colored)
- bleeding or bruising more easily than normal

**Hormone gland problems**

- headaches that will not go away or unusual headaches
- eye sensitivity to light
- eye problems
- rapid heartbeat
- increased sweating
- extreme tiredness
- weight gain or weight loss
- feeling more hungry or thirsty than usual
- urinating more often than usual
- hair loss
- feeling cold
- constipation
- your voice gets deeper
- dizziness or fainting
- changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness

**Kidney problems**

- decrease in your amount of urine
- blood in your urine
- swelling of your ankles
- loss of appetite

**Skin problems**

- rash
- itching
- skin blistering or peeling
- painful sores or ulcers in your mouth or in your nose, throat, or genital area
- fever or flu-like symptoms
- swollen lymph nodes

**Problems can also happen in other organs and tissues.**

**These are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA. Call or see your healthcare provider right away for any new or worsening signs or symptoms, which may include:**

- chest pain, irregular heartbeat, shortness of breath, swelling of ankles
- confusion, sleepiness, memory problems, changes in mood or behavior, stiff neck, balance problems, tingling or numbness of the arms or legs
- double vision, blurry vision, sensitivity to light, eye pain, changes in eyesight
- persistent or severe muscle pain or weakness, muscle cramps
- low red blood cells, bruising

**Infusion reactions that can sometimes be severe or life-threatening.** Signs and symptoms of infusion reactions may include:

- |                                   |                            |
|-----------------------------------|----------------------------|
| • chills or shaking               | • dizziness                |
| • itching or rash                 | • feeling like passing out |
| • flushing                        | • fever                    |
| • shortness of breath or wheezing | • back pain                |

**Rejection of a transplanted organ.** Your healthcare provider should tell you what signs and symptoms you should report and monitor you, depending on the type of organ transplant that you have had.

**Complications, including graft-versus-host-disease (GVHD), in people who have received a bone marrow (stem cell) transplant that uses donor stem cells (allogeneic).** These complications can be serious and can lead to death. These

**Continued on next page.**

complications may happen if you underwent transplantation either before or after being treated with KEYTRUDA. Your healthcare provider will monitor you for these complications.

**Getting medical treatment right away may help keep these problems from becoming more serious.** Your healthcare provider will check you for these problems during treatment with KEYTRUDA. Your healthcare provider may treat you with corticosteroid or hormone replacement medicines. Your healthcare provider may also need to delay or completely stop treatment with KEYTRUDA if you have severe side effects.

**Before receiving KEYTRUDA, tell your healthcare provider about all of your medical conditions, including if you:**

- have immune system problems such as Crohn's disease, ulcerative colitis, or lupus
- have received an organ transplant
- have received or plan to receive a stem cell transplant that uses donor stem cells (allogeneic)
- have received radiation treatment to your chest area
- have a condition that affects your nervous system, such as myasthenia gravis or Guillain-Barré syndrome
- are pregnant or plan to become pregnant. KEYTRUDA can harm your unborn baby.

**Females who are able to become pregnant:**

- Your healthcare provider will give you a pregnancy test before you start treatment with KEYTRUDA.
- You should use an effective method of birth control during and for at least 4 months after the final dose of KEYTRUDA. Talk to your healthcare provider about birth control methods that you can use during this time.
- Tell your healthcare provider right away if you think you may be pregnant or if you become pregnant during treatment with KEYTRUDA.
- are breastfeeding or plan to breastfeed. It is not known if KEYTRUDA passes into your breast milk. Do not breastfeed during treatment with KEYTRUDA and for 4 months after your final dose of KEYTRUDA.

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

**How will I receive KEYTRUDA?**

- Your healthcare provider will give you KEYTRUDA into your vein through an intravenous (IV) line over 30 minutes.
- In adults, KEYTRUDA is usually given every 3 weeks or 6 weeks depending on the dose of KEYTRUDA that you are receiving.
- In children, KEYTRUDA is usually given every 3 weeks.
- Your healthcare provider will decide how many treatments you need.
- Your healthcare provider will do blood tests to check you for side effects.

- If you miss any appointments, call your healthcare provider as soon as possible to reschedule your appointment.

**What are the possible side effects of KEYTRUDA?**

**KEYTRUDA can cause serious side effects. See “What is the most important information I should know about KEYTRUDA?”**

**Common side effects of KEYTRUDA when used alone**

**include:** feeling tired, pain, including pain in muscles, rash, diarrhea, fever, cough, decreased appetite, itching, shortness of breath, constipation, bones or joints and stomach-area (abdominal) pain, nausea, and low levels of thyroid hormone.

**Side effects of KEYTRUDA when used alone that are more common in children than in adults include:** fever, vomiting, upper respiratory tract infection, headache, and low levels of white blood cells and red blood cells (anemia).

**Common side effects of KEYTRUDA when given with**

**certain chemotherapy medicines include:** feeling tired or weak, nausea, constipation, diarrhea, decreased appetite, rash, vomiting, cough, trouble breathing, fever, hair loss, inflammation of the nerves that may cause pain, weakness, and paralysis in the arms and legs, swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina, mouth sores, headache, weight loss, stomach-area (abdominal) pain, joint and muscle pain, and trouble sleeping.

