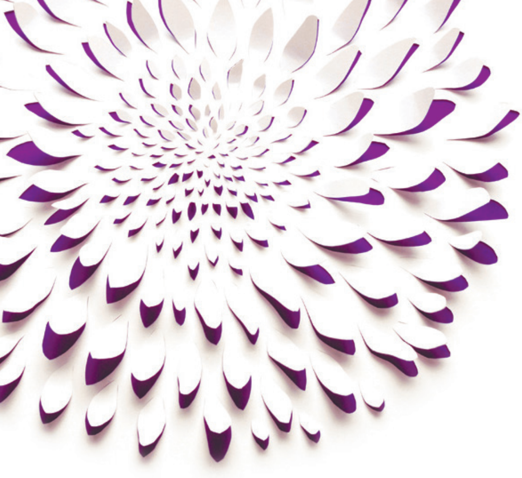
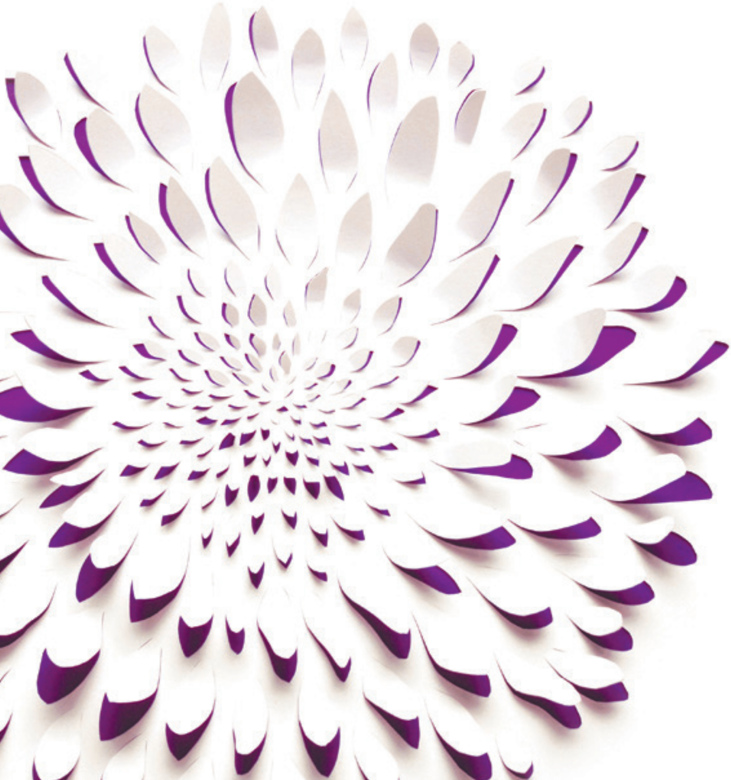


HOPE & HURDLES

Metastatic Breast Cancer:
Hope & Hurdles Information Guide



Breast
Cancer
Network
Australia

This *Metastatic Breast Cancer: Hope & Hurdles Information Guide* is based on the *Hope & Hurdles Information Guide* which was first published in 2007.

4th edition June 2020

2020 ISBN 978-0-9752053-0-3

Hope & Hurdles is dedicated to all people living with metastatic breast cancer, and their carers. It was inspired by Veronica Macaulay-Cross, whose voice and passion contributed to its concept and development. The photographs in *Hope & Hurdles* are of people with metastatic breast cancer and their families and friends. The quotes in this guide were gathered from people living with metastatic breast cancer. Some names have been used with permission, other quotes, where no names are attributed, were provided through anonymous surveys. In addition, some names have been changed to protect people's privacy. We are grateful for their messages and their contributions to *Hope & Hurdles*.

The *Metastatic Breast Cancer: Hope & Hurdles Information Guide* has been endorsed by the following organisations:

- Breast Surgeons of Australia and New Zealand
- Cancer Council Australia
- Cancer Nurses Society of Australia
- Clinical Oncology Society of Australia
- McGrath Foundation
- Medical Oncology Group of Australia
- National Breast Cancer Foundation
- Oncology Social Work Australia
- Palliative Care Australia
- Royal Australian and New Zealand College of Radiologists
- Royal College of Pathologists of Australasia

Australian Government
Cancer Australia

This guide is a Cancer Australia *Supporting Women in Rural Areas Diagnosed With Breast Cancer* Program initiative, funded by the Australian Government.

Published by:

Breast Cancer Network Australia
293 Camberwell Road Camberwell, Victoria, 3124, Australia

Telephone: **1800 500 258**
Email: **contact@bcna.org.au**
Website: **bcna.org.au**

Breast
Cancer
Network
Australia

BREAST CANCER NETWORK AUSTRALIA

Breast cancer is the most common cancer in Australian women and affects approximately 1 per cent of men. There are currently no reliable figures on the number of people living with metastatic breast cancer as this data is not routinely collected. It is estimated about 5 to 10 per cent of people diagnosed with breast cancer each year will have metastatic disease at presentation. In addition, of those diagnosed with early breast cancer, about 20 to 30 per cent will go on to develop metastatic disease even with the best care possible.

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We support, inform, represent and connect people whose lives have been affected by breast cancer. We work to ensure that Australians diagnosed with breast cancer receive the very best care, treatment and support.

BCNA is represented by the Pink Lady silhouette, which depicts the organisation's focus on the people affected by breast cancer – the women, men and their families.

To contact BCNA phone **1800 500 258**, email **contact@bcna.org.au** or visit **bcna.org.au**.

]

A PERSONAL MESSAGE TO YOU

We know the experience of being diagnosed with metastatic breast cancer is different for every person. The emotional, medical and practical challenges vary and are influenced by many factors, as well as individual preferences around what might be best for each person affected by this disease.

This *Metastatic Breast Cancer: Hope & Hurdles Information Guide* has been developed to provide you with the best possible and most relevant information about living with metastatic breast cancer, as well as help you make informed decisions about your own individual treatment, care and wellbeing.

BCNA recognises that a diagnosis of metastatic breast cancer is an individual experience and affects a diverse range of people. Additional sections in this guide reflect the uniqueness of the metastatic breast cancer experience for young women, men and for those whose first diagnosis is metastatic breast cancer (referred to as de novo metastatic breast cancer).

Today, new treatment discoveries and scientific advances mean that some people are living with metastatic breast cancer for many years.

As new treatments are discovered, BCNA will continue to strive to ensure that every Australian has access to the very best care, tailored to their particular needs.

BCNA also produces a number of booklets, factsheets, podcasts and webcasts on a range of topics that you may find useful. Visit the metastatic breast cancer section of the BCNA website to see the latest additional resources available.

We hope the *Metastatic Breast Cancer: Hope & Hurdles Information Guide* will help you and your family have a better understanding of the treatment and care recommended for you and provide some comfort knowing that information, advice and support is available to you every step of the way.

With warm regards

Breast Cancer Network Australia

RESOURCES

Many people with metastatic breast cancer have suggested books, brochures, websites and other resources that they found useful and would recommend to others.

Within this *Information Guide* our recommended resources (see the example below) has an accompanying symbol to indicate its type, such as a book, podcast or website.

📖 Books
💻 Website
🏠 Organisation
📱 Podcast/App
📄 Brochures/booklets/factsheets
💿 DVD
📞 Service

MORE FROM BCNA

BCNA has a comprehensive range of information resources for people affected by breast cancer. The *Metastatic Breast Cancer: Hope & Hurdles Information Guide* is our key resource for people with metastatic breast cancer. However, if you use a smartphone or computer with the internet, you might prefer to use the My Journey online tool that is available from **bcna.org.au**.

The My Journey online tool can be used on your smartphone, tablet or computer. It contains the most recent and up-to-date information about metastatic breast cancer. After entering some details about yourself and your diagnosis, the digital tool will direct you to information that is tailored to you and your needs, including services and practical supports that may be available in your area. Visit **myjourney.org.au**.

BCNA's Helpline includes experienced cancer nurses who provide support and information for people diagnosed with metastatic breast cancer and for their family members and friends. You can talk to the cancer nurses about any concerns you may have and they can refer you to supports available. You can contact our Helpline team on **1800 500 258** on Monday to Friday between 9.00 am and 5.00 pm. (Eastern Standard Time). You can also contact us by email on **contact@bcna.org.au**.

BCNA's online network is a place to connect with others online who understand what you're going through. There is an active public discussion for anyone affected by breast cancer. There is also a private group for people with metastatic breast cancer, where only members of the group can read the discussions. Visit **bcna.org.au/onlinenetwork** for more information or call BCNA on **1800 500 258** for support.

BCNA's website bcna.org.au has additional resources for people with metastatic breast cancer including webcasts and podcasts.

The Beacon is BCNA's free twice-yearly 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. If you would like to receive *The Beacon*, phone BCNA on **1800 500 258**, email **contact@bcna.org.au** or **visit bcna.org.au**.

WHAT'S IN THIS GUIDE

This guide is for anyone who has been diagnosed with metastatic breast cancer. It may also be helpful for family and friends. The content is designed to help you make decisions about the treatment and care that is right for you. Everyone's situation is different. You may find some of the information in this book helpful now and some may be more helpful later on.

While this guide focuses on currently available treatments, new treatments and tests are continually being developed. If you hear about treatments and tests not included in this edition, please ask your breast cancer specialist or breast care nurse for more information.

Section 1: Responding to your diagnosis

The days following diagnosis can be some of the most difficult and you may experience a range of strong emotions. Section 1 provides information and strategies to help you deal with the impact of your diagnosis, helpful tips and where to find the right support to help you to make decisions that are right for you. It also includes information for people living in rural communities, people whose first language is not English and questions you might like to ask.

Section 2: Metastatic breast cancer: the facts

In Section 2 you will find information to help you understand your diagnosis and symptoms, identify key members of the treating team and their approach to care, access to public or private health care services and getting the most out of your medical consultations.

Section 3: Treatment for metastatic breast cancer

Section 3 provides detailed information about the different treatment options available to you. It also includes information about the side effects of treatments and supportive care available to ensure you continue to live your life fully.

Section 4: Living well

Living with metastatic breast cancer can bring many challenges. Section 4 contains information and strategies to help manage your emotional and physical wellbeing, relationships and work. Many of these tips have been provided by people living with metastatic breast cancer who have been able to continue living their lives to the full.

Section 5: Financial and practical matters

A metastatic breast cancer diagnosis can sometimes cause financial strain due to the costs of ongoing treatment and care. It can also put pressure on many aspects of life such as family, child care and work. Section 5 provides information about the financial impact of metastatic breast cancer, federal and state government assistance programs, superannuation and insurance, employment and other sources of financial help.

Section 6: Young women

This section provides information that addresses the specific challenges young women may face and the support that may be available.

Section 7: Breast cancer in men

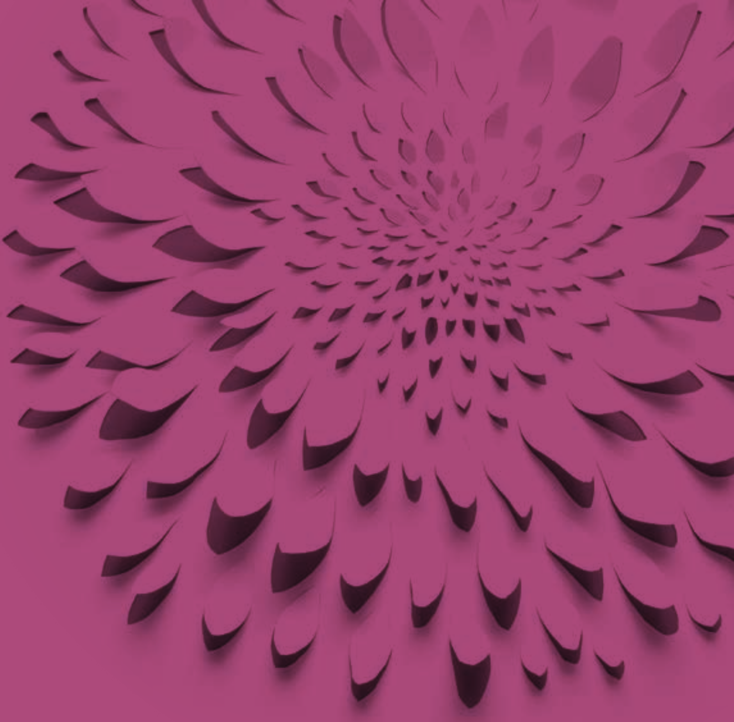
Section 7 recognises the unique issues of men diagnosed with breast cancer and the support available.

Section 8: Metastatic from the start

This section is for people whose first diagnosis is metastatic breast cancer and involves tailored information about your diagnosis, implications for treatment and the support available.

Section 9: Breast cancer drugs and glossary

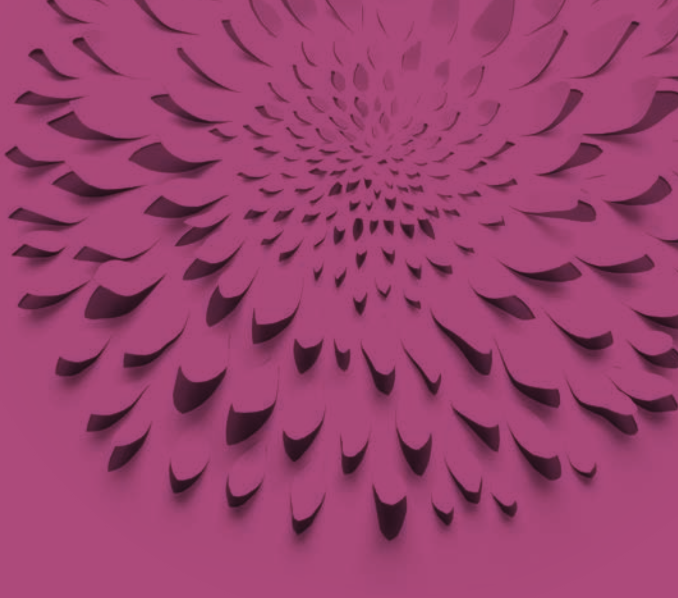
Section 9 contains a list of commonly used drugs in the treatment of metastatic breast cancer and a glossary of terms.



SECTION 1

RESPONDING TO YOUR DIAGNOSIS

It has taken me a while to get an understanding of the implications of my diagnosis but I know that every case is different and there are many treatment options. Simple and clear explanations go a long way to helping absorb the facts and come to terms with what is ahead. It can help to reduce the mental anguish which you experience and help you to process all of the new information and make sense of it.



SECTION OVERVIEW

This section provides information on:

- coming to terms with your diagnosis
- help in dealing with your diagnosis
- breaking the news
- organisations that can help you
- information for people in rural areas
- information for First Peoples
- information for people whose first language is not English
- stories from people living with metastatic breast cancer
- questions you might like to ask your doctors about metastatic breast cancer.

COMING TO TERMS WITH YOUR DIAGNOSIS

Metastatic breast cancer is breast cancer that has spread beyond the breast to more distant parts of the body. Being diagnosed with metastatic breast cancer can come as a devastating blow. At this time, metastatic breast cancer is not a curable disease and requires lifelong treatment.

The first few weeks and months can be overwhelming as you begin to absorb and process the information. You may experience many different emotions including disbelief, anger, denial, fear, anxiety, confusion, isolation and depression. You will almost certainly find yourself worrying about what lies ahead, both for you and your family and friends.

Overwhelming feelings of distress, panic, grief and difficulty sleeping can make it very hard to think clearly. Navigating these emotions and making sense of what is happening can be difficult. Allowing yourself time to grieve for the future you thought you had and to adjust to the changes thrust upon you is important. Many people experience this sense of turmoil before feeling they have some control over what's happening to them and that they're able to manage the emotional and practical issues it brings.

It's important to take time to understand what your diagnosis means for you, ask questions and talk through the treatment options and support available to you and your family. It can be helpful to speak to someone other than your family and friends who can listen to your fears and concerns and support you through this challenging time. This could be a member of your treating team such as a psychologist, breast care nurse or medical oncologist.

I would recommend finding someone to talk to straight away after diagnosis – a psychologist, counsellor, or someone else your team can recommend. It's really important to have someone to talk to if you are unable to discuss feelings with your direct family or haven no family.

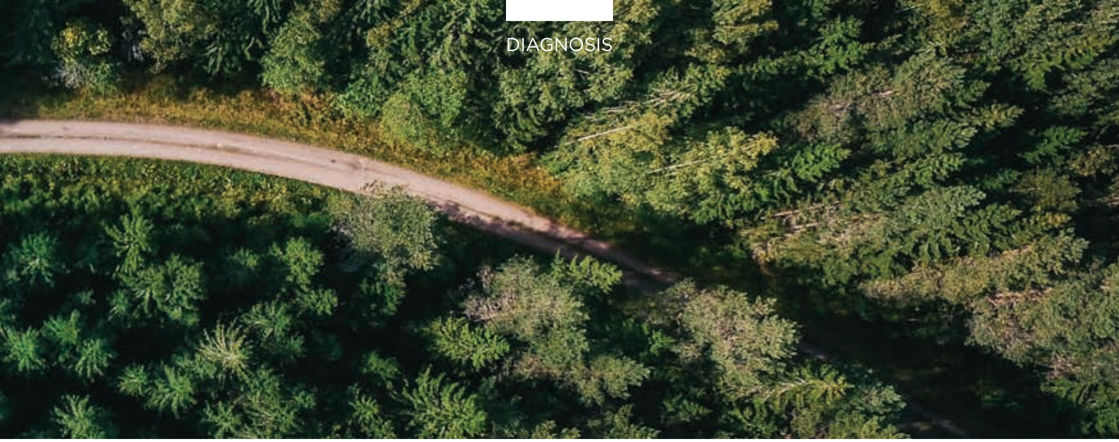
F1RST THINGS F1RST

Ask questions

Asking questions will help you understand what is recommended for you. Before you go to an appointment, write a list of questions you want to ask, putting your most important ones at the top in case you don't get time to ask them all. The questions at the end of each section can be a helpful guide.

Find a medical team that will work for you and with you

You will have a long association with your specialists so find a treating team you can trust and who make you feel cared for. Ask for second opinions if you think you need them.



Understand the costs involved

Your treatment will extend over a period of time so costs can add up, especially if you're being treated in the private health system. It's important to know up front what the costs of your tests and treatment are likely to be. Talk to your doctor and, if you have one, your private health insurer, before you make a final decision about your treatment. You can ask for a second opinion on costs if you need to.

Take your time

Most decisions about your treatment don't need to be made in a great hurry so don't allow yourself to be rushed. Taking time to ask questions if there are things you don't understand, or talking over the decisions you need to make with your family, won't affect the outcome of your treatment. It can, however, make a big difference to how prepared and in control you feel.

Keep records

If you can, take a trusted family member or friend to your doctors' appointments to help record and keep track of the information you receive. Take notes, or ask your family member/friend to, so you can refer back to the information later. Keeping a record of your bills and any rebates you receive will help you stay on top of your expenses. Store your medical or financial records in one secure place.

What does it mean for me?

As yet, metastatic breast cancer can't be cured. However, with current advances in treatment, some people with metastatic breast cancer are now living for many years.

Some people think of their disease as living with a chronic illness with ongoing treatments. Accepting this approach can provide them with optimism and hope for the future. For others, an incurable cancer is more than a chronic disease. They feel the term 'chronic illness' doesn't reflect the magnitude of incurable cancer. How you respond to your diagnosis is unique to you – there is no right or wrong way for you to feel.

Being diagnosed with metastatic breast cancer is devastating, but I have come to terms with it and I also remain determined to fight. I also have an excellent medical team looking after me and feel confident that they will do everything in their power to keep me alive as long as they can.

Finding out from my oncologist and GP, and by reading Hope & Hurdles, that metastatic breast cancer isn't the immediate death sentence I'd previously imagined … that it can be considered like a chronic ailment over a number of years … was the best thing for my acceptance of the disease.

Finding out

When people ask me how I felt at the beginning, I tell them that I did have doubts about the future; there were lots of tears, but gradually as time passes you think, 'Hey, I'm still alive', and this is the way it's going to stay. I'm not interested in statistics, I'm a person and I'm going to fight this every inch of the way. I am now way, way past my 'use-by date' and am going to be around until I'm really old and wrinkly.

If you have had a previous breast cancer diagnosis, hearing that your cancer has spread can be devastating. You may struggle to come to terms with the fact that a cure is unlikely to be possible.

If this is your first breast cancer diagnosis (de novo), you might wonder why it wasn't found earlier. Understanding available treatment and options can be overwhelming, especially as you may have no prior knowledge of breast cancer. The advantage for people diagnosed with de novo metastatic breast cancer is that it's treatment 'naive', which means it hasn't been exposed to anti-cancer treatments before and is, therefore, likely to be more responsive.

It's important to know that, whenever metastatic breast cancer is found, it can be treated even though it currently can't be cured.

I hope that I can help others who may have to deal with a diagnosis of metastatic breast cancer, to teach them not to be afraid. People are always surprised at how well I look and how positive and accepting I am. I have been this way for nine years, through three breast cancer diagnoses in that time! As long as I feel good, I consider myself very lucky.

There's no one to blame

Some people have told us they experience feelings of guilt. Some people wonder whether, if they had picked up their breast cancer earlier or done something differently, they may not have presented with metastatic breast cancer. If they had a previous diagnosis of early breast cancer they may question whether the treatments they decided to have, or not have, may have influenced their breast cancer's return.

Some people feel that, if they had had more tests and scans as part of their follow-up care, or if the doctors had paid more attention, they may have found the metastatic cancer at an earlier stage. Unfortunately, we still don't know enough about why breast cancer spreads or in whom it's most likely to spread. Some breast cancers will spread whatever treatment a person receives and whatever lifestyle changes they make. It can help to understand that, unlike early breast cancer, finding metastatic breast cancer early doesn't usually affect overall long-term survival.

Making choices

Spend time talking to people, most importantly your doctors, other health professionals and people who have experienced the illness themselves.

People react to discovering they have metastatic breast cancer in different ways. Some prefer to carry on with something as close to their daily routine as possible – for example, they may continue to work if they feel well enough to do so. Others want to transform their life completely. It's probably best to give yourself time to get over the initial shock before you make any dramatic changes. Professional support such as speaking to a psychologist might help you to explore your options and decide what will be best for you.

When I was diagnosed, I started making drastic decisions – I was going to quit my job. One of my friends suggested a psychologist to talk about things and that was really valuable.

A diagnosis of what is described as a life-limiting disease can inspire you to take stock of your life and start thinking about the things that really matter and make you feel good.

My life and my identity have changed in positive and negative ways. My priorities have changed; I'm doing things now instead of putting things off until later in life. I do more things for myself. I now work three days a week instead of five. My life is not as rushed and hectic as it used to be. I don't get upset about little things anymore.

Managing uncertainty

Generally, we like to know what to expect in life, so uncertainty can make us feel uncomfortable or anxious.

Having metastatic breast cancer adds a new and complex dimension to the uncertainty, but many people have found ways to manage this.

Involve your family in setting goals – some small and easily achieved, others long term and sometimes difficult to imagine ever accomplishing. As each goal is achieved, set new ones.

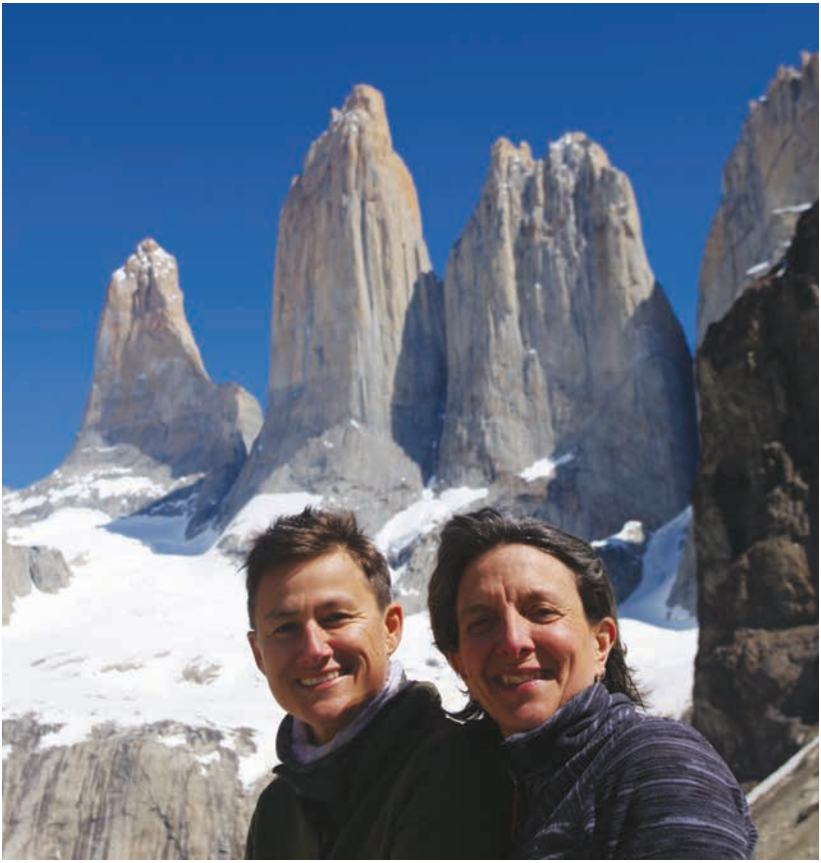
For some, knowing all about the disease and how it's likely to be treated reduces some of the anxiety that often accompanies feelings of uncertainty. If you feel that having more information would help, don't hesitate to ask your breast cancer clinician or breast care nurse.

Many people find they gradually learn to focus on the things they can control then deal with things they can't control as they arise. Relaxation, meditation, mindfulness or prayer may help with this.

The people around you

You may find you’re not only trying to manage your own uncertainty but also the fears of people around you who may not understand the implications of having metastatic cancer. This can bring additional pressure, as it’s natural to want to protect those we love from insecurity and distress.

You don’t have to feel responsible for what other people are feeling, nor should you feel you’re responsible for supporting them when you’re struggling to cope yourself. But it may help to remember that most of the people you come into contact with – and that includes health professionals as well as your family and friends – have never had to face the reality of a life-limiting illness. They may have no idea of what’s best to do or say, or how to help you. If you want your doctor to provide more or less information, say so. If you want your friend to behave as though nothing has changed, tell her. If you want her to talk to you about dying, tell her that too.



HELP IN DEALING WITH YOUR DIAGNOSIS

Being diagnosed with metastatic breast cancer is a life-altering event. In the first few weeks or months you may feel you're trapped in a never-ending nightmare. After the initial shock you will gradually start to think a little more clearly and realise there are things you can do to cope with living with your diagnosis. Remember, there is no right or wrong way to navigate through this diagnosis and experience, just your way.

Some helpful tips

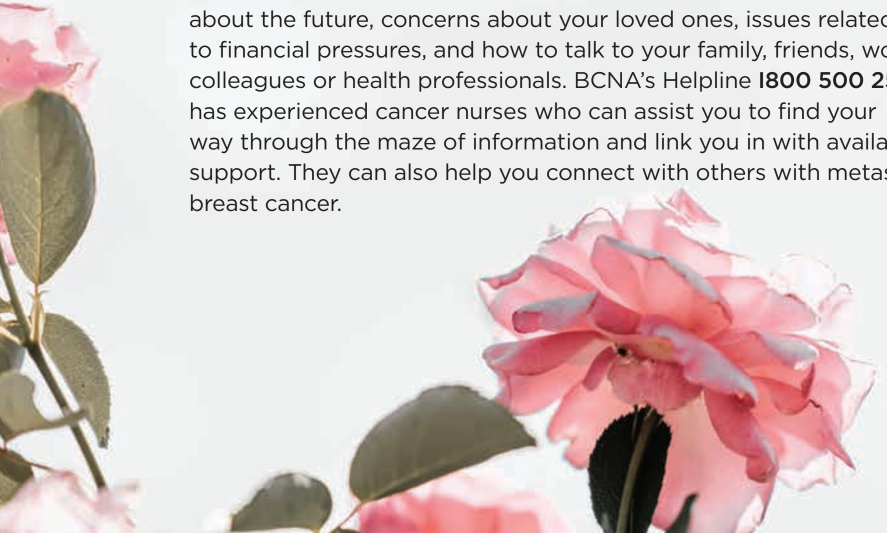
- Take some time to pause and to process what you can. There may be pressure from those close to you to follow a particular course of action.
- Think about what you want. Take one step at a time.
  It generally helps to be informed. Talk to your medical team and ask lots of questions so that you fully understand your situation and the treatment plan. Ask for second opinions if you think you need them.
- Find a medical team that works well with you and a key person you can contact if you have any questions.

  See p.53 for more information.
- Public or private health care – it's important to consider your options and ask your doctor what no-cost public health options may be available to you even if you do have private health insurance. As

an Australian citizen you're entitled to be treated through a public hospital with costs covered by Medicare even if you have private health insurance. If you have private health insurance you can also be treated as a private patient in a public hospital and choose your treating doctor. In public hospitals you should have few out-of-pocket costs. For people with private health insurance, it's important to know that, while inpatient procedures are covered (although not always fully), outpatient care such as radiotherapy, visits to specialist rooms and blood tests may not be covered. Before you start treatment as a private patient you may want to speak to your health fund to clarify what is covered. You can also talk to your treating doctors about their fees.

ℹ **For more information on public and private health care see p.62.**

- Ask to see a breast care nurse (BCN). 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. The McGrath Foundation raises money to place BCNs across communities in Australia and are dedicated to increasing the number of BCNs trained to care for people with metastatic breast cancer. BCNA's Helpline can help you connect to a breast care nurse if you don't have one. Phone **1800 500 258**.
- Store all your medical and financial records in one place so you can find them easily if they're needed. Having all your medical records in one place is also helpful if you decide you want a second opinion about your treatment and care. My Health Record is an Australian government secure system that stores your health information. Visit **myhealthrecord.gov.au** for more information.
- It's normal to experience a range of concerns such as uncertainty about the future, concerns about your loved ones, issues related to financial pressures, and how to talk to your family, friends, work colleagues or health professionals. BCNA's Helpline **1800 500 258** has experienced cancer nurses who can assist you to find your way through the maze of information and link you in with available support. They can also help you connect with others with metastatic breast cancer.



- Anxious thoughts will often pop up and can gain momentum. If you have trouble managing anxious thoughts, you might like to seek professional help. A professional can also help you with strategies for talking to family members, including children, and work colleagues and friends. There may be social workers or psychologists at your treatment centre, or your GP may be able to help you or refer you to a psychologist or other counsellor through a GP mental health care plan. This plan allows you to have up to 10 Medicare-subsidised counselling appointments each year.
- Put yourself first. If it helps, allow family members to screen your phone calls, and don't feel that you have to update everyone who rings. It's exhausting. Choose who you want to see, and when. You may wish to start a blog or do a group email to keep your family and friends up to date.
- Allow others to help and support you and your family. Don't be afraid to ask for help or accept help when it's offered.
- Try to keep up your regular exercise routines that suit you. Walking, gardening, mindfulness or music can be good therapy to help you cope through this challenging time.
- Take time out. It's important to treat yourself to some pleasant experiences – spend time with a friend, walk along the beach or go away for the weekend. Give yourself a 'cancer-free' day where you just get on with living and stop thinking about cancer all the time.
- Talking to other people who have metastatic breast cancer can be helpful. BCNA's online network has a private metastatic group where you can connect with others. There are also face-to-face metastatic breast cancer support groups or telephone-based support groups available. Phone BCNA on **1800 500 258** or Cancer Council on **13 11 20** for more information.
- If you decide to search for information online, use websites offering reliable, good quality information that will help you understand what your diagnosis means for you. Sites run by reputable organisations like BCNA, cancer centres, government or cancer specialist organisations such as Cancer Australia or Cancer Council are good sources of information.

  See the Resources section p.31 for a list of websites that you may find helpful.

  Remember that not all the information you read will be relevant to you and your diagnosis. The best way to use your research is to compile a list of questions for your doctor.

BREAKING THE NEWS

At the same time as you need to deal with it, your family needs to deal with it as well. There's no easy way of telling them that you have advanced disease.

Telling friends and family that you have metastatic breast cancer is not easy. Even explaining what metastatic breast cancer means can be difficult. As well as your own emotions, you have their reactions to deal with. You may find it hard to answer their questions, or to raise subjects such as fears for the future or death and dying that are important to you but which they seem reluctant to talk about.

Telling your partner

If you have a partner, they may have been with you at the time of your diagnosis. If not, they will probably be the first person you tell. As your partner is likely to be the person who supports you, it's a good idea to be completely honest from the start.

Changes to your relationship are inevitable. The challenge of living with a life-limiting illness will often bring couples closer together but it can also drive them apart. While you might be feeling guilty about needing more care and support, or worrying about becoming a burden, your partner might be feeling equally worried about letting you down, or guilty about thinking about a life without you. These kinds of emotions aren't easy to talk about but the more you communicate, the better your chances of feeling like a team. It can often be helpful for your partner to have someone they can talk to about their own concerns at this time. There may be social workers or psychologists at your treatment centre, or your partner's GP may be able to refer them to a psychologist or other counsellor. Your partner can also use the BCNA telephone support service.

For more information on the people in your team who may be able to help, see p.54.

Telling your parents

The thought of telling your parents about your diagnosis can be daunting. Depending on their age and circumstances, they may already be coping with their own medical problems and may even have been relying on you to help them live comfortably in their own home or in supported care.

It's devastating for a parent to hear that their adult child has a potentially life-limiting illness, and could die before them; it's against the natural order of things.

I was living in a different state and my mother was very elderly, so I asked my sister to tell her about my diagnosis. I knew how sad and shocked she would be. I then spoke at length to Mum on the phone. One of the first things she said to me was 'Daughters are not supposed to die before their parents', at which we both dissolved into floods of tears.

Your parents don't have to be told about your diagnosis immediately – it isn't an emergency. You may choose to share information about your diagnosis in stages and give them updates if your condition changes.

Remember that your parents' attitude to cancer may date back many years, or even decades, so it's important to check their level of understanding and let them know about advances in treatment.

It can be helpful to think about local support and people they can talk to after you tell them about your diagnosis, particularly if you have to break the news by phone.

My parents were in their early 70s when I was diagnosed with metastatic breast cancer. Before I rang to tell them, I rang their minister (they are regular church goers), explained who I was, that I lived a few hours away and that I had been diagnosed with advanced breast cancer. I asked him to visit them in the near future.

After phoning my parents with the news, I sent an email to them and to my siblings explaining the diagnosis, treatment plan etc, so that they all got the correct information. I explained that they were welcome to ring me, but hoped they would understand if I wasn't up to talking.

You might decide not to tell your parents about your diagnosis, perhaps because your relationship with them is complex or you don't believe they could cope. You need to do what feels right for you – and, of course, you may come to think differently over time.

Tips for talking to your parents

- Provide clear, concise information that is easy to understand.
- Be prepared to repeat information.
- Be prepared to explain to them the advances in breast cancer treatment, and that some people live for many years.
- If they use the internet, send them links to some reliable websites.
- If you have brothers or sisters or other family members who are nearby, ask them to spend some time with your parents to provide support, or even be there to help break the news if they are able.

Telling children

For many people, the most distressing concern is their children. We all want to protect our children from pain and sadness and the thought that this diagnosis will hurt them can cause enormous grief. It's hard.

You don't deserve it and nor do they. However, you can make a difference to how this affects your children and there are things you can do to make this easier for them.

For more information about talking to children see p.219.

Telling family and friends

Family and friends could respond to you in unusual ways. I had to remind myself to be patient with them. They were in shock on hearing my news too.

Even when you're talking to adults, you may not get a reaction you would have hoped for when you tell them you have metastatic breast cancer.

Worrying about what's going to happen and the fear of losing you can affect how family and friends relate to you. Your diagnosis may also make them think about their own mortality. Often, people with the very best of intentions have no idea what to say. They may be so afraid of saying the wrong thing and upsetting you that they don't say anything at all, and so seem to withdraw from you at the time you need them most.

It might be necessary to take the lead in talking about how you feel and what you want or need. It might seem unfair that you should have to worry about other people's emotions when you're struggling with your own but once they see that you're not your cancer – that you're still the same person they have always laughed and joked with, complained to and talked to about the future – your relationships are more likely to continue to flourish.

Some people have such negative preconceived ideas about my illness and prognosis. Everyone expected me to die very quickly after my diagnosis. The only one that was positive was my medical oncologist and luckily he was the only one who got it right!

Maintaining hope

You may feel that being diagnosed with metastatic breast cancer has robbed you of hope. The automatic assumption that everything is a disaster can be hard to shake. The reality is, however, that most people can learn to balance hope and coping. Hopes and dreams are important to emotional health and everyone's needs will be different.

Gaining information about your treatment and care could help you to feel more optimistic and in control over decision-making about what is right for you.

My oncologist said: 'You're not going to be dead in 10 minutes. I promise I'll give you plenty of warning.' I felt better, then realised I'd been holding my breath.

I heard that someone had survived for 15 years and I thought bloody hell this is amazing – I didn't realise that someone could survive for that long. It gave me so much hope and I just thought 'Well if she can do it I can too.'

Over time, most people come to realise that hope hasn't gone, although its nature will have changed. Your hope may now centre on long periods of disease control and feeling well, or enjoying a trip or a special event.

When I was first given my prognosis, I thought I would not see my two daughters married, see any grandchildren or see much more of life. However, both our daughters are married and we have five wonderful grandchildren. I work part-time, do voluntary work, travel every year, including walking holidays, and lead a very full and hectic life.

Managing your worries

Having dark thoughts from time to time is normal. However, if these start to dominate your thinking it can be useful to develop some techniques for challenging them. One technique is called 'worry postponement'. Constant worry is exhausting – but setting aside a specific time every day to 'worry' can help you to feel calmer for the rest of the day. If other strategies have helped you to cope with difficult times in the past you may be able to draw on them again.

For more information about managing feelings and emotions see Section 4: Living Well.

Buy yourself a small gold box with a lock. Into this box, place all your worries and lock it. Open the box once a day for five to 10 minutes. Worry then while the box is open. Close the box, and worry no more. Allow yourself to worry about your health and future like this once a day. Don't ruin the rest of life with constant worrying. Life is too wonderful to spoil worrying about what might be and what could have been. Celebrate what it is!

ORGANISATIONS THAT CAN HELP YOU

Breast Cancer Network Australia

bcna.org.au or phone **1800 500 258**

As well as this *Metastatic Breast Cancer: Hope & Hurdles Information Guide*, BCNA provides a variety or resources for people affected by metastatic breast cancer.

- BCNA's website provides a wide range of information in different formats, including video and audio. The site is integrated with the online network, which helps people connect with each other for support and information. The website can also connect you to live and recorded webinars or podcasts of interest and other useful online resources.
- The website also provides access to the My Journey online tool, which can be used on your smartphone, tablet, laptop or computer. It provides up-to-date information about metastatic breast cancer, treatments and supports available to you.
- BCNA's Helpline includes cancer nurses who provide support and information about breast cancer. Phone **1800 500 258**.
- BCNA's local service directory lists breast cancer-related services suggested by people who have experienced breast cancer, and health professionals.
- BCNA's magazine *The Beacon* is available to BCNA members twice a year. To subscribe phone BCNA.
- BCNA distributes a monthly email newsletter you can receive by registering online at **bcna.org.au**.

Cancer Australia

canceraustralia.gov.au

Cancer Australia was established by the Australian Government in 2006 to minimise the impact of cancer, address disparities and improve the health outcomes of people affected by cancer in Australia by providing national leadership in cancer control. The Cancer Australia website provides a wide range of evidence-based information about cancer, and also offers evidence-based resources to download.

This includes the *Cancer Australia Statement – influencing best practice in metastatic breast cancer*. The statement highlights 10 key appropriate and inappropriate practices as priority areas for metastatic breast cancer treatment and care. Detailed information about the statement including videos can be found on the Cancer Australia website **thestatement.canceraustralia.gov.au/metastatic**.

