

Your Journey Starts Here

Living With Metastatic Breast Cancer







Metastatic Breast Cancer



Finding out that you have metastatic breast cancer is daunting. You will have questions, concerns, anxiety, and may feel uncertain about who you can turn to.

Why me?

What have I done wrong?

How do I tell my family and friends?

How long will I live?

Where can I get support?

What happens next?





Patient Journey



1 When you find a lump in your breast

Don't panic.

Most lumps are not breast cancer. It could also be something less serious. To be certain, check with your doctor/General Practitioner (GP).

4 Positive test results

If the lump is cancerous, tests will be done to determine the stage and type of your cancer. For this, your doctor/GP will send you to see an oncologist.

To find out more about the different types of cancer and stages, please check **Chapter 1: Understanding Metastatic Breast Cancer**

For more information on oncology services in Malaysia, please check **Oncology Services in Malaysia**

3 Negative test results

If your doctor/GP finds nothing abnormal but you are still worried that there might be something, it is a good idea to get a second opinion. This will give you peace of mind.

5 When you find out you have mBC

Knowledge is power: Educate yourself about your condition

Learning all you can about the specifics of your own cancer and how to best treat it, will help you to deal with the challenge you are going through. Educate yourself about your condition and familiarize yourself with the medical terms that you get confronted with.

Find out more in **Chapter 1: Understanding Metastatic Breast Cancer**

6 Plan your treatment

Plan your treatment together with your oncologist

Based on your test results and treatment preferences, you can decide on the most suitable treatment for you with your oncologist.

Find out more in **Chapter 3: Treatment Options**

2

During your doctor/GP's consultation

Your doctor/GP will ask you questions about:

- Your health
- Family medical history
- How and where you have discovered the lump

Your doctor/GP will examine the area of the lump, the armpit area as well as conduct a physical examination of other organ systems for:

- the size
- the texture and mobility
- any enlarged armpit lymph node

Additional tests might be necessary to learn more about the lump.

- Diagnostic Mammogram
- Breast ultrasound
- Breast magnetic resonance imaging (MRI) scan
- Biopsy

To find out more about the tests and procedures, please check **Chapter 2: Cancer Assessment (Diagnosis) – Test and Procedures**

7

Regular checks are important

Make sure that you go for regular checks of your treatment results. The results will indicate if the treatment is working. Each hospital visit is therefore important. Make the most of each visit.

To find out more about how to monitor your treatment and how to make the most out of each hospital appointment, please check **Chapter 4: Treatment Monitoring**^{1,2,3,4}

During all this time, make sure you live your life to the fullest! You can find tips for your body, mind and soul as well as your family and friends in chapters 6 and 7.



The fact is, a cancer diagnosis is frightening.

But knowing more about the disease makes it less fearful. And that involves educating ourselves about the diagnosis and understanding treatment paths from diagnosis to long-term survival.

While many people know about early stage breast cancer, it remains a challenge to find good information for women with mBC. The goals of this book are to help patients with mBC understand their disease, and to tell them about tests and treatments recommended by breast cancer experts in Malaysia.

We hope you find this mBC patient guidebook to be invaluable as you and your family navigate through your cancer journey.

*Although I stay
as positive as possible,
there is always the horrible doubt
of "what if" and "when".*

mBC patient,
from Secondary Breast Cancer Research, BCNA, 2014



This cancer
isn't going to
control me.



Cancer is not
a death sentence.

I can live a normal life
and
you can too.
One day at a time.



I am not afraid of cancer
because I believe in science.
Treatment for breast cancer
has advanced so much
over the years.

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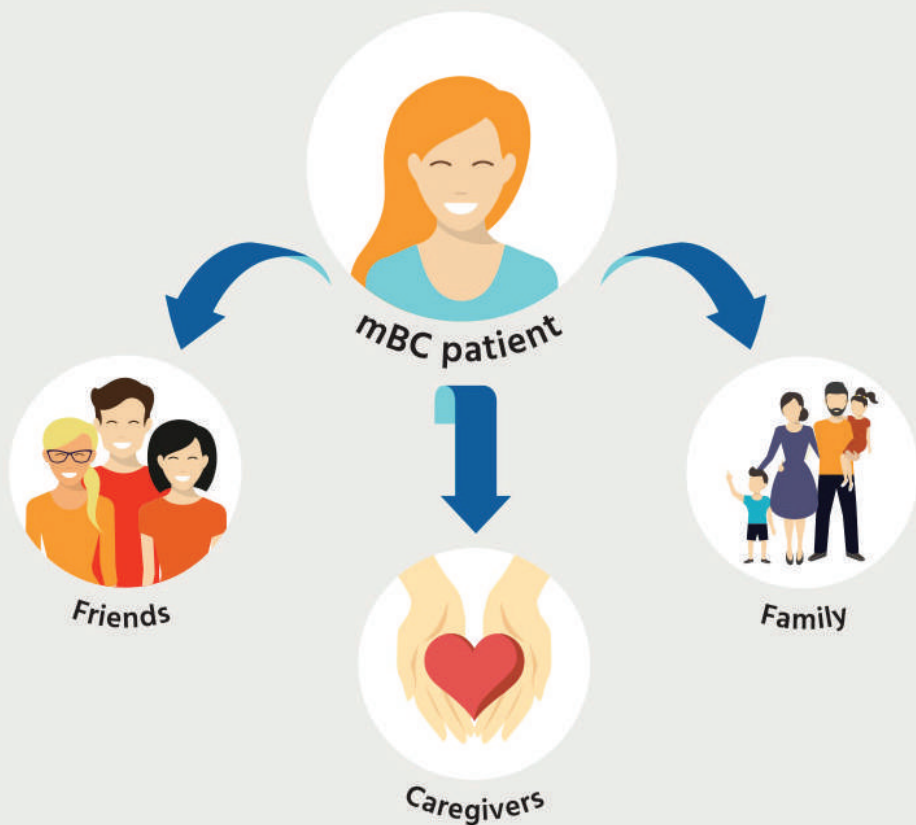


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This book is useful for:





Discuss and decide with doctor(s) the best care plan for you. You may also find it useful to create a list of questions to ask your doctors.

Many medical terms

Don't be discouraged as you come across unfamiliar medical words used to describe cancer, tests and treatments in books, and from your doctor or treatment team. Most of the information may be new to you, and there is a lot to learn.

Keep reading and don't be afraid to ask your doctor to explain a word or phrase that you do not understand as some phrases may be abbreviated e.g. mBC for metastatic breast cancer.



Does the whole book apply to me?

There is important information in this guidebook that is applicable to mBC patients in Malaysia for many situations. Hence, you will likely not get every test and treatment listed. The recommendations in this book include expert opinions and treatment options offered by oncologists, based on their experience and scientific facts. As every patient is different, these recommendations may not be right for you. Your doctors may suggest other tests or treatments based on your health and other factors. If your treatment team suggests other options, feel free to ask them why.



It changes
you forever.
But it can be
*a positive
change.*

- Jaclyn Smith -



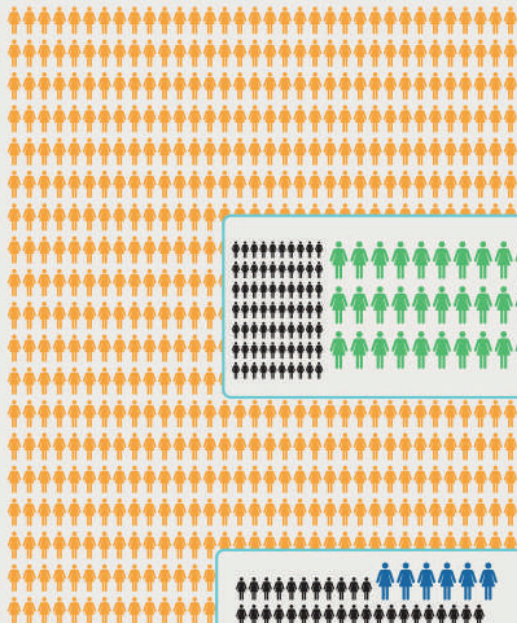
CHAPTER 1

**Understanding
Metastatic Breast Cancer**





Metastatic breast cancer is **the most advanced stage of breast cancer** and occurs when the disease spreads beyond the breast to other parts of the body.⁵



There are nearly **2.1 million** new cases of breast cancer diagnosed each year worldwide⁶

Up to **30%** of women diagnosed with and treated for early breast cancer will go on to **develop metastatic breast cancer**⁷

5% - 10% of women **present with primary metastatic disease** at initial diagnosis⁸

Initial diagnosis at a **more advanced stage** of the disease is associated with poorer prognosis and is more common in less developed than in developed countries⁹



(similar to countries outside APAC in General Population survey – range 45% - 80%)

The public in Asia Pacific has unrealistically high expectations of treatment success in breast cancer. Surveys showed that 4 in 10 believe that patients diagnosed and treated early will not progress to the mBC stage.¹⁰

FACT CHECK

20% - 30% of women will progress to mBC regardless of treatment or preventive measures¹¹

Note: Per country, across 8 APAC countries from both surveys (range 47% - 78%)

Globally, the number of deaths from breast cancer is anticipated to increase

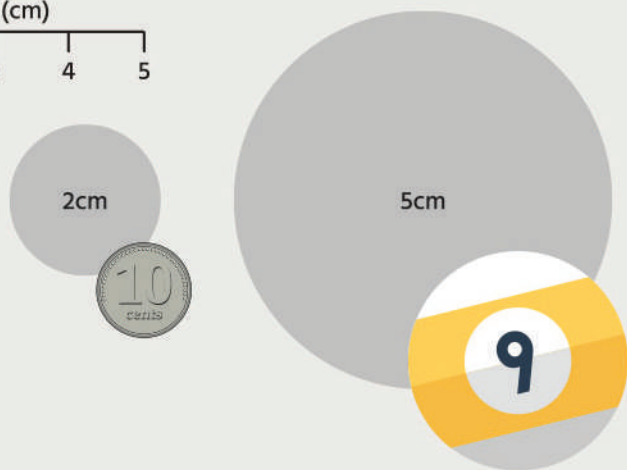
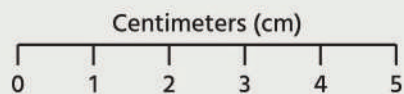
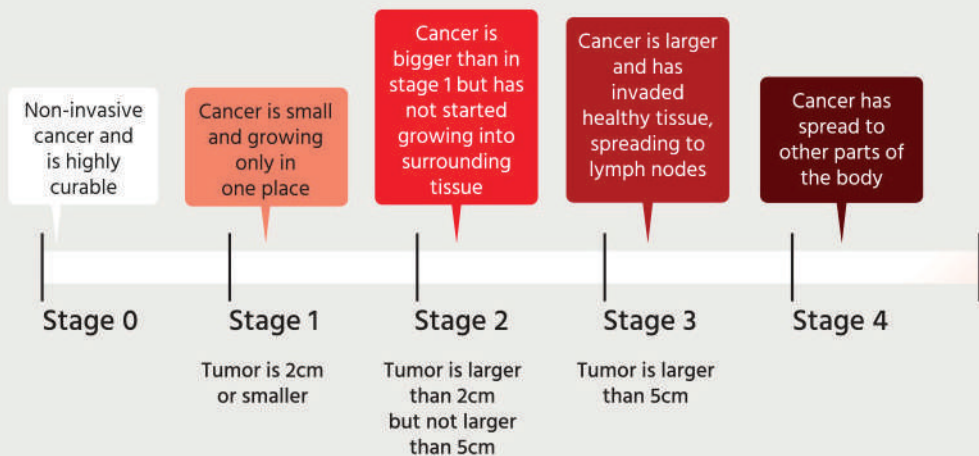


43%
from 2015
to 2030,

the majority of which are a result of metastatic disease.¹²

Cancer progression

Cancer stage describes how much cancer has grown and spread. Cancers are staged from Stage 0 to Stage 4.¹³ The importance of knowing the stage of your cancer helps the care team understand your prognosis (how the cancer is going to affect you) and determine the treatment that will be recommended.



