ME AND METASTATIC BREAST CANCER



ME AND METASTATIC BREAST CANCER



Me & METASTATIC BREAST CANCER

EVERY DAY IS PRECIOUS



Today, ...just breathe.

Whatever you are feeling today – it is all right. There is no "right" or "wrong" way to feel about it. You may feel like you are alone with your diagnosis, but there are many women in the world right now who have also just found out they have metastatic breast cancer, and are feeling what you are feeling. And every one of you will find a way to live with this disease and you will eventually feel stronger – a little bit more each day.

It is difficult for you to hear that you have metastatic breast cancer. Instantly, you will have many questions — and will be looking for answers. There is a special group of women from across Europe and the Middle East who have come together to talk about what you might need to know.

And we, the women of the "*Every Day is Precious Group*" and Pfizer Oncology, have suggested some solutions here that may help.

Some of us are living with metastatic breast cancer. Others are breast cancer survivors. We believe that this information will help you to understand your disease better. It will help you decide what your next step might be, what is the best for you – because *every day* is precious. We hope that you will use this booklet as a guide to help you – as much or as little as you want. And we hope it will help you make the most of every day.

Women of the Every Day is Precious Group





ME AND METASTATIC BREAST CANCER

Preface

The *Every Day is Precious Group* has kindly permitted the Breast Cancer Welfare Association Malaysia (BCWA) to translate, localise and reproduce materials from the Me & Metastatic Breast Cancer (mBC) handbook.

This exercise to customise it to fit the Malaysian culture, tone and content, was led by patient advocates and healthcare professionals from BCWA with the involvement and support of Pfizer Malaysia.

The Me & mBC handbook is a project by the *Every Day is Precious Group* in collaboration with Pfizer Oncology. It was steered by a committee comprising Michal Melamed-Cohen, Founder of the Israeli "Me too" Facebook group; Doris C. Schmitt, Communications Trainer from Germany; and Eva Schumacher-Wulf, Editor-in-chief of Mamma Mia! Das Brustkrebsmagazin, Germany.

The sections, ME & MY TREATMENT and MY TREATMENT A-Z, were reviewed by Nadia Harbeck (MD, PhD), Professor and Head of the Breast Centre, University of Munich, Germany, who also provided expert medical input.

The *Every Day is Precious Group* are women from Austria, Egypt, France, Germany, Israel, Italy, Jordan, Poland, Saudi Arabia, Spain, Sweden, Turkey, the United Arab Emirates and the United Kingdom.

BCWA is indeed very appreciative to the women of the Every Day is Precious Group who have so generously shared their knowledge and wisdom with us.

Ranjit Kaur

President



ME AND METASTATIC BREAST CANCER



"While early stage breast cancer often makes headlines, the needs of women with mBC are often neglected. Many patients feel they do not have enough information about their disease. This handbook is a valuable resource to help women understand what their mBC diagnosis means, the treatment options available to them, and the decisions they may want to make. Perhaps, most importantly of all, it helps women with mBC to realise that, despite mBC, they can still determine how they want to enjoy their life."

Nadia Harbeck, MD, PhD

Professor and Head of the Breast Centre, University of Munich, Germany

MOV & METASTATIC BREAST CANCER

EVERY DAY IS PRECIOUS

Content Editing and Localisation

- Ranjit Kaur, President of Breast Cancer Welfare Association Malaysia
- · Waifai Lo, Editor

Medical Reviewers

- Dr Mastura Md Yusof, Consultant Clinical Oncologist & BCWA Board Member
- Dato' Dr Yip Cheng Har, Consultant Breast Surgeon & BCWA Board Member
- Dr Patricia Alison Gomez, Consultant Breast Surgeon & BCWA Board Member



ME AND METASTATIC BREAST CANCER

How TO USE THIS GUIDE

Part 1

Answers the most urgent questions you may have on your diagnosis, treatment, and how to cope with daily life.

Part 2

Gives you more detailed information about how metastatic breast cancer is diagnosed and treated.

Part 3

Provides a list of resources for more help – where to find more information, patient support groups, a doctor or counsellor, financial support, and other resources in your area.

Part 4

Glossary & Cancer care during COVID-19

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Part 1

ANSWERING YOUR MOST URGENT QUESTIONS



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1.1 My Diagnosis

Learning the Facts

"Be your own advocate. Never stop reading. Never stop asking questions. If something doesn't settle right with you, do something about it. Do your research. It's now second-nature for me to keep up-to-date with research and news in the breast cancer community. "It's important to be able to trust your doctor. I decided that my doctor's decision also didn't have to be the end-all, be-all."

Sarah Reinold, 31 Living with mBC for 3 years

When you understand what your diagnosis means and how it is affecting your body, it can help if you talk openly with your doctors about what the best care options are for you.

You can be diagnosed with **metastatic breast cancer** (mBC) straight away or your cancer has come back (relapse) after you have completed treatment for early breast cancer in the past.¹

Why Did My Cancer Come Back?

It is still not known why some breast cancers come back and others do not. Since your breast cancer came back it does not necessarily mean that you were given the wrong treatment when you first had breast cancer, or, that you did not look after yourself.¹

The truth is, anyone who had breast cancer in the past can have a recurrence and relapse at any time. Sometimes, the cancer comes back even after many years being in remission.

· What Does This Mean For Me?

mBC is different from earlier stages of breast cancer. In mBC, the cancer has spread from the breast to other organs in the body. The breast cancer cells growing in these different parts of the body are called metastases. Although the cancer has spread to other organs it is still called **metastatic breast cancer** because of the origin of the disease being from the breast.

mBC is also sometimes referred to as Stage IV breast cancer.2

If you had treatment for breast cancer in the past, it was probably given for a few months up to several years at most, with the intent to cure.3

mBC is a chronic disease. The treatment in mBC is to slow down the growth of cancer, possibly even stop it for a while, but it needs lifelong treatment.⁴

What Type Of Tests Do I Need To Confirm My Diagnosis?

You will need more than one test to confirm that you have mBC. Your doctors will do tests to find out everything about your cancer, such as, the type of cancer, and to which organs it has spread in the body. The results of the tests will help the doctors to choose the best and the most successful treatment for you.⁵



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My Diagnosis

Your doctor may recommend a series of tests for you⁵:



There is more information about these tests in Part 2 of this Guide

Every person does not get the same tests – it depends on your symptoms, whether you had breast cancer in the past as well as the standard procedure practised in the hospital where you are being seen

You will be having a whole range of diagnostic tests again even if you have had such tests for your breast cancer in the past. Your doctor wants all the information about your present condition.

It is important to remember that you have done nothing wrong – it is beyond your control and it is not your fault. What is important is to find solutions for your cancer.

Main Points To Consider About Your Diagnosis

- Metastatic breast cancer means that the cancer that was in your breast has spread to other parts
 of your body.¹
- The aim of the treatment is to prevent the cancer from growing and spreading further and to help you live longer with the best quality of life possible.⁴
- Metastatic breast cancer is considered a chronic disease, which means it will probably remain in you for a long time. It is different from early stage breast cancer.¹
- Each person can have a different experience in terms of symptoms. Symptoms of metastatic breast cancer vary depending on the location of the cancer.¹

"mBC hit my life like a tornado, stirring everything up. Then, the dust settled. You don't know what will happen at first; you think nothing will ever be normal again. But what you find is that the wind has whisked things of unimportance away, leaving the world clean and shining bright."

Ann Silberman Living with mBC and author of Breast Cancer

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My Diagnosis

Ask Your Doctor These Questions About Your Diagnosis

1.	My oncologist's name is:	
2.	2. Phone: 3. E-n	nail:
4.	4. Name of my nurse or other office staff:	
5.	5. Where has the cancer spread? (Tick where applica Brain Bone Lymph system	· _
6.	6. How fast is my cancer growing?	
7.	7. Will I get any symptoms due to the cancer that ha	s spread?
8.	8. What type of tests or scans will I need and how lo	ng will each take?
9.	9. What type of breast cancer do I have? (Tick where Hormone receptor-positive Hormone recep HER2-positive HER2-negative Tri	tor-negative
0.	0. Based on the type of breast cancer above, what ty	pe of treatment can I get?
11.	Have you given treatment for this type of cancer be	pefore?
2.	2. What else do I need to know?	
3.	3. What did I learn?	
14.	4. What is important to me?	
15.	5. What questions do I have?	



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1.2 My Treatment

What to Expect

"Patients with mBC may become overwhelmed with information provided to them the moment diagnosis is made. It is important to explain the treatment and its potential success rate and side effects in simpler terms and a reassuring tone while allowing room for questions from them."

Dr Mastura Md Yusof, Oncologist, Malaysia.

What To Expect From My Treatment?

The main goal of treatment of mBC is to prevent or slow the spread of cancer and to relieve you of any pain or discomfort. 5 Your oncologist will tell you about the choices of treatment that are suitable for you and have the fewest side effects. Talk to your oncologist to understand your treatment plan better.

A good decision about treatment can be made only after you have received and understood all information pertaining to treatment choices.

What Is The Best Treatment For Me?

There is no single 'best' treatment for mBC. What is suitable for one person may not be suitable for you. 5 Talk to your doctor about the goals and expectations of each treatment. 6

There are different factors contributing to which treatment is Best For You. These factors include where in the body the cancer has spread to, presence and level of hormone receptors and/or HER2 in the tumour, gene mutations in the tumour, specific symptoms, previous cancer treatments, and your overall health.⁶

The aim of the treatment is to help control the spread of cancer in your body and improve your quality of life.^{5,6}

TREATMENT CAN CHANGE

Cancer can develop resistance to a certain treatment. So, you may need to change to another treatment which may be more effective in controlling the spread of the cancer.² You may also need to stop taking a treatment because of bad side effects.

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My Treatment

Each person responds differently to different treatments.⁵ It is not possible to tell in advance whether your treatment will benefit you. Not everyone will receive the same treatment. Thus, it is important to discuss with your doctor to better understand which treatment might be best suited for you.⁵ Some patients with mBC may experience during treatment that their disease has advanced, and will need to have their treatment changed based on their response to treatment.²

What Are The Main Types Of Treatment For mBC?

The two main types of treatment for mBC include local therapy and systemic therapy. Local therapy focuses on a certain area, and includes surgery and radiation therapy. Systemic therapy on the other hand, works throughout the body and includes endocrine therapy, chemotherapy and targeted therapy. Bone-targeted therapy may be given to help relieve bone pain or reduce the risk of bone problems, especially in instances of bone metastasis or to counteract treatments of mBC which cause bone loss. Common drugs used in bone-targeted therapy include, zoledronic acid, pamidronate, and denosumab.

You Will Have Regular Check-ups

You will be advised to do regular check-ups to monitor your condition, to make sure that your treatment is working and to find out how you are feeling. Your doctor may also conduct medical tests to better understand your progress.⁷

Should I Join A Clinical Trial?

Your doctor may suggest that you take part in a clinical trial. This will help you get hold of a new drug or a drug that is not available yet in Malaysia. Clinical trials are research studies to find out if a new treatment is effective, can be accepted by the body, and probably better than the standard treatment that patients receive for the same condition.⁵

Since treatment for mBC keeps changing, your doctor may suggest that you take part in a clinical trial to enable you to obtain a new treatment that could be helpful for your condition.⁵

You can get more information about the different types of treatments for mBC and more information about clinical trials in Part 2 of this Guide.

What Are The Possible Side Effects I May Have?

Side effects depend on the type of treatment you are undergoing – and they are different with different drugs. Furthermore, every person reacts differently to treatment.⁵ The side effects experienced by others may be different from the ones you have to cope with.

Some common side effects of cancer treatment include feeling more tired than usual (fatigue), hair loss, mouth sores, nausea, vomiting, diarrhoea, anaemia, weight changes (weight gain or loss) and increased tendency to infections.^{6,8}

Always inform your doctor or nurse about any side effect you are experiencing. There may be ways to help lessen as well as prevent your discomfort due to treatment-related side effects.⁸

You may think it is a side effect, but it could be a sign of the cancer growing.

GIVE YOURSELF TIME TO ADJUST TO TREATMENT-RELATED SIDE EFFECTS

It is better to plan your days well ahead since you will not know how you feel. Avoid planning for events that you cannot cancel for the first few days after your treatment. Take time to care for yourself.



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My Treatment

THERE IS NO "MAGIC MEDICINE" that will get rid of the side effects of the treatment. You need to explore what works best for you. For example, some women benefit from exercises and complementary therapy such as yoga, qigong or acupuncture. Talk to your doctor regularly to let him/her know about any new side effects or changes in existing side effects that you may be experiencing.⁹

Not everyone experiences the same side effects even when given the same treatment for the same type of cancer.⁹

How Can I Use My Time With The Doctor Effectively?

