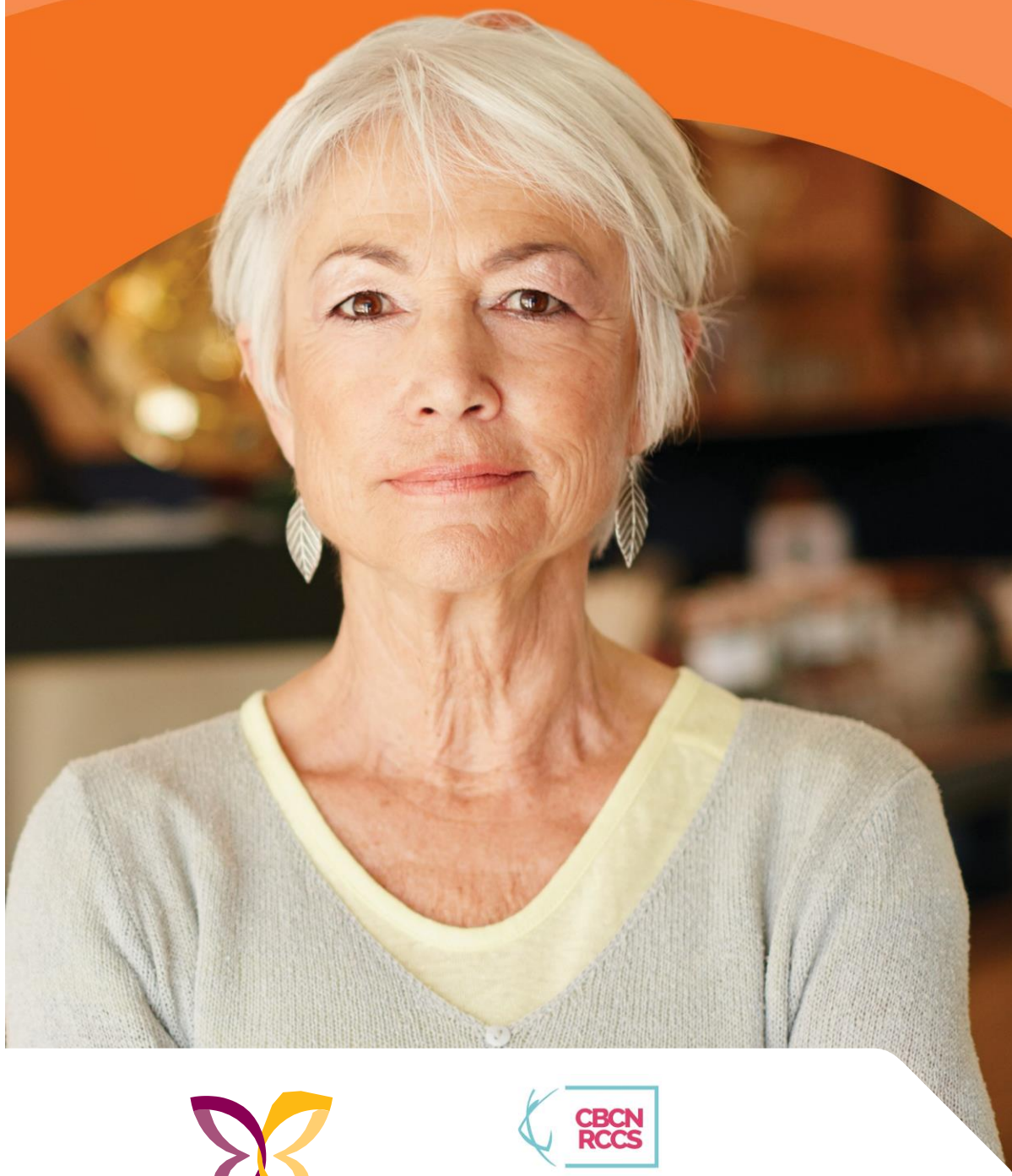


METASTATIC BREAST CANCER SERIES

# Guide for the Newly Diagnosed

CANADIAN VERSION




**LIVING BEYOND  
BREAST CANCER®**



Canadian Breast Cancer Network  
Réseau canadien du cancer du sein

**mbcn** | METASTATIC  
BREAST CANCER  
NETWORK

The background is a solid light orange color. It features two large, dark orange curved shapes that sweep across the page. One shape starts from the left edge and curves upwards and to the right. The other shape starts from the bottom left and curves more steeply upwards and to the right, partially overlapping the first shape. The overall effect is a modern, minimalist design.

The photos in this guide are being used for illustration only.  
The people shown in these photos are professional models.

# Dear Friend:

Whether this is your first breast cancer diagnosis or you have had breast cancer before, learning you have metastatic breast cancer is likely to be overwhelming. This booklet is designed to give you information and support in French, so you and your family can make informed decisions about your treatment. It will also help you manage your emotions during the first few months after a metastatic diagnosis.

**Living Beyond Breast Cancer**, the **Metastatic Breast Cancer Network** and the **Canadian Breast Cancer Network** worked together to create this resource. Our organizations understand the many challenges you and your family may face as you cope with the disease. You will find sections on the tests and treatments you may have, and sections that look at the impact metastatic breast cancer can have on your emotional well-being and your relationships.

If this is your first diagnosis, you may want to learn more about breast cancer in general. If this is a recurrence, you'll want more details about metastatic breast cancer. We cover both in section 2. Throughout the guide, you'll notice the words of people who, like you, know what a metastatic diagnosis means and how it feels. A group of these women, as well as a group of healthcare providers, helped LBBC and MBCN create this guide.

Living Beyond Breast Cancer, Metastatic Breast Cancer Network and the Canadian Breast Cancer Network are here to help you and your family get the information you need to handle a breast cancer diagnosis. For more information, visit [LBBC.ORG](http://LBBC.ORG), [mbcn.org](http://mbcn.org) or [cbcn.ca](http://cbcn.ca).

Warmly,



Jean A. Sachs, MSS, MLSP  
Chief Executive Officer  
Living Beyond Breast Cancer



Shirley A. Mertz  
President  
Metastatic Breast Cancer Network



Cathy Ammendolea  
Board Chair  
Canadian Breast Cancer Network

## A STAGE IV DIAGNOSIS IS NOT HOPELESS

Please know that the best thing you can do for you and your family is to get medical care for stage IV, metastatic breast cancer. People who are diagnosed with this disease can live for many years — as long as they get treatment, and start treatment right away. There are many medicines available to keep the disease under control, and many ways to help you cope with side effects. Don't give up.

We know that hearing you have breast cancer can be very scary. Talking with doctors about the diagnosis and your care can be very overwhelming, even if you know English well. If English is your second (or third, or fourth!) language, it can be hard to understand what your doctors are telling you and your family. It's easy to get frustrated and give up hope.

If English is not your first language, there are often translators at your cancer centre. This means that if you ask for one, your hospital or treatment centre should be able to give you a trained, fluent and experienced person who can help explain your diagnosis and treatment options to you and your family in your first language. Translators at the cancer centre may be better at explaining breast cancer to you than a loved one you bring to help translate, because the translator is also trained in explaining complex medical topics. Call before your appointment to inquire about a translator.

**SECTION 1**

<b>Understanding Your Diagnosis</b>	4
Coping With Your Diagnosis	5
Managing Breast Cancer for the First Time	6
Managing Breast Cancer as a Recurrence	8 A
Note on Personal Research and Statistics	9
Telling Others: Friends, Family and Co-workers	9 A
Note on Spouses, Significant Others and Children	10

**SECTION 2**

<b>Understanding Metastatic Breast Cancer</b>	12
Breast Cancer Basics	13
How Breast Cancer Metastasizes	14
What Makes Metastatic Breast Cancer Different	15
Understanding New Terms and Your Pathology Report	17
Knowing the Cancer's Subtype	18
A Note on BRCA Genetic Testing	19
Creating a Healthcare Team You Trust	19
A Note on Second Opinions	20

**SECTION 3**

<b>Understanding Treatment Options</b>	22
Common Treatment Options	25
Clinical Trials and Your Treatment	26
Integrative and Complementary Therapies	28
Palliative Care for Well-Being	28

