

mybreastcancercompass

Metastatic Breast Cancer Toolkit





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For more information, and to download
the Metastatic Breast Cancer Toolkit, visit

mybreastcancercompass.ca

Disease Management Guide





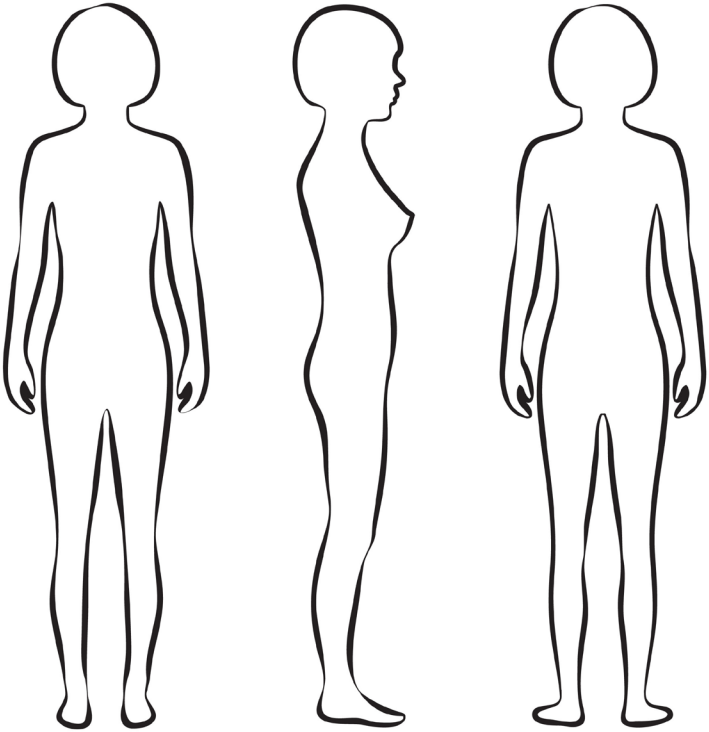
If you have been diagnosed with metastatic breast cancer, there is some important information you should capture. By filling out the following questions, this will help you understand your breast cancer diagnosis and treatment.

My cancer

Tumour Stage 4

Metastases

Places on my body where cancer has spread to: _____



Biomarker status

HER2: _____

Estrogen receptor: _____

Progesterone receptor: _____

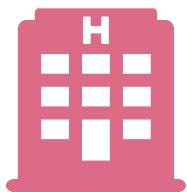
BRCA 1/2 mutation: _____

Doctor Diagram



Treating metastatic breast cancer may include one or more of the same treatments used in earlier stages. For metastatic cancer the goal is to control the disease for as long as possible and improve or maintain quality of life.

Your healthcare team will select the best treatment based on your type of cancer. Treatment can include hormone therapies, chemotherapies, targeted biological therapies, radiation, palliative care and surgical treatment. Another treatment option may be to participate in a cancer clinical trial where new cancer treatments are being studied.



Types of treatments

Hormone therapies (Endocrine therapies) – If your tumour is estrogen positive, then it may be treated with a hormone therapy, also known as endocrine therapy. This treatment blocks the estrogen signal to stop the tumour from growing.

Chemotherapy – Chemotherapy is the use of drugs to control cancer anywhere in the body. There are many types of chemotherapy used for breast cancer and your medical oncologist will determine if one is effective for your type. Chemotherapy is commonly delivered by intravenous injection (IV) or orally in pill form.

Targeted biological therapies – These treatments are designed to target specific cancer cells or other cells related to cancer growth. For example, when the tumour produces more than the normal amount of the HER2 protein, there are treatments that target that protein.

Radiation – Radiation uses high-energy rays to kill cancer cells.

Palliative (supportive) treatment – Palliative care specialists include doctors, nurses, social workers and others who can provide a combination of physical, emotional, social and spiritual care to help maintain well-being. This support can be provided over the course of months or years. Palliative therapy can include radiation, or medicines for pain, nausea, shortness of breath and other symptoms.

Surgical treatments – Your health care team will review and discuss surgical options. The choice for your surgery is yours and will depend on the type of breast cancer and your personal preferences.