Resources can be downloaded online (**canceraustralia.gov.au/resources**) Or, for more information, you can phone **1800 624 973** or email **enquiries@canceraustralia.gov.au**.

Cancer Councils

cancer.org.au

Cancer Councils in each state and territory provide a range of services including telephone support and counselling, informative websites, peer support programs, assistance with accommodation, financial support, seminars and forums. They also have a range of brochures, booklets and fact sheets on many topics related to breast cancer.

The national Cancer Council website provides information to help people affected by cancer from the point of diagnosis through to treatment and survivorship, including living with incurable cancer. It also provides links to the state and territory Cancer Council websites.

The national **Cancer Council 13 11 20** cancer information and support line will automatically direct you to the Cancer Council in your state or territory for the cost of a local call. Staff can provide information and materials for you and your family. Services vary slightly between states and territories.

INFORMATION FOR PEOPLE IN RURAL AREAS

If you live in a rural or remote part of Australia you may be facing a range of additional challenges including being a long way from specialists and treatment centres, having limited access to medical and support services, and being away from family and friends if you have to travel for treatment.

Many regional support services have been put in place to ensure people living in rural and remote areas are able to access the same quality of care as people in metropolitan areas.

Your breast care nurse, social worker or GP, BCNA's Helpline staff or **Cancer Council 13 11 20** should be able to advise you about services that you're eligible for and provide information about:

- financial assistance schemes to help with the costs of travelling to medical appointments and treatment (e.g. reimbursement for petrol, train or plane fares and accommodation)
- subsidised accommodation near your treating hospital
- other financial or practical assistance programs or services in your state or territory.

Some of the specific rural assistance schemes that may be available to you include:

- Patient Assisted Travel Scheme (PATS), which provides people living in regional and rural areas of Australia with financial assistance towards the cost of travelling to, and staying near, specialist medical services
- Rural Financial Counselling Service – information and referrals for people who are facing, or at imminent risk of facing, financial hardship
- Farm Household Allowance – a payment that assists farmers and their partners experiencing financial hardship with income support, financial planning and training to support long-term financial improvements.

Section 5: Financial and practical matters has more information about financial assistance

Telehealth consultations with medical specialists

If you live outside a major city, you may be able to reduce travel time by replacing some face-to-face medical consultations with online video calls, called telehealth services. If you're interested, ask your breast cancer specialists whether they offer the service and, if so, whether this option is appropriate for you.

You may be able to stay at home for telehealth consultations but they're more likely to take place at a local medical clinic where your GP or another health professional, such as a breast care nurse, can sit in with you.

Specialists such as psychiatrists, psychologists and consulting physicians may also offer telehealth consultations.

If you have a telehealth consultation, you may receive two invoices – one from the specialist and one from the health professional who provided the service and sat in on the consultation. Medicare rebates are available for both services.

If you prefer talking face-to-face, there's no obligation for you to accept a telehealth consultation even if your specialist suggests it.

Accommodation

A number of treatment centres in major towns provide accommodation for people travelling from rural areas for cancer treatment. Your state or territory **Cancer Council 13 11 20** will be able to help you locate accommodation, or you can check with the hospital social worker.

Local service clubs such as Rotary and Lions clubs, or the local branch of the Country Women's Association, may also have ideas for accommodation.

You might also want to contact the state or territory tourism bureau for information about things you can see and do while you're there.

INFORMATION FOR FIRST PEOPLES

Aboriginal and Torres Strait Islander health workers or liaison officers are available at most treatment centres across Australia. If there isn't one near you, you can ask to speak to a social worker. The Aboriginal and Torres Strait Islander Health Service in your state or territory should also be able to give you information and support.

Cancer Australia has information about breast cancer for Aboriginal and Torres Strait Islander people. Visit **canceraustralia.gov.au/affected-cancer/atsi**.

INFORMATION FOR PEOPLE WHOSE FIRST LANGUAGE IS NOT ENGLISH

Someone may be reading this to you if your preferred language is not English. If there's anything you don't understand, don't be afraid to ask the person to read it to you again. BCNA has information about metastatic breast cancer in Greek and Chinese. These booklets can be downloaded or listened to from **bcna.org.au**. If you need help from an interpreter, phone **13 14 50** and ask the interpreter to contact Breast Cancer Network Australia.

There are also videos on the BCNA website where Greek and Chinese women share their stories of being diagnosed with metastatic breast cancer in their own language. The videos have English subtitles.

Things you can do

- When you go to medical appointments, ask for a qualified interpreter. Phone the doctor's clinic or hospital beforehand and ask them to organise this for you and whether you have to pay for the service. Interpreter services are free in Australian public hospitals.
- Translating and Interpreting Service (TIS National) is a national telephone interpreting service available to any person or organisation in Australia. TIS National is available 24 hours a day, seven days a week on **13 14 50**. If you need an interpreter to speak with BCNA, phone TIS National during business hours. The service is free when you contact BCNA. It's also free if you need to contact Cancer Council.
- In most Australian states and territories, Cancer Council **13 11 20** provides information and support for people who don't speak English. You can talk to a cancer nurse at Cancer Council through an interpreter over the phone. Cancer Council staff can arrange this or you can call the Translating and Interpreter Service and they will organise it for you.
- Cancer Australia provides information in languages other than English that can be downloaded from **canceraustralia.gov.au** or phone **1800 624 973**.

STORIES FROM PEOPLE LIVING WITH METASTATIC BREAST CANCER

Way back in 2000, I was fit and well when I felt the lump in my breast that was early stage breast cancer. I found support through BCNA and Cancer Council Vic, but my focus was on getting through treatment and getting on with my life

A diagnosis of metastatic breast cancer has been a different experience. My health was deteriorating for many months while investigations failed to uncover the cause. The eventual diagnosis was both expected and a shock! The first months passed in a whirlwind of medical procedures, new information and fielding concerned questions from family and friends.

Often I found myself reassuring people that no, I'm not going to die for a good while yet. Once the routines of managing metastatic breast cancer became more settled, it was the process of seeking – and giving – support that helped me find purpose and meaning in the multiple challenges of living every day with a disease that will be with me till I die. Reaching out to others can be so hard when we find ourselves overwhelmed by the terrible, frightening – and never-ending – round of medical appointments, scans, blood tests, medications and side effects, and all the disruption and chaos they cause. But not reaching out can mean suffering and struggling alone. Sharing this experience with others who understand because they are living it too helps me make sense of metastatic breast cancer and face the uncertainty, the losses, highs and lows.

Judy

I was diagnosed with early breast cancer in 2009, aged 32 and had a year of treatment. In 2014 ductal carcinoma in situ (DCIS) was detected in my other breast and I had radiotherapy. In 2017, following back pain and an enlarged lymph node, breast cancer was found to have metastasized to my bones. This was a great shock as I was active, feeling well and successfully running a business. That initial shock lasted six months or so, but I was glad I didn't make any quick decisions. My oncologist settled me into treatment and, with the help of an exercise physiologist, my back pain decreased and I became more mobile and active again.

It's now a little over two years down the track and I'm about to start my fifth line of treatment. The cancer has progressed to my liver but currently remains stable in my bones. I'm disappointed that, as yet, on average the treatments I've had haven't worked for long but I'm fortunate that through most of my treatment I've been able to remain active and feel well. Whenever symptoms arise my oncologist takes action; we are both keen to ensure I continue to have a good quality of life for as long as possible.

A year ago I decided to sell my business. Doing so allowed me to travel, including spending time with my family overseas, and I was able to focus on exercise to maintain good physical and emotional health. My wonderful partner Anna supported me to take this break from work. The time off really benefited me and I am now considering returning to work – to whatever extent might fit best for us, and in terms of my treatment. I'm learning not to plan ahead too much but at the same time I'm confident there's a lot I can still look forward to.

Georgie

It was January 2016 and I had been feeling run down for several months. I had been experiencing lots of aches in my hips, back and ribs which my GP and I thought was muscular. But then I noticed my right breast seemed 'heavier' – no lump, it just felt different. It was at this point that everything started spiralling out of control. First it was confirmed I had breast cancer then, just days later, that I had stage IV breast cancer with metastases in my bones, liver and possibly lungs. I was 49 years old and had three girls aged nine, 12 and 14 years old. To say I was devastated was an understatement.

I remember my oncologist telling me not to panic, I was not going to die any time soon. And, although she was trying to reassure me that I was looking at years not months, I did not find her words reassuring. I had a life-limiting illness with an uncertain prognosis. The future I had taken for granted no longer existed. How was I ever going to come to terms with living for the rest of my life with this illness? How would my family come to terms with this diagnosis?

The past four years have certainly not been easy – there have been lots of tears and, sadly, I have lost many amazing friends to metastatic breast cancer. But if someone had told me four years ago when I was sitting confused and frightened in my oncologist's office that in 2020 I'd be working full-time, that I'd be selected to represent NSW in the Senior B Dragon Boat team, and that I would indeed find a way to live well with this terrible disease, I simply would not have believed them. But with the support of my healthcare team, my family and friends, and the people in my metastatic breast cancer support group, the impossible has been made possible. I would never say life with metastatic breast cancer is easy but, with help, it's bearable.

Andrea

QUESTIONS YOU MIGHT LIKE TO ASK ABOUT METASTATIC BREAST CANCER

People have told us they found these questions useful to ask when they were first diagnosed with metastatic breast cancer. Add any others you think of before you go to appointments and, if you can, take someone with you to take notes.

- What type of metastatic breast cancer do I have and where in my body has it been found?
- What will happen now? Do I need more tests? What information will the test results provide?
- What treatment will I have, how will it be given and what are the possible side effects?
- What will the treatment cost me?
- Is there someone I can talk to for emotional support? What will the cost be? Am I eligible for any subsidies?
- Can I have treatment in a public hospital so I don’t have to pay or can I access any financial assistance programs?
- Is there specific information available for my needs?
- Can you help me connect with other people who have metastatic breast cancer?
- Is there a metastatic support group at this hospital?
- Can I access a breast care nurse who specialises in metastatic breast cancer?
- I have a My Health Record. Are you able to upload my results and reports to my digital record?
- Are there treatments that I can access via clinical trials?
- Do I need to have surgery to remove the cancer/tumours? If not, can you please explain why surgery is not a viable option in the metastatic setting?

RESOURCES

Organisations

Breast Cancer Network Australia (BCNA)

bcna.org.au or phone **1800 500 258**

In addition to this *Metastatic Breast Cancer: Hope & Hurdles Information Guide*, BCNA provides a range of information and support programs for people diagnosed with metastatic breast cancer.

Cancer Australia

canceraustralia.gov.au or phone **1800 624 973**

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

Cancer Council

cancer.org.au or phone **13 11 20**

Cancer Councils are located in each state and territory.

They provide a range of services, including telephone support and counselling, peer support programs, assistance with accommodation, financial support, seminars and forums.

For information and support on cancer-related issues, call **13 11 20** which will divert you to the Cancer Council in your state or territory for the cost of a local call.

Cancer Council Australia website:

cancer.org.au

State and territory websites:

ACT – actcancer.org

NSW – cancercouncil.com.au

NT – nt.cancer.org.au

QLD – cancerqld.org.au

SA – cancersa.org.au

TAS – cancertas.org.au

VIC – cancervic.org.au

WA – cancerwa.asn.au

McGrath Foundation

mcgrathfoundation.com.au or phone **02 8962 6100**

The McGrath Foundation funds the appointment of breast care nurses in hospitals and community health centres across Australia.

Breast care nurses are registered nurses specially trained to provide information and support to people with metastatic breast cancer. Contact the McGrath Foundation to find a breast care nurse near you.

Carers Australia

carersaustralia.com.au or phone **1800 242 636**

Carers Australia represents Australia's carers to improve the health, wellbeing, resilience and financial security of carers. The Carers Australia website also provides links to the different state and territory carers associations.

Palliative Care Australia

palliativecare.org.au or phone **(02) 6232 0700**

The national peak body for palliative care aims to improve access to, and promote the need for palliative care. It provides access to resources, advance care planning, information for carers, and a directory of services (searchable by category or postcode).

Online resources and publications

Finding the words – starting a conversation when your cancer has progressed

Cancer Australia
Download from the Cancer Australia **canceraustralia.gov.au**

This resource has been developed to help people with metastatic cancer talk about how palliative care might help them to live as well as possible when cancer has spread.

When someone close to you has metastatic breast cancer

Breast Cancer Network Australia
bcna.org.au or phone **1800 500 258**

This booklet is designed to help partners, family members, friends or colleagues support someone who has been diagnosed with metastatic breast cancer.

When the woman you love has metastatic breast cancer

Cancer Australia
Podcast section of the Cancer Australia **canceraustralia.gov.au**

When a woman is diagnosed with metastatic breast cancer, the news and its implications can be enormously challenging for her, and also for her partner and family. This podcast series (also available as a CD) provides advice and information to male partners on how to deal with their own needs and feelings.

Understanding metastatic breast cancer: a comic book for children 8-12 years old

Breast Cancer Network Australia
bcna.org.au or phone **1800 500 258**

Understanding metastatic breast cancer is a comic for children aged eight to 12 years of age. In it, the Medikidz superhero characters take two children on an adventure through the human body to learn about what happens after a metastatic breast cancer diagnosis.

Anxiety, depression and breast cancer

Breast Cancer Network Australia and Beyond Blue: the national depression initiative
bcna.org.au or phone **1800 500 258**

This fact sheet, developed by BCNA and Beyond Blue, explains the links between anxiety, depression and breast cancer, the signs and symptoms of anxiety and depression, current treatments, and how to help yourself or someone close to you.

Feeling sad or worried (the Easy English version of the Anxiety, depression and breast cancer fact sheet)

Breast Cancer Network Australia
bcna.org.au or phone **1800 500 258**

The Easy English version of the Anxiety, depression and breast cancer fact sheet provides text and images to convey information clearly and is suitable for those who may have reading difficulties.

GP Mental Health Treatment Plan

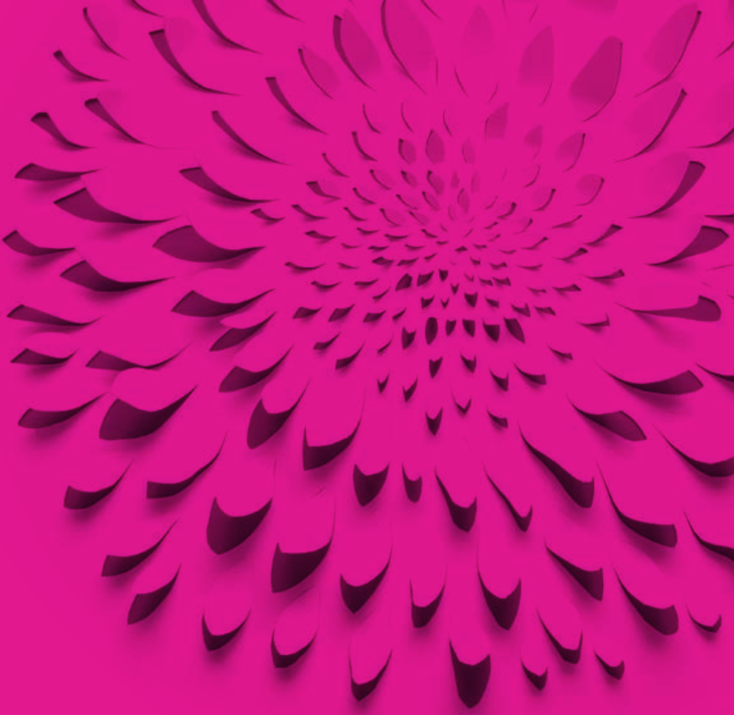
Breast Cancer Network Australia
bcna.org.au or phone **1800 500 258**

Sometimes a diagnosis of breast cancer can lead to ongoing emotional issues that can interfere with your quality of life and your ability to live well and interact with family and friends. These might include anxiety, ongoing sadness, a feeling of hopelessness, stress or depression. If you are experiencing emotional concerns and you think you would benefit from professional ongoing support, you can ask your GP whether a GP Mental Health Treatment Plan might be appropriate for you. This fact sheet includes more information about a GP Mental Health Treatment Plan, and some commonly asked questions.

Getting the most from the web: a guide to breast cancer information on the internet

Breast Cancer Network Australia
bcna.org.au or phone **1800 500 258**

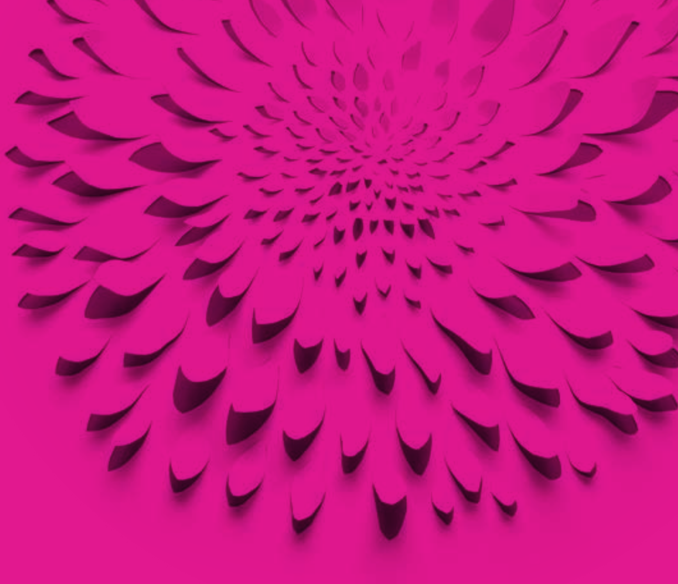
People tell us that, when they are first diagnosed with breast cancer, they often turn to the internet looking for answers to their questions. While a lot of high-quality information about breast cancer is available online, there is also information that is out-of-date, inaccurate or unhelpful. Sometimes, it can be hard to tell the difference. This fact sheet provides a list of reliable Australian and international websites that offer good-quality information about breast cancer, along with a summary of the content on each website. The digital (downloadable) version of the fact sheet provides clickable links to each of the sites and sections discussed.



SECTION 2

METASTATIC BREAST CANCER: THE FACTS

Metastatic breast cancer has taught me to be proactive in my care, keep up with the latest information and keep seeking answers until I am happy with them.



SECTION OVERVIEW

This section provides information on:

- what is metastatic breast cancer
- subtypes of metastatic breast cancer
- metastatic breast cancer survival and prognosis
- symptoms you may experience
- finding a medical team to suit your needs
- treatment as a public or private patient
- getting the most out of your medical consultations
- questions you might like to ask about your diagnosis.

METASTATIC BREAST CANCER

To understand the nature of metastatic breast cancer it can be helpful to begin with a general understanding of cancer and how it develops.

Cancer

Cancer (carcinoma) occurs as a result of abnormal changes in the genes that regulate the growth of cells in the body. These genes are located in the cell's nucleus sometimes referred to as the 'control centre' of each cell. Normally, the cells in our body replace themselves in an orderly process of cell growth and repair (new cells replace old worn cells). But sometimes abnormal changes (mutations) can occur that 'turn on' certain genes and 'turn off' other genes in a cell.

As a result, the changed cell develops the ability to keep dividing and growing in an uncontrolled way forming a cancerous or malignant tumour. If left unchecked, the cancer cells may then spread into the surrounding tissue and to other parts of the body. When cancer spreads into the body's tissues, it is called invasive cancer (invasive carcinoma).

Breast cancer

Women's breasts are made up of a type of tissue called 'glandular tissue'. This tissue has ducts and lobules supported by fibrous and fatty connective tissue. There are around 12–15 major ducts in each breast that come together to drain into the nipple (Figure 1). Men's breasts have ducts but few, if any, lobules.

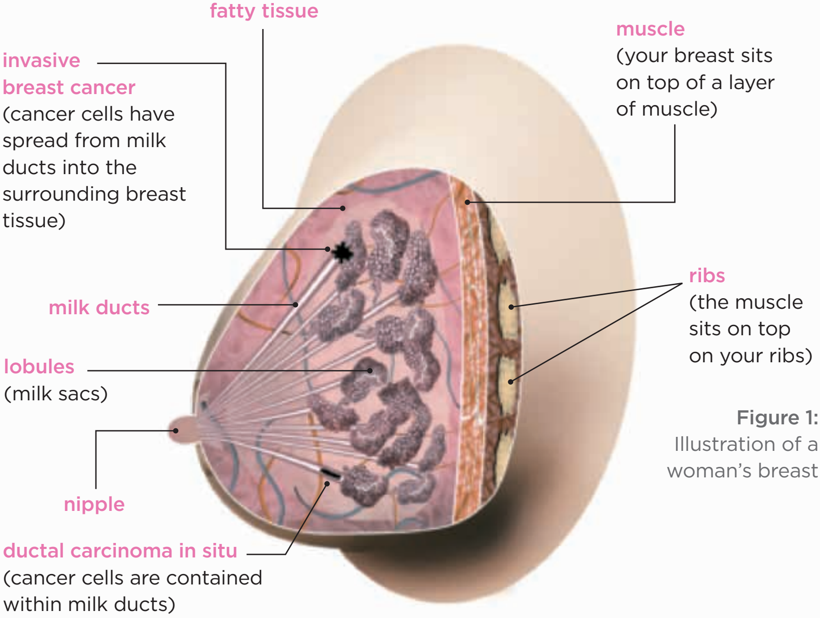


Figure 1: Illustration of a woman's breast

Breast cancer is the abnormal growth of cells lining the breast lobules (milk-producing glands) and breast ducts (passages that drain milk from the lobules towards the nipple). Sometimes it can also begin in the fatty and fibrous tissue of the breast. The breast cancer cells grow uncontrollably and over time can spread into surrounding breast tissue.

Metastatic breast cancer

Metastatic breast cancer is when cancer cells have spread from the original cancer site in the breast to more distant parts of the body. Terms such as advanced breast cancer, secondary breast cancer, stage IV breast cancer, metastases and secondaries are all different ways of describing metastatic breast cancer – they all mean the same thing. The original cancer in the breast is known as the ‘primary’ breast cancer.

If you have been diagnosed with metastatic breast cancer, it means that cancer cells have travelled from your breast through your blood or lymphatic system and started to grow in other organs or tissues in your body.

The parts of your body most likely to be affected are the bones, liver, lungs or, more rarely, brain, although cancer has the potential to spread anywhere in the body. For example, the skin, ovaries or abdomen can be affected. Where it spreads and to how many sites varies between people and different types of breast cancer (See Figure 2). Having metastatic breast cancer doesn’t mean that breast cancer will spread to all these areas of the body.

Metastatic breast cancer can be treated effectively, which often leads to long periods of disease control and improved quality of life. It can’t currently be cured.

Wherever metastatic breast cancer is found in your body, it’s still breast cancer and is treated as breast cancer. Metastatic breast cancer in the bones, for example, doesn’t contain bone cancer cells. The cells are breast cancer cells that have invaded the bone so it’s treated with breast cancer drugs.

People often want to understand why they have developed metastatic breast cancer, especially if they had treatment for early breast cancer. Unfortunately, even the best treatment for early breast cancer doesn’t always remove every cancer cell.

Most metastatic breast cancers are breast cancer cells that remained in the body after treatment, been dormant (inactive) and unable to be detected. For some unknown reason the cancer cells begin to grow again. This process is being researched and is not well-understood at this time.

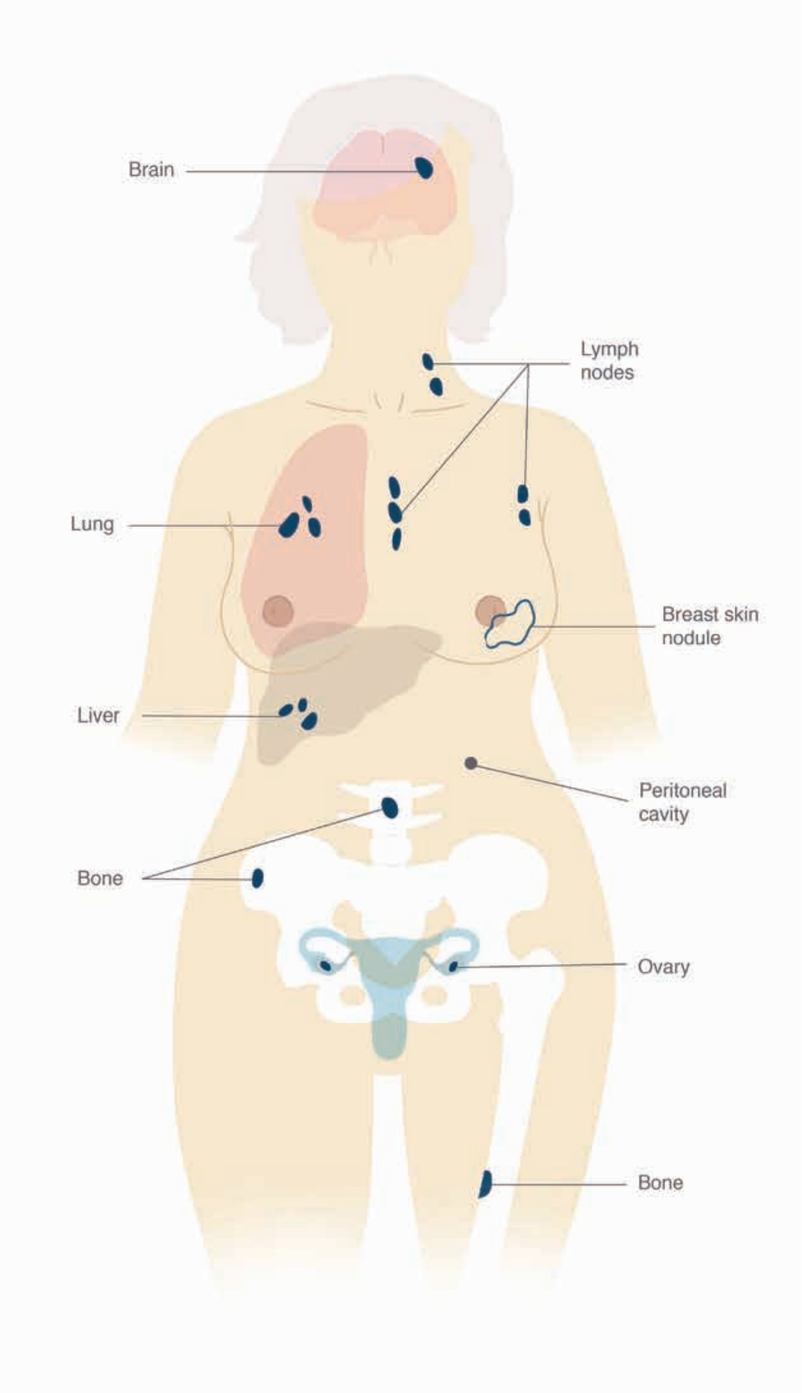


Figure 2: Sites where breast cancer may spread

The risk of metastatic breast cancer

Breast cancer can come back months or years after diagnosis and treatment. Approximately 20-30 per cent of people diagnosed with early-stage breast cancer will develop metastatic disease. It's important to understand that metastatic breast cancer is not your fault.

The risk of metastatic breast cancer after treatment varies between people and depends on the:

- biology (characteristics) of the original tumour cells
- stage of your original breast cancer at diagnosis
- treatments you have had in an attempt to prevent recurrence of the breast cancer.

Sometimes, cancer cells have already started to travel around the body when cancer in the breast is found. If there's already cancer outside the breast large enough to see on a scan, metastatic breast cancer may be diagnosed at the same time as the primary breast cancer. In some cases, a metastatic cancer is the first to be found and diagnosed. This is called de novo metastatic breast cancer. Approximately 5-10 per cent of people diagnosed with breast cancer will have metastatic breast cancer from the start.

ℹ **For more information about having metastatic disease as your first diagnosis see Section 8: Metastatic from the start.**

Being diagnosed with metastatic breast cancer is devastating, but I have come to terms with it and I also remain determined to fight as long as I can. I have an excellent medical team looking after me and feel confident that they will do everything in their power to keep me alive as long as they can. That gives me an enormous amount of comfort and confidence for my future, even if we don't know how long that will be.

Subtypes of breast cancer

Three main subtypes of breast cancer have been identified but it's likely that this number will grow as we learn more about the inner ('molecular') workings of each type of breast cancer. Consequently, treatment will become more and more specific to an individual cancer. Developing this 'personalised' treatment is the main goal of current research.

These are subtypes identified so far.

1. Hormone receptor positive metastatic breast cancer

Hormone receptor (HR) positive cancers have what are called oestrogen receptors (ER) and/or progesterone receptors (PR) on the surface of the cancer cells. This means that hormones (mainly oestrogen) and hormone-blocking treatments can directly influence the activity of these cancer cells via the receptors. When oestrogen attaches or binds to the receptors the cell starts to grow and divide, producing new cells. Hormone-blocking treatments work either by attaching to the receptors and blocking oestrogen from binding to them, or by preventing the production of oestrogen in the body. Both of these effects prevent oestrogen from stimulating growth of the cancer cells. Around 70 per cent of metastatic breast cancers are hormone receptor positive and 10 per cent of these are also HER2-positive.

2. HER2-positive metastatic breast cancer

HER2-positive cancers have more so-called HER2 receptors than normal on the surface of the cancer cells. These receptors allow growth factors to stimulate the growth of the cancer cells. Treatments that block the HER2 receptors prevent this growth stimulation, in turn controlling the cancer. Around 20 per cent of metastatic breast cancers are HER2- positive. Around half of these cancers are also hormone receptor positive.

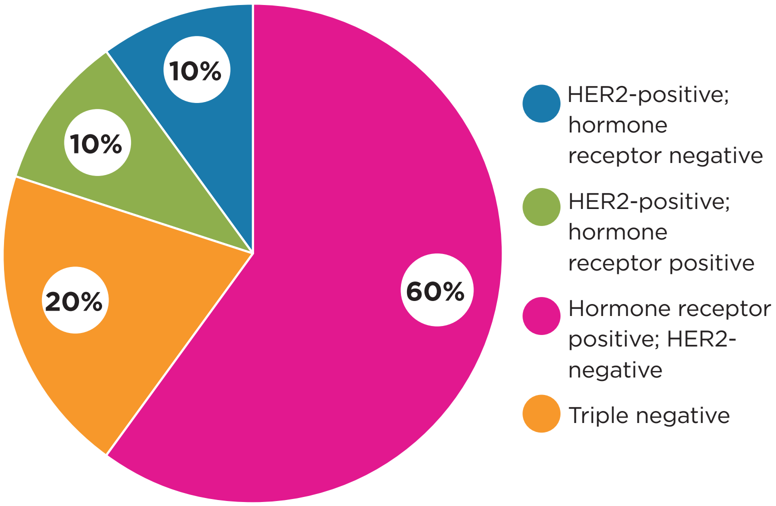
3. Triple negative metastatic breast cancer

Triple negative breast cancers don't have oestrogen, progesterone or HER2 receptors on the surface of the cancer cells. This means they don't respond to treatments that block these receptors.

However, they are particularly responsive to chemotherapy, and this is the backbone of treatment for these cancers. Research is focusing on identifying receptors and other targets in these triple negative breast cancer cells to allow additional treatment options and some of these are beginning to become available. Around 20 per cent of metastatic breast cancers are triple negative

ⓘ **For more information BCNA has developed booklets on each subtypes of metastatic breast cancer, 'visit bcna.org.au to download a copy. Current information can also be found in the My Journey online tool. Visit myjourney.org.au.**

SUBTYPES OF METASTATIC BREAST CANCER



How do I know what subtype of breast cancer I have?

If possible, you will have a biopsy of the cancer cells wherever they are located in your body.

A pathologist will test the biopsied tissue to determine whether it has hormone receptors (hormone receptor positive) and whether it has an over-expression (extra copies) of HER2 receptors (HER2-positive). Based on these tests, your specialists will be able to explain what subtype of breast cancer you have. It may be hormone receptor positive and HER2-positive. Around 20 per cent of breast cancers have no receptors and are classified as triple negative breast cancers.

If you had an early breast cancer before being diagnosed with metastatic breast cancer tests will have been done on the original breast cancer. If it's possible, a biopsy of the metastatic breast cancer will be done to confirm whether the receptor results have changed, which happens in about 10 per cent of cases.

If a biopsy of the metastatic cancer isn't possible the results from the initial cancer will be used.

If you have presented with metastatic breast cancer as your first diagnosis you'll need a biopsy to confirm the diagnosis and to check the receptor status.

Increasingly, treatments are able to target specific features of particular breast cancer subtypes. This is an area of ongoing research, but targeted treatments are already making a difference for many people with metastatic breast cancer. They have led to better control of the cancer for longer periods and improved quality of life.

The pathology of your breast cancer is quite a complex subject, especially if metastatic breast cancer is your first diagnosis of breast cancer. It's okay to keep asking your treatment team questions until you understand the subtype of cancer you have and what that means for your treatment options.

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 5 states it is ‘appropriate to offer biopsy of accessible metastases to assess biological markers (such as oestrogen and progesterone receptors, and HER2 status), and to offer germline genetic testing for BRCA1/2, if the result is likely to lead to a change in the management of patients with metastatic breast cancer’.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.

Genetic Tests

People diagnosed with metastatic breast cancer may find it helpful to find out if they have an inherited a genetic mutation that caused their breast cancer.

Three well-known genes that can undergo abnormal changes (mutations) and increase the risk of breast and/or ovarian cancer are BRCA1, BRCA2 and PALB2. Women who inherit these mutation from either their mother or father have a higher risk of developing breast and/or ovarian cancer. Men who inherit these mutations, in particular BRCA2, have an increased risk of breast cancer and also possibly prostate cancer. Inherited genetic mutations account for up to 10 per cent of all breast cancers.

Testing positive for certain genetic mutations can affect your treatment choices. It could also mean that you may be eligible for a clinical trial that can provide a new treatment option. Talk to your medical oncologist about whether genetic testing is right for you.

METASTATIC BREAST CANCER SURVIVAL AND PROGNOSIS

When people are diagnosed with metastatic breast cancer they often ask how long they have to live.

This is a difficult question to answer because no two people are the same and no two cancers progress in the same way. A number of factors will influence survival times including the subtype of the breast cancer (hormone receptor positive, HER2-positive and triple negative), the site of metastases, time since treatment for early breast cancer, how the cancer responds to treatment and whether there are other health issues not related to cancer.

Your medical oncologist can give you an idea of how the future might look. Research has shown that it's better for doctors to talk with you about survival times as a range of possible scenarios, including best-case, most likely and worst-case, because this is more accurate and helpful. For example, if a clinical trial shows the median survival time for a group of people with the same diagnosis having the same type of treatment is four years, it could be explained this way.

If we imagine 100 people in exactly the same situation, then we'd expect:

- the five to 10 who did best would live longer than 12 years (best-case scenario)
- the five to 10 who did worst would die within one year (worst-case scenario)
- the middle 50 would live two years to eight years (typical scenario).

Most people find this kind of information more helpful than being told only the median survival for your cancer is four years. Everyone is different, and while some people want to know their prognosis, others do not. Some people simply want to know if they will be able to reach a certain life goal or attend an important event.

It's important to talk to your oncologist about the type of information you'd like, and in how much detail. It's also ok to tell your doctor if you don't currently want information about your prognosis. Some people prefer not to speak about it at all, or prefer their oncologist to discuss it with family members instead.

Oncologists take many factors into account when considering your prognosis including information about you, your cancer and your treatments as well as their experience of treating other people in similar situations.

What prognostic questions should people with metastatic breast cancer consider asking their oncologist?

- What can I expect in the future?
- Will this cancer shorten my life?
- How long can I expect to live?
- Will the treatment help me live longer?
- What will my quality of life be like on this treatment?
- What happens if I stop treatment?

The desire to know what I was facing was important to me. I found myself running in circles not knowing how long I had left to do the many things I needed to do and wondering if I would be well enough to do them. My psychologist suggested I work out a Plan A for things I could do in the short term and a Plan B for when or if I am unable to live independently. This strategy helped me clarify my priorities.

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 2 states it is ‘appropriate to communicate effectively and sensitively in a culturally safe environment with metastatic breast cancer patients and their families, and provide timely, comprehensive, patient-centred information on matters including:

- prognosis and the intent of treatment
- potential benefits and harms of treatment (including complementary and alternative therapies)
- cost and practical implications of treatment
- supportive and palliative care’.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic

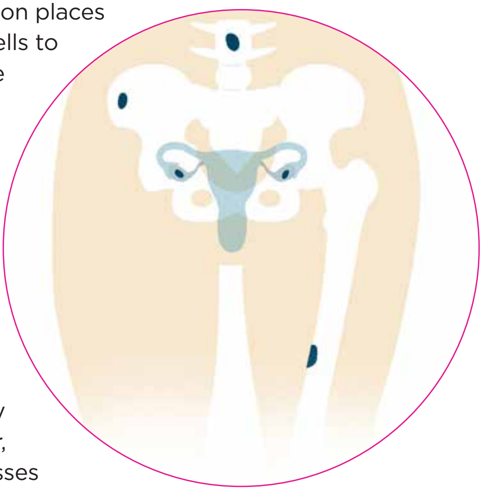
SYMPTOMS YOU MAY EXPERIENCE

Every person's experience of metastatic breast cancer is different. The symptoms you experience will depend on the extent of the cancer and the part of the body affected, as well as any other health issues you may have.

Some people with metastatic breast cancer will have general symptoms such as feeling more tired than usual, feeling generally unwell or having a reduced appetite. Some people will experience many symptoms while others will experience very few or none at all. It's important to discuss any new symptoms with your doctor.

While the sites discussed on pages 48-50 (bone, liver, lung and brain) are the most common areas for metastatic breast cancer, there is potential for breast cancer to spread anywhere in the body.

Metastatic breast cancer in the bone



The bones are the most common places for metastatic breast cancer cells to develop. Common sites are the ribs, spine, pelvis and the long bones of the arms or legs. One of the main symptoms is a noticeable pain in the affected bone. This could feel like a nagging ache, which you might be aware of day and night and may increase when you are active and moving around. This may be caused by damage to the bone by cancer, or cancer in the bone that presses on the nerves. It can be hard to tell the difference between pain from bone metastases and pain from arthritis or a strain so it's always a good idea to discuss any pain or changes with your doctor.

Metastatic breast cancer in the bone may gradually damage and weaken the affected part of the bone, which could cause the bone to fracture (break). A sudden severe pain and inability to move may be symptoms of a break in the bone.

Fatigue, weakness, loss of appetite and/or dehydration and confusion may indicate high levels of calcium in the blood (hypercalcaemia) due to bone breakdown.

Pain in the back or neck, numbness or weakness in the legs, problems passing urine or changes in bowel habits can indicate spinal cord compression. Cancer in the vertebrae of the spine can cause pressure on the nerves in the spinal cord that control bodily functions. It's important you seek medical assistance immediately if you experience these symptoms.

Diagnosing bone metastasis may involve imaging tests such as a bone scan, x-rays, CT scan, MRI or a PET scan. Blood tests to check for high levels of calcium may be ordered and in some cases, a biopsy may also be used to confirm the diagnosis.

Metastatic breast cancer in the bone can be treated with medication, radiotherapy or surgery. Medication can also strengthen bone, reduce pain and help prevent fractures. Prompt treatment can help by preventing problems or addressing them early, before fractures or further weakening occurs.

For more information, see BCNA's booklet *Metastatic breast cancer in the bone*. You can also find information in the My Journey online tool. Visit **myjourney.org.au**.

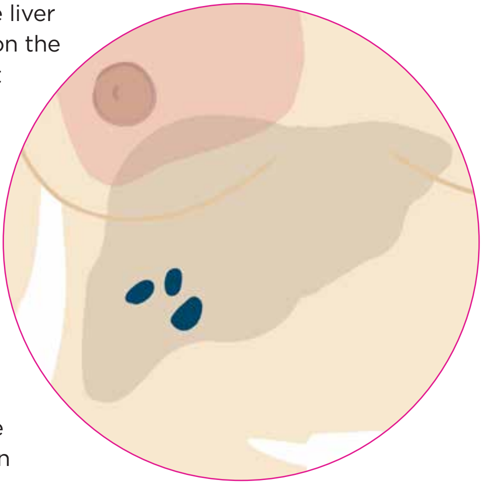
Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 8 states it is 'appropriate to consider single fraction radiotherapy initially for uncomplicated painful bone metastases in patients with metastatic breast cancer, rather than routinely using radiotherapy with extended fractionation schemes (> 10 fractions)'.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.

