

Metastatic Breast Cancer: an introduction



This information booklet is specifically designed for people who have recently been diagnosed with metastatic breast cancer.

It is estimated that more than 10,000 people are living with metastatic breast cancer in Australia.

Whether you have previously undergone treatment for early breast cancer, or this is your first encounter with breast cancer, it is important to know that metastatic breast cancer can occur despite the best care and efforts. In fact, approximately 20 per cent of individuals with early breast cancer will develop metastatic disease.

This diagnosis may be your initial experience with breast cancer, as happens for around five to ten percent of those diagnosed each year. We recognise that learning you have metastatic breast cancer from the start can feel like a double blow, and we want to assure you that you are not alone.

The purpose of this introductory information booklet is to provide you with key facts about metastatic breast cancer, offer reassurance that this condition can be treated, and instil hope that you can live as well as possible with your cancer under control.

Breast Cancer Network Australia (BCNA) is Australia's leading breast cancer consumer organisation.

BCNA has produced this booklet, with review by:

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This booklet is not a substitute for professional help or advice from your treating team. It is important to discuss any concerns with your health professional.

BCNA excludes itself from all liability for any injury, loss or damage incurred by user of, or reliance on, the information provided in this booklet.

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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. Several words are commonly used to describe metastatic breast cancer, which can make it sound complicated and confusing. However, these terms mean the same thing.

Metastatic breast cancer is also called:

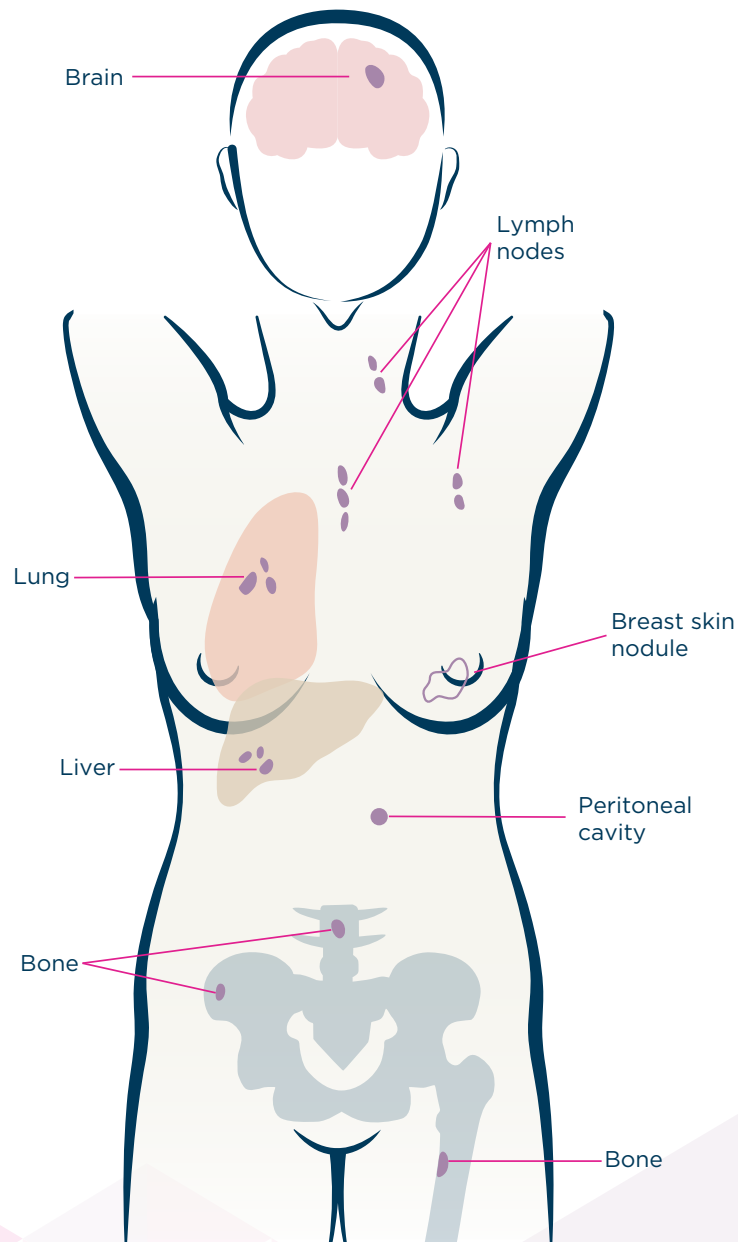
- stage 4 breast cancer
- secondary breast cancer
- advanced breast cancer

When referring to a specific area or “site” of metastatic breast cancer, the term “secondary” is often used, e.g. a secondary site in the bone. The word “metastases” can also be used to describe these secondary sites, e.g. bone metastases. The original cancer in the breast is referred to as the “primary” site.

