



Canadian
Breast Cancer
Network

METASTATIC BREAST CANCER (mBC)

HANDBOOK

A guide for individuals living with **stage IV** breast cancer



INTRODUCTION

Learning that you have stage IV breast cancer, also referred to as metastatic breast cancer, whether it is your first diagnosis or a recurrence, can leave you feeling frightened and overwhelmed. This handbook has been developed to give you information about your diagnosis so that you and your family can make informed decisions about your healthcare. It will also give you the tools you need to manage your daily life and to support your emotional well-being as you navigate this new chapter in your life.

We have designed this handbook so that you can easily flip between sections. You do not need to read this book from front to back. You may choose to read these sections in order or to read only the ones you feel apply to you at certain times. We have also chosen to separate the subjects of palliative care and end-of-life care because palliative care can begin at any point in your treatment of mBC. If you are feeling symptoms from your cancer or treatment, know that you can access the benefits of palliative care at any time which can help you have a better quality of life. We hope that the information and resources provided in this handbook help you and your family feel prepared for living with metastatic breast cancer.

While each person's experience is different, it is important to remember that there are others living with metastatic breast cancer who are going through similar experiences. About 1,200 women are diagnosed with mBC every year in Canada. What was once a rarely talked about disease is getting more attention and awareness.

Living with metastatic breast cancer will become a part of your daily life but it does not need to define you. Right now, it may feel overwhelming and that is normal. This diagnosis will bring about many emotions and at different times throughout your treatment. It's ok not to feel positive and strong all the time. It is important to remember that you are not to blame.

The Canadian Breast Cancer Network exists to ensure that patients are supported through information, education and advocacy. We are here to help you get the information you need to support you after a breast cancer diagnosis.



The Canadian Breast Cancer Network has been working for 25 years to voice the views and concerns of Canadians with breast cancer. As a patient-directed national organization, we are committed to continuing to promote education, information, advocacy and knowledge sharing to better meet the needs of patients and families in Canada.

CBCN is governed by a pan-Canadian volunteer board of directors who have all personally experienced a breast cancer diagnosis. The insights, knowledge and lived experience of our directors guide the work of CBCN and development of patient resources. Thank you to this dedicated group of women:

Cathy Ammendolea - Quebec - Board Chair

Cathy Hemeon - Newfoundland

Diana Ermel - Saskatchewan - Past-Chair

Jackie Greenham - Labrador

Judy Donovan Whitty - Prince Edward Island

Juliette Inglis - Alberta

Sharon Young - Manitoba - Vice-Chair

Suzanne Leblanc - New Brunswick

Wendy Panagopoulos - Nova Scotia

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This edition was authored by Rebecca Armstrong and edited by Cathy Ammendolea, Bukun Adegbenbo, Jenn Gordon, Niya Chari and Wendy Hall. Translation was provided by Anne Fortier. The design was beautifully created by Unika Studio.

This resource is dedicated to the women and men living with metastatic breast cancer and to those who are no longer with us but whose legacy lives on. It is with deep gratitude that we acknowledge the following women who helped advocate for people living with metastatic breast cancer and whose insight and perspectives shaped this book:

- Susan Anthony
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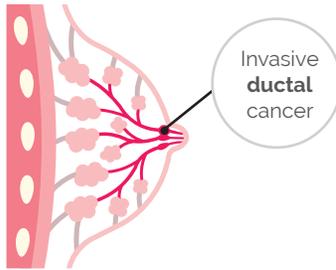




SECTION 1
UNDERSTANDING
Metastatic Breast Cancer

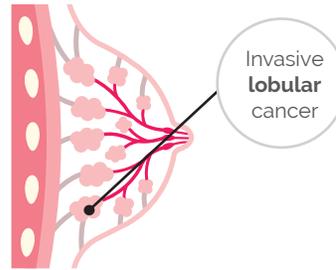
BREAST CANCER BASICS

Breast cancer occurs when cells inside your breast grow and divide out of control. Normally healthy breast cells grow and divide and then die as they age or become damaged. Sometimes these damaged cells can have **mutations** or errors in the cell's DNA that cause them to continue to grow and resist cell death. When they grow out of control they can form a mass or tumour. Breast cancer can come in different types and subtypes. Most often, breast cancer starts in either the cells of the ducts or the lobules.



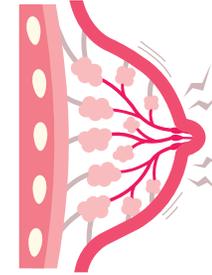
INVASIVE DUCTAL CANCER

is breast cancer that begins in the breast ducts, or the passageways that carry milk from the glands to the nipple and has spread to the surrounding breast tissue.



INVASIVE LOBULAR CANCER

is breast cancer that begins in the lobules (the glands that create breastmilk) and have spread to surrounding breast tissue.



INFLAMMATORY BREAST CANCER

is a rare but aggressive form of breast cancer that does not present as a lump but instead causes the breast to appear red, swollen and tender, often resembling an infection.

LOCALLY ADVANCED BREAST CANCER refers to a breast cancer that:

- Is large in size (typically over 5cm) and/or
- Has spread to the lymph nodes, usually in the armpit and/or
- Has spread into tissue around the breast such as the skin or muscle

Breast cancer that has spread to other parts of the body, most commonly the liver, lungs, bones and/or brain, is called **metastatic** or **stage IV** breast cancer.

Breast cancer is also broken down by **subtype**. Many targeted treatments are developed to treat certain subtypes of breast cancer. Knowing your subtype can help you and your doctor choose what treatment is right for you.

HR+

HORMONE RECEPTOR-POSITIVE (HR+) breast cancer refers to cancers in which cell growth is driven by the female hormones estrogen and progesterone. Breast cancer can be estrogen-receptor positive (ER+) if it has receptors for estrogen, and/or progesterone-receptor positive (PR+) if it has receptors for progesterone.

HER2+

HER2-POSITIVE (HER2+) breast cancers are known for the overexpression of the human epidermal growth factor receptor 2 (HER2) protein. In healthy cells, HER2 receptors are involved in controlling normal cell growth. When the cells overproduce the HER2 protein, there is uncontrolled division and growth of cells, leading to HER2+ breast cancer.

TNBC

TRIPLE-NEGATIVE breast cancer (TNBC) refers to cancers whose growth is not driven by the hormones estrogen or progesterone or by the overexpression of HER2 proteins. Treatments developed for HR+ and HER2+ breast cancers are often ineffective against TNBC.

A person can have a single subtype of breast cancer, or a combination of subtypes. For example, a breast cancer can be hormone-receptor positive and HER2 positive. Knowing your subtype(s) can help determine what targeted treatments will work best for your cancer. It is often important to be retested for these subtypes if you have already been treated for breast cancer at an early stage in the past because your subtype can sometimes change with recurrence.