You can get a lot of information when you see the doctor. Here are some tips:

- Make sure you have your list of guestions with you so that you do not forget anything.
- Bring a family member or friend along for each appointment to listen and take down notes.
 In this way, you would not miss anything the doctor or nurse tells you.
- Take down notes during the appointment with the doctor so that you can refer to them later.
- Take your time and do not be afraid to ask for more time with the doctor, and this will allow you
 to be actively involved in making decisions about your care and treatment.

There is no single way to treat mBC that is right for everyone.

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My Treatment

Main Questions To Ask You Doctor About Your Treatment

1.	What type of medicines will I be taking?
2.	What could be the possible side effects?
3.	What can I eat or drink before and after the treatment to prevent nausea, diarrhoea or other side effects?
4.	What can I do to help myself manage fatigue which can be due to the cancer or the treatment?
5.	I am worried about losing my hair. Is there anything I can do to prevent this?
6.	How often will I need to have the treatment?
7.	Will the treatment be given by intravenous line or through a chemopot?
8.	How long will I need to be in the hospital for each visit?
9.	When and how will you be checking my progress?
0.	Will I need any radiation or surgery?
1.	How can I benefit if I join a clinical trial if there is one for me?
2.	What did I learn?



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My Treatment

13.	What matters to me?
14.	What questions do I have?

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1.3 My Emotions

Coping with My New Reality

"When you are told you have cancer, don't immediately assume it's a death sentence. Many are quick to think it's the end before hearing the doctor out. Always know that there is hope, and that you can overcome it. It is all about your mind and willpower. I have undergone three years of continuous chemotherapy, and it is important to learn how to manage the side effects properly."

Amy Yeo, 55 Living with mBC for 13 years, Singapore

No matter how you may be feeling, the important thing is that you do not have to go through this alone.

There are many ways to get help. There are trained staff and volunteers who can be useful resources for women with mBC. They can help you cope emotionally with your situation.

Try to listen to your own feelings and fears. This can take time. Trust your instincts and hunches. Be honest about what your needs are. You do not have to feel positive all the time. Nobody should tell you to feel positive, think positive and behave positive. Just be your own best friend.

Who Can Help Me With My New Situation?

There are different resource persons in different hospitals and areas who can help you. You can get information from the doctor on who can help you – even though you are not needing this help yet. There are different health professionals and volunteers who can help women living with mBC, such as:





ME AND METASTATIC BREAST CANCER

My Emotions

Psycho-Oncologists or Clinical Psychologists

These are specialists who can help with the psychological issues and challenges you are facing in adjusting to your condition and to deal with the impact on your relationship with others.

The Palliative Care Team

This is a multidisciplinary team of doctors, nurses and therapists who can help improve the quality of life for you and your family and provide psychological support during your illness. Palliative care can include symptoms management, pain management, complementary therapies and family counselling. You can also get professional counselling and the services of social workers in major hospitals. Refer to Me & My Plan in Part 2 of this Guide for more information about palliative care.

Breast Care Nurses

They are specialised in symptom management and support for breast cancer patients. They could help answer your questions relating to your condition, and they can link you up with different healthcare professionals and support services.

Patient Support Groups

This is where you will have the opportunity to meet other women like you, who have mBC. These women may have similar feelings, concerns and questions. You will gain mutual support and a sense of special friendship because you understand and appreciate each other's situation. If there are no such patient support groups nearby, you can also find them online. The Resources Section of this Guide has a list of local and online patient support groups for mBC patients.

You are not alone on this journey.

Key Points To Consider About How You May Be Feeling

- · Many women like you seek support from people outside your immediate family and friends.
- There are counsellors and doctors who are specially trained in helping women with mBC.
- Patient support groups help you link up with other women with mBC who are going through the same experience as you.



ME AND METASTATIC BREAST CANCER



My Emotions

Questions To Ask Your Doctor or Nurse

1.	Who is available in this hospital to help me with an	xiety or depression?
2.	Is there a psycho-oncologist or clinical psychologi people with metastatic cancer who can help me?	st with experience in treating
	(a) Name:	Tel:
	(a) Name:	Tel:
	(a) Name:	Tel:
3.	Can I have the name of the breast care nurse who	works with mBC patients?
4.	Which are the patient support groups for women w	vith mBC in my area?
5.	Where else can I go to talk to other women with m	BC?
6.	Are there professionals who can help me talk to m	y family?
7.	Are these services covered by my medical insuran	ce?
8.	What did I learn?	
9.	What matters to me?	
0.	What questions do I have?	



ME AND METASTATIC BREAST CANCER

1.4 My Health

Feel Better in My Body

"For me, 'living life over cancer' means I don't worry about things I used to worry about. I live my life more intentionally. I love to travel with my husband and our two sons. They know I have mBC, but at this point, our life isn't sidetracked by cancer treatments."

Lisa MacGregor, Founder, Hope Scarves and living with mBC

What Can I Do To Make Myself Feel Better?

There is a lot you can do for yourself to feel good, to take control of your life after knowing that you have mBC. You can find out what makes you feel good, what makes you feel stronger and what helps you. You may also want to be in the company of people who make you feel good. It is okay to have good days and bad days.

Should I Change My Food?

"Since my diagnosis I worry about food – what to avoid and what is good for me. I consulted a dietitian recommended by my doctor. I felt the need to do this for myself because I needed to make healthier choices."

mBC patient in KL, aged 37

Although you may be reading about recommendations and promotion of food types, there is no 'cancer diet' that is particularly recommended once you already have cancer. Of course, eating a healthy diet is a good choice to strengthen your immune system – whether you have mBC or not. A healthy diet helps you stay strong and feel well while you undergo treatment for mBC.

Remember to eat a variety of foods, especially foods rich in protein, fats, carbohydrates, vitamins, and minerals. Also consume enough fluids to stay hydrated.¹⁰

If you are interested in changing your diet, get your doctor to refer you to a dietician who can help you make effective changes slowly.⁵ He/She can also help you make informed diet changes.

ME AND METASTATIC BREAST CANCER



My Health

Are Exercises Good For Me?

Regular exercises can be useful in managing your physical and emotional health. Exercises can help reduce the symptoms of mBC, including fatigue and poor appetite, reduce stress, induce sleep, and reduce pain.

Exercise is recommended for women diagnosed with mBC.11 Do exercises which are suitable and which you feel good doing. Do any physical activity that makes you feel good such as line dancing, qigong, etc. Make sure you listen to your body and stop when you are tired. Talk to your doctor about what exercises are suitable for you if you are concerned.

Remember, the type and amount of exercise you are able to do depend on your level of fitness before treatment, the type of treatment you are getting as well as the side effects you are experiencing.¹¹ Avoid heavy movements if your cancer is in your bones, affecting your nerves or you have symptoms affecting your bones.

Complementary therapies when used alongside medical treatment can be useful in helping you to cope with your cancer physically especially the side effects, and may also lessen the stress of treatment.12

There is more information In Part 2 of this Guide, about different therapies that can help you feel better. You can explore to see what you are comfortable with as shown below 12:

- Acupuncture
 Music therapy
- Tai chi Qigong
- Massage
 - Meditation
- Naturopathy and
 Reiki
- Yoga
- homeopathy

 Art therapy
 - Reflexology and hypnotherapy

Make sure you tell your doctor if you are taking any complementary therapy because this can change the effect of your cancer treatment.12

Some Things To Consider When Making Yourself Feel Better

- There are no special diets for you to follow. You can eat whatever makes you feel good.
- · Exercises can make you feel better physically and mentally, even if it is just a few minutes of walking.
- Continue to do your activities as long as you feel good doing them.
- Sometimes complementary therapy can help reduce side effects and anxiety.



ME AND METASTATIC BREAST CANCER

My Health

List Of Questions To Ask Your Doctor Or Nurse

1.	Can I see a dietitian who can advise me about my d treatment?	e about my diet while I am undergoing		
	(a) Name:	Tel:		
2.	What can I do to feel less tired?			
3.	Can you refer me to anyone who can offer me composer with patients like myself?	plementary therapy or those who		
4.	Is there any complementary practitioner in this hos	pital or any other hospital?		
5.	What did I learn from these questions?			
6.	What is important for me?			
7.	Any other questions?			

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1.5 My Relationships

Talking with people who care about me

"I told my parents face-to-face. But for my co-workers and friends, I sent out an email. I'm sure for many, it was a shocking email to receive, but I didn't want to go through the story over and over again. Some people called me right away, but to be honest, I didn't feel like chatting. I probably should have made some comment about giving me a bit of space before we actually spoke. My reaction to the amount of love, hope and support I received gave me even more strength to fight this. For me, this is not something I could do alone."

Michelle Riccio, 35 Living with mBC, USA

It is your choice whether you wish to speak to the people in your life about what you are experiencing.

Cancer affects not only you but also your loved ones, family members, friends and colleagues. It may be difficult to tell your loved ones about your diagnosis of mBC, be it an initial diagnosis or a recurrence. You may be concerned about upsetting your family and friends and find it difficult to communicate openly with them.

The conversation you have will be different depending on whom you are talking to; be it your spouse, children, a close friend, or your colleagues at work. It is always important to understand that you are always in control of the conversation and that the amount of information and depth of feelings that you intend to share is entirely up to you.¹³

How Do I Keep This From Taking Over My Intimate Relationship?

The worry of an uncertain future can bring tension to your relationship with your spouse. Sharing your fears and concerns and speaking about it openly with each other can be hard for your spouse and you. You may feel that your spouse could give you more support.

Just like you may feel your cancer journey is full of emotional ups and downs, your spouse may be feeling the same, too. He may feel helpless and hopeless that he cannot do anything to help you. Couples who are very close also face such problems and you may not always feel the same as your spouse each day.

Talking to each other openly about your feelings can be helpful for both of you to cope with the challenges of the disease.



ME AND METASTATIC BREAST CANCER

What Else Can Be Helpful For The Both Of You?

DO NORMAL THINGS TOGETHER GIVE YOUR PARTNER TIME TO FIGURE OUT ON HIS OWN CONFIDE IN SOMEONE BESIDES YOUR PARTNER

GET HELP FROM YOUR RELIGIOUS/ SPIRITUAL LEADER JOIN METASTATIC BREAST CANCER SUPPORT GROUPS HAVE A CONSULTATION SESSION WITH THE PSYCHO-ONCOLOGIST ALONE

How Do I Do This On My Own?

It can be equally difficult for single individuals although your issues and challenges may be different.¹⁴

- You will certainly find people in your social circle who are willing to help you.
- You can also get a part-time helper to do your household chores or get help for transport to and from the hospital.
- You can speak to a counsellor who can be helpful in reducing your anxiety.

If you are dating someone, you may hesitate to tell him that you have cancer. You will know when the time is right to bring up this news. You will then need to give your partner some time to deal with this – do not fear that he will give up on the relationship because of your cancer. Whatever his reaction, it is not your fault for telling him about your cancer. You are just being honest,

You can talk to a friend and go through with him or her regarding what and how you want to say it when you break the news to your partner.

How To Tell My Children That I Have mBC?

"My husband and I explained to our daughter that my cancer returned. We explained that it's called metastatic breast cancer, stage IV cancer, and that I will be on medicine for the rest of my life, I didn't sugar-coat the seriousness of the situation, but I tried to convey that I am going to be as healthy as I can be and we are going to continue to live life fully."

Adrienne Lee, 45 Living with mBC, Singapore

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My Relationships

Children respond according to the actions of adults. Figure out how much they can understand before you decide what and how you will tell them. Very young children can also sense that something is not right, and they may be confused and fearful. It is advisable to share the news with them sooner than later.¹⁵

Speak to your doctor to refer you to a child psychologist if your children need professional help in coping with their feelings and the drastic changes happening around them.

