

CONQUERTM

the patient voiceTM

BREAST CANCER SPECIAL ISSUE SERIES



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Official patient magazine of
Academy of Oncology
Nurse & Patient Navigators

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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](https://www.keytruda.com/high-risk-early-stage-TNBC)

If you need help with medication costs,
call 855-257-3932 or visit [keytruda.com](https://www.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, bones or joints, and stomach-area (abdominal) pain; decreased appetite; itching; diarrhea; nausea; rash; fever; cough; shortness of breath; and constipation.

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 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



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KEYTRUDA[®]
(pembrolizumab) Injection 100 mg

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**

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
- swelling of your ankles
- blood in your urine
- 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, bones or joints and stomach-area (abdominal) pain, decreased appetite, itching, diarrhea, nausea, rash, fever, cough, shortness of breath, and constipation.

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 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-2107r043 as revised July 2021.

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MAS, HON-ONN-CG

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About the Cover: Colors of Hope. *Painting by Jessilyn Park*

Colors of Hope was created for a charity event benefiting the Charles Lewis Institute at MD Anderson Cancer Center in Orlando, FL. To view this and other works by Jessilyn Park, please visit www.fineartamerica.com/profiles/jessilyn-park.

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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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Many Treatment Options, Many Goals of Care—Which Are Right for You?



By **LILLIE D. SHOCKNEY, RN, BS, MAS, HON-ONN-CG**

University Distinguished Service Professor of Breast Cancer
Professor of Surgery, Johns Hopkins University School of Medicine
Co-Developer of Work Stride—Managing Cancer at Work, Johns Hopkins Healthcare Solutions
Co-Founder, AONN+

If you have visited any breast cancer websites or chat rooms, you have most likely discovered that when it comes to treatments for breast cancer, one size doesn't fit all.

As you learn about breast cancer and gather information from your treatment team about the prognostic factors, biomarkers, stage, grade, and other features of the cancer cells that present in your body, you will find that your clinical situation is truly unique to you. So, I want to caution you about comparing your treatment with that of others, because it will most likely result in confusion and frustration. For example, if you meet someone with the same diagnosis, say, an estrogen receptor-positive breast cancer, you may find that you each are taking a different hormonal therapy. It is important to remember that there are many factors that go into treatment decision-making specifically for you. It is also important to remember that there are more treatment options now than ever before.

A family friend of ours was diagnosed with breast cancer 55 years ago. At that time, there was only 1 surgical option (total radical mastectomy), 1 chemotherapy drug, and 1 hormonal therapy drug, and radiation could not be targeted to 1 specific area. I was diagnosed with breast cancer 29 years ago, and thankfully, there were more options. But now, there are many surgical options, chemotherapy regimens, biologic targeted therapies, immunotherapies, radia-

tion therapies, and hormonal therapies. With more options, the more likely it is that you can receive treatment that is tailored to your unique situation.

Goals of care are also unique to you. Goals of care go beyond just surviving; they include your personal goals and should be incorporated into the treatment planning process. These might include milestones such as starting a family, attending your daughter's high school graduation, your 25th wedding anniversary, or your son's college graduation.

For example, if you are planning to start a family in a year or so, then it is important to make this known so that you are referred to a fertility preservation specialist.

For specific events, you want to be sure that you will feel well enough to attend. Discuss with your treatment team, especially your breast cancer navigator, the importance of these events so that treatment can be planned around them. For example, it would not be wise to start a new treatment that may cause diarrhea 2 days before your son's graduation. Instead, request that you begin treatment after the celebration.

You have a myriad of treatment options that provide the possibility of tailoring your treatment to your specific breast cancer biology. And when your treatment team factors in your life goals and milestone experiences, you will receive truly patient-centered care. ♦

Lillie Shockney

Co-Founder **AONN** Academy of Oncology Nurse & Patient Navigators

Lumpectomy vs Mastectomy

The Practical (and Emotional) Aspects of This Critical Milestone

By **AVA ARMANI, MD, FACS**

Breast Surgical Oncologist, University of California, San Diego

Surgery is an integral part of breast cancer treatment. With any surgery, it is helpful to prepare for your practical needs postsurgery. But unlike other types of surgery, breast surgery can carry a higher level of emotional implications for women. While there are practical things you can do to prepare and make the days following your surgery a bit easier, it's also important to acknowledge your feelings about the surgery and consider healthy ways to cope with the emotional impact.