**Common side effects of KEYTRUDA when given with**

**chemotherapy and bevacizumab include:** tingling or numbness of the arms or legs, hair loss, low red blood cell count, feeling tired or weak, nausea, low white blood cell count, diarrhea, high blood pressure, decreased platelet count, constipation, joint aches, vomiting, urinary tract infection, rash, low levels of thyroid hormone, and decreased appetite.

**Common side effects of KEYTRUDA when given with axitinib**

**include:** diarrhea, feeling tired or weak, high blood pressure, liver problems, low levels of thyroid hormone, decreased appetite, blisters or rash on the palms of your hands and soles of your feet, nausea, mouth sores or swelling of the lining of the mouth, nose, eyes, throat, intestines, or vagina, hoarseness, rash, cough, and constipation.

These are not all the possible side effects of KEYTRUDA.

Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**General information about the safe and effective use of KEYTRUDA**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. You can ask your pharmacist or healthcare provider for information about KEYTRUDA that is written for health professionals.

Based on Medication Guide usmg-mk3475-iv-2112r048 as revised December 2021.

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**With the ongoing COVID-19 pandemic,  
we would like to remind breast cancer survivors to  
work closely with their healthcare team to determine  
appropriate safety measures when receiving care.**

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## Education, Advocacy, and Empowerment Bloom Eternal at Tigerlily Foundation

*An interview with Maimah Karmo about her life's work of empowering young women with breast cancer*

By **KRISTIN SIYAHIAN**

Sixteen years ago, Maimah Karmo established the Tigerlily Foundation. Her vision was to create a global organization to provide education, awareness, advocacy, and support to young women before, during, and after breast cancer, and to transform the lives of patients as well as the healthcare ecosystem to achieve health equity for all.

Establishing a foundation with these goals is a huge undertaking, not to mention a noble one; but what's astounding about Tigerlily's founding is the timing. Maimah, a young mother to then 3-year-old Noelle, created Tigerlily while in the midst of receiving chemotherapy for triple-negative breast cancer.

The only way Maimah knew how to deal with or make sense of her diagnosis was to use her experiences to give back to this community—a community that she didn't yet fully understand. She describes the decision to establish Tigerlily as divinely inspired as she recounts the evening she went to bed “bald, sick, and scared” and asked God to restore her spirit. In return, she would do whatever God asked of her.

She says she awoke a new person. Her mind flooded with new ideas, and she began writing them down as quickly as they came to her. Those ideas were the beginnings of the Tigerlily Foundation.

Today, Tigerlily Foundation is a national leader (with a growing global footprint) in breast cancer education, awareness, and advocacy for young women. Maimah reports that the work is enriching and beautiful.



*Maimah Karmo is Founder and CEO of Tigerlily Foundation and a 16-year breast cancer survivor.*

# interview with the advocate



**Tigerlily ANGEL Advocates and supporters at the Tigerlily Foundation's Young Women's Breast Health Day on the Hill.**

I was fortunate enough to have the opportunity to speak with Maimah about the significance of the Tigerlily flower, the importance of advocacy, and the changes she's seen in oncology care. What follows is our thoughtful exchange.

## **Curiosity is getting the better of me, why is the foundation named after the Tigerlily flower?**

Lilies are perennial. They are dormant in the fall and winter, but they will bloom again in the spring. Just like a lily that loses its petals for a season, a woman going through breast cancer treatment may lose her hair, she may lose one or more breasts, but it is possible to come through treatment stronger, more beautiful, and transformed by the journey. She can bloom again, even in the midst of her journey.

## **Advocacy is a big part of the Tigerlily mission. How would you advise a newly diagnosed woman to advocate for herself?**

When a woman is diagnosed, her most common initial reaction is fear. When she contacts Tigerlily, the very first thing we do is love her and reassure her that she is not alone. We're here for her; we will hold her hand throughout the process.

Then, we listen. We ask about her immediate

needs, and we listen closely so we can help to meet those needs.

Ultimately, we want to instill a badass mentality in her! (Please excuse the expression!) We want her to go from fearful to educated and empowered. An educated and empowered woman is best able to advocate for herself and make important, timely decisions about her healthcare options and planning. At Tigerlily, we have many programs to educate and empower our members. In fact, we just launched our "Barrier Toolkit" series to empower women to remove barriers to their care. The toolkits address topics such as health literacy, financial barriers, healthcare access, and other social issues in the healthcare system. Women

can access and download these toolkits directly from our website.

## **What about women who have not experienced breast cancer firsthand, how does Tigerlily advocate for them?**

While it's important to reach women who are patients, it's just as important to reach women who have not had breast cancer to teach them about their personal risk factors. We want all women to be better equipped to reduce their risk, access timely screening, detect cancer early, and access personalized and targeted treatments.

We teach women to live a healthy lifestyle in the hope of reducing risk; and while we don't know how to prevent cancer, we want to find it early.