Metastatic breast cancer in the liver



Metastatic breast cancer in the liver can cause pain or discomfort on the right side of the abdomen, just under the ribs. Some people feel tired, generally unwell and have less energy while others feel nauseous, lose their appetite, lose weight or experience bloating or yellow tinting to skin or whites of the eyes (jaundice).

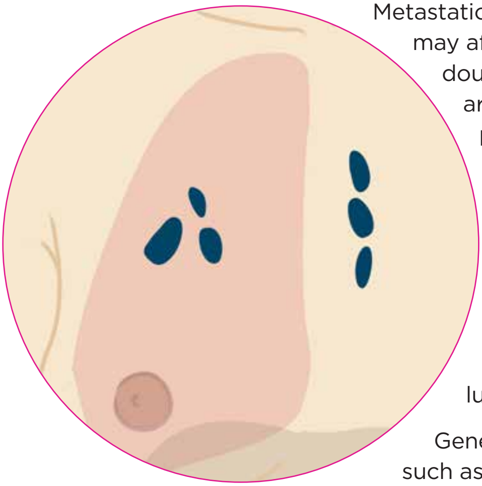
Imaging tests (MRI, CT scan, ultrasound or PET scan), a biopsy and blood tests may be used to diagnose metastases in the liver.

Symptoms will improve with treatment of the cancer and there are also many treatments, including anti-nausea medications, steroids and analgesics (pain relievers), that can help relieve symptoms.

Chemotherapy is the most common treatment for liver metastases. Hormone-blocking therapies such as tamoxifen and aromatase inhibitors may be prescribed if the cancer is hormone receptor positive. Local treatments may include radiotherapy.

For more information, see BCNA's booklet *Metastatic breast cancer in the liver*. You can also find information in the My Journey online tool. Visit myjourney.org.au.

Metastatic breast cancer in the lungs



Metastatic breast cancer in the lungs may affect the lung tissue or the double layer of membrane around the lungs, called the pleura. Symptoms include a persistent cough, pain in the chest and shortness of breath.

Imaging tests (e.g. chest CT scan or PET scan), mucus samples and biopsy may be used to diagnose lung metastases.

General breast cancer treatments such as chemotherapy or hormone blocking therapy can help to prevent and treat symptoms. If fluid builds up in the pleura – a pleural effusion – a tube may be inserted into the pleural space to drain the fluid and ease discomfort and shortness of breath.

For more information, see BCNA's booklet *Metastatic breast cancer in the lungs*. You can also find information in the My Journey online tool. Visit myjourney.org.au.

Metastatic breast cancer in the brain

It's much less common for breast cancer to spread to the brain than bones or the lungs. The idea that metastatic breast cancer may move to the brain and cause some loss of control can be frightening. However, symptoms related to brain metastases can be well controlled and new targeted radiotherapy techniques have fewer side effects than radiotherapy treatments used in the past.

Tests to diagnose metastatic breast cancer in the brain may include an MRI or CT scan and more rarely a biopsy. A lumbar puncture may be used to test a small amount of the cerebrospinal fluid to check for the presence of cancer cells.

The most common symptom of brain metastases is a headache resulting from increased pressure when cancer cells cause a build-up of fluid in the brain. This type of headache is often worse in the morning. Other symptoms may include nausea and vomiting, changes in vision, unsteadiness and seizures.

The usual treatment for brain metastases is radiotherapy, although sometimes surgery and medication are recommended.

For more information see BCNA's booklet *Metastatic breast cancer in the brain*. You can also find information in the My Journey online tool. Visit myjourney.org.au.

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 10 states is it 'not appropriate to use whole brain radiotherapy for metastatic breast cancer patients with brain metastases, without considering initial surgery or stereotactic radiosurgery'.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic

FINDING A MEDICAL TEAM TO SUIT YOUR NEEDS

Metastatic breast cancer isn't currently considered curable but it is very treatable and, for most people, can be controlled for years.

You will probably see more than one health professional in the course of your treatment. As your medical oncologist will most likely lead the team, this choice is likely to be your starting point – and it's an important decision. The quality of this relationship could influence how you feel about your treatment, how many questions you ask and your sense of being generally well cared for.

While you may be referred to a particular specialist, if you're having treatment in the private system you have a choice about who you see. You may also like a second opinion.

Seeking a second opinion

If you had an early breast cancer it's okay to seek a second opinion and/or choose a different team from the one that treated you. If you would like a second opinion, you can ask your medical oncologist for a referral to someone suitable.

Most oncologists are very happy to do this but, if you'd rather not ask, you can either ask the health professional who gave you the original referral or your GP. A frank and honest discussion about the sort of care you want will help them to refer you to a medical oncologist who can meet your needs.

Your health professional will write a referral letter to the new oncologist and include your test results and medical history. If you feel more comfortable with the new oncologist, they may ask your original oncologist for any test results, scans or other information not included in the referral, or you can request a copy of your medical records yourself. It's important to take as much information as possible with you when you meet a new oncologist, including the drugs you have had in the past, and when you started and stopped taking them.

To make the most of the appointment you have for a second opinion, spend time putting all of your treatment records together. This may seem tedious but it will mean you can have an informative and worthwhile discussion to help you decide whether you would prefer to see this new team.

Your medical oncologist must be your number one companion during this journey. If you don't like your oncologist, then change.

People on your treatment and care team

Multidisciplinary care

The management of metastatic breast cancer is complex so it's important that all appropriate specialists in a multidisciplinary team are involved. Team members may include medical oncologists, surgeons, radiation oncologists, imaging experts, pathologists, nurses, clinical trial research staff, social workers, psychologists and palliative care specialists.

You can ask your doctor whether your team follows the best practice of coming together to discuss and review your care. If your team members are not based in the same treatment centre, which is often the case in rural areas, they may use telehealth (i.e. video conferencing or teleconferencing facilities) for their meetings. This model encourages good communication, treatment and care.

You will usually have one main contact person who can answer your questions. Ask a member of your team if you're unsure who this is.

I found a good GP who I see regularly, and I have a good medical oncologist. They both listen, check that I understand their advice and talk optimistically about the future – they give me hope!

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 1 states it is ‘appropriate to involve a multidisciplinary team to consider effective evidence-based anti-cancer therapies in the management of patients with metastatic breast cancer. A key contact person should be agreed to support communication and coordination of patient-centred care’.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.

General practitioner

Your medical oncologist is often the key specialist guiding your care but you will still need a GP to help you manage your day-to-day needs. Your GP can assess problems as they arise and, if they’re serious and cancer-related, arrange an urgent appointment with your medical oncologist.

Your GP can clarify information for you, help with advice and counselling, and refer you to other medical specialists and health professionals. A good GP will see you when you need to be seen and visit you at home if necessary.

Many people with metastatic breast cancer find that they have more contact with their GP than any other health professional apart from their medical oncologist. If you don’t already have a good GP, finding one could make a big difference to your care.

My GP is an integral part of my team. I feel blessed that I don’t have to explain my story every time I go to the doctors for things that may not even be related to my cancer.

Medical oncologist

Medical oncologists treat cancer using chemotherapy, hormone-blocking therapy and other targeted therapies such as the HER2 treatments. Your medical oncologist will refer you to other specialists when required and is often the key person coordinating your treatment and care.

Radiation oncologist

Radiation oncologists specialise in treating cancer using radiation (radiotherapy). Their role is to determine whether radiotherapy will be useful and, if so, to prescribe the appropriate dose and duration. They are often members of the multidisciplinary team and work closely with medical oncologists.

Psychologist

Many people with metastatic breast cancer will seek counselling at some stage. A psychologist can help you and/or your family to talk through and deal with your worries and concerns. In particular, a psychologist can help you to manage relationship issues, cope with anxiety and fear, work through loss and grief and understand the effects your illness might have on you and your family.

Ask your doctor whether you're eligible for treatment under a GP mental health treatment plan, which entitles you to up to 10 Medicare-subsidised appointments with a clinical psychologist.

Some psychologists specialise in supporting people who have been diagnosed with cancer in a field knowns as psycho-oncology.

Specialist surgeon

Surgery is sometimes used to treat metastatic breast cancer – for example, to remove a metastatic brain cancer or put a pin in a bone to strengthen an area affected by metastatic bone cancer. Sometimes a cancer is surgically removed from the lungs to reduce its effect if it's causing a blockage, discomfort or other complications. If metastatic breast cancer is your first diagnosis of breast cancer, your specialists may consider surgery on the breast to control the cancer in the breast after initial drug treatment. This surgery isn't always necessary or appropriate.

Oncology/chemotherapy nurse

Oncology nurses administer chemotherapy and other anti-cancer treatments and help with radiotherapy. They can also provide advice on managing pain, nausea and other symptoms or side effects of treatment.

Patient navigator or cancer care coordinator

A patient navigator can help guide you through the complex information and difficult decisions that may arise during your treatment. Ideally, this will be a specialised breast care nurse or specialised oncology nurse who is part of the team of experts managing your care. However, depending on the health care centre where you receive your treatment, a different, qualified team member may take on this role.

If you think a patient navigator might be helpful, ask your oncologist or your nurse whether this service is available.

Breast care nurse

A breast care nurse is a specialist registered nurse who provides Information, education and support, and is often the key contact person in coordinating your care.

If you would like to see a breast care nurse, ask your medical oncologist or GP for a referral. Most breast care nurses are also happy for you to self-refer and make direct contact. If you liked a breast care nurse who was part of your original breast care team you can let them know you'd like to have their support again.

The McGrath Foundation has nurses throughout Australia who can support women diagnosed with metastatic breast cancer. This support is provided free of charge and you don't need a referral from another health professional. The McGrath Foundation website (**mcgrathfoundation.com.au**) has a search function to help you find a breast care nurse in your area.

Supportive and palliative care services

Supportive and palliative care services provide specialist experience in complex pain and symptom management. Large multidisciplinary teams include doctors, nurses, social workers and others with a range of specialist skills. They can also provide specialised care for your social, emotional, cultural and spiritual needs and those of your family. You can take advantage of supportive and palliative care services any time after your diagnosis and use whatever services you find helpful on a regular or intermittent basis.

ⓘ **For more information about how supportive and palliative care services can help, see p.104.**

Social worker

Social workers can help you and/or your family to cope with the impact of metastatic breast cancer on emotional, psychological and practical matters. Oncology social workers provide counselling and support around issues such as coming to terms with your diagnosis, talking to children and family, relationships and existential concerns as well as dealing with grief, loss and coping with fear, sadness and anxiety.

Social workers can also help you with employment, finances, accommodation and legal matters. They can provide information and links to any practical help and services that may be available to you, such pensions or benefits, and refer you to legal services and other appropriate organisations. If you spend time in hospital, a social worker can help to plan your discharge and arrange any care you may need at home.

Pastoral care worker

Pastoral care workers respect all faiths and religious beliefs. They can help you to adjust to your situation and explore possibilities for personal and spiritual growth. By helping you to reflect on and talk about your life and its meaning, they may help you to feel more hopeful and focus on things that bring you joy.

Psychiatrist

Your doctor may refer you to a psychiatrist if you are depressed or have other emotional needs that may benefit from specialist care. Psychiatrists can talk to you about how you feel and how you're coping, and prescribe medication if they believe that could help. You might like to talk to your GP about being referred to a psychiatrist and the costs involved. The costs can be subsidised by Medicare.

For more information on making the most of your GP, see Section 5: Financial and practical matters.

Pharmacist

Your pharmacist can help by explaining how to take your medication and discussing possible side effects and ways you may be able to alleviate them.

I have found having a well-informed, supportive pharmacist helps with decisions about laxatives, non-prescription medicines, toothpastes, chewing gum, mouth sprays, etc.

Allied health professional

Allied health professionals, such as physiotherapists, exercise physiologists, occupational therapists and dietitians, can help you to manage a range of symptoms and concerns you may experience. Some physiotherapists and occupational therapists are also trained in the management of lymphoedema.

You may be eligible for a GP management plan (GPMP), Medicare-subsidised appointments with a range of allied health professionals. Your GP can help you make a plan to support your overall health care needs and provide you with access to different allied health professionals. To find out more, visit the BCNA website **bcna.org.au** and download the *Chronic disease management plan* fact sheet.

For more information about how allied health specialists can improve quality of life see Section 4: Living well.

Physiotherapist

Physiotherapists can help you to manage some of the side effects of metastatic breast cancer and its treatment by helping to relieve pain without medication, teaching you breathing and coughing techniques, helping you to become mobile after a bone fracture and finding appropriate ways for you to exercise and stay active. They can also help you to manage lymphoedema, the swelling in the arms or breast that may follow removal of, or damage to, the lymph nodes.

Exercise physiologist

Accredited exercise physiologists (AEPs) specialise in exercise for the prevention and management of chronic diseases and injuries. AEPs provide support for people with medical conditions including breast cancer. They have completed a four-year university degree and are recognised by most private health insurers. AEPs work in a variety of settings such as private clinics and hospitals where they can help develop and supervise an individual exercise program that is safe and appropriate for you. This can improve your muscle and bone strength, reduce tiredness and fatigue and help improve your general health and wellbeing.

Lymphoedema practitioner

Lymphoedema practitioners use specialist massage, compression garments and bandaging, exercise therapy and other therapies to help you manage lymphoedema. They can also provide advice and teach techniques you can use at home. Lymphoedema practitioners include physiotherapists, occupational therapists, registered nurses and massage therapists who are specially trained in the management of lymphoedema. They work in a variety of settings, including public and private hospitals, private clinics and individual practices.

Occupational therapist

Occupational therapists can visit your home and suggest changes to make your life easier. These might include ways of making some day-to-day tasks less demanding so that you can conserve your energy. They can also suggest home supports or equipment to improve your quality of life.

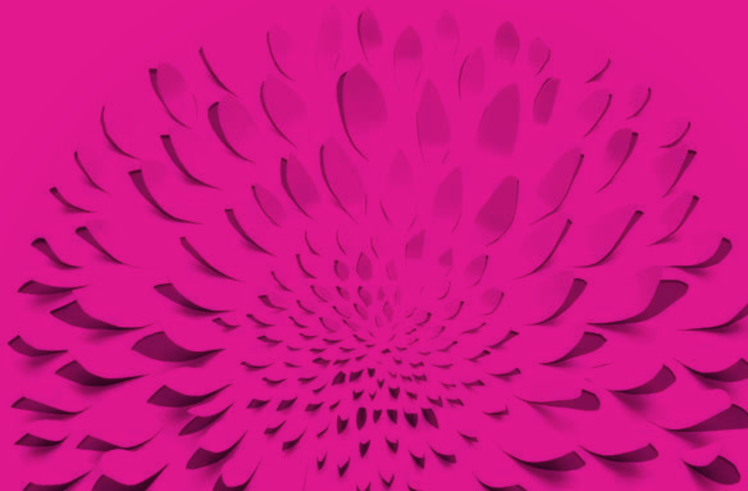
Nutritionist or dietitian

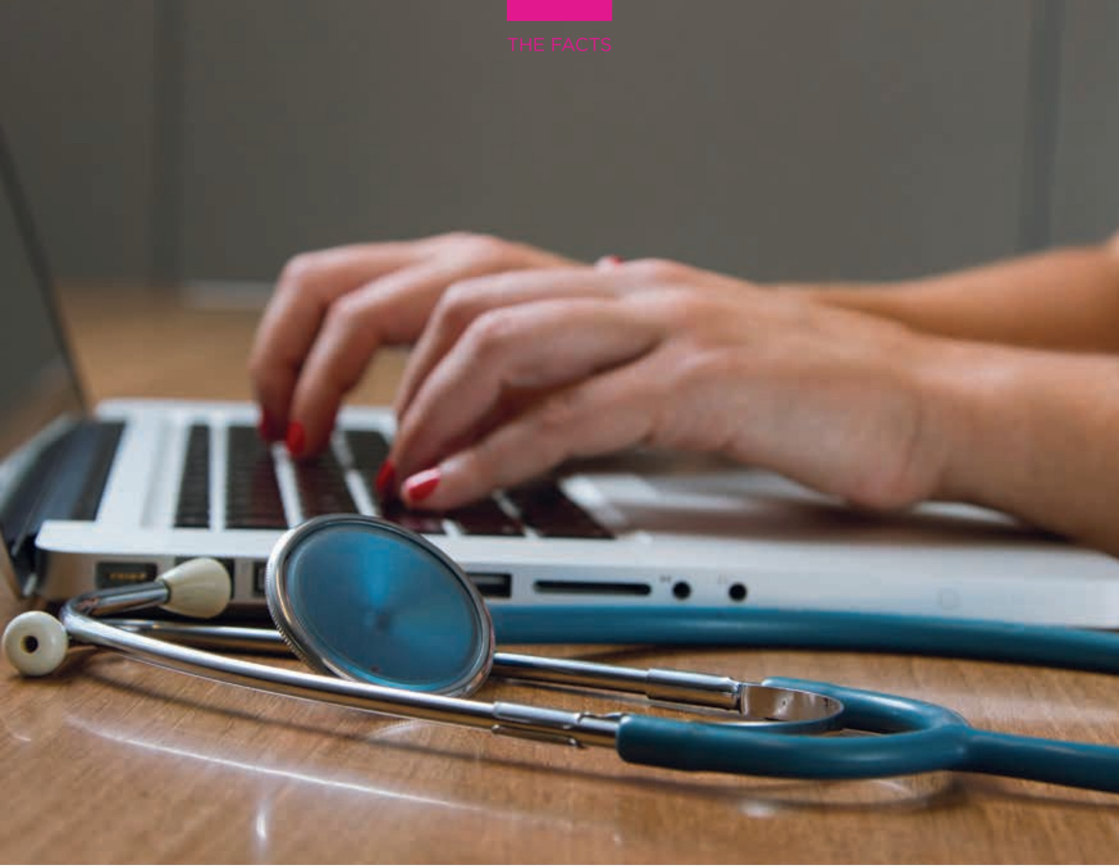
Nutritionists and dietitians can provide advice on nutrition and help you to assess your diet. They can also help resolve problems such as poor appetite, nausea and constipation.

CHOOSING A MEDICAL ONCOLOGIST

Some people like to involve their GP, family members or close friends when choosing their medical oncologist. While this can be helpful, it is important to make the decision based on your own needs and feelings rather than what other people think is best for you. Here are some questions for you to consider.

- Does the medical oncologist have a special interest and experience in managing metastatic breast cancer patients?
- Are they linked to other services such as radiotherapy, psychology or palliative care?
- Are they easy for you to get to, close to home and transport?
- Would you consider joining a clinical trial? If so, will this oncologist be able to help you access trials? (See p.94 for more information)
- Some people like to question every decision while others would rather leave decision-making to their doctor. Does the medical oncologist understand and feel comfortable with your preference?
- Some people feel more in control with an intensive treatment plan even if that means coping with unpleasant side effects. Others are more concerned with their day-to-day quality of life and avoiding particular side effects such as hair loss. Will this medical oncologist support your choices?
- Do you feel comfortable that you can voice your needs and feelings and that they will be taken into account?
- Would you feel comfortable discussing complementary or alternative therapies with this oncologist?





TREATMENT AS A PUBLIC OR PRIVATE HEALTH PATIENT

Treatment as a public patient

In Australia, everyone can be treated as a public patient in a public hospital. If you have private health insurance you can still choose to be treated as a public patient. In this case, your doctors will be nominated by the hospital and most of your treatment and care will be funded under Medicare. If some aspects of your care, such as pharmacy costs, are not covered, you may qualify for extra financial assistance.

One benefit of having treatment in the public system is that you're more likely to have access to the support of allied health workers such as social workers, physiotherapists or dietitians. It's also more likely that all of your treatment team will be in the same hospital setting, which may make it easier to coordinate your care.

One of the disadvantages is that, as you could see many different doctors and other medical staff during the course of treatment, you may not have a sense of continuity of care. You might also have to wait longer for appointments, tests and treatment than in the private health system.

Treatment as a private patient

Anyone can choose to be treated in the private system but there may be significant costs, especially if you don't have private health insurance.

If you have private health insurance

You will be able to choose your treating doctor and hospital and your health fund will pay some of the costs of treatment depending on your level of cover. Private health insurance may not cover the total cost of the doctor's services provided to you in hospital, which may leave you with an out-of-pocket expense. This is called a 'gap'.

Can I use the public health system if I have private health insurance?

You can choose to be treated as a private patient in a public hospital. You will be able to choose your treating doctor and, in some hospitals, you will have no out-of-pocket expenses. You can also choose to have some of your treatment in the private system and some in the public system – for example, surgery and chemotherapy in the private system and radiotherapy in the public system.

If you would like to consider these are options, talk to your treating doctor and hospital about what they offer. You can also talk to your health fund about what your out-of-pocket expenses might be.

We had good private cover, but there are still lots of costs attached to having cancer. Complementary therapies, tests, medications, wigs, turbans, creams, etc. These relatively small costs all add up surprisingly quickly.

As a private patient, you can choose your specialists, which can provide continuity of care throughout your treatment. Depending on your level of cover, you may be able to stay in a private hospital and have a private room. However, private rooms in both public and private hospitals are allocated on a medical needs basis. It doesn't matter what level of cover you have; medical needs take priority.

Sometimes people are disappointed and annoyed that they have been paying for private health insurance for many years only to find themselves faced with substantial out-of-pocket costs for their treatment. For instance, depending on your level of cover, you may have to pay an 'excess' or gap for any hospital stays. You may also have to pay a gap for specialists such as surgeons and anaesthetists.

Private health insurance only covers inpatient procedures, so you will not be covered for outpatient care such as radiotherapy, radiology, pathology tests and visits to specialists in their rooms. While these do attract Medicare rebates, they may not always cover the whole fee.

As a private patient you may be less likely to have access to a breast care nurse and allied health professionals such as a social worker, physiotherapist or dietitian. It may be worth checking with your oncologist whether the hospital where you're having most of your treatment has ready access to allied health professionals.

Before you start any treatment as a private patient you may want to clarify how much it will cost and exactly what is covered by Medicare and your private health insurance fund. Your doctor can provide a fee quote. It's okay to ask for a second opinion if the fees quoted are higher than you can afford or want to pay.

For more information on seeking a second opinion, see p.53

A staff social worker at the hospital was able to advise when a series of hospital stays, gaps and expenses strained my finances. Being able to talk things through and learning the correct wording made the steps of asking for the right help simpler.

You can also talk with an adviser from your private health fund who will be able to answer questions such as these about costs.

- Which treatments are covered by my insurance?
- Which treatments are not covered by my insurance?
- Will there be gaps between how much I pay and how much I am reimbursed?
- What other services can I claim and how much of the costs will be covered – for instance, wigs or lymphoedema garments or drugs that are not covered by the PBS?

If you don't have private health insurance, you can pay to be treated as a private patient. However, costs associated with this option are prohibitive for many people. Your doctors will be able to give you the details.

GETTING THE MOST OUT OF YOUR MEDICAL CONSULTATIONS

Ask lots of questions and remember, 'knowledge is power'.

When you're first diagnosed with metastatic breast cancer, you may decide to follow your doctors' advice as they usually know more than you do. However, there may be a number of treatment options available to you, so the more you understand about metastatic breast cancer, the easier it will be for you to take part in making treatment decisions that are right for you.

Tips for talking with your treating team

Some people find it overwhelming to receive lots of information, while others want as much information as possible. It may also take a while for you to feel comfortable or confident enough to ask questions of your treating team.

The following tips may help.

- Tell the people managing your care how much you want to be involved with decisions about treatment.
- Ask as many questions as you need and ask for clarification or repeat your question/s if you don't understand the answer.
- Write down questions when you think of them and take them with you to your appointment so you remember to ask them.

- Ask a relative or friend to come to appointments with you and take notes.
- If your doctor agrees, record your discussions on your phone or another device so that you and your family can listen again later.
- If you can't record and you don't have anyone with you, ask your doctor or nurse to write down what was said during your appointments.
- Ask if you can meet a breast care nurse who can answer any other questions you might have.

You may want to ask your medical team how they prefer to communicate – for example, email, face-to-face appointments, video conferencing (telehealth) or phone calls.

If you have a lot of questions it's a good idea to write them down and prioritise your list before your appointment so that the most important issues are covered first. You may also be able to request a double appointment so you have more time to discuss your concerns.

My family was there for every appointment. They remembered details that I was too distressed to remember.

If you would like family members to have an opportunity to ask questions, ask for a family meeting with your medical oncologist. This is a good opportunity for them to be involved in your care.

QUESTIONS YOU MIGHT LIKE TO ASK ABOUT YOUR DIAGNOSIS

People have told us they found these questions useful to ask when they were first diagnosed with metastatic breast cancer. Add any others you think of before you go to appointments and, if you can, take someone with you to take notes.

- Can I bring a friend /family member to my appointments?
- Can I record our discussion so I can listen later?
- Where is the metastatic breast cancer? Ask the doctor to draw it on a picture of the body.
- Can you write down what you have told me and what my recommended treatments are?
- Who are the members of my treating team?
- Who will be the main contact person? What about after hours or on weekends or public holidays?
- Will I be supported by a dedicated metastatic breast cancer nurse or cancer care coordinator?
- Is it likely I will need to travel for treatment?
- How will my treatment change if I choose to have it in the public or private health system?
- Am I entitled to any assistance with my health care costs?
- Can you refer me for a second opinion?

RESOURCES

Breast Cancer Network Australia (BCNA)

bcna.org.au or phone **1800 500 258**

In addition to Hope & Hurdles, BCNA has a number of optional treatment-related booklets for people diagnosed with metastatic breast cancer. You can download the booklets from the BCNA website or for the most up-to-date information sign up to the My Journey online tool. Visit **myjourney.org.au**.

1. *HER2-positive metastatic breast cancer*
2. *Hormone receptor positive metastatic breast cancer*
3. *Triple negative metastatic breast cancer*
4. *Metastatic breast cancer in the bone*
5. *Metastatic breast cancer in the liver*
6. *Metastatic breast cancer in the lung*
7. *Metastatic breast cancer in the brain*
8. *Planning ahead*

Find a specialist

Cancer Council Australia

cancer.org.au

Cancer Council Australia's website has a directory that can help with finding a doctor who specialises in a particular field of cancer or cancer treatment.

Other helpful websites

Cancer Australia

canceraustralia.gov.au

Cancer Australia, established by the Australian Government, aims to reduce the impact of cancer. The Cancer Australia website provides comprehensive information, guidelines and recommendations for the treatment of women diagnosed with metastatic breast cancer.

Cancer Council

cancer.org.au

Cancer Council provides a range of brochures, booklets and fact sheets related to metastatic breast cancer treatment. Call **13 11 20** to speak to specially trained staff who can answer your questions about cancer and offer emotional or practical support.

Health Direct

healthdirect.gov.au/australian-health-services

Health Direct's National Health Services Directory is a comprehensive online directory of health services including general practice, allied health and hospital services.

Breast Cancer Now

UK
breastcancernow.org

The UK website has a wide range of information on metastatic breast cancer, including a chat room for people with metastatic breast cancer and live chat sessions about specific breast cancer topics, including metastatic breast cancer.

BreastCancer.org

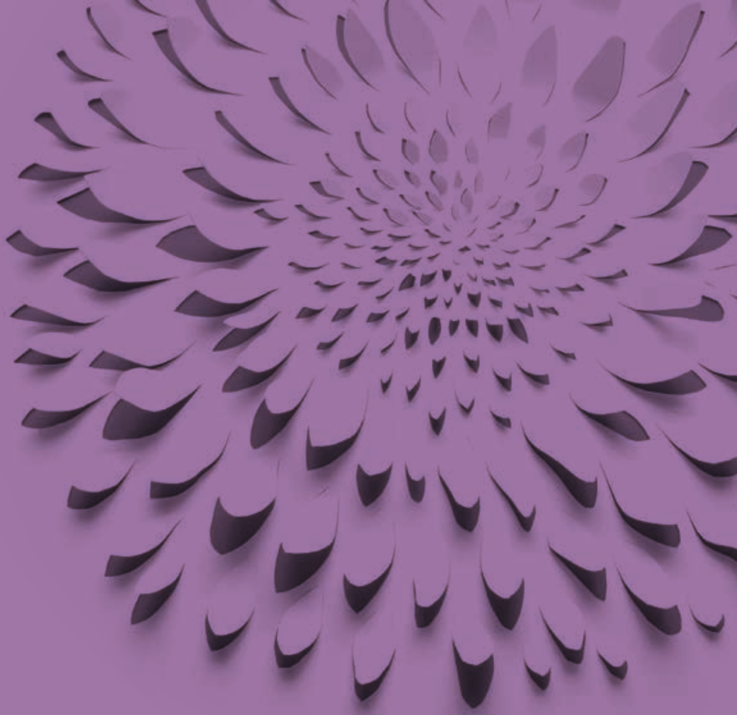
USA
breastcancer.org

This USA-based website has an extensive range of information about breast cancer, including a section on recurrent and metastatic breast cancer, with discussion boards and chat rooms where people share their experiences of metastatic breast cancer. It has input from people and health professionals. Australian people are able to participate.

American Society of Clinical Oncology

USA
asco.org

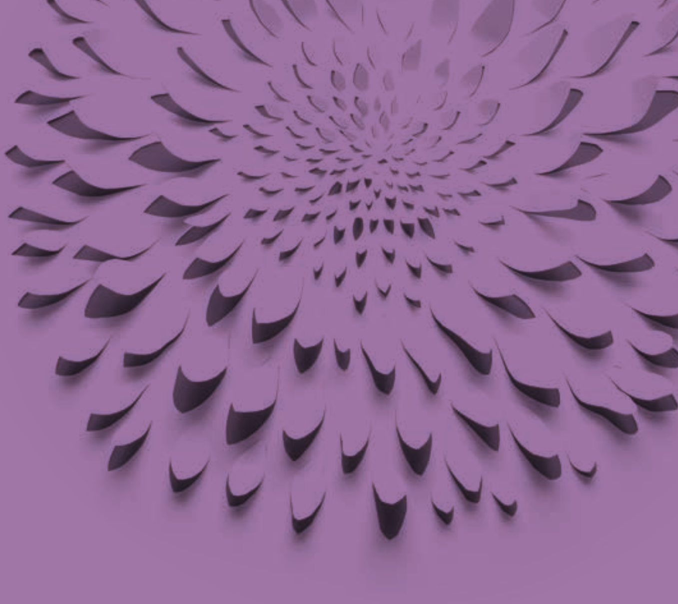
The American Society of Clinical Oncology is a world-leading professional organisation for physicians and oncology professionals caring for people with cancer.



SECTION 3

TREATMENT FOR METASTATIC BREAST CANCER

Keep in mind that there are treatments available and new ones are being developed. And remember that, like me, there are many people who have been living many years with metastatic breast cancer.



SECTION OVERVIEW

This section provides information on:

- types of treatments available
- treatments according to breast cancer subtype
- clinical trials
- accessing new drugs
- palliative and supportive care
- planning ahead
- managing symptoms and side effects of treatment
- complementary and alternative therapies
- taking a break from treatment
- medical emergencies
- questions you might like to ask about your treatment.

TREATMENT FOR METASTATIC BREAST CANCER

I have a good oncologist who explained the diagnosis perfectly. He said the diagnosis meant there's no cure but it didn't mean there's no treatment, and there are many treatment options. He explained that the aim is to slow the cancerous growth and to reduce symptoms and pain. I felt he was taking care of me and I also felt like part of the team. As well as giving me information he gave me hope.

Treatment for metastatic breast cancer aims to stop the cancer from growing or slow its growth as much as possible, and to control pain, discomfort and any other symptoms.

There have been significant advances in treatment in recent years as research has provided a better understanding of the biological characteristics of breast cancer. Better treatments have led to longer survival for many people.

Treatment options are guided by the subtype of breast cancer you have as treatments target the specific characteristics of each subtype. Current treatments have led to better control of the cancer for longer periods and improved quality of life.

Choosing the right treatment for you

Treatment for metastatic breast cancer does not follow a simple formula. Everyone's cancer is different. Cancer cells can be found in different parts of the body and people can respond differently to the same treatments. This is why treatments are tailored to individuals and their particular type of breast cancer.

The choice of treatment depends on:

- the subtype of breast cancer (such as hormone receptor status or HER2 status)
- where in the body the metastases are located
- any breast cancer treatments you have had before
- your symptoms
- your age
- whether you have any other health issues
- your individual preferences for treatment, needs and priorities.

Aim of treatment

The aim of treatment for metastatic breast cancer is both to lengthen survival and improve quality of life. The best way to achieve these aims is to control the cancer.

Treatments may include:

- localised treatments, such as radiotherapy and surgery
- systemic treatments, such as chemotherapy, hormone-blocking therapy and targeted therapy
- treatments to control symptoms (e.g. surgery for a broken bone)
- other supportive care measures such as palliative care to improve quality of life.

Treatment for metastatic breast cancer is usually ongoing from the time of diagnosis, although there may be times you can have a break. This means you may require regular blood tests and scans to monitor the activity of your cancer and how well it's responding to the treatment you're having. Importantly, regular monitoring also helps to assess and manage any side effects you may be experiencing from treatment.

Your needs and priorities are of central importance and a balance between the goals of treatment outcomes and side effects is vital to ensure quality of life – the ability to participate in daily life activities, work, take care of children or other dependents and pursue interests – while aiming to extend life.

TYPES OF TREATMENT

Hormone-blocking therapy, chemotherapy and targeted therapy are known as systemic treatments because they affect your whole body. They travel through the bloodstream, treating cancer cells wherever they happen to be. Radiotherapy and surgery are referred to as local treatments as they are limited to a single part of the body.

SYSTEMIC TREATMENT

Hormone-blocking (endocrine) treatment

Hormones occur naturally within the body and control the growth and activity of some normal tissues. However, hormones, and particularly oestrogen, can encourage the growth of breast cancers with hormone receptors. Known as hormone receptor positive, these cancers can be defined more specifically as oestrogen receptor positive (ER positive) or progesterone receptor positive (PR positive).

If your cancer is oestrogen and/or progesterone receptor positive your doctor will probably prescribe hormone-blocking therapy at some point. This is a treatment designed either to lower the level of oestrogen in your body or to block oestrogen from entering the cancer cells. Hormone-blocking therapy is not the same as hormone replacement therapy (HRT) used to treat menopausal symptoms.

It may be a few months before your doctor can tell whether a particular treatment is working. If it isn't, or if it stops working after a time because the breast cancer develops resistance to the endocrine treatment, there are generally other hormone-blocking treatments to try.

Chemotherapy

Chemotherapy uses drugs known as cytotoxics to kill cancer cells or disrupt their growth. There are many different types of chemotherapy that may be used alone or in combination. Commonly used chemotherapy drugs for example include doxorubicin, cyclophosphamide, nab-paclitaxel, carboplatin and capecitabine.

Chemotherapy works by targeting fast-growing cells. Unfortunately, while these include cancer cells, there are also fast-growing cells in other areas of the body such as the hair, nails, gut and bone marrow, where blood cells are made. This is why side effects such as low blood counts and hair loss may occur.

Side effects of chemotherapy

Each chemotherapy drug is a little different in its side effects. Not all treatments cause nausea or vomiting, nor do they all cause hair loss. Different ones can cause nerve ending damage (pins and needles and/or numbness of fingers and toes), redness and soreness of the hands and feet or body aches and pains.

All chemotherapy treatments affect your blood counts, making you more susceptible to infection. It's very important to seek urgent medical attention if you have any signs of infection, especially a temperature over 38°C.

Your medical oncologist and chemotherapy nurse will help you manage any side effects of treatment. There are also helpful information sheets about each chemotherapy treatment on the eviQ website which your team should provide. EviQ is an evidence-based national information resource for cancer treatments and you can find out more on the eviQ website **eviq.org.au**.

For more information on managing side effects of treatment p.108.

Chemotherapy is most commonly delivered by drip, known as intravenous Infusion, directly into a vein, or as a tablet.

For more information about different chemotherapy drugs and how they are administered, see p.261.

Questions to ask about chemotherapy

- How often will I need chemotherapy?
- How long will the course last?
- What are the possible side effects?
- Is there medication to help if I experience side effects such as nausea?
- If I have any problems at night or at the weekend, who should I call?
- Will I experience any fever or problems with infection? If so, how will I know and what should I do?
- Will I lose my hair? Is a cold cap (see p.124) available to help protect my hair during chemotherapy?
- Can you provide information for me to read?
- Will I need to have blood tests?
- When and how will we assess how well the chemotherapy is working?
- If a chemotherapy drug stops working will I be able to try something else?

How can I avoid having problems with my veins from chemotherapy?

Ports and PICCs

Chemotherapy drugs are most commonly given intravenously – injected or dripped into a vein through a cannula (thin plastic tube) inserted into your arm or hand. Because you may be having chemotherapy regularly over a period of time, there are options that can make this easier and avoid irritation and pain from cannulation of veins.

A central venous access device, also known as a port-a-cath, infusaport or simply a port (Figure 1) is one option. It provides access via a very slender, flexible tube that feeds directly into one of the major veins near the heart. A port is implanted under the skin in the chest wall or, less commonly, the arm, and it can stay in place for as long as you need it. The procedure to insert a port can be done in the radiology department under local anaesthetic or in surgery under general anaesthetic.

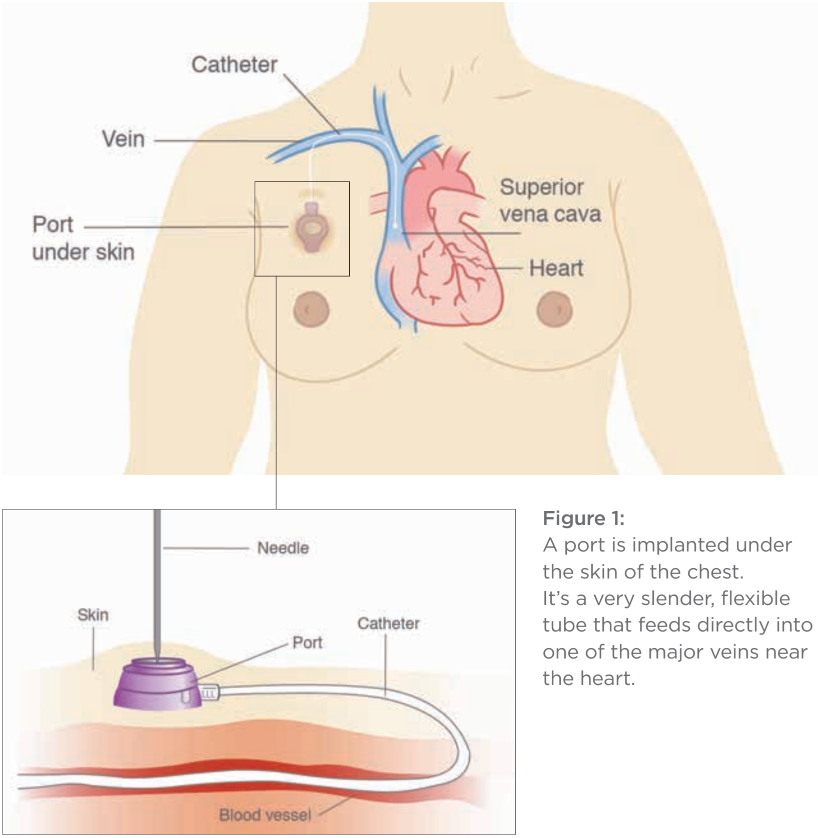


Figure 1: A port is implanted under the skin of the chest. It's a very slender, flexible tube that feeds directly into one of the major veins near the heart.

