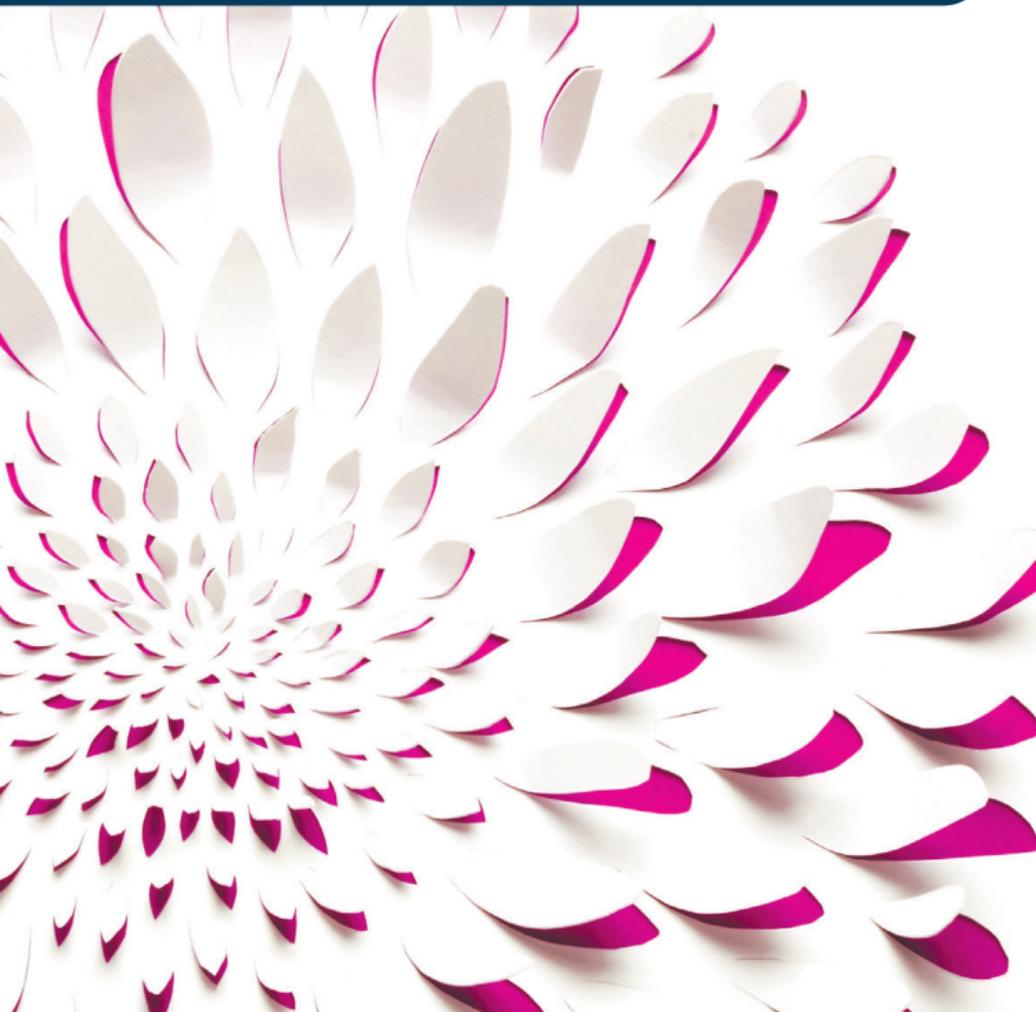


Breast  
Cancer  
Network  
Australia



# Metastatic breast cancer: an introduction





This booklet has been written for people who have just found out they have metastatic breast cancer.

Most people feel devastated when they are told they have metastatic breast cancer. Many will have lived through the trauma of being diagnosed and treated for early breast cancer and may have believed they were cured. For others a diagnosis of metastatic breast cancer might be the first time they have experienced breast cancer.

This brief information booklet has been developed to provide:

- the key facts about metastatic breast cancer
- reassurance that this condition is very treatable
- hope: many people with metastatic breast cancer live for years with their cancer under control – you may be one of these people too.

# What is metastatic breast cancer?

Metastatic breast cancer is breast cancer that has spread beyond the breast to other organs in the body, most often the bones, lungs, liver or, less commonly, brain.

There are many words used that make it all sound very complicated. However, a lot of the words actually mean the same thing.