- CHILDREN PREFER TO BE TOLD THE TRUTH. Use the word "cancer" when speaking to children. It is vital for them to know the difference between a critical illness and an ordinary ailment. In this way they can better understand that your disease will be there for a long time.¹⁵
- Adults, too, will find it hard to process the information at first. They may need time to think about it
 and what it means to them.¹⁵
- BE READY TO ANSWER CHALLENGING QUESTIONS. If your children are very young, think
 about the words you want to use before you speak with them. This can help keep things simple and
 make it easy for them to understand.¹⁵
- CHILDREN OF ALL AGES CAN HAVE ANXIETY AND FEARS that you may die, and they may
 ask you why your cancer has returned or what treatment you will be getting.¹⁵
- EVEN IF YOUR CHILDREN REMAIN SILENT, IT DOES NOT MEAN THEY DO NOT HAVE
 QUESTIONS. Children tend to hide their feelings or thoughts at times. You could ask your child if
 he/she has any questions and let them know that you are there to answer any questions or clear
 any doubts they may have.¹⁵

You can also surf for online resources of cancer support groups that can help you choose the words and type of language. You will certainly find one that is easier for you to use. You can also provide older children with reliable information on mBC, as your children will also be searching for information themselves which can be unreliable and incorrect.¹⁵

Important Things To Consider About Telling Others

- You do not have to tell everyone immediately. Take your time.
- Keeping it a secret or trying to protect other people is normal but it can tire you out.
- Most people prefer you to be honest about it. However, be ready to receive various responses or no reaction at all.
- There are resources available to support your children and help you cope with daily life so you can keep things as 'normal' as possible.



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My Relationships

Questions For Your Doctor Or Nurse

1.	Do you have any guideline for me on how I can tell others about my diagnosis?			
2.	Can you refer me to a child psychologist who works with serious illness in the family?			
	(a) Name: Tel:			
3.	Give me information or brochures about the effect of the diagnosis on my family?			
4.	Can my treatment affect my intimate relations with my partner?			
5.	What did I learn?			
6.	What is important to me?			
7.	Any other questions?			

ME AND METASTATIC BREAST CANCER



1.6 My Work

Managing my Working Life and Responsibilities

"I chose to tell my boss and asked that she tell everyone in my department. I wanted everyone to know why I wasn't at the top of my game. They were wonderful. My boss allowed me to work from home and encouraged me to take more breaks ... I threw myself into work as much as I could. It gave me a sense of normalcy, and it was the first place that I would forget about cancer."

mBC patient, Australia

You may want to make changes to your work and personal life to create a balance so that you can make time for treatment and focus on your health as well.

This can affect your financial situation and your ability to contribute to the family's income. These changes can be difficult to cope with, as it is you, who are facing your cancer. Anyone in your situation will feel this way. It is important to think about all possible options including your rights at work. Plan your finances early when you are still feeling physically strong.

Can I Continue To Work?

The effect of a diagnosis of mBC on work life may be different for every person. 16 Some women may wonder if they should continue working, while others may feel the need to work to support the cost of treatment for mBC. 16

The stability of your financial situation is a likely factor to decide whether to keep working or not. There are those who want to continue working to maintain a routine or be gainfully employed. Or you may rather want to do the things that you had put off for years instead of working.

Work is often a huge part of our lives, and it can be strange to think about not working. If you are not sure whether to keep working, it might be useful to wait until you have started your treatment, and to see how it affects you mentally and physically.

Breaking The News Of My Diagnosis To My Employer

It is important to understand your employment rights before having a conversation with your employer. Having a discussion with your employer alone can be helpful in enabling both of you to see how you can get support. Your employer also needs to know that you may need more time off work and perhaps work flexi-hours. It is not necessary for you to share all the details of your condition and treatment. In larger organisations, having a chat with the human resource officer is also advisable. You can get information on the type of support your employer can offer you.

If you are concerned that you may lose your job due to discrimination by your employer, seek the help of the labour department near you. Contact your doctor and the local support group for help.



ME AND METASTATIC BREAST CANCER

My Work

Can I Get Financial Compensation If I Stop Working?

If your condition prevents you from working, you can apply to SOCSO (PERKESO) for monthly financial assistance or apply to EPF to withdraw from your Account 2 to pay for medical expenses for mBC as it is a critical illness. Consult your oncologist regarding these applications. You can also seek funding from Zakat. if you have an insurance package that covers both medical expenses and daily allowance for being unable to work, do submit your claims for compensation.

Think carefully, find out the procedures, get all the legal and financial facts and get the right advice before you decide to stop working.

What To Consider If You Plan To Continue Working Or Not?

- If you decide to stop work or reduce your working hours you will need to be prepared for a reduced income or no monthly income at all.
- Although you do not have to tell your employer about your diagnosis, it may be useful if your
 employer gets the information directly from you.
- You may also want to get the advice of a financial planner.

ME AND METASTATIC BREAST CANCER



My Work

What To Ask Your Doctor

1.	How long can I continue to work while I am getting treatment?
2.	How and when will we know that the treatment is working for me?
3.	Will I experience the feeling of being better on certain days so I can go to work?
4.	What do other patients like me do regarding their work?
5.	What did I learn?
6.	What is important to me?
7.	What other questions do I have?

Part 2

MORE INFORMATION FOR YOU



ME AND METASTATIC BREAST CANCER



2.1 My mBC in Detail

How does the doctor diagnose and monitor the growth of metastatic breast cancer?

In order to get the best possible care, you should be able to trust and feel comfortable with your doctor and the facilities. This section provides you detailed information about your diagnosis and treatment, and it addresses some difficult questions:

- How is metastatic breast cancer (mBC) diagnosed?
- · What are the different types of mBC?
- What are the tests to be done for your diagnosis?

What Is mBC?

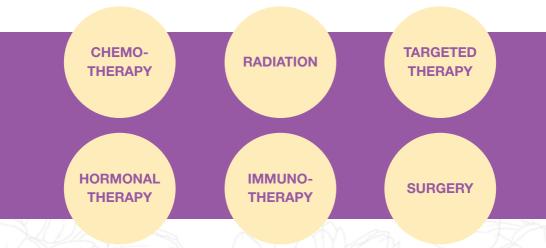
mBC is cancer that has spread from the breast to different parts of your body. The tumours in these parts are called metastases. Metastasis can occur in the bones, liver, lungs, or brain. However, the condition will still be called Breast Cancer, metastasised to the bones or liver or lungs or brain.

Different Types Of mBC

So as to give you the best possible treatment, the doctor has to determine what type of cancer you have.

Breast cancer can have genetic markers of HER2 and hormone receptors (HR) on your breast cancer cells. These markers can indicate the best treatment for you.⁵

Chemotherapy, radiation, targeted therapy, hormonal therapy, immunotherapy and surgery are the difference treatment choices.⁵





ME AND METASTATIC BREAST CANCER

My mBC in Detail

There are four main types of mBC 18,19:

1. Hormone Receptor-Positive, HER2-Negative

About 65 percents of breast cancers are positive for oestrogen receptors, while 80 percents of breast cancers are positive for progesterone receptors (receptor for the progesterone hormone).

2. Hormone Receptor-Negative, HER2-Positive

When the breast cancer cells generate too much HER2 protein, they grow faster than normal cells, and, also, faster than other cancer cells. This is called HER2-positive breast cancer. Between 15-20 percents of breast cancer patients are HER2-positive.

3. Hormone Receptor-Positive, HER2-Positive

The HER2 and hormone receptors have "tested positive" in this type of breast cancer.

4. Hormone Receptor-Negative, HER2-Negative, Also Called Triple-Negative

This type of breast cancer does not have HER2 or the hormone receptors oestrogen and progesterone. About 15 percents of mBC are triple-negative.

If you have a recurrence of breast cancer, your cancer cells have to be tested again for HER2 and hormone receptor status because these can be different from the original cancer.

Why Is My Cancer Called Stage IV Breast Cancer?

Breast cancer is categorised into different stages that is, from Stage 0 to IV depending on the size of the tumour and whether it has spread to the nearby lymph nodes and other parts of the body.⁵

mBC is Stage IV breast cancer 5

Stage IV breast cancer means the cancer has spread or metastasised to the other organs in the body.5

Doctors also use another method to do staging of your breast cancer called the **TNM classification** where $\bf T$ stands for tumour, $\bf N$ for nodes, $\bf M$ for metastasis.⁵

What Is The Difference Between mBC And Other Stages Of Breast Cancer?

Stage 0 is noninvasive	This cancer is found only inside the ducts or lobules. It has not spread to the surrounding breast tissue. ⁵
Stages 1, 2 and 3 are invasive	Cancer has grown outside the ducts, lobules or breast skin. Cancer might be in the axillary lymph nodes. ⁵
Stage 4 is metastatic	Cancer has spread to distant sites. Stage 4 mBC can be your initial diagnosis or it may have developed from earlier stages. ⁵

ME AND METASTATIC BREAST CANCER



My mBC in Detail

Where Does The Cancer Spread?

Your doctor will conduct imaging tests to determine where your cancer has spread. These imaging tests will enable your doctor to better ascertain your treatment plan.⁵

Where are the sites (places) and what are the symptoms of the different metastases?

- The most common sites for breast cancer metastases are the bones, the liver, the lungs, and the brain.⁵
- There is no set formation for the sites where the breast cancer cells can spread. Each case is different.
- Each type of metastasis could show certain symptoms as described below.¹

Inform your doctor if you get any unusual symptoms. Do not wait too long.

Symptoms Of Metastatic Breast Cancer

Brain	Symptoms will differ when the cancer affects different parts of the brain. Some symptoms include headache, nausea, exhaustion (fatigue), weakness, confusion, memory loss, speech problem and fits (seizures).
Lungs	Lung metastasis usually does not cause symptoms. If a lung metastasis does cause symptoms, they include pain or discomfort in the lung, shortness of breath, persistent cough, and others.
Liver	Liver metastasis often does not cause symptoms. If a liver metastasis does cause symptoms, they include pain or discomfort in the mid-section, fatigue and weakness, weight loss or poor appetite, fever, and others.
Bone	The most common symptom of bone metastasis is a sudden, noticeable new pain, bone fractures due to bones getting weaker, and spinal cord compression. ^{1,5} Breast cancer can spread to any bone, but usually spreads to the ribs, pelvis, or the long bones in the arms and legs. ¹

My Guide To Cancer Monitoring

Tests and scans will be used at diagnosis and, also, again throughout your treatment and check-ups. These tests will enable your doctor and you to know whether your treatment is working and the tumour has stopped growing (stable disease) or it has shrunk (remission), or whether the treatment has to be changed because the tumour is growing again (progression).^{5,20}

Lab Tests

These are blood tests where your blood will be sent to the laboratory for testing. If you have had cancer in the past or having active treatment, your haemoglobin, white blood cell and platelet cell count will also be checked routinely.

Unusually high or low levels of certain substances in your body can be a sign of cancer. Therefore, lab test of blood, urine or other fluids that measure these substances will enable your doctor to make the diagnosis. However, abnormal lab test results are not a confirmed sign of cancer.

ME AND METASTATIC BREAST CANCER

My mBC in Detail

Imaging Procedures

In imaging, the doctor will be able to see the inside of your body via photographic images to check for any tumour. The photos can be made using different methods^{5,21}:

CT or CAT SCA	ULTRA	ASOUND	PET SCAN PET/CT SCAN
X-RAYS	N	//RI	NUCLEAR or RADIONUCLIDE SCAN
CT or CAT Scan	This computed tomography (CT) or computerised axial tomography (CAT) machine is linked to a computer and it takes several photographs of your organs. You may get an injection of a dye or contrast material to focus on areas in the body and to make it easier to see the images. This procedure may take at least half an hour at the Imaging Department in the hospital.		
Ultrasound	An ultrasound uses high-energy sound waves to form pictures of the inside of your body. This imaging test is useful to show small areas of cancer that are on or near the surface of the body. ⁵		
PET Scan PET/CT Scan	A positron emission tomography (PET) scan uses a radioactive drug called a tracer to identify the location of your cancer and to see how it is growing. Cancer cells show up as bright spots on PET scans. CT may be combined with PET and this combined test is called a PET/CT scan. ⁵ This procedure can take a few hours and it is carried out in the Nuclear Medicine department of the hospital.		
X-rays	An x-ray uses low-dose radiation to take pictures. Your doctor may conduct x-rays if your bones hurt or were abnormal on a bone scan. ⁵ This test is done at the Imaging Department of the hospital.		
MRI	A magnetic resonance imaging (MRI) scan uses radio waves and powerful magnets to take pictures of the inside of your body. ⁵ This session takes a few hours and it is done in the Imaging Department of the hospital.		
Nuclear (or Radionuclide) Scan	You will get an injection of radioactive material called a tracer. It trave through the blood stream and goes to certain bones or organs. A scand detects and measures the radioactivity. The scanner makes photos bones or organs on the computer screen or on the film. This is call radionuclide scan. ²¹ Do not worry, your body will get rid of the radioact material quickly. This procedure takes place in the Nuclear Medic department at the hospital. Examples of this scan is bone scan and P scan. ²¹		rtain bones or organs. A scanner. The scanner makes photos of en or on the film. This is called body will get rid of the radioactive place in the Nuclear Medicine

ME AND METASTATIC BREAST CANCER



My mBC in Detail

Biopsy

Biopsy is a procedure whereby your doctor removes a sample of tissue or fluid and sends it to the lab for testing. A pathologist will test this biopsy sample and write a report called a pathology report. Your doctor may order a biopsy even if you were treated for earlier stages of breast cancer, as the tumour may have changed or mutated, impacting treatment options. The sample may be removed using one of the following methods:

· Using A Needle

The doctor uses a needle to remove tissue or fluid. A biopsy is usually performed with guidance from a CT scan or ultrasound. 20

Endoscopy

The doctor examines areas inside the body using a thin, lighted tube called an endoscope. The scope is inserted through a natural opening, such as the mouth. Then, the doctor uses a special tool to remove tissue or cells through the tube.