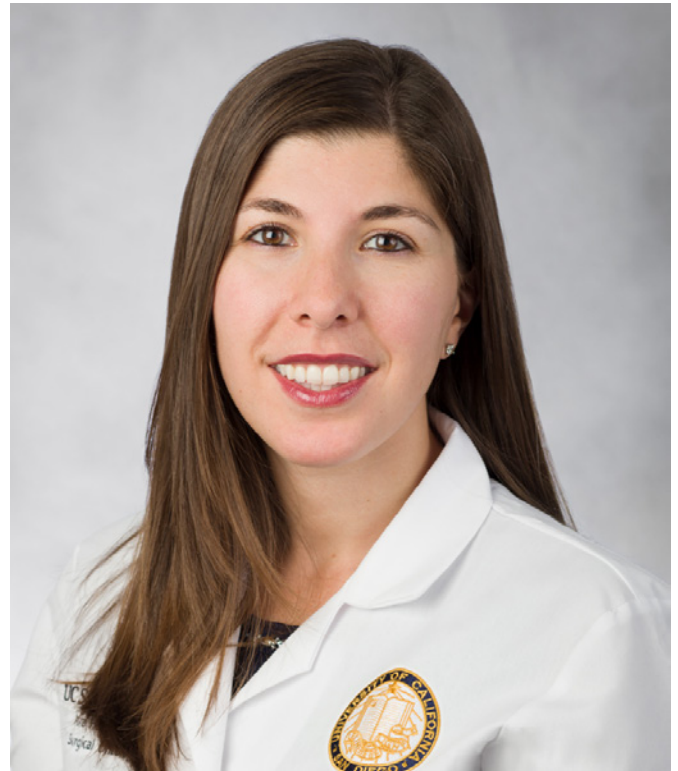
To start, let's talk about the 2 types of surgery for breast cancer: lumpectomy and mastectomy.

DEPENDING ON THE SIZE OF THE LUMPECTOMY, THERE MAY BE SLIGHT CHANGES IN THE SIZE AND SHAPE OF THE BREAST.

LUMPECTOMY

Lumpectomy, also known as a partial mastectomy or breast-conserving surgery, refers to the removal of the tumor (or "lump") only. If you undergo a lumpectomy, you will likely be able to go home from the hospital the same day as the procedure, unless you have medical concerns that require additional monitoring.

With lumpectomy, the breast is preserved. The goal of a lumpectomy is to remove the tumor intact with some of the normal surrounding tissue to ensure that no cancer cells are left behind. This is confirmed by the absence of cancer cells on the edges of the tissue removed. The tissue from surgery is sent to the pathologist, who will issue a report that



includes either "negative" or "positive" margins. Negative margins mean no cancer is present on the edges of the tissue. If the margins are positive (meaning cancer cells are present on the edges of the removed tissue), then a second surgery is needed to remove more tissue to ensure clearance of the cancer.

Sometimes, a "sentinel lymph node biopsy" is performed at the time of lumpectomy. The sentinel nodes are the first nodes in the chain of lymph nodes in the underarm. If these lymph nodes do not contain cancer, then it can be assumed that cancer has not spread outside of the breast.

Depending on the size of the lumpectomy, there may be slight changes in the size and shape of the breast.

Almost always, radiation therapy is recommended after a lumpectomy for breast cancer.

PREPARING FOR AND RECOVERING FROM A LUMPECTOMY

A lumpectomy with or without a sentinel lymph node biopsy is performed as an outpatient procedure under general anesthesia. Many centers offer nerve blocks prior to surgery to help with pain control after surgery. You will likely feel tired after surgery for a few days; it is recommended to take up to a week off from work. You will be able to complete your activities of daily living, and the only main restriction is no heavy lifting (more than a gallon of milk) to allow the area to heal. A few suggestions:

- You will not be able to shower for a few days after surgery, so you will want to shower the day before or the day of surgery
- Ask your healthcare team which medications you should take prior to surgery and which medications you should stop
- You will need a ride home from the hospital on the day of surgery
- Choose 1 person as the point of contact for the surgeon and have that person communicate with a list of people you want to be kept informed.