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.

If you have metastatic breast cancer at your first diagnosis of breast cancer, it 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 you were diagnosed with early breast cancer, and it may occur during or long after completion of your initial treatment.

Sites where breast cancer might spread



Metastatic breast cancer is different from:

- Early breast cancer (stage 1 or 2) which is invasive breast cancer that is contained within the breast that may or may not have spread to nearby lymph nodes (e.g. axilla).
- Locally advanced breast cancer (stage 3) breast cancer, which is invasive breast cancer that is generally large and may have spread to nearby areas such as lymph nodes above the collarbone, skin or the chest wall.

Why did I get metastatic breast cancer?

It is not well understood why some breast cancers spread to other areas and others do not. It is also not well understood why some spread relatively early, and may result in de novo metastatic breast cancer, and others do not spread for many years.

For those with early-stage breast cancer, surgery aims to remove the cancer that can be seen or felt in the breast and lymph nodes under the arm. Treatments such as radiotherapy, chemotherapy, targeted therapies and hormone-blocking therapies aim to remove the breast cancer cells that may be left in the breast, armpit or other parts of the body, but cannot be detected. Although these treatments reduce the chances that the cancer will recur or spread, there is no 100 per cent guarantee.

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

How is it found and diagnosed?

Metastatic breast cancer may be found on scans that are done at the time of a diagnosis of primary breast cancer. It may be found on scans that are done to investigate symptoms that have occurred months or years after a diagnosis of early breast cancer, or scans and other tests that are done for completely unrelated reasons. It may be clear from the scans, or it may be necessary to take a needle biopsy of the cancer and send it to the laboratory to confirm the diagnosis and/or type of cancer.



Why was it not found earlier?

It is important to understand that finding metastatic breast cancer earlier does not necessarily change the results of treatment. Whenever metastatic breast cancer is found, it can be treated.

You may feel like you should have had more tests and scans as part of your routine follow-up care after a diagnosis of early breast cancer. However, research shows that having more tests does not improve the length or quality of life of people who have been treated for early breast cancer and do not have concerning symptoms. 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 normal to wonder if this means you will die soon. Although metastatic breast cancer is currently not considered curable, it is treatable and, for some people, can be controlled for years. A small number of people have no evidence of metastatic disease for so long that 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.

Your prognosis, the likely course your disease will take, can vary depending on cancer type and how the cancer responds to treatment, among other factors. Your treating team cannot tell you exactly how long you may live, but they can provide you with information on the expected typical, best-case and worse-case scenarios for people similar to you. They can also help you understand the likelihood of achieving things you have planned or need to do.

You, your family and carers are encouraged to discuss this with your treatment team, so you can be reassured that although the treatment may not cure the cancer, it can help you live as long as possible and improve your quality of life. Whether and when you do this is completely up to you.

How is it treated?

Several treatment options are currently available. Research continues to provide new treatments for metastatic breast cancer.

Many factors about the nature of the cancer itself and your own health and circumstances influence the treatment that will be offered to you. You do not need to be concerned if you are offered different treatment options than someone else you have met with metastatic breast cancer.



What are anti-cancer treatments?

Anti-cancer treatment usually involves “systemic” treatment that treats the whole body, such as hormone-blocking therapy or chemotherapy. You and your doctor will decide on what is the best treatment for you. There are different forms of treatment, including tablets, injections and intravenous infusions. Tablets can be just as effective as intravenous treatments, so do not worry if you are not receiving intravenous treatment.

Treatment is given for as long as it remains effective against the cancer and does not cause excessive side effects. This means most people with metastatic breast cancer will be on some form of treatment for the rest of their lives. At any time, you can talk to your treating team about having a break, stopping or changing treatment, if you feel that the current treatment is not suitable.

Anti-cancer treatments

- Hormone-blocking (anti-oestrogen) treatments
- CDK4/6 cell cycle inhibitors
- Chemotherapy
- Targeted treatments
- Immunotherapy
- Radiotherapy
- Clinical trials
- Surgery



What is supportive care?

The goal of supportive care in metastatic breast cancer is to prevent or treat symptoms as early as possible.

Supportive care may include:

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

Other supportive care measures for you and your family:

- access to information about your condition from trusted health professionals (eg. medical oncologist and breast care nurse)
- access to a psychologist (early access to psychological support such as counselling can be helpful for you and family)
- access to a team of allied health professionals (e.g. physiotherapist, exercise physiologist and dietitian)
- various supportive care programs to help you to live as well as you can and to access the care and support you need.

A palliative care team can help you manage symptoms and offer support. Anyone with metastatic cancer can be referred to a palliative care team at any point after diagnosis, not just at the end of life.

