

Treatment Decisions



**LIVING BEYOND
BREAST CANCER®**

With you, for you.



Dear Friend:

After a diagnosis of early-stage breast cancer, you have important decisions to make. You'll work with your cancer care team to create a treatment plan that best fits you. But right now, you may feel overwhelmed and like you don't know where to start. These are normal and expected feelings.

At Living Beyond Breast Cancer, we have helped thousands of people who faced a new diagnosis of breast cancer, as you do now. From listening to them, we have learned the best place to begin is with the basics — the type of cancer you have and the treatments available to you.

This brochure will get you started. It explains the tests to be done on the breast cancer, what the results mean and how they guide treatment decisions. Use it as a tool to ask your providers questions as you create a plan of action.

Please take comfort in knowing we are here for you every step of the way.

Warmly,

Jean A. Sachs, MSS, MLSP
Chief Executive Officer

Fill out our online survey today for a chance to

win a \$25 gift card!

VISIT: surveymonkey.com/r/2016LBBC



Tell us what you think of the *Guide to Understanding Treatment Decisions*.

Thank you

for helping Living Beyond Breast Cancer improve our programs and services.

Everyone's experience is different.

If you have stage IV (metastatic) breast cancer, visit LBBC.ORG for resources created just for you.



LIVING BEYOND BREAST CANCER®

With you, for you.

Toll-Free Breast Cancer Helpline
(888) 753-LBBC (5222)
lbbc.org/helpline

All people pictured in this guide are LBBC volunteers whose lives have been affected by breast cancer. We thank them for sharing their experiences.

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Now What? First Steps in Making Decisions

Right now, you might feel you would do anything to get rid of the breast cancer. Remember, breast cancer is rarely a medical emergency, although it can feel like an emotional emergency. Living with a new diagnosis and worries about your future can be very difficult.

When you're first diagnosed, you and your doctor know very little about the cancer. Tests will soon tell you what makes the cancer grow, how fast it is growing and whether it has traveled to other areas of your body. The test results help your doctors recommend treatments best for your situation.

You are unlikely to make treatment decisions overnight. Instead, you, your healthcare team and key family or friends will go through the process together. It may take several weeks to gather the information you need. This is safe. Take the time you need to get your questions answered. Ask your doctor how much time is reasonable to take.

“At the moment I was diagnosed, I entered a scary and unknown world. Everything changed in an instant. I didn't know if I had the strength and will that I thought it would take.”

Treating Breast Cancer Today

Just 20 or 30 years ago, doctors viewed breast cancer as a single disease. There were very few treatment choices. Doctors typically told women what to do without talking about their options, needs or lifestyle.

Today, treatment is no longer “one size fits all.” We now know there are many different types of breast cancer, each with its own features. Breakthroughs in research have helped doctors learn who is most likely to benefit from certain treatments.

You may be surprised to learn that your treatment could be very different from the treatment your friend, family member or co-worker received. This does not mean you are not getting the best treatment for you. Your treatment plan should be based on the unique features of the cancer, your overall health and health history, and other issues you discuss with your healthcare team.



Creating Personalized Treatment Plans

To tailor treatment, doctors will do tests on tissue taken from the cancer. The results explain what makes the cancer grow and how it behaves. This information makes up your **pathology report**, a profile of the cancer that guides your healthcare team in choosing the best treatments for you.

Sometimes the pathology report makes the best course of treatment very clear. In other cases, it may show you have several equally good options. Deciding among them may be a matter of what makes most sense for you. Sections 2 (page 8) and 5 (page 36) help you think about questions you may face with each treatment.

If you are having trouble making a decision or feel “stuck,” talk with your care team and contact our **Helpline at (888) 753-LBBC (5222) or via online chat at lbbc.org/helpline**. Sometimes asking a different question, or thinking in a slightly different way, may be all you need to do to take your next steps.

Use caution at this phase. The Internet is filled with information. It may not help, and increase your anxiety. As your particular situation becomes clearer, the internet may be more useful and less anxiety-provoking.”

Getting Started: Surgery and the Pathology Report

To plan treatment, your doctors need to learn about the makeup of the breast cancer. This process began with your **biopsy**, when a doctor removed a small amount of your breast tissue. This sample was sent to a **pathologist**, a doctor who diagnoses diseases by looking at tissues under a microscope. After seeing cancer cells in the sample, your pathologist diagnosed breast cancer.

This diagnosis was included in your first pathology report. Yet many questions remain. To learn more, you will have one or more surgeries to take out all the breast cancer and to check for cancer in one or several **sentinel lymph nodes**, the first nodes to which the breast cancer is most likely to travel.

Breast Cancer Surgery

Surgery lowers the risk for **local recurrence**, the cancer coming back in the same area of the breast or lymph nodes.

You will need at least one surgery to remove the breast cancer. The surgery may be a **mastectomy** or a breast-conserving surgery, called **lumpectomy**. If you have breast-conserving surgery, only the cancer or the part of your breast with cancer, plus a small rim of healthy tissue around it called the **margin**, will be removed. If you have mastectomy, the whole breast will be removed. Many times, which surgery you have is your choice. There are pros and cons to either.

Your pathology report (page 16) will say whether the surgery removed all the cancer. If it reports **negative margins**, you should not need further breast surgery. But if it shows **positive margins** or **close margins**, you will need more surgery. This will be either a second lumpectomy, also called a **re-excision**, or a mastectomy.

Sometimes mastectomy is the only option. Other times doctors can offer lumpectomy or mastectomy. If your chances of **distant recurrence**, the cancer coming back in an area far from the breast, are about the same whether you have one surgery or the other, your doctor should give you the choice. In past studies, lumpectomy plus radiation therapy worked equally well as mastectomy without radiation therapy in those who were able to have either surgery.

If you have a choice of surgeries, it may be a relief, or it might feel nerve-racking and uncertain. Please know that either response is normal. Many, many people stood in your place before, not knowing what to do. If you feel uncertain at all, it is OK to ask why you have both options. This is also the best time to discuss options for rebuilding your breast (page 15), if this is of interest to you.

I did not schedule the surgery until my body gave me a ‘Yes’ to do so. Honoring my own time table helped me feel empowered in making my decisions.”

Of the many choices you make during treatment, this is among the most personal. Only you know what having your breast means to you. It may mean a lot, nothing at all or something in between.



START BY ASKING THESE COMMON QUESTIONS:

1. How important is it to me to keep my breast? Is my breast part of my self-image and identity? Does my breast play a role in my romantic relationships?
2. What is the risk of this cancer coming back in an area far from the breast? What were the outcomes in past clinical trials for people who had the surgery I want?
3. How do I feel about my risk for recurrence in the breast or lymph nodes? What is the difference in risk of recurrence between surgeries? In some cases, lumpectomy may put you at higher risk than mastectomy for the cancer coming back in the same place.
4. How would I feel if removing the cancer takes more than two surgeries? What if only one more surgery would be needed?
5. How does the size of the cancer compare to the size of my breast? Ask how your breast is likely to look after lumpectomy. Your doctor may even have photos. Are you OK with how your breasts may look, or would you rather have a mastectomy with reconstruction (page 15)?
6. How could my other treatments impact my choice of surgery? Ask if pre-surgical therapy, called **neoadjuvant therapy**, is an option and, if so, whether you could then get a lumpectomy. Radiation therapy could affect the choice and timing of reconstruction.
7. Can I have radiation therapy? Lumpectomy is almost always paired with radiation for you to get the benefit you would receive from mastectomy alone. If you have mastectomy,

your doctor may recommend radiation to lower the risk of cancer coming back in the chest wall, skin or nearby lymph nodes.