Surgery

Surgery can be excisional or incisional.

- Excisional biopsy: the surgeon removes the whole tumour and usually a bit of the surrounding healthy tissue is also removed.
- · Incisional biopsy: the surgeon removes part of the tumour.



ME AND METASTATIC BREAST CANCER

2.2 My Treatment A to Z

Learning about the different treatment options and side effects

My Treatment Options

The purpose of your treatment is to prevent your cancer from spreading further, to reduce the pain due to the cancer, and to give you the best quality of life possible.

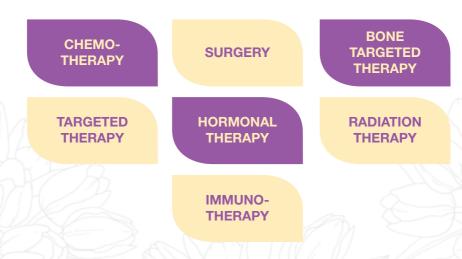
This section will enable you to know more about:

1	The Different Types Of Cancer Treatments Available And How You Will Take Them
2	How Your Doctor Measures If Your Treatment Is Working
	Importance Of Clinical Trials
7	Help Manage Side Effects Of Treatment

Main Types Of Treatment

The main goals of mBC treatment are to make sure that you have the longest survival possible with the disease, fewest possible side effects from the cancer and its treatment, and the best and longest quality of life possible.⁶

The main types of treatment for mBC are explained below.5



ME AND METASTATIC BREAST CANCER



My Treatment A to Z

Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells; by preventing their growth and division.⁶ There are different types of chemotherapy drugs that are used to treat mBC.⁵ Chemotherapy can be given on many different schedules, and is often given continuously as long as it is working against the cancer and the patient is not experiencing too many side effects.⁶

Some chemotherapy drugs are pills that you can take at home. Other drugs are given by intravenous line or through a chemoport at the hospital.

Chemotherapy may not be suitable for all types of mBC. Your doctor will decide whether you need chemotherapy or not and this depends on your health status, menopausal status, the type of medicines you have been given in the past and the type of cancer you have.

There are different types of chemotherapy. If you suffer from too many side effects with one, your doctor will change to another type of chemotherapy.

Radiation Therapy

Radiation therapy consists of high-energy rays that can kill cancer cells. In mBC, radiotherapy is given to control your cancer. Radiation therapy can be given alone or before or after surgery to slow the growth of the cancer. It is also applied to reduce bone pain where it is radiated on the bone metastases that cause the pain.^{5,8}

Radiotherapy in mBC is given either as one dose or a short course over a few days in an outpatient setting. Side effects of radiotherapy can be different depending on which part of the body is getting radiated.

Targeted Therapy

Targeted therapy is the use of medicines to block the specific way in which breast cancer cells divide and grow, thus controlling the progression of the cancer. Targeted therapy is recommended for women with a certain type of breast cancer. There are several medicines that target HER2 receptors, which are effective for patients who have high levels of HER2 in the cancer cells.^{5,6}

They are also prescribed for menopaused women with hormone receptor positive HER2 negative type cancer.^{4,5} However, they do not work for those without HER2 in the cancer cells.

Targeted therapy is also used for patients with mBC who also carry the gene for hereditary breast cancer (BRCA). The treatment which is specific for this condition involves taking a medicine called PARP inhibitors.⁶

CDK4/6 inhibitors are a class of targeted therapy that target a group of enzymes within the cancer cell, called CDK4 and CDK6. CDK is cyclin-dependent kinase, and it is an important enzyme responsible for cell division and growth. Breast cancers that are of ER/PR positive and HER2 negative, are more likely to have reliance on the enzymes CDK4/6 in the growth and progression of the cancer. The CDK4/6 inhibitor drugs target the CDK4/6 enzymes and interrupt the function of the enzymes which results in inhibition of the growth and division of ER positive HER2 negative type of cancerous (malignant) cells.^{5,6}. CDK4/6 inhibitors such as Palbociclib, Ribociclib, and Abemaciclib have been developed to inhibit these enzymes and reduce the growth of the cancer cells.⁶

They must be given together with hormone therapy, aromatase inhibitors or fulvestrant in post-menopausal women, while in pre-menopausal women, additional goserelin to induce a menopausal state is necessary before patients can start on the hormone therapy and CDK4/6 inhibitors.⁵⁶



ME AND METASTATIC BREAST CANCER

My Treatment A to Z

Hormonal Therapy

Hormonal therapy is given to patients whose breast cancer is sensitive to hormones, especially oestrogen. There are various hormone-based therapy drugs that work differently on the body.⁶ This is given in the form of pills or injections.²² They may be better than chemotherapy in the patients with hormone receptor positive HER2 negative type of cancer.⁴

Before your doctor decides to treat you with hormonal therapy, and which is the suitable type, he/she will have to consider whether you have menopaused, the type of treatment you have already received or are receiving, how long it had been before your cancer recurred, how widespread the cancer is and if you have symptoms that need to be managed.^{5,6}

Immunotherapy

Immunotherapy is the use of drugs that work on activating your immune system to kill the cancer cells. Doctors will perform tests on your cancer tissue to determine if your cancer is suitable to receive immunotherapy. It may be given alone or with other types of treatment (e.g. chemotherapy) in suitable patients.⁶

Bone Targeted Therapy

Bone stabilising agents are given to treat metastases in the bone. They help to make your bones stronger and can reduce bone pain and risk of fractures.⁵ They can be taken as pills or injections. Injections are given every four weeks or every 12 weeks.

Surgery

Surgery is not the main or primary treatment option for mBC. It may be used to remove the tumour, to reduce the tumour load, improve your body function or relieve pain.^{5,6} If you undergo surgery, you will also get drug therapy and/or radiation.

TREATMENTS FOR SPECIFIC CANCER TYPES 5,6

Cancer Type	Treatments That Can Be Used	
Hormone receptor- positive, HER2-negative	Drugs that suppress the production of hormones oestrogen and progesterone, or drugs that block the receptors for these hormones (hormonal therapy) CDK4/6 Inhibitors	
Hormone receptor- positive, HER2-positive	HER2-targeted drugs and hormonal therapy	
Hormone receptor- negative, HER2-positive	HER2-targeted therapy and chemotherapy	
Hormone receptor- negative, HER2-negative Also called triple negative breast cancer (TNBC)	Chemotherapy Immunotherapy	
Germline BRCA Mutation	PARP inhibitor therapy	

ME AND METASTATIC BREAST CANCER



My Treatment A to Z

How Often And For How Long Is My Treatment?

Treatment for mBC patients is life-long compared to early breast cancer patients whose treatment is for a certain length of time. In mBC, treatment has to be continued in order to control the cancer and prevent it from getting worse. You will need continuous treatment for symptoms of metastases. You will get one drug or a mixture of drugs. ^{5,6} After some time, you may get different drugs.

There are many treatment options for mBC. However, not everyone responds similarly to one particular treatment. You may stop taking a certain treatment for a while because it cannot control your cancer. 5 Sometimes treatment is stopped or switched due to side effects.

You may be prescribed drugs that are given intravenously in the hospital every week or every two or three weeks or less often. Radiotherapy is given over a certain period of time.^{5,6} Radiotherapy and drugs may be given to you alternately.

REMEMBER, THERE IS NO BEST WAY TO TREAT MBC. EVERY PERSON'S CONDITION IS DIFFERENT

Some patients may want to stop treatment because either they feel better or it may make them feel worse. It is important to continue with treatment for as long as your doctor advises. Talk to your doctor if you are thinking of stopping the treatment.

How Will My Doctor Know If My Treatment Is Working?

Your doctor will do several tests over time to find out if the treatment is working. These tests may include:

Blood tests	Your doctor may carry out blood tests to monitor the level of tumour markers in your blood, which may be indicative of disease progression. ²³ Not every cancer produces tumour markers. Each patient is different. Blood chemistry tests may be performed to evaluate how well certain organs (e.g. liver, kidney) are functioning. ²³
Tumour markers	Tumour markers are proteins or other substances that are usually, but not always, found in the blood when tumours are active in the body. ²³ If the level of tumour markers is high, it shows that the disease is active. The doctors use tumour marker tests over time to monitor whether the treatment is working on you. Not every cancer produces tumour markers. Each patient is different.
Imaging tests	Imaging tests such as CT scan, MRI, X-rays, bone scan, and PET scan may be carried out to check if the cancer has spread to other sites. ²³ The more the cancer spreads in the body, the more serious it is, and your treatment may need to be changed.

ME AND METASTATIC BREAST CANCER

My Treatment A to Z

Biopsy	Your doctor may conduct a biopsy of suspicious tissue to determine if it is cancerous. ²³
Level of circulating tumour cells	Circulating tumour cells (CTCs) are a rare population of cells which are detectable in the blood of cancer patients. CTCs are regarded to be biomarkers of disease progression. ²⁴ Your doctor may monitor the level of CTCs in your blood to see how well the treatment is working on you. However, this test is still not standard and is expensive; hence, is not routinely done.

What Do I Need To Know About Clinical Trials?

Clinical trials are research studies on patients who volunteer to participate. These research studies examine whether a new treatment is effective, can be tolerated, and, also, whether it is better than other treatments for a specific condition. Your doctor may propose that you participate in a clinical trial to get access to a new drug that is being tested for your type of cancer. Not every patient is suitable for a clinical trial.²⁵ You can discuss with your doctor regarding the role of clinical trials in your treatment plan at any time.

The Benefits Of Participating In A Clinical Trial ²⁶

- You can have access to a treatment that is not available yet, and is likely to prolong your life or improve your quality of life.
- You would be getting regular and careful attention from some of the best cancer doctors.
- The treatment offered may be free or low in cost.
- You would be contributing to research that may save lives in the future.
- Deciding to participate in a clinical trial is one way to take an active role in your own cancer care.

The Possible Disadvantages 26

- You may not be able to choose which treatment you get as you would be randomly assigned to a specific treatment which may be a placebo (sugar pill).
- The new treatment may not work for you, even if it benefits other people in the same trial. It is also
 possible that the new treatment may not be as effective as currently available treatment options.
- The new treatment may be associated with more severe side effects compared with current treatments. However, the clinical trial has been approved by the authorities in our country and by the local ethics committee responsible for your doctor's practice. These processes help to make sure that the new treatments in the clinical trial are safe and effective enough to be tested in the
- Participating in a clinical trial may require you to undergo more frequent testing and doctor visits.

Before joining a clinical trial, it is important for you to get as much information as possible. You will receive information pamphlets about the trial, and you will also need to give your consent to participate in the trial.²⁵

Ask your doctor and the medical team all the possible questions about the trial before joining. You can ask questions at any time, including even after the trial has started.

You can leave the trial at any time.²⁵ If you are thinking about leaving the trial, discuss with your doctor first.

ME AND METASTATIC BREAST CANCER



My Treatment A to Z

Questions To Ask If You Are Thinking Of Joining A Clinical Trial

1.	What is the purpose of the trial?
2.	How long will the trial last?
3.	What are my responsibilities if I agree to participate in the trial?
4.	What are my possible benefits?
5.	What are my risks, including side effects?
6.	What type of therapies, procedures and/or tests will I have during the trial?
7.	Will I be able to take my regular medicines during the clinical trial?
8.	Where will I have my medical care and follow-up?
9.	Who will be in charge of my care and follow-up?
0.	How will this trial affect my daily life?
11.	Can I meet another patient who is participating in the trial?
2.	Do I need to pay for any part of the trial?
3.	Will my travel cost be covered while I am on the trial?
4.	Can I leave the clinical trial at any time?



