

Guide for the Newly Diagnosed



**What to expect...
today, tomorrow and beyond**

Steps for coping with the medical, emotional
and practical concerns of breast cancer



**LIVING
BEYOND
BREAST
CANCER**

LBBC.ORG

Dear Friend:

If a doctor, nurse or friend gave you a copy of this guide, you recently heard words you never wanted to hear: “You have breast cancer.”

You probably have a range of emotions, including shock, fear, stress, anger or numbness. Maybe you feel overwhelmed by the medical terms you are hearing. Perhaps you are worried about the well-being of your family, the costs, or the possibility of pain, hair loss or other side effects of treatment. You may be asking, “How will I get through this? Will I live?”

Living Beyond Breast Cancer’s *Guide for the Newly Diagnosed* is designed to help you cope with the next few days, weeks and months of your life. Working closely with healthcare providers and women who have had breast cancer, LBBC developed this brochure to help you understand your diagnosis, the possible treatment options and the availability of support.

Every woman deals with breast cancer in her own way. Many women want to talk to someone who has been through it. When you are ready, we encourage you to call our [Survivors’ Helpline at \(888\) 753-LBBC \(5222\)](#) for guidance, information and peer support. Our trained volunteers are here to listen and help you through this difficult period.

We hope you will keep this booklet nearby to serve as your guide. Together, we will help you make it through.

Warmly,



Jean A. Sachs, MSS, MLSP
Chief Executive Officer

LIVING BEYOND
BREAST CANCER

FREE HELPLINE
(888) 753-LBBC (5222)

All women pictured in this brochure are LBBC volunteers whose lives have been affected by breast cancer.

We thank them for sharing themselves and their experiences.

Facing Your Diagnosis: Dealing with This Moment

Coping with the News

Each year, millions of Americans learn they have cancer. Yet the words “You have cancer” never lose their power.

Cancer has different meanings to different people, and the way you respond to your diagnosis will be as unique as you are. It will reflect your personality, your past experiences with and memories about cancer or other health issues, the way you manage stressful situations, and other things happening in your life at the moment. Your response may be quite different than the response of someone else who has had breast cancer.

During the first few weeks after a diagnosis, it is not unusual to have many different feelings. Anger, fear, anxiety or sadness may be among them. Your feelings may change from day to day, or even hour to hour, as you start to cope with the news. It may be helpful to concentrate just on getting through the next day, or even the next hour. Try not to judge yourself. Almost all women find the first few weeks after diagnosis to be extremely difficult emotionally. Allow yourself to experience your feelings. Things will improve over time as you gather information.

For more information on coping, call us or visit lbcc.org to order your free copy of LBBC’s *Guide to Understanding Your Emotions*.

Telling Family and Friends

Sharing news of a breast cancer diagnosis with family and friends is never easy. But the people who know you and love you will want to be there for you. By telling them about your diagnosis, you are allowing them to help you and give you support.

It is your decision to share the news with others, and you can share it when and how you choose. You do not have to share the news immediately or with everyone you know. When you begin to tell others, they may ask more questions than you want to answer. Remember, you are in control of how much information you share. Do what makes the most sense for you.

Just as you have your unique way of dealing with the news, so will your family and friends. Sometimes people do not respond the way you expect. Sometimes they just don’t know what to say. Remember that these responses have to do with their own fears and worries and not with how they feel about you.

During this time, it is very important for you to focus on your own needs. Try not to rely on people who cannot support you. If you feel that those closest to you cannot help, consider calling on other family members or friends or on LBBC’s Survivors’ Helpline.

Telling Young People and Children

If you have a young person close to you—a child, grandchild, or niece or nephew—we strongly encourage you to share the news.

Children sometimes feel anxious when they sense adults are hiding something. They may have questions if they notice changes in the way you look or behave. Talk to children in a way that makes sense for their age and emotional development. Be clear and reassuring.

With small children, you do not need to be very specific. You can say, “Mommy is sick, but I am taking medicine to make me better. The medicine may make me tired or make me lose my hair, but I am still the same mommy.” Using real words like “cancer” and “chemotherapy” helps children understand that they won’t lose their hair or have other side effects the next time they get sick. Consider using one of the many picture books available to help the young people in your life understand cancer. Think about what you want to say beforehand, or call our Survivors’ Helpline for tips from another parent.

10 COMMON FEELINGS AND FEARS AT DIAGNOSIS

- ① Am I going to die?
- ② Why me? What did I do to get breast cancer?
- ③ Could I have prevented it?
- ④ Will I lose my breast?
- ⑤ Will I lose my hair?
- ⑥ Are my children at risk of getting cancer?
- ⑦ Will I feel pain?
- ⑧ How will I tell my family, friends, boss?
- ⑨ Who will take care of my family if I am sick?
- ⑩ Will I still be able to work?



What Is Breast Cancer?

Most of us learn about breast cancer from the news and from events and studies that get us closer to “the cure.” But in reality, researchers are looking for many cures, because breast cancer is not a single disease. Breast cancer is a group of diseases that are related because they involve the tissues of the breast.

Breast cancer occurs when normal breast cells grow and reproduce out of control, turning into **malignant** (cancerous) cells. These abnormal cells grow so much that they fill the ducts (ductal cancer) or the lobules (lobular cancer) of the breast. The **lobules** are glands that produce breast milk, and the **ducts** are the passageways that carry the milk from the lobules to the nipple.

Ductal cancers and lobular cancers are named by the way they look under a microscope. **Ductal cancers** tend to grow together in a mass, making them somewhat easier to find. **Lobular cancers** tend to grow in more than one area of the breast in a pattern like a sheet, making them more difficult to find. There are other special types of breast cancer, but in general doctors treat them in similar ways.

When cancer cells stay inside and fill the walls of the ducts, this is called **in situ** breast cancer or **ductal carcinoma in situ (DCIS)**. Other times the cells escape and grow through the walls of the ducts and lobules, invading nearby tissues. This is called **invasive** or **infiltrating cancer**. Invasive cancers can enter the bloodstream or blood vessels and possibly travel to the lymph nodes under the arm, or even to organs beyond the breasts.

When you first receive your diagnosis, you will have little information about the cancer, its behavior or whether it has traveled beyond your breast. Over the next few weeks, your doctors will do tests to learn more about the features of the cancer. Once you know more, you and your doctors can determine together the most appropriate treatment plan for you.

Who Gets Breast Cancer...or “Why Me?”

Anyone with breast tissue can get breast cancer—even men. Women of all ages, including very young women in their 20s or 30s, can develop breast cancer. But your risk increases with age, so the older you are, the more likely you are to develop breast cancer.

People of all ethnicities get breast cancer. Women with different lifestyle habits and from different walks of life develop breast cancer. Women with breast cancer can be fit or overweight, vegetarians or meat-eaters, regular exercisers or “couch potatoes.”

What all people with breast cancer have in common are “bad copies,” or **mutations**, in the DNA of their breast cells. **DNA** makes up the genes of a cell. It carries a set of directions that tells cells when to grow and how to stop growing.

These mutations can come from your mother or father at birth. More often, these mutations develop at some point in your life. Some people are more likely to develop a mutation because cancers run in the family. Others have been exposed to certain things during their lives that make them more likely to get a mutation. We are still learning about the causes of these mutations and why people get them.

Breast cancer is less common in women whose menstrual periods start at a later age, whose menopause starts early, who breast feed, who have children before age 30, who exercise and who are not overweight. But even these traits do not prevent breast cancer—they only give you some protection from developing it. Nothing can completely protect you.

You may be asking yourself, “Why me? What did I do to bring on this breast cancer?” Your questions are a reasonable response to the shock of diagnosis. There is no single cause of breast cancer. There is nothing that you did or missed doing that caused you to develop breast cancer. Over time, either on your own or with family and friends, you may find your own answer to this difficult question.