8. Where is the cancer in my breast? Your mammogram may show **calcifications**, tiny clusters of hard calcium associated with DCIS and invasive cancers. If they are in more than one area, you may need more surgery.
9. Am I at very high risk for a future breast cancer? You might have higher risk if your family has a known BRCA mutation (page 26) or a strong family history of breast or ovarian cancer. Are there other ways to improve your chances for living cancer-free after treatment?
10. Will removing my breast make me less worried about my risk for recurrence? Even if lumpectomy and mastectomy work equally well in cases like yours, you may simply feel better without your breast.

Lymph Node Surgery

To find out whether cancer is in the lymph nodes, a doctor first removes lymph nodes under the arm in a surgery called **sentinel lymph node dissection**. This surgery is done at the same time as your first breast surgery, after a biopsy shows you have breast cancer.

Removing the sentinel lymph node or nodes is standard treatment for most **invasive** breast cancers, which grow beyond the **ducts** and **lobules** of the breast into nearby tissue. If you have a **noninvasive** DCIS diagnosis, you and your doctor will talk about whether you need this surgery.

If cancer is found in the sentinel node or nodes, you may need an **axillary lymph node dissection**. This surgery removes most of the lymph nodes in the armpit and helps your doctor assign the cancer a stage. Axillary dissection increases the risk of developing side effects such as shoulder stiffness and **lymphedema**, the build-up of lymph fluid in the tissues that can cause arm swelling and numbness.

TO FIND OUT WHETHER YOU NEED AXILLARY SURGERY, CONSIDER THESE KEY QUESTIONS:

1. How much cancer was found in the sentinel lymph nodes? If it was a small amount, you may not need axillary surgery.
2. Were the lymph nodes in my armpit swollen at diagnosis? If so, you may need **chemotherapy** before surgery. If they were not swollen, you might have them removed before you start chemotherapy.
3. Do I have symptoms of **inflammatory breast cancer**? This cancer rarely forms a lump. Instead, the breast looks swollen, hot, pitted or red; feels thick or heavy; and sometimes causes pain. With this diagnosis you must have chemotherapy before surgery.
4. Should I get systemic therapy before surgery? **Systemic therapies** kill cancer cells wherever they are in the body. They include chemotherapy, hormonal therapy and targeted therapy. If the breast cancer cannot be removed without severely misshaping the breast, or if it is in multiple lymph nodes, you might need these treatments before surgery.

Breast Reconstruction

Your breast may be rebuilt in a surgery called breast reconstruction. Sometimes this surgery can be done at the same time as a mastectomy in an **immediate reconstruction**. It is also possible to wait weeks, months or even years. **Delayed reconstruction** may be a good option if your doctors know that you will need radiation therapy (see page 40) after surgery. This is because radiation therapy can damage rebuilt breast tissue or cause scarring around an implant.

Breasts can be rebuilt using tissue from other parts of the body, such as the stomach, thighs, back muscle or buttocks, or with an implant filled with silicone gel or saline (salt water). Sometimes a combination of tissue and implants are used.

If your provider forgets to talk about breast reconstruction, it is OK to bring it up. You have the right to learn more, even if you aren't ready to do anything. Deciding against reconstruction is also a valid choice.

While you may choose to ask others for opinions, this is your decision. If you do not rebuild your breast, you may get a breast form, or **prosthesis**, to place in your bra after surgery to match the size and shape of your remaining natural breast.



Reading Your Pathology Report

Over several days to several weeks, your pathologist will run tests on the tissues removed from the surgery on your breast and lymph nodes.

Some of these tests look at the actions of **genes** that make up the cancer cells. Genes contain directions, called **DNA**, that tell human cells when and how to grow. The genes of cancer cells often have mistakes in their DNA: extra copies, missing data, misspellings and other problems. Knowing the types of genetic mistakes helps doctors understand how the cancer is likely to behave and respond to treatments.

The results of these tests make up your final pathology report. You may get your complete report all at once or in parts. You may even get a few reports at a time. Meet with your doctors and ask them to explain each test result and what it means for your care. It is OK to ask questions during the meeting, and to contact your doctor's office later if you did not understand something.

“Keep a running list of the questions you want to ask your doctors. Take the list with you to your next doctor visit. If you need an answer sooner, call and speak to a nurse.”

10 TIPS FOR GETTING YOUR PATHOLOGY REPORT

- 1** Practice patience. Waiting can be very trying. It is normal to feel anxious, stressed, sad or worried.
- 2** Find out if the tests will be read at your treatment facility or sent to outside labs. Early on, make sure your health insurance covers outside labs. Someone in your doctor's office can help you find out.
- 3** Learn when the results will arrive. Ask how long it may take and how you will be told. Call if results do not arrive on time.
- 4** Ask if the doctors looking at your tests see many breast cancer cases. If not, consider a second opinion.
- 5** Ask where, how and how long your breast tissue will be stored. If your doctors need to run more tests, they may be able to use the same samples. You can also use them for a second opinion.
- 6** Take someone with you or record your conversation, with your doctor's permission. A relative or friend can take notes so you can focus on the discussion.
- 7** When you get the report, try not to focus on any single result. Your doctors look at the findings as a whole to make your treatment plan.

- 8** Find out if you could benefit from a genomic test (page 30). These test results, together with findings from the pathology report, may predict how likely the cancer is to respond to certain treatments.
- 9** Get a copy of the full report. Your test results belong to you. Keep your report and copies of your imaging tests in a safe, secure place.
- 10** Exhale. Even though you have many decisions ahead, you now have vital information to help you.



Parts of Your Pathology Report

Most pathology reports begin with a brief history of your medical state. They then describe how the tissue sample looked to the naked eye, called its **gross description**. Your report will state where the sample came from in your breast, called the **anatomic site**.

In another section, the pathologist will detail how the sample looked under a microscope, called its **microscopic description** or **synoptic summary**. It names each test done to the sample and gives results. This section is important in planning treatment because it describes the cancer itself.

Among the issues covered in this section of the report are

- the size of the cancer
- the number of lymph nodes with cancer, if any
- whether cancer was found in one area or several areas in your breast
- whether the surgeon removed all the cancer, called the **margin status**
- how the cancer cells look under the microscope, called **histologic grade**
- how quickly the cancer cells grow, called **mitotic rate** or **proliferative index**
- hormone receptor status of the cancer, its HER2 status and other important tumor markers
- the stage of the cancer

At the end of the report, the pathologist will sum up what was found in a section called Impression, Final Diagnosis or Summary with Pathological Staging.

LEARN MORE

To learn more about each of these issues, visit LBBC.ORG.

10 QUESTIONS ANSWERED IN YOUR PATHOLOGY REPORT

QUESTION 1: What type of cells make up the cancer?