We advocate for all women to know their family health history. Even if you do not have breast cancer in your family, you can be your own health advocate by knowing your body, performing your breast self-exams each month, speaking up if something isn't right, and talking with your family about your health history.

Women can explore these topics on our site. For example, our BREATHE Tv series features several episodes on the power of advocacy as well as the role family plays in understanding cancer risk.



# interview with the advocate

## Can you tell us about the Tigerlily ANGEL Advocacy Program?

Yes, of course. ANGEL stands for Advocate Now to Grow, Empower, & Lead. The ANGEL Advocacy Program works to address disparities and barriers to care for women of color, particularly black women, but it's open to all women.

Women between the ages of 21 and 50 years who have been impacted by breast cancer can become an ANGEL Advocate. Advocates receive educational trainings on breast cancer and disparities that affect certain groups of women, as well as trainings on creating change, how to become a better self-advocate, and advocating on behalf of others. Once trained, we provide opportunities to join advisory boards or speak on panels. We give them tools to conduct community outreach. There are opportunities to join scientific platforms and partner with stakeholders, including pharmaceutical companies or other advocacy organizations, to serve as expert advisors locally and nationally. ANGEL Advocates have amazing opportunities to improve care and improve lives.

## During your 16 years as a survivor, what has changed the most for women with breast cancer?

I believe general awareness of breast cancer has increased, and screening has become more available to women at younger ages. Also, survivorship support and psychosocial support are more accessible now.

Mostly, I feel like the patient's voice is more highly respected and valued now. I strongly encourage all women going through breast cancer treatment to think of themselves as an expert. Just like your oncologist is an expert at treating cancer, you are an expert at living with cancer. As an expert, you are an equal partner on your

healthcare team. As an equal partner, your voice should never be dismissed.

## What still needs to change?

Health equity is still a major issue, and there's a lot of work to be done to achieve equity in healthcare in this country. At Tigerlily, we launched our #InclusionPledge and received more than 10,000 signatures from community-based to global organizations and major cancer centers in several weeks. People who sign the pledge make specific, measurable, tangible actions that will result in health equity for black women.

## Is there a Tigerlily success story you'd like to share?

Honestly, there are so many! I could tell you about the woman whose insurance company wouldn't cover screening when she found a lump. We got involved and helped her navigate access to screening, and thankfully, it was not cancer. I could tell you about the woman who was homeless while navigating breast cancer, but with our support she's now working and her family life is stable, as is her health. I could tell you about the young girl who volunteered at Tigerlily years ago and because of that experience chose to work in the healthcare field and still volunteers with us to make a difference. To me, every woman we come into contact with is a success story.

## What about you? What is your biggest success?

I think that the biggest success for me personally is that I get to be here to raise my daughter. That's my success. I just marked the 16th anniversary of my diagnosis. My daughter and I spent that day together; we had manicures and pedicures, we went out to dinner, and we just sat there and smiled at each other. Being able to do life with her is my biggest success and gift! ♦



**Tigerlily  
Foundation**  
*Beauty. Strength. Transformation.*

To learn more about Tigerlily Foundation and the many programs they offer, please visit [www.tigerlilyfoundation.org](http://www.tigerlilyfoundation.org).

## Preparing for Side Effects of Breast Cancer Treatments

### A Guide to Common Side Effects and What You Can Do About Them

By **CHERYL BELLOMO, MSN, RN, OCN, HON-ONN-CG**  
Nurse Navigator, Intermountain Cancer Center, Cedar City, UT

**A**fter a breast cancer diagnosis, you and your oncology team will put together a treatment plan specifically designed for you. Your personalized treatment plan will be made up of 1 or more specific treatments that are intended to target cancer cells in different ways and reduce the risk of future breast cancer recurrence. Along with treatments come side effects. In

THE ROLE OF SURGERY IS TO LOWER THE RISK OF THE CANCER COMING BACK IN THE SAME AREA OF THE BREAST OR LYMPH NODES.

this article, I will provide an overview of each type of treatment. At the end of the article, you will find helpful lists of the possible side effects from each treatment and, most importantly, what can be done to prevent, lessen, or stop them. As always, if you are experiencing any side effects from your



treatment, it is important to inform your treatment team right away.

#### **SURGERY**

Surgery is usually the first line of treatment for breast cancer. The role of surgery is to lower the risk of local recurrence (the cancer coming back in the same area of the breast or lymph nodes). Breast surgery options include lumpectomy, mastectomy, sentinel or axillary lymph node dissection, breast reconstruction, and prophylactic mastectomy. Selecting the type of surgery depends on many factors: the type of breast cancer, the stage (size and extent) of the cancer, the desired cosmetic appearance, and your personal preferences.

#### **RADIATION THERAPY**

Radiation therapy is a local treatment that uses high-energy x-rays to kill cancer cells and shrink tumors by damaging the DNA of the cancer cell. It is typically used after surgery to destroy any cancer cells that may remain to help lower

the risk of the cancer recurrence. You will meet with a radiation oncologist to discuss the number of treatments needed and the method of radiation delivery.