**SECTION 4**

<b>Maintaining Your Everyday Well-Being</b>	30
Improving Your Daily Life	31

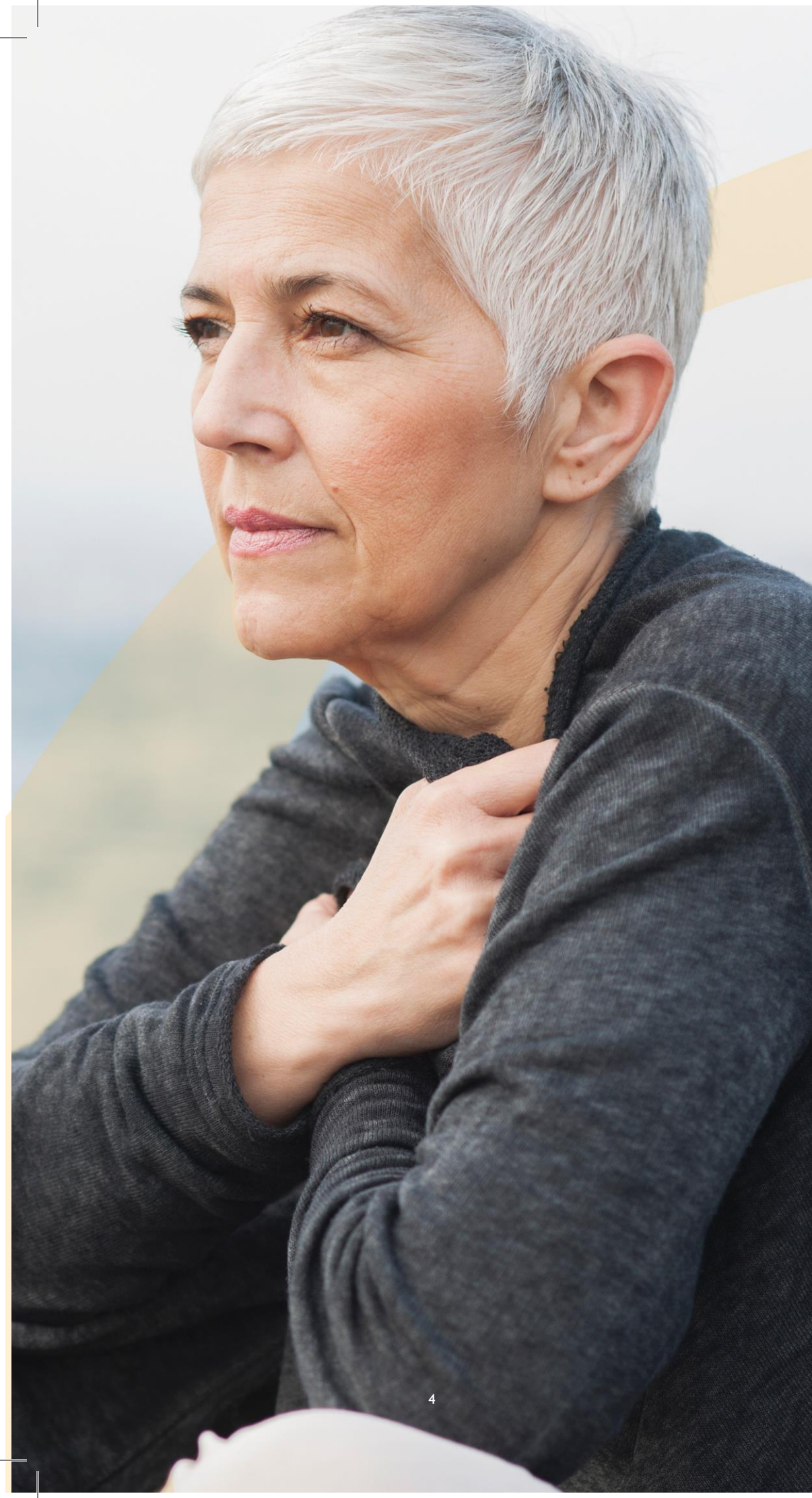
**SECTION 5**

<b>Looking Toward the Future</b>	34
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**SECTION 6**

<b>Resources</b>	36
Organizations That Can Help	37
Tests to Expect	40
Common Treatments	41
Words to Know	42





# Understanding Your Diagnosis

Right now you and your family may be feeling and thinking many things all at once. Life may feel out of your control. It is natural to ask: Who can help us? What happens next? What do we do now?

Know that metastatic breast cancer can be managed long-term, and some people live many years with it. Getting prompt care is key.

About 1,200 women are diagnosed with metastatic breast cancer every year in Canada. What was once a rarely talked about disease is getting more public attention. People with metastatic breast cancer are working to educate the public and to advocate for more treatments to extend lives. With the help of organizations like Living Beyond Breast Cancer, the Metastatic Breast Cancer Network and the Canadian Breast Cancer Network, people with metastatic breast cancer are finding that they, like you, are not alone.

Metastatic breast cancer is life changing. Managing the disease will now be part of your daily life. But advances in research and treatment options have made it possible for many to live longer, happier lives than in the past. The disease varies from person to person. Your treatment experiences will be unique.

*I will live the rest of my life as a cancer patient, but I have comfort knowing that I do not travel this road alone.”*

## Coping With Your Diagnosis

No matter how familiar you are with breast cancer, the next few days, weeks and months will likely be challenging. You'll

- hear new medical terms
- have many diagnostic tests
- meet new medical professionals

Getting used to ongoing treatment may take time, but there are many ways to prepare.

It is OK to feel many emotions all at once. People facing a serious diagnosis often feel anger, loss, confusion and fear. There is no “right” way to feel. Your emotions are affected by

- your situation
- your personality
- your coping style
- your culture

These feelings may change throughout your treatment as you face new challenges. Some people find it helpful to share feelings with family members or others living with metastatic breast cancer. Others may seek out support groups or one-on-one counseling.

“Once I understood [my diagnosis], I accepted my reality and was able to start living in the moment. That is the challenge.”

Whatever your reactions, allow yourself to feel them. Know that resources are available to support you and your family. A metastatic diagnosis comes with different worries at different times. No one expects you to be strong, brave or together all the time. No one expects you to handle this alone.

“Allow yourself to grieve. Don’t try to be the strong person all the time. There’s a lot of pressure to be that inspirational person and be the ‘perfect’ cancer patient who doesn’t complain. But you have to be true to yourself.”

## Managing Breast Cancer for the First Time

Hearing you have breast cancer is difficult news, but your emotions may be stronger when you learn that it has **metastasized**, or spread to areas of the body outside the breast or nearby lymph nodes. Along with the shock of diagnosis, you are given a lot of new medical information.

It may help to write notes during all your appointments. Knowing as much as you can may empower you. When you have your first meeting with your doctors, you may want to take someone with you. A trusted, reliable loved one can take notes or record what you talk about. You may want a way for you and your family to review the important information you’ll get.

You might want to keep a running list of all

- medicines you take
- tests you get
- symptoms and side effects you experience

Your notes may help you remember questions that you have for your doctors. If you prefer to record conversations with your doctor rather than take notes, let the doctor know.

“Make it a practice to keep a journal of visits with questions, answers, tests, appointments and treatments. It will come in handy in the future.”



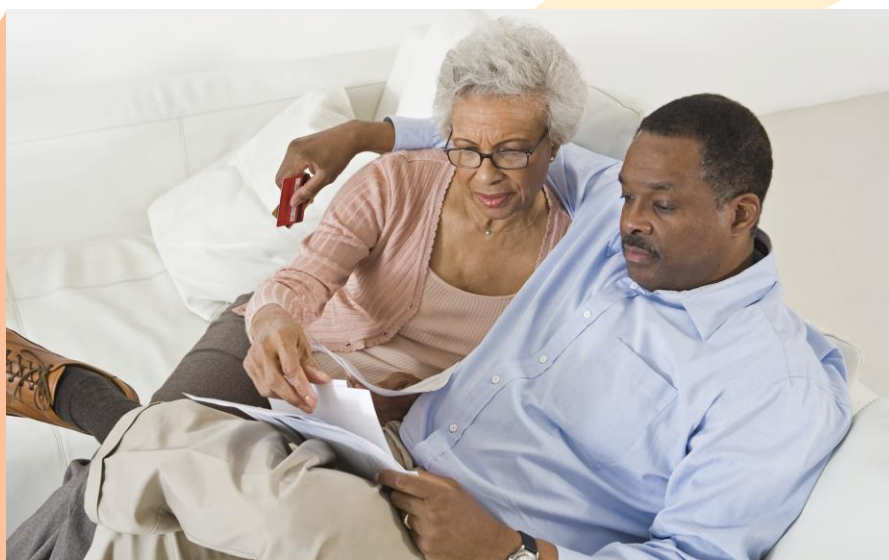
Your doctors might also recommend resources to you and your family. It's OK to ask for resources in French. Information about metastatic breast cancer can be found online as well. Be aware of how reading online resources makes you feel. If they cause more anxiety or stress, you may want to stop reading or ask someone you trust to do research for you.

**“Every breast cancer patient should educate themselves about their particular type of cancer and seek out a doctor who will offer them personalized treatment.”**

It is common to be overwhelmed by information you find. As you find resources that you trust, make a list for the future. Keeping a personal or online journal may provide an outlet for anxiety. It also makes a great record of concerns you may wish to talk about with your doctors and other support professionals.

### **REMEMBER:**

Whether this is your first time having breast cancer or you've had breast cancer before, you can ask to have access to a translator at the cancer centre. These people will be able to help explain your diagnosis and treatment options to you in your first language. Call before your appointment to ask for a translator and see what's available to you and your cancer centre.



## Managing Breast Cancer as a Recurrence

No matter how long it's been since you had breast cancer, finding out that the cancer is back may bring feelings of shock, disbelief, anger, betrayal and sadness. You may also feel guilty, or believe that you or your doctors could have done something to prevent the cancer's return. Remember that metastatic disease can be treated for a long time. With prompt care you can live many years after diagnosis.

You are not alone. Researchers believe that up to 30 percent of people first diagnosed with early-stage disease will get metastatic disease.

**It's OK to feel what you are feeling. Allow yourself the same compassion you would offer a good friend. Be realistic about who can handle the emotions and fears you may need to share."**

The media tends to focus on stories of survivorship, and to praise people who appear to have "fought their battle" with breast cancer, heroically and successfully. It might leave you and your loved ones feeling alone, misunderstood and unsupported.

Even with the best treatments for a first breast cancer, it is possible for the cancer to return later. There was always a chance for recurrence, even if that chance was very small. Regular tests or noticing symptoms might have helped find the metastasis earlier, but research shows that finding metastatic breast cancer early does not change the outcome. **You are not to blame.** Even if you had the best possible treatment in the past, there remained a chance some cancer cells would survive and cause metastases someday. (To learn more about what causes metastatic breast cancer, see page 14.)

It is normal to feel that you've lost trust in your doctors or treatments, or to be angry with your medical team or yourself. As you learn more about your diagnosis and your treatment options, these feelings may fade. Don't rush yourself. Allow time for you and your family to make sense of the news and to feel your feelings.



## A Note on Personal Research and Statistics

When you're faced with questions like *What are my chances?* and *How long do I have?*, a statistic might seem like helpful information. But statistics are not specific to you.

Statistics help researchers understand how metastatic breast cancer affects large groups of people, not individuals. In the research setting, these numbers help show how the disease acts, what medicines it reacts to and other issues that help doctors develop treatments. Average percentages often reflect thousands of people in research done sometimes years ago — but never just one, today. **You are not a statistic.**

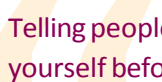
Doing online research about your diagnosis and its symptoms and side effects may heighten worry and anxiety. It's important to listen to yourself and be aware of when to stop reading. It may be helpful to consider your research a jumping-off point to talk with your doctors, not a definite example of what will happen to you. Your healthcare team can speak to your specific concerns.

Start with trusted online sources from hospitals or from the government, community leaders, nonprofits or universities. As you and your family read, keep in mind that every person is different. No one else's experience will match your own.

For a list of trusted resources, see page 37.

## Telling Others: Friends, Family and Co-workers

Talking with others about your diagnosis can be a great source of comfort. It can also be very stressful. Finding the right time *for you* is important. It is OK to wait until you make sense of the diagnosis yourself before you tell others.



**Telling people is highly personal. Sometimes you have to work it out within yourself before you open the doors to let everyone else in."**

Who you tell and when you tell them is a personal choice. You may only tell one or two people at first, or you may want to tell as many people as you can. Take this step in the way that is most comfortable for you.

Writing down what you want others to know about your situation may help you say it more clearly. The words you use may bring about powerful emotions for all of you.

It may not be possible to predict other people's reactions. At a time when you need comfort, you may find yourself comforting others. The thought of disrupting the lives of your family and friends, or fear about how they will respond, may make you wary of telling everyone or anyone. Remember, though, that the people closest to you are sometimes the best support system.