An alternative to a port is a peripherally inserted central catheter (PICC) line (Figure 2). A PICC is inserted into a vein in the arm near the elbow and travels into a larger vein near the heart. PICC lines are generally inserted under local anaesthetic in the radiology or outpatients department. The procedure usually takes about 30 minutes and you will then need a chest X-ray to check that it's in the right position. A PICC can be used in hospital settings or at home and can stay in place for weeks or months if needed.

Both a port and a PICC can be used for giving chemotherapy drugs, blood transfusions and antibiotics when needed as well as taking blood for tests, so there's no need to find a suitable vein each time.

I had a central venous access device inserted and at first I was apprehensive, but now I think it's great as it really makes intravenous treatment easier. There is no need to find a vein each time I go in for treatment. The port has improved my quality of life considerably.

The advantages of a port are that, because it's under the skin, it's less susceptible to infection and does not require dressings. As it's not visible, other than as a swelling under the skin, it's also less intrusive than a PICC line, which requires weekly dressings that must be waterproof. You are able to go swimming with a port in place though not with a PICC line. For more information about port or PICC lines speak to your oncologist or oncology nurse.

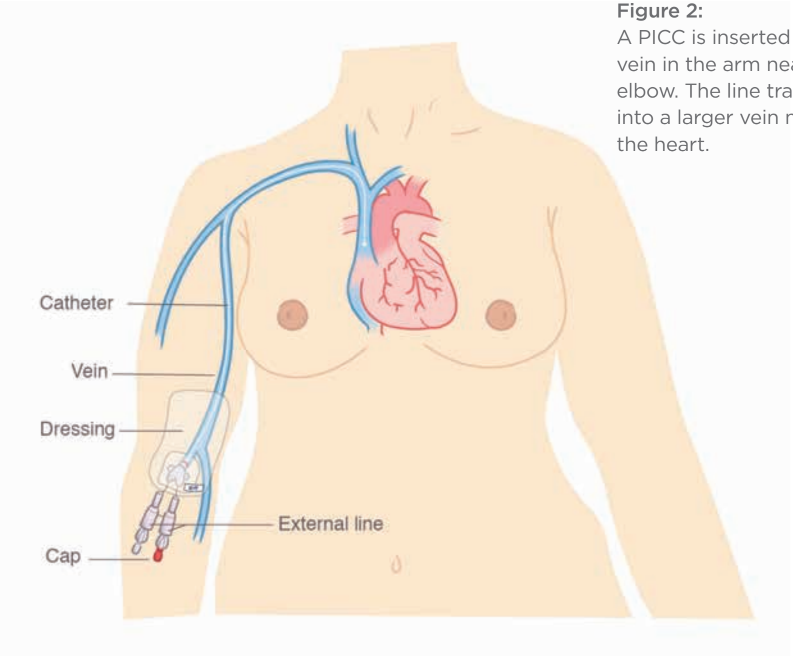


Figure 2:
A PICC is inserted into a vein in the arm near the elbow. The line travels into a larger vein near the heart.

Targeted therapies

In addition to chemotherapy and hormone-blocking therapy, there are treatments that can attack specific breast cancer cells without harming normal cells. These therapies are called targeted therapies. Targeted therapies work in a variety of ways:

- by delivering toxic substances directly to cancer cells to kill them without affecting normal cells
- by blocking the action of growth factors that speed up the growth of cancer cells
- by blocking the action of certain enzymes, proteins or other molecules involved in the molecular workings of cancer cells, preventing the growth and spread of cancer cells
- by helping the immune system kill cancer cells.

The CDK 4/6 inhibitors palbociclib (Ibrance), ribociclib (Kisqali) and abemaciclib (Verzenio) are examples of newer targeted therapies for the treatment of hormone receptor positive, HER2-negative metastatic breast cancer. The CDK 4/6 inhibitors are given with a hormone-blocking drug, such as letrozole or fulvestrant, and make hormone-blocking treatment more effective.

HER2 therapies such as trastuzumab (Herceptin), pertuzumab (Perjeta), T-DM1 (Kadcyla) and lapatinib (Tykerb) that block the action of HER2 receptors on cells are well-known targeted therapies for HER2-positive breast cancers.

A major focus of current cancer research is the identification of new targets in cancer cells and the development of drug treatments against these targets.

Immunotherapy

Immunotherapy is treatment that uses certain parts of a person's immune system to fight diseases such as cancer. This can be done by stimulating the immune system to find or detect cancer cells, or by adding components to a person's immune system such as man-made immune system proteins. It appears that triple negative breast cancer (e.g. testing positive for PD-1 or PD-L1) is one of the types of breast cancer most likely to respond to these treatments. Trials underway in triple negative breast cancer and HER2-positive metastatic breast cancer are testing the effectiveness of immunotherapy agents.

LOCAL TREATMENT

Radiotherapy

Radiotherapy uses X-rays and other forms of radiation, such as high energy electrons, to destroy cancer cells. It's used to treat one area at a time and can be administered externally or within the body. Radiotherapy can be particularly helpful for easing pain or discomfort in the bones, parts of the brain and the skin. It may be some weeks before pain in the bone eases after radiotherapy but most people do experience relief, and many report that the pain has gone away completely.

Depending on the part of the body being treated, radiation can cause tiredness, skin reactions, nausea and vomiting. It may also damage surrounding normal cells, although these can repair themselves.

Radiotherapy for metastatic breast cancer is usually administered in short courses of between one and 10 treatments in order to minimise side effects.

For more information about managing the side effects of treatment, see p.108.

Surgery

Surgery is a less common treatment for people with metastatic breast cancer. It may be used to prevent and/or treat a bone fracture, remove ovaries, reduce fluid that has accumulated around the lungs (pleurodesis) or remove a cancer from the brain.

Sometimes neurosurgery is recommended for spinal metastases, and bypassing or stenting procedures may be used to treat blockages – for instance, in the bile duct near the liver or the ureter. New surgical options are also emerging for solitary (single) liver metastases.

If metastatic breast cancer is your first diagnosis of breast cancer, surgery on the breast may be considered to control the cancer in the breast after initial drug treatment, though this surgery isn't always required.

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 9 states is 'not appropriate to routinely use extensive locoregional therapy in metastatic breast cancer patients with minimal symptoms attributable to the primary tumour'.

ℹ **More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.**

- Locoregional therapy may refer to treatments such as surgery or radiotherapy.

TREATMENT FOR METASTATIC BREAST CANCER ACCORDING TO BREAST CANCER SUB-TYPE

First line treatment for metastatic breast cancer is the one accepted as the best treatment for you. Second or later line treatments are given after the first line treatments have stopped working, or if they cause significant troublesome side effects.

Hormone receptor positive (HR+) HER2 negative metastatic breast cancer

Treatment will usually start with hormone-blocking therapy given in the form of oral tablets with or without one of the targeted therapies called CDK 4/6 inhibitors.

Occasionally, if there’s concern that your cancer may cause serious problems for you in the near future (for example, if you’re experiencing many symptoms or liver metastases are affecting liver function) a course of chemotherapy may be given first to gain control quickly. Following this you will usually be able to proceed with hormone-blocking therapies to control the cancer.

Hormone-blocking therapies

Hormone-blocking therapies block the effect of oestrogen on cancer cells. Several different medications can be used, including:

- anti-oestrogens: tamoxifen (Tamoxifen), fulvestrant (Faslodex), toremifene (Fareston citrate)
- aromatase Inhibitors: anastrozole (Arimidex, Anastrozole FBM), letrozole (Femara, Letrozole FBM), exemestane (Aromasin)
- progestins: medroxyprogesterone acetate (Provera), megestrol (Megace)
- ovarian suppression (e.g. goserelin [Zoladex] injections) or surgical removal of the ovaries.

Each treatment is continued until it's no longer effective or there are troublesome side effects. Often a sequence of these treatments controls the cancer for a number of years.

One of the challenges of treating hormone receptor positive metastatic breast cancer is that the cancer cells ultimately develop resistance to the hormone-blocking therapies. Current research is investigating a variety of drugs that target and block pathways in cancer cells that are responsible for resistance to hormone-blocking therapies. As a result of this research there are now newer drugs that, when given in conjunction with hormone-blocking therapies, control the cancer for longer.

CDK4/6 inhibitors

The CDK4/6 inhibitors (palbociclib, ribociclib and abemaciclib) are targeted treatments currently being used in combination with hormone-blocking therapies. The CDK 4/6 inhibitors work by blocking the enzymes in the pathway that help control how cells grow and divide.

These enzymes are commonly found in higher than normal amounts in breast cancer cells. Clinical trials have shown the combination of CDK4/6 inhibitors with hormone-blocking therapy extends both the time before the cancer progresses (spreads) and overall survival compared with hormone-blocking therapies alone.

Which treatment should be used?

This will depend on a number of factors:

- what breast cancer hormone-blocking therapies you have taken previously — for instance following an early breast cancer diagnosis
- whether you were still taking a breast cancer hormone-blocking therapy when metastatic breast cancer was diagnosed
- whether you're premenopausal – still having periods so your ovaries are producing oestrogen
- whether you're postmenopausal – your periods have stopped and your ovaries have stopped producing oestrogen.

For people with de novo metastatic breast cancer the choice of hormone blocking will depend on whether you're premenopausal or postmenopausal.

First line hormone-blocking treatment

The treatment recommended will depend on what hormone-blocking therapies, if any, you have previously taken for early breast cancer. The first hormone-blocking therapy you take for metastatic breast cancer, whichever one is recommended for you, is called first line treatment.

Treatment if you're premenopausal

You will most likely receive treatment to 'shut down' the ovaries (ovarian suppression or 'ovarian treatment') and bring on menopause in addition to one of the hormone-blocking medications.

Ovarian suppression can be achieved in one of three ways:

- surgical removal of ovaries (oophorectomy, usually performed via keyhole surgery)
- monthly injections under the skin (goserelin [Zoladex]), which results in menopause for as long as you're receiving the injections
- radiation treatment to ovaries, which is less common.

Hormone receptor positive breast cancer relies on oestrogen to grow and treatment to make you postmenopausal takes away most of the oestrogen in your body.

Aromatase inhibitors and fulvestrant are only effective if your ovaries are not producing oestrogen (i.e. you're postmenopausal). If you undergo oophorectomy or radiation treatment to your ovaries, you will become permanently postmenopausal and your hormone-blocking therapy will be as for postmenopausal women.

Sometimes, if your cancer is very slow growing and causing minimal problems for you, an anti-oestrogen may be recommended without ovarian suppression and menopause. Usually this would be with tamoxifen, although occasionally toremifene is used. At present, all other breast cancer hormone-blocking therapies have only been shown to be effective in postmenopausal women.

Treatment if you're postmenopausal

Treatment recommendations will depend on whether or not you were taking hormone-blocking therapy when metastatic breast cancer was diagnosed.

If you were not taking an aromatase inhibitor

Aromatase inhibitors are considered the most effective treatment so, if you haven't taken one within the past 12 months, this will generally be the first choice. Anastrozole and letrozole are considered equivalent and either one may be recommended. Occasionally, tamoxifen will be recommended as an alternative, usually because of a personal preference – yours or your medical oncologist's – or because of concerns about possible side effects.

If you were taking an aromatase inhibitor

Three options are available.

- Exemestane. Although this is also an aromatase inhibitor it has quite a different chemical structure and can work after anastrozole or letrozole has stopped working.
- Tamoxifen. This is also a good option, especially if you have never taken it before or it's some years since you did. However, if you've had a blood clot (deep vein thrombosis [DVT]) or a clot in the lungs (PE/pulmonary embolus) in the past, it may not be appropriate for you. You should discuss this with your medical oncologist.
- Fulvestrant. This is an effective option but it's rarely used as it's not currently on the Pharmaceutical Benefits Scheme (PBS) – the Australian Government scheme that subsidises medications.

If you were taking tamoxifen when metastatic breast cancer was diagnosed

An aromatase inhibitor will most likely be recommended. This could be anastrozole or letrozole or, if you have received one of these in the past, your medical oncologist may suggest exemestane.

How long can you continue on first line hormone-blocking treatment?

You will continue to take your first line treatment until it's no longer working, or side effects are too troublesome for you to continue. Usually, you'll be able to go onto an alternative second line hormone-blocking therapy.

Second line hormone-blocking therapy

If your cancer progresses or treatment side effects are interfering with your quality of life, your medical oncologist may recommend a different hormone-blocking therapy – again depending on your previous treatments.

You will continue on your second line treatment as for first line treatment. It may then be possible to offer a third line of hormone-blocking treatment and sometimes even a fourth line.

CDK 4/6 inhibitors may also be given in combination with hormone-blocking therapy for first, second or later line treatment. However, at the time of writing they're only listed on the PBS for first line treatment and so you may be required to pay for later lines of treatment yourself. Ribociclib for second line treatment can be currently accessed free of charge through the drug company's SPARK Plus access program though it's given with fulvestrant, which will incur a cost. There's also a patient access scheme which provides abemaciclib free of charge for third or later line treatment. In this setting, it can be given on its own or with fulvestrant. Speak to your medical oncologist for more information about these programs.

Overall, your oncologist will try to continue hormone-blocking therapies for as long as possible. It's very likely that you will be treated with most of them over a period of time.

Side effects of hormone-blocking therapies

Most side effects of hormone-blocking therapies are those associated with menopause, though everyone is different and also each treatment may be different in the side effects it causes. The most common are:

- hot flushes
- night sweats
- fatigue
- poor sleep
- mood changes including anxiety and depression
- joint pain
- body aches and pains
- vaginal dryness
- reduced libido
- poorer short-term memory

Please speak to your doctors or nurses about any side effects you experience as there are often ways to manage them.

Read more about management of treatment side effects on p.108.

Chemotherapy

Chemotherapy will be considered in the following situations.

- If the cancer is causing troublesome symptoms, a course of chemotherapy may be recommended to gain control. It may be possible to return to hormone-blocking therapies afterwards.
- If there are concerns that metastases in the organs are affecting their function (visceral crisis) or if you develop hypercalcaemia (high calcium levels in the blood).
- When it appears that hormone-blocking treatments are no longer controlling the cancer.

For more information, see BCNA's *Hormone receptor positive metastatic breast cancer* booklet. You can also find information in the My Journey online tool. Visit myjourney.org.au

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 7 states it's 'not appropriate to use chemotherapy in preference to endocrine therapy (with or without a CDK inhibitor) as initial treatment for patients with metastatic breast cancer that is hormone receptor positive and HER2 negative, unless there's a visceral crisis'.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.

HER2-positive metastatic breast cancer

The backbone of treatment for HER2-positive metastatic breast cancer are the drugs:

- trastuzumab (Herceptin)
- pertuzumab (Perjeta)
- trastuzumab emtansine (TDM-1; Kadcyla)
- lapatinib (Tykerb).

Anti-HER2 treatment targets the HER2 receptors on the surface of breast cancer cells. This blocks growth factor signals normally transmitted by these receptors, which in turn prevents the cancer from growing. Anti-HER2 treatment works best when combined with chemotherapy although, once the cancer is controlled, continuing the anti-HER2 treatment alone can keep the cancer under control for long periods of time. Provided anti-HER2 treatment is well tolerated, it will be continued long term.

The treatment of HER2-positive metastatic breast cancer is complex and depends on many individual factors.

Most people with HER2-positive metastatic breast cancer will receive a sequence of treatments. Your medical oncologist will work with you to find the best choice of treatment for you.

The ‘standard’ treatment recommendations are as follows.

First line treatment

Trastuzumab + pertuzumab + taxane chemotherapy (paclitaxel or docetaxel). The chemotherapy is usually given for approximately six cycles, with anti-HER2 treatment (trastuzumab and pertuzumab) continuing until the cancer progresses (grows again).

Second line treatment

Trastuzumab emtansine (TDM-1). TDM-1 is trastuzumab with a chemotherapy (emtansine) attached to it which is delivered very specifically to the cancer cells in conjunction with the trastuzumab. No additional chemotherapy is needed and treatment continues until the cancer progresses.

Later lines of treatment

There are a number of further treatments that will be given in sequence as considered appropriate. These include lapatinib (oral anti-HER2 treatment) plus capecitabine (oral chemotherapy) and trastuzumab plus chemotherapy. Various trastuzumab plus chemotherapy combinations are effective. New agents such as neratinib (Nerlynx) have also become available for later line treatment. Clinical trials are continuing to study the effectiveness of other agents in HER2 positive breast cancer.

Side effects of anti-HER2 treatments

Anti-HER2 treatments don't generally cause many day-to-day side effects. However, they may be associated with:

- increased fatigue
- headaches
- skin rashes
- occasionally, reduced heart function.

Trastuzumab emtansine can sometimes cause abnormalities in liver function and reduction in platelets (blood cells responsible for clotting).

Lapatinib is associated with more side effects than the other anti-HER2 treatments, including:

- diarrhoea
- nausea
- mouth ulcers
- troublesome skin rashes.

For more information, see BCNA's *HER2-positive metastatic breast cancer* booklet. You can also find information in the My Journey online tool. Visit **myjourney.org.au**.

HER2-positive and hormone receptor positive (HR+) metastatic breast cancer

Approximately half of HER2-positive metastatic breast cancer cases are also hormone receptor positive. This is sometimes called ‘triple positive’ metastatic breast cancer. If your cancer is triple positive, hormone-blocking therapies (p.83) will be recommended in addition to the anti-HER2 treatment and chemotherapy.

Triple negative metastatic breast cancer

The backbone of treatment for triple negative metastatic breast cancer is chemotherapy. These treatments are usually used individually though two may be used in in combination.

First line treatment

An initial course of chemotherapy, called first line treatment, will usually start within a few weeks of the diagnosis of triple negative metastatic breast cancer.

It may be delayed a short time if radiotherapy or surgery is required. Chemotherapy is usually given in cycles of three to four weeks, or other sequences such as two out of three weeks, depending on the drug or drugs used. Chemotherapy will continue until there are too many side effects or it’s no longer controlling the cancer.

Second and subsequent lines of treatment

You may be able to have a break when a treatment is completed or need to start another treatment immediately. Either way you will be advised to proceed with the next treatment when symptoms, scans or examination show that the cancer is active and worsening. This next treatment is called second line treatment and will usually be a different type of chemotherapy drug. The treatment proceeds as for first line treatment.

When the second line treatment is no longer controlling the cancer, you may proceed on to other types of chemotherapy (third, fourth, fifth line etc.), as considered appropriate by your medical oncologist and your wishes about treatment.

In summary, you will receive a sequence of treatments over time, each adding a period of cancer control. Where possible, you will have chemotherapy-free periods between different treatments and the choice of chemotherapy drugs will take possible side effects into account.

Current research

There are no targeted treatments available for triple negative breast cancer at present except in clinical trials. We already know that triple negative breast cancer is made up of a number of subtypes with different molecular characteristics, each with different targets for treatment. It's likely that additional subtypes will be identified as research continues.

These treatments are closest on the horizon.

- PARP inhibitors: olaparib (Lynparza). PARP inhibitors are effective for BRCA mutation-related metastatic breast cancer and may be used alone or in combination with chemotherapy. Olaparib is a well-tolerated oral medication not yet available in Australia.
  A PARP (poly ADP-ribose) inhibitor is a medication that blocks an enzyme in cells called PARP, which helps repair DNA when it becomes damaged. In cancer treatment, blocking PARP may help keep cancer cells from repairing their damaged DNA, causing them to die.
- Immunotherapies. Trials are underway with pembrolizumab (Keytruda) and other immune checkpoint inhibitors for triple negative breast cancer testing positive for PD-1 and PD-L1. Atezolizumab (Tecentriq) given with nab-paclitaxel (chemotherapy) has shown meaningful benefit in PD-L1 positive triple negative metastatic breast cancer.

For more information see BCNA's *Triple negative metastatic breast cancer* booklet. You can also find information in the My Journey online tool. Visit myjourney.org.au

How can I get a new drug that's not available on the PBS?

CLINICAL TRIALS

I had nothing to lose and a lifetime to gain. Being on a clinical trial meant I had access to leading-edge treatments.

The aim of clinical trials is to find new and/or better cancer treatments or to see whether a new treatment is better than the current standard treatment. We tend to think of trials in terms of new drugs, but radiotherapy and surgical, psychological and other procedures are also tested in clinical trials and research studies. Trials can also focus on emotional wellbeing or the symptoms and side effects of cancer treatment such as fatigue and sleeplessness.

There are usually two groups of patients included in a clinical trial.

- Intervention group – those who receive the new treatment.
- Control group – those who receive the current standard treatment.

The two groups enable researchers to check whether the new treatment is better than the standard treatment. Participants can't usually choose whether to have the new treatment or the standard treatment. When a new treatment proves to be both safe and more effective than the current standard treatment it becomes the standard treatment. Talk to your doctor about clinical trials available for your type of breast cancer.

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 4 states is its 'appropriate for patients with metastatic breast cancer to be offered participation in suitable and relevant clinical trials from the time of diagnosis and throughout treatment'.

ⓘ **More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.**

Types of clinical trials for cancer drugs

Clinical trials are conducted in a series of steps or different phases. Each phase has a different aim and builds on information gained from the previous phases. Participants in any phase trial are watched closely and treatment is stopped if any serious side effects develop.

Phase I trials

Phase I trials are designed to determine if a treatment is safe. They're usually small trials that may only involve 15-50 participants. Phase 1 trials may investigate the best way for a drug to be given or the highest dose that can be tolerated without serious side effects.

Phase II trials

Phase II trials are designed to determine how effective a drug is and study side effects. They're slightly bigger than Phase I trials, involving up to 100 participants. The dose and method of administration determined by the Phase I trial is the starting point and the researchers monitor participants to see if the treatment has benefits in terms of shrinking the cancer or stopping further growth. Phase II trials may also look at whether the drug increases survival times or improves quality of life.

Phase III trials

Phase III trials compare a new drug to existing treatments that are standard of care. They're usually large, possibly involving thousands of people, and they're usually the last step before the government approval process which makes a drug available for sale in Australia.

Participants in Phase III studies will usually be randomised to either the new drug treatment or standard treatment. This means you will not be able to choose which treatment arm you receive.

Phase IV trials

Phase IV trials usually look at whether the treatment offers benefits or produces long-term side effects that weren't studied or seen in the Phase II or Phase III trials. They're usually conducted after a drug has been approved for use and are less common than Phase I, II and III trials.

Benefits of clinical trials

Access to new treatments

Participating in a clinical trial can give you early access to new treatments or new ways of receiving treatment that may not otherwise be available to you. This may slow down progression of the cancer and possibly increase survival time. This might be important to you if existing treatments are not working well or if a new treatment has been developed and is demonstrating effectiveness in treating your subtype of cancer.

Close monitoring

Another benefit of a clinical trial is that you will be closely monitored by breast cancer specialists, research nurses and other cancer experts.

Developing new treatments

Participation also helps researchers to develop new treatments for metastatic breast cancer that will hopefully benefit other people in the future.

Prescribed treatment

Some people worry that they will receive no treatment at all if they are allocated to a control group – the group that provides a comparison by not receiving the new treatment. In fact, clinical trials are very carefully regulated to ensure that all patients receive at least the level of treatment that would have been prescribed for them if they had not been participating in the trial. Nevertheless, a clinical trial is not for everyone.

The negatives of clinical trials

You may not be eligible

Many criteria are taken into account such as your age, the subtype of your cancer, where your cancer has spread, the stage of the cancer, what treatment you have already had and whether you have any other health issues.

Time consuming

You may need to set aside extra time for appointments or pay more visits to the clinic than if you were on the standard treatment.

A different team

Not all medical oncologists and oncology centres offer all trials, so you might need to be referred to another oncologist for the period of the trial. If you live in a rural or regional area and are being treated locally, you may find it difficult to access a clinical trial as the majority are run in major metropolitan or regional centres.

No guarantees

You may not be in a trial group that receives the new treatment or the new treatment may not work as effectively as expected. You also need to consider what the side effects of the new treatment might be and whether you feel you can tolerate them, although you're free to leave the trial at any time.

You may feel that, on balance, the negative aspects outweigh any possible benefits. But, if you're interested, it's always worth asking whether any trials may be available to you in your treating centre or elsewhere.

Finding out about clinical trials

Clinical trials are run through public and private hospitals. Your medical oncologist is likely to be your best source of information for any trials that may be relevant for you. If you're eligible for a clinical trial that interests you, you can discuss the details with your doctor. The discussion should cover possible benefits and risks, both short and long term, what tests are involved and how this treatment option compares with others available to you. There are also practicalities to consider, such as how much extra time you will need to set aside for treatment and testing, whether there will be any out-of-pocket costs and how far you will need to travel.

If the clinical trial is being run at another centre and your oncologist has no involvement, you will need to be referred to an oncologist and/or team that is participating in the trial. You can then opt to be referred back to your original oncologist when the clinical trial treatment has been completed.

If you decide to go ahead, you will be asked to sign a consent form — a detailed document that explains what is involved in the trial as well as your rights and responsibilities. There's no need to rush into this. Take the time to make sure you understand everything you're agreeing to and, if you wish, discuss it with your family and friends or another doctor.

Even if you get as far as starting treatment you have the right to withdraw at any time without giving a reason. If the treatment doesn't work for you, it will be stopped and other options considered. Whatever happens, a trial should have no effect on your relationship with your doctor or the quality of your future treatment.

More information on clinical trials

For more information about clinical trials and to search for current trials in metastatic breast cancer, see:

- The Australian Government's Australian Clinical Trials site **australianclinicaltrials.gov.au**
- Breast Cancer Trials (BCT) **breastcancertrials.org.au**
- Australia and New Zealand Breast Cancer Trials Group **anzbctg.org.au**.

ARE THERE DRUGS I CAN PAY FOR?

With advances in research, there are now many more treatments available for metastatic breast cancer than there were 13 years ago when BCNA developed the first edition of *Hope & Hurdles*. New and emerging treatments mean that today there may be many different types of treatments that may benefit you. However, at some point, you may reach a stage where there are no more government-subsidised treatments available to you.

You may hear from your medical oncologist or through the media about a new drug you could pay for (often thousands of dollars per month) or even a drug as yet unavailable in Australia that can be bought overseas.

While it can be reassuring to know that new drugs are constantly being developed and tested in clinical trials around the world, the reality is that it can take many years for a new drug to go from clinical trials to 'approved for use' in Australia and listed on the Australian Government's Pharmaceutical Benefits Scheme (PBS).

For information on the processes new drugs go through before they are listed on the PBS, visit the Treatment > *How breast cancer medicines are subsidised* page of the BCNA website bcna.org.au.

It can be particularly distressing when you know there's a new drug that might be beneficial to you but you can't afford it.

BCNA is committed to ensuring that Australians have access to new and innovative cancer drugs. We recognise the despair that people can experience when they hear that a new drug is improving survival outcomes but is not within their reach. BCNA continues to advocate on behalf of our members around the importance of improving approval processes for new cancer drugs to ensure they become available as quickly as possible to those who may benefit from them.

There are some ways you may be able to access new drugs before they are listed on the PBS, and sometimes before they're even approved for sale in Australia. We have listed a number of avenues here – be wary of other options you may hear about. There are many unscrupulous operators around, particularly via international websites, promising to provide you with treatments that may not be legitimate. Talk with your oncologist before making any decisions about accessing drugs not approved for use in Australia.

Patient access programs

Sometimes drugs that have been approved for use in Australia but are not subsidised through the PBS are made available through a patient access program offered by the pharmaceutical company that produces the drug.

These are offered at the discretion of the pharmaceutical company, and the drugs are provided to individuals on a case-by-case basis. They all operate differently but usually you will be asked to make a contribution towards the cost of the drug. For example, you may be asked to pay for the first two or three treatments and then, if the drug is shown to be benefiting you, the pharmaceutical company will pay for the some or all of your remaining treatments until either the drug is listed on the PBS or it stops working for you.

Your medical oncologist can let you know whether any suitable treatments might be available through one of these schemes and, if so, apply to the pharmaceutical company on your behalf.

Compassionate grounds

In rare cases, a pharmaceutical company will provide a drug free of charge on compassionate grounds. If you're unable to meet the cost of a new drug, talk to your medical oncologist about whether this might be possible for you.

Private health insurance

Some private health insurance policies allow you to claim benefits towards the cost of drugs not listed on the PBS. If you have private health insurance, ask your insurance company if you're able to claim benefits towards the cost of a particular drug. It's unlikely that your insurer will cover all of the costs so make sure you get a quote in writing before you go ahead.

Crowdfunding

Crowdfunding provides an opportunity to raise money from family, friends, work colleagues and others through an internet-based platform. Many people are now using crowdfunding for all sorts of purposes, including to fund medical treatment. There are a number of different crowdfunding platforms available.

PeoplePledge is a free Australian online platform that helps people fundraise for a loved one with an illness or disability. Other sites include mycause and GoFundMe. BCNA has no association with these platforms so please review their websites carefully or contact them for more information before making any decisions.

Purchasing from overseas

In some circumstances, your medical oncologist may be able to obtain drugs not yet available in Australia direct from the pharmaceutical company or from an overseas supplier. There's a process for this and you should discuss this option very carefully with your medical oncologist. Your oncologist is required to document your informed consent to the use of an unapproved medicine and to notify the Australian Therapeutic Goods Administration of any unexpected side effects that you experience. There may also be issues bringing intravenous drugs into Australia as hospitals may not allow their staff to administer them.

The website **TheSocialMedwork.com** is a global online platform for people to purchase, with the help of their clinicians, drugs that have been registered for use in some countries but not in others. It may be a way for you to purchase new drugs not yet registered for use in Australia. To ensure the drugs they offer are legitimate, TheSocialMedwork only supplies those that have been approved for use by regulators in the USA, Europe or Japan. The drugs are likely to be expensive to purchase, so this is not an option for everyone. It's important to remember that even when new drugs have good results in clinical trials they don't work for everyone. You could pay thousands of dollars for a drug that doesn't benefit you.

TheSocialMedwork will require written documents from your oncologist to confirm that the drug you wish to purchase through them is suitable for you. There may also be costs to bring drugs bought overseas into Australia. We encourage you to have a very carefully considered discussion with your oncologist and your family before going ahead with this option.

HOW WILL I KNOW IF THE TREATMENT IS WORKING?

Your doctor needs to know whether the treatment is working or if the cancer is growing, but being tested, waiting for results and perhaps hearing that a treatment is no longer working can be stressful and upsetting. It's important to be aware of this and to think about ways of managing this worrying time. You might want to talk with your oncologist beforehand about possible alternatives if the results are not good news. It can be reassuring to know that other options are available.

Waiting for test results is one of the most worrying times... when the results are known, positive or negative, a huge weight is lifted off my shoulders and I allow myself to deal with the next issue.

Scheduling your scans as close as possible to the review appointment will mean you don't have to wait as long for the results, though you'll want to make sure your oncologist has all of the test results before the meeting.

A variety of tests can be used to monitor metastatic breast cancer and determine whether your treatment is working. These include physical examinations, X-rays, scans such as computerised tomography (CT/ CAT), magnetic resonance imaging (MRI), positron emission tomography (PET) and blood tumour marker tests. Scan results are not usually considered in isolation. Other factors will help to provide a more complete picture of what might be going on. Often the most useful way of assessing whether your treatment is working is to monitor your symptoms – if you consistently feel better, this is usually an indication that your cancer is responding.

Ask your doctor if you're unsure about the tests you're having, how long you may have to wait for results, what the results really mean and how they will influence treatment recommendations.

CONCERNS ABOUT YOUR CARE AND GETTING A SECOND OPINION

It's okay to get a second opinion. You're not being disrespectful or disloyal to your doctor, you're just checking things out. Your doctor would do the same.

Treatment for metastatic breast cancer is ongoing and your relationship with your treating team will be an integral part of your care so it's vital they listen to you and respond to your needs and concerns.

If you're uncertain about, or unhappy with, the care you're receiving, either from your doctors or through the health care system, it's important to voice your concerns. You could raise the issue yourself by explaining your feelings to the health care professional in question. If you do, it might be best to arrange an appointment where you focus specifically on your concerns. You might also want to take someone with you who can help you explain your concerns and take the emotion out of the discussion.

Medical oncologists and other doctors are very happy to provide you with a referral if you decide you want to get a second opinion, so don't be afraid to ask.

For more information on getting a second opinion, see p.53

PALLIATIVE AND SUPPORTIVE CARE

Palliative and supportive care helps people live as fully and comfortably as possible with a life-limiting illness that can't be cured, such as metastatic breast cancer. Palliative care identifies and treats symptoms and is based on your individual needs.

I'm having palliative care now and I'm not at the end of my life … I'm teaching my family that palliative care isn't a scary thing … it's great. This is what I need. The more I know about it and the more information I have about it the better equipped I will be.

Palliative care can help your family too

Palliative care is a family-centred model of care – there not just for you but for your family and friends as well. Your family and carers can all receive practical, emotional and physical support.

The benefits

Palliative care can improve the quality of your life and help you manage concerns, whether they're physical, emotional, spiritual or social. Palliative care services can complement your treatment and help you manage your illness, particularly pain and mobility, so you can continue to live life the best you can. Support is flexible, differing for each person according to their needs. It may include:

- relief of pain and other symptoms such as vomiting or shortness of breath
- provision of equipment needed to help you live as independently as possible at home, such as wheelchairs, special beds, shower chairs
- assistance for families with talking about sensitive issues, such as counselling for your children
- links to other services such as home help, financial support
- help with meeting cultural obligations
- emotional, social and spiritual support
- counselling and grief support
- referrals to respite care services.

Your palliative care team

Your GP, breast care nurse and other health professionals can play an important role in providing palliative care, as can your family and informal carers. If your symptoms become difficult to manage, your usual health care providers may seek advice and support from palliative care specialists. In some cases, a short inpatient stay may be needed – to fine-tune pain management, for instance. This can have the additional benefit of giving your family and carers time to recharge in the knowledge that you are being well cared for.

Palliative care may be provided:

- at home
- in hospital
- in a hospice
- in a residential aged care facility.

The earlier the better

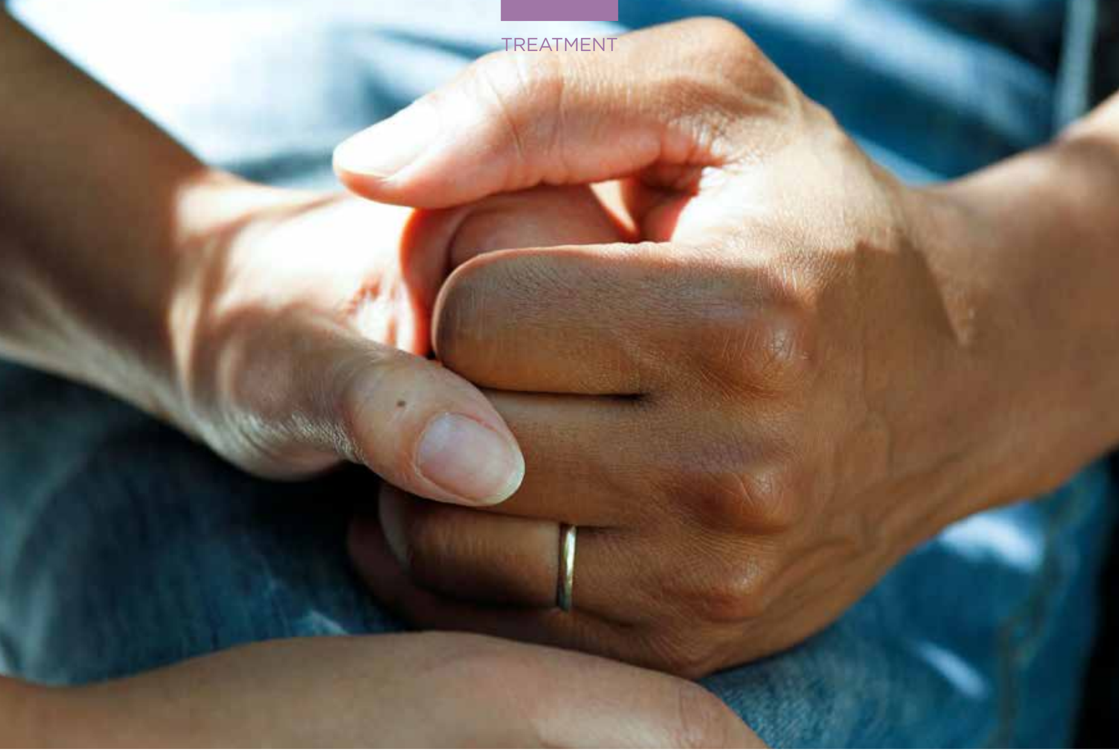
Palliative care can be used to help prevent and relieve symptoms and side effects related to cancer and its treatment, such as pain, nausea and fatigue. Controlling these symptoms is an important part of treatment. You should never hesitate to tell your health care team about any pain or other symptoms you may experience.

Getting to know your palliative care team soon after you have been diagnosed can help you feel more comfortable about approaching them later – for example, if you have symptoms that are not being well controlled.

At diagnosis I was given a team that included a palliative care nurse and that really stunned me and the rest of the family. (But) in a way it helped [me] to come to terms with it. It gave me a perspective on what I have to do and achieve in the next while.

Early access to palliative care can also ensure you have all the supports you need to maximise your mobility and quality of life for as long as possible.

For more information on palliative care, see Cancer Australia's *Finding the words: starting a conversation when your cancer has progressed*.



PLANNING AHEAD

As well as working with your treatment and care team to make decisions about the care you want now, it's good to think ahead and talk to them about the care you might want if your disease progresses.

It would be good to know about palliative care and what happens to your body as the cancer becomes more invasive. That is, what to expect and how to talk about the 'elephant in the room'.

Palliative care teams are experienced at helping patients and their families talk about their goals and preferences for care. This can include difficult discussions about balancing the quality and length of life, remembering that such preferences may change as your disease progresses. While these reflections and discussions may be confronting, many people also find them empowering. It means that their wishes will continue to be respected throughout the course of their illness.

Whatever is within my control I want to do ... Empowerment is important for me.

One useful tool to help you reflect on your values and preferences for care is the Dying to Talk Discussion Starter at **dyingtotalk.org.au**.

This useful tool walks you through a personal reflection, and then provides tips for talking with your family and doctors about your preferences for care.

When you have thought about the care you want you might consider documenting your wishes in an advance care plan.

Advance care planning is a process that helps you plan your medical care ahead of time in case you should become too unwell to make decisions for yourself. For more information and documents about advanced care planning that apply in your state or territory, go to Advance Care Planning Australia **advancecareplanning.org.au/contacts-and-links**.

You can make your views more easily available by uploading it to your My Health Record **myhealthrecord.gov.au** where it will be available to health care providers whenever it's needed.

Planning ahead can be difficult but, once you've started the conversation, you may find it easier to talk about your feelings and preferences than you had expected. It can also help your family feel at peace with decisions they might one day need to make, knowing it was what you wanted.

Dealing with the shock, uncertainty and initial fear around planning for the worse was challenging … but then [it was about] getting on with things and deciding that, for as long as I can, I will live life to the full and continue to do the things I had planned to do prior to my diagnosis.

ℹ **For more information about planning ahead refer to BCNA's Planning ahead booklet. You can order it by phoning 1800 500 258. You can also find information in the My Journey online tool at myjourney.org.au.**

MANAGING SYMPTOMS AND SIDE EFFECTS

You may have experienced very few symptoms in the lead-up to your diagnosis and it may be a long time before any develop that affect your quality of life. When they do, your treating team will be able to recommend many different strategies and treatments to help control them.

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.

The following section provides information on managing many, though not all, possible symptoms and side effects. Remember, everyone is different and some people experience very few or they have little impact.

You may not want to read all of this section right now as some of the information won't be relevant to your treatment or where you are now. You can always refer to it later if you start a new treatment or are concerned about new a symptom.

Pain

I take my regular pain meds so that I can rest and sleep as much as I can. This means that I can do the things I want to do or need to do more often than not, which helps contribute to my wellbeing most of the time.

Many people believe that pain associated with metastatic breast cancer is inevitable; this is often one of the greatest fears. However, some people experience no pain at all and others very little.

It's important to know that pain can almost always be controlled. There are a number of treatments aimed at reducing or eliminating pain caused by metastases as well as many different pain-relieving drugs (analgesics) that can be used on their own or in combination.