The side effects depend on the type of radiation therapy you are receiving (external or internal/brachytherapy), the technique (whole-breast or partial-breast radiation), and the area being treated (the breast or an area where the cancer has spread, such as the lymph nodes). Your radiation oncologist and team will be monitoring you for side effects throughout your treatment.

## HORMONAL THERAPY

Hormonal therapy works by lowering the amount of estrogen in the body or by preventing breast cells from absorbing estrogen to lower the risk of cancer returning in the breast or in other parts of the body. This type of therapy is only effective for people with hormone receptor-positive breast cancers. There are several types of hormonal therapy medicines that you and your medical oncologist will discuss based on your breast cancer stage, bone density, history of blood clots, menopausal status, and plan for pregnancy/fertility preservation.

## IMMUNE-TARGETED THERAPIES

Immune-targeted therapies are treatments that target specific characteristics of cancer cells (such as a proteins, enzymes, or mutations) that enable the cancer cells to grow in a rapid or abnormal way. These medicines can also help fight breast cancer by alerting the immune system to destroy cancer cells.

## CHEMOTHERAPY

Chemotherapy treatment uses anticancer drugs to weaken and destroy cancer cells in the body, including cells at the original cancer site and any cancer cells that may have spread to another part of the body. Chemotherapy is used to treat all stages of breast cancer, including cancer that has come back in the breast or cancer that has spread to other parts of the body (metastatic disease). There are many kinds of

chemotherapy medications, combinations, and treatment schedules that can be utilized. When deciding which chemotherapy medicines would be best for you, you and your medical oncologist will consider the stage and other characteristics of the cancer, such as hormone receptor status, HER2 status, menopausal status, as well as any other treatments you have received.

As chemotherapy treatment can affect the whole body, there can be a wide variety of side effects. You will want to discuss the possible side effects related to your exact type of chemotherapy with your medical oncologist. Your team will be able to share options to lessen, manage, or stop side effects.

## ENSURING A GOOD QUALITY OF LIFE

In recent years, breakthroughs in research have resulted in treatment advances against breast cancer, bringing new hope and excitement. Instead of only 1 or 2 options, today there is an overwhelming variety of treatment choices that fight the complex mix of cells in each individual cancer. Breast cancer treatment is no longer “one size fits all.” The decisions—surgery, then perhaps radiation, hormonal (antiestrogen) therapy, and/or chemotherapy—can feel overwhelming. You and your team will tailor a treatment plan based on the unique features of your cancer, your overall health and health history, and your preferences. As a part of your treatment plan discussion, prepare questions to discuss with your team about recommended treatments, side effects of those treatments, and ways to manage side effects to ensure quality of life as well as quantity of life.

## Helpful Resources

American Cancer Society. Treating Breast Cancer. [www.cancer.org/cancer/breast-cancer/treatment.html](http://www.cancer.org/cancer/breast-cancer/treatment.html). February 2022.

Breastcancer.org. Treatment and Side Effects. [www.breastcancer.org](http://www.breastcancer.org). February 2022.

Living Beyond Breast Cancer. Treatments and Research. [www.lbbc.org/learn/treatments-and-research](http://www.lbbc.org/learn/treatments-and-research). February 2022. ♦



## Possible Side Effects of Breast Surgery

Side Effect	What Can Be Done?
Axillary web syndrome, also called "cording," is a ropelike structure/scar tissue under the skin of the inner arm	Cording can be managed with stretching/flexibility exercises and massage therapy.
Hematoma, a buildup of blood in the surgical wound	Usually, hematomas are reabsorbed by the body. In some cases, they may need to be surgically drained.
Lymphedema, the swelling of the soft tissues, is caused by a buildup of lymph fluid when lymph nodes are removed	Lymphedema can be managed by a specialist with the use of massage, physical therapy, and/or compression bandages.
Seroma is a buildup of clear bodily fluid where tissue has been removed during surgery	Usually, a seroma will be reabsorbed by the body. In some cases, a seroma may need to be drained.

## Possible Side Effects of Radiation Therapy

Side Effect	What Can Be Done?
Skin changes, much like sunburn, can include redness and possible itching, burning, soreness, peeling, blisters, or darkening of the skin	Skin reactions can be managed with the use of moisturizers, wearing loose-fitting shirts, avoiding underwire bras, and avoiding friction/rubbing of the skin in the treatment area.
Fatigue	Fatigue can be managed by balancing periods of rest with activity, relieving stress, eating a healthy well-balanced diet, as well as by complementary medicine techniques such as massage, meditation, and yoga.
Lymphedema, or swelling in the arm	Lymphedema from radiation is less common but can occur when lymph nodes under the arm are treated. Lymphedema can be managed by a specialist with the use of massage, physical therapy, and/or compression bandages.