For detailed description of breast cancer stage, please see next page.

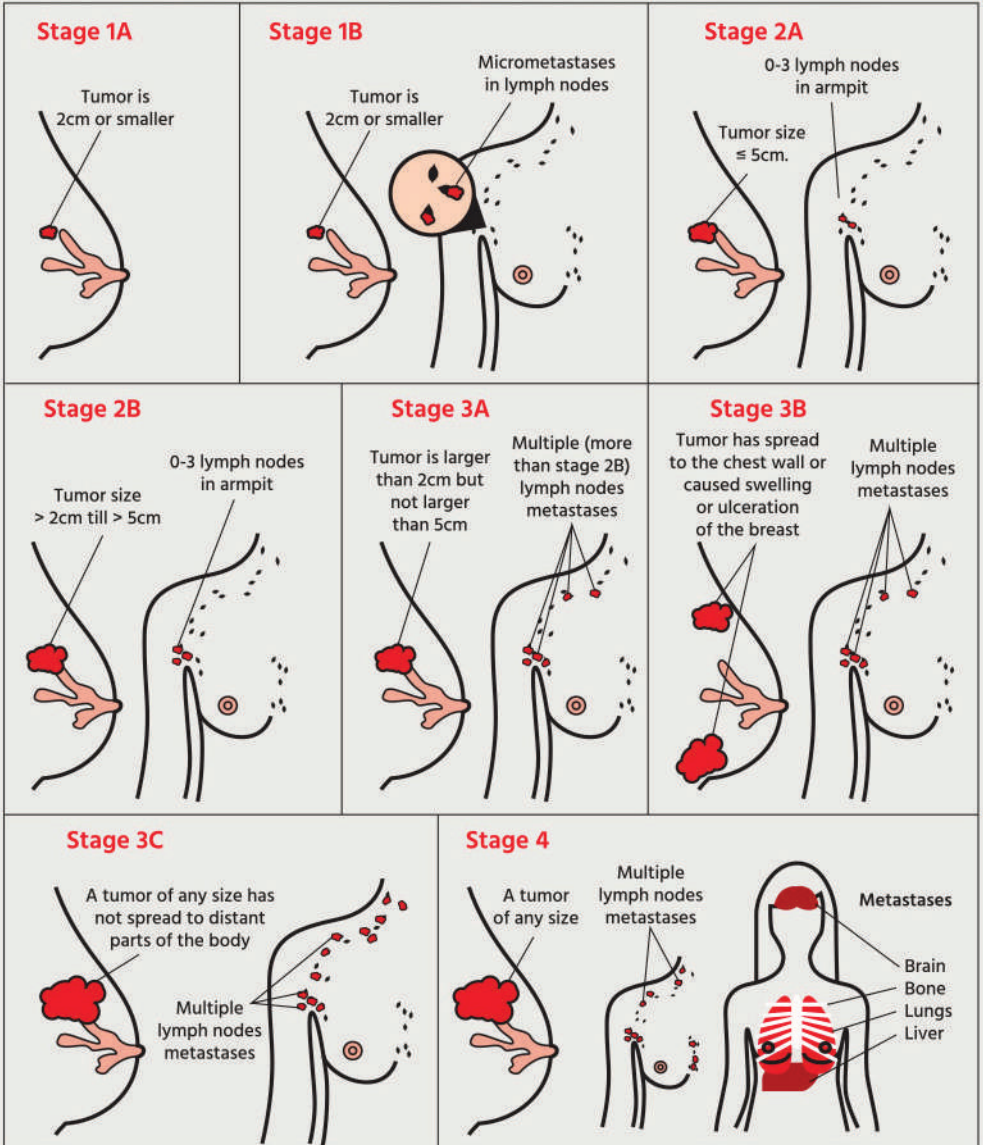
American Joint Committee on Cancer (AJCC) stages of breast cancer

The AJCC stages depict cancer progression from the initial tumor at primary site (Stage 1) through the formation of distant metastasis (Stage IV).

Stages are defined by three classifications:

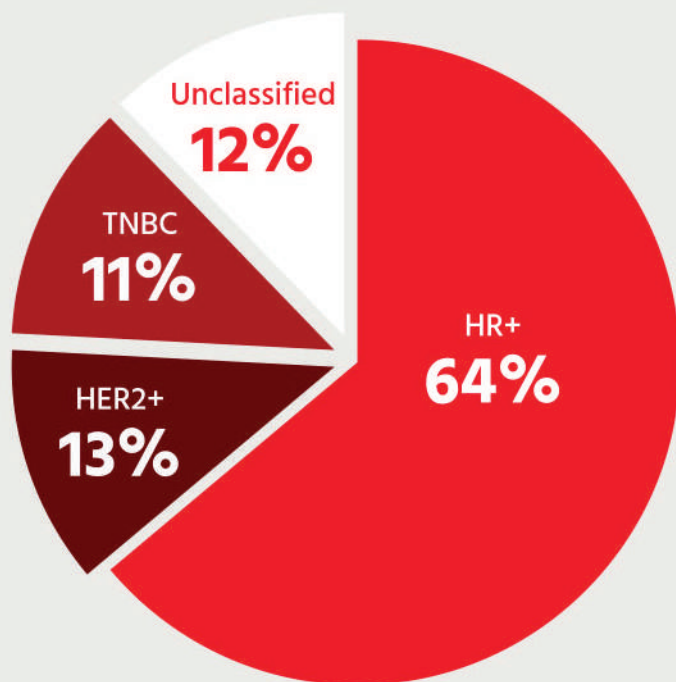
- Tumor (T)
- Lymph nodes (N)
- Metastasis (M)

The below diagram may only illustrate one subtype of staging of your cancer. Seek your oncologist's advice for more clarification.



Breast cancer can be categorized into 3 main subtypes

US Surveillance, Epidemiology and End Results Registry Data^{14, 15}



TNBC Triple-negative breast cancer (TNBC) means that the tumor is estrogen receptor-negative, progesterone receptor-negative and HER2 negative.

HER2+ Human Epidermal Growth Factor Receptor 2 (HER2+) breast cancer is a breast cancer that tests positive for a protein called human epidermal growth factor receptor 2 (HER2), which promotes the growth of cancer cells.

HR+ Hormone receptor positive (HR+) breast cancer means that the cancer cells grow in response to the hormone estrogen and/or progesterone.

Unclassified Unclassified breast cancer diagnosis.

Risk factors

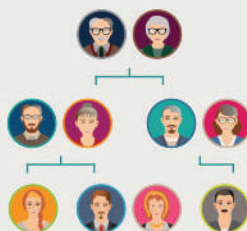
These are the risk factors affecting breast cancer, including metastatic disease¹⁶:



Age
(> 55 years old)



Previous breast cancer diagnosis



Family history



Genetic mutations
such as BRCA1
and BRCA2



Obesity



Alcohol consumption



Sedentary lifestyle



Starting period
before age 12



Menopause
after age 55



Hormone therapy
after menopause



You gain
**strength,
courage**

— & —

confidence

by every experience
in which you really
stop to look fear
in the face.

- Eleanor Roosevelt -

CHAPTER 2

Cancer assessment (diagnosis) – Tests and procedures

Before you start any treatment, your doctor will perform a series of tests. Here's what you can expect.



Physical examination



Blood tests



Imaging tests



Laboratory examination
(biopsied tissue)

Here are some information your doctor will need to know about you.

- Health history
- Medication
- Past treatments
- Relatives' health history (as breast cancer can run in families)
- If you are pregnant or planning to get pregnant



Physical examination

Here's what you can expect from your Clinical Breast Examination (CBE):

- You may be asked to sit, stand and/or lie down
- Your doctor will examine your breasts and lymph nodes for abnormalities
- Your doctor also will examine your lungs, heart and abdomen



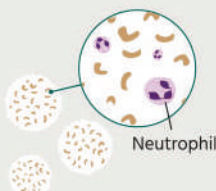
Blood tests

A Complete Blood Count (CBC) will be carried out to look for any abnormalities. CBC measures the number of white blood cells, red blood cells and platelets which have a different function in your body:



Red blood cells

Carry oxygen to your tissues



White blood cells

Fight infections



Platelets

Blood clotting

CBC test is an important measure because cancer and cancer treatments can affect the cells in your blood.

Neutrophil in your blood count is a type of germ-fighting white blood cell that is the first to travel to an infection site. Low neutrophil levels can put you at risk of serious infections.

Liver function tests will assess the liver functions. Renal function tests (RFT) will assess your kidney functions.

Imaging tests

Imaging tests provide detailed pictures of the insides of your body and show how far the cancer has spread. Some imaging test requires you to stop eating, drinking and taking certain medicines.

Computed tomography (CT)

You will be advised to fast a few hours before the test. A contrast dye is injected into your vein to improve the quality of the image but may cause flushes or hives. Tell your doctors if you have had bad reactions before. **During the scan, you will lie face up on a table that moves through the CT machine.**



Magnetic resonance imaging (MRI)

Your doctor may order an MRI if you have symptoms that suggest that cancer has spread to the brain or spine. A contrast dye may be used. The scan will take 20-45 minutes to complete.

Bone scan

To assess if the cancer has spread to your bones, a radiotracer will be injected into your vein. It gives off radiation which is detected by a camera that scans the bones while you lie still on a table. It takes about 3 hours for the radiotracer to enter your bones and another hour to scan. Hot spots that show an intense accumulation of radiotracer is an abnormality.

Your doctor may order other imaging tests such **positron emission tomography (PET) scans** or **X-rays** in addition to a CT or bone scan if results from other tests are unclear and have low visibility of cancers.



Laboratory examination

These tests are used to gather more information about your breast cancer so that your doctor can guide you towards a treatment plan that works.