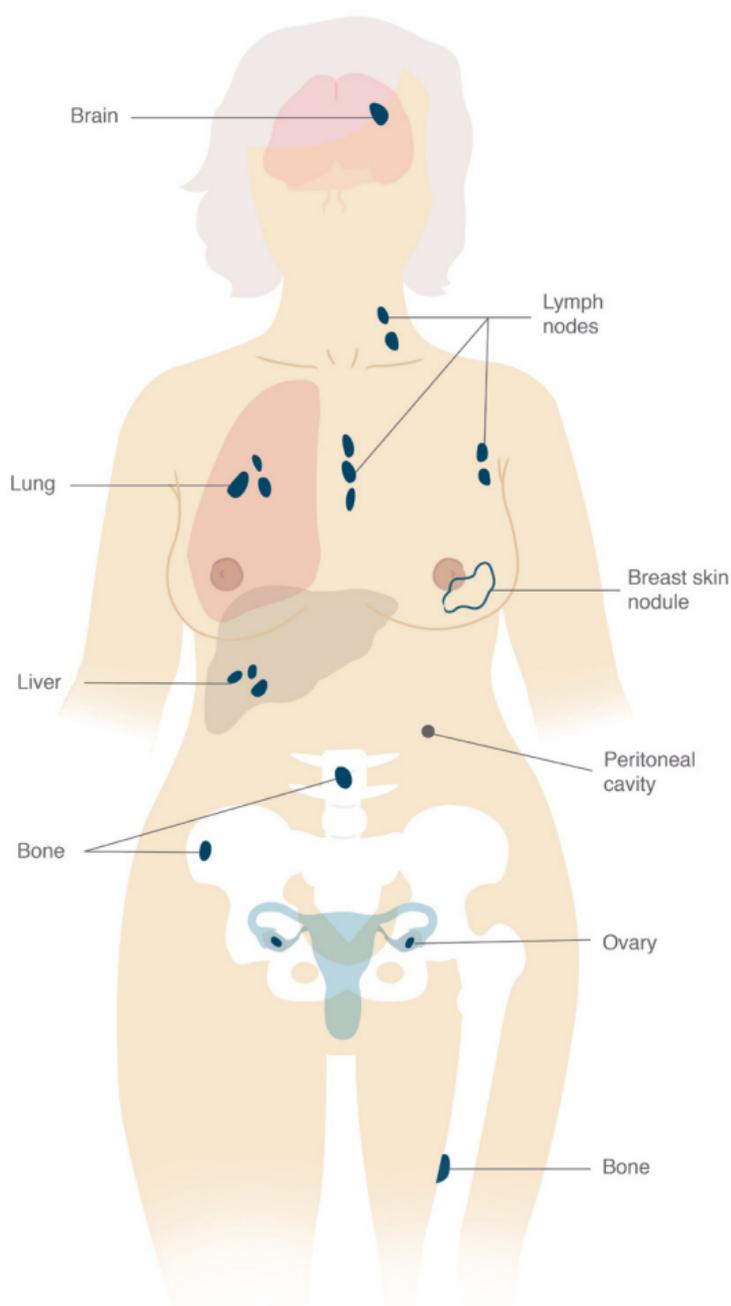
## **Metastatic breast cancer is also called:**

- stage IV (4) breast cancer
- secondary breast cancer
- advanced breast cancer

When referring to a specific area or 'site' of metastatic breast cancer, the term 'secondary' is often used — for example a secondary in the bone. The word 'metastases' is sometimes also used to describe these sites, e.g. bone metastases. The original cancer in the breast is referred to as the 'primary'.

Although metastatic breast cancer has spread to another part of the body, it is considered and treated as breast cancer. For example, breast cancer that has spread to the bones is still breast cancer (not bone cancer) and is treated with breast cancer drugs, rather than treatments for a cancer that began in the bones.

## Sites where breast cancer might spread



Sometimes people are found to have metastatic breast cancer at their first diagnosis of breast cancer. This is called 'de novo' metastatic breast cancer.

It is more common for metastatic breast cancer to occur months or years (sometimes more than 20 years) after a person has completed treatment for early breast cancer.

## Why did I get metastatic breast cancer?

It is not known why some breast cancers spread and others don't. It is also not known why some spread very early, and may result in de novo metastatic breast cancer, and others do not spread for many years.

The treatments, such as surgery, radiotherapy, chemotherapy, targeted therapies and hormone therapies, for an early breast cancer, reduce the chances that the cancer will spread, but they are not 100 per cent effective, and metastatic disease can still occur in some cases.

There is no evidence that specific events, such as an operation, another illness or a stressful life event can cause metastatic breast cancer.