How You Will Learn More About the Type of Breast Cancer You Have

Before you and your doctor agree on your treatment plan, your doctor must gather more information.

By now, you probably know whether the cancer is noninvasive (DCIS) or invasive (or infiltrating). Now you need to learn the extent of the cancer. What size is it? Is there just one tumor in your breast? If it is invasive, is it only in your breast or has it traveled to other areas of your body? Does it involve the lymph nodes under your arm? To find out, your doctor may do a **sentinel lymph node**

biopsy (surgery to check for cancer in several lymph nodes under your arm) and blood tests, a chest x-ray, CAT scan, MRI, bone scan or PET scan. Your doctor will get answers to other questions by looking at tests you already had, including the mammogram, ultrasound or biopsy. Other tests may be done on pieces of tissue taken from your breast during the biopsy. Taken together, the results of these tests will create a “profile” of the cancer that will help you and your treatment team decide on next steps.

If others in your family have had breast cancer, your doctor might speak with you about genetic testing to see if a gene mutation runs in your family. That information may influence your treatment decisions.

To learn more about tests, order a free copy of LBBC’s *Guide to Understanding Treatment Decisions*, or visit lbcc.org.

A Note on Waiting, and Patience

One of the most difficult things about a new diagnosis of breast cancer is waiting: waiting for tests, for results, for explanations. Waiting may make you feel anxious, helpless or frustrated because you want answers and you want to get started with treatment. Waiting can make you feel that your life and your health are out of your control.

Remember that you have time to make good decisions and gather information so that you and your team can plan the treatment that is best for you.

This time between when you make your decisions and start treatment requires patience. Prepare yourself mentally and physically for this waiting period. The next few weeks of your life will be filled with doctor’s appointments and tests. Plan calming activities for times when you may feel anxious. Talk with your doctors about a reasonable time frame for results. If you feel you have waited long enough, you should call your doctor or nurse and ask for information.

Save some patience for yourself. You are learning new medical terms and making important decisions about your health and future. No one expects you to understand everything right away. If you have questions but you are not sure how or what to ask, you have many resources available to you. Your doctors or nurses may have names of people who already had breast cancer and will speak with you. You can also talk with a mental health provider. Many social workers, psychologists and psychiatrists have special experience working with people newly diagnosed with cancer. Ask your doctor to refer you. We also invite

you to call the LBBC Survivors’ Helpline, and we will talk through your questions together.

10 THINGS TO DO RIGHT AWAY

- 1 **Make a list of your doctors and their contact information.**
- 2 **Decide whether you want a second opinion.**
- 3 **Find out whether you can take time off from work should you want to do so.**
- 4 **Talk with your family and friends about your fears and concerns.**
- 5 **Think about what you need most right now.**
- 6 **Take good care of yourself.**
- 7 **Seek information about breast cancer from trusted sources.**
- 8 **Make necessary doctor’s appointments.**
- 9 **Keep track of your medical records and make copies of everything you receive.**
- 10 **Get a notebook or journal to write down questions or other information.**

Your Medical Team...or “Who Are All These People?”

Your healthcare providers are a key part of your support team. Many hospitals take a team-based approach to care, meaning your doctors work together to follow your case and meet regularly to discuss your treatment.

When putting together your team, ask yourself: “Do I trust and feel confident about this person? Do we communicate well? Did the doctor listen to my questions and concerns?”
These people may play a role in your care:

- ▶ A **radiologist** reads pictures of organs and tissues and looks for disease. The radiologist does mammograms, sonograms, ultrasounds, MRIs, CAT scans, bone scans and PET scans. Some radiologists specialize in breast imaging, while others are general radiologists.
- ▶ A **pathologist** diagnoses disease by looking at tissues under a microscope and figuring out the specific type of breast cancer.
- ▶ A **surgical oncologist** removes cancer during surgery. Surgical oncologists are general surgeons who receive special training in the diagnosis and surgical treatment of cancer. In some cases, the surgical oncologist serves as the main doctor in charge of your treatment.

- ▶ A **medical oncologist** diagnoses and treats cancer with medicines such as chemotherapy, hormonal therapy and targeted therapy. In some cases, your medical oncologist serves as the main doctor in charge of your case.
- ▶ A **nurse navigator** is a nurse who guides you and your caregivers through the healthcare system so you can get the care you need to make informed decisions about treatment.
- ▶ A **radiation oncologist** treats cancer with radiation therapy.
- ▶ A **plastic or reconstructive surgeon** reshapes or rebuilds the breast after surgery.
- ▶ A **primary care physician** provides you with your regular medical care and may manage your care with your other doctors.
- ▶ A **medical oncology nurse** is a registered nurse with special training in the medical and emotional needs of people with cancer. Oncology nurses give anti-cancer treatments, including chemotherapy, hormonal therapy and targeted treatments. They can help you manage side effects and the emotional parts of dealing with cancer.
- ▶ A **surgical oncology nurse** is a registered nurse with special training in the surgical treatment and emotional needs of people with cancer. Before surgery, surgical oncology nurses talk to you about surgery and give tests. After surgery, they help you with wounds and ongoing care.
- ▶ A **nurse practitioner** is an advanced practice registered nurse with special training in the treatment and emotional needs of people with cancer. NPs can give or prescribe medicine and help you manage side effects and access support services.
- ▶ A **social worker** or counselor talks with you and your family about your emotional needs and helps you find support services.
- ▶ A **physician assistant** is a licensed health provider who can diagnose and treat cancer with a doctor's oversight. PAs can order tests, assist with surgery and prescribe medicine.
- ▶ A **patient navigator** is a nurse, social worker or other person who helps you and your loved ones get access quickly to the tools you need to get treatment and keep your quality of life.
- ▶ A **physical therapist** performs and teaches exercises to help you maintain strength before starting treatment and to improve recovery.

When you start treatment, ask which doctor will coordinate your care. If you have questions, you should be able to contact your main doctor, even if you just want to ask which person to call.

Making Sense of Your Pathology Report

If you had a needle biopsy, your doctors will need to remove more tissue to learn more about what type of breast cancer you have. This surgery may be called a **surgical biopsy** or a **lumpectomy**.

After this surgery, the pathologist will put together a **pathology report**, which will serve as a guide for you to discuss treatments. You may get an early copy of the report, but it will not have all the information your doctors need until you have the **definitive surgery**, a final surgery with negative (cancer-free) margins. (See page 7 for more information.) You should get your own copy of your final pathology report from your surgeon's office.

The report will be divided into three sections. The first section will contain the **gross description** of the tissue, or what the pathologist saw when looking at the tissue with the naked eye. The next section will describe how the cells look under the microscope. This part will focus on how many of the cells are actively dividing (growing) and how different they look from normal cells. The final section will sum up all the information the doctors learned.

Your pathology report may include:

- ▶ The **pathological diagnosis**, or whether the cancer is noninvasive (ductal carcinoma in situ, or DCIS) or invasive (ductal or lobular carcinoma).
- ▶ The **anatomic site**, or where the tumor was located.
- ▶ The **size**, measured in millimeters (mm) or centimeters (cm).
- ▶ The **histopathologic grade**, which explains how many of the cells are growing and how different they look from normal breast cells.
- ▶ The **Ki-67 proliferation index**, or MIB-1, which reports what percentage of the cells are dividing or reproducing.
- ▶ **Lymphovascular invasion**, or whether the cancer is in the blood vessels or the lymph channels in the breast tissue. The lymph channels carry fluid through the body.
- ▶ **Hormone receptor status**, or whether the cancer grows in response to estrogen or progesterone. If the cancer grows in response to these hormones, your

report will show the cancer is estrogen receptor positive (ER+), progesterone receptor positive (PR+) or both. Your report also should show what percentage of cells is sensitive to these hormones.