Over-the-counter pain medications

Over-the-counter drugs include paracetamol (Panadol), which is effective for mild pain and is most effective if you take it regularly rather than waiting until the pain returns or worsens. It's important to speak to your oncologist about which over-the-counter medications are safe for you to use.

Prescription medications for pain

Panadeine and Panadeine Forte (a stronger, codeine-containing analgesic), are available on prescription from your oncologist or GP.

The opiate painkillers are the prescription drugs that provide the backbone of managing moderate or more severe pain. There are several opiate painkillers, and new ones are introduced from time to time. They are usually prescribed in a slow-release form as oral medications or patches that are placed on the skin and renewed every few days. Examples are:

- Oxycontin, Targin (containing oxycodone)
- MSContin or Kapanol (containing morphine)
- Jurnista and Dilaudid (containing hydromorphone)
- Durogesic (Fentanyl) patches.

You may also be able to use fast-acting pain medication for what is called 'breakthrough pain' – pain that occurs despite the slow-release medication. Examples of these fast-acting medications are:

- Endone, Dilaudid (tablets)
- Morphine mixture (liquid)
- Actiq, Abstral (fentanyl lozenge).

The steroid medication dexamethasone can sometimes be very helpful for pain associated with metastases in, for example, the bone or liver.

Radiotherapy for pain relief

Radiotherapy can be very effective in reducing pain associated with bone metastases.

Who can help me control my pain?

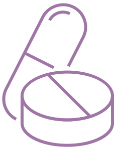
It should be possible to achieve good control of your pain. It's important for you to let your treating team know whenever you're in pain as a change in dose or use of different drugs may be helpful. In some cases, your oncologist might suggest you see someone who specialises in cancer pain management, perhaps at a pain clinic or through palliative care. Palliative care physicians usually provide this advice in a cancer treatment team.

It's also important to describe any pain as accurately as possible as this can help your doctor to prescribe the most effective treatment. You might want to keep a diary noting the following details.

- If 0 is no pain at all and 10 is the worst pain you could imagine, what number is yours?
- What does it feel like – a dull ache, stabbing or burning?
- Is it constant or intermittent?
- If it comes and goes, when is it at its worst and how long does it last?
- Is it easy to pinpoint or more generalised?
- Is there anything that provides relief or that makes it worse?
- If you have tried different medications, did one work better than another?

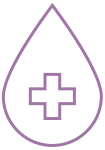
Some people worry that, if they take too much pain medication, they'll become dependent on it, or that needing more pain medication means the cancer is getting worse. These are just two of the many myths about pain relief and cancer, particularly morphine.

Myths around morphine



MYTH 1 – If I take morphine I'll get addicted.

Using morphine for pain relief does not cause people to become addicted.



MYTH 2 – If I take morphine now it won't work if my pain gets worse.

This is not true. If your pain becomes more severe, the dose can be adjusted to manage it.

MYTH 3 – If my doctor recommends morphine it means my cancer is getting worse.

If your doctor recommends morphine it's because they want you to feel well and free from pain and other medications have not achieved that. Morphine is far from a 'drug of last resort'. Many people use varying doses of morphine over several years.

MYTH 4 – If I take morphine I'll be too 'out of it' to do anything.

Like any other drug, morphine can have side effects which must be balanced against the benefits. It can be quite sedating at first but, in most cases, the body quickly adjusts to this so that feeling sedated is not a major problem for most people.

MYTH 5 – Morphine is too strong to take if I'm taking other medication.

While morphine can be effective on its own it's quite commonly used in combination with other pain medication like paracetamol. Some antidepressant medications increase the pain-relieving benefits of morphine so this is another fairly common and often very effective combination.

For more information, call 13 11 20 to request a free copy of the booklet, Overcoming Cancer Pain.

Non-medical pain relief

Complementary therapies can help to reduce or control pain. Massage with an aromatherapy blend may help you to relax but ask your masseur to avoid any inflamed or swollen areas. Some oncologists prefer that people with metastatic cancer see an accredited oncology massage therapist.

For more information on oncology massage therapists, see p.176, Section 4: Living well.

Research shows that acupuncture can relieve pain. Relaxation techniques such as breathing or yoga may also help. Because cold packs decrease the flow of blood they can provide effective relief for pain related to inflammation, joint pain or muscle aches and spasms. Warm packs increase blood flow, which makes them more effective for pain caused by stiffness or muscle tightness. Neither heat nor cold should be applied to areas being treated by radiotherapy, and cold packs should not be used where circulation is poor.

If your pain is exacerbated by pressure, there are frames to protect you from the weight of your bedding. Back supports may make sitting more comfortable and other devices can help with specific problem areas. Most of these aids can be hired for a relatively small fee. Your doctor, social worker or palliative care team should have the information you need or be able to refer you to a physiotherapist or occupational therapist.

Neuropathy (nerve pain)

Neuropathy is the general term for pain or discomfort caused by damage to the nerves of the peripheral nervous system. Your peripheral nervous system is made up of the many nerves that bring signals from the brain and spinal cord to other (peripheral) parts of the body, such as the hands and feet. Damage to those nerves can affect the way the body sends signals to muscles, joints, skin and internal organs. This can cause pain, numbness, loss of sensation and other symptoms.

Some intravenous chemotherapy drugs, including eribulin and the family of drugs called taxanes, can cause neuropathy as can oral forms of chemotherapy, such as Xeloda (capecitabine) and Navelbine, and some of the targeted therapies.

Chemotherapy-associated neuropathy can start any time after treatment starts and may worsen as treatment continues. Usually it begins in the toes, but it can expand to include the legs, arms, hands and fingers. The most common symptoms include:

- pain, tingling, burning, weakness, tickling, or numbness in arms, hands, fingers, legs and/or feet
- sudden sharp stabbing pain
- reduced sensation of touch
- difficulty using fingers to pick up objects or fasten clothing, or type on a keyboard or mobile device.

Neuropathic pain can also occur if cancer damages nerves.

Treatment for neuropathy

Medications that can help reduce the pain and discomfort associated with neuropathy include Lyrica (pregabalin), Neurontin (gabapentin), Tegretol and Endep.

Having a rest from chemotherapy drugs that cause nerve damage can sometimes improve symptoms, or your oncologist may be able to switch your treatment to a drug without that side effect.

If you enjoy activities such as knitting, embroidery, sewing or painting, or you use your hands constantly for keyboard work, let your oncologist know that neuropathy could affect your quality of life.

Joint pain

Any treatments that result in menopause may cause joint pain as a side effect. In particular, if you're taking an aromatase inhibitor (anastrazole, letrozole or exemestane) you may experience some joint stiffness or pain.

Joint stiffness most commonly occurs in the morning and it tends to improve as you move around. Some people find that gentle exercise and stretching such as hydrotherapy (exercise in water), swimming, tai chi and yoga help to reduce stiffness and discomfort.

ℹ **For more information about exercise see Section 4: Living well.**

Over-the-counter drugs such as paracetamol, or non-steroidal anti-inflammatory drugs (NSAIDs) such as Nurofen or Voltaren, may also help. However, if you're having chemotherapy or CDK4/6 inhibitors, you should speak with your medical oncologist or oncology nurse before taking medication containing ibuprofen such as Nurofen or other anti-inflammatory medications.

Acupuncture has been shown to reduce joint pain for some people, and research trials are continuing in this area. Glucosamine and fish oil could also be helpful while some people find relief by applying gentle heat with a heated wheat bag or heat pack. Talk to your doctor about what option/s may be best for you.

Low blood counts and risk of infection

Chemotherapy and CDK 4/6 inhibitors can reduce the number of white blood cells your body produces and so increase your risk of infection. While you're being treated you're likely to have regular blood tests to monitor your blood count. If you have a fever of 38°C or more you must immediately contact a member of your treatment team or attend a hospital emergency department as this may be a sign of infection.

Fatigue and tiredness

Fatigue is a common symptom of metastatic breast cancer and can also be a side effect of treatments including chemotherapy and radiotherapy.

Poor nutrition, dehydration, lack of sleep, pain and psychological issues such as stress, anxiety and depression can also leave you feeling exhausted and lacking in energy. This can then have a negative impact on your ability to cope, your quality of life and your independence. Many of these factors are treatable, so be sure to raise any issues with your doctor.

Sometimes chemotherapy or the cancer itself causes anaemia, which can worsen fatigue. Regular blood tests will check your blood cell count while you're being treated.

Taking steps to adjust your lifestyle can help you to conserve and make the most of your energy

- Exercise can help to manage fatigue as well as other symptoms and side effects. Try to incorporate light exercise, such as a walk, into every day.
- Adequate rest is vital but, as too much can leave you feeling more exhausted, it's important to find the right balance.
- Having someone else do the housework for you will leave you with energy for things you enjoy more. You might be eligible for home help from your local council.
- Eat as well as you can and take any supplements recommended by your doctor or dietitian.
- Get some rest or have a nap before a special occasion.
- On days when you don't have much energy, save it for the things you enjoy. Accept other people's offers of help.
- Allow yourself to relax and enjoy reading, listening to music or watching TV without worrying about what you 'should' be doing.
- Break goals or tasks down into small, manageable steps so you can feel a sense of satisfaction from relatively small achievements.
- Plan to rest on the days when you know your side effects might be at their worst.

Nausea

Nausea is occasionally caused by the cancer itself, especially if the liver or brain is affected or metastases in the bone are causing hypercalcaemia (high levels of calcium in the blood). Nausea may also be a side effect of chemotherapy, radiotherapy to the abdomen or brain, or strong pain killers. It can also be a symptom of constipation, and anxiety can worsen the feeling.

Drugs used to control nausea are known as antiemetics. They work in different ways. If one isn't effective another one may be, so be sure to let your doctor know. If you feel too sick to swallow a tablet, many antiemetics are available as suppositories, injections, or lozenges or wafers that dissolve under the tongue. Steroids can also help control nausea caused by chemotherapy and liver and brain metastases.

Thanks to modern anti-nausea drugs you're much less likely to experience excessive vomiting but talk to your doctor if you do.

Complementary therapies, such as relaxation therapy, hypnosis and acupuncture, can also help to manage nausea and vomiting.

Practical suggestions to help manage nausea and vomiting

- Have small, frequent meals.
- Avoid fatty or fried foods or food with a strong odour.
- Rest before and after eating.
- Sip fizzy drinks such as soda water, dry ginger or lemonade.
- Follow the antiemetic schedule recommended to you by your oncology support team.
- Ask your oncologist for additional medications you can take if you feel nauseated between taking your regular antiemetics.
- Sip plenty of fluids throughout the day.
- See a dietitian for advice on what foods to avoid.

Constipation

Constipation can make you feel really uncomfortable and unwell. Unfortunately, it's very common in people with metastatic breast cancer as it can be caused both by the cancer and its treatment, especially chemotherapy and medications such as antiemetics and analgesics. It may get worse if you stop exercising during treatment or change your eating and drinking habits.

Maintaining a healthy fluid intake is very important. You may find it easier if you take frequent sips throughout the day. Small, regular amounts of fluid and food are often more easily tolerated. Try to eat plenty of fresh fruit and vegetables and choose high-fibre foods such as wholemeal breads and cereals. Regular exercise such as a daily walk can also make a difference.

If these strategies don't help, your doctor may recommend a laxative such as Coloxyl with Senna or Movicol. Fibre supplements such Fybogel or Metamucil are not recommended for constipation related to medicines or cancer as they're likely to make this worse.

Tips for coping with constipation

- Start a gentle exercise routine.
- Increase your fibre intake by eating more fruit, vegetables and grains.
- Avoid lactose products – for example, dairy products such as milk, ice-cream and cheese.
- Avoid alcohol.
- Limit foods and beverages with caffeine.
- Increase your water intake.
- Don't be afraid of taking laxatives regularly – this is often needed and by far the most effective method of managing constipation related to medications, especially morphine. Talk to your doctor about which laxatives are recommended.
- Ask your doctor whether you should change your pain medication.

Diarrhoea

Some chemotherapy drugs can damage the healthy cells that line the small and large bowel, causing diarrhoea. In particular, chemotherapies that contain the drug 5-FU (5-fluorouracil), Taxotere (docetaxel) and the oral chemotherapy Xeloda (capecitabine). Diarrhoea can be associated with the CDK 4/6 inhibitors, in particular abemaciclib and can also be caused by an infection or drugs used to treat constipation.

Diarrhoea may be an unwanted minor side effect of treatment but it can sometimes be more serious. If you're having more than six watery diarrhoea episodes in 24 hours, or if diarrhoea continues for more than 24 hours and is not responding to changes in your diet or diarrhoea medications, it's important to let your oncologist, nurse or GP know immediately. You should also seek medical advice if you have diarrhoea and experience any of the following symptoms:

- fever of 38°C or higher
- moderate to severe abdominal cramping/pain/straining/bloating
- dizziness
- dark (concentrated) urine
- dry mouth
- black stools or blood in stools
- sudden or rapid heartbeat.

As well as losing fluid from your bowel you can also lose salts such as sodium and potassium. You can purchase rehydration fluids such as Gastrolyte over the counter at your pharmacy to replace both the water and salts. You can also purchase medication such as Imodium or Gastro-Stop (loperamide) to control persistent symptoms.

The consequences of uncontrolled treatment-induced diarrhoea can be physically, psychologically and socially devastating. Uncontrolled diarrhoea may lead to dehydration, electrolyte imbalance and kidney problems, so contact your oncology nurse or doctor just to be safe.

Poor appetite

There are many things associated with cancer that can cause you to lose your appetite, including your illness, treatment side effects such as a sore mouth or altered taste, fatigue, constipation, diarrhoea, and feeling anxious, sad or frustrated.

Many of them can be treated, so let your doctor know if you're struggling to eat well, or seek advice from a dietitian. The better you can describe the changes in your appetite, the better your chances of managing the problem. It can help to keep a note of any weight you have lost or gained, when your appetite is better or worse, and whether it's associated with other symptoms such as nausea, constipation or stomach pain.

Simple changes to help improve your appetite

- Try eating small amounts throughout the day rather than sitting down to large meals at set times.
- Explain to friends and family why you're not eating big family meals. Make it clear that this is a positive strategy rather than a sign you're not eating enough.
- Make it easy to eat. Stock up on nourishing foods that are easy to prepare, ask others to prepare food for you, or use healthy, ready-prepared foods when you're too tired to cook.
- Reduce food and cooking smells – turn on a fan or open the windows.
- Where possible, choose nutritious foods you enjoy – but don't force yourself to eat things you don't fancy just because they're 'good for you'.
- Keep a glass of water handy if your mouth is dry but restrict yourself to small sips – too much water may make you feel full. You could also try sucking on small ice cubes.
- Don't rush, and don't force yourself to eat.
- If you're finding it difficult to eat solid food, drink protein and carbohydrate mixes for energy, protein and vitamins.
- Soft foods may be more appealing if your mouth is dry or sore. Try soft, slow-cooked stews and soups, custards and yoghurts.

People who eat a quality, balanced diet don't generally need supplements. However, when you have cancer, problems with appetite may mean your diet isn't as balanced as it could be. Daily multivitamin and mineral supplements might help improve your appetite and your doctor, pharmacist or dietitian will be able to help you find the most appropriate for you.

For more information, see BCNA's *Healthy eating and breast cancer* booklet. Visit bcna.org.au to download a copy. You can also find information in the My Journey online tool. Visit myjourney.org.au.

Weight loss or gain

I lost a lot of weight and was surprised that, when I went for my treatment, the nurses didn't comment on it or offer to help. I eventually saw a dietitian who recommended a particular protein drink for cancer patients, which helped me put some weight back on.

If you feel you aren't able to eat enough to maintain your weight, your doctor may prescribe medication to stimulate your appetite, such as steroids. It's important to remember that food can be a great source of pleasure. Indulging in foods that 'hit the spot' or satisfy a craving can provide a vital psychological lift.

Not everyone with metastatic breast cancer loses weight. Some people gain weight, particularly during chemotherapy treatment. Some drugs used to manage the side effects of chemotherapy can add to weight gain, and some women gain weight because of changes in their metabolism, including those due to menopause brought on by treatment. Others respond to anxiety by eating more, and doing less exercise can also be a factor.

Many chemotherapy regimens include a steroid that reduces nausea but can increase appetite, which leads to weight gain. People taking a steroid may also notice that their face looks more puffy than normal. This will subside when the treatment stops.

Gaining weight can affect you both physically and emotionally, so ask your doctor or a dietitian for help.

Depression

Most people with metastatic breast cancer find their mood can be affected by everything from symptoms and side effects of treatment to anxiety about what the future may hold or issues at home and with relationships. It's quite normal to feel great one day and pretty ordinary the next. But if you find you're low for more than a couple of days at a time, can't enjoy the things you normally would, or feel overwhelmed and unable to move forward, you may be depressed.

Depression is common in people with metastatic breast cancer. Being depressed is not a sign that you're not trying hard enough. There are very effective treatments, including non-pharmaceutical strategies, so talk to your medical oncologist or GP about what could help you.

For more information about depression and its management, see p.158, Section 4: Living well.

Sleeplessness

One of the ironies of metastatic breast cancer is that you might feel exhausted through the day yet find it difficult to sleep at night. There are many physical and psychological reasons for this. If physical symptoms like pain or nausea are interfering with sleep, they can probably be treated, but having a lot on your mind can also keep you awake.

Do what you can to sleep well. Strategies you can try for better sleep include:

- Take a warm bath.
- Have a relaxing massage.
- Drink warm drinks you enjoy such as malted milk, milk with honey or chamomile tea.
- Reduce caffeine intake, preferably to no more than two coffees a day and none after lunch.
- Try to avoid ‘energy’ drinks late at night.
- Have a routine – aim to go to bed at the same time every night and get up at the same time every day.
- Make your bedroom comfortable – make sure your mattress and pillows support your neck and spine and that your room is quiet and dark.
- Avoid using technology such as laptops or phones immediately prior to sleep.
- Deal with barriers to sleep – If you have pain, take some pain relief before going to bed so that it doesn’t wake you.
- Practice relaxation techniques – exercises such as yoga, mindfulness, meditation and tai chi may lessen worry and stress. Slow, deep breathing can also help with relaxation.

If these don’t help, consider talking to your doctor about sleeping tablets. Today’s improved formulations are far less likely to leave you feeling drowsy the following day.

BCNA’s *Sleepless nights* fact sheet includes tips and strategies that may be helpful if you’re having trouble sleeping. It also describes resources and supports that are available. Visit **bcna.org.au** to download a copy.

Hair loss

If metastatic breast cancer is your first diagnosis of breast cancer you'll probably wonder if your treatment will cause you to lose your hair. If you have already experienced hair loss from breast cancer treatment you may dread the thought of losing it again. Hair is part of who you are and losing it can cause you to feel as if you've lost your sense of identity.

You could also feel you have less privacy around your diagnosis – that the whole world can see you're being treated for cancer.

Women from many cultures and backgrounds find that hair loss affects their self-esteem and how they view their bodies and femininity so it's perfectly normal to feel distressed at the thought that your hair might thin or fall out completely. On the other hand, some people are less concerned about hair loss and see it as a sign they're doing something proactive to treat their disease. Everyone is different. If avoiding hair loss is important to you, or you have a special event coming up, talk to your medical oncologist. Some chemotherapy drugs are more likely to cause hair loss than others, particularly the anthracyclines and taxanes, so it may be possible to avoid or reduce that side effect.

Your hair will grow back once you have finished chemotherapy treatment but it may be a different texture and/or colour. Taxane chemotherapies may also cause temporary loss of body hair, including eyebrows, eyelashes and pubic hair. Radiotherapy to the brain can also cause hair loss. Usually it will grow back several months after completing radiotherapy though it may be thinner and have a different texture.

Over the last 17 years I have lost my hair three times. During the winter months I wore beanies around the house and to bed to keep warm. When I wanted to be 'out there', I would wear my football beanie. I found bandanas very comfortable and light, and they come in a great range of colours. I had a wig but found the bandanas and beanies a lot more comfortable.

Use of cold caps

Some oncology day centres offer cold caps (scalp cooling) to prevent or reduce hair loss in people receiving certain types of chemotherapy. Cold liquid circulates through the cap, which is strapped on and remains in place through every chemotherapy session. The cooling effect is thought to work by putting the hair follicles into hibernation and there have been good results for people having the taxane chemotherapy drugs.

However, some people find cold caps uncomfortable. They also lengthen your time in the chemotherapy unit as you need to wear them for a time before and after treatment – and cold caps aren't available at all chemotherapy centres. If you would like to learn more about cold caps and whether they would be suitable for you talk to your medical oncologist or oncology nurse.

ℹ **If hair loss is a concern for you, you might like to read BCNA's *Hair loss during breast cancer treatment* fact sheet. Visit bcna.org.au to download a copy.**

Mouth ulcers

Mouth ulcers can occur with chemotherapy and some targeted therapies such as everolimus. They usually appear five to 10 days after the start of each treatment cycle and clear up within one to two weeks. Good oral hygiene helps to reduce the likelihood, but if they do occur they can be treated with analgesics such as aspirin or paracetamol, by applying a local anaesthetic gel or by using sodium bicarbonate (baking soda) as a mouthwash.

Biotene is a mouth care product line designed specifically for chemotherapy patients. Talk with your pharmacist about whether it might be right for you. Using a soft toothbrush and maintaining good dental hygiene, including regular appointments with your dentist when it's safe to do so can also help avoid complications from mouth ulcers associated with chemotherapy. It could help to suck ice chips or an icy pole during your chemotherapy infusion and for a time afterwards.

Talk to your doctor before using mouth washes containing alcohol, which can aggravate symptoms or temporarily stain your teeth. Sometimes chemotherapy can cause other mouth infections such as cold sores or thrush. Your doctor or pharmacist will be able to recommend some good over-the-counter medication to treat these conditions. If you're prone to cold sores, let your oncologist know before you start treatment.

Nail problems

Fingernails and toenails may be affected by chemotherapy, becoming cracked and discoloured. Sometimes they also become tender. Some treatments, such as the HER2 therapies, can cause the soft tissue around the nail bed to become infected.

You can help to prevent or manage nail changes by:

- using a nail strengthener such as Revitanail
- wearing dark-coloured polish to protect your nails from sunlight
- using nail polish remover that does not contain acetone
- keeping your nails clipped short
- regularly applying moisturising cream to your nails and cuticles
- keeping your hands and nails clean to avoid infection
- wearing protective gloves while you're doing household chores, particularly washing dishes
- avoid infection by using a topical antiseptic cream such as Savlon if your nails split or break.

If these tips don't help and you're feeling distressed by these side effects, talk to your oncology nurse. It may also be worth considering ice gloves during chemotherapy infusions. Otherwise, skin and nail changes generally resolve themselves once you have finished treatment.

Feeling vague: ‘chemo brain’

While being treated with chemotherapy, and/or endocrine therapy, some women feel vague – as if they’re ‘in a fog’ – or find they have memory or concentration problems. This is often referred to as ‘chemo brain’ though, as it’s not clear exactly what causes these problems, this may not be an accurate description.

Doctors prefer to talk about mild cognitive impairment (MCI) or cognitive dysfunction. People with cognitive changes may notice they’re not able to do some things quite as well as before they had cancer.

Some of the symptoms people describe include:

- memory loss and forgetting things you normally remember
- difficulty finding the right word for something
- difficulty following the flow of a conversation
- trouble focusing on or doing more than one thing at a time (multi-tasking)
- difficulty organising things or planning ahead.

Ongoing research is being conducted to improve our understanding of how best to manage the symptoms of cognitive impairment related to chemotherapy.

These strategies might be helpful.

- Any kind of yoga or mindfulness practices such as sitting or walking meditation can help you develop your ability to pay attention, which could lead to better memory retention.
- ‘Brain exercises’ or ‘brain training’ including activities, such as word puzzles or maths quizzes.
- It’s been shown that memory and decision-making improve after mild to moderate physical exercise.
- Carry a notebook with you and write down things that are important to remember. Alternatively use the notes function on your mobile phone.
- Focus on your strengths rather than your weaknesses – do things you know you can do well and don’t be too hard on yourself. Think about stress management techniques that have worked for you in the past.

Sore eyes

The chemotherapy drug 5-FU (5-fluorouracil) can cause sore, gritty eyes. Eye drops can relieve the symptoms but not all over-the-counter preparations are suitable so talk to your oncology nurse first. Wearing sunglasses to protect your eyes from bright light and wind can also help, as can saltwater eye baths.

Taxotere (docetaxel) can cause watery eyes. An ophthalmologist (specialist eye doctor) can treat this effectively so, if this is a problem for you, ask your medical oncologist to arrange an appointment.

Urinary symptoms

Chemotherapy treatments, and cyclophosphamide in particular, can irritate the bladder. Drinking plenty of fluids can help, but let you doctor or oncology nurse know if you have any urinary problems. The anthracycline group of drugs, including Adriamycin, are red in colour and will stain your urine pink/orange for 24-48 hours after each treatment.

Heart problems

The anthracycline group of drugs can affect the muscle in your heart, though this is an uncommon side effect of chemotherapy. The HER2 therapies can also affect your heart function. Your heart may be tested before and during treatment with these drugs. Your oncologist will talk to you more about this.

For more information about cardiac testing during HER2 therapies see BCNA's *HER2-positive metastatic breast cancer* booklet.

Swelling in the arms and legs

Some chemotherapy drugs, particularly docetaxel (Taxotere) and gemcitabine, can cause fluid retention. Swelling is most common in the feet and ankles because of gravity. The steroid premedication taken with docetaxel helps to minimise fluid retention so it's important to take it as prescribed.

Skin changes

Hand-foot syndrome, or palmar plantar syndrome, is associated with a number of chemotherapy drugs. If you experience symptoms such as dryness, itching, pain, swelling, redness or peeling of the skin ask your doctor or nurse for advice. Unperfumed moisturisers may also help. Some drugs make your skin more sensitive to the sun, so it's important to cover up outdoors and use sunscreen.

When you're being treated with radiotherapy the skin may become reddened, dry and itchy. Radiotherapy staff can recommend ways to manage this.

The following suggestions may also help.

- Avoid chemicals that can irritate the skin such as perfumes, deodorants and hairsprays.
- Use the unscented cleansers and moisturisers you can purchase over the counter from most pharmacies.
- Wear sun-protective clothes and sunscreen over the treated area when you're outdoors.
- Avoid damaging the skin in the treated area and keep skin folds dry.

Breathing problems

Being short of breath is frustrating when it limits your activity and it can also be frightening. It's sometimes referred to as dyspnoea (pronounced dis-nee-a).

Breathlessness doesn't necessarily mean the cancer is getting worse. It could be due to a build-up of fluid on the lungs, an infection, blood clots or anaemia, all of which can be treated.

Good pain control is very important. If it hurts to breathe deeply or to cough, you're likely to avoid doing both. This could cause secretions to gather in your chest and restrict your breathing.

In some cases, oxygen may help. Morphine can also be prescribed as it relieves anxiety as well as breathlessness. While it's normal to feel anxious if you're having trouble breathing, the anxiety can actually make the problem worse.

If breathlessness persists, you may find some of the following helpful.

- Try sleeping sitting up, supported by pillows.
- Take things slowly and try to focus on what you can do rather than becoming frustrated and angry about what you can't.
- Open the window or use a fan to create a feeling of air in the room.
- Ask your doctor whether seeing a physiotherapist could help.
- Do what you can to avoid feeling anxious and fearful – relaxation or mindfulness techniques sometimes help.
- Talk to your doctor about trying anti-anxiety or antidepressant medication.

If you have a sudden episode of unresolved breathlessness you can't explain, seek medical advice to rule out the possibility of a blood clot needing urgent medical treatment.

Headaches

Headaches may be mild or severe, occasional or more frequent, and due to a number of causes such as muscular tension, exhaustion, dehydration, hypercalcaemia (high calcium), migraines or the side effects of anti-nausea medication. More rarely, headaches that continue and don't respond to medication could be a symptom of secondaries in the brain, so seek medical advice if you're concerned.

It's best to discuss any headache with your doctor so that they can investigate the cause and suggest treatment options. You may also consider increasing your water intake and using heat packs on your neck to relieve tension. A physiotherapist may be able to suggest exercises or strategies to help you.

Menopausal symptoms

Menopause is the change that occurs in your body when your ovaries stop producing oestrogen. Treatments for metastatic breast cancer can trigger menopause, either temporarily (chemotherapy or hormone-blocking therapies) or permanently (surgical removal of the ovaries).

You may experience one or more side effects of menopause, such as hot flushes and sweats, tiredness, insomnia, vaginal dryness, weight gain, decreased libido, aches and pains and mood swings. Each woman will experience the effects in different ways. If you're already going through menopause at the time of your diagnosis your treatment may intensify the symptoms.

Your doctor can advise you about creams and treatments for vaginal dryness and medication for hot flushes. Regulating your body temperature by having tepid baths, wearing layered cotton clothes and limiting hot drinks and alcohol will also help. Many women find that exercise, meditation and relaxation exercises can be helpful.

If severe menopausal side effects that are affecting your quality of life, talk with your oncologist about medications that might assist you.

ⓘ **BCNA's *Menopause and breast cancer* booklet includes further strategies for managing some of these symptoms.**

ⓘ **For more information on managing menopausal symptoms, see Cancer Australia's *Managing menopausal symptoms after breast cancer – a guide for women*. Visit canceraustralia.gov.au.**

COMPLEMENTARY AND ALTERNATIVE THERAPIES

Conventional therapies, complementary therapies and medicines, and alternative therapies are not the same thing.

Conventional therapies are the standard treatments doctors use to treat cancer: surgery, chemotherapy, radiotherapy and hormone-blocking therapy. Clinical trials have shown these to be effective and safe.

Complementary therapies, such as meditation, yoga, reiki and tai chi are used to enhance conventional treatments and improve wellbeing.

‘Integrative medicine’ is a term sometimes used to describe the combination of complementary therapies and conventional treatments. There’s an increasing amount of research into this area and its impact on people with cancer.

Complementary medicines are products sometimes used in addition to conventional medical treatments to help improve wellbeing. They include vitamin and mineral supplements. While some may be beneficial others can cause unwanted side effects. Always speak with your medical oncologist or oncology nurse if you’re considering any complementary treatments to make sure they won’t interfere with your breast cancer treatment.

Alternative therapies are used instead of conventional treatments – for example, following a special diet instead of taking prescribed medication. Alternative therapies have not been scientifically proven and there’s no credible evidence they’re effective in treating metastatic breast cancer.

For more information about complementary medicines see p.170, Section 4: Living well.

TAKING A BREAK FROM TREATMENT

You may need to be kinder to yourself. If you have more and more treatment, it really knocks the stuffing out of you. Recognise when you need to stop for a break.

Many people will be offered regular cycles of treatment to keep their cancer under control. However, it can be a challenge to balance the side effects with your lifestyle and daily activities, and there may be times when you would like to take a break from treatment. If you have a special occasion coming up, or are planning a trip or holiday, you may want to enjoy yourself without having to manage treatments and their side effects.

At some point you may look for a longer break, especially if you feel that side effects are starting to overwhelm you and are affecting your ability to enjoy life and do the things you want.

Sometimes a break from treatment will allow your body to rest and recuperate. However, if you're considering a break for any reason, it's important to do this in consultation with your medical team. Any decision should be acceptable to you and should allow you to continue to live a life that is meaningful for you.

Making a decision to stop treatment altogether

As long as treatment is working well for you and you're coping with it, it's not unreasonable to have successive lines of treatment. Some people have six, or even more.

However, coping is very individual and, although stopping treatment is a big decision, you should feel free to have this discussion with your medical oncologist, and your family if that is important to you, and make this decision when it feels right for you.

Your oncologist may also suggest this to you if they feel the chance of responding to another line of treatment is remote or your wellbeing is suffering excessively from treatment, or if they consider you're not well enough to receive treatment.

If you reach a point where treatment doesn't seem to be very effective or side effects are more than you feel you can manage, you may decide not to have further treatment and focus instead on supportive care measures to help you to live well.

Best practice in metastatic breast cancer

The *Cancer Australia statement- Influencing best practice in metastatic breast cancer* highlights 10 key appropriate and inappropriate practices as priority areas in metastatic breast cancer treatment and care.

Practice 6 states it's ‘not appropriate to use chemotherapy in patients with metastatic breast cancer who are unlikely to benefit, such as those who have received multiple lines of prior therapy for advanced disease, and with low performance status (3 or 4) or at high risk of toxicity.

More information about the statement can be found at thestatement.canceraustralia.gov.au/metastatic.

MEDICAL EMERGENCIES

From time to time, people with metastatic breast cancer develop new or persistent symptoms requiring urgent medical attention.

It's important you know who to contact if you need urgent help and have a plan in place to manage this situation. The plan will depend on whether you're being treated in the public or private system and whether you live in a rural, regional or metropolitan area. It's a good idea to have this conversation with your medical oncologist and GP early in the course of your illness and develop the plan together.

You should also have a Plan B and even a Plan C in case your main contact isn't available. Let your partner, friend or another caregiver know your plans.

There are two conditions in particular associated with metastatic breast cancer that may require urgent medical attention:

- febrile neutropenia
- spinal cord compression.

Febrile neutropenia

Some chemotherapy drugs cause neutropenia – a low white blood cell count – which typically develops seven to 14 days after treatment. This means your immune system is compromised and you're at risk of developing a potentially life-threatening bacterial infection or sepsis. If, while you're being treated with chemotherapy, you develop symptoms or signs of infection or a temperature of more than 38°C, you need urgent medical attention. You will need to be assessed and have your white cell count checked, and you may require hospital admission for intravenous antibiotics.

Spinal cord compression

If cancer has spread to the bones in your spine the cancer cells can cause spinal cord compression by pressing on the spinal cord and nerves. This is very uncommon.

The symptoms include

- having difficulty walking or feeling your legs are giving way, and/or
- problems passing urine, such as difficulty controlling your bladder or passing very little or no urine at all.

While this is a very serious situation, early treatment can be very effective.

For more information on spinal cord compression, refer to the BCNA *Metastatic breast cancer in the bone* booklet.

QUESTIONS YOU MIGHT LIKE TO ASK ABOUT YOUR TREATMENT

- What is the recommended treatment for me and why?
- Will my treatment and care be discussed at a multi-disciplinary (MDT) meeting?
- What do you expect the recommended treatment to do?
- What are the side effects of the treatment/s you're recommending?
- Who should I contact if side effects occur?
- Can I access a clinical trial?
- How and when will we know if the treatment is working?
- What are my options if this treatment doesn't work?
- How do I access palliative care support if I need it for myself or my family?

RESOURCES

Breast Cancer Network Australia (BCNA)

bcna.org.au or phone **1800 500 258**

In addition to *Hope & Hurdles*, BCNA has a number of treatment-related booklets for people diagnosed with metastatic breast cancer. You can download the booklets from the BCNA website or, for the most up-to-date information, sign up to the My Journey online tool.
Visit **myjourney.org.au**.

- *HER2-positive metastatic breast cancer*
- *Hormone receptor positive metastatic breast cancer*
- *Triple negative metastatic breast cancer*
- *Metastatic breast cancer in the bone*
- *Metastatic breast cancer in the liver*
- *Metastatic breast cancer in the lung*
- *Metastatic breast cancer in the brain*
- *Planning ahead*

BCNA's online network

Australia
bcna.org.au

BCNA's online network is a good place to go if you think that talking about your thoughts and feelings online with others in a similar situation will help. There's an active, public discussion area for anyone affected by metastatic breast cancer. There's also a private group exclusively for people with metastatic breast cancer where only members of the group can read the discussions. If you need help to access the private group, phone BCNA for support.

Cancer Australia

canceraustralia.gov.au

Cancer Australia, established by the Australian Government, aims to reduce the impact of cancer. The Cancer Australia website provides comprehensive information, guidelines and recommendations for the treatment of women diagnosed with metastatic breast cancer (search for 'metastatic'breast cancer).

Cancer Council

cancer.org.au

Cancer Council provides a range of brochures, booklets and fact sheets related to metastatic breast cancer treatment. Call 13 11 20 to speak to specially trained staff who can answer your questions about cancer and offer emotional or practical support.

Aussie Breast Cancer Forum

bcaus.org.au

This website is designed for those affected by breast cancer and for their family, friends, carers and loved ones to discuss concerns and ask questions online. It has a separate section for those wanting to share with others living with metastatic breast cancer.

Group for Women with Advanced Breast Cancer

advancedbreastcancergroup.org

This website features online forums for women living with metastatic breast cancer throughout Queensland, their partners, family members and friends.

Breast Cancer Now

UK
breastcancernow.org

The website has a wide range of information on metastatic breast cancer, including a chat room for people with metastatic breast cancer.

BreastCancer.org

USA
breastcancer.org

This USA-based website has an extensive range of information about breast cancer, including a section on recurrent and metastatic breast cancer, with discussion boards and chat rooms where people share their experiences of metastatic breast cancer. It has input from women and health professionals. Australian women are able to participate.

ABC Global Alliance

abcglobalalliance.org

An international organisation whose goal is to improve the lives of people living with metastatic breast cancer. It plays an important advocacy role.

BC Mets – Metastatic Breast Cancer Information and Support

USA
bcmets.org

Online forums for women with metastatic breast cancer are part of this website. Their ‘book of knowledge’ is a compilation of information based on women’s experiences over the years.

Living Beyond Breast Cancer

USA
lbbc.org

This website has an advanced breast cancer section with information about treatment and clinical trials and frequently asked questions. Australian women can join a message board for women with metastatic breast cancer.

American Society of Clinical Oncology

USA
asco.org

The American Society of Clinical Oncology is a world-leading professional organisation for physicians and oncology professionals caring for people with cancer.

Choosing your treatment team

Find a specialist

Australia

cancer.org.au

Cancer Council Australia's website has a directory that can help with finding a doctor who specialises in a particular field of cancer or cancer treatment.

Clinical trials

Australian Cancer Trials

australiancancertrials.gov.au

This Australian Government website has information on the latest clinical trials in cancer care, including trials that are currently recruiting new participants. It's updated daily.

Australia and New Zealand Breast Cancer Trials Group

anzbctg.org

Many Australian clinical trials for breast cancer are coordinated through this group.

Breast Cancer Trials

breastcancertrials.org.au

Breast cancer trials explore and find better treatments through clinical trials research.

Cancer Council

Phone **13 11 20**

Cancer Council can provide further information about clinical trials.

Complementary and alternative therapies

Medicines Line

Australia
nps.org.au or **mydr.com.au**

Phone **1300 633 424** (cost of a local call) to speak to a pharmacist
Monday – Friday 9am – 5pm

Medicines Line provides independent information about prescriptions, over-the-counter and complementary medicines.

National Centre for Complementary and Integrative Health

USA
nccih.nih.gov

This is the website of the US agency that conducts scientific research on the diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. It provides information about complementary and alternative medicines, including information about specific drugs, alerts and research.

Memorial Sloan-Kettering Cancer Centre: About Herbs, Botanicals and Other Products

USA
mskcc.org

This website provides evidence-based information about herbs, botanicals, vitamins and other supplements, including information about effects, side effects, drug interactions and other details of each product listed, as well as links to scientific research.

Dr Stephen Barrett’s Quackwatch

USA
quackwatch.com

Quackwatch’s purpose is to combat health-related frauds, myths, fads, fallacies, and misconduct. It includes information on unproven remedies.

Lymphoedema

Lymphoedema fact sheet

BCNA
bcna.org.au or phone **1800 500 258**

This fact sheet provides information about lymphoedema, including tips to reduce your risk of developing lymphoedema, managing symptoms, travelling with lymphoedema, and state- based subsidies available for compression garments.

National Lymphoedema Practitioners Register

Australia and New Zealand
Australasian Lymphology Association (ALA)
lymphoedema.org.au

The ALA National Lymphoedema Practitioners Register is maintained by the Australasian Lymphology Associate. It's a public register of lymphoedema practitioners in Australia and New Zealand.