Hormone therapy: _____

Details: _____

Chemotherapy: _____

Details: _____

Targeted biologic: _____

Details: _____

○ Radiation: _____

Details: _____

○ Palliative treatment: _____

Details: _____

○ Surgery type: _____

Details: _____



There will be ongoing tests conducted to monitor your health and response to treatment(s). These tests may include:

Blood test - This test can help determine how your body is responding to the treatment and that it is generally safe for ongoing treatment.

Chest x-ray - This x-ray checks the health of your lungs and look for any sign of lung disease.

Ultrasound - This test uses sound waves to produce pictures of your organs and other structures in your body.

Bone scan - This test is used for patients whose cancer shows a possible risk of spreading to the bones based on the stage of the cancer.

CT or CAT scan - This 3D scan can show if the cancer has spread to the liver, lungs, brain or bone. This test is used to examine the major organs and is helpful in measuring if treatment is working. It is commonly done at regular intervals during a course of treatment.

Magnetic Resonance Imaging (MRI) - This test uses magnetic forces and radio-frequency waves to make a 3D image of specific areas in the body (i.e. liver). It can be helpful in certain situations when results from a CT scan are uncertain or when a very close look at one area (i.e. the brain) would be helpful.

Positron Emission Tomography (PET) scan - PET scan is an imaging test that helps reveal how your tissues and organs are functioning.

Heart scan - You may have a heart scan, echocardiogram or MUGA scan, to determine the strength of your heart. This is only done if you are receiving meds that can affect your heart.

Tumour Markers CEA / CA15-3 - Some tumour markers can be used to determine the response of the cancer treatment. Your oncologist can decide if this is applicable for your diagnosis.



Clinical trials are research studies that test new treatments or approaches to determine if they are effective or provide better results than current methods.

Through clinical trials scientists, researchers and health care professionals are constantly looking for new ways to treat and prevent breast cancer. As a patient, you may want to ask about potential clinical trials available to you. The possible benefits and risks will be explained to ensure you can provide informed approval should you be eligible for a clinical trial and decide to proceed.

You can find out what clinical trials are currently available by speaking to your health care team or searching on-line via the links below.

www.canadiancancertrials.ca or
www.cancer.gov/clinicaltrials/search

Clinical Trials

I am eligible for: _____

Study details: _____

Questions: _____



Nutrition is an important part of staying healthy. Through proper nutrition and exercise you can keep your body strong and have more energy. If you're currently undergoing treatment for breast cancer or you've been treated for breast cancer in the past, eating well is especially important for you.

If you're going through treatment, you may feel tired more often. To help keep your energy level up, you'll need more calories and protein. People need to also ensure they are well hydrated.

Tips to help increase your calorie and protein intake:

- Eat smaller and more frequent snacks throughout the day.
- Eat every few hours.
- Drink high protein shakes.
- Increase your source of protein by adding fish, poultry, lean red meat, eggs, dairy products, nuts and nut butters, dried beans, peas, lentils and soy food to your diet.
- Add more carbohydrates and fats to your diet to help increase your calories. Foods high in calories include cheese, yogurt and whole milk.

Talk to a registered dietitian or another member of your health care team who can give you a proper nutrition plan as you go through your treatment.



The way you feel about spirituality and how it affects you is different for everyone. Spirituality can be defined as an awareness of something greater than the individual self, or an individual's sense of peace, purpose, connection to others and beliefs about the meaning of life.

A cancer diagnosis may impact how you feel about religion and spirituality. For some, long-held beliefs may be challenged, while for others a cancer experience can introduce new or stronger beliefs.

Spirituality can be expressed in many different ways, including through religion and prayer, reading spiritual books, meditating or connecting with members of a spiritual community. Research has not shown that spirituality can cure cancer, but may be a helpful addition to conventional medical treatment.

Talk to a member of your healthcare team if spirituality is important to you or if you'd like to explore the role it can play in your life.



Complementary therapies do not treat the cancer itself, they are used in addition to standard, conventional medical treatments.

Your health care team can discuss the possible benefits and / or any potential risks of complementary therapies with you.