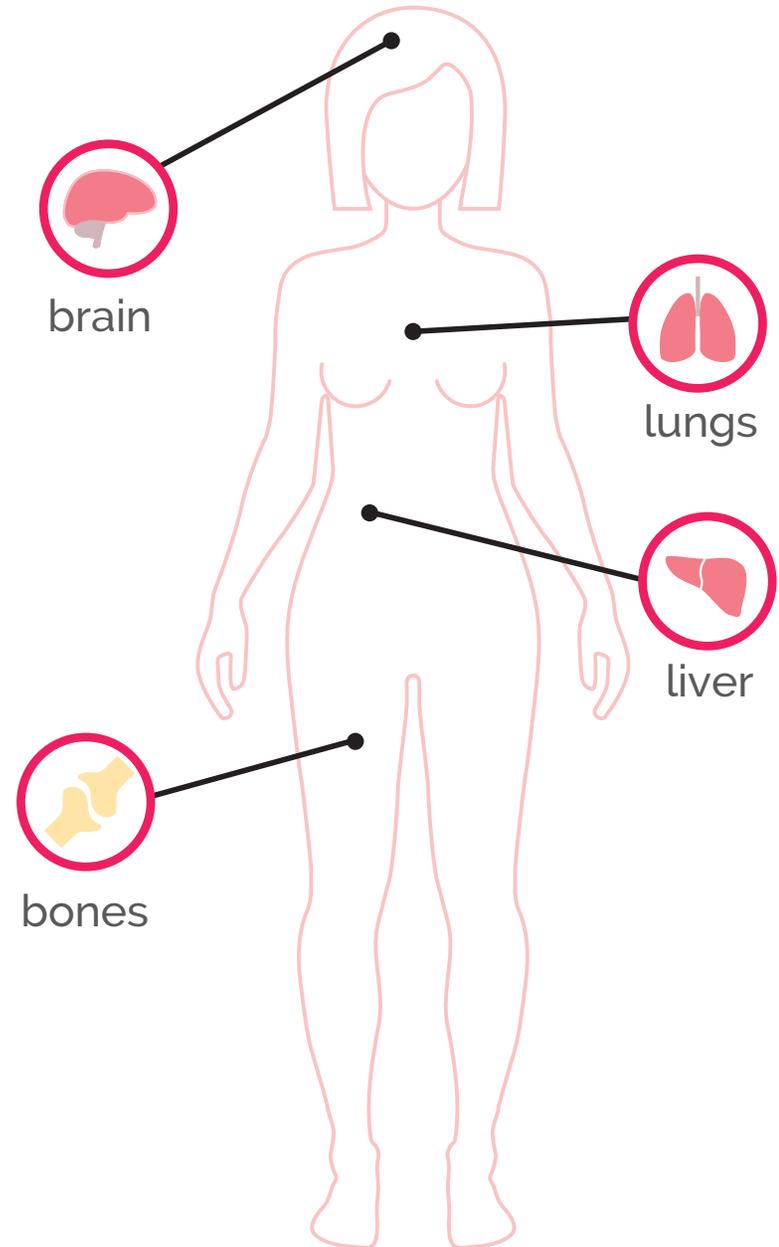
HOW BREAST CANCER METASTASIZES

Metastatic breast cancer occurs when the cancer cells inside the breast spread through the lymphatic system or bloodstream to other organs in the body. The most common places for breast cancer to metastasize is to the **bones, liver, lungs, or brain**.

Metastatic breast cancer can be **de novo**, meaning your first breast cancer diagnosis is stage IV, or **recurrent**, meaning your previously treated breast cancer has returned elsewhere in your body and is now stage IV.

Cancer cells that have spread beyond your breast are **still considered breast cancer and will be treated with breast cancer treatments**. For example, if your cancer has spread to your bones, it means that there are breast cancer cells in your bones, not bone cancer.

Although there continues to be research done to understand metastases, we don't know for sure why some cancer cells spread while others don't, nor can we predict when a cancer may recur elsewhere.



HOW METASTATIC BREAST CANCER IS DIFFERENT FROM EARLY STAGE BREAST CANCER

Metastatic breast cancer is different from early stage breast cancer because it means you will be living with cancer for the rest of your life. It means that you will always be treated and monitored by your healthcare team. While early stage breast cancer is treated with the goal to remove the cancer entirely, metastatic breast cancer at present, is not considered curable. Instead, the goal of treatment is to manage the disease by slowing the growth of the cancer cells, managing symptoms and to prevent the disease from continuing to spread so that you can continue to live a full and meaningful life.

Everyone reacts to treatment differently. For some people, certain treatments may work for long periods of time while other treatments may not work as well. If your cancer responds well to treatment it can either stop growing (known as **stable disease**) or it can decrease in size (known as **regression**). It is possible to have periods of time where your tests show no evidence of disease; this is commonly known as "**NED**." Even if you respond well to treatment, your cancer can eventually grow to resist it, meaning that you will need to move on to another treatment. When your cancer continues to grow, or when new tumours appear, it is called **progression**. When one treatment stops working, you and your doctor will look at what other treatment options may be available for you.



IMAGING AND TESTS

During your diagnosis and treatment your healthcare team will run various standard medical tests to monitor the growth or stability of your cancer. Here are some tests you may receive:



BIOPSY: A test that takes a small piece of tissue from your body to be examined for disease in a laboratory setting.



BLOOD MARKER OR TUMOUR MARKER TEST: A blood test that is performed to look for substances produced by tumours. These can be helpful while you are on treatment because the levels can often go down if the treatment is working to control the cancer, and the levels can start to slowly go up when the treatment is not working anymore. However, some breast cancers do not make these markers so they are not helpful to monitor in certain people.



BONE SCAN: An imaging test that looks at bone abnormalities and can help diagnosis bone metastases, or cancer that has spread to the bone.



CT/CAT (COMPUTERIZED AXIAL TOMOGRAPHY) SCAN: A 3D imaging machine that takes multiple x-rays at different angles to look at organs or abnormalities within the body.

MRI (MAGNETIC RESONANCE IMAGING): A specialized imaging machine that uses magnetic and radio waves to create detailed images of specific areas in the body.

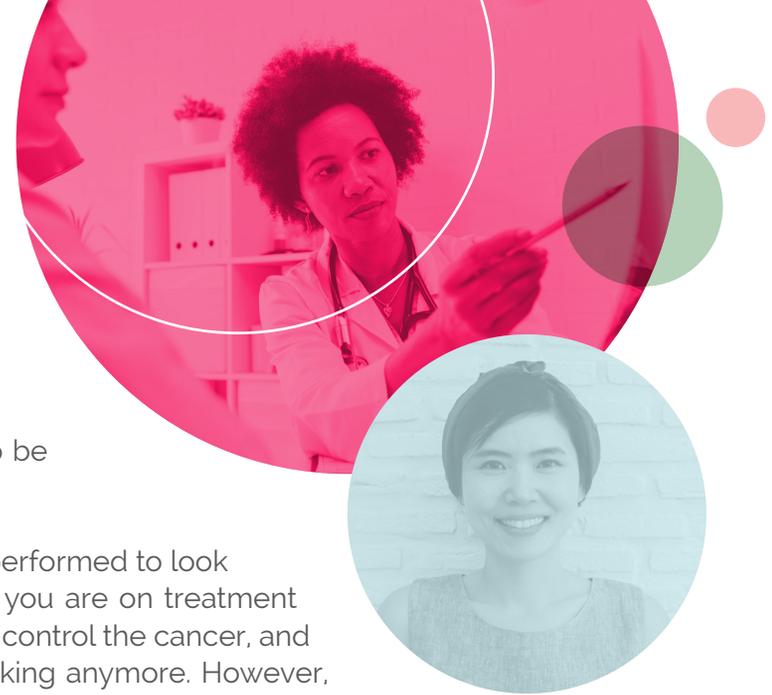
PET (POSITRON EMISSION TOMOGRAPHY) SCAN: An imaging test that uses a radioactive tracer to see where in the body there are highly active cells. These often represent cancer cells, but sometimes the cells can be highly active due to inflammation or infection.



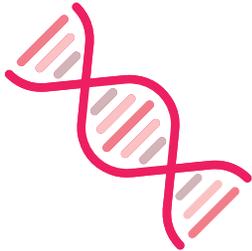
ULTRASOUND: An imaging test that uses sound waves to create images of your body.



X-RAY: An imaging test that uses small amounts of radiation to create images of inside your body.



GENETIC TESTING



Some breast cancers are considered hereditary, meaning families have inherited genetic mutations that can increase their risk of developing certain kinds of cancers in their lifetime. The most common and well-known genes associated with breast cancer are mutations in the BRCA1 or BRCA2 genes. Both men and women can test positive for BRCA gene mutations. Knowing your status may also qualify you for BRCA targeted treatments or clinical trials.

If you are concerned about your BRCA status, speak with your doctor to see if you are eligible for testing. If you are eligible, you can be referred to a genetic counsellor who will assess your family's cancer history and explain the pros and cons of testing. Genetic testing can be done through a simple blood test.

If you test positive for a BRCA gene mutation, the genetic counsellor can help you better understand how it will affect you and your family.

WORKING WITH YOUR HEALTHCARE TEAM

After your metastatic breast cancer diagnosis, you will have access to a team of healthcare professionals. This may include:



MEDICAL ONCOLOGIST: This doctor is often responsible for your primary care relating to your cancer and treatment. He or she will work with you to make decisions about the types of treatments you will receive. He or she can help you manage any symptoms from your cancer or side effects from the treatment. You can also ask if there is a pain and symptom management team at your centre that you could meet to get help with managing your symptoms.



RADIATION ONCOLOGIST: This doctor is responsible for prescribing the use of radiation therapy.



SURGICAL ONCOLOGIST: This doctor is responsible for performing cancer surgery if and when appropriate.





ONCOLOGY NURSES: Nurses provide cancer care to patients in a variety of ways. They will likely be a central point of contact throughout your diagnosis and treatment, and they will arrange for you to receive your treatment. A nurse's role can be very different at each cancer centre and may include navigation, accompaniment, referrals, health education, and counselling.