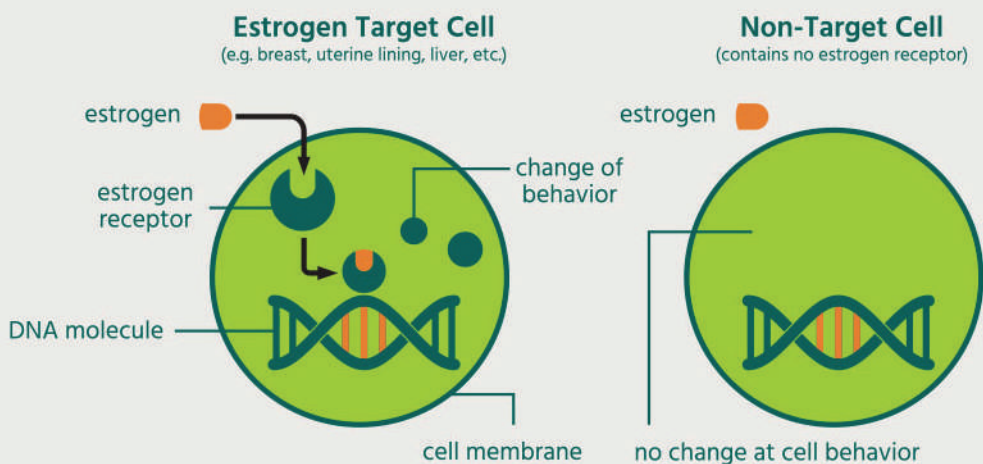


Biopsy

Biopsy is a method used to extract a small sample of tissue or fluid from your body for testing. Your doctor will perform this procedure to confirm if the distant site (other parts of the body) has cancer and to find out the type of cancer you have. If you have been treated for early stage breast cancer, your doctor may want another biopsy of your mBC.

Cancer cell tests

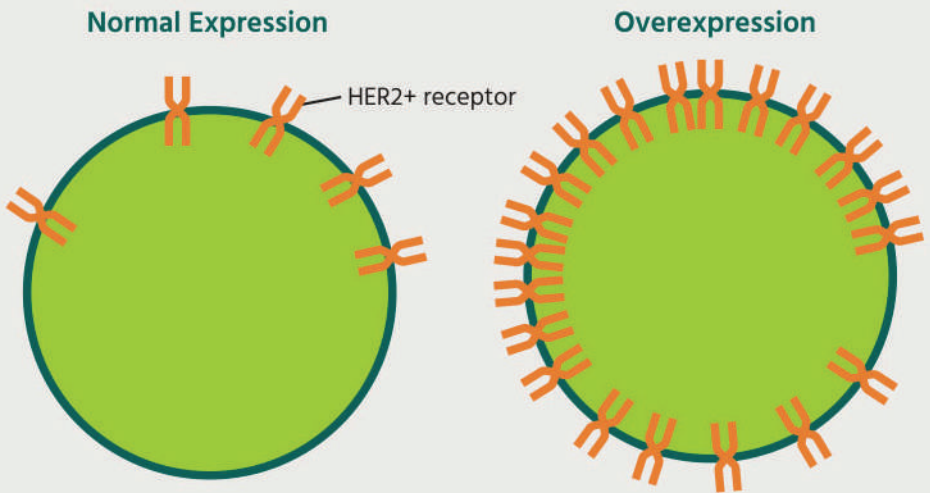
Breast cancer cells are not all alike. These cancer cells can differ by the type of receptors they have. A receptor is a protein found in the cell membrane or inside of cells. There are two hormone receptors: estrogen (ER) and progesterone (PR). Estrogen and progesterone are hormones that increase during puberty in girls, causing their breasts to grow. For some breast cancers, the cancer cells have a high number of hormone receptors.



Testing for hormone receptors is important because your cancer may be driven by this excess hormone and there are drugs that stop hormones from causing cancer growth. Immunohistochemistry (IHC), a lab test, is used to check if your cancer cells have hormone receptors. If at least 1 out of every 100 cancer cells stains positive, the cancer is called hormone receptor (HR)-positive. If cancer cells are lacking in hormone receptors, the cancer is called hormone receptor-negative.

HER2 receptor tests

Human epidermal growth factor receptor 2 (HER2) is found within the cell membrane. When HER2 is activated, it causes breast cancer cells to grow and divide. When breast cancers have cells with more than 2 copies of the HER2 gene, this will generate too many HER2 receptors, and subsequently breast cancer cells grow and divide fast. The cancer is called HER2 positive.





Triple positive breast cancer

ER+, PR+, HER2+



Triple negative breast cancer

ER-, PR-, HER2-



ER+, HER2-



ER-, HER2+

Always ask for a copy of your test results.



Hereditary breast cancer is often caused by mutations in BRCA1 and BRCA2 genes. The function of BRCA genes is to help prevent tumor growth by fixing damaged cells and helping cells grow normally. Genetic testing can tell if you have BRCA mutation. The likelihood of you having hereditary breast cancer will be assessed by your doctor using your age, medical history and family history.



CHAPTER 3

Treatment options



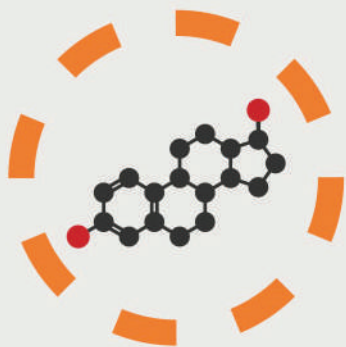
You learned that you have mBC. The next step is to plan a treatment based on test results, your treatment preferences and other factors. You should understand that cancer is a complex disease and may be treated with a combination of treatment options.



There are many ways to treat cancer. Some patients may only have one type of treatment and others will have more than one. Treatment selection is based on several factors such as characteristics of cancer cell, where the cancer has spread, past treatment, your symptoms and general well-being.

Treatment goal is to slow or stop cancer growth while relieving symptoms caused by cancer and improve quality of life. Summary of medicines available for use in Malaysia is listed in Appendix 1.

Types of treatment used to treat Metastatic Breast Cancer



Hormone therapy



Chemotherapy



Radiotherapy

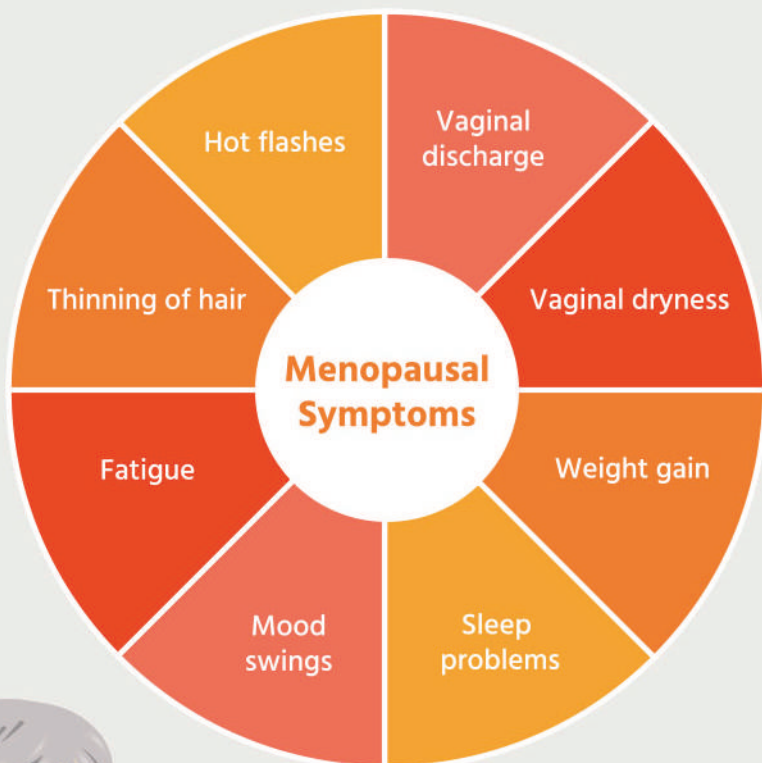


Targeted therapy

Hormone therapy

Estrogen and progesterone are hormones that cause some breast cancer cells to make more cancer cells. Estrogen is mostly made by ovaries and made in small amounts by the adrenal glands, liver and body fat. Progesterone is mostly made by the ovaries. Blocking these hormones from working or lowering hormone levels may help stop breast cancer cells from growing.

Hormone therapy may cause menopause-like symptoms. Menopausal symptoms include hot flashes, vaginal discharge or dryness, sleep problems, weight gain, thinning of hair, fatigue and changes in mood.



You may experience different symptoms from other women as everyone responds differently to treatments.

Antiestrogen



How it works:

Stops the effects of estrogen on cancer cell growth.



Drugs:

Tamoxifen and Fulvestrant



What to expect:

Antiestrogen treatment (taken orally in a pill format or given by intra-muscular injection) has few side effects, however menopausal symptoms are common in women who are on this treatment.

Aromatase inhibitor



How it works:

Blocks the protein that makes estrogen.



Drugs:

Anastrozole, Letrozole, and Exemestane (used in postmenopausal women only, as the drugs cannot stop the ovaries of premenopausal women from producing estrogen).



What to expect:

Aromatase inhibitors (taken orally in a pill format) can cause loss of bone density and may cause muscle or joint pain. Sometimes menopausal symptoms might also be felt.



Quick Fact

Ovarian ablation



What it is:

Ovarian ablation is a medical term used to describe different ways of stopping the ovaries from working. Ovarian ablation is only suitable if:

- you have not yet had menopause (you are pre-menopausal)
- you have estrogen receptor positive (ER positive) breast cancer.

This is because ER positive breast cancer is the type of cancer that responds to hormonal therapy treatment.



Quick Fact

There are 3 different ways to stop the ovaries from producing estrogen:

- surgery to remove the ovaries
- hormonal therapy to 'shut down' the ovaries (ovarian suppression)
- radiotherapy to stop the ovaries from working



How it works:

Surgery is when you undergo an operation to remove your ovaries, this is called an oophorectomy. Removing the ovaries produces an immediate and permanent menopause. **Hormonal therapies** use drugs that stop the brain from producing a hormone called luteinizing hormone which stimulates the ovaries to make estrogen. **Radiotherapy** means giving high energy x-rays and can be given to the ovaries to stop them working and producing oestrogen



What to expect:

For **surgery**, local or general anesthesia may be used. For **hormone therapy**, your doctor may give a monthly or 3-monthly injection (LHRH agonists drug) to cause a temporary menopause by suppressing the ovaries from producing estrogen. Estrogen levels usually drop within three weeks of starting treatment and remain like this as long as treatment continues. **Radiotherapy** can be received over a few days as an outpatient procedure. Some side effects from radiotherapy include diarrhea and feeling sick. Radiotherapy causes permanent menopause.

How to evaluate menopausal status

Postmenopausal – Age >60 or age <60 and no period for one year or had removal of ovaries.

Premenopausal – Still experiencing menstrual periods.