The Lymphoedema Handbook: Causes, Effects and Management

Australia
Lymphoedema Association of Victoria
lav.org.au or phone **1300 852 850** or email **info@lav.org.au**

This book explains the lymphatic system and how and why lymphoedema occurs, and has information about signs, symptoms and approaches to managing the condition.

Pain

Overcoming Cancer Pain

Cancer Council
cancer.org.au or phone **13 11 20**

This free booklet explains treatment for pain caused by cancer and provides strategies for helping to manage pain.

Call **13 11 20** to request a free copy or download a PDF from your local Cancer Council website.

Pain Australia

Australia
painaustralia.org.au

The Pain Australia website includes strategies for managing pain and where to go to get help for pain. It also has a state-by-state list of pain management clinics across Australia

Palliative Care

Palliative Care Australia

palliativecare.org.au or phone **(02) 6232 0700**

Palliative Care Australia is the national peak body for palliative care in Australia. The website provides information useful for those diagnosed with metastatic breast cancer, carers and health professionals.

Finding the words – starting a conversation when your cancer has progressed

Australia 2016
Cancer Australia
Download from Cancer Australia **canceraustralia.gov.au**

This resource has been developed to help people with metastatic cancer talk about how palliative care might help them to live as well as possible when cancer has spread.

Hair loss

Cancer Council

Phone **13 11 20**

Cancer Council staff can help with information on looking after your hair and scalp, and adjusting to changes in your appearance. Cancer Council may also have information about local wig suppliers and headwear.

Hair loss fact sheet

Breast Cancer Network Australia
bcna.org.au or phone **1800 500 258**

This fact sheet has been developed with input from women who have experienced hair loss from cancer treatment. It explains how to prepare yourself for hair loss or hair thinning, steps you can take to reduce its impact, and supports and services that can help.

Look Good … Feel Better

Australia
lgfb.org.au or phone **1800 650 960**

Look Good … Feel Better is a free community service program dedicated to helping women undergoing treatment for cancer. The purpose of the program is to help them manage the appearance-related side effects of chemotherapy and radiotherapy, thereby helping to restore their appearance and self-image.

Fatigue

Cancer Council

Phone **13 11 20**

Cancer Council staff can provide information about fatigue, including suggestions for conserving your energy.

Depression

BCNA Helpline

bcna.org.au or phone 1**800 500 258**

BCNA's Helpline team includes experienced cancer nurses who can talk to you about a range of reactions and emotions you may experience as a result of your metastatic cancer diagnosis. They can also refer you to ongoing support with a mental health practitioner if needed.

Anxiety, depression and breast cancer fact sheet

BCNA
bcna.org.au or phone **1800 500 258**

The *Anxiety, depression and breast cancer* fact sheet, developed by BCNA and beyondblue, explains the links between anxiety, depression and breast cancer, the signs and symptoms of anxiety and depression, current treatments and how to help yourself or someone close to you.

Lifeline Australia

Phone **13 11 14** for 24-hour telephone counselling or visit **lifeline.org.au** for information

For immediate support if you're in crisis, call Lifeline on 13 11 14. The Lifeline website also has a 'service finder' directory where you can search for free or low-cost services in your local area.

beyondblue

beyondblue.org.au or phone **1300 224 636**

Beyondblue is Australia's national depression initiative, providing information about depression and anxiety disorders and their treatments. beyondblue provides 24-hour telephone support with a trained mental health professional and also provides online support 3.00 pm to 12.00 am seven days per week.

Health Direct

healthdirect.gov.au/australian-health-services

Health Direct's National Health Services Directory is a comprehensive online directory of health services including general practice, allied health and hospital services.

Menopause

Breast Cancer Network Australia (BCNA)

bcna.org.au or phone **1800 500 258**

In addition to *Hope & Hurdles*, BCNA has a number of general information booklets that may help with managing menopause- related symptoms:

- *Menopause and breast cancer* booklet – more detailed information and advice about menopause and breast cancer.
- *Bone health and breast cancer* fact sheet – information about how to maintain your bone health during and after treatment.
- *Sleepless nights: breast cancer and sleep* fact sheet – information about sleep, tips and strategies that may help and resources and available supports.

Cancer Australia

canceraustralia.gov.au or phone **1800 624 973**

Cancer Australia's booklet *Managing menopausal symptoms after breast cancer – a guide for women* provides more information on managing the side effects of breast cancer treatment. It's available to download from **canceraustralia.gov.au**.

Jean Hailes for Women’s Health

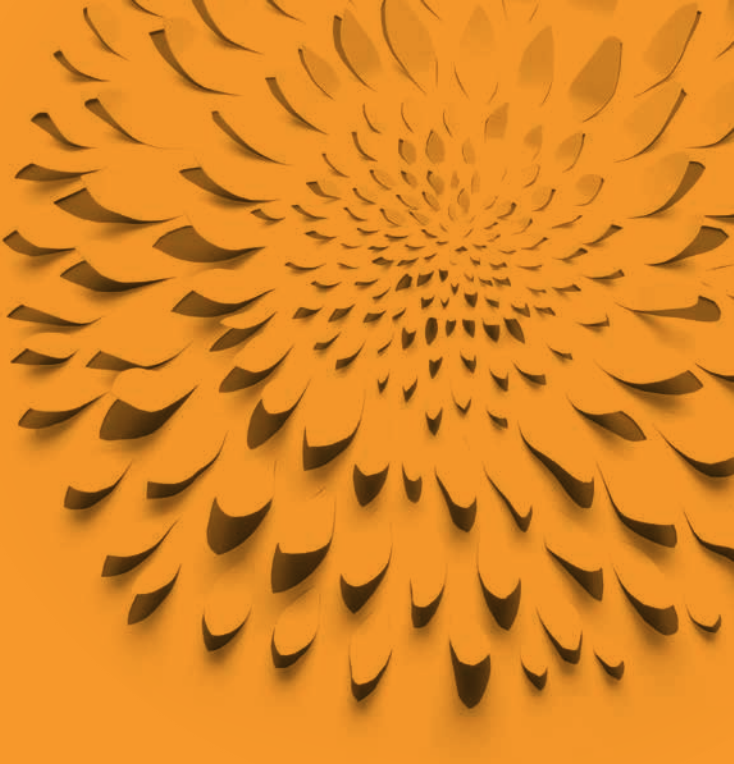
jeanhailes.org.au or phone **1800 532 642**

Jean Hailes for Women’s Health is a not-for-profit organisation dedicated to the physical and emotional wellbeing of women across Australia. Jean Hailes produces fact sheets and written advice on its website about menopause, bone health, sleep, vitamin D, nutrition for women, and more.

MSAC (Menopause Symptoms after Cancer) clinic

Victoria: **thewomens.org.au**, WA: **wnhs.health.wa.gov.au/services/menopause/msac.htm** or phone: **08 6458 1355**

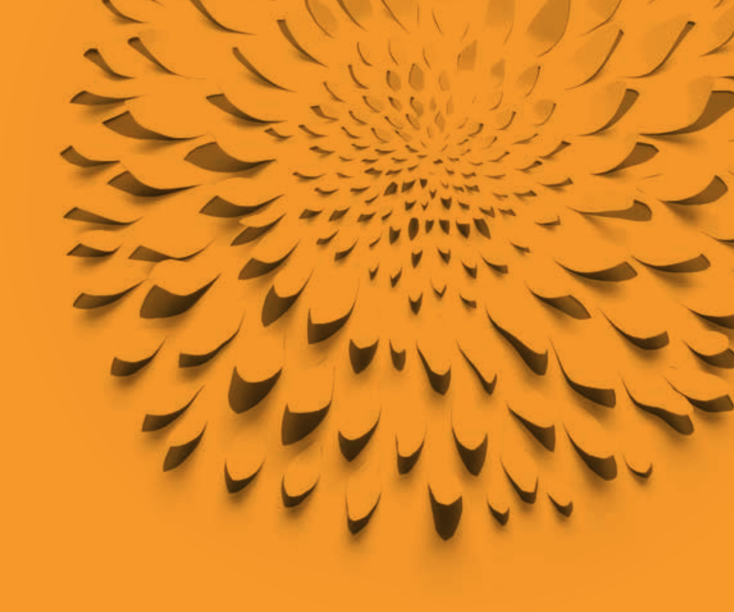
The MSAC clinic in Victoria is located at the Royal Women’s Hospital and in WA at the King Edward Hospital. The MSAC clinics provide evidence-based advice and support by a team of specialists for women with menopausal symptoms and a history of cancer (including metastatic cancer).



SECTION 4

LIVING WELL

Instead of looking narrowly, the shutters came off and I gave myself permission to live. I had prepared myself for dying, so I knew how to die with the disease but I didn't know how to live. Bonuses and things that I didn't plan for have come out of my experience of living with metastatic disease.



SECTION OVERVIEW

This section provides information to help you to live well with metastatic breast cancer, including:

- managing relationships with partners and others
- talking with family and children
- talking with friends and work colleagues
- caring for yourself emotionally
- caring for yourself physically
- questions you might like to ask about living well.

I live with metastatic breast cancer, but I don't let it control my life. Be kind to yourself. You're not to blame. It was just bad bloody luck. None of us would ever choose breast cancer – but we can choose how we allow it to impact our lives and the journey we take.

Life after a diagnosis of metastatic breast cancer is different for everyone. No two people's circumstances are the same. You may have the desire, opportunity and resources to make big changes in your life. Or you may find it comforting to have your day-to-day life continue much as before. But it's not unusual if you find yourself thinking about what it means to deal with more uncertainty in your life.

Many people feel that uncertainty is the most difficult aspect of the illness to manage. Some cope best by living in the present and not thinking too much about the future. Others find that planning ahead gives them more sense of control. The only right approach is the one that works best for you.

There's more to life than cancer – initially I felt as if I was in shock, later I experienced grief and loss. I have moved from that stage. Now my diagnosis is part of my life. Treatment is part of my life. To date it has not been so bad.

Other changes may be thrust upon you — for instance, if fatigue or pain limits your mobility and independence. In this case you're bound to feel frustrated and upset sometimes, but simple changes to your environment, your routine and perhaps even your attitude to your illness can help you to make the most of the pleasures available to you.

Many people find that how they feel physically and emotionally goes in cycles. You may find it easier to cope by 'going with the flow' — making the most of the good days and allowing yourself to rest and enjoy less demanding activities on the not-so-good days.

I found it was important to get on and enjoy life. I now celebrate what I have and have moved on and learnt to live with the disease, so I'm not consumed by it.

THE PEOPLE IN YOUR LIFE

Metastatic breast cancer has a powerful emotional impact on you, and also on your family and friends. It might be difficult for you to talk to the people around you about your diagnosis and treatment. It can be difficult to explain what metastatic breast cancer is, and it can also be hard to deal with the emotional responses of others during this time.

Family and friends sometimes respond in unusual ways. You may not always get the response you hoped for when you tell friends you have metastatic breast cancer. Some people may not know what to say or feel afraid of upsetting you. They may not know how you're feeling or whether you want to discuss it. Try to tell them how you feel and what you need from them. Most people find that speaking openly about their situation helps their relationships during this time.

SINGLE OR DATING

If you're single, you may not have one person you turn to in times of need. Instead, the main person supporting you might be a friend or family member. It's tempting to avoid asking close friends or, if you have them, your children for assistance as you don't want to feel a burden or to disrupt their lives. Think of it instead as a positive way that you can help others to help you and show their love for you.

Remember, too, that allowing others to help means that you can keep your emotional and physical reserves for things that matter and give you pleasure.

After your diagnosis, you may find some people in your life don't provide the support and understanding you need. They might start to avoid you, or say things that are well-meaning but unhelpful. Don't feel that you have to maintain all these friendships. Concentrate your energy on being with the people who you love the most and who are there for you.

Dating

Dating or starting a new relationship can be daunting at any time. Since your diagnosis, you might also be worried about how your illness will affect your future relationships. You may have a lot of questions and worries on your mind, such as:

- when is the right time to tell a new partner about your diagnosis?
- how do I start the conversation?
- how do I look forward to a bright future when there's a lot more uncertainty for me?

The answers to these questions are different for each person. A counsellor or psychologist may be able to work through these issues with you and help you to clarify your goals and values. They can also help you to find the right words to have some of these conversations.

PARTNERS

Living with a life-threatening illness is a big stress and it's also a big stress for the person who lives with you.

Being the partner of someone with metastatic breast cancer brings unique and often complex challenges. The nature of every relationship is different – some couples have been together for many years, others only briefly. Your partner's age, personality and past experiences will shape their reactions, as will any pre-existing tensions between the two of you.

The needs of partners can vary. Research has shown that partners can feel as overwhelmed or depressed as the person with cancer, and experience similar levels of anxiety or depression. While the person with cancer has a treating team for support, partners sometimes say they feel like passive bystanders, which can leave them feeling helpless and not in control.

Your partner may also find themselves acting in the role of carer, taking on additional responsibilities to ensure you feel supported. This may not be something they have experienced before or feel comfortable with Finding time to talk about how you're both feeling can help. Partners can sometimes also benefit from professional support or going to a support group.

Whatever the nature of your relationship, at least some of the following will most likely apply to your partner:

- feeling helpless and uncertain about how to respond to your needs
- feeling isolated
- finding it hard to express their own grief and frustration about the situation (including thoughts like, 'They're the one with cancer, I have to hold it together.')
- feeling fearful about what the future holds but being apprehensive about expressing these fears in the mistaken belief that they have to be strong and protect you from distress
- feeling that talking about the situation will be too painful.

If you have young children, your partner may also worry about being left alone to raise them.

BCNA's booklet *When someone close to you has metastatic breast cancer* has been written to help partners, family, friends and colleagues understand your needs. To download a copy visit bcna.org.au.

Relationships Australia provides relationship support services including counselling and education programs. For more information, visit relationships.org.au or phone 1300 364 277.

Lesbian, gay, bisexual, transgender, intersex and queer/questioning (LGBTIQ) couples

LGBTIQ couples have unique needs and concerns in addition to the common concerns all couples experience when dealing with a metastatic breast cancer diagnosis.

These can include whether or not to tell members of their medical team about their sexuality, worry about whether they may be discriminated against, and concerns about finding the support they need.

LGBTIQ couples may also worry that health professionals and health systems won't recognise them as a couple and so important decisions will be made without the involvement of them both.

Though much has changed in health systems over recent times, it's important you find a medical team that supports your needs. The Australian Lesbian Medical Association (ALMA) has set up DocLIST, a website listing doctors and mental health professionals recommended by women within the LGBTQI community as capable of providing a safe and comfortable healthcare experience. Visit the ALMA website **almas.org.au** to search the list. If you're looking for further support, you might like to consider the following resources.

- You can ask your breast care nurse if they know of any useful sources of information and support in the local community.
- Your state or territory Cancer Council (**13 11 20**) may know of counsellors or support groups who will be sensitive to your needs. Cancer Council's Cancer Connect program may be able to connect you with other couples in a similar situation who have experienced breast cancer.
- The National LGBTI Health Alliance provides information on organisations and individuals who provide health-related programs and services focused on LGBTI and other sexuality, gender and bodily diverse people and communities. Visit the National LGBTI Health Alliance website or call **(02) 8568 1123**.
- Qlife is a national counselling and referral service for people of diverse sex, genders and sexualities. Qlife provides an online chat (3.00 pm – 12.00 am daily) or you can call **1800 184 527**. For more information, visit the Qlife website.
- ACON is a NSW-based organisation that promotes health and wellbeing of members of the gay, lesbian, bisexual and transgender community. ACON provides support to women with cancer who are in same-sex partnerships. For more information visit the ACON website or call **1800 063 060**.

- Living Proud Inc (formerly Gay & Lesbian Community Services of WA Inc) provides support, information and resources to the Western Australian gay, lesbian, bisexual, transgender and intersex community, including a peer counselling phone line, and health and wellbeing initiatives. For more information, visit the Living Proud website, or call **(08) 9486 9855**.
- If you feel that you and your partner would benefit from talking through your issues with a professional, you can speak to your GP and ask to be referred to a relationship counsellor, or you can contact Relationships Australia on **1300 364 277** for support. Your GP can also refer you to a psychologist or psychiatrist through a Mental Health Treatment Plan and you will be eligible for a Medicare rebate for counselling sessions.
- Cancer Australia provides information for partners of people diagnosed with breast cancer. Visit **canceraustralia.gov.au**. The beyondblue website has information, resources and support services on depression and anxiety, and where to get help specifically for LGBTIQ communities. Visit **beyondblue.org.au**.

Things you can do to help your partner

- Be open and honest in communication, even if it’s difficult. Trying to keep strong feelings to yourself is hard work, and sharing them can feel liberating.
- Set time aside each day to talk openly to your partner about how things are going and how you’re both coping with the change in your roles.
- Opening up the discussion allows you and your partner to share a real closeness rather than using energy to keep a lid on things.
- Tell your partner how you’re feeling – don’t expect them to know.
- Let your partner know what you’ll find helpful. You might want them to just listen, rather than give answers or try to fix things.
- Recognise that your partner needs some space too. Being together 24/7 isn’t ideal for even the most loving of couples; having some personal time will help your partner to support you better.
- Encourage your partner to think about his or her own needs and seek counselling if they are finding things tough.

For more information on counselling, see p.161. Your GP can also refer you to ongoing support with a mental health practitioner if needed.

Intimacy and sex

I think the deep sense of loss and grief at the change in my sexual life needed to be mourned and acknowledged – not just the change in sexual wellbeing but the change in how I view my body and my loss of trust in my body.

Intimacy can be fundamental to your sense of self, and sexual confidence can be linked to your overall feeling of wellbeing. When you have metastatic breast cancer you might feel unwell, anxious and insecure about your appearance You may also face intimacy and sexual problems due to tiredness, a lowered libido, pain, vaginal dryness or physical restrictions. Little wonder if you find your feelings around your sexuality have changed!

If you feel you've lost interest in sex, remember that sex isn't only about intercourse. You and your partner can continue an intimate closeness through stroking and cuddling. Some partners express their love through massage – few people lose the ability to experience pleasure through touch.

It may not be easy, but it's more important than ever to speak plainly and openly with your partner at this time. It's the best chance you have of getting your needs met, and avoiding painful misunderstandings. It's also easy to get caught up in the routine of treatment, especially if the stresses of family life or work life continue. Spending time as a couple – such as having a coffee together or a weekend away – can give you both time to unwind and connect. Some couples find it helpful to talk to a counsellor to identify strategies to build emotional and physical intimacy. Others find it beneficial to talk to their GP or to join a support group.

BCNA's *Breast cancer and sexual wellbeing* booklet includes strategies that can help you manage a range of sexual wellbeing issues, including building emotional and physical intimacy with your partner. To download a copy visit bcna.org.au

FAMILY AND CHILDREN

Tell your family as much as they will be able to deal with. Explain that it means you might not always be bright and bouncy but you're going to handle any changes and challenges that come your way with their help and understanding.

Whenever I have a tiff with my children or my husband I have to remind myself that most arguments come from the fact that we are all frightened and we are all living under the most incredible stress.

Talking about metastatic breast cancer isn't easy, but good communication can help to hold relationships together. Your family may have no idea of what to say to you, and whether you want to discuss your illness or not. For people who have lost loved ones, your experience may bring up sadness or anxiety for them.

Some people write down the things they want to say to each person they care about, or that they want each person to know. They then arrange specific meetings when everything will get said.

If you have children or grandchildren, you will undoubtedly worry about how they will understand and accept your diagnosis. Information should be adapted to the age and maturity of the child. There are many different resources available to help in communicating with children and teenagers about what's going on or what might happen in the future.

For information about talking to young children and teenagers, see p.219, Section 6: Young women.

If there's some conflict between people you love, or open communication has never been easy within your family, a breast care nurse, pastoral care worker, social worker or counsellor may be able to help you get your messages across.

FRIENDS AND COLLEAGUES

I alienated myself from friends at first, because I didn't want to see that look of pity on their faces or listen to people not knowing what to say to me. This only lasted a couple of weeks, as I realised I needed support and my family needed support too.

It can be hard to talk to friends or colleagues about your diagnosis and treatment. Often it's best to just be upfront and let people know how you would like them to treat you. You may welcome their questions about how you're going, or you may prefer not to discuss your health. It might help to establish early on that it's okay to cry. Whatever your choice, it helps for people to know.

While people generally mean well, they can sometimes offer unrealistic or unhelpful opinions, ideas and suggestions, such as information about the latest treatment or cure. This can be frustrating and, sometimes, even distressing. People might offer advice on how you should or shouldn't live your life, such as suggesting dramatic changes to diet and lifestyle. The constant message from others to 'be positive' can be unhelpful and annoying.

There is a lot of pressure for me to stay positive and upbeat and on the days when I'm not like that I tend to not go out. When people ask me how I am, I start talking about my treatment and people just glaze over and that's fair enough. I don't have a problem with that but when people ask how you are, you think, do they really want to know or are they just being polite?

You may find that after a diagnosis, some friendships don't provide the level of support and understanding that you need. Concentrate your energy on being with friends who are there for you.

Don't listen to any negative stories from friends or relations who 'know someone' who has the same. No two people are the same. Every one of us is an individual. Just concentrate on you. Your cancer and therefore your treatment are just for you.

Friends or colleagues of people with metastatic breast cancer can phone BCNA 1800 500 258 to find information, talk to experienced cancer nurses about how they're feeling and discuss support that may be available.

Dear family and friends,

I thought it was hard for you when I was first diagnosed at age 29 with metastatic breast cancer but I was in too much shock/turmoil to really take in what you were going through. I had hit a brick wall with being told 'Yes it's breast cancer' but then each individual brick came crashing down on me one at a time days later when I received the report that 'Yes it has already spread'. I thank you for your ability to guide me in your own individual way. For some it was to do my ironing, others to take my three-year-old for a while, to really listen then ask questions so that together we could fathom out this new medical world we were thrust into. It was only later that I realised just how hard it is and how much it affects you too. Thank you for your patience, the chats, the reminiscences, cuppas, tears, laughs and hugs when I needed them. I thank you all for your individual support on this journey.

– Meg

CARING FOR YOU

Having metastatic breast cancer poses lots of challenges. Coping with symptoms, making choices about treatments and having ongoing tests and scans can feel all-consuming at times. It can be tempting to focus on the physical side of things and try to keep a lid on feelings. If you get pressure from others to be positive, or comments about how well you look, it makes it even harder to admit that having metastatic breast cancer can be emotionally exhausting.

No two people with metastatic breast cancer are the same. For each person, the meaning is shaped by who we are, our journeys up until now, our supports and a myriad of other things such as having young children or financial strain. Every person will handle their situation differently. There is no rule for how to handle emotions. You need to listen to what your heart says is right for you – and, of course, that can change over time.

EMOTIONS AND COPING

I give space to my emotions. It's impossible to be positive all the time. When I'm feeling low I cry … I usually find after a great big cry that I feel so much better

There's only so much you can talk about with friends and family — you don't want to overburden them. It was a relief to see a psychologist — I really appreciated her honesty.

For most people with metastatic breast cancer, being able to talk about emotions is helpful. Sometimes, talking to family members and friends is the most important way of handling feelings. But the downside of this is that you can't always share the dark thoughts or talk about 'what if?'. This may be partly because you don't want to upset them and partly because they might give you unwanted advice.

Talking to someone outside your circle of close friends and family can be a great relief. You don't have to protect trained counsellors from things that are worrying you. They won't criticise or trivialise your concerns.

Spirituality

Spirituality typically involves a search for meaning in life. For many people, facing their mortality reinforces their existing beliefs about life and its meaning. For others, it's a time to rethink current beliefs or even to engage deeply for the first time with some of these matters.

Spirituality can provide a means of support for many people as they live with the realities of a life-limiting cancer diagnosis. It can help people make sense of their lives and the challenges of living with metastatic breast cancer. Benefits may also include reducing stress and anxiety and the development of inner resources to manage uncertainties and fear. It can also help people to live their life fully with a more positive sense of well-being.

Spirituality is not necessarily about being religious, although some people may associate their religion or their faith with spirituality. Sometimes it can be hard to talk to family members, but there are many other people you can speak to. If you're interested in exploring spirituality further, ask to talk to a pastoral care worker at your local health service or palliative care service, or ask a member of your treatment team for a referral.

Anxiety and depression

Most people with metastatic breast cancer find their mood can be affected by everything from trying to manage symptoms and side effects of treatment to anxiety about what the future may hold, issues at home and maintaining relationships. It's quite normal to feel great one day and emotionally flat the next.

Your diagnosis may also result in a range of emotions including stress, sadness, fear and anger. If you're feeling these emotions intensely and for long stretches of time, you may be experiencing anxiety or depression. Anxiety and depression are common for people with metastatic breast cancer.

Anxiety is more than just feeling stressed or worried, which is normal in a stressful situation. The anxious feelings may be stronger or continue after the event has passed, making it hard to cope with everyday life.

Some common symptoms of anxiety include:

- racing heart
- tightening of the chest
- snowballing worries
- focusing on worry and not being able to distract yourself
- difficulty with sleeping
- feeling jumpy, restless or shaky.

Depression is more than just a low mood – it's a serious condition that has an impact on both your physical and emotional wellbeing.

Some common symptoms of depression include:

- being preoccupied by negative thoughts
- feeling low for most of the day, every day
- feeling guilty or worthless, or a burden to your family
- withdrawing from close family and friends
- losing interest in work, hobbies and things you usually enjoy
- feeling anxious or irritable or finding it hard to concentrate
- changes in appetite with significant weight loss or gain
- feeling overwhelmed, indecisive and lacking in confidence
- increased use of alcohol and/or drugs
- trouble getting to sleep or staying asleep and feeling tired during the day.

When you have metastatic breast cancer, there can be many changes to your life that may make you feel stressed or anxious or may lead to depression. These include:

- coming to terms with the diagnosis
- wondering ‘why me?’
- dealing with uncertainty
- dealing with tiredness, pain and other side effects of treatment
- dealing with practicalities such as family, work and financial adjustments
- dealing with the responses of your partner, children, family and friends to your diagnosis.

Where to get help

Anxiety and depression are treatable, and the earlier you seek help the quicker you’re likely to recover. If you’re feeling anxious, or think you may have depression, talk to your GP right away.

Some GPs have specialist training and can provide psychological treatment. If not, your GP can refer you to a specialist such as a clinical psychologist, social worker, counsellor or psychiatrist. Talk to your doctor about whether you’re eligible for treatment under a GP mental health treatment plan that entitles you to up to 10 Medicare-subsidised appointments each year.

For further details about GP management plans or team care arrangements, talk to your GP or visit the Department of Health website at **health.gov.au**.

BCNA also has a number of fact sheets that may be useful.

- *Anxiety, depression and breast cancer*, developed by BCNA and beyondblue, outlines the signs and symptoms of anxiety and depression and ways to manage them.
- *Chronic disease management plan*, which provides information about GP management plans and team care arrangements, including possible costs of allied health services and how they can be arranged.
- *GP mental health treatment plan*, which outlines the benefits of a mental health treatment plan that provides access to Medicare-funded counselling services and how one can be arranged.

ℹ **Fact sheets can be downloaded from the BCNA website bcna.org.au**

Other things that might help.

- Spend time with people who make you feel good.
- Relax and do things you enjoy such as reading, listening to music or spending time in the garden.
- Say no to invitations or activities you don't feel up to.
- Limit your alcohol intake – alcohol acts as a natural depressant.
- Try to exercise regularly. Regular exercise, such as walking, has been found to be helpful in preventing and treating mild and moderate depression.
- Join BCNA's online network, or a face-to-face or telephone breast cancer support group, where you can talk to other people whose experiences are similar to yours.
- Relaxation or meditation can help to keep your emotions in balance.
- Consider treating yourself regularly to things that give you joy, such as facials, manicures or visits to the cinema or galleries.

For more information on both anxiety and depression, go to the beyondblue website beyondblue.org.au.

Counselling

Counselling has saved me. At my lowest points, talking with someone who is objective and independent has helped me to work through my thoughts and emotions and put in place strategies that allow me to live each day with joy.

The term 'counsellor' is a broad one and can include your GP, a psychologist, psychiatrist, social worker or other trained therapist. You don't need to be depressed or suffering from extreme anxiety to benefit from seeing a counsellor. You might find that seeing your GP from time to time works best for you, or you might see a psychologist, oncology social worker or psychiatrist who specialises in oncology support.

What counselling offers

This really depends on what you need. You could learn relaxation techniques that help you cope with anxiety, or strategies for dealing with unhelpful or troubling thoughts. You could get help with talking to your children or partner. If you and your partner have counselling together, it could help you with issues that affect you as a couple. At its most basic, counselling is a chance to be heard, and to feel valued and supported without being judged. It can also be a huge relief to let go of the pretence that you're in control, and counselling can help you to deal with anger and fears or concerns about the future. It can also help if you're depressed, although you may also benefit from taking medication.

Some people use counselling sessions to talk about other issues, such as a difficult relationship. It's natural that you will feel more at ease with one counsellor than another. If you're not comfortable, consider seeing someone different. It's important to feel that you can work together as a team.

Many people also tell us it's important to see a counsellor who is experienced in working with cancer. They find it's easier to talk with someone who understands the specific complexities associated with living with metastatic cancer. They can also understand the experiences and reactions of family and friends.

Telephone counselling can work well for people who find the thought of a face-to-face counselling session intimidating.

It's also particularly helpful for people who live rurally or remotely who may not have access to local services. Telephone counselling can be provided by your mental health practitioner if you have one. The Cancer Council in your state may also offer a telephone counselling service, or you can contact general telephone counselling services such as those provided by beyondblue or Lifeline.

More information about the 'Better Access to Mental Health Care' initiative that provides subsidised access to mental health support is available from health.gov.au.

Counselling resources and services

- Some hospitals have specific pyscho-oncology counsellors who work closely with the other oncology health professionals. Ask your oncologist or nurse if this service is available to you.
- You may be eligible for a GP mental health treatment plan – see p.195. If you're still working, your employer may also provide a small number of free confidential counselling sessions through an employee assistance program.
- BCNA's trained Helpline officers and cancer nurses are available to listen to your concerns and provide information and support. They can refer you to a mental health practitioner for ongoing support if needed.
- Beyondblue provides information about depression and anxiety disorders and their treatments. Beyondblue also provides 24-hour telephone support with a trained mental health professional as well as online support from 3.00 pm to 12.00 am seven days per week.
- Health Direct's National Health Services Directory is a comprehensive online directory of health services including general practice, allied health and hospital services.
- In some states, you can access counselling through **Cancer Council 13 11 20**.

For more information on counselling see the resources pages at the end of this section.

Building your support network

Peer support

Emotional support may be hard to find. A local support group can be a good way to meet people who understand what you're going through and connect with others who are facing similar challenges and treatment.

Some support groups cater specifically for people with metastatic breast cancer and provide a safe place for people to come together for information and support. There are also general support groups for people affected by breast cancer.

The Cancer Council NSW conducts Australia-wide telephone-based support groups for people with metastatic breast cancer. Phone **13 11 20** to find out more.

BCNA can help you find a support group in your area. Call 1800 500 258.

Many people find BCNA's online network a great way to connect with other people, share experiences and seek advice. It includes a private group for people with metastatic breast cancer. Visit **bcna.org.au** to find out more or to join the online network.

I felt so alone and like the only one on the planet who had ever been diagnosed from the start with metastatic breast cancer. Then I discovered BCNA's online network. What a godsend to me! I can chat to other people in my position and my age. I no longer feel alone. I feel so helpful being able to chat to others who have recently been diagnosed and to let them know of my experiences.

My greatest inspiration has come from the friendships with other women living with breast cancer, particularly metastatic breast cancer. Our fears are similar, even though our life circumstances may be different. We learn what treatment side effects we may experience, what has been successful for pain relief, give each other practical advice, emotional counsel, and so often give one another strength of spirit, and courage which leads to empowerment.

Travel

For some people, knowing they have metastatic breast cancer sparks a desire to fulfil lifelong dreams of travel. For others, travel is a longer-term goal. Either way, if you're thinking about travelling you will have a few extra things to consider.

Domestic travel

If you're planning to travel within Australia, your doctors may be able to suggest options for medical support that make it easier for you to continue with your regular treatment, or simply provide some peace of mind.

I'm having Herceptin every three weeks and sometimes I feel pretty bad. We decided to organise a beach holiday. I arranged to get my Herceptin at a local clinic. It took a bit of organising but it was great to get away. You know, sometimes we need a holiday from this breast cancer business.

Domestic travel tips

- If your airfare has to be pre-paid, try to find one that is flexible in case you need to make last minute changes or delay your trip.
- Book accommodation using last minute websites such as Wotif.
- Check whether you can cancel your booking without any fees should your travel plans need to change.

- Make sure you have current ambulance cover in case any emergencies arise while you're away.
- Make sure you get a doctor's certificate if you need to cancel your travel plans and want to claim on insurance or seek refunds from travel providers.

International travel and travel insurance

International travel is more complicated because you're not covered by Medicare once you leave the country and your private health insurance is unlikely to help with any medical costs. It can also be very difficult to get travel insurance when you're living with cancer.

Australia has reciprocal health care agreements (RHCAs) with New Zealand, United Kingdom, Republic of Ireland, Italy, Belgium, Finland, Netherlands, Norway, Sweden, Slovenia and Malta. When you're travelling in these countries any medical care you need will be covered by the local public health system to varying degrees. For more information about reciprocal health care agreements, go to **servicesaustralia.gov.au**.

After all the hassle of getting the drugs organised, doctors' letters and trying to organise the insurance that I couldn't get anyway, I finally went overseas. I didn't have one day of illness. Why did it take me six months to do that trip? It's the uncertainty, isn't it? And we are all living with that.

Most international travellers take out travel insurance to cover things like lost luggage, accidents and medical cover. Some travel insurance policies will cover you for the incidentals but you're unlikely to obtain cover for medical costs related to your cancer as this is a pre-existing condition.

Sometimes people decide to travel without insurance to countries without a reciprocal agreement. This is a personal decision and it's a matter of weighing up the risk of needing medical care against the possible cost.

Some travel insurance companies may be more flexible about covering people with breast cancer. Ask a travel agent or specialist travel insurance consultant what's available.

I had really wanted to travel to the USA but when I realised I wouldn't be covered for hospital costs I just wasn't prepared to take that risk.

International travel tips

- If you're planning an overseas trip, talk with your medical oncologist before you make any payments. It may be better to hold off on making payments for as long as possible in case your health changes.
- Consider carefully any trips to developing countries or countries with poor sanitation and health care.
- When travelling overseas, make sure you take a letter from your oncologist detailing any medications you're carrying and the reasons you have them. Keep them all in their original packaging.
- Make sure you have enough of your prescription medication for all the time you're away.
- Consider taking antibiotics with you in case you need them.
- Ask your oncologist to provide you with a brief summary of your breast cancer history and treatments you've had in the past. Store this information somewhere safe when you travel and leave a copy with family or friends back home.
- Check in with your oncologist or GP just before you travel and make sure you act on any symptoms that crop up before you leave.

Travelling overseas can be complicated but, with some forward planning, you can reduce your risks of having an experience that causes trouble when you're away.

My family have allowed me the dignity of risk. I have just returned from travelling overseas with the encouragement of my oncologist, but without insurance.

I know that when I decided to go ahead with our trip, the fact that I was able to access medical care in the United Kingdom was one of the things that helped me decide to go.

Travel resources

Travel insurance fact sheets

bcna.org.au/fact-sheets or phone **1800 500 258**

Breast Cancer Network Australia's series of travel insurance fact sheets include information for people with metastatic breast cancer.

Travel Compare Insurance

comparetravelinsurance.com.au or call **1300 659 411**

This company provides comparative quotes and detailed information on a range of insurance providers for overseas travel, including insurance providers that may offer some degree of cover for people with cancer.

Cancer Council

phone **13 11 20**

Cancer Council has a list of low-cost or free holiday accommodation for people dealing with cancer.

OTIS Foundation

otisfoundation.org.au or phone **(03) 5444 1184**

The OTIS Foundation offers retreats in selected locations in Australia, available free of charge for people with breast cancer and their families. Each retreat is located in a beautiful environment, allowing guests to draw on nature for strength and comfort.

Corporate Angel Network of Australia

corpangelnetwork.org

The Corporate Angel Network of Australia includes corporations and individuals in hospitals, cancer and leukaemia support groups, aviation companies and businesses who work together to assist patients affected by cancer, and their families with transport to hospital.

CARING FOR YOUR BODY

Nutrition

Nutrition combined with meditation, living in a stress-free environment, daily walking and deep breathing are all sound ingredients that I have comfortably woven into my lifestyle.

Some people choose to make drastic changes to their diet after their diagnosis. There is no scientific evidence that people with metastatic breast cancer need a special diet, or that a particular diet can make a difference to your long-term prognosis.

However, a healthy, nutritionally balanced diet can help you to feel your best. When you feel well enough to eat, try to include something from all five food groups.

- Plenty of vegetables, fruit and legumes. Aim for five serves of vegetables and two serves of fruit each day.
- Whole-grain cereals, such as wholemeal bread, rice, pasta and noodles.
- Some lean meat, fish and poultry. Try to eat fish two to three times a week and limit your intake of red meat to 500g a week.
- Fat reduced dairy foods including milk, yoghurt and cheese. Try to consume around three servings of low-fat dairy foods each day.
- Plenty of water. Try to drink six to eight 250 ml glasses daily – a total of around 1.5–2 litres.

It's also recommended that you cut back on the following.

- Foods high in saturated fat and salt, such as fatty and processed deli meats, takeaway food, salty snacks and cakes.
- Food and drink high in sugar, such as biscuits, fruit juice and soft drink.
- Alcohol. It's recommended that you avoid alcohol if possible, or aim for no more than four standard drinks per week with two alcohol-free days per week. Liver metastases can impair the liver's ability to break down alcohol. Your oncologist will be able to give you specific advice around alcohol consumption.

An accredited practising dietitian (APD) can be a great help in managing your diet and ensuring you're meeting your nutritional requirements. To find an APD near you visit the Dietitians Association of Australia at **daa.asn.au > For the Public > Find an accredited practising dietitian**.

If you have a GP Management Plan and Team Care Arrangement – see p.195 in Section 5 – you may be eligible for a Medicare rebate for these appointments.

The Australian Guide to Healthy Eating is a handy visual guide showing how much of each food group you should aim to eat or drink each day to stay as healthy as possible. The guide is available online at **eatforhealth.gov.au**.

Phyto-oestrogens in soy products

Phyto-oestrogens are naturally occurring substances in some plant foods which may act like oestrogen when they are consumed. The main dietary sources of phyto-oestrogens are soybeans and soy products including tofu, tempeh and soy milk. There are a lot of myths around the role of phyto-oestrogens in breast cancer and the evidence regarding their impact is mixed. Soy products can be consumed in moderation as part of a balanced diet. Cancer Council Australia recommends that people with breast cancer, early or metastatic, are cautious about consuming large quantities of soy foods, highly-concentrated soy products such as vegetarian protein powders or phyto-oestrogen supplements. Soy supplements include soy protein isolates and isoflavone capsules.

Weight management

Weight loss and weight gain are both common symptoms of metastatic breast cancer treatment. It's important to try to achieve and maintain a healthy weight. If you're underweight, an accredited practising dietitian can help you to gain or maintain weight as you could be at risk of poor nutrition. This can significantly impact the way you feel, your recovery from any treatments and your energy levels.

If you're overweight, an accredited practising dietitian can help you to lose weight safely. An accredited exercise physiologist can also help you to increase your activity with a tailored exercise program (see p. 173). This may help improve your quality of life as well as your self-esteem and fatigue levels.

For more information on healthy eating, see BCNA's booklet *Healthy eating and breast cancer*. Download a copy form bcna.org.au.

Complementary medicines

Complementary medicines are products that are sometimes used in addition to conventional medical treatments to help improve wellbeing. Some examples include:

- vitamin and mineral supplements
- herbal medicines, including Chinese and Ayurvedic (Indian) medicines
- homeopathic remedies.