MASTECTOMY

The second type of surgery is a mastectomy, which is the removal of the entire breast. Usually, patients undergoing mastectomies are admitted to the hospital for pain control. Mastectomies can be performed with or without reconstruction. Depending on the type and extent of breast cancer, reconstruction can be started at the time of mastectomy or delayed until the breast cancer treatment is completed. If a patient does not wish to have reconstruction, or it is recommended that reconstruction be delayed, the breast tissue along with the nipple is removed, and the chest is left flat. With reconstruction, the nipple can be preserved if it is free of cancer.

Drains are placed at the time of the mastectomy to collect fluid that develops as a normal response of the body anytime tissue is removed.

PREPARING FOR AND RECOVERING FROM A MASTECTOMY

Although you will be able to complete your activities of daily living, you will want to have support



available. No heavy lifting is permitted, and recovery can be 4 to 6 weeks depending on the type of reconstruction. A few suggestions:

- You will not be able to shower for a few days after surgery, so you will want to shower the day before or the day of surgery
- Ask your healthcare team which medications you should take prior to surgery and which medications you should stop

MASTECTOMIES CAN BE PERFORMED WITH OR WITHOUT RECONSTRUCTION.

- Choose 1 person as the point of contact for the surgeon and have that person communicate with a list of people you want to be kept informed
- Pack a hospital bag with loose comfortable clothing that opens easily in the front
- Organize your closet and dressers so that these types of clothes are easily accessible when you come home
- You will go home with a bra from the hospital, but you may also want to have comfortable bras or camisoles at home for when you are allowed to remove your hospital bra
- You can pin your drains to whatever bra or shirt is comfortable, purchase bras with

pouches for drains, or hang your drains on a lanyard around your neck

- Prepare and freeze some meals prior to surgery, stock up on groceries, or have pre-made food available when you come home.

LYMPH NODES

In many cases, lymph nodes may be removed during your surgery, especially for invasive breast cancer. Information from lymph node sampling can provide important prognostic information, and in some cases, it may help to guide treatment decision-making postsurgery.

CHOOSING WHICH SURGERY
IS BEST AND ADJUSTING TO
LIFE AFTER SURGERY ARE
CHALLENGING.

The type of lymph node surgery depends on the extent of the cancer. If there is no evidence of breast cancer in the lymph nodes on exam or imaging, then a sentinel lymph node biopsy is performed. As described above, sentinel nodes are the first nodes in the chain of lymph nodes in the underarm. If these lymph nodes do not contain cancer, then it can be assumed that cancer has not spread outside of the breast.

If there is evidence of cancer in the lymph nodes prior to surgery, then an "axillary node dissection" is

performed, which involves removal of most of the lymph nodes in the underarm.

THE EMOTIONAL COMPONENT OF SURGERY FOR WOMEN

For many women, choosing which surgery is best for them and adjusting to life after surgery are challenging. Be gentle and patient with yourself: this is a big adjustment.

With a lumpectomy, you will have a permanent scar on your breast. You may have a change in the shape and size of your breast. Overall, however, most women adjust well to having a lumpectomy.

With a mastectomy, the emotional impact is greater. For some women, losing their breasts can greatly affect their feelings related to femininity and sexuality. All of this is normal, and you are certainly not alone with these feelings. There are things you can do to help cope with the shock of a diagnosis and your feelings related to your new body. My best advice is to allow yourself the time to heal, both physically and mentally. Keep an open dialogue with your loved ones. Talk to your breast cancer team. Join a support group through your treatment center to connect with other women who have experienced what you are going through. By talking through your feelings, I hope you find that you will move beyond any negative emotions a mastectomy can bring. ♦

Resources

American Cancer Society. Surgery for Breast Cancer. www.cancer.org/cancer/breast-cancer/treatment/surgery-for-breast-cancer.html. Breastcancer.org. Mastectomy vs. Lumpectomy. www.breastcancer.org/treatment/surgery/mast_vs_lump. Susan G. Komen. Deciding Between Mastectomy or Lumpectomy. www5.komen.org/BreastCancer/DecidingBetweenMastectomyandLumpectomy.html?ecid=emklmay11:28.