ME AND METASTATIC BREAST CANCER

My Treatment A to Z

Possible Side Effects From My Cancer And Treatment

Side effects depend on the type of treatment you are being given. It may vary with different drugs.6

Remember, although you are getting the same drug, you may not have the same side effects⁶ as someone else because everyone responds differently. Tell your doctor if you are having side effects. To find out whether the side effects are due to the treatment or the cancer, ask your doctor who will be able to help you.

Speak to your doctor immediately if the side effects of your treatment are difficult to tolerate. The doctor may want to adjust the dose of the treatment or change the drug so that you do not have to suffer from the side effects.

Common Side Effects

Pain

Cancer does not always give pain, but if you experience pain, let your doctor know. He/She can give you medicines to help, and, also, refer you for pain relief therapies. Record down how often and how intense the pain is, or if it gets worse at night or when you are doing something specific. You will feel much better when your pain is reduced. It can also reduce fatigue, anxiety, depression and enable you to sleep and feel better. If you need a stronger medication like morphine, do not worry that you will get addicted to it because the morphine will be used to reduce the pain. Cancer pain can be dull, achy, sharp or burning. It can be constant, intermittent, mild, moderate or severe. Always remember that cancer pain is manageable and controlling your pain is important to your treatment.²⁷

What You Need To Tell Your Doctor

- How severe is the pain?
- What type of pain do you have?
- Where do you feel the pain?
- When do you feel the pain?
- What brings on the pain?
- What makes the pain worse or better?
- What pain relief measures do you use?
- How long does the pain last?

Cancer pain can be controlled with medicines and complementary therapies. Complementary therapies include acupuncture, massage therapy and relaxation techniques. Exercises can also help reduce pain.

Fatique

Fatigue is commonly described as feeling tired, weak or exhausted. Fatigue could be due to the physical effect of the cancer or the side effect of treatment. It could also be due to a change in sleeping pattern, hormonal changes, poor nutrition, anaemia, as well as anxiety, stress or depression.²⁸

How To Manage Fatigue

- Take medications to treat the underlying cause of your fatigue.²⁸
- Take it easy and make sure you have enough rest.²⁸
- Conserve your energy.²⁸
- Ask for help when you need it.
- Do the most important tasks first and leave the rest for later.
- Maintain your energy by drinking lots of fluids and eating well.²⁸
- Limit or avoid caffeine and alcohol.28
- Do light exercises throughout the week to preserve your energy levels.²⁸
- Do not feel bad if you need to cancel plans when you feel very tired.
- Take regular naps.

ME AND METASTATIC BREAST CANCER



My Treatment A to Z

Nausea and vomiting

Nausea is a common side effect of most breast cancer treatments.²⁹ Vomiting is usually the result of nausea. mBC treatment such as chemotherapy, targeted therapy and hormonal therapy may cause you to vomit.³⁰

How To Manage Nausea And Vomiting 29,30

- Take anti-nausea medications. 29,30
- Drink clear liquids such as water, broth or herbal tea to stay hydrated.³⁰
- Do gentle exercises and breathe in fresh
- · Try taking lemon.
- · Eat small meals at regular intervals.
- Eat small amounts of dry, bland food such as plain rice or dry crackers.^{29,30}
- Eat ginger-based foods to help ease the nausea.²⁹
- Open the windows in your house to let in fresh air.
- · Avoid spicy, oily or very sweet food.

Insomnia

You may have insomnia if you frequently cannot fall asleep, cannot stay asleep, or do not get enough sleep to be rested. Certain treatments such as chemotherapy, hormonal therapy, some forms of targeted therapy, and pain medications may contribute to insomnia.³¹ Talk to your doctor if you have trouble sleeping.

How To Manage Insomnia³¹

- Your doctor may either recommend or prescribe sleeping aids suitable for you.³¹
- Complementary techniques such as massage, meditation, and yoga may help you relax and sleep well.³¹
- · Practice mindfulness.
- Keep a diary at your bedside to write down thoughts or worries that keep you awake.
- Exercise.31
- Avoid alcohol, nicotine and caffeine.31
- Set a regular time to go to bed and wake up to help you relax and fall asleep more easily.³¹
- Make sure your room is quiet and dark enough to create a conducive atmosphere for sleeping.

Lack of concentration and cognitive changes

Breast cancer treatments such as chemotherapy, radiotherapy, and hormonal therapy have been associated with cognitive impairment³² such as forgetfulness, loss of concentration, trouble with speaking or recognising people or things. Not being able to focus mentally can be due to emotional and physical changes. It may not be due to treatment. Do let your doctor know if you face problems concentrating.



ME AND METASTATIC BREAST CANCER

My Treatment A to Z

Hair loss

You may lose your hair or may experience thinning or drying of your hair due to chemotherapy. Additionally, hormonal therapy such as tamoxifen and aromatase inhibitors may cause hair thinning. In preparation for hair loss and to be in some control of the situation, you may want to cut your hair short. 30 Do what you think is right.

Where You Can Get Help For Hair Loss

- You can contact BCWA to select a wig and get an appointment with BCWA's volunteer hairstylist to get your head shaven and your wig styled. If you are far away from BCWA, get help from your local hospital or support group.
- For some, but not for all chemotherapy, scalp cooling using a scalp-cooling machine during chemotherapy may be an effective way to prevent hair loss.³³ Ask your doctor whether this may help for your particular treatment and whether scalp cooling is <u>offered</u> at the <u>hospital</u>.
- Some cancer centres provide resources for wigs and may recommend scarves and caps for head coverings after hair loss.³³
- Patient support groups can provide advice and support on coping with the changes in how you look.



ME AND METASTATIC BREAST CANCER



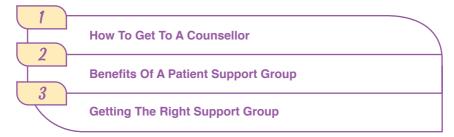
2.3 My Support

Coping with my feelings

Getting Support For My Feelings

The emotional impact of getting the news of diagnosis of mBC continues even after you leave the hospital. You may find it helpful to talk about your fears, worries and frustrations. While some women choose to share their feelings with friends and family, others may prefer to talk to cancer support groups. Your doctor may be able to recommend experts such as an oncology social worker, psychiatrist, psychologist or a counsellor for you to talk to.³⁴

The information below may help you to get support to cope emotionally and physically with your condition. In this section you will learn



The Type Of Support Available For Me

Besides your doctor treating your body and controlling the progression of your cancer, there are other aspects of your life that need attention. There is a need to adjust to the new changes and continue to live your life with cancer.

Many mBC patients like you need emotional and psychological support to help you cope with your situation and learn to live with mBC every day.

Firstly, ask your doctor or nurse where you can get emotional support. Emotional support is an important part of your total care and it helps you to get through your medical treatment as well.³⁴

Your nurse can also help you to cope with the physical symptoms such as pain and other side effects of your treatment.



ME AND METASTATIC BREAST CANCER

My Support

Family and friends can give you support but they themselves may be affected because they are too close to you.

Asking for professional help is a sign of strength and you are helping yourself, which is important.

Patient Support Group

Every individual is different in how she chooses to cope with her situation. You may want to manage it privately with your family and friends. But you may also find benefit from a patient support group.

Support groups are groups of people with similar situations as yourself. A support group usually meet on a regular basis to share their views and concerns in handling their issues.³⁵

The right support group can give you a safe space to share your feelings, fears and concerns. You can be open with the members of the support group as compared to being hesitant about certain issues when speaking with family and friends.

Being part of a group of women living with mBC can enable you to feel you are not alone experiencing the disease, the treatment and its side effects including fatigue. The experiences and mutual sharing with other women with mBC can give you the strength and knowledge on managing your situation.

Is The Patient Support Group Suitable For Me?

The majority of patient support groups are for women with early breast cancer and these groups have difficulty relating to what you are experiencing because your cancer is more advanced than theirs.

Try to seek the support of a group that is specifically for women with mBC.

- Try asking other women with mBC in your hospital if there is any such support groups. You could
 also get your nurse to refer you to an appropriate group.
- Try to search online for support groups for women living with mBC. You could also join online groups or WhatsApp groups. Contact Breast Cancer Welfare Association Malaysia (BCWA) if you wish to join the WhatsApp support group for Pink InspirerS who are women with mBC.³⁶



ME AND METASTATIC BREAST CANCER



2.4 My Well-being

Getting to know how complementary therapies can help me

Caring For My Body And Mind

There are many things you can do to help yourself. Be gentle on yourself. You will have good days and bad days, followed by more good days. You cannot be feeling positive all the time. When you are stressed, remember this can change at any time. Some women will find complementary therapies very helpful in easing the symptoms of mBC, lessen treatment-related side effects, and improve their quality of life³⁷ when their stress, anxiety and physical side effects can be managed.

In this section you will get to know about:

DIFFERENT TYPES OF COMPLEMENTARY THERAPIES

HOW TO CHOOSE A THERAPIST OR SUPPORT CENTRE

How Are Complementary Therapies Helpful?

Complementary therapies can help balance, strengthen and energise you physically, mentally and emotionally.³⁷ While it is difficult to guess what will work for you, there are some approaches that have helped other women which may be helpful for you, too.

Be mindful that complementary therapy approaches are not a replacement for medical treatment but an additional care for you.³⁸ Inform your doctor if you are receiving any complementary therapy.

Complementary therapy is an addition to clinically approved treatment.³⁸

Types Of Complementary Therapies¹²

Complementary Therapy	Details	
Acupuncture	Acupuncture is a central part of traditional Chinese medicine. In acupuncture, the practitioner places sterile, hair-thin needles into acupuncture points (specific points on your skin), and gently moves them to stimulate your nervous system. It is believed that acupuncture may help relieve symptoms of breast cancer and its treatment-related side effects. ³⁸ It can be sought from Institut Kanser Negara, Pusat Perubatan Universiti Malaya, some private hospitals and commercial centres in the community.	
Art Therapy	Art therapy can help you express your emotional or physical issues through art. It is more like talking with yourself and introspecting about the purpose of life. It can create positive mental and physical well-being. ¹²	

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My Well-being

Massage therapy is believed to boost immunity and ease anxiety, pain and fatigue. Make sure you work with a licensed practitioner who is trained to avoid the sensitive and affected sites of your body.38	
Find a quiet place away from the distractions of daily life to help your mind and body become calm and relaxed. There are many different practices of meditation and all are forms of <i>mindfulness</i> . Mindfulness is not attached to any religion. It just means being aware and present in each moment. Yoga is a practice of moving meditation.	
Music and sound can help you express your emotions to cope with the disease and your treatment.	
Reiki, an ancient Japanese healing technique, involves the practitioner placing his/her hands lightly on or over specific parts of your body to manipulate bioenergy. This is to channel energy, ensuring its smooth flow through your body that can help you on a physical, psychological, emotional and spiritual level. Most women who have tried Reiki report feeling relaxed and having reduced pain. ¹²	
Tai Chi and qigong are ancient Chinese practices that are centred on manipulating your energy via gentle movements while being focused on breathing and meditation. ¹²	
Yoga has been shown to increase energy, vitality and quality of life. Women with breast cancer should opt for gentle styles of yoga such as hatha and restorative yoga. These styles of yoga are mainly focused on breathing, gentle movement and relaxation. 12	

Choosing The Right Complementary Therapist

When you have decided to go for complementary therapy, it is important to choose the right therapist.

You can check the qualifications and experience of complementary therapy practitioners to ensure that they are reliable. You can also check with other cancer patients who may be able to guide you.

Your doctor or nurse or someone you trust can also help you to seek a reliable complementary therapy practitioner.

ME AND METASTATIC BREAST CANCER



2.5 My Relationship

Sharing my diagnosis with friends and family

The Impact Of mBC Diagnosis On Family And Friends

When someone is diagnosed with mBC it affects the whole family. Your loved ones and you will need to adjust to this new situation, and it can be a very difficult time for all of you.¹³

Generally, it is better to be open and honest about your condition. Keeping it a secret can be exhausting and cause more stress for you. In this section you will learn:

1	
	About Your Sex Life
(2)	
	Talking About Your Diagnosis
3	
	Specific Help For Telling Your Parents
4	
7	What To Say To Your Friends

Can I Still Have Sex?

Sex can still be an important part of your life even after cancer. Nevertheless, your ability to feel good about sex can be disturbed by the symptoms of your cancer, the side effects of treatment and the emotional crisis you are facing. If you do not have the desire for sex, remember that this is common. Sex can become painful or uncomfortable. However, this does not happen to everyone. 39,40

Sexuality is more than the physical act of sex. It includes feelings and actions you have for the person you love. The diagnosis may make you feel emotionally disconnected from your partner. You may suffer from body image issues. Your partner may also have his own fears and barriers towards sex. For example, he might be worried that by having sex he may make the cancer worse. 39,40

While it may be embarrassing to talk about it at first, you will realise that talking can help break down these barriers with your partner. This is not an easy topic to discuss. These are common difficulties people face.⁴⁰

It may help if you speak to your doctor or nurse, or the counsellor or the support group members who may have faced a similar situation in the past. Do not feel embarrassed to talk to them.