Keeping a group of supportive and caring people in your life may help you cope with metastatic breast cancer. As you go through treatment, you may benefit from the support of having someone

- with you at appointments to take notes
- to drive you to and from treatments
- to help with daily chores when you don't feel up to it

People may feel more at ease when they can be helpful, so tell them what you need. Doing so may help you save energy for what you want to enjoy most.

Many will want to be there for you, but some may surprise you by the way they react to your news. Some may even pull away. Your friends and family may need time. They may feel sad, angry, scared or confused. Sometimes people want to help, but don't know what to do or say. Some people won't respond in a supportive or sensitive way. Most of the time, people's comments are grounded in their own fear and discomfort. They may fear that they can catch breast cancer from you. Let them know that breast cancer is not a disease that can be passed from person to person. It is safe for them to be around you.

It may be helpful to plan ahead for how you want to respond to insensitive reactions. It may be as simple as saying you prefer to talk about your situation with your medical team, or changing the subject. It's also fine to be direct. Consider saying, "This is not helping me right now." If someone is not helpful to you, it is OK to set boundaries.

At work, you also have a right to privacy. You don't have to give out personal information if you don't want to. Since you may see your co-workers every day, carefully consider who, if anyone, you want to tell about your diagnosis. Decide if sharing the news may disrupt your day-to-day work life or expand your support network.

If you need to take time off for treatment, use disability benefits or change your work hours, you will have to give some information to your human resources representative. You can contact Service Canada at [canada.ca](http://canada.ca) or (800) 206-7218 for more information on employment insurance and sick leave benefits. The Ministry of Labour in your province or territory can also help if your employer denies a request for medical leave.

## A Note on Spouses, Significant Others and Children

A metastatic breast cancer diagnosis brings uncertainty and stress to even the best relationships. It can be very challenging for your spouse or significant other and your children. You may worry about not being around to care for your family.

Openly talking about your feelings, worries and fears with the people closest to you may help your relationships. Keep in mind that your partner will have his or her own worries and concerns and will need time, comfort and support.

It can be very hard to tell children about your diagnosis. Though not telling them may seem best at first, children of all ages often pick up on the stress and emotions of their parents or may overhear conversations. Not telling them may leave them confused and anxious.

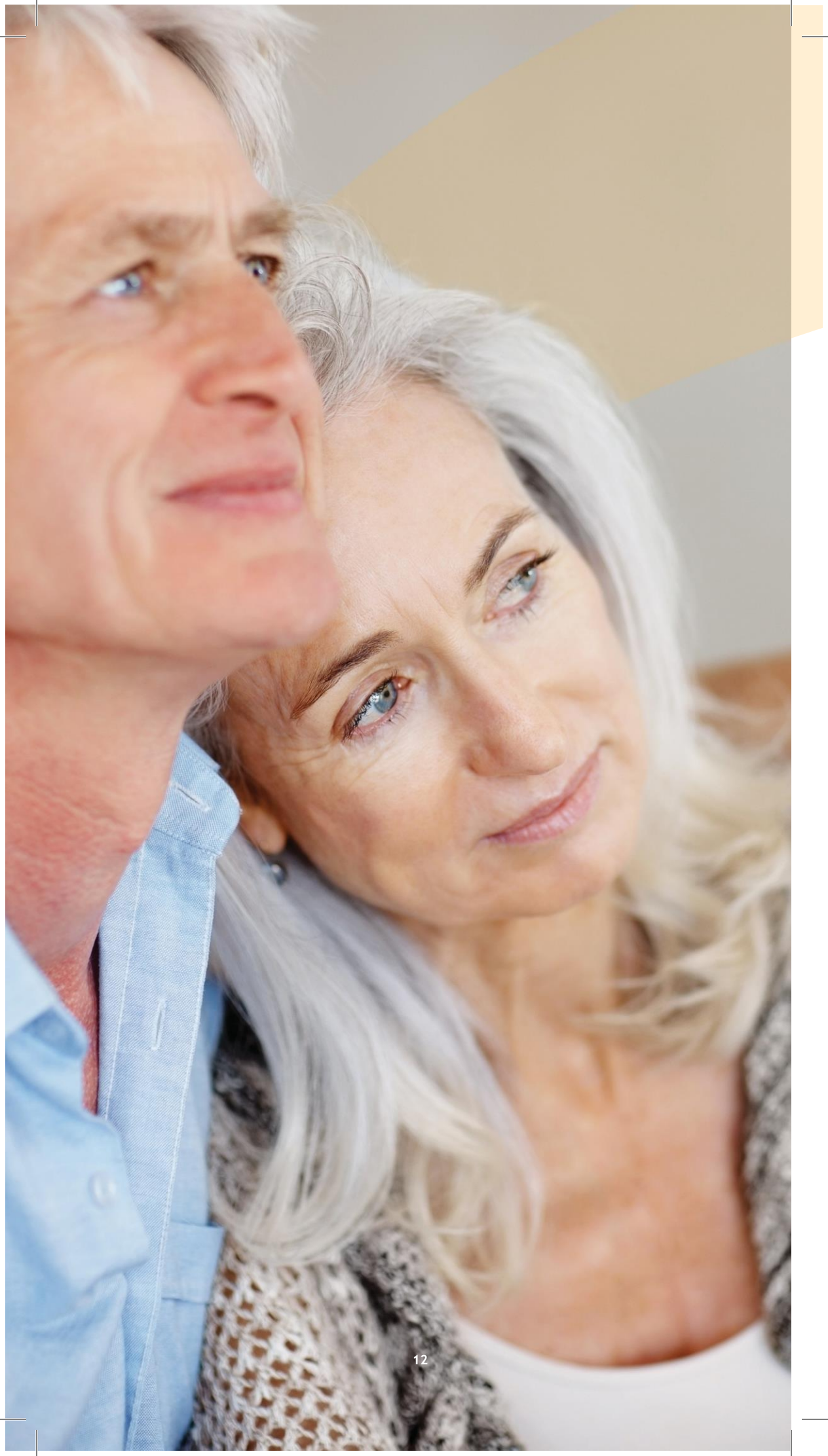
With very young children, it may help to explain in simple terms that you are sick and you are working with doctors to feel better. With children who are old enough to follow what adults are talking about, using the word “cancer” may be helpful because they will likely hear the term. Talking about cancer with your children may also help them understand that they did not somehow make you sick. If your treatment has side effects like hair loss, let your children know you will lose your hair, but that you will still be you.

You are the best judge of what your children can understand and process. Depending on age and developmental stage, children can respond to the news with a wide range of reactions, which will change over time. For support resources for family and caregivers, see page 38.

*I have been blessed to have had these last 3 years and look forward to many more, science willing. I am grateful for the support I have received from my friends. The sense of feeling cared about is extremely healing.”*









# Understanding Metastatic Breast Cancer

If this is your first cancer diagnosis, understanding the disease will help you and your family talk with your healthcare providers. This section gives you a basic understanding of

- breast cancer
- how it metastasizes
- how metastatic breast cancer is different from early-stage disease

The first section, Breast Cancer Basics, briefly describes breast cancer, some types of breast cancer, and how doctors interpret and use stages. How Breast Cancer Metastasizes, starting on page 14, and What Makes Metastatic Breast Cancer Different, starting on page 15, go into more detail about the biology of metastatic disease. These sections may be useful whether the cancer has returned, or metastatic breast cancer is your **primary diagnosis** — your first diagnosis of breast cancer.

## Breast Cancer Basics

Like many diseases, breast cancer comes in several types that grow and respond to medicines differently. All breast cancers start in the tissues of the breast, when breast cells grow out of control. This happens because of a **mutation** (error) in cell DNA that causes them to reproduce without stopping, making the cells **malignant**, or cancerous. The most common types of breast cancer are ductal and lobular.

**Ductal cancers** begin by growing in a mass inside the **ducts** of the breast, the passageways that carry milk from the lobules to the nipple. They later spread through the wall of the ducts into the tissue of the breast. When a ductal cancer travels through the wall, it causes a reaction around itself, forming a scar that leads to a well-defined mass.

**Lobular cancers** start in the **lobules** of the breast, which make breastmilk. They can sometimes grow without forming a mass, making them harder to find.

**Inflammatory breast cancer** is an aggressive but uncommon form of breast cancer. Instead of forming a mass, it usually starts with redness, swelling or tenderness in the breast and can be very fast growing.

When breast cancer cells spread beyond the ducts or lobules, they are called **invasive** or **infiltrating**. These cancers have the ability to spread beyond the breast and can affect nearby lymph nodes to the armpit, neck or chest. They can spread to other organs through lymph channels or through the bloodstream.

Doctors put breast cancer into five stages: stage 0, which is considered **non-invasive** (in situ) and stays within the ducts or lobules, and stages I through IV. All cancers above stage 0 are considered invasive cancers. Stages are based on

- tumor size
- whether there is cancer in the lymph nodes
- whether the cancer has spread beyond the breast and nearby lymph nodes to other parts of the body

When cancer is metastatic, the cancer has traveled away from the breast and lymph nodes to other parts of the body. Though cancer at any stage can become metastatic, **metastatic cancer** is the term used to refer to **stage IV** cancer.

Breast cancer is also broken down by subtype. Subtypes are based on the cancer cells' reaction to the hormones estrogen and progesterone, usually recognized by the presence of hormone receptors in the cells (referred to as **hormone receptor status**), or too much of the HER2 protein, called the **HER2 status**. Your doctor will also note how the cancer grows (in a sheet or in a mass) and the **proliferation index**, which tells what percentage of the cancer cells are actively dividing.

Knowing the subtype can help you, your family and your doctors choose the best course of treatment for you. Many targeted medicines have been and are being developed for specific subtypes. **All subtypes of breast cancer can become metastatic.**

## How Breast Cancer Metastasizes

When breast cancer metastasizes, the cancer cells enter the lymph channels or the bloodstream and spread to lymph nodes or other organs of the body.

Breast cancer cells can travel away from the breast and get into the bloodstream fairly easily, but only a select few can survive and grow in other organs. Typically, the body rejects or attacks things it doesn't recognize (like germs). But in the case of metastasis, cancer cells are enough like normal cells that different areas of the body allow them to grow. The most common places breast cancer metastasizes are the liver, bones, lungs and brain.

If you had breast cancer before, this new diagnosis may be called **recurrent disease**. Some of the primary cancer cells survived the treatments you had after your early-stage diagnosis. Systemic therapies (see page 25) like hormonal therapy and chemotherapy aim to destroy cancer cells in the breast as well as those that started traveling to other parts of the body. But in some cases, those cells escape the treatment and begin to grow later.