- ▶ **HER2 status**, or whether the cancer cells overexpress (make too much of) the HER2 protein on their surface.

After your definitive surgery, the report also will have:

- ▶ The **surgical margins**, or whether the tissue surrounding the tumor is free of cancer cells, or how close the cancer cells are to where the surgeon cut out the tissue.
- ▶ The **lymph node status**, or whether the cancer is in your lymph nodes.
- ▶ The **stage** of the cancer.

How Doctors Figure Out the Cancer Stage

Doctors use the **TNM system** to assign a stage to the breast cancer. T stands for the size of the tumor and whether it involves the skin lying over it or the muscle underneath; N stands for lymph node involvement; and M stands for metastasis, or whether the cancer has traveled from your breast to another area in your body.

Breast cancer has five stages, 0 to IV. Doctors use these stages to predict your chances of survival. For example, a stage 0 cancer, or noninvasive cancer, has an almost 100 percent chance of long-term survival. A stage IV cancer, where the disease has traveled throughout the body, has a much lower chance of long-term survival.

These are the five major breast cancer stages:

Stage 0 breast cancer is noninvasive, or DCIS. It is confined to the ducts of the breast.

Stage I breast cancers are invasive. They have grown into tissue outside the ducts or lobules of the breast. Stage I breast cancers are small tumors of 2 centimeters across or less in your breast, with no cancer in the lymph nodes.

Stage II breast cancers are invasive. They are put into two groups.

Stage IIA cancers are:

- ▶ Medium tumors larger than 2 centimeters but less than 5 centimeters across in your breast, *or*
- ▶ Small tumors of 2 centimeters or less in your breast, with cancer cells in your axillary lymph nodes, *or*
- ▶ Not in your breast but in your axillary lymph nodes.

Stage IIB cancers are:

- ▶ Medium tumors larger than 2 centimeters but less than 5 centimeters across in your breast, with cancer cells in your axillary lymph nodes, *or*
- ▶ Large tumors of 5 centimeters across or more in your breast.

Stage III breast cancers are invasive. They are put into three groups.

Stage IIIA cancers are:

- ▶ Large tumors of 5 centimeters across or more in your breast, with cancer in the axillary lymph nodes. The cancer may also be in the lymph nodes near your breast-bone (**internal mammary lymph nodes**), or attached to one another in the lymph nodes (**matted**) or to other parts of your body, *or*
- ▶ Medium tumors larger than 2 centimeters but less than 5 centimeters across in your breast. The cancer may also be in the internal mammary lymph nodes, or attached to one another in the lymph nodes or to other parts of your body, *or*
- ▶ Small tumors of 2 centimeters or less in your breast. The cancer may also be in the internal mammary lymph nodes, or attached to one another in the lymph nodes or to other parts of your body, *or*
- ▶ Not in your breast but in your axillary lymph nodes, attached to each other or to other parts of your body. In some cases, the cancer may be in the internal mammary lymph nodes.

Stage IIIB cancers are small, medium or large and:

- ▶ Are in your chest wall or the skin of your breast *or*
- ▶ Are **inflammatory breast cancer**, a type of breast cancer that grows in the lymph vessels and makes the breast feel warm and swollen, *or*
- ▶ Are in your axillary lymph nodes, and may be attached to each other or other parts of your body or to the internal mammary lymph nodes.

Stage IIIC cancers may be small, medium or large, or your doctors may not be able to find a tumor in your breast but find it in your chest wall or on the skin of your breast. These cancers are:

- ▶ In the lymph nodes of your collarbone *and*
- ▶ In the axillary lymph nodes and internal mammary lymph nodes.

Stage IV cancers are invasive. They have traveled away from the breast to other organs in the body, like the bones, liver, lungs or brain. This is also called **metastatic breast cancer**. If you have this diagnosis, LBBC has unique guides and support for you. For more information, visit lbcc.org.

You may see many unfamiliar words on your pathology report. Ask your doctor or nurse to explain what they mean. It is OK to keep asking questions until you understand the results and what they may mean for you. Another brochure, our *Guide to Understanding Treatment Decisions*, takes you step-by-step through your pathology report.

10 QUESTIONS TO ASK YOUR DOCTOR ABOUT YOUR PATHOLOGY REPORT

- 1 Is the cancer invasive or noninvasive?
- 2 What stage is the breast cancer? How large is it?
- 3 Is it a ductal or a lobular cancer?
- 4 Has the cancer traveled to my lymph nodes?
If yes, how many nodes are affected?
- 5 Has the cancer traveled elsewhere in my body?
- 6 Is the breast cancer estrogen receptor positive (ER+) or progesterone receptor positive (PR+)?
- 7 Is the cancer HER2 positive?
- 8 Did the surgeon remove all the cancer from my breast?
- 9 Besides the main site of the cancer, do I have cancer or other problems in other parts of my breast?
- 10 Are there areas of concern in my healthy breast?

A Note on Treatment Goals

Depending on the stage and extent of the cancer, as well as your personal needs, you may set a variety of goals for your treatment. For example, if you have a stage 0, or DCIS, diagnosis, your treatment goal may be to remove the tumor and protect your body from invasive cancer in the future. If you have a stage IV, or metastatic, cancer, your treatment goal may be to get rid of as much cancer as possible and maintain your quality of life.

Your wishes should be included in your treatment goals. Discuss your feelings and desires about treatment with your healthcare providers. Don't be self-conscious about what you want. Let your healthcare team know if you have worries about side effects, how a treatment could impact your day-to-day activities or your long-term risk for the cancer coming back.



What Are the Treatments for Breast Cancer?

There are two parts to breast cancer treatment: local therapy and systemic therapy.

- ▶ The goal of **local therapy** is to control the disease in the breast and nearby lymph nodes.
- ▶ The goal of **systemic therapy** is to get rid of very tiny cancer cells that may have traveled away from the primary breast tumor to other sites, such as the lymph nodes, bones, liver, lungs or brain. All invasive cancers have the potential to travel from the primary tumor to another part of the body.

Local therapies include surgery (lumpectomy or mastectomy) and radiation. These therapies are sometimes offered in combination with each other, and other times surgery alone is enough. In most cases, lumpectomy and radiation go together, but each case is unique and so is each treatment plan.

Systemic therapies include chemotherapy, hormonal therapy and targeted treatment. The choice about which systemic therapies, if any, you receive depends on the type of breast cancer you have and the chances of it come back (**recurring**) either in the breast or somewhere else in your body. Many factors go into the decision about which systemic therapy will be most effective in reducing your risk for distant recurrence.

What Local Treatments May Be Offered?

SURGERY

Almost every woman diagnosed with breast cancer will have some kind of surgery. The goal of surgery is to remove the cancer from your breast. There are two types of breast surgery, breast conservation and mastectomy.

In **breast conservation**, the surgeon performs a **lumpectomy** (also called a partial mastectomy or segmental excision), which is followed by radiation treatment to the remaining breast tissue. Lumpectomy removes the tumor from your breast, along with a rim of normal tissue, called the **margin**. The surgery must remove all the cancer from your breast. Because cancer often cannot be seen, sometimes it may take two or three surgeries to remove it all.

Not everyone can have breast conservation surgery. In general, the tumor needs to be less than five centimeters across and be in only one area of your breast. Also, your

breast must be large enough for the surgery to leave a good-looking result. You must be able and willing to receive radiation therapy.

If you cannot have breast conservation because of the size or extent of the tumor and you wish to do so, you may be able to get chemotherapy or hormonal therapy before surgery to shrink the tumor, called **neoadjuvant therapy**. This type of treatment is an option for many types of breast cancer. It is the standard treatment for inflammatory breast cancer and several other kinds of stage III breast cancer.