SOCIAL WORKERS: A social worker in the cancer centre is available to help you, your family, and your caregiver deal with the experience of managing your cancer. They are skilled healthcare professionals who can help with psychological, social, emotional, financial and spiritual issues that people face as part of the cancer journey. They can also help with practical needs, like finding accurate information, making difficult healthcare decisions, transitioning between care, and talking with family members.



NAVIGATORS: Some cancer centres have professionals available to help you navigate the cancer system and your treatment. These navigators vary from centre to centre but they can often help you access resources and supports, navigate the treatment process and assist you with accessing financial support for medications not covered by the provincial formularies. In Ontario, for example, Drug Access Navigators exist to ensure you have access to treatments necessary for your care. If you do not have a patient navigator in your cancer centre, social workers and oncology nurses are available to help you in these circumstances.



PHARMACISTS: Pharmacists are responsible for filling and preparing the prescriptions for your treatment drugs. They can also help explain the schedule of your treatments, any potential side effects of your treatments and they can be an excellent resource to answer any questions about your medications. It is important to have your pharmacist also check any supplements or vitamins that you are thinking about taking. These products may not be safe or may cause unwanted side effects when they are taken during your cancer treatment.



REGISTERED DIETITIANS: Some cancer centres have dietitians on staff to help you eat well during your treatments. They can help you manage many treatment side effects like difficulty chewing, weight loss, constipation, diarrhea, bloating, mouth sores and loss of appetite.



PALLIATIVE CARE TEAM: The palliative care team is a group of healthcare professionals that can help relieve your pain, manage symptoms and improve your quality of life. Your palliative care team can include doctors, nurses and social workers who specialize in palliative care, as well as physical therapists and spiritual care providers. While you may be able to access this team during your cancer treatment, they will also be the team responsible for your end of life care. Access to palliative care services may differ between provinces. Ask your medical oncologist if you are able to access these services while receiving active treatment or, if not, a team specializing in pain and symptom management.

Depending on the cancer centre, you may have access to these or other professionals who can help you during your treatment.

A doctor in a white coat is sitting on the left, gesturing with her hands as she speaks to a patient on the right. The patient is sitting on a chair, listening attentively. The background shows a clinical setting with a desk, a lamp, and some papers. The entire image is overlaid with a semi-transparent teal color.

SECTION 2
TREATMENT OPTIONS:
What Are They

UNDERSTANDING METASTATIC BREAST CANCER TREATMENT

As we mentioned earlier, the goals of treatment are different for metastatic breast cancer. Because treatment is not curative, the focus of treatment is to help patients live with good quality of life for as long as possible, while keeping their pain and other symptoms managed. Everyone responds differently to treatment. If it is working, your treatment will continue. You can be on one treatment for a long period of time if the cancer responds well to it. If the cancer grows or spreads while you are on the treatment, or you are having too much difficulty handling a particular treatment, your oncologist will look to see what other treatments options may be available.

Your treatments can be decided based on these factors:

- Subtype (hormone receptor status or HER2 status)
- Location of your breast cancer metastases (lungs, liver, brain, bones, etc.)
- Menopause status
- Whether or not you have symptoms from your cancer
- Age
- Previous treatments you have received for breast cancer

Based on scientific research, there are guidelines that oncologists follow when deciding what medication to use and when to use it. The very first treatment you receive is called first-line; the second treatment is called second-line and so on. Certain medications are approved only to be used in certain line-settings ie: only in first-line.

Sometimes, you and your doctor may decide for you to take a break from treatment. This could be delaying your treatment date to accommodate travel or special events. It also might be necessary if your side effects are significantly impacting your daily life or if your body just needs a bit of a rest.

WHAT ARE BIOSIMILARS?

Some medications to treat cancer, like trastuzumab and pertuzumab, are called biologics and are complex medications made from living cells. Biosimilars, are drugs that are made to be highly similar to the original biologic treatment and are expected to work just as well as the original treatment. For more information about biosimilars visit www.cbcn.ca



Healthcare in Canada is provided at the provincial level, which means that options may vary between provinces and territories depending on what treatments are funded through provincial formularies. CBCN has developed **MedSearch**, a breast cancer drug navigation tool that lists all of the breast cancer treatments approved by Health Canada and indicates what provinces or territories publicly fund them. CBCN's **FinancialNavigator** database can also provide 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; contact your provider to find out what is covered.

MedSearch

Visit www.cbcn.ca/medsearch to learn more about the metastatic breast cancer drugs approved for use in Canada.

FinancialNavigator

Visit www.cbcn.ca/financialnavigator to find financial resources and supports.

SOME QUESTIONS TO ASK YOUR DOCTOR

Metastatic breast cancer can have a tremendous impact on your life. Here are some questions you may want to ask when making decisions about your treatment:

- ? What are the potential side effects?
- ? How can we manage these side effects?
- ? How is this treatment given?
- ? How long does it take to receive this treatment?
- ? Will this medicine make me feel sick and stop me from working or taking care of my family?
- ? What side effects mean I should call you right away?
- ? If this treatment doesn't work, or makes me feel too sick, are there other options?
- ? How often will I receive this treatment?
- ? What's my personalized treatment plan?

COMMON TREATMENT OPTIONS

Treatments for metastatic breast cancer can include systemic therapies or local therapies.

Systemic therapies are delivered to the entire body through the bloodstream. For metastatic breast cancer, they are the primary form of treatment, meaning that they are the first and main treatment you will receive. They can be given by infusion through an I.V.; a central line (PICC or PORT); or as a pill.

Sometimes, your doctor will recommend that you use a **port**, also known as a port-a-cath, to receive your treatment. It is a small device that is inserted surgically under your skin in the chest. A nurse will insert a needle through the skin and into the port. This allows easy access to your veins for blood tests, to get treatments and sometimes it can be used for the injections for scans. Your doctor may suggest you get a port if you require treatment for an extended period of time.

Your doctor may offer the option of a **PICC line** (peripherally inserted central catheter), a tube inserted into a vein in your arm. Unlike a port, a PICC line does not require surgery and has a tube that will stick out of your skin. A dressing holds the tube in place. The dressing needs to be changed and the tube needs to be flushed with saline once a week. It does, however, have a higher risk for infection and cannot get wet. You can wear a plastic shower sleeve for bathing.

Some systemic therapies are offered in pill form, also known as **take-home cancer medications**. These are often easier on your daily life because they do not require you to go to the hospital or cancer centre to receive your treatment. However, it is important to know that just because these medications are given as pills and do not require you to go to the cancer centre, they can still have serious side effects. If you develop any serious side effects on pill treatments, you should call your oncologist's office right away. Access to public funding for take-home cancer medications varies by province in Canada. Check with your healthcare team to see if you have coverage.

Systemic treatments include hormonal therapy, targeted therapy, immunotherapy, and chemotherapy.



HORMONAL THERAPY also known as endocrine therapy, is used to treat hormone receptor-positive (HR+) breast cancers. They can block the estrogen or progesterone receptors on the cancer cells; stop the ovaries from producing these hormones; or lower the levels of the hormone in the body by blocking the actions of aromatase, an enzyme used to make postmenopausal estrogen. Hormone therapies include drugs such as tamoxifen, fulvestrant, letrozole, anastrozole and exemestane.





TARGETED THERAPY blocks or targets certain parts of the cancer cells (specific proteins or genes) that make the cancer grow and spread. There are different types of targeted therapies depending on what part of the cell is being targeted. The treatment specifically targets the abnormal cells while leaving most normal cells alone. Targeted therapies for HER2+ breast cancer, for example, specifically target or block the HER2 protein. Targeted therapies are available for HR+ breast cancer as well. Targeted therapies include drugs such as trastuzumab, pertuzumab, trastuzumab emtansine, lapatinib, abemaciclib, palbociclib, ribociclib, everolimus, tucatinib and olaparib.



IMMUNOTHERAPY is a form of targeted therapy that uses the body's immune system to help attack the cancer cells. Immunotherapy is a relatively new form of therapy for breast cancer. It has shown some promise in the treatment of triple-negative breast cancer, but it is still being studied further. There are clinical trials underway studying the possible benefit of immunotherapy to treat other subtypes of breast cancer as well. At the time of publication of this book, only one immunotherapy, atezolizumab, has been Health Canada approved for the treatment of breast cancer.



CHEMOTHERAPY attacks rapidly dividing cells in the body to damage or destroy cancer cells. Sometimes the chemotherapy cannot tell the difference between rapidly dividing cancer cells and rapidly dividing healthy cells, leading to it affecting some healthy cells as well. This is why strong doses of chemotherapy can cause hair loss, diarrhea and brittle nails. For metastatic breast cancer, chemotherapy usually works quickly and so it can also be effective in helping to ease symptoms of the cancer itself.