ME AND METASTATIC BREAST CANCER

My Relationship

Hints On How To Share Information About Your Diagnosis

Talking to your loved ones about your diagnosis can be extremely challenging.¹³ Everyone around you may cope with your cancer news differently. While some people recover fast, others will need more time to come to terms with your illness. Others will try to be stoic and strong for you. Some friends will have difficulty about what to say and how to comfort you.

Dealing with the reactions of friends and family members can be difficult. Here are some hints on how you can help people come to terms with your cancer:

Tell Them How You Feel 34

Most often people do not know what to say or how to react around you. While it seems unfair, you may need to bring up the issue and tell them how you are feeling and what you need from them.

Ask For Help 34

Tell them how they can help you. For example, you want them to drive you to the hospital, or accompany you to your hospital appointments and therapy sessions, or if you need a hug or need someone to listen to you.

Offer Information And Support ³⁶

Your family and friends may need support themselves, so let them know that they, too, can get it from the local support group.

Telling Your Parents

Whatever your age, you are still a child to your parents. All parents have a natural tendency to protect their child. You may find it hard to tell your parents that you have mBC if you feel they will have difficulty coping with the news. Nobody wants to make their parents suffer, particularly if they are old.⁴²

Your parents may have a more intense emotional reaction to your cancer. They feel helpless about your condition. You can break the news to them step by step and do it when you are ready to handle the situation. They may try to do more than you want them to do and interfere in your care. This may cause conflict and stress. 42

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My Relationship

You can tell them that you will update them about your situation regularly.

You can also give them responsibilities and get them involved in your journey.⁴²

Reaching out to other family members can help in breaking the news to your parents.

Discussing Cancer With Friends

You can decide how and what you want to tell others about your cancer. Take your time and tell other people when you feel the time is right. It is alright if you want to wait until you have a grip of your diagnosis before you share it with your wider circle of friends and relatives.⁴³

Relationship with friends may change after your diagnosis. While some relationships get stronger, others may not be so. Not everyone can handle cancer, and that is why some friends may have difficulty coping with their own feelings. Without realising, some friends may say or do something that could be insensitive and hurt you.⁴³

It will be better for you to stay away from relationships that cause you unnecessary hurt and stress while you are trying to cope with your illness. Try to stay focused on the encouraging support you are getting from those who care for you.⁴³

Give yourself time to think carefully about how you wish to tell your friends so that you can express your feelings more clearly. Be honest about how you are feeling and what you need. In this way, the communication is more open and your friends can understand how they can support you.



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2.6 My Plan

Financial planning and end-of-life care

Giving It A Thought: My Financial Plan And My Care Plan

"Yes, it's a shock. Acknowledge that, mourn, cry, and then make a plan. Do not give away your possessions, enjoy them. As a matter of fact, buy those pretty earrings if you want! Travel if that's your thing. Quit your job if it doesn't bring you joy but keep working if you love your work. Even with pain or side effects of treatment, you can find fulfilment in life."

Anon Living with mBC

It can be very difficult just to think about what will happen after you are gone. However, it does help bring peace of mind and give you a sense of empowerment if you make practical decisions to manage future concerns. It will also be helpful for your family members to know that they can do things according to your wishes. These can include how you want your care and treatment and your financial property to be handled.

In this section you will know about:

PALLIATIVE CARE END-OF-LIFE CARE DECISIONS FINANCIAL AND PROPERTY PLANNING

How Can Palliative Care Be Included In My Treatment Plan?

Palliative care helps to improve your quality of life, manage your cancer symptoms, and offer you psychological and spiritual support. You get palliative care at every step of your cancer. For example, pain management and medicine to treat nausea are an important part of palliative care.⁴⁴

When you decide to receive ONLY palliative care, then you are choosing to stop taking treatments that can control the growth of the cancer.⁴⁴

Shifting to palliative care is a personal choice. Palliative care can help reduce your burden of living with cancer.⁴⁴

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My Plan

Remember, palliative care includes your values, decisions, approach to diagnosis and wishes for you and your family.⁴⁴

Palliative care can be available at your home, in the hospital or in a hospice centre. The team includes doctors, nurses and social workers who are experts in palliative care. The services can include nursing care, counselling, bereavement support, complementary therapies, and respite care.⁴⁴

Thinking About End-of-life Care

You need to take time to consider how you ideally want to have a good end-of-life experience. Giving this topic a thought and taking steps forward can help reduce your fear and anxiety.

You could think about the support and care you want at the end-of-life, rather than what you do not want. You can make your own choice of what you would like. 45

Discussing this with your family or your palliative care team can create a mutual understanding of your thoughts, values and desires for the best care for you.⁴⁵

You will also need to speak with your doctor who is treating you before you make end-of-life decisions. In this way, your doctor and nurses understand your decision and what action they will need to make.⁴⁵

While conversation about end-of-life wishes can be difficult and awkward, it is better for your family to know your preferences much earlier so that it is easy for them to make decisions when the time comes.⁴⁵ This can also prevent conflict and misunderstanding.



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My Plan

What About A Will?

A will is an official document that can ensure your financial and personal property are distributed and invested according to your wishes. Make sure that all relevant documents, financial statements, deeds, and insurance papers are kept in a secure place where your family can get to them.⁴⁶

Written instructions to let others know about the type of care you want if you are seriously ill are called 'living wills'. A 'living will' records your end-of-life care wishes in case you are no longer able to speak for yourself.⁴⁶

MAKE SURE YOUR DOCTOR AND FAMILY HAVE SEEN YOUR LIVING WILL AND THEY UNDERSTAND YOUR INSTRUCTIONS.⁴⁶

SOMETIMES PEOPLE CHANGE THEIR MIND AS THEY GET OLDER OR AFTER THEY BECOME ILL. REVIEW YOUR DECISIONS FROM TIME TO TIME AND MAKE CHANGES IF YOUR VIEWS OR YOUR HEALTH NEEDS HAVE CHANGED. MAKE SURE YOU DISCUSS THESE CHANGES. 46

Do get further advice of a financial advisor or lawyer about wills and financial matters.⁴⁶

Making Decisions About Final Arrangements

Planning ahead for when the time comes is your own choice. Although this can be a difficult and awkward conversation, it can help your family understand about how you would want your life to be celebrated and remembered.⁴⁷

You could think about the support and care you want at the end-of-life, rather than what you do not want. You can make your own choice of what you would like. 45

If you find these conversations difficult, get the support of professionals.⁴⁷

Disclaimer: Unreferenced information in this handbook is based on expert opinion.

Part 3

RESOURCES NEAR YOU





ME AND METASTATIC BREAST CANCER

Resources

Resources Near You

It is often hard to know where to look for support and accurate information when you have been diagnosed with metastatic breast cancer (mBC). The following is a list of organisations and resources available that you may find useful.

3.1 CANCER INFORMATION RESOURCES

Breast Cancer Support Groups In Malaysia

Breast Cancer Welfare Association Malaysia (BCWA)

5th Floor, Bangunan Sultan Salahuddin Abdul Aziz Shah, 16 Jalan Utara, 46200 Petaling Jaya Selangor

www.breastcancer.org.my

- www.facebook.com/breastcancerwelfareassociation/
- 03-7954 0133
- 03-7954 0122
- info@breastcancer.org.my

Johor

Breast Cancer Support Society Kluang

4A. Jalan Kapur, 86000 Kluang, Johor

- 010-793 8663 (Fu Fuk Ying Mandarin speaking only)012-714 3383 (Tan Sar Fee)012-711 9378 (Jenny Teh)
- 3.00 pm 5.00 pm (Every Sunday)

The Breast Cancer Support Society Segamat (BCSS)

438A-438B, Jalan Chelliah, 85000 Segamat, Johor

- www.facebook.com/segamat.bcss/
- 07-932 5228
- □ 07-932 5228
- bcss_sgt@yahoo.com
- 012-722 8540 (Pn. Zorrilah President)
 019-772 0138 (Siam Hwee King)
 012-799 5056 (Mdm Lim)
- 9.00 am -1.00 pm (Monday to Friday)

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Resources

Kelantan

Reproductive Health Association Kelantan (REHAK)

4261-F, Jalan Kebun Sultan, 15350 Kota Bahru.

Kelantan

- 09-743 2407
- 09-748 3323
- 09-748 3323 / 013-963 6505/ rehakelantan@gmail.com (Tengku Nur Fadzilah) 019-910 9073 / meklawa@gmail.com (Mei Lin)
- 8.30 am 4.30 pm (Saturday to Wednesday) 8.30 am - 1.00 pm (Thursday)

Breast Cancer Awareness & Research Unit (Bestari)

Hospital Universiti Sains Malaysia (Hospital USM) Jalan Raja Perempuan Zainab 2, 16150 Kubang Kerian, Kelantan

- 09-767 4056 (Puan Roslaini)
- breastcenter@usm.my / roslaini@usm.my
- 8.10 am 5.10 pm (Sunday to Thursday)

Kuala Lumpur

National Cancer Society of Malaysia

66, Jalan Raja Muda Abdul Aziz Kampung Baru 50300 Kuala Lumpur

03-2698 7300

www.cancer.org.my

Melaka

National Cancer Society Malaysia, Melaka Branch

347C & 349C. Jalan Ong Kim Wee 75300 Melaka

- 06-292 1231
- 6-292 1232
- 012-323 9300/ miki@cancer.org.my (Miki Chua)



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Resources

Negeri Sembilan

Breast Cancer Support Society Negeri Sembilan

Lot 1410/18, 3.5 Miles Jalan Pantai, 71050 Port Dickson Negeri Sembilan

- 06-647 1109
- 017-367 9570 (Padma Menon President)
 012-239 7269 (Dr. Naveen)
 012-338 5546 (Chai Moei Ho)
 016-386 4416 (Pn.Che Yah)

NSFPA Breast Cancer Awareness Support Team

No 3, Jalan Dr. Krishnan 70000 Seremban, Negeri Sembilan

016-279 6103 (Cynthia Tay)

- www.fb.com/pg/NSFPA 1962/
- 06-762 2969

012-222 5279 (Mdm Sue Loy - Chairman) 012-635 0844 (Mdm Sathyea) 010-204 4629 (Mdm S.F.Wong) 016-917 6203 (Rasanayag)

Penang

Penang Breast Care Society

Mount Miriam Cancer Hospital 28, Jalan Bulan, Fettes Park 11200 Tanjung Bungah, Penang

- 04-892 3962
- 017-406 8381 (Ms. Joon President)
- 9.30 am -12.00 noon (Monday to Friday)

Cancerlink Penang

2-U, Lorong Delima 17 Island Glades,11700 Penang

- 012-457 4912 (Ruth Chong)
- 10.00 am 4.00pm (Monday to Wednesday)
 (Loh Guan Lye Specialist Centre)

Pahang

Kuantan Breast Cancer Support Society

B3682, Lorong Galing 6, Jalan Haji Ahmad 25300 Kuantan, Pahang

- 019-987 6722 (Whatapp only Mdm Gauri) 012-215 6722 (Prof. Dato Dr Humairah Abdul Samad Cheung) 013-958 2522 (Matron Tannam)
 - 012-909 0052/ masriayu@hotmail.com (Erlinda)
- 3.00 pm 6.00 pm (Monday to Friday)

Cancer Support Group

Hospital Sultan Haji Ahmad Shah Temerloh Jalan Maran, 28000 Temerloh, Pahang

- 09-295 5333 (En. Azmi Bin Hassan) 013-952 5528 (Sister Rohana)
- 8.00 am − 5.00 pm (Monday to Friday)

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Resources

Perak

Persatuan Pink Champion Perak

Level 4, Pantai Hospital Ipoh 126, Jalan Tambun, 31400 Ipoh, Perak

- www.fb.com/persatuanpinkchampionperak/
- 012-516 1240 (Mardianah Mohd Yusof) 016-533 0282 (Angie Ng) 017-566 2535 (Jamaliah)
- 12.00 noon 4.00 pm (Monday to Friday)

Ipoh WeCare Cancer Society

Dr. Chan Ching Phng's Clinic, Hospital Farimah Suite 11 Jalan Dato Lau Pak Khuan Ipoh Garden, 31400 Ipon, Perak