In some cases, your surgeon may recommend a **mastectomy**, or removal of the entire breast. This is done for a variety of reasons, including personal choice, multiple tumors in different parts of the breast, tumors in the nipple area, previous breast cancer in the same breast, large tumors or aggressive tumors.

Lumpectomy or Mastectomy?

You may have the option of lumpectomy or mastectomy. Studies show that lumpectomy followed by radiation therapy works as well as mastectomy in treating early-stage breast cancers. In making your decision, remember there is no "right answer," just the best one for you. Try not to base your decision on what someone else did who had the same type of cancer as you. The decision is yours.

Weigh both the medical issues and your concerns about your quality of life. Ask why the doctor recommends one surgery over the other. Is keeping your breast the most important thing to you? Are you willing and able to have weeks of radiation therapy after surgery? Will you live with constant worry of the cancer returning if you don't have a mastectomy? If you like, talk through your decision with people you trust or call LBBC's Survivors' Helpline to talk with a woman who made this decision.

Is the Cancer in the Lymph Nodes?

If you have an invasive cancer, your surgeon will need to look at the lymph nodes under your arm, called **axillary nodes**, to see whether they contain cancer. This surgery will be done at the same time as your breast surgery. This information will help you and your treatment team learn the stage of the cancer and figure out what treatments you need in addition to surgery and radiation.

In some cases you may have a **sentinel lymph node biopsy** at the time of your surgery. In this surgery, the doctor removes the sentinel nodes, the few axillary lymph nodes that drain fluid from the breast. If cancer travels away from the breast, it will go to the sentinel nodes first. There are many ways to find the sentinel nodes, and your doctors should describe their method to you.

The surgeon will test the sentinel nodes to see whether they have cancer. If they do not, it is likely no more lymph nodes will be removed. If they do, your surgeon may remove more axillary lymph nodes, either at the time of your sentinel node biopsy or at another surgery.

In other cases, you may have an **axillary lymph node dissection**, or removal of most lymph nodes under the arm. Your surgeon may do this type of surgery if tumor cells are found in an axillary lymph node. Axillary dissection has a higher risk than sentinel biopsy for long-term side effects, including lymphedema.

Lymphedema occurs when extra lymph fluid gathers in the tissues, causing swelling of the arm or hand. It is an uncomfortable possible side effect of any lymph node surgery or radiation. It is much more common after axillary dissections than sentinel lymph node biopsies. Learn more about this side effect in LBBC's *Guide to Understanding Lymphedema*.

Before surgery, ask whether you will have a sentinel lymph node biopsy or axillary dissection. Ask why the doctor recommends one surgery over the other, and ask about the risks for short- and long-term side effects.

A Note on Reconstructive Surgery

If you have a mastectomy, you may choose to have **breast reconstruction**, or surgery to rebuild your breast. There are many types of reconstructive surgery, and you can choose to have your breast rebuilt at the time of your mastectomy or even months or years later.

Another option is a **prosthesis**, an artificial breast form that fits into your bra. A prosthesis helps you keep a breast shape when you wear clothes. Or you may choose not to have reconstructive surgery or use a prosthesis. You have options, and you can take your time to decide which one makes most sense for you and your lifestyle.

RADIATION THERAPY

Radiation treatment is another local therapy. The goal of **radiation** is to treat any cancer that remains in the area where the breast cancer was found. It helps protect you from the breast cancer coming back in the same place (**local recurrence**). When radiation is given after surgery as part of the primary treatment, it is called **adjuvant therapy**.

Radiation treatment is very effective against cancer in the specific area it is directed, but it will not treat cancer in other areas of the body. Because it is a local treatment, the side effects of radiation are related to the area where the treatment is given. It is unlikely to cause side effects elsewhere. Except for the time you are getting radiation treatment in the cancer center, you are not "radioactive" and do not need to worry about exposing family members to radiation.

How Does Radiation Work?

Radiation focuses the power of high energy x-rays on areas where cancer cells may remain, such as the tissue left after surgery to your breast and lymph nodes. The sites for radiation treatment vary and depend on where the cancer was found. You may receive radiation to part of your breast, your whole breast, the chest wall, the area above your collarbone or under your arm.

How Do I Know if I Need Radiation?

You will meet with a radiation oncologist, a doctor who specializes in treating cancer with radiation. This doctor will talk with you about your medical history, other illnesses and your diagnosis of breast cancer. With this information, the doctor can talk with you about the role of radiation in your treatment plan.

If you have breast conservation surgery, you probably will also have radiation treatment. If you have a mastectomy, you may not need radiation. To decide whether you need radiation after mastectomy, your doctor will look at the size of the tumor and whether cancer traveled to the lymph nodes or other areas such as the muscle below your breast or your skin.

How Is Radiation Given?

Usually, radiation is given from outside your body by external beam. It also can be given from inside the body.

What Happens at Treatment?

Radiation treatment must be very precise. To find the right places to give radiation, your doctor will give you a **CAT** (or CT) **scan**. This special x-ray takes pictures of the inside of your breast from many different angles. Then, to make sure the exact same spot is always radiated, your radiation oncologist will give you tiny tattoos—about the size of the top of a pin—on the areas to be radiated.

Several days to a week later, you will begin treatments. How long radiation treatment takes depends on the kind of treatment you receive.

The standard treatment is **whole breast radiation**, given daily by external beam for five to seven weeks. Each treatment takes about 15 minutes. The treatment to the entire breast is for about five weeks. The last one to two weeks may include a **boost**, an extra dose of radiation given over several days, to the area where you had surgery. **Accelerated external beam radiation**, a newer treatment, gives whole breast radiation over three to four weeks.

Partial breast radiation treats only the part of the breast where the tumor was found. It can be given by external beam, or it can be delivered internally, through **brachytherapy**, when a surgeon puts a balloon or **catheters** (hollow, flexible tubes) in the cavity where the tumor was found. You are then treated with radiation two times per day over a week. These treatments may take up to a half hour. The balloon or catheters are removed when you complete treatment.

Doctors are still studying the effectiveness and side effects of partial breast radiation. If you want this treatment, explore the risks and benefits with your doctor.

What Are the Side Effects?

Fatigue is a common side effect of radiation treatment. Because the impact of radiation therapy builds up, your fatigue may increase later in your treatments. Expect to feel tired in the last few weeks of treatment, and plan time for naps and resting.

The skin on or near the radiated area may become dry, sore, red, blistered or scaly. Ask your radiation nurse and radiation oncologist for ideas to keep your skin moist and comfortable.

External radiation increases your risk for developing lymphedema, rib fractures and some rare cancers. Discuss all the benefits and possible side effects with your doctor.

What Systemic Treatments May Be Offered?

The systemic treatments for breast cancer are chemotherapy, targeted therapy and hormonal therapy. Your doctors may recommend that you receive some or all of these treatments based on the results of your pathology report and other tests that explain how the cancer behaves.

From the pathology report, your doctors will consider the size of the tumor and how fast it is growing. They will look at whether the cancer has grown into nearby tissues, is in the lymph nodes, grows in response to the hormones estrogen and progesterone or overexpresses (has too many) HER2 receptors.

Genomic tests give more details about the traits of the cancer, how likely it is to return and how effective certain treatments might be. If you have a genomic test, your doctors will talk with you about how the results could impact your treatment.

The treatment your doctors recommend should take into account other important factors, like your age, your overall health, your lifestyle and the chances the breast cancer could come back.

In some cases, you may have a single treatment option. Or you may have a choice among several equally good options. One treatment option may be taking part in a **clinical trial** (see page 15), which compares a new medicine or approach to the standard to see which is more effective.