Some treatments may be taken on their own, known as a single-agent or monotherapies. Other treatments may be required to be given in combination. In some circumstances, some treatment options would eliminate your ability to take other treatments. Talk to your doctor about your plan for future treatment options including combination therapies and the order in which you will be taking them so that you know what you can expect if your current treatment stops working. Some common chemotherapy drugs used for the treatment of breast cancer are capecitabine, carboplatin, cisplatin, cyclophosphamide, doxorubicin, docetaxel, epirubicin, gemcitabine, nab-paclitaxel, paclitaxel, vinorelbine and 5-fluorouracil.

Local therapies are treatments that are given directly to the area where the cancer is. Radiation and surgery are the two most common forms of local therapy for treating cancer. When treating metastatic breast cancer, radiation and surgery are sometimes used, when applicable, to ease pain and improve quality of life. Radiation can also be used for the treatment of brain metastases.

Support medications are additional treatments that may be prescribed to you by your healthcare team to help manage the symptoms of your cancer or the side effects of your treatment. Bone-strengthening medications are prescribed if you have bone metastases to help prevent fractures or pain. Medications may also be prescribed to help prevent common side effects of chemotherapy such as nausea.

CLINICAL TRIALS

Clinical trials are another avenue to access treatments for metastatic breast cancer. Clinical trials test potential new treatments to see how well they work and how safe they are for standard use. At one time, the standard therapies used today were once tested in clinical trials.

It is not uncommon for people to worry or have questions about participating in a clinical trial. You may fear that you will be treated like an experiment. In order to run a clinical trial in Canada, researchers follow a strong set of guidelines developed and regulated by Health Canada to ensure patient safety.

There are three phases of clinical trials:



PHASE I trials test new treatments in a small group of people for the first time. They look at how safe the drug is, what the side effects are, and they determine a safe dosage. Typically, people in phase I trials have already tried and stopped responding to all available standard treatments.



PHASE II trials test treatments in a larger group of people (usually around 100 people). In this phase they continue to track how effective the drug is at treating the disease, how safe it is, and they adjust the dosage to find what works best.



PHASE III trials are given to larger groups of people (typically 1,000 or more). This trial continues to monitor effectiveness and side effects, but it also looks at how this new drug compares to standard treatments. The data from this trial is commonly used when Health Canada is reviewing and approving the drug for widespread use.

It is important to know that in cancer clinical trials you will always be treated with medicine. You will either receive the therapy that is being studied or you will receive **the standard of care**, which is a current treatment widely used by medical professionals when treating the disease. If you are in a study that uses a **placebo**, a substance that contains no medical ingredients, you will still be treated with a standard therapy.



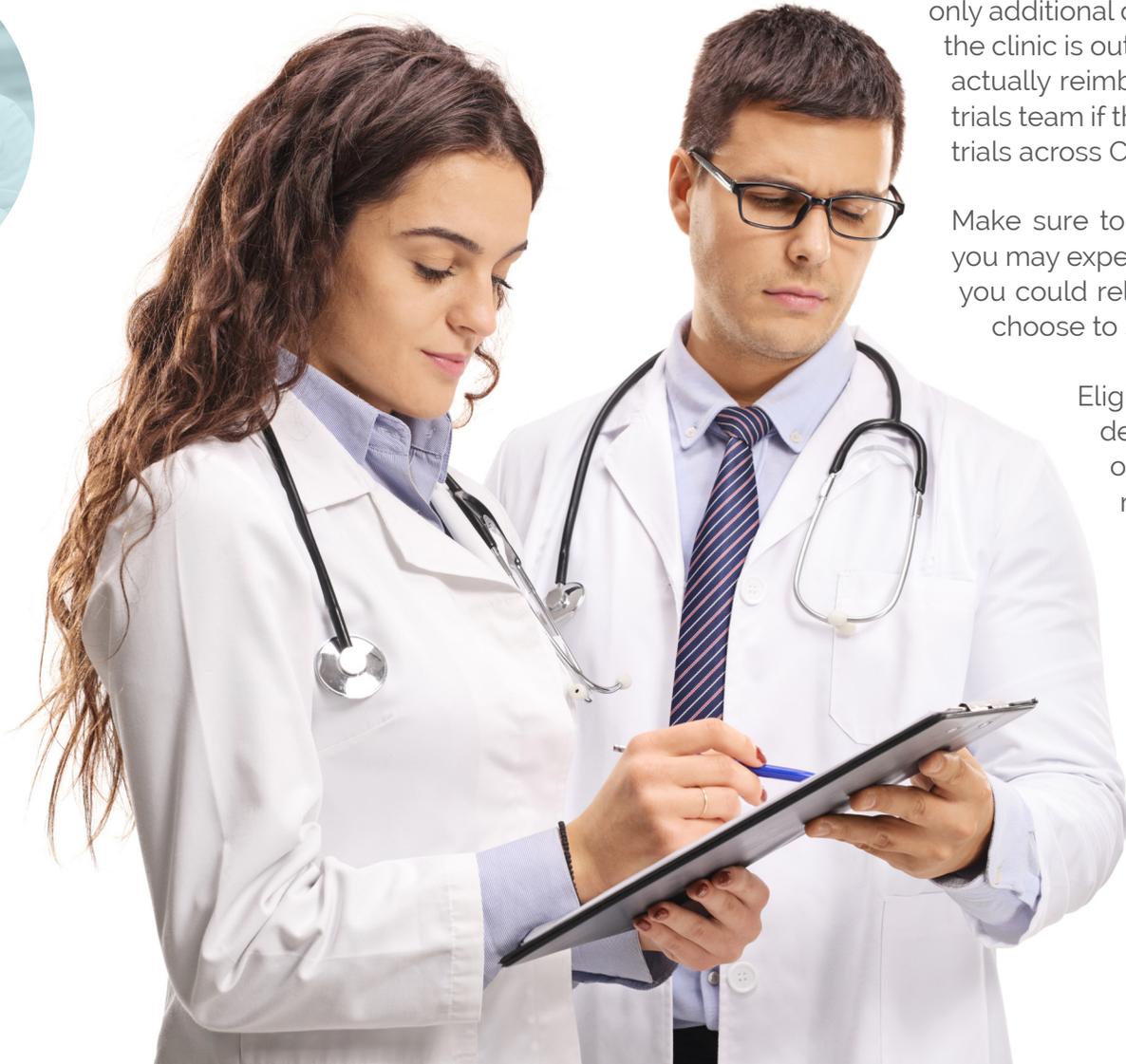


There is a common misperception that clinical trials are a last resort. But in fact, there are many clinical trials in Canada that only accept people who have not had previous treatments. Looking at clinical trials before you begin treatment might open you up to more treatment options.

Joining a clinical trial may require you to travel to a different clinic or be monitored by another healthcare team. It could also mean more follow-up appointments or tests to allow the researchers to record and monitor your progress more closely. You will not have to pay any additional costs to participate in a clinical trial. Any treatments or tests are covered by the trial and your routine care will continue to be covered by the province. The only additional costs you may have to consider are travel costs if the clinic is outside of your city or town; some clinical trials may actually reimburse these costs so you should ask your clinical trials team if this is an option for you. You can search for clinical trials across Canada by visiting www.trial-finder.ctontario.ca.

Make sure to contact your doctor to report any side effects you may experience while on a clinical trial and ask about how you could relieve these symptoms. You and your doctor can choose to stop participating in the trial at any time.

Eligibility for clinical trials can be strict and can depend on things like your type and subtype of cancer, your prior treatment, your age, your menopause status and many other factors. Talk with your oncologist to learn more about available clinical trials and to see if you qualify.



COMPLEMENTARY THERAPIES

Complementary therapies work alongside conventional medicine and can be used to treat the physical and emotional side effects of cancer and its treatments. There are many different kinds of therapies that can be integrated with your regular treatments.



EXERCISE can have many benefits beyond increasing your energy. It can help with fatigue, pain, depression and stress. It also comes in many different forms. Aerobic activities can increase your heart rate and improve blood flow. Resistance training can build and strengthen your muscles, and yoga can improve balance and flexibility. Some exercises may be harmful if you have bone metastases so ask your doctor how to safely incorporate exercise into your daily life.