Many doctors have researched the process of metastasis, but today no one can predict how long cancer cells will be inactive before they begin to grow and can be found.

Even though the cancer cells spread to a different area of the body, your doctors will still treat them as breast cancer. Having bone metastasis is not the same as having bone cancer. Under a microscope, the cancer cells in the bone still look the same as breast cancer cells. They have many of the same mutations and a similar genetic makeup to the cells that caused the cancer in the breast. If you had early-stage breast

cancer before, your doctor may decide to do a biopsy to see if the tumor cells remain similar to your original diagnosis.

If this is your first cancer diagnosis, it is possible your doctors discovered you have breast cancer because you had symptoms in a different area of your body, like your bones. Your doctors were able to make the diagnosis because breast cancer cells remain breast cancer cells, no matter where they are.

Your doctors should run tests to make sure that the cancer cells from the metastatic site are the same as your primary diagnosis (if you had one). They will adjust your treatments if necessary, for the best results possible. Learn more about tests and biopsies on pages 17 and 40.

## What Makes Metastatic Breast Cancer Different

You may have heard others talk about breast cancer as a disease that can be cured. At the end of treatment for your first diagnosis, maybe you felt your experience was over. Perhaps your doctors mentioned the chance of the cancer returning, but it sounded unlikely.

There are many people who have treatment and never have to deal with cancer again. A metastatic breast cancer diagnosis is different. It means you will actively deal with breast cancer for the rest of your life. Some people live many years with it.

With metastatic breast cancer, the goal of treatment is to shrink or weaken the cancer, manage your symptoms and side effects and prevent the cancer from spreading further. Changes in treatment are made as the cancer grows or spreads to new places in your body. You and your doctors will talk about **progression**, the growth of tumors or spread of cancer, and **regression**, decreases in tumor size or the cancer's reach. When one treatment stops working, you and your doctors will look at new options.

When talking with your doctor, ask about treatment side effects. Maintaining your usual daily activities, taking care of your family and being able to take part in the things you enjoy are essential to your overall well-being. It may be helpful to talk with your medical team about how symptoms and side effects impact you every day.

At stage IV it is difficult to fully remove cancer with surgery or medicine. New tumors may appear over time, or cells may stop responding to different treatments. While metastatic breast cancer is not considered curable, it is possible to have periods where tests show no evidence of disease, often called "**NED**" in English. While reaching NED may not always be possible, it is likely that you will have periods when the cancer does not grow. This is called **stable disease**.

Being diagnosed with metastatic breast cancer can happen to anyone, at any time. Even stage I cancer can become metastatic. Years after completing treatment, someone with stage I cancer may learn the cancer is back and is now metastatic. The stages are meant only to predict your risk of cancer returning.

The main goal is choosing the treatment that will best get rid of tumors and stray cancer cells. But you, your family and your doctors may also want to think about what you are willing to try and what you aren't, so that you continue living the way you want to live.

“Every day I wake up remembering that I have metastatic breast cancer. That will never change. What I am hoping to help change is the general misconceptions that are floating around the world of pink. I want to help change the fact that metastatic breast cancer is not curable. I want to be a part (if even a small part) of helping to find a cure.”



## Understanding New Terms and Your Pathology Report

In the time leading up to and after your diagnosis, you will have many medical tests. These tests help your doctor see

- what kind of breast cancer you have
- how quickly it is growing
- where it has spread

The information is put in your **pathology report**, a profile of all of your test results that helps doctors choose your treatment path.

It's important to get copies of all test results, including imaging, for your own records. Having them may make things easier if you get a second opinion or need to change doctors. If possible, get a copy of your pathology report from your first diagnosis. Should you repeat tests now, your doctor can compare your earlier pathology report to your current one to see if the cancer has changed. Between 15 and 20 percent of metastatic cancers have different pathology traits than at early-stage diagnosis. Many doctors now do a **confirming biopsy**, a **biopsy** on the metastatic site to find out the cancer cells' subtype (see page 18). A biopsy tests a sample of tissue taken from the affected site, or from a lump or tumor removed with surgery.

A confirming biopsy may bring you the comfort of knowing more about your diagnosis, as well as better targeting your treatment. It will show your healthcare team whether the cancer became sensitive to certain hormones or has too much of a certain kind of protein. Though it's rare, it is possible that a confirming biopsy will find that what looks like breast cancer metastasis is something else, such as a **benign** (not harmful) growth or another disease.

If your diagnosis was not confirmed by biopsy, it's OK to ask your healthcare team why or to ask for one. In some cases, such as in brain or bone metastasis, biopsy may be difficult. Your doctors will rely on scans, symptoms and blood work to confirm your diagnosis instead.

Your doctor may also order a **blood marker test** or **tumor marker test**, a test that looks for specific proteins or tumor cells in your blood. The proteins and tumor cells are small pieces that break off the cancer and enter the bloodstream, making it possible to find them with a blood test. In some cases, doctors use blood marker tests to help with diagnosis. More often, they are used to monitor spread of disease. Sometimes a biopsy will confirm metastatic disease even when blood markers are not at high levels. Some providers prefer not to use tumor marker tests because of concerns they are not reliable. Like any illness, cancer has its own vocabulary. If this is your first diagnosis, it may be helpful to keep a running list of terms you want defined to help you make sense of everything. Don't be afraid to ask your doctor, nurse or other medical provider to explain what they mean more clearly. Ask for a medical translator before your appointment (see "A Stage IV Diagnosis Is Not Hopeless" at the beginning of this guide). For a list of words used in this guide, see page 42.



## Knowing the Cancer's Subtype

As researchers have learned more about breast cancer, treatment options have become tailored to specific types. Your pathology report will include the type of cancer you have, and whether it is a single type or a combination of types. The known subtypes are:

- **Hormone receptor-positive or negative (ER+/- or PR +/-):** Cancer cells that grow in response to certain hormones test positive and those that do not test negative. Some hormone-sensitive cancers respond to medicines called hormonal therapies. These treatments block estrogen from binding to cancer cells, lower estrogen levels, or lessen the number of estrogen receptors on the cells.
- **Human epidermal growth factor receptor 2-positive or negative (HER2 +/-):** The HER2 protein is part of normal cell growth. In some cancer cells the amount of HER2 proteins is too high. This is called HER2-positive breast cancer. It can be treated with anti-HER2 targeted therapies.
- **Triple-negative breast cancer:** These types of cancers test negative for estrogen and progesterone receptors and human epidermal growth factor receptor 2 (HER2). This means the cancer cells grow without estrogen, progesterone or HER2 proteins present. These cancers do not respond to anti-HER2 or hormonal therapies. Triple-negative cancers are best treated with chemotherapy.





## A Note on BRCA Genetic Testing

Breast or ovarian cancer runs in some families. Genetic counseling and testing to find mutations in your **BRCA1** or **BRCA2 genes** may give you more insight into your diagnosis. The BRCA genes are **tumor suppressors**, genes that make proteins that help control cell growth. BRCA gene mutations are something a person is born with. People born with these mutations have a higher chance of getting breast and ovarian cancer.

BRCA testing may give your doctors more information about the breast cancer, and can provide other members of your family information on their chances of getting cancer, too. Knowing your BRCA status may also qualify you for specific clinical trials.

Your doctor may recommend genetic testing if you

- were diagnosed under age 45
- were diagnosed with triple-negative breast cancer under age 60
- have a strong family history of breast or ovarian cancer
- are of Ashkenazi Jewish heritage

## Creating a Healthcare Team You Trust

After a metastatic breast cancer diagnosis, it is important to have a healthcare team you trust. Your healthcare providers will support you over a long period, so it is important you feel comfortable. They should listen to your concerns and help you get the care you need. You can ask if French-speaking doctors are available at your treatment centre. If not, remember that you can ask for a medical translator to come to your appointments.

The most important part is being able to communicate with your care team in the way that is most comfortable for you. You and your family may want many questions answered, or you may feel more at ease following the doctor's suggestions.

It is important that your healthcare team considers what matters to you. Will your doctors answer or return your phone calls in a reasonable amount of time? Do they listen when you voice your concerns about symptoms or treatments? Do they share your values, or at least respect your beliefs? You may be able to find a healthcare provider or someone on their team who speaks your language and understands your cultural concerns. You may also want to seek out professionals such as a palliative care specialist (see page 28) who focuses on pain and symptom management.

If you already have a healthcare team from a past diagnosis, it is OK to change who cares for you. You can do this at any time.

You always have the right to a second opinion. Your cancer centre may also offer specialized registered nurse case workers, patient navigators or oncology social workers who can help.

Some of the professionals you may see include: radiologists, pathologists, surgical oncologists, medical oncologists, radiation oncologists and primary care physicians (PCPs). Oncology and surgical oncology nurses, social workers, psychotherapists, chaplains and physical therapists may play a role in your care. They will help you with care before and after treatments, with your and your family's emotional needs, and with finding resources for support.

If you think you may be interested in **complementary therapy** (see page 28), non-medical therapies used alongside your medical treatment, you may consider adding a complementary or integrative care expert to your team. If you have private insurance some of your complementary therapies may be covered, connect with your insurance provider to see which ones qualify for coverage.

## A Note on Second Opinions

A second opinion may bring a fresh point of view and shed light on new treatment ideas. Or, if you feel like you are not getting the information you need, a second opinion may help you find a doctor more suited to you and your situation.

Your doctor should support you if you wish to seek a second opinion. Your original doctor will likely communicate with your second opinion doctor to choose the best treatment for you.

Even if the second opinion is the same or similar to the first, getting one may give you confidence that you are on the right path, with the right team helping you. When you go for a second opinion, consider taking a list of questions to help you get the most out of your appointment. Sometimes people decide to change care providers as a result of a second opinion.

**It's important to read and talk to friends, family and other women with metastatic disease before the second opinion. They can help you form questions to ask."**









# Understanding Treatment Options

The goal of treatment in metastatic breast cancer is to prevent or slow growth of the disease while easing symptoms and treatment side effects. Your healthcare team will focus on enhancing your overall well-being while working to reduce the amount of cancer in your body.

Because metastatic breast cancer is treatable but not curable, it is important to know that at times, treatments may not seem as aggressive as those given for early-stage breast cancer. This is because treatment for early-stage breast cancer is short-term, with the goal of getting rid of all of the cancer. Treatment for metastatic breast cancer relieves symptoms over the long-term.