To confirm menopause, your blood will be tested for estrogen or follicle-stimulating hormone (FSH) levels.

If you have been taking LHRH agonists drug, it isn't possible to know your menopausal status until you are off the drugs for a while.

Chemotherapy



How it works:

Chemotherapy, given via **an infusion** or **orally**, kills cancer cells by damaging their DNA (deoxyribonucleic acid), disrupting the DNA-making process or interfering with cell parts that are needed for making new cells.

Discuss the potential side effects of chemotherapy with your doctor. Come up with a plan together so that you can manage the side effects better.



What to expect:

- You may be asked to stop other medication or supplements which can cause chemotherapy to not work well or may cause health problems while on chemotherapy.
- Your treatment may consist of one drug (single agent) or a mix of drugs (combination regimen), which will be given for a specific cycle i.e. 7 days, 21 days, or 28 days, followed by days of rest.
- Common side effects include low blood cell counts, lack of appetite, nausea, vomiting, diarrhea, hair loss and mouth sores.
- You may be given another drug to help you fight nausea and vomiting.
- Side effects of chemotherapy depend on the drug type, amount taken, length of treatment and the individual.

There are four categories of chemotherapy drugs used to treat mBC:

Categories	Generic drug name	Mechanism
Alkylating agents	Carboplatin, cisplatin, cyclophosphamide	Damage DNA by adding chemical to it
Anthracyclines	Doxorubicin, epirubicin	Damage and disrupt the making of DNA
Antimetabolites	Capecitabine, gemcitabine, fluorouracil, methotrexate	Prevent 'building blocks' of DNA from being used
Microtubule inhibitors	Docetaxel, emtansine, eribulin, ixabepilone, paclitaxel, virorelbine	Stop a cell from dividing into two cells

Radiotherapy



What it is:

It uses high energy x-rays to destroy cancer cells. This can be given to troublesome metastatic sites such as bone or brain metastases.



How it works:

Usually treatments are given daily for 5 minutes each day over 1-5 weeks.



What to expect:

You may experience skin irritation, tiredness, aches and swelling on the treatment area.



Targeted therapy



How it works:

Targets and kills specific proteins or markers that help cancer cells to grow, leaving healthy cells alone.



Drugs:

Subtype	Generic drugs name
HER2+	Trastuzumab Lapatinib Pertuzumab Ado-trastuzumab emtansine
HER2-	Bevacizumab
HR+ / HER2-	Everolimus Palbociclib Ribociclib
	Abemaciclib

Note: Some of these treatments may be used in combination with another therapy.



What to expect:

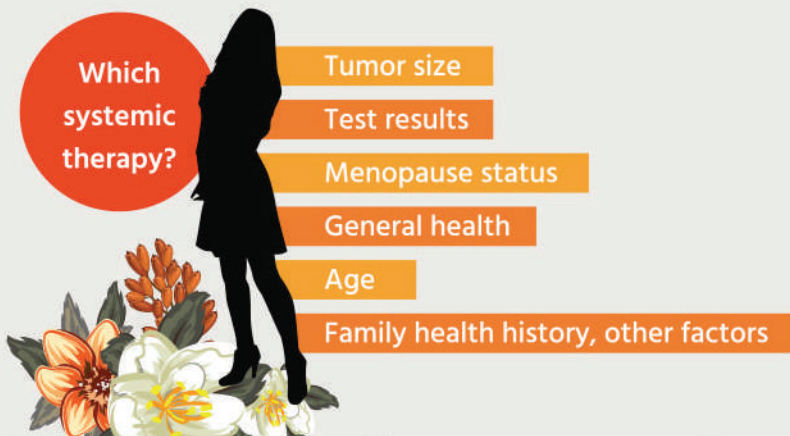
Your doctor will prescribe a targeted therapy that is suited to your specific diagnosis. Most targeted therapies used in mBC can be given orally or by needle, and have various side effects depending on the treatment.

Treatment guide

Choosing the right therapy for you

Note: The following section is for HR+ patients.

The type of systemic therapy first used is critical and is based on many factors.



If you are hormone receptor-positive

hormone therapy often works well alone or in combination with targeted therapy.

If cancer is spreading quickly within internal organs such as liver or lungs

chemotherapy is used to quickly control the cancer growth, followed by hormone therapy.

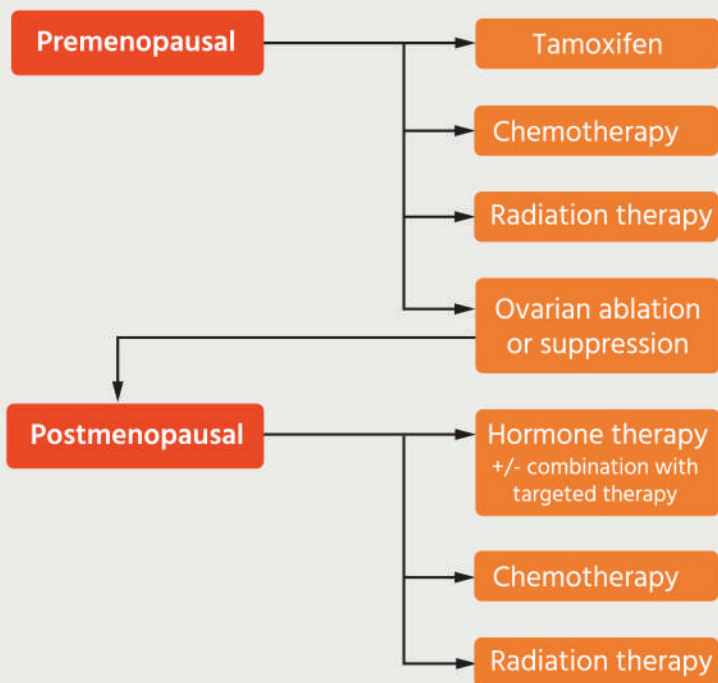
If you are postmenopausal, and have not had hormone therapy in the past year

an aromatase inhibitor +/- combination with targeted therapy is often given.

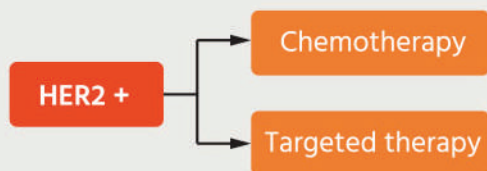
If you have taken hormone therapy in the past year

the next hormone therapy +/- combination with targeted therapy you will take depends on what you took before.

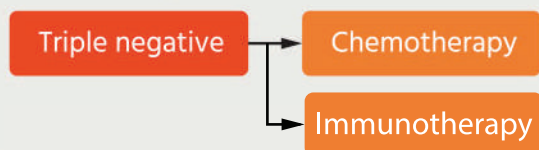
Treatment option based on menopausal status



Treatment option based on HER2+



Treatment option for TNBC



Palliative care or best supportive care may be your best option if you refuse treatment or are deemed unsuitable for active treatment. This supportive care is used to relieve symptoms from the cancer or treatments and does not treat the cancer.

What should you ask your doctor?



Ask your doctor as much as you can. No question is too small or silly. It is important to make use of your doctor's knowledge and remember – **you have the right to know! Don't be afraid to ask.**

Here are some questions suggested by the National Comprehensive Cancer Network¹⁷ and American Cancer Society¹⁸ which you can consider asking your doctor. Write down the answers given by your doctor for easy reference.

Questions about mBC

1. What is metastatic breast cancer? What does 'metastatic' mean?
2. Why wasn't my metastatic breast cancer found sooner?
3. What are tumor markers?
4. What is the difference between advance breast cancer and metastatic breast cancer?
5. Where in the body does breast cancer usually spread?
6. What does it mean that mBC is not curable?
7. If it can't be cured, what is the goal of treatment?
8. What treatments are available for mBC patients?
9. What are the factors that determine how long I will live?
10. How rapidly is my cancer growing?

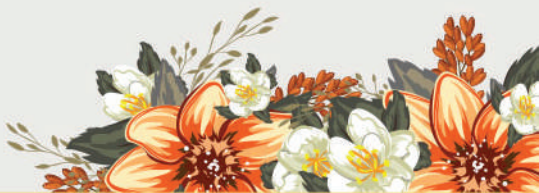


Questions about tests

1. What are my available test options?
2. What tests do you recommend, and why do you think it's best for me?
3. What is the process of the test? How long will it take and what can I expect?
4. When will the results be ready and who is going to explain the results and next steps to me? Can I have a copy of the results?
5. Should I bring someone to accompany me for these tests?

Questions about treatment

1. What are my available options of treatment?
2. What are the treatments you recommend, and why do you think it's best for me?
3. What are the benefits and effectiveness of this treatment? What are the risks?
4. Can you explain to me the process of this treatment?
5. How soon do I need to begin the treatment and where will it take place?
6. How much will the treatment cost?
7. What are the side effects that this treatment might have? What can we do to address the side effects?
8. How will this treatment affect my daily activities?
9. Would it help for me to get a second opinion? Can you point me somewhere that I can get a second opinion before I begin with the treatment?
10. Are there any other treatment options like clinical trials, for example, that I can consider?



Bring someone you trust to accompany you to your doctor. They can encourage you to talk openly with your doctor about your condition and feelings.



Quick Fact¹⁹

In evaluating treatments, the majority of patients (63%) from a study of 282 US mBC patients indicated they preferred treatments with a longer disease control, which they associated with:





CHAPTER 4
Treatment monitoring

Once you are diagnosed with breast cancer, tests will be performed during and after treatment to monitor how well your therapies are working and if they are causing any side effects.

Performance status scales are used to measure the state of your general health. One of the scales used is from the Eastern Cooperative Oncology Group (ECOG).²⁰

GRADE



ECOG PERFORMANCE STATUS

Fully active, able to carry on all pre-disease performance without restriction



Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work



Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours



Capable of only limited self-care; confined to bed or chair more than 50% of waking hours



Completely disabled; cannot carry on any self-care; totally confined to bed or chair



Quick Fact

During follow-up visit, blood samples will be drawn to perform these tests.



ROUTINE BLOOD INVESTIGATION

- Side effects monitoring
- Assess liver function, kidney function, bone marrow function



TUMOR MARKERS

- Although not routine, any available raised marker may be used to monitor treatment progress

Imaging tests may be used to check treatment results as CT, PET-CT and bone scans can show tumor shrinking or growing larger, and detect new areas of cancer.



Make the most of your hospital visit – here's a guide to help you with what to prepare and what to expect.²¹



Before your appointment:

Make a list of all medicines you are taking. If you're not sure of the name of your medicines, you can bring the items to show the doctor.

- Vitamins
- Lotions
- Supplements
- Herbs/Traditional medicines

Take note of any abnormal symptoms and tell your doctor if you feel unwell.