Possible answers:

- **Ductal cells:** If the cancer cells look like ductal cells, which come from the pathways in the breast that carry milk, the pathology report will say you have invasive ductal carcinoma or IDC. **Noninvasive** ductal cells mean you have ductal carcinoma in situ or DCIS. Cancers of the breast duct are the most common type.
- **Lobular cells:** If the cancer cells look like lobular cells, which come from the sacs in the breast that make milk, the pathology report will say you have invasive lobular carcinoma or ILC. It could also say you have noninvasive lobular disease, called lobular carcinoma in situ or LCIS. LCIS puts you at higher-than-average risk for a future cancer in either breast.
- **Other cancer cells:** Cribriform, medullary, mucinous, papillary and tubular cells are subtypes of ductal cancer that are less common than ductal and lobular cancers. Cancers that involve the skin are called inflammatory breast cancer and Paget's disease.

QUESTION 2: Did the cancer travel outside the milk ducts?

Possible answers:

- **No.** The cancer is noninvasive. It stayed inside the ducts or lobules of the breast, where it started. This is called **in situ**. It cannot travel away from the breast to the lymph nodes or other body parts.

Yes. The cancer is invasive. It grew outside the ducts or lobules of the breast into nearby tissue. It has the potential to travel away from the breast to other areas of the body.

Yes, but some stayed inside the ducts, too. The cancer is mixed. Some cancer cells stayed inside the ducts or lobules of the breast, and other cells invaded nearby tissues. Some of the cancer is invasive and some is noninvasive.

QUESTION 3: How large is the cancer?

Possible answers:

The size of the cancer after surgery is measured in centimeters across its widest point. One inch equals about 2.5 centimeters. If the cancer is less than 1 centimeter (cm), the pathology report will state the size in millimeters (mm). Doctors use size to assign the cancer a stage. Just because a cancer is small or large does not make it easy or hard to treat; it is just one piece of the puzzle.

QUESTION 4: How do the cancer cells look and act compared with normal breast cells?

Possible answers:

Similar to normal cells. The cancer cells are called grade 1, low grade or well differentiated. Under the microscope, they look and act much like healthy cells.

Unlike normal cells. The cancer cells are called grade 2, moderate grade or moderately differentiated. They grow faster than normal breast cells.

Not at all like normal cells. The cancer cells are called grade 3, high grade or poorly differentiated. They look different than and act different from normal breast cells. These cancer cells grow quickly.

QUESTION 5: Are there cancer cells elsewhere in my breast?

Possible answers:

Yes. Cancer cells were found in your breast's blood vessels and lymph channels, tubes that carry blood and fluid around the body. The report may call this **lymphovascular invasion** or LVI. There's a higher chance the cancer may travel outside the breast or return in the future.

No. Cancer cells were absent in the lymphovascular system, lowering the chances they will travel away from the breast or return later.

QUESTION 6: Did the surgeon remove all the cancer during surgery?

Possible answers:

Yes. The test was negative (or clean) for cancer in the margins, the rim of healthy tissue removed with the cancer.

No. The test was positive. The pathologist found cancer cells throughout the healthy tissue and to the edge of the rim of tissue.

No. The test was close. The cancer was removed along with some healthy tissue around it, but some cancer cells were found near the rim.

QUESTION 7: Do I have cancer in the lymph node or nodes removed from my underarm?

Possible answers:

No. The test was negative or clear. No cancer was found in the lymph nodes.

Yes. The test was positive. Cancer is in the lymph nodes. The pathology report should say the number of lymph nodes with cancer and the amount of cancer in each node. Lymph nodes can hold anything from a few tiny cancer cells to large areas of cancer.

QUESTION 8: What is the stage of the breast cancer?

Possible answers:

- Stage 0: The cancer is noninvasive. It is **ductal carcinoma in situ**, DCIS, confined to the ducts of the breast.
- Stage I: The breast cancer is invasive. These cancers are 2 centimeters or smaller across and are not in the lymph nodes.
- Stage II: The breast cancer is invasive. The tumor is any size and has not grown into the chest wall or muscles behind the breast. It is not in the skin of the breast. There is either no cancer in the lymph nodes, or cancer has traveled to up to three lymph nodes in the armpit or near the breast bone. They are put into two groups, A and B, based on size and lymph node status.
- Stage III: The breast cancer is invasive. The tumor is any size, but the cancer has grown into the chest wall or muscles behind the breast. It may have spread to the skin of the breast. There is either no cancer in the lymph nodes, or cancer has traveled to as many as 10 lymph nodes in the armpit or near the breast bone. These cancers are put into three groups, A, B and C, based on many factors.
- Stage IV: The breast cancer is invasive. It has grown into tissue outside the ducts or lobules of the breast and traveled to other organs, such as the bones, liver, lungs or brain. If you have this diagnosis, LBBC has tailored services for you. Visit LBBC.ORG.

Note: Your doctor may change the stage if further tests show cancer in distant areas of the body.

QUESTION 9: Do hormones fuel the growth of the cancer cells?

Possible answers:

- Yes. The hormone receptor tests are positive. Estrogen and progesterone fuel the growth of cancer cells. The cancer cells have estrogen or progesterone **receptors**, proteins that tell cancer cells to grow. The cancer cells may test positive for one or both hormone receptors. You will see a percentage, rating or other number that explains how sensitive the cancer is to hormones; the higher the percentage or rating, the more sensitive.
- No. The hormone receptor tests are negative. Estrogen and progesterone do not fuel the growth of the cancer cells.

QUESTION 10: Does the cancer make too much HER2 protein?

Possible answers:

- Yes. The cancer scores 3+ on the IHC or immunohistochemistry test. The cancer cells have too many copies of the **HER2** gene, which directs proteins in the cancer cells to grow, divide and travel away from the breast.
- No. The cancer scored 0 or 1+ on the IHC test. The cancer cells do not make too much HER2.
- Uncertain. The cancer scored 2+ on the IHC test. It is uncertain whether the cancer cells make too much HER2. To find out, an ISH or In Situ Hybridization test should be done. ISH will report the cancer as positive for HER2 (yes) or negative (no). The ISH test result can also be between positive and negative (called equivocal), but this is uncommon.

Note: It is not routine to test DCIS for HER2.

Genetic Testing

A genetic test looks for gene **mutations**, mistakes in the gene DNA that raise the risk for developing breast and ovarian cancer. We inherit these gene mutations, such as *BRCA1* and *BRCA2*, from our father or mother at conception. A mutation in either BRCA gene greatly increases the risk for a future breast cancer. Other gene mutations are under study to find out if they may play a role in developing either cancer.

Between 5 and 10 percent of women and men with breast cancer test positive for a BRCA mutation. You might explore genetic counseling and testing if:

- You were diagnosed with breast cancer at age 50 or younger
- You have a personal or family history of cancer in both breasts
- Several family members have had breast or ovarian cancer, or both
- You have a personal history of ovarian cancer
- You have male family members who have had breast cancer
- You have a personal or family history of triple-negative breast cancer diagnosed under age 60
- You had two separate (two primary) breast cancers
- Your background is Ashkenazi (Central or Eastern European) Jewish

Because male breast cancer is one of the factors considered in a family history, men who are diagnosed with breast cancer are encouraged to get genetic counseling.