If you were treated for breast cancer in the past, it is unlikely you will get the same medicine you got for early-stage disease. The cancer cells may not respond anymore to those medicines, or the treatments may be too toxic to your body to use more than once. In most cases, a metastatic diagnosis means a new treatment plan.

In metastatic breast cancer, treatments change over time as the cancer adapts to and stops responding to therapies. Typically, a treatment is used until the cancer grows or spreads. Then your healthcare team will suggest a new course of treatment. It is hard to predict how long a specific treatment may work in any person. Some treatments work for many years, while others need to be changed more often. It's important to keep up with your medical appointments and take medicines according to your doctor's instructions.

In addition to what's available for everyone, many new Health Canada-approved treatment options are available only to people with stage IV breast cancer. Healthcare in Canada is provided at the provincial level, which means that treatment options may vary between provinces and territories depending on what treatments are funded through the provincial formularies. CBCN has developed MedSearch, a metastatic breast cancer medicine navigation tool that lists all of the breast cancer treatments approved by Health Canada and indicates what provinces/territories publicly fund them. This tool also provides a list of other programs that you can access to help cover the cost of medications if they aren't listed on the public formulary. If you have private insurance you may have additional coverage for treatments that aren't publicly funded, so contact your provider to find out what is covered.

In some cases, you and your doctor can schedule [treatment breaks](#) for special events, like weddings or vacations, where it might be hard to get treatment or the side effects may disrupt your experience. It also is possible to take breaks just to give your body a rest from treatment and side effects. If you think you may need or want a treatment break, talk with your healthcare team as early as you can.

## 10 QUESTIONS TO ASK ABOUT TREATMENT

Managing metastatic breast cancer is as much about living your life as it is about treating the cancer. When making treatment decisions, you may want to ask these questions:

- 1 How does this treatment help?
- 2 What are the short-term side effects?
- 3 What are the long-term side effects?
- 4 How is the medicine given?
- 5 How long does it take to get treatment?
- 6 Will this medicine make me feel sick and stop me from working and taking care of my family?
- 7 What can I do to make sure I can do the things I love while I take this medicine?
- 8 What side effects mean I should call you right away?
- 9 Why do you believe this treatment is the best option for me?
- 10 If this treatment doesn't work, or makes me feel too sick, what are my other options?





## Common Treatment Options

The most common treatments for metastatic breast cancer are hormonal therapy, targeted therapy, chemotherapy, radiation therapy and surgery.

Chemotherapy, hormonal therapy and targeted therapies are **systemic**, meaning they travel through the bloodstream and treat the whole body. Surgery and radiation therapy are **local**, only affecting cells in and around tumors. Most treatments will be given either by vein or as a pill.

❑ **Hormonal therapies** are targeted, systemic treatments used to treat hormone receptor-positive breast cancer. In hormone-sensitive metastatic breast cancer, hormonal therapies are often the first treatment. They are the best approach for this type of cancer and have fewer side effects than chemotherapy.

❑ **Targeted therapies** are systemic treatments that attack specific proteins or genes on or within cancer cells that help the cells grow. Targeted therapies include medicines that treat HER2-positive metastatic breast cancer. Others under study, like PARP inhibitors and anti-VEGF therapies, target specific processes involved in cell and tumor growth. Many types of targeted treatments are in clinical trials.

❑ **Chemotherapy**, a systemic therapy, is given by infusion into a vein or **access port** or is taken as a pill. It kills quickly dividing cells to slow or stop the growth of cancer. An access port, sometimes called a port-a-cath, is a small device under the skin that allows access to your veins. Another option is a **PICC line** (peripherally inserted central catheter), a long, flexible tube inserted into a vein in the arm that gives access to larger veins. In many cases, chemotherapy will be given if the cancer grows during treatment with another kind of medicine, to prevent the cancer from growing again. Together with your family and your doctor, you will consider the physical and emotional side effects of chemotherapy. Depending on the type of cancer you have, your age and treatments you've had in the past, your doctor may advise for or against chemotherapy.

❑ **Radiation therapy**, a local therapy, works to damage cancer cells in specific areas of the body. In metastatic breast cancer, radiation therapy is used to ease pain and improve your quality of life. It is also sometimes used to treat brain tumors.

❑ **Surgery**, a local treatment, can sometimes ease or prevent symptoms and side effects at the original or metastatic site (for example, the brain). If one or a few metastatic sites stay stable over time, surgery may be used to remove the disease. Some small studies suggest that removing the original tumor in those first diagnosed with metastatic breast cancer may lengthen life, but this needs to be confirmed in larger studies. Ongoing trials are exploring surgery to remove the primary tumor in people with metastatic disease. Talk with your doctor about new findings.

There are many options for the order, frequency and combination of treatments. Some medicines work better when given with other treatments as a combination therapy, while others may be taken one after the other. When you take only one medicine at a time, this is called single-agent therapy. Your treatment will be based on many factors, such as the cancer type and your past treatments. You may want to ask if combining medicines or taking them in a certain order makes the medicines stronger or changes their side effects.

You might also choose to get your treatment through a clinical trial (see page 26). If you are interested in a clinical trial, talk to your doctor early in your care so you have more options.

## Clinical Trials and Your Treatment

Your doctor may suggest you get treatment through a **clinical trial**, a research study that tests how well new medicines and procedures work in people. Clinical trials either compare standard Health Canada-approved treatments to new treatments, or study new therapies. All of today's standard therapies were once part of clinical trials.

If you have not taken part in a clinical trial before, you might worry that doing so will make you a "guinea pig." This is a common fear. In reality, the researchers who run clinical trials want to prove their treatment works and is safe. They want you to be as well as possible. There are also many laws and rules in place to protect participants in clinical trials.

Clinical trials are not a last resort. If your providers suggest one, it doesn't mean they have given up. Sometimes it's better to join a study before you try other standard treatments. Some trials only include people who have not taken certain medicines in the past. Joining a clinical trial before you try other treatments may give you more options over a longer period.

When you join a clinical trial, you usually won't be expected to go to a lab and remain there during treatment. You may have to travel to a different clinic or work with a different doctor. Some trials require you stay in a hospital or visit a doctor's office each day, but you will be told this upfront, before you join. Typically, your treatment experience won't be much different than usual. Most new medicines are available in the same forms as traditional medicines (through injection, pill or infusion). The main difference is that you may have more follow-up appointments or tests to allow the researchers to record your progress and compare it to your peers'.

There are three trial phases in which you may be able to take part.

- **Phase I trials** test a medicine or method in a small number of people because little is known about the risks and benefits of the treatment. Those who choose to participate have usually tried other treatments that no longer work, or they have not been helped by standard treatments in the past. The goals are to find out how to give the new treatment, how much to give and what the side effects are. Phase I trials are often not specific to one type of cancer.
- **Phase II trials** test the new treatment in a slightly larger group of people with a specific disease. The goals are to see if it works in treating that specific disease and to look at side effects and how bad they are. The method and dose from the phase I trial is used during treatment.
- **Phase III trials** test medicines in very large groups of people after they have been studied in phase I and phase II trials. By now, doctors already know how well the treatment works and what side effects might occur. These trials compare the new treatment to standard treatments to find risks and benefits and guide medical professionals.

During your treatment in a clinical trial, a team of doctors and nurses will talk with you regularly about any discomfort or side effects you have and how you feel overall. They will also watch the progress of the cancer. You will always be treated with medicine. You will get a **standard therapy**, a treatment that is accepted by providers as proper therapy for a type of disease and is widely used by healthcare professionals, or the

therapy under study added to standard therapy. This is even true in studies that include a **placebo**, an inactive substance sometimes given with a standard therapy. You will never go without at least standard active cancer treatment.

If you feel any side effects between appointments, you can contact your trial doctors or nurses to report the symptoms and talk about how to relieve them. You or your doctor can choose to remove you from the trial at any time. You don't have to complete it. Though you have the freedom to leave a trial, staying helps researchers maintain a stable group and gives them a better chance of understanding the therapy under study.

A clinical trial gives you access to treatments that may work well but are not yet approved by Health Canada. Many trials are designed to treat specific kinds of breast cancer. Ongoing and upcoming trials are focused on metastatic breast cancer and seek people with hormone receptor-positive, HER2-positive or triple-negative cancers. Other studies are testing how treatments already in standard use for other types of cancer work in breast cancer, and seek Health Canada approval from the results.

There is no cost to participate in clinical trials in Canada. The treatments being studied and any additional tests will be covered as part of the trial and routine care is covered by your provincial public health system. But taking part in some clinical trials may involve extra travel expenses. For resources on low-cost or free hotel rooms, see page 38.

To learn more about clinical trials, talk to your doctors. Because trials focus on very specific types of breast cancer, guidelines to join are strict and may be based on your prior treatments, type of cancer, age and other factors.

**The road gets hard and knocks us down, but the important thing is not letting it keep us down. We have to brush ourselves off and stand up again and muster up the courage and energy to fight one more round."**



## Integrative and Complementary Therapies

Today, many centres offer treatment plans that integrate Western medicine with complementary therapy to fully support your physical, emotional and spiritual well-being. By caring for the whole person, integrative treatment plans can strengthen your body, ease your mind, bring you calm, or even help you find what is most important to you.

There are many kinds of complementary therapy. Search for activities that centre and empower you. Every person is unique. What might give you a physical and spiritual release might be different for someone else. There are common practices to complement your traditional treatments:

- **Exercise** helps keep the body strong and muscles relaxed. Certain types, like yoga, have been shown in studies to have healing benefits in breast cancer by reducing fatigue and stress and improving sleep.
- **Nutrition** can help you maintain a strong and well-nourished body. During treatment, good nutrition prepares your body for medicines and for healing over time.
- **Mind-body practices** use the mind to calm stress and anxiety. They include yoga, hypnosis, meditation, guided imagery, and music and art therapy.
- **Meditation and mindfulness exercises** combine meditation, yoga and awareness of the body. These practices can teach you about your body's physical responses to stress, how to relieve that stress, and help you strengthen your body through light exercise.
- **Body work therapies** focus on physical sensation as a source to relieve pain and tension. They include therapeutic massage, acupuncture and acupressure.
- **Chinese and herbal medicines** are natural supplements that are believed to target the buildup of toxins and regulate the flow of fluids and energy in the body. The medicines are herbal combinations created to treat the source of the cancer.