Examples of complementary therapies include:

- Acupuncture
- Aromatherapy
- Guided imagery
- Hypnosis
- Massage therapy
- Meditation
- Tai chi
- Yoga

You can refer to the “[Your Health Care Team](#)” section in this kit or your hospital’s Resource Centre to determine who is best to ask about these potential complementary therapies.



I am considering: _____

Potential benefits: _____

Potential risks: _____

I am considering: _____

Potential benefits: _____

Potential risks: _____

I am considering: _____

Potential benefits: _____

Potential risks: _____

Your Health Care Team



Treating breast cancer involves a team of health care professionals, all working to develop a plan based on your specific disease type. When a group of health care professionals comes together as a team it is called taking a “multidisciplinary” approach. The combined knowledge and expertise of your health team aims to provide you with the best care. At any one time one of the specialists may be working with you more directly. This will happen when their specific area of treatment expertise is being delivered or recommended.

In the following pages you will find a description of some of your possible health care team members that may be involved in your care. Keep track of their names and contact details in the spaces below.

The titles of certain types of health care providers may vary by hospital. For example a cancer nurse may also be known as a pivot nurse or a clinic nurse. Some hospitals may also have specific roles for health care professionals that others may not have.



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This doctor works in treating cancer using something called systemic treatments (i.e. medications) that are delivered to the entire body such as chemotherapy, hormone therapy, biologic therapies and other medications. Medical oncologists are usually responsible for your overall care during the course of your treatment.

Types of questions to ask:

- Information about your type of breast cancer
- Treatment options relevant to your specific type of breast cancer (including chemotherapy, hormone treatment and biological treatment)
- The goal of the treatment and potential benefits and risks
- Schedule of planned therapy, frequency of treatment, duration and potential additional testing required
- How treatment works and how often do you need it
- Potential side effects and how to manage them
- Plan to make sure that the treatment is working
- Clinical trial options and eligibility

My medical oncologist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This doctor uses radiation therapy to manage cancer cells, shrink tumours and relieve certain symptoms (such as pain). Radiation uses high-energy x-rays targeted at the affected areas of your body.

Types of questions to ask:

- The goal of the radiation treatment
- What to expect before, during and after radiation
- How radiation works and how often to receive radiation
- What are the potential side effects
- Clinical trial options and eligibility

My radiation oncologist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This health care professional works with the radiation oncologist to plan and deliver your radiation treatment, and help manage the side effects.

Types of questions to ask:

- What to expect before, during and after radiation
- Potential side effects from radiation

My radiation therapist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



Also called an oncology surgeon, this doctor performs surgery to remove tumors and manage certain cancer-related symptoms. This professional uses special training in specific surgical techniques required for treating various cancers. Depending on where you are treated, your surgery may be performed by a surgical oncologist or a general surgeon.

Types of questions to ask:

- What to expect before, during and after the surgery
- The goal of the surgery
- Side effects and expected recovery from surgery
- Clinical trial options and eligibility

My surgical oncologist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This health care professional gives you medical and supportive care, including administering chemotherapy and helping manage symptoms. Your cancer nurse can answer many questions you might have on medical and practical issues.

Types of questions to ask:

- Where to find pamphlets or other materials about your disease and treatments
- Specific questions about treatment including what types of side effects to expect and how to manage them
- The coordination of care between your health team, including connecting you with other health care professionals

My cancer nurse: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This health care professional prepares and dispenses medications. Pharmacists understand how medications work with each other, and will explain how often and when to take your drugs. Your pharmacist will also share any special instructions such as taking medication with food or avoiding certain foods or supplements. He or she can also give you advice on side effects and how to manage them. If you have a pharmacist outside of the hospital make sure that they know about your diagnosis and treatment.

Types of questions to ask:

- Details about your medications including how much and when to take them
- How your medications work and interact with other drugs, food and supplements
- What types of side effects to expect and how to manage them

My pharmacist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This health care professional helps guide women and their families through the health care and cancer systems. Depending on where you live, this navigator may help coordinate care from different health care professionals, provide additional information and resources and counselling services. Some centres have navigators to help access funding for medication; they are called a drug navigator.

Types of questions to ask:

- How to navigate the health care or cancer system
- Information about drug funding, reimbursement and other expense coverage

My patient navigator: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This health care professional is an expert on nutrition and can help you make sure you are eating right. He or she can also recommend foods that are good for you when you are not feeling well.