On the day of your appointment:

- Inform the nurse when you arrive.
- Your height and weight will be measured before you are led to the examination room where you may have to change into a hospital gown.
- Blood may be tested to determine if you are fit for treatment.
- You will be asked a series of questions by the medical team.
- They may examine the area of your body where the tumor is located.
- Your medical team may want to talk to you about your treatment plan. Don't feel rushed – take the time you need to understand as much as you can and tell the doctor if you need more time to talk.
- Remember to ask about your next appointment before you leave.





CHAPTER 5

Treatment decisions



Now that you've learned more about mBC and its tests and treatments, you'll have to decide if you want to go along with your doctor's treatment plan or seek another opinion.

Get a treatment plan, the roadmap for your journey

A treatment plan is a written course of action through treatment and beyond. This plan addresses all cancer care needs while respecting your beliefs, wishes and values. Parts of the plan will change and expand as you go through treatment.



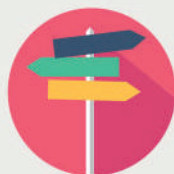
Cancer
information



Cancer
treatment



Stress and
symptom control



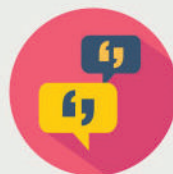
Decide your role



Advanced care



Treatment team



Get 2nd opinion

Factors in treatment planning

In planning your treatment, you will be making decisions based on:



Location of
the hospital



Public or
private hospital



Your feelings
about side effects



Treatment
side effects



Your general
health



Changes to
your life

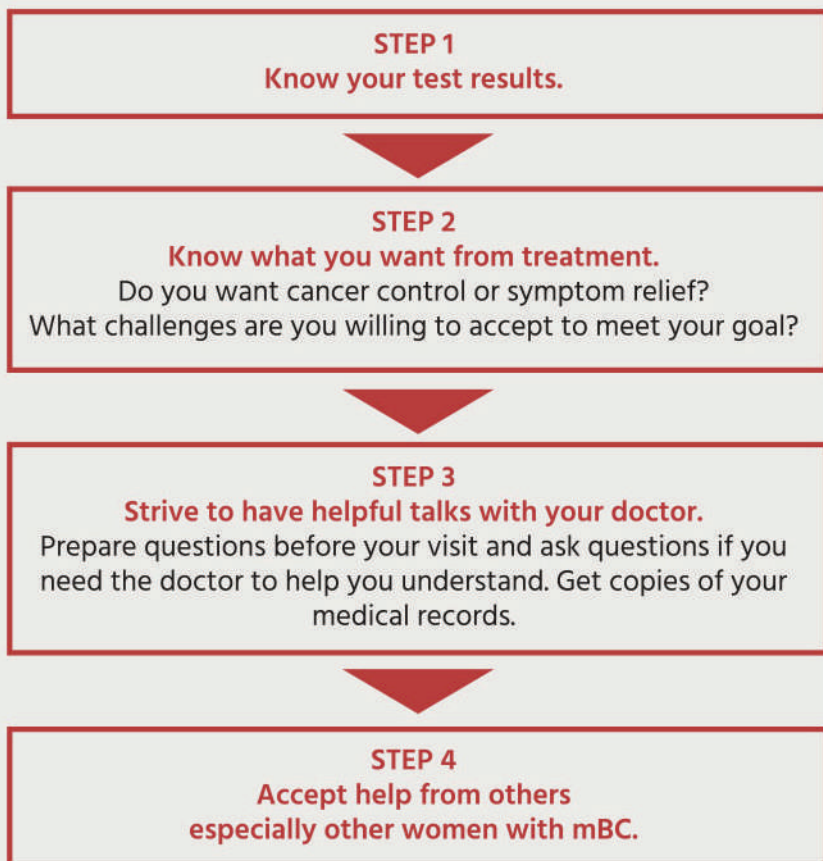


What you want
from the treatment



Costs of
treatment

Here are four steps to shared decision making:



What's your role in decision making for treatment planning?

Some women may want to know everything and share decision making with their doctors while others want to be involved as little as possible.



Palliative care/Best supportive care

When cancer can't be cured, a care plan for the end of life can be made. Most time, such talks often happen too late or not at all. Your doctor may delay these talks for fear that you may lose hope, become depressed or have shorter survival. These fears are strong but there are many benefits to advanced care which is useful for:

- Setting expectations
- Making the most of your time
- Lowering stress of caregivers
- Having your wishes followed
- Having a better quality of life
- Getting good care
- Hospice care

Palliative care is specialized medical care that is focused on providing relief from the symptoms of a serious life-threatening disease. The goal is not to cure but to improve the quality of life of the patient.



Quick Fact

In the Breast Cancer Center Survey by Pfizer in 2015, it was found that 568 mBC patients identified needs that went beyond medical treatment. This highlights the different considerations that patients had while they were on their treatment process.

Breast Cancer Center Survey, Pfizer 2015.

- **72%** placed importance on the quality of life, focusing on pain control/management, nutritional intake and managing their symptoms.
- **79%** needed emotional/psychosocial, family and social support as well as the availability of caregivers and physicians.
- **32%** saw a need in the management of mBC with more effective and alternative treatment options.
- **31%** identified their needs as financial in nature.

Funding sources in Malaysia²²

Knowing your funding options in Malaysia will help you make an informed decision about your treatment provider.



Government General Revenue



SOCSSO & EPF



Employers





Personal



Insurance





CHAPTER 6
**Living your life
to the fullest**



Health and nutritional tips

The following nutritional tips can help your body to remain strong, deal with side effects and fight infections:



Have a healthy, balanced diet that includes bread, grains, fruits, vegetables and dairy. Make sure your food is low in saturated trans fats, sugar and sodium.^{23, 24}



Eat more high-protein foods to keep your body strong and help it to deal with side effects.^{23, 25}



Listen to your body's needs and respond to it. There will be days when you feel like eating, and some days when you don't. Sometimes only certain things will taste good to you. Adapt and listen to what your body tells you. Try eating five to six small meals throughout the day, instead of three bigger ones. This will give you enough energy during the day.^{23, 26}

Loving yourself is so important.

While going through treatment, pay extra care to your diet and nutrition. Nourish your body with food that is good for you to help you in your treatment and/or healing process.



Staying active and positive during your journey

Your cancer treatments will exhaust you physically, mentally and emotionally – which is why you need to live well, an important part of getting and staying well.



Be physically active. Physical activity has a positive impact on your mental and emotional health. It also helps your body to deal with your treatment. Take a walk. Go outside. Join some friends for some light exercise.



Avoid tobacco smoke and recreational drug use. If you drink alcohol, try to limit it to one drink or so per day to minimise the depressant effect of alcohol.



Keep your stress level down. A positive state of mind is important for your well-being.



Indulge in what you like. Pleasure can be a powerful tool for health and well-being.

Get enough rest.²⁷

You'll have good days, and bad days. Days when you just want to hide from the rest of the world.

But that's okay.

Because you will need that time to recharge your body, mind and spirit.

Go ahead and read your favourite book. Write a letter. Watch TV. Or just dream. It will go a long way in helping you stay strong and positive.



Psychosocial support

It's normal to be overcome by anxiety and depression during your journey with mBC. Talk to your treatment team and get the help you need. Here are some useful tips that could help you to manage stress, anxiety, fear and feelings of helplessness.



Meditate or seek training in relaxation and stress management.



Exercise. Consider a jog/run or swim to alleviate the stress and improve your mood.



Find and attend support groups.

Social support in a group setting often helps minimize the feeling of loneliness and sadness.



Consider counseling or therapy.

Seeking guidance from professionals may help alleviate the mental pressure.



Consult a doctor. Should you go through an extra stressful situation and feel anxiety or depression taking control over your mind, a trip to your doctor should be considered.²⁷

Caring for your caregiver

Your caregiver provides the best possible care for you, to make sure you can live your life to the fullest, despite your diagnosis. Sometimes it's easy to forget that caregivers need to be taken care of too.

Give your caregiver a hug for the exceptional support you are being given.



Have open, honest conversations with your caregiver and build a better relationship with the one who is selflessly taking care of you. Share your thoughts, fears, happiness, needs and wishes.

Support your caregiver and let him/her know how much you value his/her presence in your life. Go the extra mile to lighten the load or lend a hand so that he/she has time for his/her own interests.

Stay connected with friends and family

Social interactions with friends and family are very important. Keeping in touch with your friends affects your overall health and your emotional well-being.

Don't lock yourself at home. Avoid keeping yourself at home and limiting social interactions. Plan activities with loved ones and friends. It will help you to lead a normal life.

Live for the moment. Those who live for the moment, learn new ways of enjoying their lives. This mindset helps them to reduce their emotional burden.²⁸

The importance of external support groups in your life

Know that you are not alone in this challenging journey. When you reach out and connect to other mBC patients for emotional support, you'll be talking to someone who knows what you're going through. And that will help you cope better.

- **Breast Cancer Support Groups** exist both through regular meetings, by phone and online.
- **Get involved** in the breast cancer community and join their activities. They regularly organize fun and interesting activities.

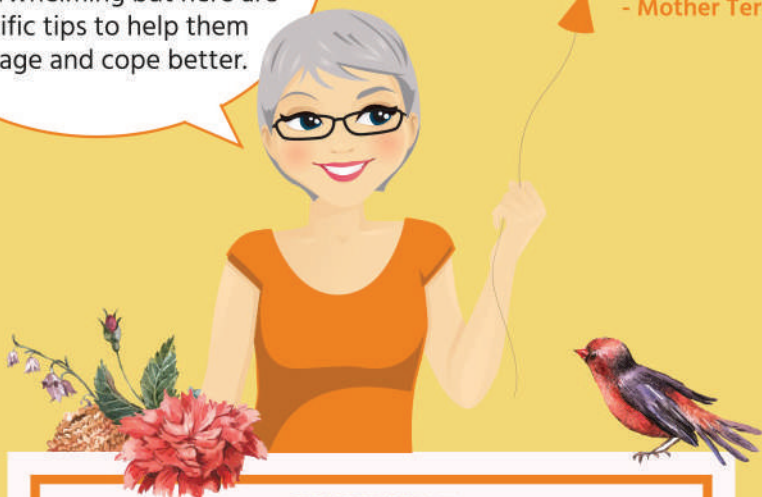


It is not
how much
you do, but

This section is for caregivers, friends and family; people who are crucial to your well-being. Being a part of your network of support can sometimes be overwhelming but here are specific tips to help them manage and cope better.

how much
love
you put
in the doing.

- Mother Teresa -



CHAPTER 7
Helpful tips
for family and friends

A letter to caregivers



Dear Husband/Partner, Son, Daughter, Sister, Brother, Friend,

As you walk alongside your loved one while she faces the greatest challenge in her life, you will find your lives intertwined in a special partnership that are experienced by a rare few.

You're not just her caregiver. You're also her cheerleader, companion, a shoulder to cry on, health aide, housekeeper, financial manager, personal assistant and more. And each role you play is indispensable in your loved one's life.

We hope you find strength in the next few pages as we share some helpful tips and insights that will help you find a sense of meaning and pride as you embrace your role as caregiver to your loved one.