If you are interested in genetic testing, your doctor may recommend you meet with a **genetic counselor**, a healthcare provider trained to help you weigh the risks and benefits of testing and learn how the results could impact you. Your counselor will develop a

pedigree, a chart of your family's medical and cancer history over time. For the testing, a blood or spit (saliva) sample is needed.

When health history suggests a BRCA gene mutation, genetic testing can be very helpful. If you have a mutation, your doctors may recommend more frequent screening, also called surveillance, watching you closely with regular and special tests such as breast MRI or pelvic ultrasound. **Chemoprevention** is taking medicine to try to lower your chances of developing new cancers. With **prophylactic mastectomy**, a healthy breast is removed to lessen the chances of a future breast cancer. Removing the ovaries in an **oophorectomy** surgery lowers the risk for future ovarian cancer and can also reduce the risk of future breast cancer in women who have a BRCA mutation.

The choice to have genetic testing can be complex. What you learn could impact not only your treatment but also your family and future generations, because the mutation can be passed to your children. It can take several weeks to get results, and you may not want to wait to start treatment.

A plus of genetic testing is that you may do it anytime. If you prefer to wait, you can still test later. Even if you aren't sure, consider meeting with a genetic counselor to review your family history. You won't be able to use the results today, but if you test positive for a gene mutation known to raise your risk of a second cancer, you can decide later whether to take steps to reduce that risk.

“Genetic testing was important to me. If I had been BRCA positive, I would have chosen a different surgery.”

Next Steps

When you first get your full pathology report, it is natural and normal to feel overwhelmed. Remember, you do not need to absorb the report all at once. Your doctors should go through it with you, step by step, at an appointment. Consider these questions and how the answers could affect your treatment options:

- Is the breast cancer invasive, noninvasive or mixed?
- How large is the cancer, and where is it in my breast?
- How aggressive is the cancer? Which tests suggest this?
- Did cancer cells travel away from the breast? Where?
- Did my breast surgery yield negative, close or positive margins? How wide were the margins?
- Does the cancer grow in the presence of estrogen or progesterone?
- Does the cancer have too much HER2?
- Are any test results unclear? How can I get answers?
- Do I need more tests to find out if the cancer traveled to other parts of my body?
- Could I benefit from genomic testing (page 30) or genetic testing (page 26)?

If you have more questions but aren't sure where to start, contact our **Helpline at (888) 753-LBCC (5222) or via online chat at lbbc.org/helpline**. Our volunteers can help you find the words to begin a talk with your doctor.



Understanding Genomic Tests

In the past, most breast cancers that tested positive for hormone receptors would have been treated with both chemotherapy and hormonal therapy to lower the chances of cancer returning to parts of the body far from the breast. These cancers need systemic therapy, medicines that kill cancer cells wherever they are.

Today, we know that some hormone-positive breast cancers can be treated with 5-10 years of full-body hormonal therapy alone. In these cases, chemotherapy does not add extra protection from cancer traveling away from the breast.

Genomic tests help doctors identify your risk of the cancer coming back, and also which cancers need chemotherapy to lessen the chances of cancer growing to other parts of the body. These tests, called **assays**, look at cancer cells to see whether certain groups of genes are present, absent or too active. These genes affect how a cancer is likely to grow and respond to treatment. Cancers are treated differently based on how they behave.

There are many different genomic assays. The most common are Oncotype DX, MammaPrint, Prosigna and Breast Cancer Index.

NOTE

Genomic tests are different than genetic tests for BRCA and other mutations.

Oncotype DX

Oncotype DX is the most widely used genomic test today, although others are starting to be recognized in national treatment guidelines. This test looks at the activity of 21 genes in a tumor sample to score the chance of the cancer returning within 10 years if you're taking hormonal therapy. It also predicts whether the cancer will respond to chemotherapy.

You might be able to have this test if you are a woman and the breast cancer is

- stage I or II and has not traveled to the lymph nodes
- hormone receptor-positive
- HER2-negative

Your doctor may offer you Oncotype DX if the cancer is in your lymph nodes, but so far most studies have looked at cases in which the cancer has not traveled to them.

You do not need extra surgery or needle sticks to have Oncotype DX. The pathologist will take a sample of tumor from your breast surgery or one that was stored afterward in paraffin wax. It will be sent to a central lab, and your results should arrive 10 to 14 days later. The results are given as a Recurrence Score between 0 and 100. Lower scores mean you have a lower risk of the cancer returning. Higher scores mean your risk is higher. In general, a score of

- 0 to 17** means you have a low risk for distant recurrence within 10 years if you take 5 years of hormonal therapy. The benefit of adding chemotherapy is likely to be very small.

- 18 to 31** means you have an intermediate risk of distant recurrence in the next 10 years if you take 5 years of hormonal therapy. It is uncertain whether adding chemotherapy will benefit you. Researchers are studying the role of chemotherapy in intermediate scorers.

- 32 to 100** means you are at high risk for distant recurrence within 10 years. The cancer is very likely to respond to chemotherapy treatment. Your doctors will likely recommend both chemotherapy and 5 years of hormonal therapy.

Your doctor may also suggest this test if you have ductal carcinoma in situ, DCIS, that is hormone receptor-positive and can be removed with lumpectomy. Used this way, Oncotype DX predicts the risk of cancer returning and also whether you should plan for radiation therapy after lumpectomy.

Other Genomic Tests

Though Oncotype DX is the most widely used, others may be available to you. Your doctor may recommend these tests to learn more about the cancer and how to treat it. If you are getting treatment in a clinical trial, some of these tests may be part of the study.

MAMMAPRINT

The MammaPrint test looks at the activity of 70 genes to predict whether the cancer has a high or low risk of recurrence at 5 and 10 years. It does not predict whether certain treatments will work against the cancer.

You might be able to have this test if the breast cancer is

- stage I or II
- any receptor status
- not in the lymph nodes
- no larger than 5 centimeters at its widest point

No extra surgeries or needle sticks are needed for this test. If you decide to have the test before you go in for surgery, the surgeon needs to punch a small hole in fresh tumor tissue to get a sample. This will be saved in a chemical and sent to a central lab. The lab can also take certain preserved samples from tumors that were removed in an earlier surgery. After 7 to 10 days, you will get one of these results:

🔴 **Low risk:** With no further treatment after surgery, you have a relatively low chance the cancer could travel to other parts of the body within 10 years. Whole-body treatments such as chemotherapy or hormonal therapy may further lower your risk.

🔴 **High risk:** With no further treatment after surgery, you have a higher chance the cancer could metastasize within 10 years. You could lower your risks with treatments tailored to your diagnosis.

PROSIGNA

The Prosigna test, or Prediction Analysis of Microarray 50 (PAM50), looks at the activity of 50 genes to predict risk of recurrence. It also identifies the **molecular subtype** of the cancer by looking for certain traits in the cancer cells. Research shows some subtypes respond differently to certain treatments.

You may get PAM50 if you have already started menopause and the cancer is **hormone receptor-positive**.