## Why was it not found earlier?

First of all, it is important to understand that finding metastatic breast cancer earlier does not change the results of treatment. Whenever metastatic breast cancer is found, it can be treated, but cannot currently be cured. The results of treatment are just as good whether it was found a few months ago or now. The only exception to this is if the cancer has reached a very advanced stage making you very unwell — treatments may not be able to be given, or may not work very well. Metastatic breast cancer usually does not get to this stage without a person being aware of being unwell.

Regular tests to look for metastatic disease are not done during the follow-up of early breast cancer. This is for the same reason — finding it earlier provides no advantage. Regular tests are also avoided because of concern about the excessive radiation exposure from repeated scans.

## Am I going to die soon?

When you first hear that you have metastatic breast cancer, it is very normal to wonder if this means you will die soon. This is, in fact, very rarely the case. Although metastatic breast cancer is not currently considered curable, it is very treatable, and for most people it can be controlled for years. There has been a small number of women whose metastatic breast cancer has been in remission so long, it is thought they may be cured. It is hoped that with increasingly effective treatments in coming years, this will not be such a rare occurrence.

You and your family are encouraged to discuss this with your treatment team, so you can be reassured that you can do well with treatment. If you would like more detailed information about your prognosis (the likely course your disease will take), you should also ask your treatment team. Whether and when you do this is completely up to you.

# How is it treated?

There are many treatment options for metastatic breast cancer, which is one of the reasons that it can be controlled so well and for a long time. There are many factors about the nature of the cancer itself and your own health and circumstances that influence the treatment that will be recommended for you. So don't expect to have the same treatment as somebody else you have met with metastatic breast cancer.

## **Treatments include:**

### Anti-cancer treatments

- hormone (anti-oestrogen) treatments
- chemotherapy
- targeted treatments (e.g. Herceptin, Perjeta, Kadcyła, Tykerb)
- radiotherapy
- surgery.

### Supportive care treatments

- bone strengthening treatments
- symptom management medications (e.g. pain killers, anti-nausea medications).

## **Other supportive care measures to improve quality of life include:**

- information provision
- allied health interventions (e.g. psychology, social work, occupational therapy, physiotherapy, dietitian)
- various supportive care programs to help you to live well and get support.

# Who will be in my treating team?

As there are many different treatments and interventions that will be recommended at different times, there will be a number of different clinicians involved in your care. These may include:

## Doctors

Your medical oncologist is usually the coordinator or leader of your care, but you will often be referred to other specialists such as a radiation oncologist, perhaps a surgeon, a pain specialist or palliative care physician, or other specialist doctors for specific issues. Radiologists and pathologists are also involved in assessing test results. Although not everyone has a good relationship with a general practitioner (GP), ideally your GP will be part of your team — GPs can be very helpful for the everyday health issues you may need help with.

## Nurses

Ideally a breast care nurse should be available either in your clinic or at the hospital. These nurses are experts in all aspects of breast cancer and can provide advice and guidance on a broad range of issues that you may experience. Other nurses you will come to know well, and who will provide additional advice and support, are the oncology nurses — both in the Day Chemotherapy Unit and on the ward if you require admission to hospital. Nurses in the community are also sometimes

involved in caring for people with metastatic breast cancer — district nurses, hospital-in-the-home nurses (outreach from hospitals) and palliative care nurses for symptom management.

## Allied health staff

A wide range of different skills are covered by these health professionals. Allied health professionals include psychologists, physiotherapists, occupational therapists, social workers, dietitians and lymphoedema specialists. Allied health professionals can help you to manage a range of symptoms and concerns that you may experience.



# What is multidisciplinary care?

Most oncology clinics and hospitals hold a regular meeting of the health professionals involved in breast cancer treatment and care to discuss individual cases and make individual treatment recommendations for each person. This is called a Multidisciplinary Meeting (MDM). When you are diagnosed with metastatic breast cancer, your case may be discussed at an MDM. The group of clinicians involved are referred to as the Multidisciplinary Team (MDT). Some centres have meetings specifically for metastatic breast cancer and others have meetings where both early and metastatic cases are discussed. This approach to care is designed to ensure that your treatment is well coordinated and represents the best available care.

The care available in Australia for metastatic breast cancer is 'state of the art' globally, meaning that Australian women have access to best quality treatment and care. Care in another country would be unlikely to provide you with any advantage.

## What do I tell people?

One of the most difficult things that you may be faced with is thinking about how to tell people in your life about your diagnosis. You may find you are not only trying to manage your own uncertainty but also the fears of people around you. What and how you tell people, and who you tell, about your diagnosis will be very individual and personal. Many people will probably think that your outlook is poor and you may not live long. It may help to tell them that your illness can be treated like any other chronic disease — one that requires lifelong treatment — and it is expected that you will live for some years. For much of the time you will be well, but there may be periods where you are less well and require more intensive treatment and support from those around you.