Warm wishes from

Hope



How to be an effective caregiver



Communicate with each other²⁹

Good communication allows you and your loved one to understand each other's needs, and deal better with conflict.

- **Help** her to live as normal a life as possible.
- **Encourage** her to share her feelings, thoughts and concerns. Sometimes, she might not want to talk about it, because she feels afraid or does not want to sound like she is complaining. Get a journal for her to jot down her thoughts so she can share with you when she feels comfortable to do so.
- **Reassure** her that she can reach out to you at any time.
- **Respect** each other's time and personal space. Cancer treatment can last from months to years²⁹ and both of you will get physically and mentally exhausted.



Take care of yourself, so you can take care of your loved ones

Caring for someone with mBC will take up much of your time, energy and finances. But you can manage it better when you:

- **Make time for yourself** and continue doing what you love to do to avoid burnout.
- **Learn to recognize the signs of stress** and get help from others.

If you feel good about yourself, you will be able to give quality care to your loved one.²⁹



Get ready to be part of the medical team

As her caregiver, you will be working closely with the medical team and supporting your loved one in taking drugs, managing side effects and reporting problems to the cancer care team.

You may also get involved in health decisions³⁰ as you have to keep track of prescriptions, keep the doctor informed and do all the paper work to make sure she gets the best treatment and care possible.

- **Know how to reach your medical team at all times**, including after office hours, during weekends and holidays.²⁹
- **Recognize and manage symptoms** so that you know what to do and when it is time to inform the medical team.



Maintaining intimacy with your partner

While intimacy and sex are important to every couple, they may be affected by your partner's diagnosis and treatment.

Your partner might feel less attractive as treatments might lead to weight loss and hair loss. In some cases, she will need an operation which will lead to scars or changes to her skin which may affect the way she feels about herself.²⁹

Help her by making her feel good about herself. Tell her how beautiful she is no matter the physical changes she is going through.

- **Talk about** your feelings and concerns.
- **Don't force** intimacy if you feel she is not ready for it.
- **Avoid sex** if her white blood count is low or she will risk getting an infection.
- **Enjoy other forms of closeness/intimacy** such as holding hands, hugging and kissing.
- **Be assured** that you cannot get cancer from your partner.²⁹



Text to show you care

What do you say to someone who has just been diagnosed with cancer? Talking can be awkward and most of the time, we find it difficult to express our concern.

Texting a message is one way to encourage a loved one who is going through an mBC journey. A simple text message or short email may remind them that they are in your thoughts.

It can motivate her. It may inspire her. It might make her laugh. And she can read your text messages again on days when she really needs to boost her spirit.

Here are some text messages for you to use but personalize them to be relevant to your loved one.³¹

I don't know what to say, but please know I'm always here for you.

Just wanted to let you know I'm thinking about you today.

You have always been there for me when I needed help; I am going to be here for you just like you've always supported me.

I hate that you are going through this. I am always here to listen if you want to talk.

I made dinner for your family. When can I drop it off?

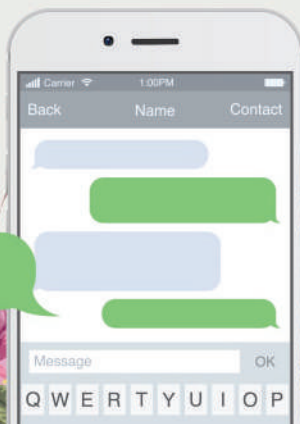
I'm heading to the market. Is there anything I can get for you and your family?

I found an online support group for cancer patients and their loved ones. Would you like to attend the next session with me?

I just found this great new bakery and bought cupcakes for us. Can I stop by to share them with you?

I'm only a phone call away.

I love you.



Resources



Websites

American Cancer Society (ACS)

www.cancer.org

Cancer.Net

www.cancer.net

WebMD.com

www.webmd.com/breast-cancer

Metastatic Breast Cancer Network

www.mbcn.org

Cancer Care

www.cancercare.org

Patient Resource

www.patientresource.com/Metastatic_Breast_Caregiving.aspx

mBC Info Center

www.mbcinfocenter.com/metastatic-breast-cancer-support

Living Beyond Breast Cancer

www.lbbc.org/news-opinion/help-helpers-why-caregivers-need-self-care

Health Line

www.healthline.com/health/breast-cancer/stage-iv-taking-care-loved-one#1

Canadian Cancer Society

www.cancer.ca/en/cancer-information/cancer-type/breast/breast-cancer

Breast Cancer.Org

www.breastcancer.org/symptoms/types/recur_metast/treat_metast

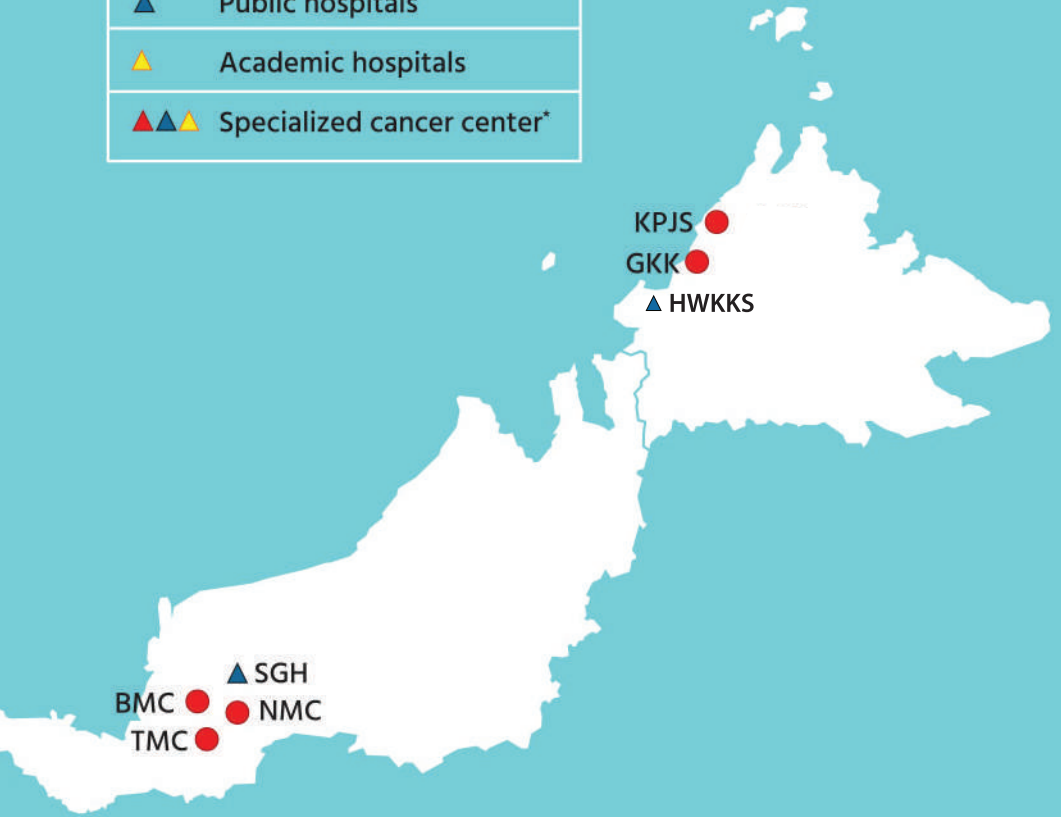
THRIVE-Malaysia

<https://www.thrive-malaysia.com/>

Oncology services in Malaysia



▲●	Private hospitals
▲	Public hospitals
▲	Academic hospitals
▲▲▲	Specialized cancer center*



Oncology Centres

KEDAH

PANTAI HOSPITAL SUNGAI PETANI (PHSP)

- 📍 No. 1, Pesiaran Cempaka, Bandar Amanjaya, 08000 Sungai Petani,
- ☎ +604 445 8888
- ✉ pantaisp@pantai.com.my
- 🌐 www.pantai.com.my/sungai-petani

KELANTAN

Hospital Universiti Sains Malaysia (HUSM)

- 📍 Jalan Raja Perempuan Zainab 2, 16150 Kota Bharu Kelantan
- ☎ +609 767 3000
- ✉ hospitalusm@usm.my
- 🌐 www.hospital.usm.my

PENANG

Gleneagles Penang (GPG)

- 📍 1, Jalan Pangko, 10050 Penang
- ☎ +604 222 9111
- ✉ mg.gpg.enquiry@gleneagles.com.my
- 🌐 www.gleneagles.com.my/penang

Hospital Pulau Pinang (HPP)

- 📍 Jalan Residentsi, 10990 Georgetown
- ☎ +604 222 5333
- ✉ hpinang@moh.gov.my
- 🌐 http://jknpenang.moh.gov.my/hpp/

Institut Perubatan dan Pergigian Termaju (IPPT)

- 📍 Universiti Sains Malaysia, Bertam 13200 Kepala Batas
- ☎ +604 222 5333
- ✉ hpinang@moh.gov.my
- 🌐 http://jknpenang.moh.gov.my/hpp/

Lam Wah Ee Penang Hospital (LWEPH)

- 📍 141, Jalan Tan Sri the Ewe Lim, Jelutong, 11600 George Town
- ☎ +604 222 5333
- ✉ hpinang@moh.gov.my
- 🌐 http://jknpenang.moh.gov.my/hpp/

Loh Guan Lye Hospital (LGLH)

- 📍 238, Jalan Macalister, 10400 Penang, Malaysia
- ☎ +604 2388187 / +604 2388188
- ✉ lsc@lohguanlye.com
- 🌐 http://www.lohguanlye.com/

Sunway Medical Centre Penang (SMCP)

- 📍 Lebuhraya 2, 13700 Seberang Jaya, Pulau Pinang
- ☎ +604-3739191
- ✉ smcpenang@sunway.com.my
- 🌐 https://www.sunwaymedicalpenang.com.my/en/

Mount Miriam Cancer Hospital (MMCH)

- 📍 23, Jalan bulan Fettes Park, 11200 Tanjung Bungah
- ☎ +604 892 3999
- ✉ enquiry@mountmiriam.com
- 🌐 www.mountmiriam.com

Pantai Hospital Penang (PHP)

- 📍 82, Jalan Tengah, Bayan Baru, 11900 Bayan Lepas
- ☎ +604 643 3888
- ✉ php.admin@pantai.com.my
- 🌐 www.pantai.com.my/penang

Penang Adventist Hospital (PAH)

- 📍 465, Jalan Burma, 10350 George Town, Pulau Pinang
- ☎ +604 222 7200
- ✉ enquiry@pah.com.my
- 🌐 http://pah.com.my

IPOH

Hospital Raja Permaisuri Bainun (HRPB)

- 📍 Jalan Raja Ashman Shah, 30450 Ipoh, Perak
- ☎ +605 208 5000
- ✉ hrpb_info@moh.gov.my
- 🌐 https://hrpb.moh.gov.my/baru/

KPJ Ipoh Specialist Hospital (KPJ Ipoh)