Ask your providers why each treatment is recommended, and why one treatment might work better than another. Find out about the side effects of your treatments and how they could impact your life.

Learn more about making choices in our *Guide to Understanding Treatment Decisions* and about clinical trials in the *Guide to Understanding Breast Cancer Treatment Research Studies*.

CHEMOTHERAPY

The goal of **chemotherapy** is to kill cancer cells that are growing or dividing quickly. It is a powerful tool to fight cancer and protect you from recurrence.

Unlike surgery or radiation, chemotherapy kills all quickly dividing cells, even healthy ones, causing some of the common side effects that often go along with treatment.

Every case is unique, so whether you receive chemotherapy depends on many factors.

These include:

- ▶ The specific type of cancer cells.
- ▶ Your age and whether you have gone through menopause.
- ▶ The size of the primary tumor.
- ▶ Whether you have cancer in your lymph nodes.
- ▶ The details (or **prognostic factors**) of the breast cancer, as explained by pathology tests and, sometimes, genomic tests.

Some important information that helps your doctor decide whether you should receive chemotherapy include the tumor's estrogen and progesterone receptor status, HER2 status, the proliferation index and the tumor grade.

How Do I Know If I Need Chemotherapy?

Your doctor will recommend chemotherapy if the cancer has a large risk of coming back outside your breast, or has traveled outside the breast already. Chemotherapy is given for large tumors, cancer in the lymph nodes and tumors with features that make them aggressive.

Sometimes it is unclear whether you should have chemotherapy, and your doctor may order a genomic test. These tests look at groups of genes in breast cancer cells to see whether they are present, absent or too active. These factors help predict how likely it is that the cancer will come back after treatment.

Genomic tests are used only for certain kinds of early-stage breast cancers. Your doctor will ask for a genomic test if the tumor is small, has not traveled to the lymph nodes, has hormone receptors on it and does not have too many HER2 receptors on it. These tests are done on a piece of tissue that your surgeon took when the cancer was removed.

In the United States, the most common genomic test is the Oncotype DX. This test looks at several features of the tumor and gives it a Recurrence Score, a prediction of the chances the cancer could return after surgery and hormonal therapy. If it is very likely the cancer will return, your doctor will recommend you have chemotherapy and hormonal therapy. If the chances are very low that the cancer will return, your doctor will recommend hormonal therapy alone.

Another genomic test, MammaPrint, looks at the activity of 70 genes in the breast cancer. It estimates the risk of the cancer coming back after surgery. Results of this test may help you decide about whole-body treatments like chemotherapy and hormonal therapy.

Genomic tests are new compared to other tests, so do not be concerned if you know women who had treatment in the past but did not have these tests. If you think you should have genomic testing and your doctor does not mention it, ask for more information. You and your doctor may be able to use the results of genomic tests, along with your pathology report, to make treatment decisions.

What If I Have a Choice About Chemotherapy?

In some cases, the risk the cancer will come back is not clearly high or low, and you may have a choice about whether to have chemotherapy. If so, explore with your doctor the benefits and risks of chemotherapy treatment. Ask about short- and long-term side effects. Consider your current health and how chemotherapy could impact your day-to-day life.

We also invite you to call or visit lbbc.org to order a free copy of our *Guide to Understanding Treatment Decisions*. This guide gives you a list of questions to consider.

How Is Chemotherapy Given?

Most chemotherapy is given as **adjuvant therapy**, after and in addition to surgery. Treatment usually starts about a month after surgery, once you have had time to heal.

Your doctor also may offer you the option of **neoadjuvant therapy**, or treating the cancer with medicines before taking it out surgically. Usually, neoadjuvant chemotherapy is done to avoid mastectomy, but it is the standard treatment for some types of breast cancer. It also is a reasonable option for you if you need to have chemotherapy at any point during your treatment. After neoadjuvant therapy, you still may need a mastectomy, or you may be able to have breast conservation therapy. (For more information about surgery, see page 9.)

There are many different types of chemotherapy medicines. These may be given alone, called **single-agent therapy**, or together, called **combination therapy**. Some chemotherapy medicines do a better job fighting the cancer when they are given together. Your doctor will figure out the

best chemotherapy treatment for the cancer based on the cancer's traits and your treatment goals.

What Happens During Chemotherapy Treatment?

Chemotherapy is put directly into your bloodstream, usually through an IV (**intravenously**) but sometimes by mouth as pills or capsules. Chemotherapy can irritate the small veins in your arms, so some surgeons put in a **mediport** or port-a-cath, a small device under the skin that allows easy access to your veins. Once you complete treatment, the port is removed.

Your doctor will explain how often and how much chemotherapy you receive. Chemotherapy may be given weekly, every two weeks, every three weeks or monthly. Some treatments, mostly pills taken by mouth, are taken daily.

What Are the Side Effects?

Because chemotherapy affects all dividing cells, it sometimes damages fast-growing, healthy cells, like those that grow hair and nails and those that protect you from infection (white blood cells). When healthy cells die, you may have side effects, such as hair loss and diarrhea.

Chemotherapy puts you at risk for infection, so you should talk with your doctor about ways to protect yourself. You may be able to take medicines called growth factors along with chemotherapy to help boost your white blood cell count and prevent infection. Wash your hands often with soap and water. If you run a fever, call your doctor immediately.

Anemia, or a lower number of red blood cells than normal, is another side effect of some chemotherapy treatments. Anemia may make you feel tired, weak or short of breath. Take good care of yourself by getting plenty of rest, drinking eight to 10 glasses of water daily, keeping protein in your daily diet and doing light exercise when you can. In severe cases of anemia, you may need a blood transfusion.

A Note on Chemotherapy Side Effects

Many of us have scary images of chemotherapy, based on rumor, "movie-of-the-week" melodramas and stories from friends or family members treated many years ago. We associate cancer and sickness with chemotherapy's side effects—hair loss, nausea, vomiting, weight gain or loss, fatigue, insomnia, dry mouth, dry skin, mouth sores and even something called **chemobrain**, problems with memory and concentration.

The truth is that while some people have a rough time

with chemotherapy, others manage quite well. Many continue to work, and others report feeling only mild discomfort. Each person has her own response.

If you feel uncomfortable during treatment, there are many medicines and methods to help you. Let your doctors and nurses know about your concerns *before* you start treatment. Ask which side effects could occur with the chemotherapy you will receive.

If your doctor prescribes a medicine to prevent nausea, do not wait to take it until you feel upset to your stomach. Take it as prescribed for several days after each treatment. If you have a new side effect or a side effect gets worse, do not hesitate to discuss it with your doctor or nurse. You do not have to suffer!

Losing Your Hair

Not all chemotherapy medicines make you lose your hair. Some thin the hair, and others do not impact your hair at all. If you take an anthracycline- or taxane-based medicine, you are very likely to lose hair in most places you have hair on your body.

You may find it helpful to cut or shave your hair so you can control when you lose it and the way you look before it falls out. Buy a wig with your hair still in place, so you can match it as best you can. Taking control of hair loss before it happens helps many women get through treatment. You can choose to wear a wig, a scarf, a hat—or nothing at all. Do what feels comfortable for you.

10 THINGS TO DO BEFORE STARTING CHEMOTHERAPY

- 1 **Indulge yourself.** Spend the day with a friend, take a weekend trip, go to a spa.
- 2 **Eat your favorite foods.** Chemotherapy sometimes makes things taste different than usual, so you may want to avoid your favorite meals during treatment.
- 3 **See a dentist to make sure your teeth and gums are in good condition.** Buy toothpaste for sensitive teeth. Chemotherapy can cause mouth pain, dry mouth or sores that put you at risk for infection.
- 4 **If you may lose your hair, make a plan.** Cut it short or shave your head before the hair falls out on its own, or preserve each hair as long as possible. Have wigs, hats and scarves on hand.