- WeCarelpoh
- 05-548 9098 (Sister Biroo)
- wecareipoh@gmail.com
- 012-501 5320 (Mdm Sau Wai President) 012-547 3389 (Carmen Yan - Treasurer)
- 8.30 am 1.00 pm (Monday to Friday) 8.30 am - 11.00 am (Saturday)

Sabah

Persatuan Sokongan Kanser Payudara Kinabalu

Kinabalu Breast Cancer Support Association Lot 2-06, 2nd Floor, Wisma Wanita Mile 2 1/2 Jalan Tuaran, 88400 Kota Kinabalu, Sabah

- www.fb.com/kinabalupinkribbon/
- 088-216 237
- 088-253 679
- kinabalupinkribbon@gmail.com
- 016-803 8553 (Careline)
- 016-831 6015 (Laura Bazan Hon Secretary)

Tawau Patient Support

016-826 2004 (Christy Salazar)

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Resources

Sarawak

Sarawak Breast Cancer Support Group

Lorong Maxwell 2, Jalan Maxwell Off Jalan Tun Abang Haji Openg 93000 Kuching, Sarawak

- swakbreastca@gmail.com
- 082-411 137 (Norati Malani)

019-827 4832 / juriahsulehan03@gmail.com (Datin Juriah Sulehan)

- 082-411 137
- **◎** 8.00 am − 5.00 pm (Monday to Sun)

Persatuan Kumpulan Sokongan Pink Ribbon

Pink Ribbon Support Group Sarawak Rumah Anjung Kasih, Hospital Umum Sarawak

019-889 0412 / suriani56@hotmail.co.uk (Hjh Suriani Hj Rapaiee)

019-566 1657 (Hjh Hajijah Zakaria)

013-824 3639 (Jamilah Abu Bakar)

Terengganu

Terengganu Breast Cancer Support Group

Surgical Outpatient Department Hospital Sultanah Nur Zahirah Jalan Sultan Mahmud 20400 Kuala Terengganu, Terengganu

- F Terengganu Breast Cancer Support Group (SAMO)
- 019-985 7511 (Khodijah Long)
- 8.00 am 1.00 pm (Sunday to Thursday)

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Resources

3.2 PALLIATIVE CARE AND HOSPICE SERVICES

Hospitals Under Ministry Of Health Malaysia

Hospital Kuala Lumpur

23, Jalan Pahang 50586 Kuala Lumpur

- http://www.hkl.gov.my
- 03-2615 5555 03-2615 6391 (Info Counter)
- 03-2698 9845
- pro.hkl@moh.gov.my

Hospital Pulau Pinang

Jalan Residensi 10990 George Town Pulau Pinang

- http://jknpenang.moh.gov.my/hpp/
- 04-222 5333
- **(4)** 04-228 1739
- hpinang@moh.gov.my

Hospital Raja Permaisuri Bainun

Jalan Raja Ashman Shah 30450 Ipoh Perak

- https://hrpb.moh.gov.my/baru/index.php05-208 5000
- **6** 05-253 1541
- hrpb_info@moh.gov.my

Hospital Selayang

B21, Lebuhraya Selayang-Kepong 68100 Batu Caves Selangor

- http://hselayang.moh.gov.my/en/
- www.facebook.com/selayanghospital
- 03-6126 3333
- **6** 03 6137 7097
- allpro@selayanghospital.gov.my



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Resources

Hospital Sultanah Bahiyah

Km 6, Jalan Langgar 05460 Alor Setar Kedah

- http://hsbas.moh.gov.my
- 04-740 6233
- 04-735 0232 / 0233
- hsb@moh.gov.my

Hospital Tuanku Ampuan Rahimah

Jalan Langat 41200 Klang Selangor

- https://htar.moh.gov.my/
- 03-3375 7000
- 03-3372 9089

Institut Kanser Negara (IKN)

4, Jalan P7, Presint 7 62250 Putrajaya Wilayah Persekutuan Putrajaya

- http://nci.moh.gov.my/index.php/ms/
- 03-8892 5555 / 5599
- © 03-8892 5588 / 5612
- ncipro@nci.gov.my

Sarawak General Hospital Palliative Care Unit

1st Floor of Lot 2067 Block 10 KCLD Jalan Tun Ahmad Zaidi Adruce 93150 Kuching, Sarawak

- www.sarawakhospicesociety.org
- 012-886 6090 (Thomas)

Hospitals under Ministry of Education Malaysia

University Malaya Medical Centre

Lembah Pantai 59100 Kuala Lumpur

- www.ummc.edu.my
- 03-7949 4422
- 03-7956 2253
- ummc@ummc.edu.my

ME AND METASTATIC BREAST CANCER



Resources

Hospital Universiti Kebangsaan Malaysia

Jalan Yaacob Latif Bandar Tun Razak 56000 Cheras, Kuala Lumpur

- f https://www.hctm.ukm.my/
- 03-9145 5555
- prohukm@ppukm.ukm.edu.my

Non-governmental Palliative Care Organisations

Johor

Clover Care Centre

2, Jalan Nusa Perintis 4/10 Taman Nusa Perintis 1 Gelang Patah, Johor 81550

- www.clovercarecentre.com
- 07-513 0034
- management@clovercarecentre.com

Palliative Care Association of Johor Bahru

44 Jalan Tun Abdul Razak, Susur 1 80000 Johor Bahru, Johor

- www.facebook.com/pg/PalliativeCareAssociationOfJohorBahrupcajb
- 07-222 9188 / 8858
- 07-222 4858
- pcajb.admin@gmail.com
- nancyyee.pcajb@gmail.com (Ms Nancy Yee)

Persatuan Hospice Ark

No. 2, 2A, 2B Jalan Sutera Merah 3 Taman Sutera, 81200 Johor Bahru, Johor

- www.facebook.com/arkcarecentre/
- 07-289 9278
- 07-289 9279
- hospice_ark@hotmail.com
- Ms Atika (Nurse)



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Resources

Kedah

Persatuan Hospis Kedah

Pejabat Kesihatan Kota Setar Lebuhraya Darul Aman, Jalan Bakar Bata 05100 Alor Setar. Kedah

- http://hospiskedah.blogspot.com
- 04-771 3487
- 04-771 3600
- 013-437 6512
- sriwahyu2006@yahoo.com.my
- U 011-3611 3397 (Staff Nurse Isma Coordinator)

Melaka

Hospice Malacca

No. 5 & 5A, Jalan Malinja 3 Taman Malinja, Bukit Baru 75150 Melaka

- www.hospismelaka.org
- www.facebook.com/Hospis-Melaka-323391687760301
- 06-281 4532
- hospismelaka@gmail.com
- 013-620 1735 (M. Krishnan Person-in-charge)

Kelantan

Persatuan Hospis Kelantan

Hospital Raja Perempuan Zainab II 15586 Kota Bharu, Kelantan

- 09-745 2000 / 2247
- @ 09-745 5418
- drimisairi@yahoo.com

Negeri Sembilan

Pertubuhan Hospice Negeri Sembilan

No. 41, Off Jalan Rasah 70300 Seremban, Negeri Sembilan

- https://www.phns.org.my/
- 06-7677 1216
- hospicens2012@yahoo.com
- 012-652 7663 (Matron Lim Cheok Hong)
 012-910 5553 (Ms.Ambika Secretary)

Pahana

Persatuan Hospis Pahang

A4614, Lorong Alor Akar 19 25250 Kuantan, Pahang

- http://hospispahang.simplesite.com/
- 09-560 6359
- hospispahang@gmail.com

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Resources

Penang

Charis Hospice

26 & 28 Lintang Paya Terubong 3 Air Itam, 11060 Penang

- www.charishospice.com/
- www.facebook.com/charishospice.penang
- 04-827 9668
- 011-1246 6757
- **(4)** 04-827 9667
- charishospice@gmail.com
- Ms Candy

National Cancer Society Malaysia Penang Branch

Rumah Hospis Pulau Pinang 250A, Jalan Air Itam, 10460 Penang

- www.ncsmpenang.org
- 04-228 4140
- 04-226 4676
- ncsmpg@gmail.com
- Nor Asikin Abd Kadir

Penang Hospice Society

Penang Island Office. 250A Jalan Air Itam 10460, Penang

- www.penanghospice.org.my
- Penang Hospice Society
- 04-228 4140
- **Q** 04-226 4676
- penanghospicesociety@gmail.com

Pure Lotus Hospice of Compassion

73, Jalan Utama, 10460 Penang

- www.purelotushospice.com/
- www.facebook.com/PureLotusHospiceOfCompassion/
- 04-229 5481
- **a** 04-229 5481
- Iyanshih@gmail.com (Ven. Lyan Shih Chairman)

Penang Hospice Society

Seberang Perai Office No. 5, Lorong Harmoni 2, Taman Bukit Mas 14000 Bukit Mertajam, Penang

- 04-537 4140
- 04-537 4140

ME AND METASTATIC BREAST CANCER

Resources

Perak

Perak Palliative Care Society (PPCS)

54 Jalan Sultan Azlan Shah 31400 Ipoh, Perak

- www.ppcs.org.my/
- 05-546 4732
- 05-546 4732
- 017-553 2489
- admin@ppcs.org.my
- Ms Leong Lai Peng

Taiping Palliative Society

No. 2 Jalan Merdeka Off Jalan Tupai, 34000 Taiping, Perak

- 05-807 2457
- 05-807 2457
- 016-595 0585
- 😰 veraliew@hotmail.com

(Ms Vera Liew - Contact Person)

Sabah

Home Care Hospice Programme

The Cancer Society of Sabah No.15, Lorong Tupai 3, Teck Guan Villa Jalan Penampang, 88300 Kota Kinabalu, Sabah

- www.sabah.org.my/scss/cancer
- 088-222 315
- 088-210 377
- sabahcancersociety@yahoo.com

Palliative Care Association of Kota Kinabalu

Wisma PCA, PW 7396 & 7397 Taman Rose, Off Jalan Penampang 88300 Kota Kinabalu, Sabah P. O. Box 145, 88856 Likas, Kota Kinabalu

- www.sabah.org.my/pcakks/
- www.facebook.com/pcakk1998/
- 088-231 505 / 257 507
- 088-231 506
- 016-832 7512
- pcakk2014@gmail.com
- Ms Grace Chong

Persatuan Hospice St. Francis Xavier

St. Francis Xavier's Mission Peti Surat 92, 89007 Keningau, Sabah

- 087-339 114
- 019-585 4854
- **6** 087-339 114
- hospicekgausfx@gmail.com
- Ms.Shirley (Secretary)

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Resources

Persatuan Hospis Tawau

TB 14748 Mile 3.5, Jalan James Power Off Jalan Kuhara 91000 Tawau, Sabah P.O. Box no. 1398, 91038 Tawau

- www.facebook.com/TawauHospiceAssociation/
- 089-711 515
- 089-711 514
- hospistwu@gmail.com
- 013-885 1248 (Ms Ernestina Contact Person)

Queen Elizabeth Hospital, Palliative Care Unit

Hospital Queen Elizabeth Karung Berkunci No. 2029 88586 Kota Kinabalu, Sabah

- 088-517 555
- 088-211 999 / 318 605
- pengarah.hqe@moh.gov.my

The Hospice Association of Sandakan

P.P.M No 324, Elopura 90000 Sandakan, Sabah

- www.facebook.com/pages/the-hospice-association-of-sandakan-sabah/107461789285172
- 089-232 269
- 089-232 269
- hospicesandakan@yahoo.com.my
- 012 813 2337 (Ms Michelle Chong Secretary) 089-236 219 (Ms Juraini - Nurse-in-charge)

Sarawak

Kuching Hospice Cancercare

287, Lot 2643 Central Park Commercial Centre Jalan Rock, 93250 Kuching

- 082-235 809
- 082-235 770
- cancercare.kuching@gmail.com

National Cancer Society of Malaysia Sarawak Branch

(Kuching Cancer Care) Lot 186, Jalan Nyiur, off Tabuan Road 93200 Kuching, Sarawak

- 082-235 809
- 082-235 770
- cancercare.kuching@gmail.com
- Ms Molly Tan

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Resources

Palliative Care Association Miri

No. 406, Jalan Taman Piasau Edar Piasau Garden 98000 Miri, 98000 Miri, Sarawak

- www.palliativecaremiri.org/
- www.facebook.com/palliativecaremiri/
- 085-650 538 / 012-845 6480
- palliativecaremiri@gmail.com
- Ms Melissa Nurse Coordinator