**Possible Side Effects of Hormonal Therapies**

Side Effect	What Can Be Done?
Hot flashes	Ways to manage hot flashes include avoiding hot flash triggers, such as stress, cigarettes, alcohol, caffeine, diet pills, spicy food, hot food or drink, hot tubs, saunas, hot showers, hot rooms, and hot weather, and by dressing in layers and lowering the room temperature.
Vaginal dryness	Ways to manage vaginal dryness include using a water-based (not hormone-based) lubricant during intercourse or a vaginal moisturizer to help the vaginal walls stay moisturized.
Loss of interest in sex	Ways to manage loss of libido include talking with your partner about your feelings, trying new sexual positions, and using personal lubricants and a vaginal dilator.
Insomnia	Practicing good sleep hygiene, such as going to bed and waking the same time each day, avoiding alcohol and caffeine in the evening, winding down and relaxing before bedtime, and avoiding napping during the day can help to manage problems with insomnia.
Mood changes	Hormonal changes in your body affect the chemistry in your brain, which can result in common emotions linked to mood swings such as depression, sadness, frustration, irritation, and anger. These emotions can be managed by trying to identify and avoid sources of stress, talking about your emotions with family, friends, or a counselor, and balancing exercise with rest.
Weight gain	Weight gain can be managed by eating a healthy diet, limiting saturated fat, salt, sugar, and alcohol, as well as by exercising regularly.
Osteoporosis (bone loss/loss of bone density)	Osteoporosis can be managed with calcium and vitamin D supplements, weight-bearing exercise, and prescribed bisphosphonate medications.
Joint pain	Joint pain as a result of hormonal therapy can be managed with over-the-counter and prescribed pain medications, hot and cold packs, or by switching to a different hormonal therapy.
Higher risk of blood clots in your veins	Certain hormonal therapies can increase the risk of blood clots, which can be managed by wearing compression stockings, elevating your legs, and avoiding sitting for prolonged periods of time.
Increased risk of uterine (endometrial) cancer	Certain hormonal therapies can increase your risk of uterine cancer, so it is important to discuss with your medical oncologists any risk factors or history of endometrial hyperplasia/cancer.

## Possible Side Effects of Immune-Targeted Therapies

Side Effect	What Can Be Done?
Diarrhea	Diarrhea can be managed with over-the-counter antidiarrheal medications and the use of the BRAT (bananas, rice, applesauce, toast) diet or prescription medications, if needed.
Hair loss	Changes in hair can be managed with the use of wigs/head coverings and possibly prevented with the use of cold caps and scalp cooling systems.
Fatigue	Fatigue can be managed by balancing periods of rest with activity, relieving stress, and by eating a healthy, well-balanced diet, as well as by complementary medicine techniques such as massage, meditation, and yoga.
Neuropathy, including pain, numbness, loss of sensation, or discomfort caused by damage to the nerves of the peripheral nervous system	Neuropathy can be managed by handling sharp objects carefully, avoiding going barefoot and protecting your feet from injury, and by using mats in the bath and shower, checking water temperature with a thermometer before bathing or cleaning, using acupuncture/massage, and discussing a prescription medication with your oncologist.
Nausea	Tips to help manage nausea include eating smaller, more frequent snacks/portions throughout the day, eating dry foods and ginger-based foods, and by avoiding greasy foods and using prescribed anti-nausea medications.
Rash	Any medication has the potential of causing a rash in some people. If you think your rash is an allergic reaction to a medication or a sign of infection, stop taking the medication and call your doctor immediately. If your rash is not caused by an allergic reaction, ways to manage the rash include wearing loose-fitting clothes, washing with mild soaps, avoiding perfumes/fragrances, patting your skin dry after bathing, protecting your skin with clothing and sunscreen when outdoors, avoid scratching, and using antihistamines.
Low levels of white blood cells	When your white blood cell count is low, your immunity is low, and you have a higher risk of getting an infection. Ways to manage a low white blood cell count and to prevent infection include monitoring your temperature and notifying your oncologist of fever, by avoiding large crowds, by washing your hands frequently and using a hand sanitizer, preventing cuts/scrapes, and using good first aid to an injury.



**Possible Side Effects of Chemotherapy**

<b>Side Effect</b>	<b>What Can Be Done?</b>
Anemia, or low red blood cell count	Anemia can be managed by increasing your body's iron levels by eating foods rich in vitamin B <sub>12</sub> and taking specific medications ordered by your oncologist.
Diarrhea	Diarrhea can be managed with over-the-counter antidiarrheal medications and the use of the BRAT (bananas, rice, apple-sauce, toast) diet and prescription medications, if needed.
Fatigue	Fatigue can be managed by balancing periods of rest with activity, relieving stress, and eating a healthy, well-balanced diet, as well as by complementary medicine techniques such as massage, meditation, and yoga.
Fertility issues	Talk with your oncologist and a fertility expert about your options for preserving fertility.
Hair changes, including hair loss or thinning	Changes in hair can be managed with the use of wigs/head coverings and possibly prevented with the use of cold caps and scalp cooling systems.
Infection	Avoid infection during chemotherapy by avoiding large crowds, practicing daily hygiene and frequent handwashing, washing fruits and vegetables thoroughly, and using immediate first aid for cuts/scrapes/burns. Contact your oncology team if you experience signs of infections.
Memory loss	Tips to help stimulate your memory include keeping mentally active (puzzles, reading), using memory aids (note pad, calendar, phone apps), and following a routine.
Menopause and menopausal symptoms	Ways to ease various menopausal symptoms include dressing in layers for hot flashes, avoiding stress for managing mood swings, participating in activities to ease depression, and using personal lubricants for vaginal dryness.
Mouth and throat sores	Ways to manage mouth and throat sores include avoiding spicy, hot, or acidic foods and drinks, avoiding mouthwash containing alcohol, rinsing your mouth with baking soda and salt water, and by using a soft bristled toothbrush. Call your oncology team if you notice a coating to the inside of your mouth.
Nail changes	Chemotherapy can cause changes in the color or thickness of your fingernails or toenails or changes around the nail bed. This can be managed by keeping nails trimmed and clean, avoiding biting nails and cuticles, and by avoiding professional manicures and artificial nails. Call your oncology team with signs of inflammation or infection.