What are the aims of treatment?

People who have metastatic breast cancer will have a range of different goals for their treatment, which may change over time. It may be useful to discuss with your treatment team what your goals are, so that they can support you in working towards those goals. Overall, the aim is to keep the cancer under control for as long as possible whilst maintaining the best quality of life achievable and preventing or controlling the symptoms or complications of cancer. You might choose to have the best possible quality of life, even if that means having less treatment. Or, you may want to have all treatments available to prolong your life, even if that means more side effects. Because of the variety of treatment options that are available, each with pros and cons, an individualised plan can be made to fit with your goals.

Will I have pain or other symptoms?

Metastatic breast cancer and its treatment can cause a number of symptoms and side effects. The greatest influence will be where your cancer has spread and the treatment you're receiving. Other factors, such as your general health and wellbeing, will also play a part.

Pain is not inevitable with metastatic breast cancer. However, it may occur, and there are a range of options available to treat pain and other symptoms if they arise. You may have long periods of time without any symptoms from the cancer.

It is important that you talk to your treating team about any concerns you have.



Who will be in my treating team?

Just as there will be many different types of treatments and measures offered at different times, several types of clinicians will be involved in your care. These may include a combination of various types of doctors, nurses, and allied health professionals.

Remember that *you* are at the centre of your experience, and this is a partnership between you and your treating team.

Doctors

Your medical oncologist is usually the coordinator or leader of your care, but there will be a range of other specialist doctors involved in your care.

Your GP is also an important part of your team — GPs can be very helpful for the everyday health issues you may need help with and coordinating your wider health care needs into the future.

Nurses

Breast care nurses (BCNs) are registered nurses specially trained to provide information and support to people with breast cancer. They can help you find your way through the health system and can be a regular point of contact for information and support. BCNA's Helpline (phone **1800 500 258**) can help you connect to a breast care nurse if you don't have one.

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 and specialised support.

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, exercise physiologists and lymphoedema specialists. Allied health professionals can help you to manage a range of symptoms and concerns that you may experience and greatly improve health and wellbeing.

Complementary health practitioners

Some people wish to see a complementary therapist, such as an acupuncturist, herbalist, naturopath, osteopath, traditional medicine practitioner or chiropractor. It is important to keep everyone in your treating team informed about what treatments you are receiving to make sure that they are safe and appropriate in your individual situation.

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. 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 people have access to best quality treatment and care. Care in another country would be unlikely to provide you with any additional advantages.



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. Whether, what and how you tell people about your diagnosis is individual and personal. There may be people who believe that your prognosis is poor and that you will 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. It may help to suggest that they read the information presented here. 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. People may ask what they can do to help, and it can be useful to have a list of practical suggestions prepared. It is okay to ask for help.

Where can I get more information?

Breast Cancer Network Australia (BCNA) is Australia's leading breast cancer consumer organisation. BCNA provides information and support to those diagnosed and their supporters, opportunities to connect with others going through a similar situation and work to influence a stronger healthcare system to ensure all Australians affected by breast cancer receive the very best care, treatment and support.

Website

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.

The Information and Resource Hub is where you can search and filter for articles, stories, podcast episodes and videos specific to your needs. You can also find the Hope & Hurdles series of metastatic breast cancer resources online on the BCNA website. Please visit bcna.org.au.

Helpline

BCNA's Helpline provides support and information about breast cancer for people living with breast cancer and for their family members and friends. Call BCNA's Helpline on **1800 500 258** for information, support and referral onto the services you need. You can contact our Helpline team between 9.00 am and 5.00pm (Eastern Standard Time) Monday to Friday.

The Beacon

The Beacon is BCNA's free magazine for all Australians diagnosed with breast cancer. In The Beacon you will find information about the latest treatments and supports available, as well as personal stories from Australians living with metastatic breast cancer. To view issues of *The Beacon*, visit bcna.org.au.

Online Network

BCNA has a dedicated 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 onlinenetwork.bcna.org.au or call BCNA on **1800 500 258** for information and support.

Cancer Australia

The Cancer Australia website provides comprehensive information, guidelines and recommendations for the treatment of people diagnosed with metastatic breast cancer. For more information visit 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**.



To help you get the information and support that is right for you, ask your health professional to tick the boxes below that best describe your diagnosis.

I have metastatic breast cancer

The breast cancer has spread to another part of my body:

- bone
- liver
- lung
- brain
- Other: _____

I have the following sub-type(s) of breast cancer:


- Hormone-positive breast cancer
- HER2-positive breast cancer
- Triple negative breast cancer
- Other: _____

Referred by:

Name: _____

Role: _____

HELPLINE 1800 500 258
BCNA.ORG.AU

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