The lab will look at things like the molecular subtype, tumor size and how quickly the cancer grows. You will receive a score, on a scale of 0 to 100, that represents the chance of the cancer returning in the next 10 years. From this score you will be considered in a general risk category: low, intermediate or high.

BREAST CANCER INDEX

The Breast Cancer Index (BCI) is designed to predict if a woman taking hormonal therapy is likely to benefit from receiving 10 years of that treatment instead of stopping after 5 years. It also predicts the risk of cancer returning between 5 and 10 years.

You may get the BCI if the cancer is hormone receptor-positive.

Limits of Genomic Tests

These tests only apply to certain cancers. If you have stage III or IV disease, genomic tests will not provide helpful information. Or you may have other risk factors for recurrence that make genomic tests less valid for you. Talk with your healthcare providers about the possible limits of genomic tests for your situation.

Public and private health insurance providers usually cover the costs of genomic tests, but check before you move forward. The test makers also offer patient assistance programs. For more information, download our *Guide to Understanding Financial Concerns*, available at LBBC.ORG.

Genomic tests can be very helpful in guiding treatment decisions, but they should not be used on their own. They cannot replace your pathology report. If genomic tests are right for you, you may find they provide guidance and peace of mind as you consider your treatment options.

Putting It All Together

Test results draw a detailed picture of the cancer. Yet an important part of this picture is missing: You. Tests do not know how you live, work, or play, or what you need to do to function well.

Personal concerns are as important as medical tests in choosing treatment. Some treatments work equally well but have different side effects.

TO PUT IT ALL TOGETHER, START BY ASKING:

- 1.** Do I want a second opinion? A new point of view may help you explore options or validate your choices.
- 2.** Do I want to get my treatment through a clinical trial? You will get at least the standard therapy and might get a study treatment that could lower your risk of recurrence or improve your quality of life.
- 3.** Would hearing statistics help me choose? If you don't want to hear statistics, that is OK. Let your team know how you feel.
- 4.** How much risk can I tolerate? In other areas of your life, do you tend to do whatever you can to lessen risk, even if the rewards seem small? Or do you take action only when it could bring great benefits?

5. How much will I worry about cancer coming back? If you often fear for your future or your health, even a very small difference in benefit could be very important to you.
6. Could this treatment impact plans for my future? Some cancer treatments affect fertility or require that you avoid pregnancy for some period.
7. Do I have other health problems that this treatment could affect or worsen? These include heart and lung disease, diabetes, genetic disorders, osteoporosis, arthritis, blood clots, HIV and a weak immune system.
8. Can I continue to work and care for my family? Ask how long side effects could last, and how they may impact your daily life.
9. Will I need to travel to get this treatment? You might prefer to stay close to home. But if you want that far-away therapy, explore your options.
10. Is one treatment more costly than the other? How will I pay? LBBC believes no one should go without treatment because they can't afford it or access it. If you are facing barriers, talk with an oncology social worker or nurse about patient assistance programs, and download our *Guide to Understanding Financial Concerns*, available at LBBC.ORG.

I believe it is important to find doctors who are willing to take the time to explain the process to you and answer all your questions.”

Clinical Trials

Clinical trials are research studies carried out in people. They evaluate new medicines, surgeries, tests and treatments, or new ways to give proven treatments or tests. Research studies are open to people with all stages of breast cancer, and even to some healthy women and men. They are not a last resort.

For diseases that have standard treatments available, like breast cancer, you get at least the standard treatment. You might also gain access to treatments not yet available outside the study. If the new treatment proves helpful, you may be among the first to benefit. You will always get the best breast cancer treatment available to you.

Hundreds of clinical trials are open at any time. Some trials look at surgery, chemotherapy, radiation, hormonal therapy and targeted therapy. Others look at tests that screen for and diagnose breast cancer, ways to take a biopsy or manage side effects, and the impact of breast cancer on your lifelong health.

Because there are so many different kinds of research studies, almost everyone has the option to take part. Your providers should bring up clinical trials very soon after your diagnosis. If they do not, it is OK to ask, “Do I have the option to get treatment through a clinical trial?” You may also want to ask:

- ◀ How will treatment in a trial differ from standard treatment?
- ◀ What are the possible benefits for me?
- ◀ What are the potential risks for me?

- How will you watch my health?
- What are my rights if I take part?
- If I change my mind, can I leave the study?
- Will I find out the results of the trial?

LEARN MORE

Learn more about clinical trials and how to join one in our *Guide to Understanding Clinical Trials*, available at LBBC.ORG.

Radiation Therapy

Radiation therapy is a type of **local therapy** that uses high-energy x-rays to kill cancer cells where they are found. It is usually used after lumpectomy, and sometimes after mastectomy. This treatment kills very tiny cancer cells that may still be in the area where the cancer was removed to help prevent cancer from coming back.

Radiation can be given in different ways. You might be offered **external beam radiation**, which is given from outside the body. A doctor with special training in radiation therapy, your **radiation oncologist**, will direct the radiation at the area with cancer by pointing at it with a special machine. For breast cancer, radiation is most often given to the breast, chest wall, and sometimes the lymph nodes. A **CT scan** called a simulation may be used to plan treatment.

You may get external beam radiation if you have

- DCIS
- early-stage breast cancer
- breast cancer that spread to the lymph nodes or chest wall
- inflammatory breast cancer

If your radiation oncologist recommends you have treatment from inside the body, you will have **brachytherapy**. In brachytherapy, small radioactive seeds are placed in your breast where the tumor was removed during surgery. Brachytherapy is also called **internal beam radiation**. Treatment with it is usually shorter because it delivers more radiation to more specific areas than external beam.

You may get brachytherapy if you have

- early-stage breast cancer and
- had, or will have, lumpectomy

The radiation oncologist determines how much radiation to use and how often you will come for treatment. He or she will make sure that organs such as your lungs and heart are not exposed to too much radiation. Other staff members, including radiation therapists, are very involved in your care and work closely with the doctors. They put you in the correct position for your treatments and even mark **reference points** on your skin with pin-dot-sized tattoos. (If you cannot get a tattoo, special skin markings can be used.)

Radiation therapy can be given

- once a day, 5 days a week for about 6 weeks. This is the most common treatment plan
- once a day, 5 days a week for 1 to 3 weeks, for certain situations
- twice a day over about 1 week, if you have brachytherapy

There are many different kinds of radiation and courses of treatment, so ask your doctors why they recommend a certain kind for you. It's OK to ask if you are able to get shorter treatment plans. Some are not offered at all treatment centers. Your doctor can tell you more about the options available to you.

Radiation does not hurt, but it can make you feel more tired than usual, especially toward the end of treatments. The skin in the treated area can become red, dry and scaly, like you have a bad sunburn. Your team will suggest moisturizers and other methods of keeping your skin soft and comfortable.

With most invasive breast cancers, you cannot fully benefit from lumpectomy without radiation treatment. It can often be avoided after mastectomy, but your doctor may still say you need it.