Types of questions to ask:

- Foods and supplements to eat before, during and after treatment
- Managing nausea and loss of appetite

My registered dietitian: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____

Also known as a physical therapist, this health care professional helps maintain or restore strength. They do this through physical activities that focus on everyday movements to keep muscles strong and flexible. Physiotherapists may help in the treatment of lymphedema.

Types of questions to ask:

- Your physical well-being
- Pain or discomfort in your muscles or joints, when still or moving

My physiotherapist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



This health care professional supports and gives advice to patients and families in a number of ways. A social worker may provide referrals to support groups, explain financial assistance options, and provide other educational resources. They can also give counselling to help manage feelings of isolation or loneliness as well as counselling and support for your partner and children.

Types of questions to ask:

- Navigating the health care, cancer and social services systems, including filling out forms and applications
- How to talk about your health situation with your employer, family or friends
- Accessing financial assistance or employment health insurance
- Individual and group counselling
- Resources for home care or special equipment
- Support services, including peer support groups and organizations, home help, transportation services, etc.
- Referral to palliative hospice care
- Providing counsel and support for your partner and children



My social worker: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____

A psychologist / psychiatrist is a health professional that can help you and your family cope with the emotional impacts of cancer. Individual or group counselling may be offered. They can also provide support for your partner and children.

Types of questions to ask:

- Your emotional well-being
- Stress, emotions and feelings related to your cancer

My psychologist / psychiatrist: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



Palliative care specialists include doctors, nurses, social workers and others who have specialized training to give physical, emotional, social or spiritual care that focuses on maintaining a patient's well-being as much as possible. This support can be given over months or years. Palliative therapy can include radiation, or medicines for pain, nausea, shortness of breath and other symptoms. These treatments aim to relieve symptoms, and improve quality of life.

Types of questions to ask:

- Symptoms such as pain, nausea, shortness of breath or others
- Social or spiritual support
- Advanced planning

My palliative team: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



Your family doctor plays an important role in your general health and well-being. The family doctor is an important member of your health care team. He or she may provide further support and guidance on your treatment. If you are consulting your family doctor for issues that are not cancer-related, it is still important to inform them about your cancer treatments, as they can have different effects on your body and health.

Types of questions to ask:

- Any medical concerns outside of those related to your cancer treatment

My family doctor: _____

Contact Details

Email: _____

Phone number: _____

Address / office number: _____



Support groups and patient organizations are good places to find additional information and connect with others who are living through similar experiences. Groups and organizations may offer support in-person, over the phone or online for both you and your family.

In addition to support groups and patient organizations, check to see if your hospital has a resource library for more information.

Types of questions to ask:

- What information / resources are available for patients and caregivers
- What type of support is available and in what type of forum



Examples of organizations that can be good resources of support and information include:

Canadian Breast Cancer Network

www.cbcn.ca

1-800-685-8820 • cbcn@cbcn.ca

Canadian Cancer Society

www.cancer.ca

1-800-268-8874 • info@cis.cancer.ca

Rethink Breast Cancer

www.rethinkbreastcancer.com

416-920-0980 • hello@rethinkbreastcancer.com

Wellspring

www.wellspring.ca

1-877-499-9904

Appointment Tracker





Download and print more copies of the appointment tracker pages at www.mybreastcancercompass.ca/mbctoolkit

Date	Meeting With	Test Results	Discussion About Treatment & Next Steps	Questions For/ During My Appointment	Notes



Download and print more copies of the appointment tracker pages at www.mybreastcancercompass.ca/mbctoolkit

Date	Meeting With	Test Results	Discussion About Treatment & Next Steps	Questions For/ During My Appointment	Notes

Frequently Asked Questions





Metastatic breast cancer, also known as advanced or stage IV breast cancer, is when cancer cells spread from the original tumour in the breast to other parts of the body. The areas that the cancer cells spread to may include other lymph nodes, liver, lungs, bones and/or brain.

2. If the cancer has, for example, spread to my lungs — does that now mean I have lung cancer?



Metastatic breast cancer that started in the breast and spread to other parts of the body is still referred to as breast cancer. Your treatment will depend on where your cancer started.