Talk with your insurance providers about your interest in complementary therapies. Any additions to treatment, such as herbs, vitamins or supplements, may impact Western medicines. If your doctor does not know about complementary approaches or does not support your desire to use them in your care, you may want to consider adding an integrative medicine specialist to your healthcare team. **Remember, complementary therapies are not a replacement for medical treatments.**

## Palliative Care for Well-Being

Throughout your treatment, your healthcare providers use **palliative care**, or things that ensure you are living in a way that enhances your everyday activities. Palliative care is common in Canada. It includes

- complementary practices that centre you or strengthen your body against treatment side effects
- medicines that manage pain
- activities that support your emotional, physical, social and spiritual well-being

Managing pain due to surgery is considered palliative care, even though your providers may not have used that term.

Many people associate palliative care with end-of-life care. Though it is true that end-of-life care includes palliative care, you can benefit from it at any stage of breast cancer. Lack of education about and fear of palliative care often keeps people from using it, even though palliative care could improve your and your family's daily lives. A palliative care team made of doctors, nurses, social workers and other professionals may help you cope with the effects that metastatic breast cancer has on your everyday life. Their services include pain management, emotional support, spiritual support and complementary therapies.

Palliative care does not replace regular medical care. But it may help you control the stress of cancer, and its symptoms and side effects: physical, psychological, emotional and spiritual.









# Maintaining Your Everyday Well-Being

Living well with metastatic breast cancer means different things to different people. But living well and living fully are very possible. From the day of your diagnosis forward, you may make small and large changes to your habits, routines and activities to address the challenges of living well with metastatic disease.

There may be times you fear for the future, or lose confidence in your body and in the people who support you. These are normal responses to managing ongoing illness and grieving the small and large losses metastatic breast cancer can cause. Let yourself feel how you feel. You are not alone. Ask for help if you need it. You might decide to seek out others living with metastatic breast cancer. Many people gain great strength from talking with those who share in the experience.

*“Slow down and listen to your body. It’s a matter of knowing how treatment will affect you. Don’t eliminate living by any means.”*

One part of caring for yourself and your family is about controlling the cancer with treatment. Another part is feeling in charge of your everyday well-being. Knowing what makes life meaningful to you may help you as you choose medical treatments. Ask, will a certain treatment stop me from keeping up with my responsibilities and the things I enjoy? Is the cost of losing that high or low? Everyone is different, so you may choose a treatment that others turn down — and that’s OK. Talk to your doctor about your goals. You may be able to take treatment breaks (see page 23) for special activities, like travel or family events.

## Improving Your Daily Life

Your everyday well-being, often called **quality of life**, can be broken down into four parts: physical, emotional, social and spiritual. Finding a balance in each may help you care for yourself.

📌 **Physical support** helps you maintain physical strength, flexibility and wellness. Simple exercises like walking, as well as more intense exercise like yoga or weight lifting, help you reconnect with your body, improve your mood and make you feel better physically. Your care team can help you create an exercise plan.

- ✓ **Palliative care** (page 28) and **pain management** are key to good physical support. Therapeutic massage, pain medicine and complementary therapies are other options.

🔴 **Emotional support** may help you cope with the stress and anxiety of living with metastatic breast cancer. At times, you might feel disconnected, alone or uncertain about the future. Consider taking part in programs or services, like counseling, psychotherapy or support groups. You might take classes or join clubs that support your interests. These activities may help you connect with others, cope with your emotions and stay engaged in things you enjoy.

- ✓ **Counseling and individual therapy** offer you the chance to talk about concerns you keep to yourself in a safe setting. Many people hide fears or worries to avoid upsetting others. A counselor or therapist is someone outside your usual life you can talk to. If you begin to feel overwhelmed by your diagnosis and the changes in your life, seek support right away. Don't be afraid to try a few different providers. It may take time to find the right therapist for you.
- ✓ **Support groups** provide a place to meet and talk with others coping with breast cancer. Talking with people in similar situations may help ease isolation and promote understanding. Support groups are a good way to learn about new resources. Not everyone feels comfortable in every support group. Much depends on the people in the group. If you want a support group but the first one you try doesn't meet your needs, look for another. It may help to decide what kind of people you want in your group, such as people with the same diagnosis as you, people your age, or a group of people who speak French or share your culture. The Canadian Cancer Society provides a search tool for cancer support groups in your area: [info.cancer.ca/CSD](http://info.cancer.ca/CSD). For online groups and other resources in English visit [mbcn.org](http://mbcn.org).
- ✓ **Peer counseling services** allow you to talk to someone with a metastatic breast cancer diagnosis who is in treatment like you. When you are first diagnosed, it may be hard to imagine living months or years. Many people find that talking to someone who has done just that eases worries. To talk about your questions or emotions with someone facing a similar diagnosis, we encourage you to contact the Canadian Cancer Society peer support program at (888) 939-3333.

🔴 **Social support** connects you to your community to help you maintain a healthy emotional life. Having friends, family or peers for emotional support, as well as a social life outside of cancer, may help you feel happy and enjoy a full life.

- ✓ **Scheduling time with family and friends** helps you make sure you see the people most important to you. There may be times when treatment schedules and doctors' appointments get in the way, so making dates can help your relationships stay on track.
- ✓ **Joining an online community** offers active, 24/7 communication with people living with metastatic breast cancer. These forums may be very helpful if you live in a remote place, have a busy schedule, or simply feel more comfortable talking about your challenges online. Many breast cancer organizations offer email newsletters through listservs that provide news about treatments and upcoming events, such as webinars.
- ✓ **Attending workshops, conferences and classes** offered by breast cancer organizations and hospitals can help you learn about new treatments and clinical trials, or get your questions answered. They also allow you to meet and network with others living with metastatic breast cancer. Many are available free or with scholarships.

🔴 **Spiritual support** may help you find calm, peace or deeper faith. If you are a spiritual or religious person, your diagnosis may have left you feeling disappointed, angry or uncertain. Talking with a religious leader or a spiritual counselor may help you explore your feelings. Look to your church for support.

Spirituality is different for everyone, and comes in the form of traditional religious practices as well as devotion to an activity or purpose, such as community service or art.

- ✓ **Church and prayer groups** are available at many cancer centres, hospitals and churches, and may even focus on metastatic cancer.
- ✓ **Spiritual counseling or guidance** is offered by both traditional religious groups and holistic wellness centres.

These activities may also help you find calm:

● **Volunteering** for a breast cancer or other organization may give you a new sense of purpose, or give you a break from thinking about breast cancer.

● **Personal activities** like art, music, sports or writing can be a great outlet for stress, and offer you time alone to process news, decisions or emotions.

You may want to consider your relationships and decide whether they bring you strength and comfort. Sometimes you may decide to pull away from people who cause you sadness or stress. It is OK to tell people when what they're saying is not helpful. It's hard for some people to say, "I'm here for you," and leave it at that.

While metastatic breast cancer will always be with you, you can still embrace a full life that feeds your mind, body and soul. For resources with more information about managing metastatic breast cancer, finding support for yourself or your family, and keeping up-to-date with breast cancer news, visit [LBBC.ORG](http://LBBC.ORG), [mbcn.org](http://mbcn.org), [cbcn.ca](http://cbcn.ca) or the websites listed in the Resources section of this guide, which starts on page 36.

*"I've learned my time is precious. I've also learned that quality of life is extremely important, especially when quantity of life is unknown."*









## Looking Toward the Future

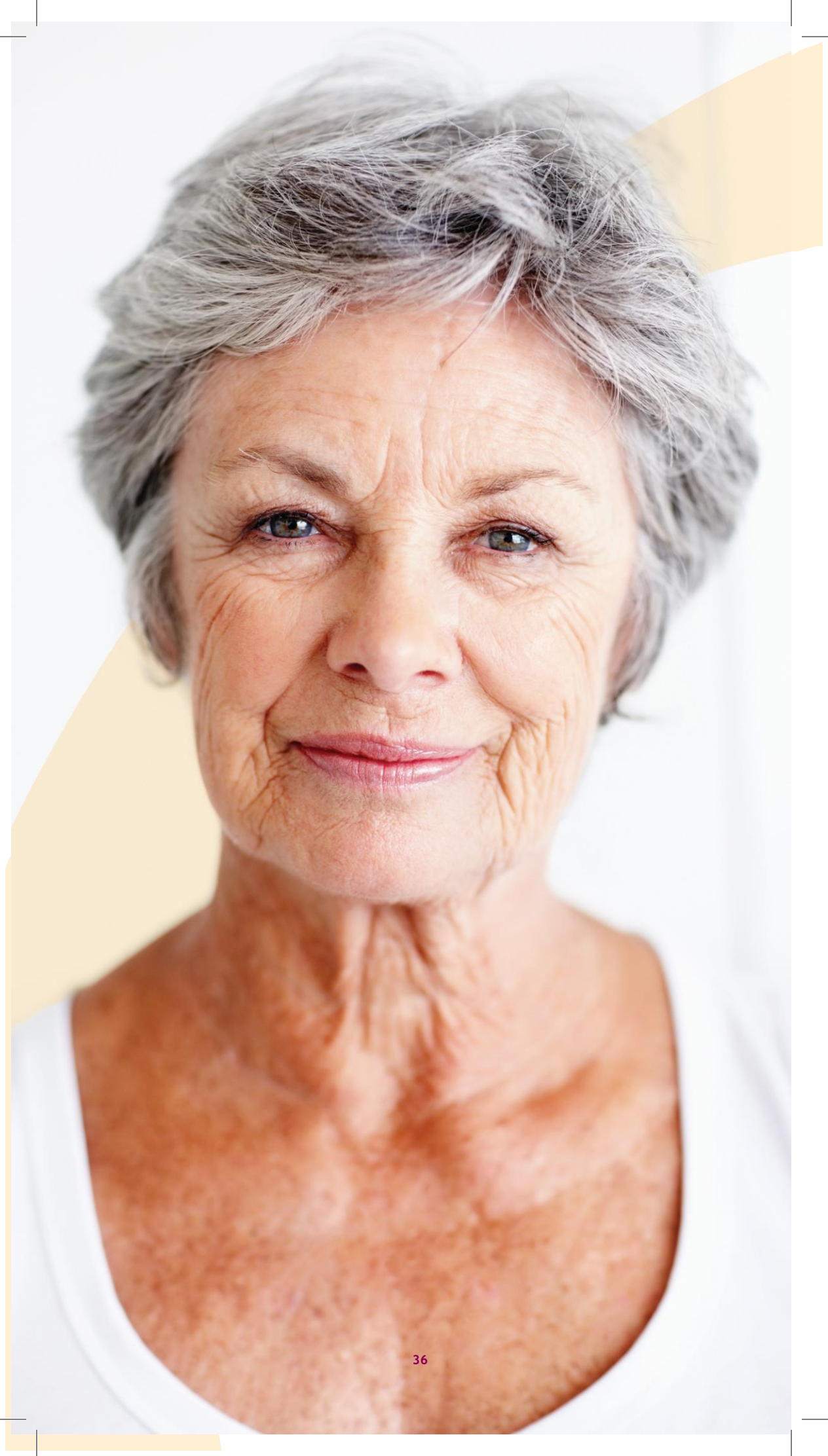
Researchers continue to look for new medicines and therapies for metastatic breast cancer. Over the years, scientists have learned a lot about how cancer cells and their parts grow and divide. The more they learn, the better doctors can tailor treatment to each person.