## Possible Side Effects of Chemotherapy (continued)

Side Effect	What Can Be Done?
Nausea	Tips to help manage nausea include eating smaller, more frequent snacks/portions throughout the day, eating dry foods and ginger-based foods, and by avoiding greasy foods and using prescribed anti-nausea medications.
Neuropathy, including pain, numbness, loss of sensation, or discomfort caused by damage to the nerves of the peripheral nervous system	Neuropathy can be managed by handling sharp objects carefully, avoiding going barefoot and protecting your feet from injury, using mats in the bath and shower, checking water temperature with a thermometer before bathing or cleaning, using acupuncture/massage, and by discussing a prescription medication with your oncologist.
Taste and smell changes	Ways to manage taste or smell changes related to your treatment include eating cold foods with less of an aroma, eating with plastic utensils, sucking on ice chips, and rinsing your mouth with tea, ginger ale, salted water, or baking soda dissolved in water before you eat to help clear your taste buds. If you cannot stand the smell of food while cooking, you can rely on prepared foods from a store or ask someone to cook for you.
Vomiting	To soothe an upset stomach and recover from vomiting, try rinsing your mouth and brushing your teeth, followed by sucking on peppermint candy if you still have a bad taste in your mouth. Drink plenty of clear liquids, such as broth, juice, flat soda, sports drinks, and water to stay hydrated and replace fluids.
Weight changes	Ways to manage weight gain include exercising and eating a healthy diet full of vegetables, fruits, and whole grains while limiting saturated fat, salt, sugar, and alcohol. Ways to manage weight loss include trying to eat small meals or snacks every hour to make sure you get enough calories, snacking on foods high in protein but low in fat, such as yogurt and cottage cheese, lean meat or fish, and lentils, and using milk in some recipes instead of water for added calories.

# Family Matters: What a Breast Cancer Diagnosis Means for Your Loved Ones

By **FRANK DELA RAMA, RN, MS, AOCNS, AGN-BC**  
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## Meet Anna



Anna is a 67-year-old woman who was recently diagnosed with breast cancer in her right breast. More than 20 years ago, she was treated for breast cancer in her left breast with lumpectomy and radiation. She did not have any genetic testing at that time.

She has a video visit today with a genetic counselor to talk about testing for an inherited genetic mutation. Anna has a sister, a brother, 2 sons, 2 daughters, and several grandchildren. Her treatment team would like to wait for the results of the genetic testing before presenting treatment options.

Anna says, "I met with the surgeon yesterday, and she told me that based on the biopsy report, they will be doing some type of gene testing on that tissue. How will this test affect my treatment? Will it affect my family too?"

## Genetics in Cancer

Genes are contained in the DNA of every cell in the body. Genes control how cells function, including how quickly they grow, how often they divide, and how long they live. To accomplish this, genes are involved in the creation of proteins; each protein has a specific function in the cell. The correct DNA sequence in the gene is essential to making a properly functioning protein. A mutation in a gene can potentially cause the creation of an abnormal protein or cause the protein to be absent altogether. Mutations can accumulate and cause cells to multiply beyond control, which leads to cancerous cells.

In cancer, it is important to recognize 2 types of mutations: somatic (also called acquired muta-

## Key Points to Remember

- ✓ Once you've had genetic testing, check with your cancer genetics professional yearly to ask about updated testing that may be available to you
- ✓ Family members of cancer survivors may be eligible for extra cancer screenings
- ✓ Genetic testing of the blood or saliva for inherited genetic mutations is different from genomic tests performed on cancerous tissue.

tions) and germline (also called inherited mutations) (**Figure**).

## Somatic Mutations

Somatic mutations, or acquired mutations, result from damage to genes in a cell over the course of a person's life. These mutations can happen randomly, but more often they are associated with risk factors such as tobacco use, ultraviolet radiation, viruses, or just aging. Somatic mutations do not occur in every cell in the body and are not passed from parent to child.<sup>2</sup>

In cancer care, somatic mutations can be identified by testing the cancer tissue from a biopsy or surgical sample. The results from somatic mutation tests can help your treatment team determine the best treatment option for that specific type of cancer.

It is not routinely recommended for family members to undergo genetic testing based on results of somatic mutation testing. However, if test results reveal a mutation in a gene related to a hereditary cancer syndrome, then germline testing should be completed to confirm if the mutation is acquired or inherited.