# Where can I get more information?

## *Hope & Hurdles*

Breast Cancer Network Australia (BCNA) has developed a free information pack for women and men with metastatic breast cancer called *Hope & Hurdles*. It has been developed with the input of experienced breast cancer clinicians and many women and men living with metastatic breast cancer.

In *Hope & Hurdles*, women share their experiences, lessons they have learnt and practical tips and strategies. There is also information about treatments, managing side effects, living well and information about other supports that may be available to you.

*Hope & Hurdles* has been developed as a core set of information that is suitable for everyone, and a series of optional booklets that you can order depending on your type of breast cancer and where it has spread. The back of this booklet has a list of the optional items available. You can ask your health professional which are most appropriate for you.

Optional items can be ordered with the core pack, or at any time in the future.

**To order your free *Hope & Hurdles* pack, visit the BCNA website ([bcna.org.au](http://bcna.org.au)) or phone 1800 500 258.**

## Breast Cancer Network Australia

BCNA's website has a comprehensive metastatic breast cancer section that has the most up-to-date information available, along with links to other trusted sources of information.

## Helpline

BCNA's Helpline provides support and information about breast cancer for women and men living with breast cancer and for their family members and friends. Our Helpline team can provide you with written information about breast cancer and issues that may be concerning you. They can also talk to you about concerns that you may be experiencing as a result of your breast cancer and can refer you to a wide range of supports available to assist you. You can contact our Helpline team on **1800 500 258** between 9.00 am and 5.00 pm (Eastern Standard Time) Monday to Friday. You can also contact us by email on **beacon@bcna.org.au**.

## *The Beacon and The Inside Story*

*The Inside Story*, a supplement for BCNA's free quarterly *The Beacon* magazine, has content specific to metastatic breast cancer. You can subscribe to a digital edition of both magazines via the website if you would like to read them online. If you would like to receive *The Beacon* and *The Inside Story* in hard copy, phone BCNA on **1800 500 250** or email **beacon@bcna.org.au**.

## Online Network

BCNA has an online network where you can share your thoughts and feelings online, if you think that talking with others in a similar situation will help. There is an active public discussion area for anyone

affected by metastatic breast cancer. There is also a private group for people with metastatic breast cancer, where only members of the group can read the discussions. To find out more, or to join the online network visit **bcna.org.au**.

## Telephone counselling service

BCNA's telephone counselling service offers free, confidential counselling support to women and men affected by metastatic breast cancer and their families.

*"I would recommend the counselling service because I felt listened to, and understood. The counsellor gave me time and never rushed our conversations, she was totally available to my needs."*

**Phone BCNA on 1800 500 258 to find out more or to make an appointment.**

## Cancer Australia

Cancer Australia's *Guide for women with secondary breast cancer* provides information to support women with metastatic breast cancer in understanding their diagnosis and options for treatment and care. For more information about this resource, visit the Cancer Australia website, **canceraustralia.gov.au**.

## State and territory Cancer Councils

State and territory Cancer Councils provide a range of information booklets, support services and education programs for people who have been diagnosed with cancer and their families. Cancer Council Australia's website (**cancer.org.au**) provides links to the state and territory websites and other trusted cancer-related information. For information and support phone Cancer Council **13 11 20**.



Breast Cancer Network Australia (BCNA) works to ensure that Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.



BCNA is the peak national organisation for Australians affected by breast cancer, and consists of a network of more than 115,000 members and 300 Member Groups. More than 90 per cent of our members have had a diagnosis of breast cancer, and the remaining members have had a personal experience of breast cancer through a family member or friend.

We are represented by the Pink Lady silhouette, symbolic of our focus on the woman diagnosed with breast cancer and all those around her.

The following optional items are available with *Hope & Hurdles*:

- Metastatic breast cancer in the bone* booklet
- Metastatic breast cancer in the liver* booklet
- Metastatic breast cancer in the lung* booklet
- Metastatic breast cancer in the brain* booklet
  
- Hormone receptor positive metastatic breast cancer* booklet
- HER2-positive metastatic breast cancer* booklet
- Triple negative metastatic breast cancer* booklet
  
- Planning ahead*  
(formerly *Getting your affairs in order*)
- Breast cancer and sexual wellbeing* booklet
- Anxiety, depression and breast cancer* fact sheet
- Cancer Australia's *Guide for women with secondary breast cancer*

**Ask your health professional which resources are appropriate for you.**