NUTRITION can be very important to your well-being. A healthy diet may help you stay strong and manage your side effects of treatment. But treatment can also affect your eating habits. Your doctor or a registered dietician can help you achieve a balanced, nutrient-rich diet.



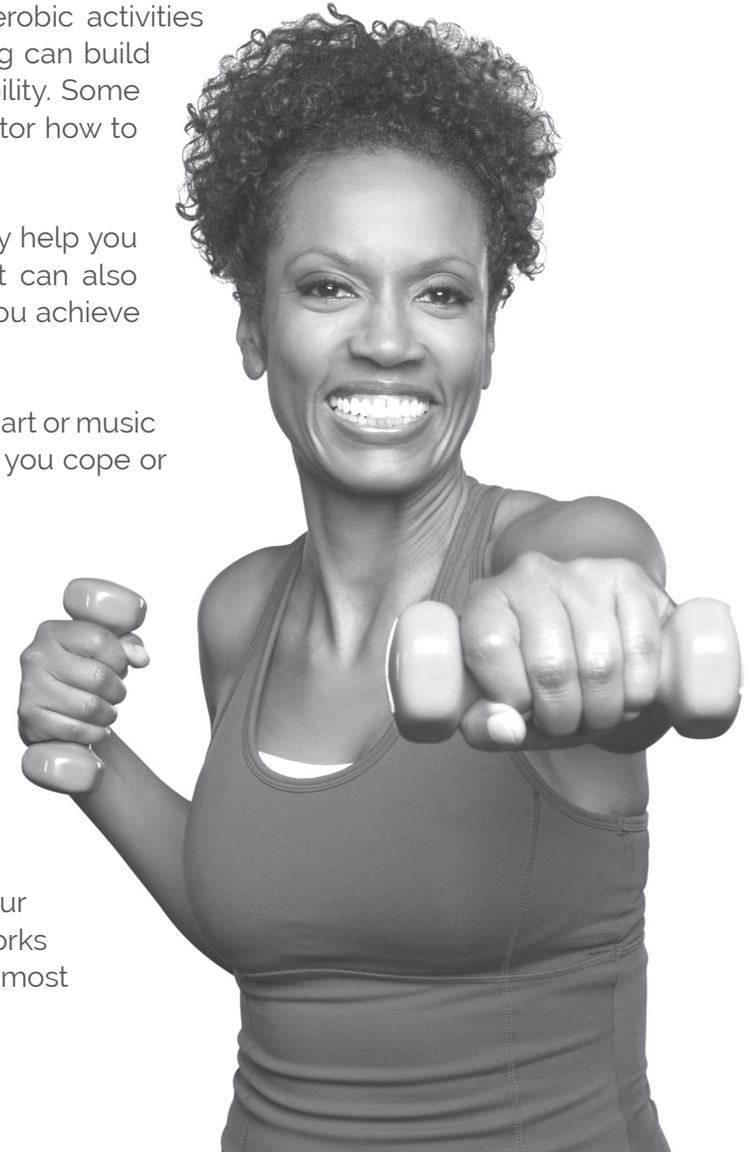
MIND-BODY THERAPIES can include yoga, meditation and reiki, as well as art or music therapy. Each of these can help to relieve stress or anxiety and can help you cope or come to terms with your diagnosis.



ACUPUNCTURE is an ancient Chinese medicine that uses the tips of very thin needles inserted into the skin at specific points. It has been shown to alleviate pain, fatigue, hot flashes and nausea.



MASSAGE THERAPY can help relieve pain and sore muscles and can also help with anxiety, depression and fatigue. There are many different kinds of massage, including some to help with lymphatic drainage if you have lymphedema. There are certified lymphedema therapists who can treat lymphedema. It is important to have an assessment before any lymphedema therapy to make sure the swelling is not related to your cancer or a blood clot. A registered massage therapist who regularly works with people living with cancer will be able to suggest what may be the most beneficial for you.





ABORIGINAL TRADITIONAL HEALING are traditions used within Indigenous communities. Healing focuses equally on the body, mind and spirit. Sweat lodges, smudging and healing circles are the most common forms of traditional healing.



NATUROPATHY offers natural approaches to healing and can include a wide variety of therapies, like the ones mentioned above. It's important to find a naturopathic provider who is specialized in oncology as some naturopathic products can interfere with cancer therapies. This form of therapy should not be used to replace your traditional treatments but can help improve your quality of life and may help manage the side effects of your cancer treatments. Be sure to let your oncologist and pharmacist know about what naturopathic therapies you are considering taking.

Before taking part in any of the additional therapies mentioned above, however, it is important to discuss them first with your healthcare team about the risks and benefits. Some of these therapies may be partially covered through your private insurance benefits. You can also discuss what options may be available through your cancer centre.

LOOKING TOWARD THE FUTURE

While 5-year survival rates continue to remain at 22% for metastatic breast cancer, it is important to remember that you are not a statistic. The scary statistics you may find during your online searches do not reflect your individual prognosis. New research continues being discovered to understand how metastatic breast cancer spreads and how it can be treated. More and more, new treatments that better target specific characteristics within the cells of tumours are being developed. This means that treatment is becoming more tailored to each person.

We may not be quite at the point of calling metastatic breast cancer a chronic condition; however, these new targeted treatments can help you live well with metastatic breast cancer.



A photograph of four young women laughing and hugging each other outdoors. The image is overlaid with a semi-transparent orange filter. The women are dressed in casual t-shirts and leggings. The background is a soft-focus outdoor setting.

SECTION 3
DAILY LIFE
and Emotional Support

IMPROVING YOUR DAILY LIFE

Maintaining a good quality of life may be just as important to you as your treatments and finding a balance between the two can help you improve your everyday well-being. Quality of life can be achieved through a combination of physical, emotional and spiritual support.



PHYSICAL SUPPORT can help you maintain your energy, strength and flexibility and can also help you reduce or manage your pain. Simple exercises or physiotherapy can help you keep your strength up and improve your mood. Requesting to see a palliative care or pain and symptom management team can also help assist you physically.



EMOTIONAL SUPPORT is also important for maintaining your everyday well-being. Living with metastatic breast cancer means you'll have days where you feel more stress or anxiety than others. Emotional well-being is often neglected but it is important to realize that your emotional and mental health are just as important as your physical health in your cancer journey.

- **Counselling or individual therapy** gives you the space to discuss your fears or emotions confidentially and in a safe environment. Ask your team at your cancer centre if there are therapists available on staff for you to speak with.
- **Support groups** allow you to speak and hear from others going through similar experiences as you. Ask your cancer centre if there are any metastatic support groups available for you to attend in your community. It may be difficult for you to find an in-person support group for MBC but there is an incredible community of women online. Visit cbcnc.ca to find out more.
- **Peer counselling** may also be available for you and may give you an opportunity to speak one on one with someone else living with metastatic breast cancer. More information on peer counselling can be found through your cancer centre or in their resource library.



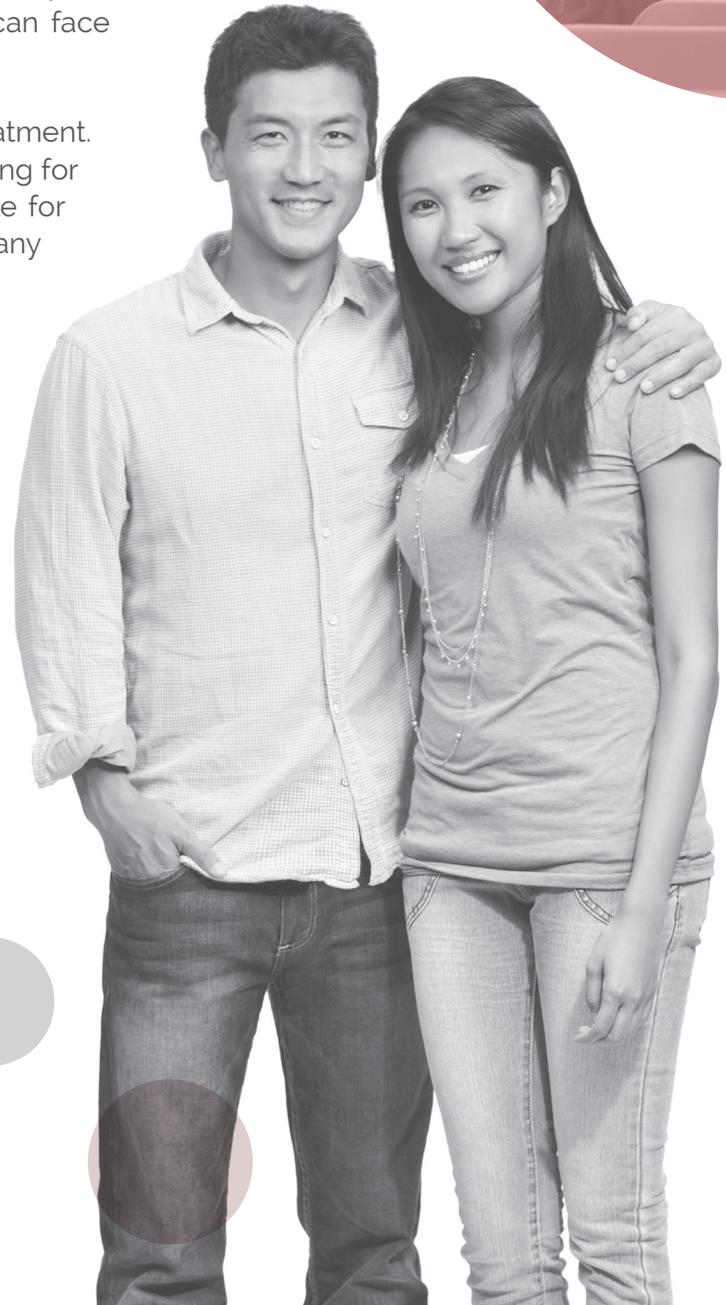
SPIRITUAL SUPPORT can help many people cope better with their diagnosis. If you are a spiritual or religious person, turning to your faith may help relieve any anxiety you may feel about death or it could affect how you decide on end-of-life care treatments. If exploring religion is new to you, consider reaching out to the Spiritual Care department at your local hospital.