## Germline Mutations

Germline mutations, also called inherited mutations, arise in the sperm or egg cell, passing directly from parent to child at conception. If passed on, the mutation will be present in every cell of the body at birth. Although much less common than acquired mutations, inherited mutations can increase cancer risk significantly, as in hereditary breast and ovarian cancer (HBOC) syndrome related to the *BRCA1* and *BRCA2* genes.

In cancer care, germline mutations are usually identified by testing a blood or saliva sample. For breast cancer patients, the results from these tests can affect the treatment plan as well as uncover risk for other types of cancer and promote additional preventive measures. Certain family members may also be tested to determine inherited risk.

## Anna's Genetic Counseling Visit



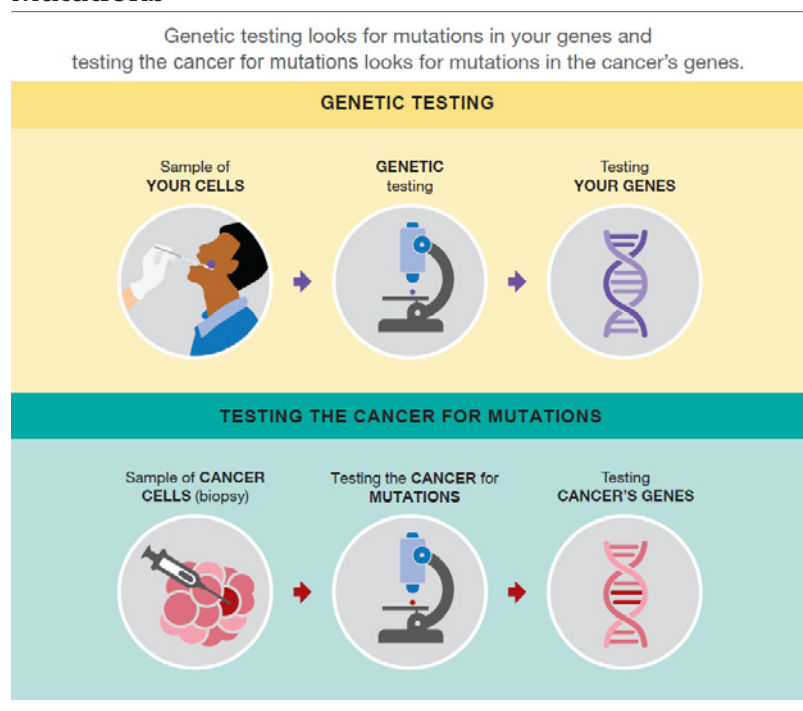
During the genetic counseling visit, Anna learns more about genetic testing for inherited mutations. She now understands that the test performed on biopsy tissue is much different from the blood test to be completed today, which includes genetic testing of the *BRCA1*, *BRCA2*,

and other genes included in a broad multigene cancer risk panel.

Anna asks, "Why didn't I have genetic testing back when I had cancer the first time?"

The genetics counselor explains that the criteria for testing have changed since then. Around the time of Anna's first diagnosis, *BRCA1* and *BRCA2* testing was only offered to women with a breast cancer diagnosis at age 45 years or younger if they did not have a family history of breast or ovarian cancer. Today, the criteria have expanded to allow for more people to undergo testing, including women with bilateral or 2 separate occurrences of breast cancer, if the first diagnosis happened at

**Figure Genetic Testing vs Testing the Cancer for Mutations<sup>1</sup>**



age 50 years or younger. Also, pancreatic and some types of prostate cancer are now taken into consideration for testing in HBOC syndrome.

Two weeks later, Anna meets with the nurse navigator to review all test results to date. Tissue testing on the biopsy sample was completed and indicated that she may not need chemotherapy, but her genetic testing showed a *BRCA1* mutation.

Anna shares her concerns, "I'm relieved that I may not need chemotherapy, but the surgeon is suggesting a more drastic surgery—removal of my breasts and ovaries. I'm also worried about my kids, especially my daughters. And I'm wondering if my sons need testing too?"

## Who Should Have Genetic Testing?

The American Society of Clinical Oncology recommends considering genetic testing for inherited risk in the following scenarios<sup>3</sup>:

- If a personal or family history suggests a genetic cause of cancer
- If a test will clearly show a specific genetic change
- If the results will help with diagnosis or management of a condition. For example, taking steps

to lower risk that may include surgery, medication, frequent screening, or lifestyle changes.

Genetic testing in breast cancer has become increasingly complex. Multiple genes are now routinely tested, and the criteria for testing have expanded to allow more people to have access to testing. Genetic counseling before and after testing is key to ensure the appropriate tests are ordered and that the implications of the results are properly explained, regardless of whether a mutation is found. Ultimately, genetic testing is a personal decision that impacts not only the person with cancer, but their family as well.

Cancer genetic professionals refer to the guidelines established by the National Comprehensive Cancer Network (NCCN) for criteria on testing for specific genes that have a significant impact on

- Have a personal history of breast cancer and are of Ashkenazi Jewish heritage.