- 5 Arrange rides to treatment with family or friends.
- 6 Drink lots of water to help prevent dry mouth, mouth sores and nausea.
- 7 Get loose, comfortable clothes that make you feel at ease and give your doctors easy access to your arm.
- 8 Ask your doctor what foods to have on hand to help you avoid feeling sick to your stomach. Stock up your freezer with foods for you and your family.
- 9 Learn the names of the administrative staff in your doctors' offices so you feel comfortable asking questions and requesting reports.
- 10 Talk to those who care about you or, if you are not feeling up to it, ask someone to communicate on your behalf. Start at lbbc.lotsahelpinghands.com or carepages.com.

TARGETED THERAPY

Targeted therapies are medicines that fight cancer by finding and killing only cancer cells. They can recognize a specific feature of the cancer cell, attach to that cell and destroy it. If the breast cancer tests positive for HER2, you may be able to receive a targeted therapy that affects only HER2 positive cells. Other targeted treatments lower the amount of estrogen in the body or stop breast cells from absorbing estrogen.

Many forms of targeted therapy are being tested in clinical trials (see page 15). They are given intravenously or by mouth as a pill. Some treatments, like trastuzumab (Herceptin), have been approved for use, but others are available if you get treatment through a clinical trial. If you have HER2 positive breast cancer, ask your doctor whether you can receive trastuzumab. If you are interested in other targeted therapies, ask your doctor about a clinical trial.

HORMONAL THERAPY

Some cancers rely on the hormones estrogen and progesterone to grow and survive. These hormones occur naturally in the body. If you deprive these types of cancers of hormones, the cancer cells die.

Hormonal therapy targets cancer cells that have estrogen and progesterone receptors on them. To respond to these medicines, the cancer must use hormones to grow. Your pathology report will say whether the breast cancer is estrogen receptor positive, progesterone receptor positive or both.

How Does Hormonal Therapy Work?

Some hormonal therapies, like **tamoxifen**, trick the cancer cells into thinking that they are estrogen. Other medicines, called **aromatase inhibitors**, prevent the body from making any estrogen or progesterone at all.

In general, both tamoxifen and aromatase inhibitors are given for five years as a daily pill. If your doctor feels you are at high risk for recurrence but you start out taking tamoxifen, you may be able to switch to an aromatase inhibitor to finish five years of treatment. Clinical trials are helping researchers figure out when and how long you should take aromatase inhibitors.

Aromatase inhibitors cannot be used if you still get your menstrual period. If you are premenopausal, your doctor will recommend tamoxifen or **ovarian suppression** or **ablation**, using medicine to stop your ovaries from making estrogen. You also may consider removing your ovaries in a surgery called an **oophorectomy**. Researchers are studying different types of hormonal therapy in premenopausal women, so ask your doctor whether you may be able to participate in a study.

If you are postmenopausal, aromatase inhibitors are the standard treatment. Aromatase inhibitors work as well as tamoxifen, but they are not for everyone. Your treatment team should discuss both options with you.

What Are the Side Effects?

Aromatase inhibitors increase your risk for bone thinning, osteoporosis, bone fractures and problems with blood cholesterol. They cause joint pain and muscle aches in about 50 percent of women who take them. Tamoxifen puts you at a slight increased risk of endometrial (uterine) cancer. Both tamoxifen and aromatase inhibitors carry an increased risk of blood clots and stroke.

Before taking hormonal therapy, you should discuss any history of heart problems or other medical conditions with your doctor. Share information about any other medicines or supplements you are taking.

The most common side effects of both types of hormonal therapy are hot flashes, fatigue, difficulty sleeping, night sweats and vaginal dryness. Talk with your doctor about the risks, benefits and side effects of each type of therapy to make the best treatment decision for you.

To learn more about these treatments and their side effects, read our *Guide to Understanding Hormonal Therapy* and our *Guide to Understanding Bone Health*.

A Note on Complementary Treatments

Complementary and alternative medicine (CAM) has become a popular way to manage treatment side effects. Complementary medicine brings together many types of treatments, including acupuncture, Qi gong, the creative arts, Chinese herbs and yoga. Some of these treatments have been used for centuries. They are used to decrease nausea, stress, pain and anxiety and to improve quality of life. Complementary therapies are used in addition to—not instead of—traditional medical treatments. Some doctors integrate CAM into medical treatment, and some hospitals even have centers studying the effectiveness of CAM.

Some complementary treatments can interfere with medical therapies, so talk with your doctors about methods you want to try or have been using.

10 QUESTIONS TO ASK YOUR DOCTOR ABOUT TREATMENT

- 1 Why are you recommending this treatment for me?
- 2 What are the pros and cons of this treatment?
- 3 What are the possible short-term side effects of these treatments? What are the possible long-term side effects?
- 4 Can I take part in any research trials?
- 5 When will the treatment start, how often will I take it and how long will it last?
- 6 How can I expect to feel during treatment and in the weeks afterward?
- 7 Will I need to take time off from work or make accommodations during treatment?
- 8 How will I know if the treatment is working?
- 9 Will the treatment lower the risk of the cancer coming back?
- 10 Are there other treatments for me to consider? What are the pros and cons of those treatments?

What Are Clinical Trials?

Your doctors may ask you whether you wish to get treatment through a **clinical trial**, any research study that tests how well new therapies, medicines or treatments work and whether they are safe and effective. These new therapies or combinations of therapies may work better than the standard treatment or may be as effective but have fewer side effects.

Each clinical trial explains what type of breast cancer you must have to take part. Federal and state laws protect your rights by having each trial reviewed for fairness by an **Institutional Review Board** made up of a diverse group of health providers and lay people.

You must volunteer to take part in a clinical trial. The process of giving your permission is called **informed consent**. During informed consent, your doctor reviews the risks and benefits of the study. You will be given an informed consent document, which explains in detail all parts of the study, including the treatment options, tests, side effects, risks, benefits and costs. During the trial, information is reported to a **Data and Safety Monitoring Board**, an independent group not involved with the trial.

Doctors discovered all the standard treatments available to you today because women like you chose to take part in clinical trials. Before you start treatment, let your doctors and nurses know if you are interested in a clinical trial.

To learn more about clinical trials, visit lbbc.org.

Should You Get a Second Opinion?

Getting a second opinion can help you confirm your diagnosis, learn more about the cancer and get another doctor's thoughts on treatment options. It can give you peace of mind that you did your research and made the best decision for your health.

You may feel a sense of urgency to make treatment decisions, but in most cases breast cancer is not an emergency. You may have more time than you think to make your decision. Talk to your doctor about how much time you may take.

Most private and public insurance covers a second opinion. If you want another opinion, ask your doctor for a referral. Most doctors are happy to help; a doctor who is not may not be the best doctor for you. Your doctor also can help you understand how long you can wait to start treatment.

Making Treatment Decisions

In some cases, you may have a single treatment option, or you may have one option among several that makes most sense for you.

No matter what the cancer type or stage of disease, think about both your medical and emotional needs. Ask yourself: “Does one treatment work better for my lifestyle? Does one offer more protection against a return of the cancer? How much risk am I willing to tolerate for the benefit of the treatment?”

Make an appointment with your doctor and ask to go through each possible treatment, step by step. Bring someone with you to take notes. Ask questions until you feel you understand your options. Use our “10 Questions to Ask Your Doctor About Treatment.” If you have other questions but aren’t sure how to ask them, or if you just want to talk more about your experience, call LBBC’s Survivors’ Helpline. We will help you think through your concerns. We also offer a free brochure, the *Guide to Understanding Treatment Decisions*, that may help you think about what to consider.