SPOUSES AND SIGNIFICANT OTHERS

You may worry about how a metastatic breast cancer diagnosis can impact your family and your children's lives. Even the strongest relationships can face challenges adjusting to this new way of life.

Oftentimes, your spouse or partner becomes your caregiver during your treatment. Your spouse may also be taking on additional responsibilities such as caring for your children or your aging parents. Support and resources are available for your caregiver too. Ask your cancer centre or oncology team if there are any avenues for emotional support that your family or caregiver may be able to access through the hospital or in your community. You can visit cbcn.ca for more information on support resources for the caregiver.

If you do not or no longer have the support of a long-term partner, being single can present additional challenges, worries and fears. It's important to remember that you are not alone. Friends, siblings, adult children, cousins, and other family members can be a valuable source of support for you. Reaching out for support may feel hard at first but can have a very positive impact on your daily life.



TALKING WITH CHILDREN

Telling your children, young or grown, about your diagnosis can be very difficult. Younger children can often sense when their parents are dealing with stressful or emotional situations. Speaking with your children's doctor can be a helpful resource for you and your child. Their doctor may be able to give you some advice or resources on how to talk to your children and how to help your children cope with this news. You can also ask your cancer care team about a social worker who can give advice on discussing this difficult topic with your young children.

If you have older or adult children, they may have a lot of questions or feelings about your diagnosis. You may consider letting them speak with your healthcare team to help them better understand and cope with your diagnosis. Sometimes, adult children might also offer additional emotional or caregiver support to you as well.

Age plays a big role in the conversations you will have with your children about your cancer diagnosis. Their reactions and emotions may also vary and change over time. Visit cbcn.ca for information and additional resources on talking with your children about your diagnosis.

TELLING OTHERS: FAMILY, FRIENDS AND CO-WORKERS

Telling others about your diagnosis can be very stressful but having a support system can also be important for maintaining your wellbeing.

Choose a time when you feel comfortable enough to share. This may come at different times for different people. This also may mean choosing to tell some people more information than others. You can decide to share as little or as much information about your diagnosis and treatment as you'd like.

Telling your work or co-workers is entirely a personal choice. You have the right to privacy, and you do not have to discuss your personal health information if it is not something you feel comfortable doing. But if you do need to take time off for treatment, you may need to disclose some information to your human resources department or management team.

Friends and family can be an incredible support system during your treatment and can help provide some much-needed assistance to make your daily life a little easier. However, be prepared for both helpful and unhelpful reactions or comments from your loved ones. If loved ones are offering help, it's a good idea to be clear in what things they can do for you such as providing meals, help with cleaning, yardwork, childcare or just being there for you to talk about something that is not related to cancer.

Others may say or do the wrong thing, not because they are unkind, but simply because they do not know how to respond. The key is not to take these comments personally, but instead focus on those people who can give you the support you need.

WORK AND FINANCES

Returning to work or continuing to work while living with metastatic breast cancer may be necessary to help you offset the costs of your diagnosis and treatment. Or you may choose to return to work because it helps you regain a sense of normalcy and purpose in your life. However, you may also feel like you need to take time off to help manage your symptoms of treatment and this is perfectly acceptable as well.

How much information you choose to share with your employer is entirely up to you. If you need to take time off work or need to modify your schedule, some information may need to be shared with them. Disclosing some or all the details of your diagnosis with your supervisor or human resources department will remain confidential and should not be shared with other members of your team.

Many employers offer benefits such as sick days, leave of absences or disability benefits. You can also discuss the option for accommodations like modifying your work hours, or if you've been on leave, a gradual return to help ease you back into your role.

A diagnosis of metastatic cancer can have a huge impact on your finances and can create added stress and anxiety. From drug costs to home care or child care, the out-of-pocket expenses can take its toll on your bank account, especially if you've needed to stop working to focus on your treatment. Finding financial assistance, applying to government programs or making claims through private insurance can feel like a full-time job. Our FinancialNavigator is an online resource directory of available avenues of financial support. It also answers questions on health insurance, government income assistance programs, planning your will, and private insurance. Visit cbc.ca/financialnavigator to learn more.



A person's hands are shown holding a heart, symbolizing care and support. The image is overlaid with a semi-transparent purple filter. The text is positioned on the right side of the image.

SECTION 4
**PALLIATIVE CARE
and Pain Management**

WHAT IS PALLIATIVE CARE?

Palliative care can be integrated into your treatment plan to provide you with the best quality of life while facing a life-limiting diagnosis. Palliative care for metastatic breast cancer focuses on relieving treatment symptoms like pain, nausea and loss of appetite. It can also provide emotional and spiritual support for you and your family. As palliative care treatment takes a personalized approach, it can adapt to your individual needs and concerns at various stages of your treatment.

While palliative care is often considered a part of end-of-life care, it does not need to begin at end-of-life. Palliative care can begin at **any point** during your diagnosis and treatment. Many people living well with MBC incorporate it early in their treatment plan to help improve or maintain the quality of their lives.

HOW PALLIATIVE CARE IS DIFFERENT FROM YOUR TREATMENT CARE

While MBC treatment looks at managing the progression of the cancer itself, palliative care focuses on your well-being and quality of life. Doctors who specialize in palliative care will always coordinate alongside your primary oncology team. Depending on your cancer centre, the beginning stages of palliative care may still be managed by your oncology team with input and direction from palliative care doctors.

Your palliative care team can consist of doctors, nurses, social workers, spiritual care providers, pharmacists, occupational therapist, physiotherapists, personal support workers, and more. Availability of services and providers may vary based on your community as there is currently no nationally regulated palliative care program. Similar to healthcare, palliative and hospice care are administered by the provinces and territories and can vary based on where you live.

Your care can be provided through a number of different ways. If you're living well with MBC and only need care on an as-needed basis, you can receive your care through regular appointments with your cancer centre. End-of-life care can be provided at home, in a hospice, or in a hospital depending on your wants and needs.

Even though you may not need in-patient hospice treatment, your local hospice may be a good source of support. Many local hospices provide out-patient support programs and groups for those who are being treated for life-limiting illnesses. To learn more about palliative care services in your community, reach out to your provincial palliative care association.





UNDERSTANDING PAIN

Pain can be a difficult part of cancer and/or cancer treatment. Pain can interfere with your quality of life. It is important to know that there are many things that can help improve your pain and your quality of life. Therefore, it is important to let your care team know if you have pain so they can help you.

Your cancer can cause pain where it lives in your bones or other organs, while your treatments may cause nerve and muscle pain. Identifying the source and location of your pain can help your healthcare team prescribe the right treatments to manage or reduce your discomfort.