Starting Your Survivorship at the Time of Diagnosis

By **LILLIE D. SHOCKNEY, RN, BS, MAS, HON-ONN-CG**

That sounds odd, doesn't it? Starting survivorship when you receive a diagnosis? Doesn't it sound like putting the cart before the horse? Many times, people think that survivorship starts once you are done with treatments. But really, your survivorship starts now.

The fear people experience after receiving a cancer diagnosis causes them to ask their oncology team to help them just survive. I want you to know, you should expect more than to just survive; you should expect a good quality of life, too, with the ability to still reach life goals. To make this happen, you need to proactively advocate for yourself. Begin by discussing strategies to minimize the possible side effects caused by treatment with your oncology team, especially your nurse navigator.

PLANNING TREATMENT DATES

For many people, a good quality of life includes participating in activities they enjoyed prior to a cancer diagnosis. This is possible—with a little planning. You may want to consider scheduling your treatment dates in a way that accounts for the possibility of side effects. Your nurse navigator can tell you when side effects are expected to occur, and then the two of you can plan accordingly. For example, let's say you have book club meetings on Tuesdays. If you receive a chemotherapy regimen that causes side effects 2 days later and usually last for 2 to 3 days, you might consider having treatment on Thursdays, with potential side effects occurring on Saturday and Sunday, and possibly Monday. You



might find that this schedule allows you to participate in your Tuesday book club.

PLANNING FOR MILESTONES

Do you have significant milestones coming up over the next year? A daughter's wedding? A grandson's graduation? A 25th wedding anniversary?

YOU SHOULD EXPECT
MORE THAN TO JUST
SURVIVE; YOU SHOULD
EXPECT A GOOD
QUALITY OF LIFE, TOO.

ry? Don't allow these to be forfeited to cancer. Provide the dates of these events to your treatment team so they can plan around these special events. It is absolutely possible to plan your treatments around an event so that you stay compliant with treatment guidelines and still attend—and enjoy—milestone events.

SHARE YOUR LIFE GOALS AND JOYS

Sharing your goals and joys with the treatment team is important. For example, maybe you are passionate about your career, and you want to create a treatment schedule that still allows you to work. Share this information with the treatment team so they can help you to attain your goal.

PALLIATIVE CARE IS A TERM THAT IS OFTEN CONFUSED WITH HOSPICE CARE. PALLIATIVE CARE IS NOT HOSPICE CARE.

Perhaps your passion is playing the piano. The treatment team should know this because there are certain treatment drugs that can cause peripheral neuropathy—numbness, pain, and tingling in your hands and feet. There may be interventions to help reduce your risk of developing neuropathy and keep you tinkling the ivories.

PALLIATIVE CARE

Palliative care is a term that is often confused with hospice care. Palliative care is NOT hospice care, nor does it mean you are “giving up.” Palliative care includes interventions that restore a person’s quality of life. If you discover that you have severe symptoms or side effects from treatment that impact your quality of life, palliative care can help to restore it.

LIFE, RESTRUCTURED

You may begin to view your life differently after a diagnosis. What was important to you before may not be as important now. You may begin to think about how you want your “new normal” to be. Do you want to spend more time with your grandchildren? Do you want to work part-time so that you can have 1 day each week to take classes at a local college? Some survivors form new meaningful relationships; others let go of current relationships. It is not uncommon for a cancer diagnosis to alter the trajectory of a survivor’s life. My advice is to take inventory of your life, create your new normal, and embrace your newly restructured life. Your survivorship starts now. ♦

Thriving While Living with Breast Cancer

An Interview with Survivor and The Chrysalis Initiative Founder Jamil Rivers

By KRISTIN SIYAHIAN

2017 was a great year for the Rivers family; 39-year-old Jamil and her family had just moved into a beautiful new home. She had landed an executive position in her company, and her husband Ricky had recently received a clean bill of health after beating colon cancer. By all accounts, the Rivers family had much to be grateful for.