Sarawak Hospice Society

c/o Radiotherapy Unit Sarawak General Hospital 93586 Kuching, Sarawak

- www.sarawakhospicesociety.org/
- 082-276 575
- 082-414 443
- tangtiengswee@gmail.com

Two Tree Lodge Hospice Kuching

Level 4, L7998, SL7, Jalan Tun Jugah Chaiyi Goldland 93100 Kuching, Sarawak

- www.facebook.com/twotreelodge
- 011-1098 2323
- 23Lodge@gmail.com

Selangor

Assisi Palliative Care Berhad (ASPAC)

49, Jalan Railway 1/2, Seksyen 1 46000 Petaling Jaya, Selangor

- www.aspacmalaysia.org
- https://www.facebook.com/assisipalliativecare/
- 03-7783 8833
- 03-7783 8899
- assisipalliativecare@gmail.com info@aspac.my
- Dr Lalitha Jeyasingam Medical Director

Hospice Klang

PT140457, Persiaran Delima / KS 09 Kota Bayu Emas, 41200 Klang, Selangor

- www.hospiceklang.org
- 03-3318 4774 / 012-622 3073
- 03-3319 4664
- hpsklang@gmail.com

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Resources

Kasih Hospice Care Society

No. 16, Jalan SS3/29 Taman Universiti 47300 Petaling Jaya, Selangor

- www.kasihfoundation.org
- www.facebook.com/assisipalliativecare/
- 03-7865 6522
- 03-7872 9420
- admin@kasihfoundation.org (general enquiries) kasihreferral@gmail.com (patient referral)

Malaysian Hospice Council

c/o Kasih Hospice Care Society No 16, Jalan SS 3/ 29 47300 Petaling Jaya, Selangor

- www.malaysianhospicecouncil.com
- 03-7865 6522
- 03-7872 9420
- malaysianhospicecouncil@gmail.com

Terengganu

Persatuan Hospis Terengganu

c/o Klinik Kesihatan Hiliran Jalan Kemajuan, Bukit Kecil 20648 Kuala Terengganu, Terengganu

- 09-623 2632 / 622 2104
- drnona31765@gmail.com ftbfly4@gmail.com

Wilayah Persekutuan Kuala Lumpur

Hospis Malaysia

Jalan 4/96, Off Jalan Sekuci Taman Sri Bahtera Cheras, 56100 Kuala Lumpur

- www.hospismalaysia.org
- 03-9133 3936
- 03-9133 3941
- patientcare@hospismalaysia.org (Patient-related Enquiries) info@hospismalaysia.org (General Enquiries)

Malaysian Association for the Study of Pain

Department of Anaesthesiology University Malaya Medical Centre Lembah Pantai, 59100 Kuala Lumpur

- www.masp.org.my
- www.facebook.com/masp1993
- maspsecretariat@gmail.com

Part 4

GLOSSARY



ME AND METASTATIC BREAST CANCER



Glossary

Definitions C	Of Medical Terms In Metastatic Breast Cancer	
Anaemia	A low number of red blood cells. May lead to feelings of tiredness, weakness or breathlessness.	
Anti-emetic Drugs	Medicines to reduce or prevent nausea.	
Hormonal Therapy	A treatment to stop or slow the growth of hormone-sensitive tumours. Hormonal therapy works by blocking the body's ability to produce hormones or interfering with hormone action.	
Biopsy	Removal of tissue to see if it contains cancer cells. See page 33 for more information.	
Bisphosphonates	Also known as bone hardening or bone strengthening treatment. These are drugs to slow or prevent bone damage. They also lower calcium levels.	
Blood Count	A blood test to show the quantities of each type of blood cell within a sample of blood. Also known as a blood cell count.	
Cells	Tiny structures that make up all living organisms and the tissues of the body. Cells replace themselves by splitting and forming new cells.	
Chemotherapy	A treatment that aims to destroy cancer cells using cytotoxic (anti-cancer) drugs.	
Chemoport	A vein-access device implanted under the skin at the upper chest or arm to allow chemotherapy drugs to be administered directly into your vein with a needle. The implantable subcutaneous venous access port or chemoport is a common procedure in patients requiring long-term venous access. Chemoport provides safe, easy and cosmetically pleasant venous access.	
Clinical Trial	Also called a clinical study. A research study testing how well new medical treatments or approaches work on patients.	
Consent	Agreeing to something or giving permission for something to be done.	
CT Scan	Short for 'computed tomography scan'. Uses a series of x-rays to create a detailed picture of areas inside the body. You may be given a dye (either to swallow or as an injection) to help the tissues and organs show up more clearly.	
Early Breast Cancer	Breast cancer that has not spread further than the breast or the axillary lymph nodes.	



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HER2	Short for human epidermal growth factor 2. A protein involved in normal cell growth. Some breast cancer cells contain many more HER2 receptors than others. This is called being HER2 positive (HER2+).
Hormone Receptors (HR)	A cell protein that binds to a particular hormone. Once the hormone has bound to its receptor, various changes take place in the cell.
Imaging Procedures	Also known as imaging tests. These involve making detailed pictures of areas within the body. Examples include CT scans and MRI scans. See pages 32 for more information.
Intravenous Line	Chemotherapy is given directly into your vein. The word 'intravenous' (IV) means 'into the vein'. With IV administration, a thin plastic tube called an IV catheter is inserted into your vein.
Lab Tests	In cancer, these tests look for signs of cancer and its progression. Examples include tumour markers tests and blood counts.
Locally Advanced Breast Cancer	Refers to stage III breast cancer, where the cancer can only be found in the same breast as the primary tumour and has not spread to other organs. Different healthcare professionals may use the term in different ways — some use it to talk about metastatic breast cancer, but this is when the cancer has spread outside of the breast to other parts of the body.
Lymph Nodes	Small organs in your body which can indicate cancer spreading by becoming inflamed or enlarged. They can be an important tool for assessing the stage of your cancer.
Metastases	Tumours that occur when the cancer spreads beyond where it started in the body. For example, when breast cancer spreads from the breast to the bone.
Metastatic Breast Cancer (mBC)	This is cancer that has spread beyond the breast to another part of the body. It may also be referred to as secondary breast cancer.
MRI Scan	Short for 'magnetic resonance imaging' scan. Uses radio waves and a powerful magnet to create detailed pictures of organs inside the body.
Oestrogen	One of the two female sex hormones along with progesterone. In women, oestrogen levels change over the course of each menstrual cycle.
PET Scan	Short for 'positron emission tomography' scan. A small amount of radioactive liquid is injected into a vein and a scanner then takes a detailed picture that can be used when looking for abnormalities in the body.
Progesterone	One of the two female sex hormones along with oestrogen. Progesterone is released by the ovaries during every menstrual cycle to prepare the breasts for milk production and the womb for pregnancy.

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Progression	When tumours get bigger and/or the cancer spreads within the body.
Protocol	In medical terminology this means a plan, such as an agreed process to be followed, after someone is diagnosed with metastatic breast cancer. A protocol may include a treatment plan and cover the practicalities of treatment.
Radiotherapy	The use of high-energy radio waves to kill cancer cells and shrink tumours.
Randomised Trial	A trial involving at least two different groups of participants. The groups are allocated different treatments (which group receives which of the possible treatments is chosen at random).
Recurrence	When cancer returns after a period of time during which no cancer could be detected. If this happens, it may occur months or years after the initial treatment.
Relapse	When cancer returns after a period of improvement.
Remission	When tumours shrink (partial remission), in some cases to the extent that they can no longer be detected by tests and scans (complete remission).
Secondary Breast Cancer	Another name for metastatic breast cancer.
Stages	The most advanced stage of breast cancer—when it has become metastatic. See page 30 for more information.
Targeted Therapy	A treatment targeting specific characteristics of cancer cells to prevent them from growing and dividing.
TNM Classification	Another classification system used by doctors to explain how far the cancer has spread in your body in order to determine your overall stage. T stages (tumour): the size of the tumour in the breast N stages: the extent to which the cancer has spread to the (nodes): lymph nodes near the breast M stages: the extent to which the cancer has spread outside (metastases): of the breast to other parts of the body such as the bone, liver, and lungs. Your doctor puts the TNM results together to give you your overall stage. This is usually what the doctor writes on your test forms.
ULTRASOUND	A scan which uses high frequency sound waves to build up a picture of the inside of the body.
X-RAY	Radiation used for taking pictures or radiotherapy.
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Cancer Care Amidst The Covid-19 Pandemic – What You Should Know As A Patient

Coronavirus disease 2019 (COVID-19), is an illness caused by the novel coronavirus. The virus spreads via small droplets, which are released from the nose or mouth during a cough or sneeze. A person may catch COVID-19 by either inhaling these droplets, or by touching surfaces contaminated by these droplets and then touching their eyes, nose, or mouth.⁴⁸

The COVID-19 pandemic continues to affect many people across the globe, forcing healthcare centres to implement new norms to ensure the safety of patients; this includes changes to cancer care.

As a cancer patient, you may be at an increased risk of severe illness from COVID-19 if you⁴⁹:

- are on chemotherapy or have received chemotherapy in the last 3 months
- are receiving extensive radiotherapy
- have had a bone marrow transplant or stem cell transplant in the last 6 months, or are on immunosuppressive drugs
- · have chronic leukaemia, lymphoma or myeloma

Understanding The Impact of COVID-19 On Cancer Care

Your cancer care team may adapt your treatment plan to optimise your healthcare needs while minimising any potential risks due to the COVID-19 pandemic. As such, it is always important to keep in touch or to always communicate with your cancer care team to ascertain the best course of action as per your current condition. Your treatment approach may differ based on your condition, the urgency of your planned cancer treatment, as well as the benefit to risk ratio of your treatment plan.⁵⁰

Tier 1

High priority

Patients whose condition is life threatening or clinically unstable and/or where the planned treatment is likely to result in significant benefit.

Tier 2

Medium priority

Patients whose condition is serious but not immediately life threatening and where a short delay in treatment can be considered. However, a delay of longer than 6 - 8 weeks could potentially impact on the outcome and/or the amount of benefit.

Tier 3

Low priority

Patients whose condition is stable enough that any treatment can be safely delayed for the duration of the COVID-19 pandemic. It includes patients whose planned treatment is unlikely to provide a significant benefit.

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Cancer Care Amidst The Covid-19 Pandemic – What You Should Know As A Patient

Possible Adaptations To Your Cancer Care

Your cancer care team may tweak your treatment plan after carefully evaluating your condition and weighing the benefit to risk ratio of your treatment plan to your overall health. Examples of treatment adaptations that your cancer care team may recommend are as follows^{49,50}:

- Delay any non-essential surgery and/or offer you neoadjuvant therapy to delay your surgery.
- Recommend a chemotherapy 'holiday' if you are on maintenance therapy and have established remission.
- Delay or modify adjuvant treatment (postoperative treatment).
- Switch to a chemotherapy regimen that requires less frequent infusions.
- · Switch from intravenous to oral chemotherapy.
- Take prophylactic growth factors to help boost your immune system and antibiotics to ward off potential infections.
- Consider accelerated or hypo-fractionated radiotherapy schedules.
- Change your treatment schedule to reduce the frequency of hospital visits.
- Delay your planned stem cell transplant if your cancer is well controlled and you are at high risk of serious complications from COVID-19.
- Communicating to your cancer care team virtually (online or over the phone) and avoid or lessen
 the frequency for physical consultations.





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Cancer Care Amidst The Covid-19 Pandemic – What Should You Know As A Patient

Understanding The New Norm For Your Clinic/ Hospital Appointments

Healthcare centres have made changes and set guidelines in place to ensure your safety during follow-ups and treatment. Some of these changes include⁴⁹:



Apart from adhering to the guidelines set by your respective healthcare centres, there are also precautionary measures which you should follow during your appointment to protect yourself and others; these include^{48,51}:

- Wash your hands often with soap and water for at least 20 seconds, and/or use a hand sanitiser that
 contains at least 60 percents alcohol.
- · Avoid touching your eyes, nose, and mouth.
- Use a tissue when you cough or sneeze, and dispose the tissue in the rubbish bin after use.
- Adhere to physical distancing of at least 1 meter from other people (or as recommended by Malaysian government).
- Wear a face mask.
- Try to attend your appointments alone. If you require someone to accompany you for your
 appointment, check with your healthcare centre on its current visitor policy.

While the World Health Organisation (WHO) is constantly monitoring the global situation of the COVID-19 pandemic, the Ministry of Health, Malaysia is closely monitoring and managing the COVID-19 situation at the national level. While there are various open information resources, it is always advisable for cancer patients to always communicate with their healthcare providers to ensure optimal management of their current condition.

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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

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