## Anna's Test Results: What They Mean for Her and Her Family



Anna's genetic counselor reviews the implications of her test results. Anna learns that having a *BRCA1* mutation provides her with more options to reduce the risk of breast cancer recurrence and the risk of developing ovarian cancer. She plans to follow up with her surgeon to consider prophylactic surgical removal of both breasts and ovaries.

The genetic counselor recommends testing Anna's close blood relatives for the *BRCA1* mutation and inherited risk for breast and ovarian cancers, starting with her 2 daughters and sister. It is also recommended that her 2 sons and brother undergo testing for possible inherited risk for male breast cancer and prostate cancer.

A KNOWN GENETIC  
MUTATION IN A CLOSE  
BLOOD RELATIVE IS A  
CLEAR REASON TO PURSUE  
GENETIC TESTING.

care.<sup>4</sup> These "high-penetrance breast cancer susceptibility genes" include *BRCA1*, *BRCA2*, *CDH1*, *PALB2*, and *TP53*. Most multigene cancer genetic tests include these genes. Women may be eligible for genetic testing if they<sup>4</sup>:

- Received a breast cancer diagnosis at age 45 years or younger (no family history required)
- Received a breast cancer diagnosis between the ages of 46 and 50 years and have multiple primary breast cancers and/or 1 or more close blood relatives with breast, ovarian, pancreatic, or prostate cancer
- Received a breast cancer diagnosis at age 51 years or older and have 1 or more close blood relatives with breast cancer at age 50 years or younger, male breast cancer, ovarian cancer, pancreatic cancer, or high-risk prostate cancer
- Received a diagnosis of triple-negative breast cancer at any age

## Inherited Genetic Risk: A Family Affair

A known genetic mutation in a close blood relative is a clear reason to pursue genetic testing. People with a family history of cancer should meet with a cancer genetics professional to review their risk for cancer and determine their need for genetic testing. If someone has a first- or second-degree relative who meets the NCCN criteria listed above, genetic testing for inherited risk should be considered.

## Anna: 1 Year Later



One year after her surgery, Anna comes in for a survivorship visit with her nurse navigator. Anna feels good about completing her aggressive treatment plan, saying "I'm glad I did everything I could to keep the cancer from coming back. I was scared at first thinking about the surgical removal of my ovaries too, but I have peace of mind now."

One son and 1 daughter tested positive for the *BRCA1* gene; both are following high-risk screening

plans. Her daughter did not opt for surgical removal of her breasts and ovaries, but her mammogram and MRI are clear so far. Her son is 42 years old and will have yearly prostate cancer screenings and breast exams.

Anna says, “All my kids seem to be dealing well with all of this. My son and daughter have access to extra screenings. My other 2 kids have a little bit less to worry about, but they are still keeping up with their regular checkups.”

## Advances in Genetics

Genetics in cancer care continues to broaden its impact as new discoveries continue to be made. In facing cancer personally, or in the family, your risk assessment for cancer needs to be an ongoing

process. The plan for screening and prevention of cancers can change over time. Your cancer care team is a great resource to stay current on the state of the science in genetics. Genetic testing for inherited risk is unique due to its potential clinical implications, not only for the individual, but for generations to come. ♦

## References

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## Pearls of Wisdom from Cancer Genetics Professionals

“Genes are like a recipe in a cookbook, they make something. The chromosome is the cookbook, and the gene is the recipe in the cookbook. Sometimes the genetic test results we get are like saying, we found a change in the recipe, but we don’t know if it messes up the cake OR makes it better. A change does not mean it is bad because you can change a recipe and make it better.”

—Cindy Snyder, DNP, ACGN, FNP-C, CBCN, on a genetic test showing an inconclusive result or variant of uncertain significance

“When you fish with a pole, you might catch a fish. But when you throw out a net, you are more likely to catch a fish. Panel testing is like fishing with a net.”

—Cindy Snyder, DNP, ACGN, FNP-C, CBCN, on multigene panels

“As a genetic counselor with over 25 years of experience, I always encouraged the patients I had the privilege to speak with to talk openly about their personal and family history with other family members and with their medical care team. Knowing your risk for cancer in advance allows experts to talk to you about risk-reducing strategies and even preventive measures. Cancer doesn’t mean a death sentence, and we ALL need to be aware of our risk and decide how best to handle that risk.

Knowing and sharing your personal and family history can save your life and the lives of your loved ones. Talking with your healthcare provider about your family history is a critical first step.”

—Shelly Cummings, MS, CGC, on the importance of personal and family history

## Resources

Cancer Support Community: Precision Medicine. [www.cancersupportcommunity.org/precision-medicine#understanding-genes-mutations-and-biomarkers](http://www.cancersupportcommunity.org/precision-medicine#understanding-genes-mutations-and-biomarkers).  
Facing Hereditary Cancer EMPOWERED. Improving the Lives of Individuals and Families Facing Hereditary Cancer. [www.facingourrisk.org](http://www.facingourrisk.org).  
National Society of Genetic Counselors. Find a Genetic Counselor. <https://findageneticcounselor.nsgc.org>.