Your doctors may say metastatic breast cancer is a **chronic condition**, a disease that progresses over a long period, like diabetes or heart disease. Everyone has different reactions to the use of this term. Making metastatic breast cancer a chronic condition is the goal of much current research. Though this is not a reality today, progress, in the form of personalized and targeted medicines, could move us in that direction.

Living with metastatic breast cancer may feel different from day to day. There will be good days, as well as bad days. But with the support of your care team and loved ones, you can live the life you want.

“Live with honesty, faith and hope. There are no givens, but there is always hope. There is always the possibility of tomorrow.”





# Resources

*Information is current as of June 2017 but may change.*

## Organizations That Can Help

### LIVING BEYOND BREAST CANCER: LBBC.ORG (English and some Spanish)

Living Beyond Breast Cancer can assist you, whether you are newly diagnosed with metastatic breast cancer or are in ongoing treatment. We are also here for your family members, caregivers, friends and healthcare providers to provide breast cancer information and support.

More information available on LBBC.ORG or in print (English only):

- 📖 *Metastatic Breast Cancer Series: Managing Stress and Anxiety*
- 📖 *Metastatic Breast Cancer Series: Treatment Options for Today and Tomorrow*
- 📖 *Metastatic Breast Cancer Series: Understanding Palliative Care*
- 📖 *Metastatic Breast Cancer Series: Understanding Symptoms and Treatment Side Effects*

### METASTATIC BREAST CANCER NETWORK: MBCN.ORG (English only)

The Metastatic Breast Cancer Network, a national, patient-led organization, works to raise awareness of metastatic breast cancer within the breast cancer community and public. MBCN encourages women and men living with the disease to raise their voices to demand support, resources and more research for metastatic disease.

More information available on mbcn.org:

- 📖 *Diagnosis: Metastatic Breast Cancer...What does it mean for you?*
- 📖 *Get the Facts Brochure*
- 📖 *Are you living with MBC? Flyer*

### CANADIAN BREAST CANCER NETWORK: CBCN.CA (English and French)

The Canadian Breast Cancer Network is Canada's leading patient-directed organization of individuals concerned about breast cancer. CBCN strives to voice the views and concerns of breast cancer patients through education, advocacy activities and the promotion of information sharing.

More information available on cbcn.ca:

- 📖 *Living with metastatic breast cancer*
- 📖 *MedSearch metastatic drug navigation tool*
- 📖 *Waiting for Treatment: timely equitable access to drugs for metastatic breast cancer*

## Resources Available in French

### CAREGIVING SUPPORT

- Le réseau aidant: [lereseauaidant.ca](http://lereseauaidant.ca)
- L'Espoir c'est la vie: [lespoircestlavie.ca](http://lespoircestlavie.ca)

### CLINICAL TRIALS

- Essais canadiens sur le cancer: [canadiancancertrials.ca](http://canadiancancertrials.ca)
- L'Institut du cancer: [cihr-irsc.gc.ca](http://cihr-irsc.gc.ca)
- Vue sur le cancer: [vuesurlecancer.ca](http://vuesurlecancer.ca)

### FAMILY RESOURCES

- Société canadienne du cancer: [cancer.ca](http://cancer.ca)
- CanSupport: [cansupport.ca](http://cansupport.ca)

### FINANCIAL CONCERNS

- Agence du revenu du Canada: [cra-arc.gc.ca](http://cra-arc.gc.ca), (800) 959-8281
- Faire face aux problèmes financiers: [cbcn.ca/fr/mbc\\_financial\\_issues](http://cbcn.ca/fr/mbc_financial_issues)
- Le Régime de rentes du Québec: [rrq.gouv.qc.ca](http://rrq.gouv.qc.ca)
- Les prestations de maladie de l'assurance-emploi: [canada.ca/fr/emploi-developpement-social](http://canada.ca/fr/emploi-developpement-social)
- Prestation d'invalidité du Régime de pensions du Canada: [canada.ca/fr/services/prestations](http://canada.ca/fr/services/prestations), (800) 277-9914
- Ruban rose programme d'aide financière: [rubanrose.org](http://rubanrose.org)

### GENERAL INFORMATION AND SUPPORT

- Ruban Rose: [rubanrose.org](http://rubanrose.org)
- Société canadienne du cancer: [cancer.ca](http://cancer.ca)
- Vue sur le cancer: [vuesurlecancer.ca](http://vuesurlecancer.ca)

## Resources Available in English

### CAREGIVING SUPPORT

- Caregiver Action Network: [caregiveraction.org](http://caregiveraction.org)
- CaringBridge: [caringbridge.org](http://caringbridge.org)
- Lotsa Helping Hands: [lbbc.lotsahelpinghands.com](http://lbbc.lotsahelpinghands.com)
- The Caregiver Network: [thecaregivernetwork.ca](http://thecaregivernetwork.ca)

### CLINICAL TRIALS

- BreastCancerTrials.org
- Canadian Cancer Trials: [canadiancancertrials.ca](http://canadiancancertrials.ca)



- 📌 CancerView: [cancerview.ca](http://cancerview.ca)
- 📌 ClinicalTrials.gov
- 📌 Institute of Cancer Research: [cihr-irsc.gc.ca](http://cihr-irsc.gc.ca)
- 📌 Metastatic Breast Cancer Trial search:  
[lbbc.org/metastatic-trial-search](http://lbbc.org/metastatic-trial-search) or [mbcn.org/education/category/metastatic-trial-search](http://mbcn.org/education/category/metastatic-trial-search)
- 📌 National Cancer Institute: [cancer.gov](http://cancer.gov)
- 📌 NCI Center for Cancer Research: [ccr.cancer.gov](http://ccr.cancer.gov)

## FAMILY RESOURCES

- 📌 Canadian Cancer Society: [cancer.ca](http://cancer.ca)
- 📌 CanSupport: [cansupport.ca](http://cansupport.ca)
- 📌 Group Loop: [grouploop.org](http://grouploop.org) (teens)
- 📌 Men Against Breast Cancer: [menagainstbreastcancer.org](http://menagainstbreastcancer.org)
- 📌 Mothers Supporting Daughters with Breast Cancer: [mothersdaughters.org](http://mothersdaughters.org)

## FINANCIAL CONCERNS

- 📌 Canada Revenue Agency medical expense tax benefits: [cra-arc.gc.ca](http://cra-arc.gc.ca), (800) 959-8281
- 📌 Canadian Breast Cancer Support Fund: [cbcsf.ca](http://cbcsf.ca)
- 📌 CBCN Facing Financial Issues: [cbcn.ca/en/mbc\\_financial\\_issues](http://cbcn.ca/en/mbc_financial_issues)
- 📌 Employment Insurance Sickness Benefits: [servicecanada.gc.ca](http://servicecanada.gc.ca), (800) 206-7218
- 📌 Kelly Shires Breast Cancer Foundation: [kellyshiresfoundation.org](http://kellyshiresfoundation.org)
- 📌 Pension Plan Disability Benefits: [canada.ca/en/services/benefits](http://canada.ca/en/services/benefits), (800) 277-9914
- 📌 Québec Breast Cancer Foundation: [rubanrose.org](http://rubanrose.org)
- 📌 Québec Pension Plan: [rrq.gouv.qc.ca](http://rrq.gouv.qc.ca), (800) 463-5185

## GENERAL INFORMATION AND SUPPORT

- 📌 Association of Cancer Online Resources: [acor.org](http://acor.org)
- 📌 Breastcancer.org
- 📌 Canadian Cancer Society: [cancer.ca](http://cancer.ca)
- 📌 CancerCare: [cancercare.org](http://cancercare.org), (800) 813-4673
- 📌 Cancer Support Community: [cancersupportcommunity.org](http://cancersupportcommunity.org), (888) 793-9355
- 📌 CancerView: [cancerview.ca](http://cancerview.ca)
- 📌 Hereditary Breast & Ovarian Cancer Society: [hbocsociety.org](http://hbocsociety.org)
- 📌 Québec Breast Cancer Foundation: [rubanrose.ca](http://rubanrose.ca)
- 📌 SHARE: [sharecancersupport.org](http://sharecancersupport.org), (844) 275-7427
- 📌 Susan G. Komen: [komen.org](http://komen.org), (877) 465-6636
- 📌 Triple Negative Breast Cancer Foundation: [tnbcfoundation.org](http://tnbcfoundation.org), (877) 880-8622
- 📌 Wellspring Cancer Support: [wellspring.ca](http://wellspring.ca)

## LEGAL INFORMATION

- 📌 Cancer and Careers: [cancerandcareers.org](http://cancerandcareers.org)
- 📌 Cancer and Work: [cancerandwork.ca](http://cancerandwork.ca)

## METASTATIC BREAST CANCER

- 📌 AdvancedBC.org
- 📌 BCMets.org
- 📌 BrainMetsBC.org
- 📌 MetaCancer Foundation: [metacancer.org](http://metacancer.org)
- 📌 METAvivor: [metavivor.org](http://metavivor.org)

## YOUNG WOMEN

- 📌 **LIVESTRONG**: [livestrong.org/we-can-help/young-adults](http://livestrong.org/we-can-help/young-adults)
- 📌 Rethink Breast Cancer: [rethinkbreastcancer.com](http://rethinkbreastcancer.com)
- 📌 Sharsheret: [sharsheret.org](http://sharsheret.org), (866) 474-2774
- 📌 Stupid Cancer: [stupidcancer.org](http://stupidcancer.org)
- 📌 Young Adult Cancer Canada: [youngadultcancer.ca](http://youngadultcancer.ca)
- 📌 Young Survival Coalition: [youngsurvival.org](http://youngsurvival.org), (877) 972-1011

## Tests to Expect

**Biopsy.** A test in which a small amount of tissue is removed from your body so a specially trained doctor can look at it under a microscope.

**Blood marker or tumor marker test.** A blood test to look for proteins that tumors produce or tumor cells that have entered the bloodstream, to see if cancer has spread to other parts of the body.