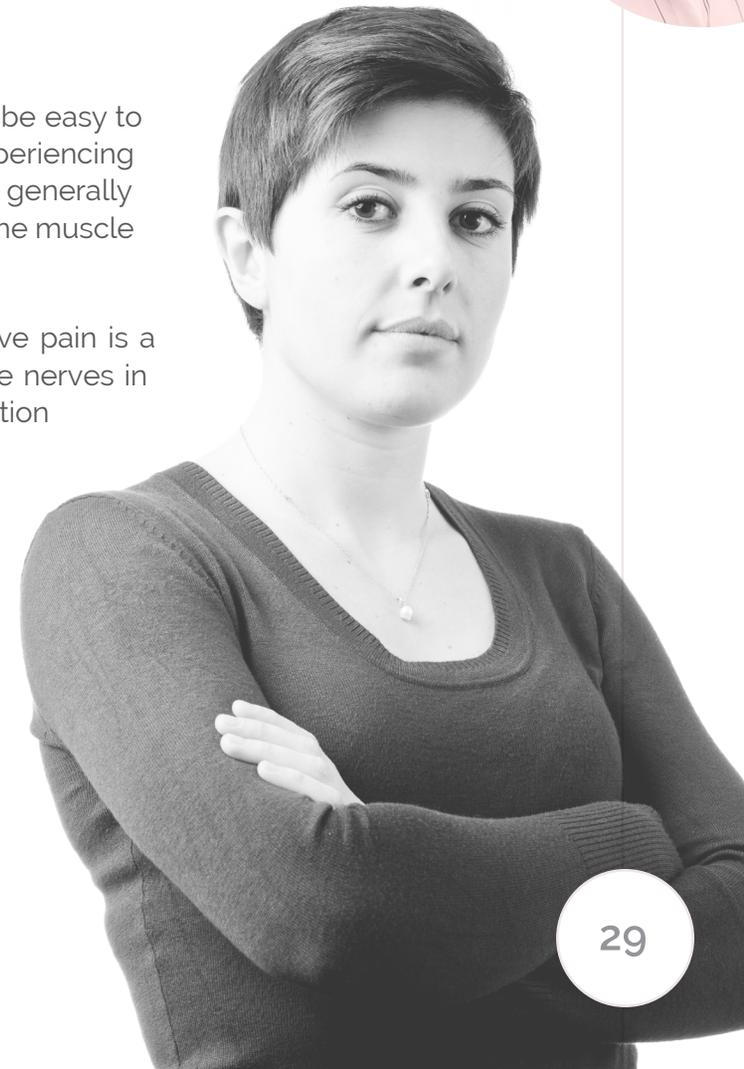
Different types of pain show different types of symptoms.

BONE PAIN AND PAIN IN YOUR MUSCLES or surrounding connective tissues can be easy to identify. **ORGAN PAIN** can tend to be more generalized. For instance, if you are experiencing pain in your kidneys, you may feel pain throughout your abdomen. These pains are generally as a result of the cancer itself, where it is located and how advanced it may be. Some muscle pain may be a result of treatments or fatigue.

NERVE PAIN brings a completely different sensation to your body. Typically, nerve pain is a result of your systemic treatments. Your chemotherapy may cause damage to the nerves in your body, typically in your hands or feet. It can result in a tingling or burning sensation that is often described as pins and needles, leaving your skin sensitive to touch.

Your level of pain and the frequency in which it occurs will help your doctors determine a course of treatment. If you're experiencing mild to moderate pain, over the counter medications may be prescribed instead of stronger medications. For more severe pain, stronger treatments may be required.

ACUTE PAIN is pain that comes on suddenly and can be sharp or severe. It usually has a direct cause, like surgery or bone fractures. **CHRONIC PAIN** is ongoing and can last long after the immediate cause of the pain has gone away. Nerve pain, for example, is a form of chronic pain. **INTERMITTENT PAIN**, pain that comes and goes, can also be considered a chronic form of pain.



PAIN MANAGEMENT SOLUTIONS

Depending on the type and severity of your pain, there are many different solutions that can be used to help manage and reduce it. Pain medications are the most common forms of pain solutions and there are various different kinds. Any pain medication, including over the counter drugs, should always be discussed with and prescribed by your doctor before you begin taking them.



OVER-THE-COUNTER MEDICINES are common pain relievers that can be purchased at your local pharmacy without a prescription from your doctor. They can be used to treat mild to moderate forms of pain. Acetaminophen (Tylenol) is a popular over-the-counter medicine that is used to treat everyday aches and pains.



NONSTEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDs) are another common type of over-the-counter medicine used to treat mild pain and inflammation. Aspirin and ibuprofen are the most popular forms of over-the-counter NSAIDs. There are stronger doses of these drugs that can be prescribed by your doctor if your pain is more severe.



OPIOIDS are pain medications prescribed for more severe pain when over-the-counter medicines or prescription NSAIDs are no longer enough to control your pain. Your physician will prescribe a low dose and increase if needed. Opioids can cause their own set of side effects, like constipation, nausea and fatigue to name a few. Your doctor may try changing your dose or switch you to another opioid to reduce these side effects.

Opioids are very effective for relieving acute pain, but your body can build up a tolerance. In a similar way to your cancer growing resistant to your cancer treatment, your body can grow used to the dose of opioids you are taking. If this happens, your doctor may look at adjusting your dosage. It's important to note that this is not the same as having an addiction to opioids.





CANNABINOIDS are chemical compounds that are commonly found in cannabis. These cannabinoids, when ingested, activate cannabinoid receptors in the body through the central nervous system or the immune system. The two main cannabinoids in cannabis are delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD). THC is a psychoactive cannabinoid that produces the high people refer to when using cannabis. CBD does not produce the high that THC does.

Cannabinoids do not have to be smoked through cannabis; they can be ingested through oils taken by mouth or sprayed under the tongue. There are also cannabinoid drugs approved for use by Health Canada that can be prescribed by your doctor. Cannabinoids may help to relieve pain, as well as anxiety, nausea, and inflammation. They can also improve your appetite. If your doctor is not comfortable prescribing cannabinoids, they can refer you to another physician who can help you with this.



RADIATION can be used as another form of pain relief for metastatic breast cancer. Bone pain caused by bone metastases can be debilitating. Radiation to the area of the metastases can help to relieve your pain symptoms. **NERVE BLOCKS** are a form of local anesthetic that can also be used in some circumstances to block pain messages to the brain.

In addition to medical treatments to manage pain, complementary therapies can also help to reduce your pain. These can include acupuncture, massage and meditation. Read more about these complementary therapies in section two on treatment options.

Addressing and managing your pain early on can make a big difference in maintaining your quality of life.



OTHER BENEFITS OF PALLIATIVE CARE

Beyond pain management, palliative care can be helpful for treating other side effects of your cancer. Nausea, loss of appetite, fatigue, and loss of mobility are all side effects you may experience. Receiving treatments for these types of issues is also considered a form of palliative care. Physiotherapists, dieticians, and your doctors can help find ways to relieve these symptoms as well.

Support groups, social workers, grief counsellors and spiritual providers can help you address the emotional and spiritual effects your illness may have on your life and your family's lives. Seeking support and guidance early on for all aspects of your diagnosis can make a positive impact on your overall wellbeing.





SECTION 5
END-OF-LIFE CARE

CHOOSING WHEN TO END TREATMENT

There will come a time when you, your family and/or your healthcare team will decide to end your treatments and focus on your end-of-life care. Making this decision can be difficult on you and your family. Hospice palliative care will provide you with the same palliative options you have been receiving but with a focus on making you as comfortable as possible as you transition to end-of-life.

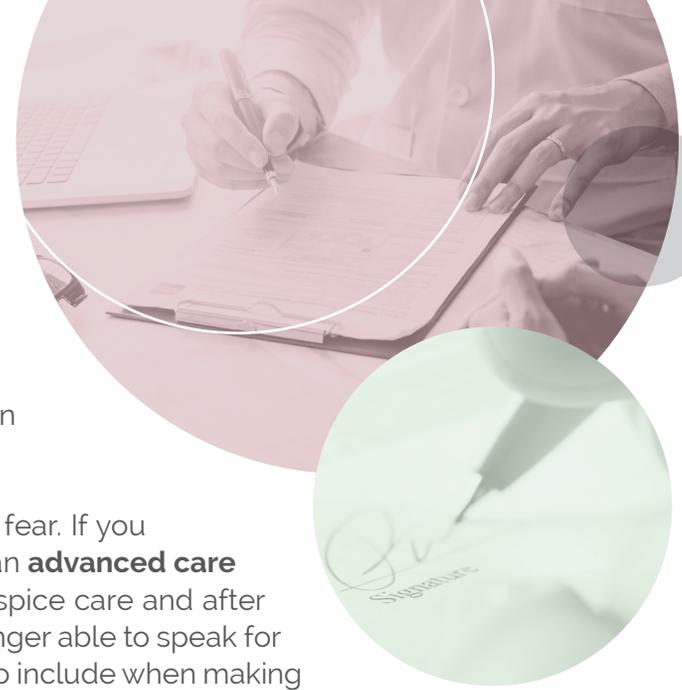
Preparing for your end-of-life care in advance may help relieve some anxiety and fear. If you have specific wishes for how your end-of-life care should be carried out, creating an **advanced care plan** can help your loved ones understand your wishes and needs during your hospice care and after your death. It can also allow you to have a say in these decisions once you are no longer able to speak for yourself. The following topics will explain the various considerations you may want to include when making an advance care plan. For additional help, visit www.advancecareplanning.ca.