Many people consider using complementary medicines such as dietary supplements, vitamins and minerals, and/or naturopathic medicines to help improve their wellbeing. While some may be beneficial, others can cause unwanted side effects – skin rashes, for example. More importantly, they can also interfere with prescription drugs, including breast cancer medicines, and can make your breast cancer treatments less effective. Vitamin C, for example, can interfere with some chemotherapy treatments, and St John's Wort can reduce the effectiveness of tamoxifen and some chemotherapies. Starting or stopping complementary medicines can also affect the way your body metabolises your breast cancer treatments.

Your medical oncologist may suggest you take calcium and/or vitamin D supplements to help strengthen your bones and reduce bone loss. This can be especially important if you're being treated with an aromatase inhibitor such as anastrozole, letrozole or exemestane as these can weaken your bones. However, you should talk to your doctor before starting to take calcium or vitamin D as they are not suitable for everyone, especially those at risk of developing, or who have developed, hypercalcaemia (high amounts of calcium in the blood).

Your doctor may also suggest nutritional treatments, for instance, medication to enhance your appetite if you're struggling to maintain or gain weight. It's important to talk to a member of your medical team before starting, or stopping, any complementary medicines or supplements. Keep in mind, however, that there are many different types, and that your oncologist needs to know the specific ingredients rather than just the brand name. If you're already using a complementary medicine, show your oncologist the bottle.

The Memorial Sloan-Kettering Cancer Centre website includes a comprehensive list of herbs, botanicals, vitamins and other supplements with evidence-based information about their use, including any contraindications (i.e. where they should not be used) and possible adverse side effects. Visit **mskcc.org**.

Medicinal cannabis

The cannabis plant has been used as a medicine and a recreational drug for hundreds of years. It has many names including marijuana, hemp, pot, grass, weed and hash.

It's important to make the distinction between medicinal cannabis (prescribed to relieve symptoms of a medical condition) and recreational cannabis (used to get 'high').

Cannabis and cancer

There's no evidence that medicinal cannabis can slow, stop or cure cancer. However, there is evidence that it may help to manage the following symptoms and side effects of treatment:

- chemotherapy-induced nausea and vomiting
- moderate or severe pain
- weight loss and muscle wasting, by acting as an appetite stimulant.

There are also conventional treatments available to help manage all of these symptoms and there's minimal evidence that medicinal cannabis is effective for people suffering chronic pain caused by metastatic cancer. It's also possible that medicinal cannabis may interact with chemotherapy and other palliative care medications, making them less effective, so medicinal cannabis is generally considered only when standard conventional treatments have stopped working.

The side effects of medicinal cannabis are not well understood and can vary according to the type and dose of the cannabis product as well as between individuals. Known side effects include fatigue and sedation, vertigo, nausea and vomiting, fever, decreased or increased appetite, dry mouth, diarrhoea, impaired coordination and anxiety.

Research is currently being undertaken in Australia and overseas to understand the potential benefits, limitations and safety issues associated with medicinal cannabis for people with cancer. In Australia, trials are investigating a range of uses, including whether medicinal cannabis can improve quality of life in people with metastatic cancer, and whether it can prevent chemotherapy-induced nausea and vomiting where standard treatments are ineffective.

For more information on clinical trials, visit the Australian New Zealand Clinical Trials Registry **anzctr.org.au** or talk to your cancer specialist.

Alternative therapies

Trust yourself, as friends will press all sorts of quack treatments on you out of love and concern.

In cancer treatment, alternative therapies are products or treatments that are used instead of conventional medical treatments such as chemotherapy and hormone-blocking therapy. Alternative therapists often claim that their therapies will cure cancer, but their claims may be based on cultural traditions, or quackery, rather than scientific evidence.

Some people choose alternative therapies instead of conventional treatment. An example would be using a special diet to treat cancer rather than treatment recommended by a specialist cancer doctor.

People may feel that alternative therapies benefit their wellbeing. However, where research has been done, there's no evidence that these treatments have any anti-cancer benefit. When a treatment is shown to be of value, it's no longer deemed 'alternative'. If you're contemplating alternative therapies, you need to give careful consideration to what you might miss by avoiding conventional treatment.

Some people try alternative therapies as well as their conventional treatments. To be safe, tell your medical oncologist and GP about anything you decide to take in case it interacts with your medical treatments.

Alternative therapies are often very expensive and may cost many thousands of dollars despite there being no scientific evidence that they work. Beware of testimonials and quick-fix promises. If an alternative treatment were really effective, the scientific community would be researching it in a clinical trial setting.

Exercise

I believe that exercise is very important. I ride my bike regularly, sometimes alone and sometimes with friends. It's another form of meditation and you get the fitness benefits too.

Although it may be the last thing you feel like doing, research shows that regular and properly supervised gentle exercise can improve the way you cope with the symptoms of metastatic breast cancer, its treatment and any side effects.

Along with a healthy diet, light exercise can help you to establish and maintain a sense of wellbeing and can improve your quality of life. Light exercise such as walking, swimming or gardening can help by:

- increasing energy levels
- reducing fatigue, pain, nausea and vomiting
- aiding digestion
- improving sleep
- improving strength and flexibility, and the functioning of your heart and lungs
- improving joint paint if you swim or walk in a warm pool.

Many people find that exercise helps them to lose or maintain weight. It can also help to reduce anxiety, stress and depression and help you to feel more in control of your body and your life.

I have found walking daily to be an outstanding way of helping me feel more in control of this disease.

Exercising with a friend provides a great opportunity to catch up and have a chat and can help to keep you motivated. Despite the benefits, many people say it's important to listen to your body and pace yourself rather than overdo it if you start to feel weary.

Exercise guidelines

A combination of aerobic exercise (e.g. walking or cycling) and resistance exercise (using weights) can help reduce cancer-related symptoms, including fatigue. If you're experiencing a period of high to severe fatigue you should still exercise but reduce the intensity, or effort, and the amount you do on that particular day.

Current weekly exercise guidelines for people with cancer recommend at least 150 minutes of moderate to vigorous aerobic exercise (about 20 minutes per day of brisk walking, cycling or swimming) plus at least two resistance exercise sessions using major muscle groups (upper and lower body).

It's important to recognise that these guidelines are general and not specific to people with metastatic cancers. However, they can still be a guide to work towards if you can.

Exercise and safety

We recommend that you discuss exercise with your doctor and gain medical clearance before starting as you might need to consider issues like compromised immunity, your bone health or lymphoedema. For example, certain exercises will be better than others to avoid putting too much stress on affected bones.

Benefits of exercise for lymphoedema

Lymphoedema, or swelling of the arm, hand or breast, sometimes develops in people whose lymph nodes were removed or damaged during breast cancer treatment. Research has shown that regular exercise can help reduce your risk of developing lymphoedema or help you to manage lymphoedema symptoms.

Aqua aerobics has really helped the lymphoedema in my arm. The water acts like a gentle massage.

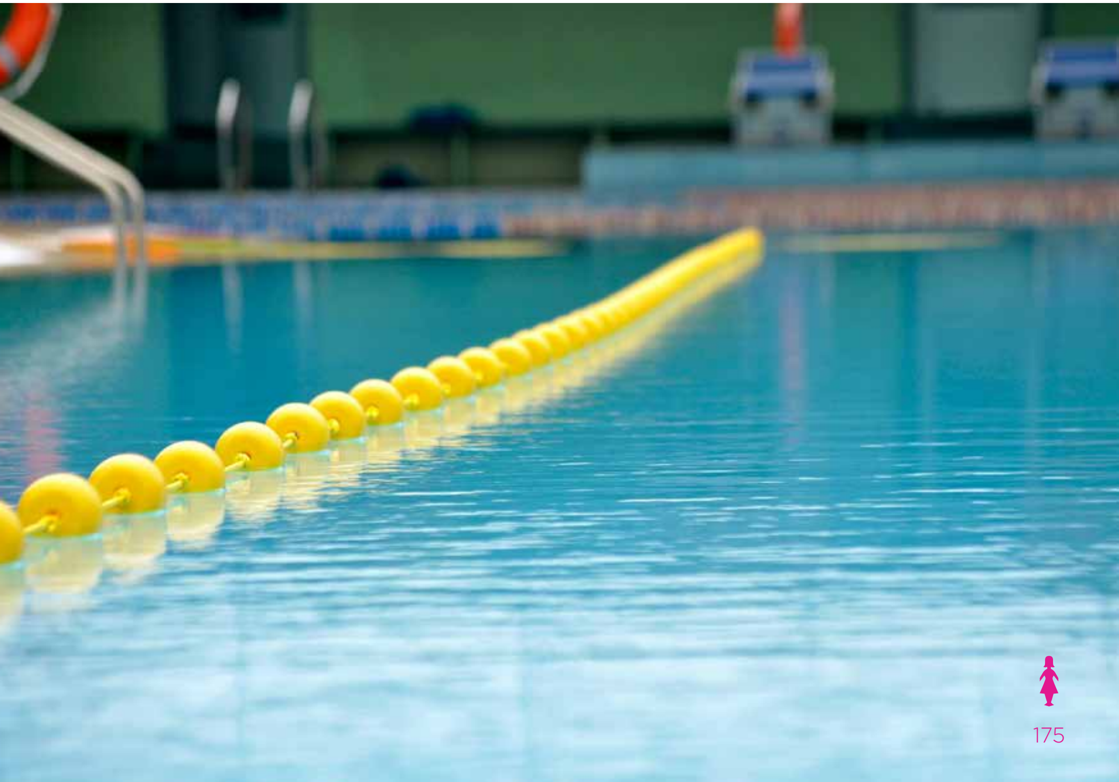
Where to go for help

The best person to develop and supervise an exercise program for you is an Accredited Exercise Physiologist (AEP) who has cancer management expertise. You may be eligible for a GP chronic disease management care plan or for rebates through your health insurance to help pay for these services.

AEPs are health professionals who specialise in exercise programs to prevent and manage chronic diseases and injuries, including conditions such as breast cancer. You can seek an AEP through your GP, a private clinic or your hospital.

If you would like to find an AEP in your area, go to the Exercise & Sports Science Australia website at essa.org.au/find-aep.

Physiotherapy helps repair damage, reduce stiffness and pain, and increase mobility. Physiotherapists use advanced techniques and evidence-based care to assess, diagnose, treat and prevent a wide range of health conditions and movement disorders. They can address a range of needs, including treating, managing or preventing fatigue, pain, muscle and joint stiffness, and deconditioning – reversing changes resulting from lack of physical activity. You can search for a physiotherapist in your area by visiting **choose.physio/your-condition**.



Touch therapy

Research has found that the use of touch therapy, particularly massage, can help to reduce pain and physical and emotional distress, as well as improve quality of life. Even the simple touches you share with family members and friends can be of benefit.

If touch is not available through your own relationships you may like to seek out a professional masseur, book a foot reflexology session or ask your hairdresser for an extended head massage as a way of receiving physical contact.

Oncology massage

Oncology massage therapists have specialist training in massage for people diagnosed with cancer. Some palliative care services provide free massage – your palliative care team will have more information.

ℹ **To find a local oncology massage therapist, see oncologymassagetraining.com.au and enter your postcode in the 'Find Your Nearest Therapist' box.**

Taking time for yourself

Have time out for yourself. This can mean a massage, a walk around the block, or acting on something that is worrying you (a homebody like me sat each afternoon and sorted out the photo album).

I achieved a life plan of moving to the country and opening a small business for a few years and still live in rural Australia. I started a breast cancer support group in our area and have made the most wonderful and honest friendships over the years with women from all walks of life.

It's okay to take some time for yourself and do the things you want to do. In fact, many people say it's essential. A list of everything, large or small, that gives you pleasure can help you make the most of things you enjoy – you can refer to it for inspiration if you're feeling down or simply have some time on your hands.

Set easily achieved short-term goals and grander long-term goals to look forward to. Tick them off as you achieve them and set new ones. Ensure your family and friends contribute to your 'bucket list' as they will also have things they want to do with you.

Give yourself permission to be happy and try to plan for some happiness in your life. Celebrate milestones. Having something to look forward to – big or small – can help you to get through trying times.

Learn to say no. If you're tired, don't say you will go out, babysit or whatever. It took me a couple of months before I learnt this lesson myself. Now I don't make any plans definite until the day is here.

I found art therapy very helpful – run by a professional artist. It's a real creative outlet which I now do at home.

I found nature very calming – my life became chaotic and I felt that the cancer was taking over my mind, my body and my life. The cancer was all-encompassing, overwhelming and suffocating, so seeing huge beautiful views that were bigger than the cancer was reassuring for me. It gave me some control back.

LIVING WELL PROGRAMS AND SERVICES

There are a number of free programs and services to help you feel better and improve your sense of wellbeing. Many cancer facilities have wellness centres that include supportive care programs. These may include support groups and a range of activities such as exercise classes or art therapy. There are also independent services that provide free information and self-care programs. Speak to your doctor or nurse to find out what living well programs or services are available in your area or call the BCNA Helpline on **1800 500 258**.

These are some of the national programs.

- Look Good Feel Better is a free national community service program dedicated to teaching cancer patients how to manage the appearance-related side-effects caused by treatment for any type of cancer. For more information visit **lgfb.org.au**.
- YWCA Encore is a free eight-week program of gentle floor and pool based exercises for people diagnosed with breast cancer. To find out if there's an Encore program in your area, visit **ywcaencore.org.au** or phone **1800 305 150**.
- Cancer Councils in a number of states and territories run exercise programs. To ask if there's an exercise program in your area, phone **13 11 20**.
- Dragons Abreast Australia is a national organisation of people diagnosed with breast cancer who get together to participate in dragon boating. People of any level of fitness can join. Many people join Dragons Abreast to help manage their lymphoedema.
  To find out if there's a Dragons Abreast group in your area, visit **dragonsabreast.com.au** or phone **1300 889 566**.

- Solaris Cancer Care in Perth provides holistic support including counselling and wellness coaching to all people in Western Australia affected by cancer, including carers and family members, through all stages of the illness, including long term survivors and bereaved families. Visit **solariscancercare.org.au**.

The bottom line

Handling metastatic breast cancer is tough. There are many things about your situation you can't change – being stressed, anxious, depressed or just plain angry and resentful are part of the deal. But you can change how these affect you, and professional support and guidance can help. Remember that not being able to see your feelings doesn't mean that they aren't real and deserving of care.

Don't be afraid to lean on others for support and be open to accepting whatever help is offered or available.

QUESTIONS YOU MIGHT LIKE TO ASK ABOUT LIVING WELL

People have told us they found it useful to ask these questions about ways to live well. Add any others you think of to the list before you go to appointments.

- Where can I get support to help with how I'm feeling?
- Is support available at my treating centre if I need help dealing with personal relationships?
- What support is available for my partner and family?
- Are there changes to my lifestyle that could help me feel better?
- Where can I get help and support with eating well?
- What type of exercise is safe for me? How can I find an accredited exercise physiologist?
- Can you suggest a 'living well' program that may assist me?
- What complementary therapies and/or medicines may be safe for me? Is there a trained practitioner you would recommend?
- Can I keep working?
- Are there any support groups where I can talk to others and share experiences?

RESOURCES

Breast Cancer Network Australia (BCNA)

bcna.org.au or phone **1800 500 258**

BCNA's Helpline team includes experienced cancer nurses who can talk to you about a range of emotions, concerns and issues you experience as a result of your diagnosis. They can also refer you to ongoing support. You can phone the Helpline team Monday to Friday between 9.00am and 5.00pm

BCNA's website has a comprehensive range of resources for people affected by metastatic breast cancer including fact sheets, podcasts and webinars of interest.

BCNA's online network available on the BCNA website is a good place to go if you think that talking about your thoughts and feelings online with others in a similar situation will help.

Please call the BCNA Helpline for further information, support or referral.

Cancer Council

cancer.org.au or phone **13 11 20**
Cancer Councils are located in each state and territory.

They provide a range of services, including telephone support and counselling, peer support programs, assistance with accommodation, financial support, seminars and forums.

WeCan

wecan.org.au

WeCan is an Australian supportive care website to help people affected by cancer find information, resources and support services and includes a range of emotional and practical information.

Palliative Care Australia

Australia
palliativecare.org.au or phone **(02) 6232 0700**

Palliative Care Australia is the national peak body for palliative care in Australia. The website provides information that will be useful to those diagnosed with metastatic breast cancer, carers and health professionals.

CanTeen

canteen.org.au or phone **1800 835 932**

CanTeen is an organisation that helps young people aged 12-25 deal with cancer in their family. This includes information and support for those who have a parent diagnosed with cancer. Young people can also connect with others in a similar situation and share their stories so they know they are not alone.

Finding the words – starting a conversation when your cancer has progressed

Cancer Australia
canceraustralia.gov.au

This resource has been developed to help people with metastatic cancer talk about how palliative care might help them to live as well as possible when cancer has spread.

Living with Advanced Cancer

cancer.org.au or phone **13 11 20**

How to cope after a diagnosis of advanced cancer, including information on the emotional impact, treatment options, managing symptoms, getting your affairs in order, and caring for someone with advanced cancer.

Partners and carers

BCNA's booklet

When someone close to you has metastatic breast cancer

This booklet is designed to help partners, family members, friends or colleagues support someone who has been diagnosed with metastatic breast cancer. To download a copy visit **bcna.org.au**

BCNA's Fact sheet

You're important too: looking after yourself as a carer

This fact sheet provides information to help support you in your role as carer. It also provides tips on looking after yourself. To download a copy visit **bcna.org.au**

Carer Gateway

carergateway.gov.au or phone **1800 422 737**

Carer Gateway is a national service funded by the Australian Government. Carer Gateway includes a website and phone service for carers to access practical information and support.

Carers Australia

carersaustralia.com.au or phone **1800 242 636**

Carers Australia is the national peak body representing Australia's carers. The Carer Advisory Service provides information and advice to carers and their families about carer supports and services.

Cancer Australia

canceraustralia.gov.au or phone **1800 624 973**

Cancer Australia has a number of resources for partners of people with breast cancer. The website includes 'Information for men whose partners have been diagnosed with breast cancer' with information on dealing with feelings, knowing what to say, where to find help and other helpful information.

Counselling services

Beyondblue

beyondblue.org.au or phone **1300 224 636**

Beyondblue has information on depression and anxiety, and where to get help.

Lifeline Australia

lifeline.org.au or phone **13 11 14**

Lifeline is a national charity providing all Australians experiencing a personal crisis with access to free, 24-hour crisis support and suicide prevention services.

Kids Helpline

kidshelpline.com.au or phone **1800 551 800**

Kids Helpline is Australia's only free, confidential, 24/7 phone and online counselling service for young people aged up to 25 years old, or their parents.

Relationships Australia

relationships.org.au or phone **1300 364 277**

Relationships Australia offers relationship counselling as well as other counselling services. Most of the counselling services are face-to-face, but there are also some online and telephone counselling services for people in remote areas (in some states only).

MensLine Australia

mensline.org.au or phone **1300 789 978**

MensLine Australia is a professional telephone and online support and information service for Australian men.

Carers Australia National Carer Counselling Program

carersaustralia.com.au or phone **1800 242 636**

The National Carer Counselling Program provides short-term counselling and emotional and psychological support services for carers. The counselling helps lower carer stress and improve carer coping skills. The counselling program is delivered through state and territory carer associations.

Wellness and hope

Petrea King's Quest for Life Centre

questforlife.com.au

Quest for Life provides a range of residential programs and services that encourage, empower and educate people living with cancer, and other serious illnesses, or who are suffering from grief, stress or trauma, and for those who care for them.

Dragons Abreast

Australia
dragonsabreast.com.au or phone **1300 889 566**

The purpose of Dragons Abreast is to promote breast cancer awareness and education while having fun. Dragons Abreast demonstrates that people can fully participate in life despite physical limitations as a result of treatment for breast cancer.

The Gawler Foundation

gawler.org

The Gawler Foundation provides a broad range of healing and wellness programs for adults of all age groups, including professional development programs, counselling, individual meditation instruction and spiritual care for the end of life.

The OTIS Foundation

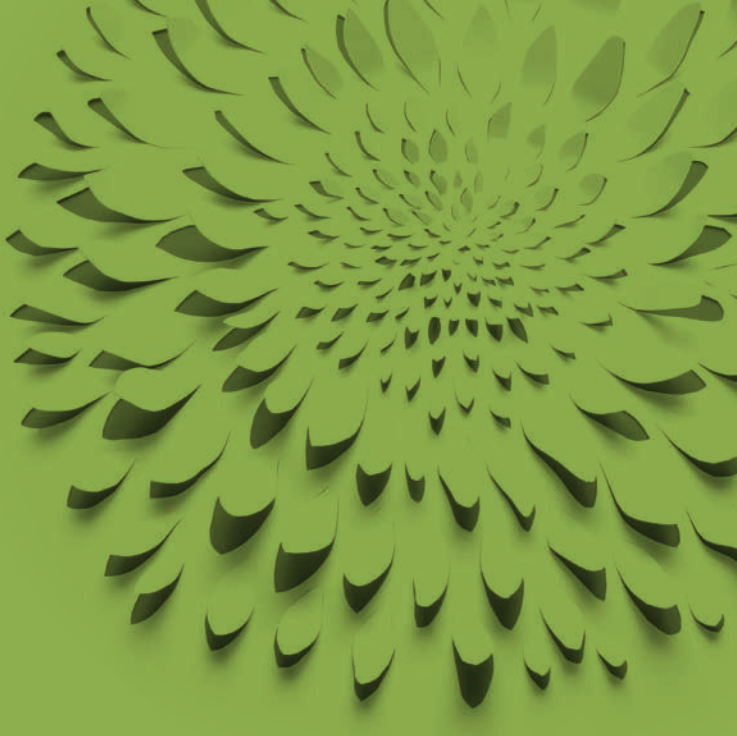
otisfoundation.org.au or **phone (03) 5444 1184**

The OTIS Foundation provides a network of accommodation retreats available free of charge for women and men living with breast cancer. Located in Victoria, NSW, NT, QLD and SA, they offer a place to take time out to relax, contemplate and regroup. Each retreat is located in a beautiful environment, allowing guests to draw on nature for strength and comfort.

VISE Angels

Australia
vise.org.au or email **info@vise.org.au**

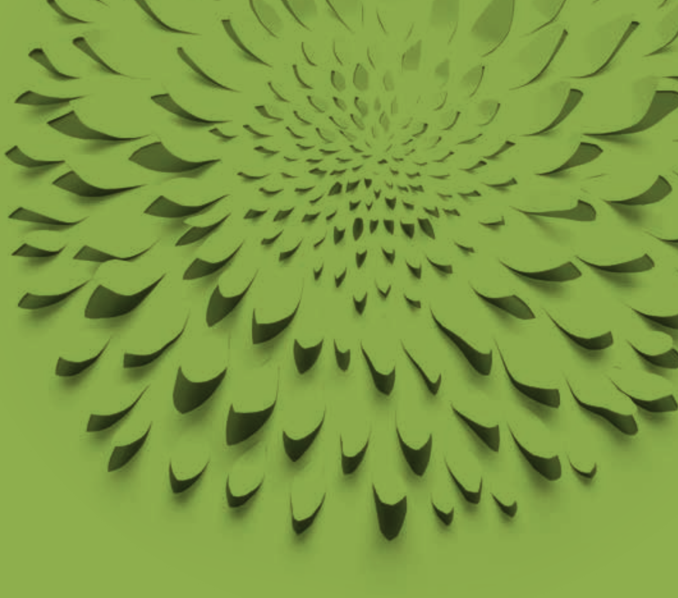
VISE volunteers can provide domestic and personal support to families living in outback Australia in the case of illness or when respite is necessary.



SECTION 5

FINANCIAL AND PRACTICAL MATTERS

I am still working out all the things I need to do. It's definitely complicated but using a trusted financial adviser has helped enormously. There has been lots of preparation to unpack our cost of living, debt and future financial commitments but it has been really worth the effort to ensure my family and I are okay financially.



SECTION OVERVIEW

This section provides information about financial and practical matters you may experience including:

- costs that may be associated with your treatment
- Medicare safety net
- federal government assistance (Centrelink)
- GP management plans and team care arrangements
- state government assistance
- community supports
- superannuation and insurance
- employment and your work rights
- questions you might like to ask about financial and practical matters.

THE FINANCIAL COST OF BREAST CANCER

For many people living with metastatic breast cancer, the financial costs associated with treatment and care can be substantial. General day-to-day expenses continue, and you might also have to pay for specialist appointments, medications, treatments and tests, counselling, massage, travel and other costs related to your breast cancer treatment and care. If you're unable to continue paid work or work in the same capacity as before you were diagnosed, the loss of income can also contribute to financial pressure on you and your family.

Costs of tests and treatments

As your treatment may continue over an extended period, your health care costs can add up considerably. Asking your doctor about the likely costs of medical tests, treatment and support services will give you a clearer idea of where you stand. If you don't feel comfortable talking about money, it might be helpful to think of health care as any other service you pay for, where you would often ask for a quote first.

When you have so many other things to deal with, you don't need to be worrying about unexpected or surprisingly high bills.

Your costs will depend on whether you:

- have your treatment in the public or private system
- are working and need to take time off or reduce your work hours
- live in a rural area and need to travel for treatment
- have a Centrelink Health Care Card or receive a Centrelink pension
- have insurance such as disability, income protection or trauma insurance.

Medicare safety net

The Medicare Safety Net is designed to protect people who have high medical costs from paying large gap fees. Once you have reached the annual threshold, visits to your doctor, or tests outside of hospital, may cost you less for the rest of the calendar year. For example, you would still pay the same amount upfront to your doctor but you may receive a higher Medicare benefit.

The Medicare Safety Net covers a range of doctors' visits and tests you receive out of hospital. It doesn't apply to any out-of-pocket costs you pay for treatment or tests as an inpatient in hospital.

Services that count towards the Medicare Safety Net include:

- GP and specialists' consultations
- scans and test such as bone scans, CT scans, X-rays, PET scans and ultrasounds
- blood tests
- radiotherapy treatment.

Medicare Safety Net thresholds are changed annually to account for inflation. There's also a PBS safety net, which helps if you have a lot of prescriptions for medications in a calendar year.

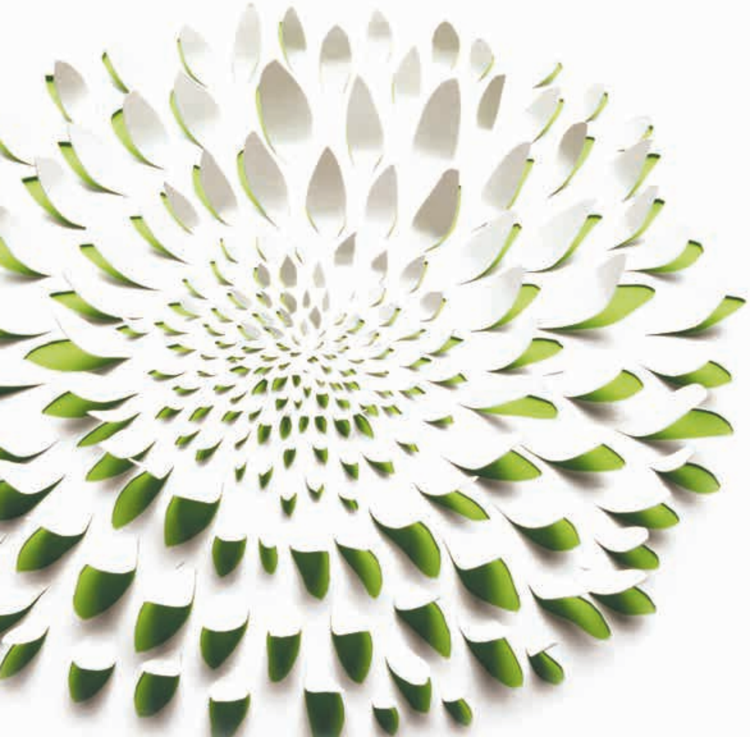
Registering for the safety net

Individuals are automatically registered for the safety net but families and couples need to register to link all individuals as one family. If you have a partner and/or children, you need to register even if you're all listed on the same Medicare card. This is to ensure that the medical costs of all family members are taken into account so you will reach the threshold as soon as possible.

There are different Medicare safety net thresholds depending on your circumstances. This includes a lower threshold for concession card holders and families who receive Family Tax Benefit.

If you're concerned about gap fees associated with doctors' appointments and tests, ask your specialist whether you can be bulk billed. Bulk-billing is when your health professional accepts the Medicare benefit as full payment for a service. Many health professionals bulk bill pensioners and Health Care Card holders.

You can also ask your specialist or service provider whether they can claim the Medicare rebate on your behalf when you pay your full account so you don't need to submit a claim. Medicare will then pay the rebate to the provider so you only need to pay the gap amount.



Pharmaceutical Benefits Scheme (PBS)

The Pharmaceutical Benefits Scheme (PBS) is a federal government system that subsidises the cost of some medications. Everyone who has a Medicare card is covered by the PBS and can access PBS-listed medications at a subsidised cost. The subsidy may not cover all of the cost; individuals usually pay a contribution known as the PBS co-payment, script fee or dispensing fee. This fee is per prescription.

Some breast cancer drugs you may hear about are not approved for the PBS and not subsidised. This is particularly common for new drugs that have not been through the extensive PBS approval process.

PBS Safety Net

The PBS safety net helps people who need a lot of prescription drugs. When you or your family reach the safety net threshold you can apply for a PBS Safety Net card. This will make PBS-subsidised drugs less expensive or free for the rest of the calendar year.

You don't need to register for the PBS Safety Net but you do need to keep a record of all your PBS drugs on a prescription record form, which you can get from any pharmacy. Some pharmacists can keep a computer record for you, but if yours can't, or if you visit different pharmacies, you will need to keep your own records.

When you get close to the PBS threshold, you should ask your pharmacist for help with applying for a PBS Safety Net card.

Some years the PBS prescriptions really mount up quickly. It helps to keep our main pharmacy updated on the receipts from other pharmacies. They can let us know if we've reached the PBS Safety Net and help us with explanation and registering.

Who can help explain the different Safety Nets and how they might apply to me?

Your pharmacist or Centrelink office can explain the safety nets associated with the cost of medications and medical bills. You can also visit the PBS website at **pbs.gov.au**.

FEDERAL GOVERNMENT ASSISTANCE

Centrelink payments

If you're on a low income or unable to work because of your breast cancer, you may be eligible for payments or services from Centrelink.

You can visit a Centrelink office or phone **13 27 17** for help with applications and claims. You can also ask to speak to a social worker (phone **13 28 50**) or contact the Financial Information Service (phone **13 23 00**) for advice. It's best to do this as soon as possible as there might be a waiting period before you start receiving payments. If you're feeling too unwell to have this discussion, you can nominate your partner or a family member to seek advice on your behalf.

Applying for a Centrelink payment or service can be confusing, frustrating and time consuming. You may need to provide lots of detailed information and documents such as letters from your doctor. If you need to speak to someone about your options, you may have a long wait but, when you finally do, it's important for you or your representative to keep on asking questions until you're sure about your entitlements.

You may also want to ask your partner, a family member or close friend to help you keep track of all the paperwork required for Centrelink.

My sister keeps track of my bills, Medicare claims, etc. I just find it way too stressful and time consuming.

There are a number of different Centrelink payments for which you and your partner may be eligible.

ℹ **For more information about any of the services or payments overleaf visit a Centrelink office, or phone 13 27 17.**

Sickness allowance

If you're employed but unable to work because of your illness, and you meet certain age and income requirements, you may be eligible for a fortnightly sickness allowance. If you have a partner, their income and assets will be taken into account, as will any outstanding sick leave you are entitled to from your workplace. You will need a medical certificate from your doctor confirming that you're not able to work.

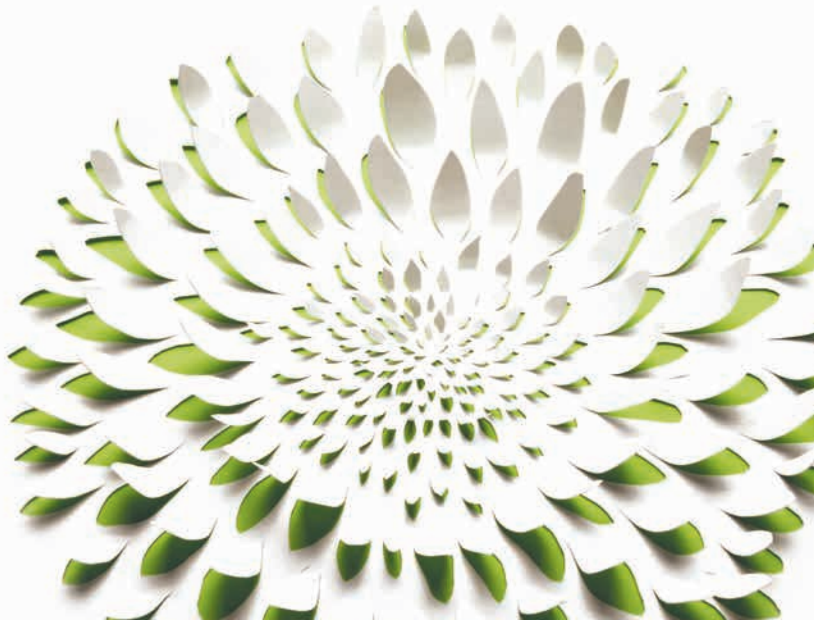
Mobility allowance

You may be able to claim the mobility allowance if you do paid or volunteer work, study or are looking for work and can't use public transport. Your doctor will need to complete the Centrelink form confirming you can't use public transport without help because of disability, illness, or injury. If you're doing volunteer work, the organisation you volunteer for may need to endorse your application. If you receive the mobility allowance, you may also be able to access a Health Care Card even if you don't meet the financial criteria.

ⓘ You can find more information and download the forms from the Centrelink website **humanservices.gov.au/centrelink.**

Disability support pension

If you're medically assessed as being unable to work for more than 15 hours per week within the next two years because of your breast cancer, you may be eligible for a fortnightly disability support pension. Your income and assets, and those of your partner, will be taken into account.



Health Care Cards

A Health Care Card is available to people who receive certain payments from Centrelink. If you qualify, you will benefit from cheaper prescription drugs, bulk-billing of Medicare services and more refunds for medical expenses. You may also pay less for water, gas and electricity, ambulance services, public transport, and dental and eye care.

If you're not receiving a Centrelink payment but are on a low income, you may be eligible for a Low Income Health Care Card. This provides the same benefits as the Health Care Card.

Carer allowance

If you have someone who cares for you, they may be entitled to a carer allowance. This is an income supplement for carers who provide daily care and attention for someone who has a disability or medical condition, or who is aged and frail.

Eligibility criteria apply and care must be provided in either your home or the home of the person you're caring for. The carer allowance is non-taxable and not asset tested, but there is an income test.

Financial information and social work services

Centrelink has Financial Information Service officers and social workers who can provide support in financially difficult times. You can call **13 63 57** for financial information and **13 28 50** to speak to a social worker. These services are free.

I saw the oncology social worker to determine my eligibility for financial assistance.

Social workers can help you if you're experiencing financial difficulty, need emotional support or are unsure how to access the right assistance.

Social workers provide:

- short-term counselling and support for difficult personal or family issues
- information about government and community support services, and referrals to them
- support for any difficulties you're having in meeting your financial obligations or requirements.

In addition to accessing a social worker through Centrelink, you may be able to see a social worker through your hospital or community health centre. Ask your specialists, breast care nurse or GP for information about how to see a hospital social worker. You may find it helpful to bring a family member or friend with you to your appointment.

Department of Veterans' Affairs

There are a number of benefits and pensions for veterans and partners of veterans.

For more information visit the Department of Veterans' Affairs website at **dva.gov.au**, or call the department on **13 32 54**. Regional callers can phone **1800 555 254**.

MAKING THE MOST OF YOUR GP

GP management plans and team care arrangements

GP management plans provide support for people with chronic medical conditions, including cancer, that are likely to continue for six months or more.

There are two types:

- GP management plan (GPMP)
- team care arrangement (TCA).

GPMPs can provide an organised approach to care by:

- identifying your health care needs
- setting out the services to be provided by your GP
- listing any other health care and community services you may need
- listing the actions you can take to help manage your condition.

A TCA provides access to other health care providers, including allied health workers, who may be helpful to you. These include physiotherapists, registered lymphoedema practitioners, dietitians, podiatrists, occupational therapists and exercise physiologists.

You may be eligible for Medicare rebates for the care provided by these health workers for up to five visits per year as long as the care is directly related to your breast cancer. You may need to make a special appointment to discuss a TCA – your GP's receptionist will let you know.

GP mental health plans

If your GP believes you would benefit from ongoing counselling, they can draw up a GP mental health plan and refer you to an appropriate specialist. A GP mental health plan allows you up to 10 individual Medicare-subsidised appointments and 10 group appointments with a mental health service provider such as a clinical psychologist, specialist GP, social worker or clinical occupational therapist.

BCNA has fact sheets with more details around the different types of GP management plans that you can download from the BCNA website bcna.org.au.

STATE GOVERNMENT ASSISTANCE

Patient Assisted Travel Schemes (PATS)

If you live in a rural area you will probably have to travel to another town or city for specialist medical services and treatment, and you may sometimes have to stay overnight. This can be expensive. All state and territory governments provide some financial assistance for these kinds of expenses through Patient Assisted Travel Schemes (PATS).

For more information, see BCNA's PATS fact sheet downloadable from **bcna.org.au** or phone BCNA on **1800 500 258**.

Lymphoedema compression garment subsidies

There are subsidies to cover some or all of the cost of compression garments for people diagnosed with lymphoedema. The schemes are run by state and territory governments.

For more information on lymphoedema subsidies, see BCNA's lymphoedema fact sheet downloadable from **bcna.org.au** or phone the BCNA Helpline on **1800 500 258** for information and support.

OTHER SOURCES OF FINANCIAL HELP

Community assistance

Local councils, community health services and volunteer organisations can provide help of different kinds.

For instance, some local councils provide home help services including:

- household cleaning
- ironing
- gardening and other property maintenance
- delivering meals
- shopping
- banking
- patient transport
- child care
- respite care to give carers a break from their caring role.

Community health services can also link you to financial advisers, social workers and other types of support. Some states and territories also have other organisations that provide these services.

Taxi concession programs

State and territory governments provide discounted taxi fares for people who meet certain residential, medical and financial criteria.

These may include whether you:

- are a permanent resident of Australia and live in that state/territory
- have a severe disability that prevents you from using public transport safely or independently
- have a permanent disability or one that will not improve with treatment
- are a Centrelink or Department of Veterans' Affairs pension card holder
- can provide proof that you're experiencing severe financial hardship.

Taxi concession cards are renewed every six years and provide half-price fares. The maximum fare you can claim is $120, when you would only be charged $60. You will need a letter from your doctor to confirm that your illness means you can't safely or independently access public transport.

For more information visit the appropriate website in your state or territory:

ACT: assistance.act.gov.au (search for taxi subsidy scheme)

NSW: transport.nsw.gov.au (search for taxi transport subsidy scheme)

NT: nt.gov.au (search for taxi subsidy scheme)

Qld: tmr.qld.gov.au (search for taxi subsidy scheme)

SA: sa.gov.au (search for taxi fare subsidy scheme)

Tas: transport.tas.gov.au (search for taxi subsidy smartcard)

Vic: taxi.vic.gov.au (search for multi-purpose taxi program)

WA: transport.wa.gov.au (search for taxi users subsidy scheme)

Other organisations that can help

Cancer Council

cancer.org.au

Cancer Councils in each state and territory offer a range of services for people affected financially by cancer. They includes:

- financial assistance schemes
- accommodation options
- travel assistance
- practical assistance, such as home help
- grants or subsidies that may be available in your state or region.

Cancer Council also has a pro bono program that provides free legal, financial and workplace assistance advice to people affected by cancer who can't afford to pay.

Phone Cancer Council **13 11 20** for more information

Financial Counselling Australia (FCA)

financialcounsellingaustralia.org.au

FCA is the peak body for financial counsellors in Australia. Financial counsellors provide information, support and personal advocacy to assist people in financial difficulty. FCA counsellors work in community organisations across Australia and their services are free, independent and confidential.