Using this example, you would not have lung cancer — but rather breast cancer that has now spread to your lungs.



When treatments are given in this setting, the goal is to control the disease for as long as possible and improve and/or maintain quality of life.

Treatment of metastatic breast cancer can include chemotherapy, biologic therapies, hormone therapies, radiation and surgery. Treatments are based on several factors and may be used in combination of different treatments and supportive therapies. These factors can include; the type of breast cancer, the pace of tumour growth, symptoms from the breast cancer, your overall health as well as your preference of treatment.

Your health care team will develop a treatment plan that is best for you.

4. What is a clinical trial?



Clinical trials are research studies that test new treatments or approaches to determine if they are effective or provide better results than current methods.

You can find out what clinical trials are currently available by speaking to your health care team or searching on:

www.canadiancancertrials.ca or
www.cancer.gov/clinicaltrials/search

5. Will my cancer be cured?



Based on current knowledge, it is unlikely that metastatic breast cancer will be cured, though in some cases the disease can be controlled for years. Each woman and each cancer story can be unique. You will need to evaluate with your oncologist as treatments unfold. The goal will be to control the disease for as long as possible and improve or maintain your quality of life.



Some people may want to get a second opinion (another doctor's point of view) about their diagnosis or treatment. Although some women may find it hard to tell their doctor they'd like another opinion, most doctors are comfortable with this and can even help with a referral. If this is what you'd like to do, be honest with your doctor and tell them what you're looking for.

Having a second opinion may help you feel more confident with your treatment decision.

Ask your doctor to suggest other doctors you could consult and then get a referral from your doctor. Also ask for a copy of your medical records, test results and biopsy results to share with the other physician. Your doctor is part of your health care team and he/she contributes to your overall care.

7. Why am I being referred to palliative care?



Palliative care specialists include doctors, nurses, social workers and others who have specialized training to provide a combination of physical, emotional, social and spiritual care that focuses on maintaining and improving a patient's well-being. This support can be given over months or years.

Palliative therapy can include medicines for pain, nausea, shortness of breath and other symptoms. These treatments aim to relieve symptoms and improve quality of life. These specialists work alongside your oncology treatment team and provide another important layer of support and care.

8. What else can I do in addition to my treatment?



In addition to medical treatments like surgery, radiation, chemotherapy and other targeted treatments, a number of other therapies have helped patients manage symptoms and relieve stress. Acupuncture, aromatherapy, massage therapy, energy medicine and yoga are just a few of the things which have shown results.

It's important to discuss the possible benefits and risks of these types of complementary therapies with your health care team. Also, complementary therapy shouldn't be thought of as an alternative to conventional treatments, as complementary therapies do not treat the cancer itself.

You have a team of different health care professionals to support you. If you have a question or concern in between your appointments, you can contact your cancer nurse who can help direct your question to the right person. For example, if you have a question about treatment side effects, the pharmacist may have advice on how to manage it.

If you have a question about your treatment plan, the nurse or medical oncologist will be able to help. You can refer to the section in this kit called “Your Health Care Team” for a more detailed description of each member’s role.



The following organizations can be a good resource of information:

Canadian Breast Cancer Network

www.cbcn.ca

1-800-685-8820 • cbcn@cbcn.ca

Canadian Cancer Society

www.cancer.ca

1-800-268-8874 • info@cis.cancer.ca

Rethink Breast Cancer

www.rethinkbreastcancer.com

416-920-0980 • hello@rethinkbreastcancer.com

Wellspring

www.wellspring.ca

1-877-499-9904

10. Should I tell my family doctor or pharmacist about the treatment I receive for my breast cancer?



Most cancer clinics will send a summary of your visit to your family doctor. It is also important that you keep in touch and have regular medical follow ups with your family doctor so that they can address other health issues.

Make sure you keep your family doctor and pharmacists up to date about the treatment you receive for your breast cancer.









FPPO



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For more information, and to download the Metastatic Breast Cancer Toolkit,
please visit www.mybreastcancercompass.ca

If you require this information in an accessible format,
please contact Roche at 1-800-561-1759.

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