HERE ARE SOME QUESTIONS TO CONSIDER:

1. How much more protection from recurrence will radiation give me? Ask for results from clinical trials of people with similar types of breast cancer.
2. Can I avoid radiation if I have a mastectomy? Sometimes, but not always. It may depend on other factors including your age, number of lymph nodes with cancer, and other features of the cancer. Ask your radiation oncologist to help clarify this for you.
3. Are there reasons I cannot have radiation? These include having had radiation treatment to the same area earlier in life, some joint conditions, or heart and lung problems.
4. How will I find the time? Plan your treatments at convenient times. Ask if you can get treatment close to home or work.
5. How will I get there? Nonprofit and religious groups can arrange free rides, or friends and family can help through a resource like LotsaHelpingHands.com. Your hospital might offer shuttle service or help with travel costs. Ask a social worker or patient navigator for help.

Chemotherapy

Chemotherapy works throughout the body, killing cancer cells wherever they are. It is standard systemic treatment for many kinds of invasive breast cancer. Systemic treatments kill cancer cells throughout the body, not just where the tumor grew. Chemotherapy lowers the risk of cancer coming back in organs far from the breast.

Many chemotherapy medicines are given **intravenously**, through a vein in the arm. Your team may suggest you get a **port**, a small device placed under the skin attached to a tube that connects to a vein. During a short surgery, your doctor will put the port just under your collarbone or in your arm. The port allows a trained nurse to give chemotherapy without searching for a vein every time.

Chemotherapy tends to follow surgery, but it also can be given before. Outcomes are as good when chemotherapy is given before as when it's given after surgery. And some studies suggest certain types of breast cancer may respond better to neoadjuvant than adjuvant chemotherapy.

If you have inflammatory breast cancer, neoadjuvant chemotherapy is the standard treatment. But neoadjuvant treatment is becoming a more common option in general. If it interests you, talk with your doctor.

There are many kinds of chemotherapy medicines. Some are given alone; others, together. Still others are given as **sequential treatment**, one (or several together) followed by another. Usually, chemotherapy is given in cycles with a day or several days of treatment, followed by a rest period of 2 to 3 weeks. Treatment lasts for 3 to 6 months.

Chemotherapy is standard treatment for some breast cancers. **Triple-negative breast cancers**, which test negative for hormone receptors and HER2, often shrink from chemotherapy. HER2-targeted therapies work better when paired with chemotherapy, so you will likely get both for a HER2-positive cancer.

For some hormone-positive cancers, hormonal therapy alone works just as well as chemotherapy at keeping the cancer from coming back. To find out if this may be true for you, your doctor can order an Oncotype DX test, but it won't always give you a clear-cut answer (page 32).

If you have a choice about chemotherapy, weigh its benefits against its possible side effects. Some chemotherapy medicines cause fatigue, nausea and vomiting, mouth sores, hair loss, nail problems, weight gain or loss and higher-than-average risk for infection. In the long term, chemotherapy may affect your fertility, intimate life, memory and thinking, ease of movement and risk for other cancers.

I decided not to listen to the conventional thinking. I would never refer to chemotherapy as ‘chemo.’ This was a way to remember that it was, indeed, therapy, and was intended for my health.”

That list may sound scary, but it is important to remember that every person responds differently to treatment. It is possible to have very few or no side effects. Some side effects are more common with certain medicines. Find out if you have choices.

No matter what your situation, ask your providers about possible side effects before you start treatment. Your team has many options to lessen, manage or stop

side effects. Just because you have cancer does not mean you must suffer.

LEARN MORE

If you have triple-negative breast cancer, or TNBC, the best treatment for you is chemotherapy. Learn more about TNBC and the chemotherapies available in our *Guide to Understanding Triple-Negative Breast Cancer*.



QUESTIONS TO ASK ABOUT CHOOSING CHEMOTHERAPY:

- 1.** Is the cancer HER2-positive? Therapies that target HER2 have been proved very effective in clinical trials when given with chemotherapy.
- 2.** Is the cancer hormone-positive? If it isn't, you will not benefit from hormonal therapy. If it is, ask your doctor how much chemotherapy could lessen your risk of recurrence.
- 3.** Is the cancer triple-negative? Chemotherapy has been shown to be very effective for this diagnosis.
- 4.** Is the cancer in more than three lymph nodes? Chemotherapy is very likely to benefit you.
- 5.** Do I have other serious health problems? Share all past and ongoing health concerns with your doctor.
- 6.** How much will chemotherapy improve the odds the cancer will not return? Even if chemotherapy lessens the chances for recurrence by 1 or 2 percent, that might be meaningful for you.
- 7.** How much risk can I tolerate? Consider how you feel about risk in other parts of your life. You can't completely rid yourself of cancer risk, but taking chemotherapy might be personally important for you.
- 8.** Do some medicines have more side effects than others? Some medicines work equally well but have different side effects.

- 9.** Will having chemotherapy make me less worried about my risk for cancer returning? You know yourself best. Consider what worries you most: The risk for recurrence or the risk of side effects. It is always OK to ask about side effects, even if you must have chemotherapy.

Targeted Therapy

Medicines that find and attack cells that have a high number of certain cancer-causing features, such as the HER2 receptor, are called **targeted therapies**. These treatments look for a specific trait in the cancer cell, and only cancers with that trait may respond to the therapy. Because they target certain parts of the cell, they cause less damage to healthy cells than other cancer medicines.

There are many kinds of targeted therapy, and researchers are likely to find others as they learn more about the traits that make certain cancers grow. Today, **trastuzumab** (Herceptin) is given with chemotherapy as standard treatment for invasive, HER2-positive breast cancer. It attaches to the HER2 proteins and blocks the messages that tell the cells to grow too quickly and cause cancer.

Given by vein either once a week or once every 3 weeks for about a year, trastuzumab lowers the risk of cancer growing to organs away from the breast. Adding trastuzumab to chemotherapy cuts the risk of recurrence in half and improves survival.

Another targeted therapy for HER2-positive breast cancer is **pertuzumab** (Perjeta). Pertuzumab may be given along with trastuzumab and chemotherapy as neoadjuvant therapy. It works the same way as

trastuzumab, by blocking the signals that tell cells to multiply.

You may be offered pertuzumab if the cancer has a high risk of recurrence, is larger than 2 centimeters, is inflammatory, or has already traveled to nearby lymph nodes. It may be given for up to 18 weeks, on the same day as trastuzumab and chemotherapy.

Trastuzumab can make you feel like you have the flu, with chills, fever, upset stomach and muscle aches. Pertuzumab usually does not cause serious side effects, but you may experience some side effects such as diarrhea, hair loss, fatigue, numbness and tingling in the hands and feet, nausea, rashes, and low levels of white blood cells.

A possible serious side effect of both medicines is damage to the heart, so you should not get trastuzumab or pertuzumab at the same time you receive other medicines that can affect the heart, such as doxorubicin (Adriamycin) and epirubicin (Ellence). If you already have heart problems, your doctor may not recommend trastuzumab or pertuzumab.

LEARN MORE

Get more in-depth information on targeted therapies in our *Guide to Understanding HER2-Positive Breast Cancer*.