**Bone scan.** An imaging test performed by a radiologist to see if cancer spread to bone.

**BRCA1 or BRCA2 genetic testing.** Blood tests to look for mutations of the BRCA genes, which may show that a family is at higher risk for breast cancer.

**Confirming biopsy.** A biopsy to see if cancer cells have changed since primary diagnosis.

**CT (Computerized Axial Tomography) scan.** Sometimes called a CAT scan, three-dimensional x-ray images to look at organs like the bones, liver, lungs, brain and lymph nodes.

**Mammogram.** An imaging test to assess breast tissue when there are no symptoms of breast cancer.

**MRI (Magnetic Resonance Imaging).** An imaging test that uses magnet and radio waves to create cross-sectional images of specific areas of the body.

**PET (Positron Emission Tomography) scan.** Usually used after diagnosis, a PET scan takes images of the whole body to find cancer cells and where they may have spread.

**Ultrasound.** An imaging test that uses high-frequency sound waves to create images of the inside of the body, and to see if a mass is solid or full of fluid.

**X-ray.** An imaging test generally used to see whether treatment is working.

## Common Treatments

The medicines listed below are already approved by Health Canada as of June 2017. New treatment options may become available over time. For up-to-date information about approved drugs in Canada, visit [cbcn.ca](http://cbcn.ca).

### HORMONAL THERAPIES

Hormonal therapies work to slow or stop the growth of hormone-sensitive breast cancer cells by blocking the function of hormones like estrogen and progesterone, or forcing the body to stop making them. Hormonal therapies include:

- Aromatase inhibitors: anastrozole (Arimidex), letrozole (Femara), exemestane (Aromasin)
- ERAs: fulvestrant (Faslodex)
- LHRH agonists: goserelin (Zoladex), leuprolide (Lupron)
- SERMs: tamoxifen
- Oophorectomy: surgery to remove the ovaries

### ANTI-HER2 THERAPIES

Anti-HER2 therapies target the HER2 gene or HER2 protein that drives abnormal cell growth in HER2-positive cancers. Some block the HER2 protein from within the cancer cell. Others encourage the body's immune system to attack it. Common anti-HER2 therapies include:

- Trastuzumab (Herceptin)
- Lapatinib (Tykerb)
- Pertuzumab (Perjeta)
- T-DM1 (Kadcyla)

### CYTOTOXIC CHEMOTHERAPIES

Cytotoxic chemotherapies are medicines that kill cancer cells by stopping cell growth or cell division, or by interfering with cell DNA, cell parts, or proteins that help them grow. Common cytotoxic chemotherapies include:

- Anthracyclines: doxorubicin (Adriamycin), epirubicin (Ellence), liposomal doxorubicin (Doxil)
- Antimetabolites: 5-fluorouracil (5-FU), capecitabine (Xeloda), gemcitabine (Gemzar), methotrexate
- Platinum-based chemotherapies: cisplatin (Platinol), carboplatin (Paraplatin)
- Microtubule inhibitors

- Epothilones: ixabepilone (Ixempra), eribulin (Halaven)
- Taxanes: paclitaxel (Taxol), nab-paclitaxel (Abraxane), docetaxel (Taxotere)
- Vinca alkaloids: vinorelbine (Navelbine)

## OTHER TARGETED THERAPIES

These medicines target other parts of cancer cells and the structures that drive them to grow. Some of these therapies work against blood vessels that feed tumors, stop cells from fixing their own DNA once other treatments damage it, or work against certain enzymes. These targeted therapies include:

- CDK 4/6 inhibitors: palbociclib (Ibrance)
- mTOR inhibitors: everolimus (Afinitor)
- PARP inhibitors (under study in clinical trials)

## OTHER TREATMENTS

If you have bone metastases, your doctor may prescribe bone-building or bone-strengthening medicine to help prevent fractures and pain. These medicines include:

- Bisphosphonates: zoledronic acid (Zometa), pamidronate (Aredia)
- RANK-ligand inhibitors: denosumab (Xgeva)

## Words to Know

**Access port.** A small device put under the skin that allows access to your veins; sometimes called a port-a-cath.

**Benign.** Not harmful.

**BRCA1 or BRCA2 gene mutations.** Mutations on the BRCA genes that can increase the risk for developing cancer.

**Chronic condition.** A disease that progresses over a long period, like diabetes or heart disease.

**Clinical trial.** Research study that tests how well new medicines and procedures work in people.

**Complementary therapy.** Non-medical therapies used with your medical treatment.

**Ducts.** The passageways that carry milk from the lobules to the nipple.

**Ductal cancers.** Cancers that grow in the ducts of the breasts as masses and may later spread through the wall of the duct into other tissues of the breast.

**HER2 status.** The measure of how much of the HER2 protein is in cancer cells.

**Hormone receptor status.** The measure of hormone receptors on cancer cells.



**Inflammatory breast cancer.** An aggressive but uncommon form of breast cancer. Instead of forming a mass, it usually starts with redness, swelling or tenderness in the breast and can be very fast growing.

**Invasive or infiltrating breast cancer.** Cancer that has spread beyond the ducts or lobules of the breast.

**Lobules.** The glands that make breast milk.

**Lobular cancers.** Cancers that start in the lobules of the breast. They can sometimes grow without forming a mass, making them harder to find.

**Local therapy.** Medicines and treatments that affect cells in and around tumors.

**Malignant.** Cancerous.

**Metastasized.** Spread beyond the breast or nearby lymph nodes to distant areas of the body.

**Metastatic cancer.** Cancer that has spread to distant areas of the body. A term used to refer to stage IV cancer.

**Mutation.** An error in cell DNA that causes breast cells to reproduce without stopping.

**NED.** A period where tests show no evidence of disease.

**Non-invasive.** Cancer that stays in the ducts or lobules of the breast. Also called in situ or stage 0 cancer.

**Palliative care.** Steps to take to ensure you are living in a way that enhances your everyday activities, such as complementary practices to centre you or strengthen your body, pain management medicines, and emotional, physical, social and spiritual support. Palliative care is common in Canada.

**Pathology report.** A profile of all of your test results that helps doctors choose your treatment path.

**PICC line.** A thin, flexible tube inserted into a vein in the arm and into a larger vein in the body, used to give chemotherapy medicine.

**Placebo.** An inactive substance sometimes given with a standard therapy during a clinical trial.

**Primary diagnosis.** The first diagnosis of breast cancer.

**Progression.** The course of a disease. In cancer, the growth of tumors or spread of the disease.

**Proliferation index.** A number that shows what percentage of the cancer cells are actively dividing at a given time.

**Quality of life.** Everyday well-being.

**Recurrent disease.** Cancer that has come back.

**Regression.** Decreases in the tumor size or spread of cancer.

**Stable disease.** Periods when the cancer does not grow.

**Stage IV.** See **Metastatic cancer**.

**Standard therapy.** A treatment that is accepted by providers as proper therapy for a type of disease and is widely used by healthcare professionals.

**Systemic therapy.** Medicines and treatments that treat the whole body by traveling through the bloodstream or lymph channels.

**Treatment breaks.** Short breaks in treatment that allow for rest or for special events like weddings or vacations.

**Tumor suppressors.** Genes that make proteins that help control cell growth.



*Many thanks to these individuals who contributed their time and expertise for the English edition of this guide:*

#### **AUTHOR (ENGLISH EDITION)**

**Nicole Katze, MA**

#### **TRANSLATION**

**MTM LinguaSoft**

#### **LIVING BEYOND BREAST CANCER REVIEWERS**

**Amy Grillo**

**Janine E. Guglielmino, MA**

#### **METASTATIC BREAST CANCER NETWORK REVIEWERS**

**Shirley Mertz**

**Katherine O'Brien**

#### **CANADIAN BREAST CANCER NETWORK REVIEWERS**

**Cathy Ammendolea**

**Laurie Kingston**

**Jenn Gordon**

#### **LEAD MEDICAL REVIEWER**

**William Gradishar, MD**

Feinberg School of Medicine

Northwestern University

Chicago, Illinois

#### **MEDICAL ADVISORY COMMITTEE REVIEWERS**

##### **Medical Oncology**

**Kathy Miller, MD**

IU Simon Cancer Center

Indiana University

Indianapolis, Indiana

##### **Oncology Nursing**

**Evelyn Robles-Rodriguez, RN, MSN, APN, AOCN**

MD Anderson Cancer Center at Cooper

Camden, New Jersey

##### **Oncology Social Work**

**Roz Kleban, LCSW**

Evelyn H. Lauder Breast Center

MemorialSloan-KetteringCancerCenter

New York, New York



**Marie Lavigne, LCSW, OSW-C**

Municipality of Anchorage  
Anchorage, Alaska

**Palliative Care Specialist**

**Betty Ferrell, PhD, MA, FAAN, FPCN**

City of Hope – NCI Comprehensive Cancer Center  
Los Angeles, California

**Research**

**Danny R. Welch, PhD**

University of Kansas Cancer Center  
Kansas City, Kansas

**Surgical Oncology**

**David Euhus, MD**

Johns Hopkins Hospital  
Baltimore, Maryland

**CONSUMER ADVISORY COMMITTEE REVIEWERS**

**Terrie Bradford Barnes**, Shreveport, Louisiana

**Nancy Janes**, Alberta, Canada

**Nazneen Lotia**, Chicago, Illinois

**Carol Miele**, Albrightsville, Pennsylvania

**Franny Mondok**, Willoughby, Ohio

**Kim Thayer**, Portland, Oregon

**Sandra Whisonant**, Ft. Washington, Maryland

**Ann Wiley**, Cary, North Carolina

**Laurie Kingston**, Ottawa, Ontario

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**CREATIVE DEVELOPMENT**

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### **LIVING BEYOND BREAST CANCER,**

founded in 1991, is a national nonprofit organization with the mission of connecting people with trusted breast cancer information and a community of support. Programs and services are available online, in print, by phone and in person. For more information visit [LBBC.ORG](http://LBBC.ORG).

### **METASTATIC BREAST CANCER NETWORK,**

a national, patient-led organization, works to raise awareness of metastatic breast cancer and encourages women and men living with the disease to raise their voices to demand support, resources and more research to improve outcomes in the clinic. For more information visit [mbcn.org](http://mbcn.org).

### **CANADIAN BREAST CANCER NETWORK**

is Canada's leading patient-directed organization of individuals concerned about breast cancer. CBCN strives to voice the views and concerns of breast cancer patients through education, advocacy activities and the promotion of information sharing.

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