- 📍 26, Jalan Raja Dihilir, 30350 Ipoh, Perak
- ☎ +605 2408 777
- ✉ kpjipoh@kpjipoh.com
- 🌐 www.kpjhealth.com.my/ipoh/

Hospital Fatimah Ipoh (FHI)

- 📍 1, lebuhraya Chew Peng Loon, Off Jalan Dato' Lau Pak Khuan, Ipoh Garden, 31400 Ipoh
- ☎ +605 545 5777
- ✉ enquiry@fatimah.com.my
- 🌐 www.fatimah.com.my

Pantai Hospital Ipoh (PHI)

- 📍 126, Jalan Tambun, 31400 Ipoh
- ☎ +605 540 5555
- ✉ phi.info@pantai.com.my
- 🌐 www.pantai.com.my/ipoh

SELANGOR

Beacon Hospital (BH)

- 📍 1, Jalan 215, Section 51, Off Jalan Templer, 46050 Petaling Jaya
- ☎ +603 7620 7979, +603 7787 2992
- ✉ info@beaconhospital.com.my
- 🌐 www.beaconhospital.com.my

KPJ Ampang Puteri Specialist Hospital (KPJAPH)

- 📍 1, Jalan Mamanda 9, Taman Dato Ahmad Razali, 68000 Ampang Selangor
- ☎ +603 4289 5000
- ✉ apsh@kpjampang.com
- 🌐 www.kpjhealth.com.my/ampang/

KPJ Damansara (KPJD)

- 📍 119, Jalan SS 20/10, Damansara Utama, 47400 Petaling Jaya, Selangor
- ☎ +603 7718 1000
- ✉ marcommmdsh@kpjdamansara.com
- 🌐 www.kpjhealth.com.my/damansara/

Subang Jaya Medical Centre (SJMC)

- 📍 Jalan SS12/1A, 47500 Subang Jaya, Selangor
- ☎ +603 3569 1212
- ✉ healthcare@rsdhealth.com
- 🌐 www.subangjayamedicalcentre.com/

Sri Kota Specialist Medical Centre (SKSMC)

- 📍 Jalan Mohet, 41000 Klang, Selangor Darul Ehsan, Malaysia
- ☎ +603 3375 7734
- ✉ enquiry@srikotamedical.com
- 🌐 https://www.srikotamedical.com/

Sunway Medical Centre (SMC)

- 📍 5, Jalan Lagoon Selatan, 47500 Bandar Sunway,
- ☎ +603 7491 9191, +603 5566 9191
- ✉ smc@sunway.com.my
- 🌐 www.sunwaymedical.com

KUALA LUMPUR

Gleneagles Hospital Kuala Lumpur (GHKL)

- 📍 Block A & Block B, 286 & 288, Jalan Ampang 50450 Kuala Lumpur
- ☎ +603 4141 3000
- ✉ my.gkl.inquiry@parkwaypantai.com
- 🌐 https://www.gleneagles.com.my/kuala-lumpur#

Hospital Kuala Lumpur (HKL)

- 📍 Jalan Pahang, 50586 Kuala Lumpur
- ☎ +603 2615 5555
- ✉ pro.hkl@moh.gov.my
- 🌐 www.hkl.gov.my

Hospital Universiti Kebangsaan Malaysia (HUKM)

- 📍 Jalan Yaacob Latif, Bandar Tun Razak, 56000 Kuala Lumpur, Wilayah Persekutuan Kuala Lumpur
- ☎ +603 9145 5555
- ✉ prohukm@ppukm.ukm.edu.my
- 🌐 www.hctm.ukm.my/en/

Onco Life Centre (OLC)

- 📍 Lot 3.1, Level 3, Wisma Life Care, 5 Jalan Kerinchi, Bangsar South 59200 Kuala Lumpur
- ☎ +603 2242 3260
- ✉ info@oncolifecentre.com
- 🌐 www.oncolifecentre.com

National Cancer Institute (IKN)

- 📍 No. 4 Jalan P7, 62250 W.P. Putrajaya
- ☎ +603 8892 5555
- ✉ ncipro@nci.gov.my
- 🌐 http://nci.moh.gov.my

Pantai Hospital Kuala Lumpur (PHKL)

- 📍 8, Jalan Bukit Pantai, Bangsar, 59100 Kuala Lumpur, Wilayah Persekutuan Kuala Lumpur
- ☎ +603 2296 0888
- ✉ my.phkl@parkwaypantai.com
- 🌐 www.pantai.com.my/kuala-lumpur

Prince Court Medical Centre (PCMC)

- 📍 39, Jalan Kia Peng, 50450 Kuala Lumpur
- ☎ +603 2160 0000
- ✉ clinical.enquiries@princecourt.com
- 🌐 www.princecourt.com

Tung Shin Hospital (TSH)

- 📍 102, Jalan Pudu, 55100 Kuala Lumpur
- ☎ +603 2037 2288
- ✉ enquiry@tungshin.com.my
- 🌐 www.tungshin.com.my

Universiti Malaya Medical Centre (UMMC)

- 📍 Lembah Pantai, 59100 Kuala Lumpur
- ☎ +603 7949 4422
- ✉ ummc@ummc.edu.my
- 🌐 www.ummc.edu.my

Sunway Medical Centre Velocity (SMCV)

- 📍 Lingkaran SV2, Sunway Velocity, 55100 Kuala Lumpur
- ☎ +603 9772 9191
- ✉ smcv-enquiry@sunway.com.my
- 🌐 www.sunmedvelocity.com.my/en/

ParkCity Medical Centre (PMC)

- 📍 Perdana, 2, Jalan Intisari, Desa Parkcity, 52200 Kuala Lumpur, Federal Territory of Kuala Lumpur
- ☎ +603 5639 1616
- ✉ pmc@rsdhealth.com
- 🌐 www.parkcitymedicalcentre.com

UM Specialist Centre (UMSC)

- 📍 Lot 28, Lorong Universiti, Lembah Pantai, 50603 Kuala Lumpur
- ☎ 03 7841 4000
- ✉ enquiries@umsc.my
- 🌐 www.umsc.my

NEGERI SEMBILAN

Aurelius Hospital Nilai (AHN)

- 📍 PT 13717 Jalan BBN 2/1, Bandar Baru Nilai, 71800 Nilai, Negeri Sembilan
- ☎ +606 850 5000
- ✉ my.ahn.enquiry@aureliushealth.com
- 🌐 www.aureliushealth.com/nilai/

MELAKA

Mahkota Medical Centre (MMC)

- 📍 3, Mahkota Melaka, Jalan Merdeka, 75000 Melaka
- ☎ +606 2785 2999
- ✉ info@mahkotamedical.com
- 🌐 www.mahkotamedical.com/

Pantai Hospital Ayer Keroh (PHAK)

- 📍 No. 2418-1, KM 8, Lebuhraya Ayer Keroh, 75450 Melaka
- ☎ +606 231 9999
- ✉ my.phak.general@parkwaypantai.com
- 🌐 www.pantai.com.my/ayer-keroh

JOHOR

Dr Radzi Oncology Clinic (ROC)

- 📍 Suite 3.01-3.02, Landmark Medical Suites, No. 12, Jalan Ngee Heng, 80000 Johor Bahru
- ☎ +607 222 2666
- ✉ Jboncology@gmail.com
- 🌐 -

Hospital Sultan Ismail (HSI)

- 📍 Jalan Mutiara Emas Utama, Taman Mount Austin, 81100 Johor Bahru, Johor
- ☎ +607 356 5000
- ✉ Info@hsi.gov.my
- 🌐 www.jknjohor.moh.gov.my/hsi/

Kempas Medical Centre (KMC)

- 📍 Lot PTD 7522, Jalan Kempas Baru, 81200 Johor Bahru
- ☎ +607 236 8999
- ✉ info@kempasmedical.com
- 🌐 www.kempasmedical.com

KPJ Johor Hospital (KPJJ)

- 📍 39B, Jalan Abdul Samad, Kolam Ayer, 80100 Johor Bahru, Johor
- ☎ +607 225 3000
- ✉ jsh@jsh.kpjhealth.com.my
- 🌐 www.kpjhealth.com.my/johor/

Regency Specialist Hospital (RSH)

- 📍 No. 1 Jalan Suria, Bandar Seri Alam, 81750 Masai
- ☎ +607 381 7700
- ✉ info@regencyspecialist.com
- 🌐 www.regencyspecialist.com

Gleneagles Hospital Medini (GHM)

- 📍 2, Jalan Medini Utara 4, 79250 Nusajaya, Johor
- ☎ +607 560 1000
- ✉ my.gmh.inquiry@parkwaypantai.com
- 🌐 www.gleneagles.com.my/medini-johor

SABAH

Gleneagles Kota Kinabalu (GKK)

- 📍 Riverson@Sembulan, Block A-1, Lorong Riverson@Sembulan, Off Coastal Highway, 88100 Kota Kinabalu, Sabah
- ☎ +608 851 8888
- 🌐 -
- 🌐 www.gleneagles.com.my/kota-kinabalu

Hospital Wanita dan Kanak-Kanak Sabah (HWKKS)

- 📍 Jalan Kingfisher Likas, Likas, 88450 Kota Kinabalu
- ☎ +6088 522 600
- ✉ hwkss@moh.gov.my
- 🌐 https://jknSabah.moh.gov.my/hwkks/

KPJ Sabah Specialist Hospital (KPJS)

- 📍 Lot No.2 Off, Jalan Damai, Luyang Commercial Centre, 88300 Kota Kinabalu, Sabah
- ☎ +608 832 2000
- ✉ info@kpjsabah.com
- 🌐 www.kpjhealth.com.my/sabah/

SARAWAK

Borneo Medical Centre (BMC)

- 📍 Lot 10992, Section 64, KTLD, Jalan Tun Jugah, 93350 Kuching
- ☎ +6082 507 333
- ✉ admin@borneomedicalcentre.com
- 🌐 www.borneomedicalcentre.com/en/

Sarawak General Hospital (SGH)

- 📍 Jalan Hospital 93586 Kuching
- ☎ +6082 276 666
- ✉ sgh@moh.gov.my
- 🌐 http://husmoh.gov.my/bm/

Normah Medical Centre (NMC)

- 📍 Lot 937, Section 30 KTLD, Jalan Tun Abdul Rahman Yaakub, Petra Jaya, 93050 Kuching, Sarawak
- ☎ +608 244 0055
- ✉ inquiry@normah.com
- 🌐 www.normah.com.my

Timberland Medical Centre (TMC)

- 📍 Lot 5164 -5165, Block 16 KCLD, 2½ Mile, Rock Road, Taman Timberland 93250 Kuching
- ☎ +6082 234 466
- ✉ marketing@timberlandmedical.com
- 🌐 www.timberlandmedical.com



Glossary

5-year survival rate: The percentage of people in a study or treatment group who are alive 5 years after they were diagnosed with or started treatment for a disease.

Adherence: The extent to which a patient continues on an agreed mode of treatment without close supervision.