QUESTIONS TO ASK ABOUT TARGETED THERAPY:

- 1. How did you test the cancer's HER2 status?**
Find out which test the pathologist used. If an IHC test came back 2+, a borderline result, ask for an ISH test.
- 2. How much will trastuzumab or pertuzumab lower my chances for recurrence? Getting the numbers may help you feel more confident.**
- 3. What other treatments will I need? If the cancer also tests positive for estrogen and progesterone receptors, a diagnosis sometimes called triple-positive breast cancer, you could also benefit from hormonal therapy.**
- 4. What can I do to manage or stop side effects?**
Some medicines and methods that treat chemotherapy-related side effects may also stave off the flu-like symptoms of targeted therapies.
- 5. Can I take part in a clinical trial of medicines similar to trastuzumab and pertuzumab? A number of trials are underway.**

Hormonal Therapy

Your team will offer you hormonal therapy, also called anti-estrogen or endocrine therapy, if the cancer tests positive for estrogen or progesterone receptors.

Hormonal therapy works by lowering the amount of estrogen in the body or by stopping breast cells from absorbing estrogen. These treatments lower the risk for cancer returning in the breast or in other parts of the body.

Several hormonal therapies come as pills. They are usually given after surgery, but it is also possible to take them before to try to shrink a large tumor. The most studied of these medicines, **tamoxifen**, works by attaching itself to estrogen receptors outside breast cancer cells. When the natural estrogen in the body tries to reach these receptors, tamoxifen blocks its path and keeps cancer cells from growing. Tamoxifen is standard treatment for women who still get a period. Postmenopausal women may take it as well. It is the only hormonal therapy approved for DCIS.

If you are premenopausal, your doctor may recommend **ovarian suppression** or removal of your ovaries along with your hormonal therapy. Ovarian suppression uses medicines called **GnRH** or **LHRH agonists** to stop your ovaries from making estrogen while you take other treatments. Your ovaries will start working again when you stop taking the suppression medicine.

Shutting down your ovaries may protect them from chemotherapy and also protect your ability to get pregnant in the future. And, major studies have shown that for some women, ovarian suppression lowers your risk of recurrence when used with tamoxifen or an aromatase inhibitor.

Your doctor may also recommend **ovarian ablation**, surgery to permanently remove your ovaries. If you have

ovarian ablation, you will start menopause right away, and you won't be able to get pregnant in the future.

Another group of medicines, called **aromatase inhibitors**, works only in postmenopausal women. The ovaries no longer make estrogen after menopause, but the body makes its own using an enzyme called aromatase. Aromatase inhibitors block this enzyme, preventing the body from making estrogen. The aromatase inhibitors available are anastrozole (Arimidex), letrozole (Femara) and exemestane (Aromasin).

With hormone-sensitive cancers, the standard treatment is to take hormonal therapy every day for 5-10 years. For invasive cancers, you may take the same treatment for all 10 years or, if you are or become postmenopausal, take several years of tamoxifen and then switch to an aromatase inhibitor. Findings from the ATLAS trial, published in 2012, showed that 10 years of tamoxifen may benefit women more than 5 years. Talk with your doctor about the pros and cons of taking treatment longer.

Hormonal therapies have varied side effects, including hot flashes, vaginal dryness, menopausal symptoms, loss of interest in sex, insomnia, mood changes, weight gain, bone loss, joint pain, higher risk of clots in your veins (**thrombophlebitis**) and, with tamoxifen, an increased risk of uterine (endometrial) cancer. You may experience some or none of these side effects.

Talk with your doctor about your concerns. If you have side effects, you may be able to switch from one hormonal therapy to another under your doctor's care. Often the problems lessen or go away after the change.

LEARN MORE

Weighing the risks and benefits of hormonal therapy can be complex. For in-depth information, please read our *Guide to Understanding Hormonal Therapy*.

QUESTIONS TO ASK ABOUT HORMONAL THERAPY

- 1. Do I need to take hormonal therapy?** If you have hormone receptor-positive breast cancer, taking hormonal therapy for 5 to 10 years after other cancer treatments has been shown to significantly lower the risk of cancer coming back. And remember, it's important to take the medicine every day.
- 2. How much more will adding hormonal therapy to my treatment lower the risk of cancer coming back?** Your doctor can talk with you about your long-term risks of recurrence, with and without hormonal therapy.
- 3. If I take this medicine, will I be able to have children later in life?** Hormonal therapy impacts your fertility while you take it, but most people are able to get pregnant once they stop, as long as they are not in menopause. Talk with your care team about how to protect your fertility before you start treatment.
- 4. What are the possible side effects?** Hormonal therapy causes symptoms of menopause, like hot flashes, vaginal dryness and bone and joint aches. Most of these side effects go away once treatment ends. Your doctor can also recommend ways to manage them when they happen.
- 5. How long will I have to take this medicine?** Whether you've started menopause, your plans for future pregnancy and your risk of recurrence may all impact how long you take it. Talk to your doctor about your unique situation.



Looking Ahead

Making decisions about your health is rarely easy, especially at times of great stress, worry and uncertainty. At this moment, it is likely you are searching for information and for answers, and your loved ones may be searching, too.

We hope reading this guide comforts you. By learning more about your choices, you are taking steps to make the best decisions for your health.

“Each time I met with a doctor, I was able to understand more.”

Once your treatment plan is in place, you may have different questions and concerns. We encourage you to visit our website, LBBC.ORG, so we can help you with this next part of treatment.

At any point along the way, we invite you to contact our **Helpline at (888) 753-LBBC (5222) or via online chat at lbbc.org/helpline**. By connecting with a woman who has had breast cancer, you may learn you are not alone.

Resources

Words to Know

Anatomic site. Location in the breast where tissue was removed during surgery.

Axillary lymph node dissection. Surgery to remove lymph nodes in the armpit and check them for cancer cells.

Assays. Another name for genomic tests that look at the genes of a tumor to find the risk of cancer returning.

Biopsy. Taking a small amount of tissue from the breast to look at it under a microscope.

Calcification. Tiny clusters of hard calcium in the breast that may increase the risk for developing ductal carcinoma in situ and invasive cancers.

Chemoprevention. Taking medicine to try to lower the risk for developing cancer.

Chemotherapy. Medicines that kill cancer cells throughout the body.

Clinical trial. A research study in humans.

CT scan. Test that takes a two-dimensional picture of organs. Also called CAT scan.

Delayed reconstruction. Surgery to rebuild the breast weeks, months or years after mastectomy.

Distant recurrence. When breast cancer comes back after treatment to an area far away from the breast.

DNA. The directions that tell a cell when and how to grow.

Ducts. Passageways that carry milk from the lobules in the breast to the nipple.

Gene. In a cell, the part that contains the directions (DNA) that tell the cell when and how to grow.

Genetic counselor. Healthcare provider trained in weighing the risks and benefits of genetic testing and in educating people about results.

Genetic test. Looks for genetic mutations that increase the risk for developing diseases such as breast or ovarian cancer.

Genomic test. Looks at groups of genes in cancer cells to see if these genes are present, absent or too active to predict how a cancer grows and may respond to treatment.

Grade. A score of how abnormally the cancer cells behave and look compared with healthy breast cells. Also called **histologic grade** on your pathology report.

Gross description. How the breast cancer looks to the naked eye.

HER2. A protein that controls how cancer cells grow, divide and repair themselves.