Do not allow yourself to get “stuck.” Agree with your doctor on a time frame to move forward. You may feel better once you finish meeting doctors and deciding on your treatment plan.

10 QUESTIONS TO HELP YOU DECIDE WHETHER YOUR DOCTOR IS RIGHT FOR YOU

- 1** Where did you get your medical training?
- 2** How long have you been treating people with breast cancer?
- 3** Do you have experience with the specific type of breast cancer I have?
- 4** Are you board certified in your specialty?
- 5** How many women with breast cancer do you treat each year?
- 6** How do you stay up to date on the latest treatments?
- 7** At what hospitals do you have privileges?
- 8** What other people do you think should be on my healthcare team?
- 9** Who do you recommend I see for a second opinion?
- 10** How can I reach you if I have a question after office hours or on weekends? Can I reach you by email or phone, or both?



The Help to Get You Through Tomorrow

Many women feel a sense of relief after making their initial treatment decision and choosing a healthcare team. Others feel anxiety, fear or excitement. Your feelings are reasonable responses to having your life turned upside down by a diagnosis of breast cancer.

A good next step is thinking about the kind of support you want around you. During your initial treatment, you will be busy with doctor's appointments, procedures, tests and follow-up visits. Which friends or family members make you feel safest and most comfortable? Who can you count on if you need a hand or if you just want someone to listen? Will you want some time alone to gather your thoughts? Does anyone close to you have medical experience or personal experience with breast cancer? Sometimes these people have special understanding and can help you.

Asking for Help

Most of us are used to caring for others, whether that means earning money to support our families, managing a busy household or giving emotional support. Whatever way you look at it, breast cancer puts many of us in the unfamiliar position of asking others for help.

No one expects you to be Superwoman while you are getting cancer treatment. Accepting support will give you energy to focus on your health and well-being. Give yourself permission to ask for help—even if it makes you feel a little uncomfortable.

Help means different things to different people, so think about what it means to you. Maybe you want help with practical tasks like running errands, cooking meals and paying bills. Perhaps you want someone to take you to doctor's appointments or to be in touch with family and friends about your treatments. Or maybe you want someone to spend an hour with you talking about something other than cancer treatment.

Many people will want to help you, and giving them something to do will make them feel useful. Be specific about what you want—and what you don't want—so you will get what you need.

10 TIPS FOR GETTING GOOD SUPPORT

- 1 Surround yourself with good listeners.
- 2 Be as open as you can about what you are thinking and feeling. Some people may be afraid to ask.
- 3 Avoid people who make you feel uncomfortable.
- 4 Ask other women who had breast cancer about resources that they found helpful.
- 5 Tell people when you need them to stop "helping" and start listening. Say, "I need you to sit down, look at me and listen to me for a few minutes so I know you're hearing what I'm saying."
- 6 Be specific about what you need.
- 7 Be specific about what you don't need. If people try to do something for you that you would rather do yourself, let them know. If you want to talk about something other than cancer, let them know.
- 8 Talk to people who put you at ease—a partner, friend or healthcare provider—and ask for tips on asking for help.
- 9 If someone starts to tell you stories or give you advice you don't want to hear, ask the person to stop. Don't be afraid to be blunt. Say, "Please stop. This is not helpful to me."
- 10 Call LBBC's Survivors' Helpline and talk to a woman who has had breast cancer about how she asked family and friends for help and got support.

Where Can You Find Support?

You may wish to look for support outside of family and friends. Your treatment center is a great place to start. Let your doctors and nurses know how you're feeling. Ask to speak with an oncology social worker or counselor. Many hospitals have libraries just for people with cancer.

If you feel comfortable in groups, ask your oncology nurse or social worker to recommend a support group. If you prefer talking to someone alone, ask to be referred to a mental health provider—a social worker, psychologist, counselor or psychiatrist.

Take advantage of the groups you belong to. You may find great comfort in your religious or spiritual communities. Talk with members of your church, synagogue, temple or mosque. Speak to the leaders of volunteer groups or community organizations. Once you begin talking about breast cancer, you will find many others whose lives have been touched by it.

Sometimes you just want to talk to someone who knows what you are going through. Ask your healthcare team for the names of breast cancer groups that can connect you directly with women affected by breast cancer. At LBBC, we offer a Survivors' Helpline, staffed by trained volunteers

who have had breast cancer. These women listen and help you think through your questions and concerns. We can even match you with a woman with a similar diagnosis or experience, if that is what you want.

LBBC and other breast cancer organizations offer many other ways for you to meet people. At LBBC we have conferences, webinars, community meetings and online support through lbcc.org. Many groups offer a variety of programs, and you can choose the ones that best meet your needs and your personality.



Moving Toward Your Future and Beyond

The Rest of Your Life

Breast cancer treatment affects many other areas of your life, both physically and emotionally. Whatever your normal daily life, you may need or want to take a break, cut back or change your responsibilities. The costs of treatment may impact your financial outlook.

Breast cancer forces its way into the most private parts of our lives, our relationships with our lovers, our parents, our friends, our colleagues and ourselves. You may find it changes the way you experience sexual intimacy and communicate with your partner. It could impact the way you feel about your body image and your femininity. You may look at your friends and family differently now.

These life changes start with your diagnosis, but they do not always end with your last treatment. People who have not had cancer may not understand this. Some people expect your life to go “back to normal” or return to the way it was before your diagnosis. That will be the case for some women. But for many others, breast cancer changes their outlook and perspective in many different ways. Recovery after active treatment ends can take six or more months, so this is another time you may need to be patient.

LBBC was founded in 1991 with the goal of helping women cope with the many feelings they have both during and after treatment. We recognize some women change with breast cancer, and breast cancer changes some

women. You may have concerns about your long-term health or your emotional well-being. You may feel sad or feel you have lost control because you are no longer actively “fighting” the cancer with treatments. You may fear breast cancer could return. You are finding a “new normal”—integrating a history with breast cancer into your whole life experience.

Even though your treatment has ended, LBBC is still here for you. If you are having difficulties or just want to talk, call our Survivors' Helpline. All volunteers have had breast cancer, so they know what you are going through. Together, we can help you put breast cancer into context—and help you learn how to live with, and beyond, your experiences with it.

10 TIPS TO LESSEN STRESS AND ANXIETY

- 1 Surround yourself with positive people. Now is the time to remove “toxic” people from your life.
- 2 Maintain a healthy lifestyle. Sleep well, eat well and exercise, even when you don't feel like it. Go for a walk, do some stretches or ride a bicycle.
- 3 Ask your doctor about trying a complementary treatment like acupuncture or yoga.
- 4 Write your thoughts and feelings in a notebook or online journal. Send it to people who want to know how you're doing so you don't have to say the same things over and over again.

- 5 Take an arts-and-crafts or adult education class to absorb yourself in something unrelated to breast cancer.
- 6 Keep a schedule, either your regular one or a new one. Keep up with your normal activities as much as possible.
- 7 Wear clothes and makeup that make you feel comfortable and good about yourself. You will feel better, and people will compliment you.

- 8 Get professional help if you want it. See a family therapist with your children, a social worker or counselor, or a psychotherapist.
- 9 Volunteer for a breast cancer organization or other nonprofit group unrelated to cancer.
- 10 Find and talk to other women who have had breast cancer, either through friends, your hospital or LBBC's Survivors' Helpline.



SECTION VI

Resources

Living Beyond Breast Cancer is here for you, no matter what your stage of treatment or recovery. Visit lbcc.org or call us at (610) 645-4567 to order our other Understanding publications:

- Fear of Recurrence
- Hormonal Therapy
- Intimacy and Sexuality
- Lymphedema
- Treatment Decisions
- Triple-Negative Breast Cancer
- Yoga and Breast Cancer
- Your Emotions

Culturally sensitive guides:

- Getting Connected: African-Americans Living Beyond Breast Cancer
- We Celebrate Tomorrow: Latinas Living Beyond Breast Cancer

Metastatic Breast Cancer series:

- Guide for the Newly Diagnosed
- Managing Stress and Anxiety
- Treatment Options for Today and Tomorrow
- Understanding Palliative Care

Information is current as of July 2012 but may change.