Adjuvant therapy: Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back.

Axillary lymph nodes: Also known as armpit lymph nodes, work as filters for the lymphatic system.

Biomarker: A biological molecule that is a sign of a normal or abnormal process, or of a condition or disease.

Biopsy: Doctor takes a small piece of your tissue or body fluid to test it to see if you have cancer.

BRCA: A gene that normally helps to suppress cell growth. A person who inherits certain mutations (changes) in a BRCA1/2 gene has a higher risk of getting breast, ovarian, prostate, and other types of cancer.

Breast cancer: Cancer that forms in the tissues of the breast; it occurs in both men and women, although male breast cancer is rare. Invasive breast cancer is a cancer that has spread from its point of origin in the breast duct or lobules to the surrounding normal tissue.

Clinical trial (interventional): Clinical trials are studies that test potential treatments in human volunteers or patients to see if they should be tested further or approved for use in the general population. However, they must first be studied in models or animals to determine the safety in testing in people – only then are treatments moved into trials. Clinical trials are an integral part of a product's discovery and development and the data from these are required by regulatory agency, such as FDA before a new medicine could be commercially available.

Alternatively, non-interventional clinical trial designs include studies measuring QoL, risk assessment, screening, and prevention.

Companion diagnostic: A medical device which provides information that is essential for the safe and effective use of a corresponding drug or biological product.

Compliance: The consistency and accuracy with which a patient follows a prescribed treatment regimen.

Cyclin dependent kinase: Protein that controls cell cycle progression in all cells.

de novo: In cancer, the first occurrence of cancer in the body.

Diagnosis: Describes your tumour or illness.

Drug toxicity: The extent to which a drug is harmful or poisonous.

Early breast cancer (eBC): Breast cancer that has not yet spread beyond the breast or axillary lymph nodes.

Early-stage disease: Cancer that is early in its growth and has not yet spread to other parts of the body. Early stages may differ between cancer types.

EGFR: A cell surface protein which epidermal growth factor binds, causing the cells to divide. Many cancer cells have abnormally high levels on their surfaces causing them to divide excessively in the presence of epidermal growth factor.

End-of-life care: This is the care given to patients who are near the end of life and have stopped treatment. Care includes physical, emotional, social and spiritual support for both the patient and their family. The goal is to ensure that the patient is as comfortable as possible and may include palliative care.

Estrogen receptor-positive (ER+): Describes cells that have a receptor protein that binds the hormone estrogen.

Evidence-based medicine: Evidence-based medicine uses the findings and results from research to inform decisions in a real-world clinical practice setting. The 4 steps to this are:

formulate a clear clinical question from a patient case study, search the literature for relevant research articles, evaluate the evidence, and then implement the findings in clinical practice.

Functional wellbeing: The ability of a person to perform usual daily living tasks and to carry out social roles.

Genomics: The study of the complete genetic material, including genes and their functions, of an organism.

Healthcare professional: An individual who provides health services to healthcare consumers.

Health-related quality-of-life (HR QoL): The subjective perceptions of the positive and negative aspects of cancer patients' symptoms including physical, emotional, social, and cognitive functions, disease symptoms and side effects.

Heterogeneous: Made up of elements or ingredients that are not alike.

Hormone receptor-positive (HR+): Describes cancer cells that contain either estrogen or progesterone receptors.

Human epidermal growth factor receptor 2-positive (HER2+): Describes cancer cells that have too much of a protein called HER2 on their surface.

Incidence: The number of new cases during a designated period of time.

Intolerance: Lack of ability to endure a stimulus over a period of continued exposure.

Invasive breast cancer: Cancer that spreads from the breast to surrounding normal tissue.

Joint decision making: Patients can actively participate with their clinicians in making choices about their care and treatment.

Ki-67 Index: Measures how rapidly tumor cells are dividing. Results <10% indicate a low division rate, 10-20% are borderline, and >20% is considered a high division rate.

KRAS: A KRAS protein involved in cell signaling pathways, cell growth, and apoptosis (cell death).

Mammography: The use of film or a computer to generate a picture of the breast, used to diagnose and locate breast tumors.

Median survival: The length of time from diagnosis until half of the patients are still alive. In a clinical trial, measuring the median survival is one way to see how effective a treatment is.

Met: Cell surface receptors for hepatocyte growth factor.

Meta-analysis: A process that analyzes data from different studies done about the same subject.

Metastasis: The spread of a cancer from one part of the body to another.

Metastatic breast cancer: Breast cancer that has spread to other areas of the body.

Mortality: Refers to the state of being mortal. Also used in medicine for death rate, or number of deaths in a certain group of people in a certain amount of time.

Neoadjuvant therapy: Treatment given as a first step to shrink a tumor before the main treatment is given (usually surgery).

Non-adherence: The extent to which a patient doesn't continue on an agreed mode of treatment without close supervision.

Oncologist: A doctor who specializes in diagnosing and treating cancer. They are often the main healthcare professional in the case of a patient with cancer and may coordinate the treatment given by other specialists.

Oncology nurse: A nurse in the field of oncology who provides care for patients with cancer. Nurses monitor patients' physical conditions, may prescribe medication and administer chemotherapy.

Overall survival (OS): The length of time from either the date of diagnosis or start of treatment for a disease, such as cancer, that patients diagnosed with the disease are still alive.

Patient support group: A group of people all with similar disease who help and support each other by sharing experiences and information.

Palliative care: The care given to improve a patient's quality of life. The goal is to treat the symptoms of a disease, side effects of treatment and any psychosocial issues related to the disease or treatment.

PARP: An enzyme involved in many functions of the cell, including the repair of DNA damage.

PD1/PD-L1: Also called programmed death-1 pathway/programmed death ligand 1. Expressed by many cancer cells.

PI3K: Also called phosphatidylinositol-3 kinase and P13 kinase. An enzyme that transmits signals in cells and that helps control cell growth.

Precision medicine: Uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat disease.

Personalized medicine: A form of medicine that uses information about a person's genes, proteins, and environment to prevent, diagnose, and treat disease.

Phase II trial: A study that tests whether a new treatment works for a certain type of cancer or other disease.

Phase III trial: A study that tests the safety and efficacy and how well a new treatment works compared with a standard treatment.

Phenotype: The observable characteristics, at the physical or biochemical level, of an individual, as determined by the genes and environment.

Pivotal trial: A study which presents the data used by regulatory agencies to decide whether to approve a drug.

Placebo arm: Placebo is an inactive form of the treatment drug being investigated – the placebo arm of a clinical trial is used as a control to assess how effective or safe the treatment drug is.

Progesterone receptor-positive (PR+): Describes cells that have a protein to which the hormone progesterone will bind.

Predictive: Anticipates whether a person's cancer will respond to a specific treatment.

Prognosis: Likely course of disease.

Progression: The course of disease as it becomes worse or spreads in the body.

Progression-free survival (PFS): The length of time during and after treatment of a disease, such as cancer, that a patient lives with the disease but it does not get worse.

Psychosocial well being: The psychological and social components of a disease and its treatment. This includes mood, belief, coping mechanisms, and relationships with family and friends.

Quality of life (QoL): The measurement of a patient's sense of wellbeing and ability to carry out day-to-day activities.

Radiation oncologist: A doctor who specializes in using radiation to treat cancer.

Real-world data: Data used for clinical, coverage, and payment decision-making that are not collected in conventional randomized, controlled trials.

Recurrence: Cancer that has recurred (come back), usually after a period of time during which the cancer could not be detected.

Registry: Collects detailed information about patients and the treatments they receive, and stores it in a searchable computer database.

Relapse: The return of a disease or the signs and symptoms of a disease after a period of improvement.

Resistance to treatment: Does not respond to treatment.

ROS-1: Growth or differentiation factor receptor expressed by many solid tumors.

Screening: Checking for disease when there are no symptoms.

Side effect profile: All of the potential side effects that may be caused by the drug. A side effect is any undesirable effects from drug treatment that are not intended as part of the therapeutic effect.

Stage III disease: Further subdivided into IIIA, B and C.

IIIA:

- Tumor may be of any size and cancer is found in 4 to 9 axillary lymph nodes or
- The tumor is > 5 cm and small clusters of breast cancer cells are found in the lymph nodes or
- Tumor is > 5 cm and the cancer has spread to 1–3 axillary lymph nodes

IIIB:

The tumour has spread to the chest wall and/or to the skin of the breast and caused swelling/an ulcer. It may have spread to:

- Up to 9 lymph nodes
- The lymph nodes near the breast bone

IIIC:

Cancer has spread to the skin and caused swelling or an ulcer and it has spread to the chest wall. It has also spread to:

- 10 or more lymph nodes
- Lymph nodes above or below the collarbone
- Axillary lymph nodes and lymph nodes near the breastbone. Cancer that has spread to the skin of the breast may also be inflammatory breast cancer.

Stage IIIC is either operable or inoperable.

Statistical significance: A mathematical measure of difference between 2 groups that is greater than what might be expected to happen by chance alone.

Subtype: Describes the smaller groups that a type of cancer can be divided into, based on certain characteristics of the cancer cells.

Supportive care: The care given to improve a patient's quality of life. The goal is to treat the symptoms of a disease, side effects of treatment and any psychosocial issues related to the disease or treatment.

Surgeon: A doctor who operates on a patient by removing or repairing parts of the body.

Systematic literature review: Rigorous and standardized methods are used to select and assess articles, which are usually peer-reviewed publications – all focused on a specific topic that try to answer a specific research question. A

meta-analysis may be performed as part of the review, which is a quantitative summary of the results.

Systemic therapy: Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body.

Targeted therapy: A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells.

Therapeutic goal: The expected outcome relating to the treatment of disease.

Triple-negative breast cancer (TNBC): Breast cancer cells that do not have estrogen receptors, progesterone receptors, or large amounts of HER2/neu protein.

Appendix 1: Common drugs available in Malaysia

Type of systemic therapy	Generic name
Hormone therapy	Anastrozole
	Ethinyl estradiol
	Exemestane
	Fulvestrant
	Letrozole
	Megestrol acetate
	Tamoxifen
Chemotherapy	Capecitabine
	Carboplatin
	Cisplatin
	Cyclophosphamide
	Docetaxel
	Doxorubicin
	Epirubicin
	Eribulin
	Fluorouracil
	Gemcitabine
	Methotrexate
	Paclitaxel
	Vinorelbine
Targeted therapy	Everolimus
	Lapatinib
	Palbociclib
	Pertuzumab
	Trastuzumab
	Ribociclib
	Abemaciclib



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Pfizer Malaysia Sdn Bhd - 197801003134 (40131-T)

Level 10 & 11, Wisma Averis, Tower 2, Avenue 5, Bangsar South,
No.8, Jalan Kerinchi, 59200 Kuala Lumpur.

Tel: 603 - 2281 6000 | Fax: 603 - 2281 6388 | www.pfizer.com.my
Please visit www.thrive-malaysia.com for more information