WILLS AND POWER OF ATTORNEY

Preparing a will is an important responsibility at any point in your life. A **will** is a legal document that outlines instructions and wishes about how your family should handle your property, finances and belongings after death. It also names an **executor**, the person legally responsible for carrying out the terms of your will. A will is also important if you have young children or dependants as it would outline guardianship instructions.

Another important document related to will planning is a choosing your Substitute Decision Maker or Health Care Proxy. A **Substitute Decision Maker** is a person you have legally assigned to make decisions on your behalf if you become unable to make decisions yourself. This person can make decisions about your healthcare needs including treatment, hospice, and other end-of-life measures. A financial Power of Attorney is responsible for dealing with your finances, taxes and bills while you are alive.

The person who you choose to be your Power of Attorney should be someone you trust. It is important for a lawyer to prepare your will and Power of Attorney. It will also need to be witnessed and signed.



FUNERAL ARRANGEMENTS

If you have specific preferences about your funeral or want to relieve your loved ones from the responsibility of arranging the services, planning your funeral arrangements in advance may be helpful. You can choose to include as much or as little detail as you wish. Simply writing down some of your wishes and keeping them with your legal documents may be enough for you. Or, if you know specific locations for where you would like your service to take place, you can pre-arrange the details in advance with the establishments.

A funeral or memorial service can take place virtually anywhere. If your faith and religion is an integral part of you, the decision to plan a funeral based on those religious beliefs may be an easy choice. If you would prefer something less traditional, you can plan a memorial service or celebration of life any way that suits you. In addition to the type of service you would like, you'll need to consider the location of your service and whether you prefer cremation or burial.

Other details you may consider in your plan can include:

- Whether to have a viewing or wake
- Flowers
- Music
- Speakers
- Prayers, poems or other readings close to your heart
- Casket or urn
- Headstone
- Obituary
- Photos
- Location of your ashes or body

If you choose to use a funeral home to deliver your funeral service, the funeral director can assist with many of these decisions. They can also coordinate with religious establishments, cemeteries, florists, or newspapers and can coordinate the order of a death certificate. Funeral homes are able to accommodate based on many different types of mourning rituals, cultures and beliefs.

The costs associated with a funeral service are also an important consideration when making your plans. Many funeral homes offer pre-payment plans that can cover the basic costs of their services. Additional costs for casket, cremation or burial would need to be incorporated as well. Ask the funeral director in advance what the costs of their services include and what additional services they may offer. Choose a funeral home or establishment that has a good reputation and ask how your money will be used; what your family will still need to pay once it comes time for the funeral; what flexibility is available once you sign the contract; and what the cancellation or transfer fees are.

Once your plans are finalized, include the details of your plan and any receipts or contracts along with your legal documents. Make sure to explain your plans or wishes to your loved ones and give all instructions to the executor of your will.

FINANCIAL PLANNING

The business of assets, loans, insurance policies and taxes can be confusing and complicated after a person passes away. The first step in setting up a solid financial plan is to review your registered and non-registered savings accounts, loans, life insurance policies and pensions and assign a beneficiary where necessary. A **beneficiary** is a person you choose to inherit the asset or money after your death. Any taxes owing will have been paid out before the beneficiary inherits the asset.

If you have a spouse, he or she may be the clear choice for your beneficiary. Naming your spouse will also ease any taxes owed. Some people also choose to add their spouse's name to their bank accounts or property to ease the transfer of assets. Joint accounts or property will not go through probate but instead it will pass on automatically to the joint successor. Adding any name to accounts and property means that person will have equal access and ownership to the asset.

Fees and taxes owed after death may include probate, capital gains tax and income tax.

PROBATE is the legal process of validating your will. Probate fees vary by province so inquire about the fees where you live.

CAPITAL GAINS TAX is tax owed on half of any interest or profits you have made on your money or property.

INCOME TAX is money owed to the government on income you have acquired up to the date of death.

Any investments left to someone other than your spouse can be subject to probate fees and capital gains tax or income tax. These would be included on the final tax return your executor would need to file. A **clearance certificate** will then be issued by the Canada Revenue Agency before anything can be distributed to the beneficiaries.

Once you have made arrangements for your estate, prepare a list of all your financial accounts, properties and beneficiaries to be included with your will and funeral plans.



HOSPICE CARE

Choosing what type of hospice care you wish to receive is a personal choice, but it also depends on the availability of support services within your family and your community. Hospice care can take place at home, in a dedicated hospice facility or in a hospital.

A **home death** can sound very appealing because for many, there is no place like the feeling of home. You are in a place you that makes you feel comforted and it is easier to ensure you are surrounded by your family. Depending on where you live, local supports can help you stay at home as long as possible or right through to the end of your life. Some provinces offer home care programs that provide professional services. These programs vary and may or may not include costs of drugs or equipment. You can also inquire with your private insurance company to see what type of home hospice support they may cover.

Other considerations for staying at home include:

- Does your family to have the resources and availability to provide you with the care you need?
- Are there stairs or other obstacles that may make it difficult to move about your home?
- Is there room in your home for the additional equipment you may need like a hospital bed, monitors and pumps?

A **hospice or long-term care facility** is another avenue for end-of-life care. A dedicated hospice can provide 24-hour care to you and can coordinate with the funeral home for funeral preparations. Many hospices may require fees for the care they provide, while others may be run in part by charitable donations. Some provinces may also offer publicly funded hospice or long-term care facilities.

Any hospice care performed in a **hospital** is typically paid for by the provincial health plan and can cover drugs, supplies, nursing, personal support and equipment.



DYING WELL

Preparing for death can bring about many emotions including grief and fear. You may have many questions about what the final days of life might feel like. Will I feel pain? Will I understand what is going on? How long will it take to die? These are natural fears and questions to have about death and dying.

Pain at the end-of-life can be similar to the pain you felt earlier in your treatment, but it can also progress depending on where the cancer is. The same avenues for pain relief that you used before are available to you now. You can also choose to receive forms of **sedation** to make you feel more comfortable. In this scenario you will receive a drug that will ease you into sleep.

Confusion may also be a symptom for people who are nearing the end-of-life. This can be difficult for you as well as your family. In the final hours of life, sedation can also be used to help ease feelings of confusion or delirium.

Nearing the end-of-life you may notice a decline in your energy and abilities to perform certain tasks like moving or eating. This decline can be gradual and can last several weeks. When you start to have trouble staying awake or taking in fluids, this usually means the final stages of your life may be approaching. These final moments may last a few hours or days.

Making decisions in advance for how and where you hope to be in the final stages of life can ease your fears and anxieties. Bereavement services are also available for your family members through the hospice, hospital or cancer centre. For resources, information and support for end-of-life and palliative care visit the Canadian Virtual Hospice, www.virtualhospice.ca, and the Canadian Hospice Palliative Care Association, www.chpca.net.



RESOURCES

CANADIAN BREAST CANCER NETWORK (CBCN)

www.cbcn.ca

CBCN exists to ensure that patients are supported through information, education and advocacy. Our aim is to ensure that all Canadians diagnosed with breast cancer have access to the best care, regardless of where they live in Canada.

LIVING BEYOND BREAST CANCER (LBBC)

www.lbbc.org

LBBC provides programs and services to help people whose lives have been impacted by breast cancer. Their goal is to provide information, community and support that you can trust, is easy for you to access and respectful of you and your situation.

METASTATIC BREAST CANCER NETWORK (MBCN)

www.mbcn.org

MBCN is a national, patient-led organization that 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.

RETHINK BREAST CANCER

www.rethinkbreastcancer.com

Rethink's mission is to empower young people worldwide who are concerned about and affected by breast cancer through innovative education support and advocacy.



Canadian
Breast Cancer
Network