That winter everyone in the family contracted colds; and they all recovered. Everyone except Jamil. Her cough just wouldn't relent.

Several doctor visits and multiple tests later, it was determined that Jamil had metastatic breast cancer. Stage IV from the start, the ER-positive, PR-positive, HER2-negative, invasive ductal carcinoma had spread throughout her body to her liver, stomach, spleen, bones, and lungs (which caused the cough).

The shocking news of her diagnosis was, of course, devastating to the young mother. But being a woman of great determination, Jamil began devising a plan. Her strategy was to learn as much as she could about breast cancer, treatments, and available support services. She made daily checklists to ensure that she was doing everything within her



power to take care of herself while receiving the best possible care.

After a year of treatment, Jamil's scans revealed no evidence of disease. To this day, she continues to take endocrine therapy to prevent a recurrence.

You might think that's the end of her story, but Jamil's diagnosis launched her on another journey: a journey of advocacy. Through her research, she learned about the staggering inequalities that exist for black and brown women with breast cancer. She felt a calling to get involved in the hope of changing the way healthcare is delivered to those in our communities at a greater risk of receiving less than optimal care.

Her role as advocate began with the simple desire to help those around her. Remember those checklists? She began sharing her lists with other breast cancer survivors she met while receiving treatment. Word spread about this empowered, positive, impassioned, determined young woman who had a plan in the form of a checklist. Women began approaching her in the hope of learning from her.

In March 2019 (which marked her 1-year "canceriversary") she founded The Chrysalis Initiative as a way of sharing her experience of thriving while fighting metastatic breast cancer.

Jamil Rivers is a metastatic breast cancer survivor and the founder of The Chrysalis Initiative. She has been featured in People Magazine, the Philadelphia Inquirer, the Philadelphia Tribune, national campaigns for Anthropologie, Novartis, Pfizer, and Cancer and Careers, as well as on CBS News and Good Morning America. She resides in southern New Jersey in the Greater Philadelphia area with her husband and 3 sons.

interview with the advocate

The mission of The Chrysalis Initiative is to ensure that every patient receives the care they deserve, especially women of disparate populations. They accomplish this mission in 2 ways: by equipping women with coaching, mentoring, and education, and by conducting training for healthcare systems in the hope of improving the delivery of care.

Today, Jamil is feeling great. She is healthy,

strong, and well equipped to lead The Chrysalis Initiative. By all accounts, Jamil still has much to be grateful for, including the impact she's had on the lives of other breast cancer survivors.

I had the incredible opportunity to speak with Jamil. I am most grateful to her for sharing her story, and I am happy to share that story with you. What follows is our thoughtful exchange.

Jamil, you've talked about how overwhelming a cancer diagnosis is. Can you describe how you got through your year-long treatments?

After my diagnosis, I tried to structure my life so that my family and I were fully supported. I accepted any and all offers of help from family, friends, and community resources. Support came in many forms—it was anything that you could think of. Meals, childcare, rides. I made the decision to start chemotherapy, and I also set a goal to continue working. But I needed support to do that. As an example, I used a transportation service offered by the American Cancer Society to pick me up from work, take me to treatment, pick me up from the hospital and take me home.

Whether I felt my family or I needed the help or not, I accepted it. I really overdosed on support!

You were able to continue working throughout your treatment. How did you deal with the side effects of chemotherapy?

I used many integrative therapies to help with side effects. I found an organization that provides free services to people with breast or ovarian cancer; through that organization, I received acupuncture and oncology massage. I also met with a nutritionist and made changes to my diet. All of these things really sustained me and allowed me to continue working full-time and keep up with the kids.

How did you evolve from “patient” to “advocate”?

When I was diagnosed, I knew I had a lot to learn about breast cancer, and so I just started reading as much as possible. I was really shocked to learn that black women with breast cancer are 71% more likely to die of the disease than white women with breast

cancer. I also learned that only 2% to 5% of research dollars are allocated to metastatic disease. I really wanted to get involved to help change these statistics.