Hormone receptor-positive. When receptors on the outside of cancer cells tell them to grow in the presence of estrogen or progesterone, natural hormones in the body.

Hormonal therapy. Treatment that lowers the amount of estrogen in the body or stops breast cells from absorbing estrogen. Also called anti-estrogen or endocrine therapy. Hormonal therapies include

tamoxifen, aromatase inhibitors, GnRH and LHRH agonists and a surgery called **ovarian ablation**.

Immediate reconstruction. Surgery to rebuild the breast at the same time as a mastectomy.

Inflammatory breast cancer. Type of breast cancer in which the breast feels warm and swollen. Grows in the lymph vessels (tubes), blocking the natural movement of lymph fluid.

In situ. Cancer that has stayed where it first grew, in the ducts or lobules of the breast. It cannot travel to other parts of the body.

Intravenously. Given by vein.

Invasive. Cancer that grows outside the ducts or lobules of the breast and invades nearby tissues. Has the potential to travel outside the breast to other parts of the body.

Lobules. Glands that make breast milk.

Local recurrence. When the breast cancer comes back after treatment to the same place in the breast or lymph nodes.

Local therapy. Treatments that kill cancer in the place it started.

Lumpectomy. Surgery to remove only the cancer or the part of the breast with cancer, plus a small rim of healthy tissue around it (the **margin**).

Lymph node. Round mass of lymphatic fluid and white blood cells that filter bacteria and waste.

Lymphedema. Condition in which too much lymph fluid collects in tissues and causes swelling.

Lymphovascular invasion. The name for when cancer cells are found in the blood vessels or lymph nodes. This means the chances of cancer traveling to other parts of the body are higher. Also called **LVI**.

Malignant. Cancerous.

Margin. Rim of healthy tissue around a breast tumor. In a pathology report, margins can be positive, negative or close. Negative margins mean no cancer cells near the edge of the healthy tissue removed. Positive means cancer cells were found throughout the healthy tissue and close means they were near, but not on, the edge. A positive or a close margin may need more surgery to remove all the cancer cells.

Mastectomy. Surgery to remove the whole breast.

Microscopic description. A report from a pathologist about how cancer cells from a tumor look under a microscope. Also called a **synoptic summary**.

Mitotic rate. A description of how quickly the cancer cells in a certain tumor grow. Included in a pathology report. Also called the **proliferative index**.

Molecular subtype. How the tumor cells of a breast cancer are described based on certain traits found in their genes. A genomic test is used to identify the cancer as one of four common subtypes.

Mutation. When a cell has a mistake in its directions. As the cell makes more copies of itself, the copies will also have the mistake.

Neoadjuvant therapy. Treatment given before removing the cancer with surgery.

Noninvasive. Cancer that stays inside the ducts or lobules of the breast.

Oncologist. Doctor with special training in treating cancer.

Oophorectomy. Removing one or both ovaries with surgery.

Ovarian suppression. Using medicine or surgery to keep the ovaries from making estrogen. When talking about surgery, your doctor may call this ovarian ablation.

Pathologist. Doctor who diagnoses diseases by looking at tissues under a microscope.

Pathology report. Report that describes the cells and tissues of a cancer, based on a pathologist having looked at them through a microscope.

Pedigree. Chart of a family's medical and cancer history.

Port. Small device put under the skin with surgery that gives easy access to veins to take blood or give medicine. Also called mediport or port-a-cath.

Prophylactic mastectomy. Removing a healthy breast with surgery to try to lessen the chances of developing breast cancer.

Prosthesis. Artificial breast that fits into a bra.

Radiation oncologist. Cancer doctor with special training in giving radiation therapy.

Radiation therapy. A local therapy that uses high-energy x-rays to kill very tiny cancer cells that may still be in the area where cancer was removed. May be given as **external beam radiation** or **internal beam radiation**.

Re-excision. Further lumpectomy done after a first lumpectomy. Re-excision is needed when cancer is found inside or close to the edge of the margin after lumpectomy.

Receptors. Protein that lives inside or on the surface of a cell and binds to something in the body to cause the cell to react.

Reconstruction. Surgery to rebuild the breast. See also immediate reconstruction and delayed reconstruction.

Recurrence. When the breast cancer comes back after treatment. See also distant recurrence and local recurrence.

Reference points. Precise spots on the body that will receive radiation therapy.

Sentinel lymph nodes. First lymph nodes to which the breast cancer is most likely to travel.

Sentinel lymph node dissection. Surgery to check for cancer in the first lymph nodes where cancer is likely to travel.

Sequential therapy. Giving one or several medicines together, followed by another medicine or medicines.

Systemic therapy. Treatments that kill cancer throughout the body.

Targeted therapy. Medicines that block the growth and spread of cancer cells by interfering with molecules that help them grow. Healthy cells are left unhurt. Targeted therapies include **trastuzumab** and **pertuzumab**, both given in HER2-positive breast cancer.

Thrombophlebitis. Clots in the veins.

Triple-negative breast cancer. Breast cancers that test negative for HER2 and hormone receptors.



Many thanks to these individuals who volunteered their time and expertise for this guide:

AUTHORS

Janine E. Guglielmino, MA

Kristine M. Conner, MA

EDITORS

Eric Fitzsimmons

Nicole Katze, MA

LEAD MEDICAL REVIEWER

William J. Gradishar, MD, FACP

Feinberg School of Medicine, Northwestern University,
Chicago, Illinois

LIVING BEYOND BREAST CANCER REVIEWER

Amy B. Grillo

PROFESSIONAL ADVISORY COMMITTEE REVIEWERS

Advocacy

Lisa D. Black

Bryn Mawr, Pennsylvania

Genetic Counseling

Ryan Bisson, MS, CGC

UF Health Cancer Center – Orlando Health,
Orlando, Florida

Medical Oncology

Kanu Sharan, MD

Cooper University Hospital, Camden, New Jersey

Oncology Nursing

Deena Damsky Dell, MSN, RN-BC, AOCN

Fox Chase Cancer Center, Philadelphia, Pennsylvania

Oncology Nurse Practitioner

Millie Cappa, MSN, CRNP, AOCNP

Rutgers Cancer Institute, New Brunswick, New Jersey

Oncology Social Work

Hester Hill Schnipper, LICSW, BCD, OSW-C

Beth Israel Deaconess Medical Center,
Boston, Massachusetts

Pathology

Shabnam Jaffer, MD

Mount Sinai School of Medicine, New York, New York

Radiation Oncology

Silvia C. Formenti, MD

New York-Presbyterian/Weill Cornell Medical Center,
New York, New York

Suneel N. Nagda, MD

University of Pennsylvania School of Medicine,
Philadelphia, Pennsylvania

Surgical Oncology

Lisa Jablon, MD

Einstein Medical Center, Philadelphia, Pennsylvania

CONSUMER ADVISORY COMMITTEE REVIEWERS

Mona Cristol Barmash, Margate City, New Jersey

Kimberly Karitis, Newburgh, New York

Pam Kops, Churchville, Pennsylvania

Virginia Macali, Columbus, Ohio

We dedicate this guide to the memory of Kara Guzzetti who contributed to an earlier edition.

CREATIVE DEVELOPMENT

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With you, for you.

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