Talking to Children

Breastcancermoms.com

CancerCare: (800) 813-4673, cancercare.org/tagged/children

Sharsheret: (866) 474-2774, sharsheret.org

People of Color

Asian and Pacific Islander National Cancer Survivors Network: (415) 954-9988, apiahf.org

Dia de la Mujer Latina: (281) 489-1111, diadelamujerlatina.org

Intercultural Cancer Council: (713) 798-4614, iccnetwork.org

Native American Cancer Research: (800) 537-8295, natamcancer.org

Sisters Network: (866) 781-1808, sistersnetworkinc.org

Learning More About Your Pathology Report

Breastcancer.org: Your Pathology Report, breastcancer.org/symptoms/diagnosis/getting_path_report.jsp

Oncolink.org: search for “breast cancer pathology report”

Susan G. Komen for the Cure:
What Is a Pathology Report?, (877) 465-6636,
ww5.komen.org/BreastCancer/WhatisaPathologyReport.html

Specific Cancer Diagnoses or Situations

HER2 positive: her2support.org

Inflammatory breast cancer: eraseibc.org, ibcsupport.org,
ibcresearch.org

Premenopausal: fertilehope.org, youngsurvival.org

Hereditary: facingourrisk.org

Triple-Negative breast cancer: tnbcfoundation.org,
triplestepforthecure.org

Lymphedema

LymphNotes: LymphNotes.org

Lymphology Association of America: (773) 756-8971,
clt-lana.org

National Lymphedema Network: (800) 541-3259,
lymphnet.org

Support Services

Living Beyond Breast Cancer: (888) 753-LBBC (5222),
lbbc.org

American Cancer Society: (800) 227-2345, cancer.org

Association of Oncology Social Work: (215) 599-6093,
aosw.org

Cancer Support Community: (888) 793-9355,
cancersupportcommunity.org

FORCE: Facing Our Risk of Cancer Empowered:
(866) 288-7475, facingourrisk.org

CancerCare: (800) 813-4673, cancercares.org

LIVESTRONG: (855) 220-7777, livestrong.org

SHARE: Self-Help for Women with Breast and Ovarian
Cancer: (866) 891-2392, sharecancersupport.org

Susan G. Komen For the Cure: (877) 465-6636, komen.org

Young Survival Coalition: (877) 972-1011, youngsurvival.org



Adjuvant therapy. Treatment given after removing the cancer with surgery.

Anemia. A lower number of red blood cells than normal. Can cause fatigue and shortness of breath.

Axillary lymph node dissection. Surgery to check for cancer in most **lymph nodes** in the armpit.

Biopsy. Taking a small amount of tissue from the breast and looking at it under a microscope.

Bone scan. Test that looks for cancer in the bones.

Breastbone. Long, flat bone in the center of the **chest wall**. Attached to the **collarbone** and first seven ribs. Also called sternum.

Breast cancer. Any of a number of a type of cancers that start in the **ducts**, **lobules** or other tissues of the breast.

CAT scan. Test that takes a series of two-dimensional pictures of organs, including the bones, liver, lungs, brain and **lymph nodes**. Also called CT scan or computerized tomography scan.

Chemobrain. Problems with thinking and short-term memory after cancer treatment.

Chest wall. The muscles, bones and joints that make up the area between the neck and abdomen.

Chest x-ray. Test that takes a picture of the lungs, heart, airways, blood vessels and bones in the chest and upper back.

Collarbone. One of two bones at the base of the front of the neck. The collarbone connects the **breastbone** to the shoulder blades. Also called clavicle.

Combination therapy. When medicines are given together.

Comorbidity. When you have illnesses in addition to breast cancer that could impact treatment. Examples are heart disease or osteoporosis.

Definitive surgery. Final surgery that results in negative (cancer-free) **margins**. See page 9 to learn more about types of surgery.

Diameter. The distance across.

Distant recurrence. See **recurrence**.

Dividing. Growing.

DNA. The information that makes up the genes of a cell.
Ductal carcinoma in situ (DCIS). See **in situ**.

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

Early-stage. Breast cancer that has not traveled outside the breast or **axillary lymph nodes**.

Estrogen receptor positive. See **hormone receptor positive**.

Fracture. Break.

Genomic test. Test that studies the genes in a cancer to learn more about its makeup and how it could affect your outcome and treatment plan. Looks at groups of genes in cancer cells to see whether they are present, absent or too active.

Grade. Gives a score of how abnormally the cancer cells behave and look compared to healthy breast cells.

Gross description. What the pathologist (see page 5) sees with the naked eye.

Growth factors. Medicines that boost white blood cell count to help fight infection.

HER2 positive. When cancer cells make too much of a protein called HER2 that controls how cancer cells grow, divide and repair themselves.

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

Infiltrating. See **invasive**.

Inflammatory breast cancer. Type of breast cancer in which the breast feels warm and swollen. Grows in the lymph **vessels**, blocking movement.

In situ. In the place where it started. Ductal carcinoma in situ (DCIS) means the breast cancer stays inside the **ducts** of the breast. Lobular carcinoma in situ (LCIS) means the breast cancer stays inside the **lobules** of the breasts. People with DCIS or LCIS are at increased risk of developing invasive cancers.

Internal mammary lymph nodes. **Lymph nodes** near your **breastbone**.

Intravenously. Given by vein.

Invasive. Cancer that grows outside the **ducts** or **lobules** of the breast and invades nearby tissues. This type of breast cancer has the potential to travel outside the breast to other parts of the body.

Lobules. Glands that make breast milk.

Local recurrence. See **recurrence**.

Local therapy. Treatments that kill the cancer in the place where it started. Examples are surgery (page 9) and radiation (page 10) treatment.

Lymph node. Round mass of lymphatic fluid and white blood cells that filters bacteria and waste from the body.

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

Malignant. Cancerous.

Mammogram. An x-ray photograph to look for breast cancer and other problems in the breast.

Margin. Rim of healthy tissue around a breast tumor.

Metastatic. When cancer travels outside the **ducts** or **lobules** of the breast to the lungs, liver, bones or brain. Also called stage IV or advanced breast cancer.

MRI. Test that uses magnets and radio waves to take pictures of part of the breast. Also called Magnetic Resonance Imaging.

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 the **lobules** of the breast. Also see **in situ**.

Oncologist. Doctor with special training in cancer.

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

PET scan. Test that looks for cancer throughout the body. Also called Positron Emission Tomography.

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

Proliferation index. Test that shows how fast cancer cells divide and grow.

Prosthesis. An artificial breast that fits into a bra.

Reconstruction. Surgery to rebuild the breast.

Recurrence. When the breast cancer comes back after treatment. It can come back in the same place (local recurrence) or in a place far away from where it started (distant recurrence).

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

Side effect. When treatment harms healthy cells. Examples are fatigue, nausea and dry mouth.

Single-agent therapy. When one medicine is given at a time.

Stage. Describes the extent of cancer in the body based on size and presence of cancer in the **lymph nodes**. (Learn more about stages on page 7.)

Systemic therapy. Treatments that kill cancer throughout the body. Examples are chemotherapy (page 11) and targeted therapy (page 14).

Tumor grade. See **grade**.

Ultrasound. Test that uses high frequency sound waves to take pictures of areas inside the body.

Vessels. Small, hollow tubes that carry cells or fluids like blood from place to place.

White blood cells. Cells that protect you from infection.



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