Through my research, I ended up connecting with the National Cancer Institute, Living Beyond Breast Cancer, METAvivor, and Susan G. Komen. I joined the Komen Metastatic Advisory Committee and the Komen African American Health Equity Initiative.

I've become involved in as many aspects of advocacy as I can. Anything from reviewing grants to policy advocacy. I've met with legislators and testified to the FDA in the hope of improving the landscape of cancer treatments. I want to ring the alarm and bring more attention to these facts because status quo isn't working.

How did you come to establish The Chrysalis Initiative?

Honestly, I feel like The Chrysalis Initiative established itself! Back when I was receiving chemotherapy, I created checklists to make sure I was doing everything I could every day to stay on point and take care of myself.

When I was in the clinic, actually receiving a treatment, another patient with stage IV breast cancer popped into my chemo room and asked me to share what I knew about our diagnosis. I shared my checklist with her, and it just grew from there. At first, I was sharing my checklist with 5 women, then 10, 15, 30 women. I noticed that all of us were doing well. Yes, we all had metastatic breast cancer, but we were just putting 1 foot in front of the other.

I felt like I was on to something. When I thought about the breast cancer landscape and what was missing, I felt that an organization like The Chrysalis Initiative was needed to help educate patients and address disparities. I decided to make The Chrysalis Initia-

interview with the advocate

five official in March 2019 on my 1-year cancer anniversary.

Since then, we've evolved to include coaching and patient navigation support for women with breast cancer and their caregivers.

What can someone expect from a Chrysalis Initiative coach?

We don't think that anyone should have to go through cancer treatment alone. Our coaches are breast cancer survivors themselves and know what other patients are going through. We have a coaching curriculum to make sure our patients have the knowledge they need when facing cancer treatment.

You're in the process of creating a mobile phone app for Chrysalis Initiative participants. Can you describe the capabilities of that app?

It's really your cancer coach in an app. The app enhances the services that we already provide in our programming. Currently, participants connect with their coach via phone, Zoom, or sometimes in person. The app is another tool to connect your support network.

The app also allows participants to directly connect to The Chrysalis Initiative. They will receive push notifications and educational information. They're also looped into our upcoming community events, activities, and webinars.

A goal of The Chrysalis Initiative is to promote treatment equity for all patients. How are you accomplishing that goal?

Of course, I always say get a Chrysalis coach. Connect with us. We want to share our knowledge about national treatment guidelines and nationally recognized standards of care.

So, if you have HER2-positive breast cancer, standard of care includes Herceptin. There isn't a scenario where you should not receive this standard of care. We want you to have this information to ensure you are receiving the best possible care.

We also want to make sure that you have access to genetic and genomic testing, which can reveal actionable targets in the cancer that you are facing.

Unless your healthcare provider is sharing this in-

formation with you, you would have no idea what to ask for. We make sure that you understand what that quality standard of care is.

We also want to help people understand the importance of participating in clinical trials—especially as black women—this is the only way to advance treatment options.

The Chrysalis Initiative offers equity training for healthcare providers and cancer institutions. What does that entail?

We have a team that evaluates the ability of a health system to deliver equitable care across the board. Meaning, that a black woman who goes in for breast cancer care is going to receive the same patient experience as a white woman who goes in for breast cancer care.

Our team assesses deficiencies and determines if they are due to bias and racism or structural and procedural issues. When the assessment is complete, we provide recommendations and can help with implementation and training.

What advice do you have for black women about breast health?

Know your risk. Before my diagnosis, I didn't know that my grandmother had breast cancer. I found out much later that she went through chemotherapy and radiation, but our family never discussed it.

Many times, in cultures of color, we don't share our vulnerabilities, but it really is important for us to know our family history. My advice is to find out what ailments, diseases, or medical challenges that your parents have had, your grandparents, your great grandparents.

If you could go back in time and give yourself advice at the time of your diagnosis, what would it be?

Breathe. Just breathe and keep putting 1 foot in front of the other.

Thank you so much, Jamil, for sharing your story. Please accept our best wishes for continued success with The Chrysalis Initiative. ♦

To learn more about The Chrysalis Initiative please visit www.thechrysalisinitiative.org.



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