ℹ **To speak to a financial counsellor by phone, or for a referral to a counsellor in your area, call FCA on 1800 007 007.**

The Salvation Army Counselling

salvos.org.au

The Salvation Army offers a free financial counselling service. Counsellors can provide information, help you to develop a plan to improve your finances and, if required, act as your advocate and negotiate with your creditors. The Salvation Army also has a No-Interest Loans Scheme (NILS), which provides loans to people on low incomes who need to purchase essential household items (a range of criteria must be met for this scheme).

ℹ **To speak with someone about financial counselling, phone 13 72 58.**

Australian Red Cross

redcross.org.au

Australian Red Cross provides patient transport services. In some states and territories, there are also child care services available.

To find out what is available visit the website or phone 1800 733 276

Dreams2Live4

dreams2live4.com.au

Dreams2Live4 is a national charity that helps make dreams come true for people living with metastatic cancer.

If we can encourage people to think of what their dreams may be and help them achieve them, they just may improve the outlook of their disease.– **Annie Robertson (organisation founder)**

To find out more information, phone 0400 914 375 or email info@dreams2live4.com.au.

SUPERANNUATION AND INSURANCE

If you have superannuation and/or insurance policies, you may be able to access your benefits or make a claim. You can do this even if you haven't reached retirement age. Superannuation can also be released at other times, such as on compassionate grounds or if you're experiencing severe financial hardship.

If you prefer, you could ask your partner or a family member for help or, if you have a financial planner or adviser, they can do it for you. You may need to provide written consent to have someone act on your behalf.

Cancer Council's pro bono program might also be able to provide you with free advice about how to access your superannuation and insurance.

Early access to superannuation on compassionate grounds

Generally you can't access your superannuation benefits until you have reached preservation age and have satisfied a condition of release, or you have reached the age of 65. However, in some circumstances, you can apply to access your superannuation under specific compassionate grounds. This includes if you need to:

- pay for medical or dental treatment for yourself or a dependent or pay for transport to the treatment
- prevent your home from being sold by the lender that holds the mortgage
- modify your home or vehicle to make it easier for you to manage everyday activities and be as independent as possible
- pay for palliative care for yourself or a dependent with a terminal medical condition
- pay for expenses associated with a dependent's death, funeral or burial.

ℹ **Contact the Australian Government Department of Human Services on 1300 131 060 for more information on accessing superannuation under compassionate grounds.**

Early release of superannuation on the grounds of terminal illness

You may also be eligible to apply for early release of your superannuation on the grounds of a terminal illness. Under Australian law, people with a terminal illness and a life expectancy of less than two years are able to get early access to their lump sum benefits from their superannuation fund tax-free.

Two medical specialists involved in your care need to complete forms to confirm your life expectancy is less than two years. This isn't easy for them to do. It can be hard to predict how a particular cancer may respond to different treatments, and clinical trials may offer new beneficial treatments that aren't widely tested or reported.

While this may be a very difficult conversation for you to consider, it could be very worthwhile if you would like to access your lump sum benefit early. You won't be required to repay the money, and there is no penalty for you or your doctors, if you live longer than two years.

There are also no rules concerning how you can spend the money. You may need it for your medical care, but you could also use it to pay off your mortgage, pay school fees for your children or take your family on a holiday, for example.

It was difficult at first. My super fund would not provide accurate information but I got some advice and pushed through the barriers and was finally able to access my super which made a huge difference to my quality of life.

Accessing superannuation early is a sensitive and complex decision for you and your family. Any decision to withdraw superannuation under the terminal illness provision must be done carefully, as it could mean you lose any insurance benefits attached to your superannuation policy. This includes life insurance and disability insurances. If you receive a Centrelink payment, you should also ask Centrelink whether this would be affected.

Insurance benefits that may be attached to superannuation policies

I received a Total and Temporary Disability benefit through my super fund (75 per cent of my normal salary) which supported me during a gradual return to work after I was first diagnosed with metastatic breast cancer.

Your superannuation policy may include insurance disability benefits that can cover you if you're no longer able to work. These insurance benefits are often attached to your superannuation account as a default option, which means you will be covered unless you chose to opt out at some point. Many people are covered by automatic insurance attached to their superannuation account without being aware of it and there are two types of benefits you may be able to claim.

Total and Permanent Disability cover (TPD) provides you with a lump sum insurance benefit if you're totally and permanently 'disabled'. Although definitions of TPD differ between insurers, the most common definition is that you can't return to your usual job or any other job because of your injury or illness, taking your age, education and experience into account.

Total and Temporary Disability cover (TTD) provides cover if you're deemed temporarily unable to return to work and your disability is not likely to be permanent. TTD benefits can also be called Income Protection or Salary Continuance depending on your policy. TTD benefits can provide a monthly payment for two years or longer.

Life insurance

Death benefit payments under superannuation insurance policies can often be accessed on terminal illness grounds. People often think death benefits are only claimable by the family once a person dies, but this is not always the case. Some death benefit policies attached to superannuation can be claimed by people who are terminally ill when they withdraw their superannuation account balance.

BCNA has developed a fact sheet *Superannuation and insurance payments for people with a terminal illness*. You can download the fact sheet from the BCNA website bcna.org.au or phone 1800 500 258.

If you're unsure what insurance is attached to your policy, you should consider getting independent financial advice. The Cancer Council pro bono program may also be able to assist you.

You can find out more about this service by calling 13 11 20.

EMPLOYMENT

If you want to work, do so. It helps mental wellbeing and keeps your mind busy with many other things.

You may want to keep working for as long as you can because you love your job, or feel you have to because you need the money. You may give up work completely to do something you enjoy more or because you feel too unwell. Everybody is different and there is no right or wrong in this situation.

If you remain at work, your employer may be able to help by reducing your hours or adjusting your role. It's important to keep in contact with your employer and to find out about your entitlements, including any paid and unpaid leave that may be available to you.

BCNA has a range of information available for employees and those who are self-employed. There is also information about managing finances, work rights and responsibilities. Visit bcna.org.au or phone 1800 500 258 for more information.

Cancer Council Australia produces a free booklet, *Cancer, Work & You*, which includes practical tips and suggestions. Visit **cancer.org.au** or phone Cancer Council on **13 11 20**.

Most employers are supportive when an employee is diagnosed with breast cancer. However, if you're worried that yours may not be sympathetic or that you're in danger of losing your job or future opportunities in your workplace, you can talk to an adviser at the office of the Fair Work Ombudsman. The adviser can provide advice on your rights and your employer's obligations, and also investigate any complaints. You can talk to an adviser online at the Fair Work Ombudsman website, **fairwork.gov.au**, or in person by calling **13 13 94**. You may also consider talking to an employee representative or union representative in your workplace.

If you're self-employed, you might be able to ease your workload by asking a staff member to step up into your role temporarily, employing someone else and/or reducing your work hours.

If you're receiving a Centrelink payment and decide to return to work, you're required to tell Centrelink in case this has an impact on your payment.

Volunteer work

If you need to give up work because of poor health, you may find that volunteering is a good way to remain active in your community. It can also help you to develop new, or maintain current, networks. Many people with breast cancer are volunteers and they say it helps them to feel 'normal' as well as being very fulfilling.

Over the years I have worked with BCNA as a Consumer Representative and have enjoyed participating in projects that have made a difference. This does help me personally and goes some way to fill the void of work. I am now no longer able to work but gee I still miss it!

QUESTIONS YOU MIGHT LIKE TO ASK ABOUT FINANCIAL AND PRACTICAL MATTERS

People have told us they found it useful to ask these questions about financial and practical matters. Add any others you think of to the list before you go to appointments.

- What will the treatment you're recommending cost?
- Will I be able to work?
- Will I need to travel for treatment?
- Am I eligible for help with travel and accommodation costs?
- How can I find out about help with child care?
- How can I find out about home help?
- Which treatments are covered by my insurance?
- Do you have a list of providers with whom you have a no-gap or known gap agreement?
- What is the gap between the cost of treatment and the private medical insurance rebate?

RESOURCES

Government assistance

Centrelink

humanservices.gov.au or phone **13 27 17**

You can phone Centrelink, visit the website or visit a Centrelink office for more information about Centrelink payments and Health Care Cards.

Working with cancer

Breast Cancer Network Australia

bcna.org.au or phone **1800 500 258**

BCNA provides a range of resources around work and breast cancer for employees, employers and those who are self-employed including rights and responsibilities.

Cancer, Work & You – a guide for people with cancer and their family and friends

cancer.org.au or phone **13 11 20**

Cancer Council has produced a booklet, *Cancer, Work & You*, to support cancer patients and their carers, and educate their colleagues and employers about their situation.

WeCan

wecan.org.au

WeCan is an Australian supportive care website to help people affected by cancer find information, resources and support services. It includes a range of practical information.

Travel assistance

Patient Assisted Travel Schemes (PATS)

bcna.org.au or phone **1800 500 258**

BCNA's PATS fact sheet provides information on each of the different state and territory schemes, including what they pay and how to apply.

Angel Flights

angelflight.org.au or phone **1300 726 567**

Angel Flight Australia is a charity that coordinates non-emergency, free flights for people in medical and financial need, and their carers, who need to travel to or from medical facilities anywhere in Australia. You can talk to your medical team about your suitability for an Angel Flight.

Superannuation

Superannuation and insurance payments for people with a terminal illness

bcna.org.au or phone **1800 500 258**

This fact sheet provides comprehensive information on access to superannuation for people with a terminal illness, including impact on any insurance benefits attached to superannuation policies.

Financial, legal and workplace advice

Cancer Council pro bono program

Phone **13 11 20** or talk to your hospital social worker

This provides free legal, financial and workplace assistance to people affected by cancer who can't afford to pay for advice. This service is means tested, which means not everyone will qualify for free advice.

Cancer Council's pro bono program includes help with:

- drafting wills
- early access to superannuation
- mortgage hardship variations
- credit and debt issues
- insurance claims and disputes
- managing workplace issues before, during and after treatment
- budgeting
- transitioning to retirement
- debt management.

Cancer Council can connect you with a lawyer, financial planner, accountant or HR/recruitment professional who can help you. Usually, you will meet them at their office but, if you're very unwell, they may be able to visit you in hospital or at home. If you speak a language other than English an interpreter can be arranged for you.

National Association of Community Legal Centres

naclc.org.au or phone **(02) 9264 9595**

Community legal centres are not-for-profit organisations that provide free legal advice and information. To find a community legal service in your local area, use the search function, 'Search for a CLC', on the National Association of Community Legal Centre's homepage.

State-based practical and financial assistance

Breast Cancer Care

WA
breastcancer.org.au or phone **(08) 324 3703**

Breast Cancer Care WA provides practical and financial support to people affected by breast cancer. To be eligible for assistance, you must be a permanent resident of Western Australia and be experiencing financial hardship.

Can Assist

NSW
canassist.com.au or phone **(02) 9216 9400**

Can Assist is committed to ensuring that all people in NSW, regardless of where they live, have access to cancer treatment and care. By providing accommodation, financial assistance and practical support to people from rural and regional NSW, Can Assist ensures that country people are given the same opportunities and treatment choices as those who live in city centres.

Hunter Breast Cancer Foundation

NSW
hbcf.org.au or phone **0419 658 875**

The Hunter Breast Cancer Foundation provides people with breast cancer with practical and financial assistance. To be eligible you must live in the Newcastle and Hunter region and have a low income.

The Buderim Private Hospital Cindy Mackenzie Breast Cancer Program

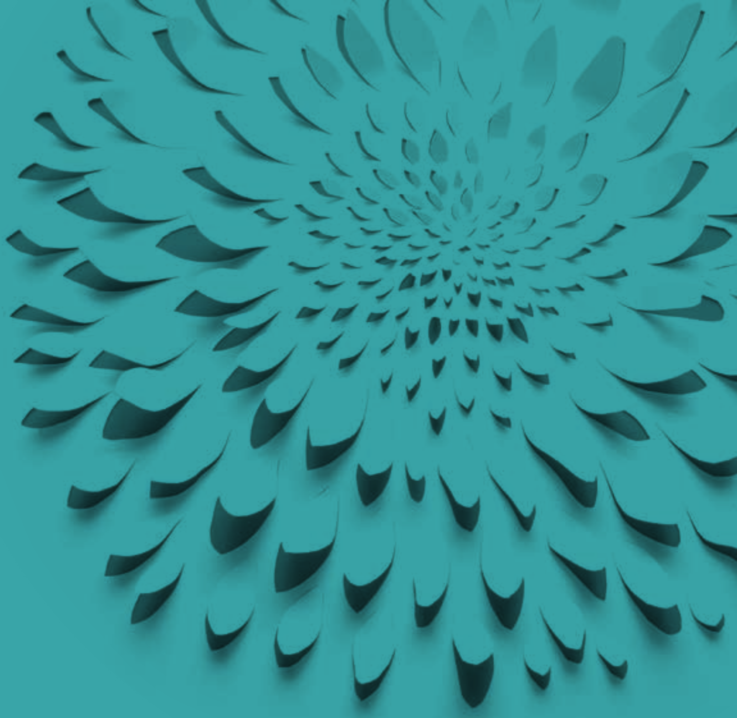
Qld
buderimprivatehospital.com.au or phone **1300 557 710**

The Buderim Private Hospital Cindy Mackenzie Breast Cancer Program provides people affected by breast cancer and living on Queensland's Sunshine Coast with a range of support services.

Louisa DaCosta Trust

SA
louisadacosta.com.au or email: **info@dacosta.net.au**

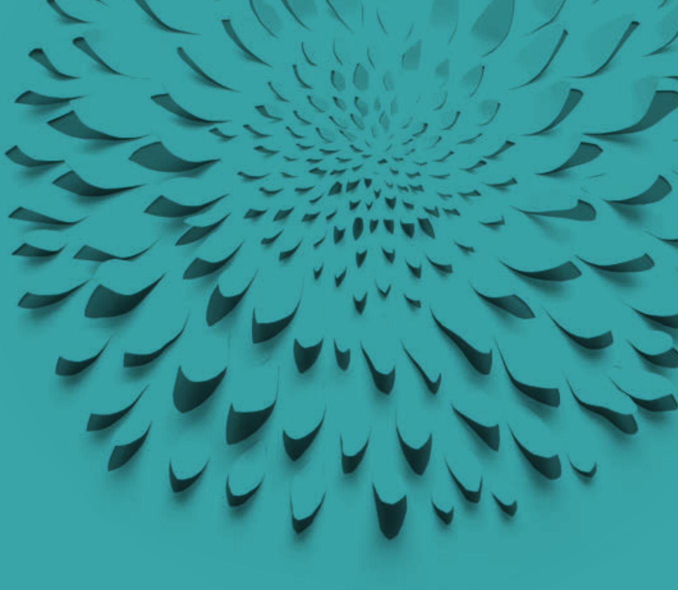
The Louisa DaCosta Trust provides financial assistance for both unplanned illnesses and lifelong illnesses for South Australian patients where government support is not available. The trust considers requests for financial assistance from SA Public Hospital patients requiring practical assistance to help their recovery.



SECTION 6

METASTATIC BREAST CANCER IN YOUNG WOMEN

The fear and uncertainty is a big challenge for me, when I am still so young and have young children.



SECTION OVERVIEW

This section provides information designed to help young women with metastatic breast cancer to live well. You will find a range of information that addresses specific challenges and sources of support for young women, including:

- emotional wellbeing and caring for yourself
- building your support network
- relationships
- talking to children
- employment and returning to work
- child care
- financial and practical support
- questions you might like to ask.

INTRODUCTION

There have been many challenges. Probably the biggest is learning to live with the reality of it all.

Metastatic breast cancer is a life-changing illness for all women, but young women face a unique set of challenges and concerns. From a medical point of view, women with metastatic breast cancer are considered 'young' if they have not yet reached menopause.

If you're in your twenties, thirties or early forties, you may be facing very different issues compared with women in later stages of their lives. You might be enjoying single life, focusing on finding a partner or be partnered/married with a young family. You may just be starting out in your career, pursuing further studies or spending time travelling.

You might be saving for your first home, living in a share house or sharing a house with your partner. You may be thinking of having children – or not thinking about it, if that's something you planned to put off until later. You may be pregnant or caring for a young family, either with a partner or on your own.

There are many crucial changes and milestones happening in a young woman's life that might make a diagnosis of metastatic breast cancer feel especially frightening, confronting and isolating. You may feel as though no one around you understands what you're experiencing, or not know where to start when it comes to seeking advice. Here are some common concerns faced by young women with metastatic breast cancer.

- How do I tell my parents and siblings about my breast cancer?
- How are my family and friends going to take this news?
- How much should I tell my children about breast cancer?
- What impact is it going to have on my relationships?
- Can I continue to work?
- What about my future?

Although you may be experiencing a lot of worry and sadness, it's important to draw on as much support as you can. There are many resources to help young women – and their family, partners and friends – feel more hopeful, connected and empowered.

Things like mental and physical wellbeing; emotional and practical support; being understood and listened to; sexuality and body image. In reality these are the really important things that need to be attended to in order for us to live happy, peaceful and manageable lives. There's no point in just 'surviving' – we want to live our life, just as anyone else does.

EMOTIONAL WELLBEING AND CARING FOR YOURSELF

A diagnosis of metastatic breast cancer can have a powerful emotional impact on you. You may feel overwhelmed at first with a sense of panic, fear or anger at the diagnosis. As a young woman, you may feel a deep sense of loss and grief about your opportunities being narrowed – the chance to pursue your career, to have children or grow your family, or to travel and explore. It could sometimes feel as if the cancer has robbed you of hope and a future just when you were starting out or hitting your stride in life. These feelings are normal and understandable.

Over time, most people come to realise that hope hasn't gone. Your hope may now centre on long periods of disease control and redefining important goals.

I see a psychologist regularly. I do Pilates and boxing, sometimes I do some meditating. I don't let little unimportant things bother me so much anymore. Your whole perspective on life changes.

I'm still living with metastatic disease after five years. It has forced me to do more of the things I love. It has brought me closer to my husband and children.

Understanding how to care for your emotional wellbeing can help you to feel more optimistic and in control. There's no rule for how to handle emotions. Being able to talk about them can be helpful. Sometimes, talking to someone outside your circle of friends and family can be a great relief. Counsellors are an excellent resource, and can include your GP, a psychologist, psychiatrist, social worker or other trained therapist.

For more information about counselling and other sources of emotional support see: Section 4 Living well.

BUILDING YOUR SUPPORT NETWORK

People with cancer like to talk to other people who are going through similar things.

It's easier to look after your emotional wellbeing if you have a strong support network. Friends, partners and family are a crucial part of that support. Many women find connecting with other young women living with metastatic disease is also helpful.

I'm 39, and having metastatic breast cancer can sometimes feel very lonely. I need someone I can talk to openly and honestly about what I'm feeling.

Connecting with women through support groups can help with building new friendships, sharing feelings with someone in a similar position and finding a different perspective. Many women tell us it's difficult to find face-to-face support groups where they can connect with other young women with metastatic disease. You may find it easier to connect through online groups, such as BCNA's online network.

It's important to be mindful that these groups aren't always professionally facilitated, so some of the posts may not align with your own views. You might also like to ask your treating team if they know of other young women with whom you can connect.

Further information

- You can connect with other young women through BCNA's online network at **bcna.org.au**. There is also a private group you can join.
- Ring the BCNA Helpline for information about local face-to-face young women's support groups and whether there's one in your area.
- Young Survival Coalition is an international organisation focused on the needs of young women with breast cancer. Their website includes a bulletin board where you can connect with other young women for support. Visit **youngsurvival.org**.

RELATIONSHIPS

Metastatic cancer is not easy for anyone – family and friends included. There are many ups and downs along the way, and there are times when it's not easy to admit that you do need help.

Relationships with partners, children, friends and family are important sources of support, but sometimes it can be hard to talk to people about your disease or how you're feeling. You might find that some people don't know what to say to you, or what they can do to help, so it's important to be open and honest about how you're going and what you need.

It's also important to be self-aware and know when you need to talk to a professional rather than putting on a brave face for everyone around you, pretending that everything is fine.

Single and dating

If you're single, you may not have one person to whom you can turn in times of need. Instead, you might draw more on your connections with parents, relatives and friends. Some women find that spending time with their parents brings great comfort and support. Others so value their independence that they would rather not have to rely on parents for care and financial support. It can be tempting to avoid asking close friends or family for help as you don't want to feel like a burden.

You may find that, after a diagnosis, some friendships don't provide the level of support and understanding that you need. Concentrate your energy on being with friends who are there for you.

As a single woman, new relationships are a challenge, especially having to manage information about my cancer to potential new partners.

If you're thinking of dating, it can be helpful to talk with friends and family about opportunities to meet new people. Dating or starting a new relationship can be daunting at times. You may have a lot of questions and worries, such as when and how to tell a potential new partner about your diagnosis.

Sometimes being stressed or feeling down can make it more difficult to start a new relationship. A counsellor or psychologist may be able to work through these issues with you and help to clarify your needs and values.

Partners

Always remember to ask how the partner is doing.

A diagnosis of metastatic breast cancer can have a devastating impact on your partner, especially when you might just be starting a new life together or caring for a young family. Your partner may feel helpless or uncertain about how to help, and may find it hard to express their feelings about the situation. Sometimes partners can be afraid that talking about it will be too painful and have thoughts like, 'I have to hold it together!'. If you have young children, your partner may have added feelings of grief and anxiety about the future.

Talking openly and honestly is usually the best way to keep any relationship healthy. Expressing your fears and discussing your needs as an individual and as a couple or family will be helpful. Recognise that, at times, your partner will need space. Having some personal time will help your partner to regroup and regain energy. It's also helpful to schedule some regular time for yourselves as a couple – a regular date night for example. This will give you some quiet time to talk and enjoy each other's company.

Lesbian, gay, bisexual, transgender, intersex and queer/questioning (LGBTIQ) couples

For LGBTIQ couples it can help to seek out health professionals who are sensitive to, and respectful of, your situation. It's important that your partner is involved in your treatment and care – and some couples also find it helpful to talk to a counsellor or join a LGBTIQ support group. See p.151 for information for LGBTIQ couples.

If you're looking for a resource to help your partner understand your needs, see BCNA's booklet When someone close to you has metastatic breast cancer. Visit bcna.org.au to download a copy.

Plans for having children

The diagnosis of metastatic breast cancer brings grief and many challenges. One that is perhaps less often acknowledged is how this affects your thinking about your family and the future. Metastatic breast cancer affects how you feel about plans to have children, and any hopes or plans are further complicated by treatments which can affect fertility – for example, by causing premature menopause. Women who have previously seen their family as complete can still feel devastated that the possibility of having further children is affected by the diagnosis and treatments.

These concerns may not be uppermost in the minds of your healthcare team whose focus is working on a treatment plan so it's vital that you raise these issues if they're important to you. Remember that your healthcare team can't know your thoughts, wishes and priorities unless you tell them. You need to talk to them about any concerns you have around your fertility and explore with them what options may be available to you.

Sexual wellbeing and intimacy

The breast cancer journey has helped put lots of things into perspective. It has made us value each other more, and made us more open to sharing ourselves physically with each other.

Sexual wellbeing is an important part of life for every woman. It's unique to you and is shaped by factors such as desire, self-esteem and body image, your physical and emotional wellbeing, and your libido and levels of sexual satisfaction.

Sometimes you might find that physical side effects and symptoms make it difficult to feel interested in sex or comfortable and confident in your body. They can include vaginal dryness, pain and fatigue and changes to your body such as scars or loss of breast tissue.

If you took the advanced cancer away I'm an otherwise healthy, active 39-year-old woman but now I'm menopausal. I still have a libido but I have symptoms from menopause that make sex less enjoyable and painful.

Loss of confidence may leave you feeling anxious or upset. Often, it's a combination of different factors that affect your libido and sexual intimacy. This can place a strain on an existing relationship, or make it more challenging to establish a new one.

Many women experience these kinds of concerns, and it can be reassuring to know you're not alone. The good news is that there are things you can do to empower yourself and manage challenges with your sexual wellbeing.

Things you can do

- **Give yourself time.** Changes associated with metastatic breast cancer can lead to feelings of grief, loss, anger and sadness. Be kind to yourself, and allow time to process what you have experienced.
- **Explore ways to feel good about yourself and your body.** While some women adjust quickly to the physical changes caused by metastatic disease, others find it more difficult. It could help to visit to the hairdresser, or treat yourself to new lingerie, a massage or manicure. Many women feel that regular exercise is also very beneficial as it can help to improve your mood, reduce anxiety and decrease fatigue. Women who are active also tend to have better body image and self-esteem.

- **Building intimacy.** Just like you, your relationship may go through a process of finding a 'new normal' after diagnosis. If your relationship is going through changes, it can be helpful to think about how you would like it to be, including your preferred level of intimacy. If you feel you've lost interest in sex, remember that sex isn't only about intercourse or foreplay. You and your partner can continue an intimate closeness in other ways. It may not be easy, but it's more important than ever to speak plainly and openly with your partner at this time about ways to meet your separate needs.
- **Seek help if you're feeling distressed.** Some women are comfortable addressing their concerns with their treating team or GP. Talking to a counsellor or therapist is another good option, as they can provide a confidential outlet for your feelings and suggest strategies to help. Some women also find it beneficial to join a support group.

BCNA has developed a free information booklet, *Breast cancer and sexual wellbeing*, to help women during and after treatment. Topics include practical strategies to help with building intimate relationships, the loss of desire, and dealing with physical symptoms like vaginal dryness. Visit bcna.org.au to download a copy.

Parents

My parents look sad when I'm sick, and it's really hard to see. I don't ask 'Why me?', but I do worry about them.

The thought of telling your parents about your diagnosis can be daunting and upsetting. It might help to share the information in stages and give them updates if your condition changes.

Depending on your circumstances and your relationship with your parents, you might decide not to tell them about your diagnosis until you have as much information as possible. Do what feels right for you – and, of course, you may come to think about this differently over time. A health professional such as a counsellor can also help.

You might need to move back with your parents for a time so they can care for you and provide some financial support. If you require additional assistance, ask your GP or a social worker to link you and/or your parents to local services and supports.

TALKING TO YOUR CHILDREN

There are no easy answers on how to talk about advanced disease within your family – it's a fine line between 'protecting' your kids and being honest.

If you have children, especially young ones, concern about their welfare and how they'll take the news of your diagnosis can be the most distressing issue of all. You will undoubtedly worry about how they'll understand and accept your diagnosis and treatment. It may be difficult to find the right words and to know how much to tell them. Discussing cancer with children, and how they react and cope, will be influenced by their age and maturity.

Early childhood

I didn't know what to say about the cancer to the children. We were advised to keep things concrete for them. We have decided to tell them very little about the intricacies of the cancer and just focus on what affects them – things like 'Mum needs to have a nap sometimes because the treatment makes her tired', or 'Mum has chemo at the hospital every week', or 'Today Mummy can't pick you up from kinder because she has a doctor's appointment'.

Young children don't understand chance or bad luck – they think that everything happens for a reason. It's normal for young children to believe in fairies and magic – think about making a wish when blowing out candles on a birthday cake – and this extends to believing they can make bad things happen. If you add these things together it makes sense that a young child might feel they have done something to cause your cancer.

Most young children don't have the ability to express these concerns verbally or to seek reassurance. They commonly respond to fear and guilt by behaving badly or reverting to less mature patterns of behaviour. A five-year-old might become defiant and rough with a younger sibling, or a six-year-old might start to wet the bed. When parents are tired, ill or anxious, it can be hard to see beyond the behaviour to the reason behind it – that it's the child's way of saying, 'I'm scared'.

Sometimes children, and especially girls, respond to anxiety by being extra good, as though this will magically put things right. The danger here is that, while this behaviour might be praised, their distress may not be acknowledged. You can make a real difference by telling your children that the cancer is not their fault. There is nothing they have done to make this happen.

Routine and structure are also enormously reassuring for young children. If you feel exhausted, it can be tempting to let young children stay up late rather than struggle with bed-time. Keeping to a consistent routine as far as possible will help them feel confident and safe. This will ultimately help everyone.

Middle years

My husband contacted the kids' teachers, as we did the first time round, so that they would be informed. My younger one (then nine) was offered the opportunity to see the school psychologist, which she took up enthusiastically. Once or twice a week, while I was having radiotherapy, she would see him and come home with crafty 'get well' messages. It seemed to be a positive experience for her. On the other hand, my 12-year-old was not at all interested in the psychologist option, in keeping with her strong dislike of talking about emotional issues.

From about eight to 12, children start to recognise that sometimes things just happen and that bad things aren't necessarily their fault. You can help them to understand what's within their control and what's not. You're not ill because of anything you did or anything they did.

You're trying to be well. Tell them it's not up to them to try to fix it. Although they now seem to have amazing language skills and can talk endlessly about things that interest them, they still need to be able to play. Play and physical activities are important ways for them to cope with strong feelings or worry. If you don't feel well, it can be a real effort to take children to normal activities, but research shows that these help children to cope. Ask a friend to take them if you aren't well enough or don't feel up to it.

At this age, children start to look for acceptance from others, and a child whose family is different for any reason will often be acutely aware of this.

A friend went to her young child's class to explain why she had no hair – the kids had been asking. I suggested she take some wigs, bandanas and hats to make the session fun.

Children in this age group often try to be brave, and can feel overwhelmed by their feelings as they struggle to be grown-up. This may be in the face of confronting and intensely distressing comments from other children such as, 'Your mum has cancer. She's going to die.' Well-meaning family and friends may tell them to be brave and grownup, which isn't helpful, and may discourage them from expressing their feelings.

You might find it useful to discuss with family and friends how you would like them to respond to your children – for example, telling a grandparent that you're okay with your child expressing their concerns rather than being told to 'be brave'.

Feeling that they're helping out can really improve children's confidence, so having a list of chores is generally a good idea. Make sure you only give them chores they can manage – it's important they don't feel pressure to do something that's difficult for them.

Adolescence

Initially I tried to hide what was happening to me from my daughter. But I realised that she needed to know and when I explained things in small pieces, she coped well.

Adolescents (12-19 years) are just starting to think in abstract terms, although their ability to think logically often fluctuates. They might start to realise how their behaviour affects other people and to be able to see things from someone else's point of view.

Being accepted and part of a group is important and self-esteem can be very fragile. Adolescence is also a time of developing a sense of self and identity, and thinking about adult roles, relationships and responsibilities. Teenagers may need to feel separate from the family while still needing support and reassurance. Having ongoing social activities and opportunities to have fun will help them cope.

It's common for teenagers to have wildly fluctuating and conflicting demands and expectations of their family. Emotions can be very intense and it's easy to feel isolated. Teenagers whose mother has metastatic breast cancer may feel on one hand that no one else understands how different their lives are and, on the other, that they don't want to be treated any differently. Talking to them about how they would like to help is important.

Things you can do

We all want to protect our children from pain and sadness, and we want to be there for them. In the first few days and weeks after your diagnosis your feelings are likely to be very intense. It's tempting to feel that keeping the situation secret from children will protect them from worry.

- Many people say they try not to cry in front of their children, however, it's important for children to know that crying when we are sad is normal.

- However upsetting, talking is essential, and it's important to help children feel that their needs and concerns will be addressed. They need to hear that they matter too, and that you realise they are also affected by the diagnosis.
- Children cope best if they have the chance to talk to you about how they feel, including their fears. Telling your children from the beginning that you won't keep secrets can help them feel less anxious and worried about being away from you for a short time.
- Children may ask difficult questions. Consider what might be behind your children's questions and find ways to encourage them to talk or share their feelings. Emphasising that it's okay for you all to share even very sad feelings can give you an opportunity for greater closeness.
- Information should be adapted to the age and maturity of the child. For young children in particular, it may be better to give information in stages rather than all at once. Remember, too, that young children don't have a good concept of time. When you're four years old, 'three big sleeps' till your birthday seems like forever, so saying that something could happen next year has no meaning for them.
- You can help your older children to feel supported by discussing things they can do in an emergency – for example, when they may need to call an ambulance or which neighbours or relatives to ring.
- Consistency is important for children. This means keeping to their normal routines as much as possible and drawing on the support of your partner, family and friends to help out if you're feeling overwhelmed or need any extra help.

For more information on communicating with your children, you can download the parent's guide on talking to your kids about breast cancer. Visit rethinkbreastcancer.com.

Can Teen is a national support organisation for young people (12-25 years) living with cancer or dealing with a parent, friend or family member with cancer. For more information visit canteen.org.au or phone 1800 226 833.

My sons were nine and seven when I was diagnosed with early breast cancer. They both remember it being a frightening, long time with me being away from them. Since I was diagnosed with metastatic breast cancer three years ago, they have both taken an active role in my care, including attending doctors' and oncology appointments and asking questions. Neither of them remembers our life before breast cancer, but now they finally feel in control.

EMPLOYMENT AND RETURNING TO WORK

For many young women, work can be an important source of meaning, income and wellbeing. Deciding what to do about work after your metastatic breast cancer diagnosis is a personal decision. Take time to evaluate your work and financial situation and what's going to be best for you. Some of the options you may want to consider are to:

- continue working in your current routine
- change your working hours/days to suit your needs – for example, working part-time
- take a temporary break from work
- if practicable and you want to, resign.

Before you make any changes it's important to seek expert financial advice. This will help you understand the impact they could have on your finances or entitlements from Centrelink, superannuation and any insurance you have.

I took 18 months' leave from work. I wanted my hair to have grown before I went back. I also reduced my working hours to better suit me and my family.

Planning to return to work

You may feel uncomfortable about disclosing your diagnosis but, once your employers know, they can help by adjusting your duties, your hours or both. For your part, you should communicate with them regularly and agree on a return to work plan if you're taking leave. It's also important to find out about your entitlements and rights.

Things you can do

- Establish a return to work plan with your employer and review it with them regularly.
- Look at options for flexible/part-time work arrangements.
- Notify employers in advance of any leave you may need to take.
- To assist with memory and concentration, take notes and use a calendar and diary regularly.
- Keep a diary of meetings, tasks, important conversations with your employer and any leave you have taken.
- Some employers offer employee assistance programs. These provide short-term counselling and emotional support free of charge.

Support with discrimination and other workplace issues

Most employers are supportive when they find out that an employee has been diagnosed with breast cancer. However, if yours is not so understanding, or you're in danger of losing your job, you can talk to an adviser at the office of Fair Work Ombudsman. They can tell you about your rights and your employer's obligations and also investigate any complaints. You can talk to an adviser online at the Fair Work Ombudsman website, **fairwork.gov.au**, or by calling **13 13 94**.

- If you're experiencing workplace bullying or harassment, you can contact the Fair Work Commission, which deals with issues such as bullying and unfair dismissal. You can visit the Fair Work Commission website, **fwc.gov.au**, or call **1300 799 675**.
- You could also consider talking to an employee representative or union representative in your workplace.

Cancer Council also has a program that provides free legal, financial and workplace advice to people affected by cancer who can't afford to pay for advice.

ℹ For more information phone Cancer Council **13 11 20**. Cancer Council also produces a free booklet *Cancer, Work & You*, which includes practical tips and suggestions.

ℹ BCNA has a range of information available for employees and those who are self-employed. There is also information about managing finances, work rights and responsibilities. Visit **bcna.org.au** or phone **1800 500 258** for support.

CHILD CARE

If you have young children, child care can be a complex issue. Cancer treatments such as chemotherapy involve periods where you're immunocompromised and your treating team will advise you to avoid exposure to possible sources of infection. This could include keeping young children away from childcare centres to reduce the risk of their passing on a cold or other infection.

If you have limited options for child care, you may need extra assistance. The national Child Care Access Hotline **1800 670 305** can provide general information about government financial assistance for child care such as the Child Care Subsidy and Additional Child Care Subsidy. The Family Assistance Office, set up by the Australian Government, provides information for families including payments and services to help when you're raising children. It includes information on:

- child care services in your local area for which you may be eligible
- services operated privately and by your local council or shire
- government financial assistance for child care, such as the Child Care Subsidy.

For further information about child care assistance you can visit the Department of Human Services website servicesaustralia.gov.au or phone 13 61 50.

The Australian Government's website **childcarefinder.gov.au** also provides information on:

- the types of care available (e.g. long day care, family day care, occasional care and in-home care)
- the location of child care services in your area, and any possible vacancies
- the fees charged
- how to choose a quality child care service
- how the Australian Government can help with the cost of your child care (Child Care Subsidy).

Additional Child Care Subsidy

It's so difficult sole parenting young children with little to no support. Managing the day-to-day housekeeping and cooking has been challenging.

If you already receive the Child Care Subsidy, you might be eligible for extra hours under the 'exceptional circumstances' provision. If your illness has caused hardship and you're having difficulty paying your child care fees, you may be eligible for the temporary financial hardship subsidy. Your child care provider will have more information.

If your children are not in approved child care and you would like to access this while you're receiving treatment, you can contact the Child Care Access Hotline on **1800 670 305** or TTY Service **1800 810 586**.

In-Home Care Program

The Australian Government's In-Home Care Program provides child care in your home through an approved educator. The program has limited places and, to be eligible, you must meet a set of criteria.

ℹ **To find out more about your eligibility for the program, contact the Department of Education and Training on 1300 566 046 or visit education.gov.au/in-home-care.**

Mummy's Wish

Mummy's Wish is a Queensland-based organisation that provides practical support to families with a child under 12 while a mother is having cancer treatment. It's available across Australia, not just in Queensland.

Support includes help with child care options, housecleaning and housekeeping, provision of meals, financial assistance and food vouchers.

ℹ **For more information, phone 1300 045 741 or email contact@mummyswish.org.au.**

Local government

Some local councils provide home help services, and may also be able to help with child care. You can contact them directly, or talk to your GP, oncology nurse or social worker to find out what services are available in your area.

FINANCIAL AND PRACTICAL SUPPORT

Financially it has been a struggle, as I haven't been able to have a full-time job since being diagnosed.

Most young women find their diagnosis affects them financially in some way. This includes costs not covered by Medicare, loss or reduction of income and incidental costs associated with treatment such as parking, travel and child care. Many people are living with financial pressure before metastatic breast cancer – you may have mortgage repayments, rent, university fees and other commitments.

For a young woman, the out-of-pocket costs of cancer diagnosis and treatment can add to these financial pressures, especially if you haven't had the opportunity or time to build up your savings. If you have to reduce your working hours or stop working, loss of income can leave you unable to pay regular bills. There are services that can assist you, although some of these have eligibility criteria such as a financial means test.

Your hospital social worker, GP or breast care nurse can help you find services that may be appropriate. This could include specific local support such as:

- one-off payments to help with utility bills (gas, electricity, water)
- interest-free loans
- discounted car parking at hospitals and clinics.

You can also talk to your bank or home loan provider if you're having trouble meeting your loan repayments.

Government payments and allowances that you might be able to access include:

- Centrelink payments
- travel reimbursement schemes for people in rural and remote areas
- taxi concession programs.

Cancer Council and Salvation Army also offer a range of financial assistance schemes.

For more information about financial support, see Section 5: Financial and practical matters.

QUESTIONS YOU MIGHT LIKE TO ASK

Young women have told us they found it useful to ask these questions after being diagnosed with metastatic breast cancer. Add any others you think of to the list before you go to appointments.

- Where can I get help and support?
- Who can I talk to about how I'm feeling?
- Who can I talk to at my treating centre if I have concerns about my children, partner or family?
- Is there support available for my partner and family?
- Is there a support group available for young people?
- Can I continue to work while I have treatment?
- What financial support is available to me? Who is the best person to speak to?
- What practical support (e.g. child care) is available to me? Who is the best person to speak to?

RESOURCES

Breast Cancer Network Australia (BCNA)

Australia
bcna.org.au or phone **1800 500 258**

BCNA's My Journey online tool has up-to-date information about metastatic breast cancer treatment and care. It also has information on supports available for young people, including webcasts and podcasts addressing a variety of issues. Go to **myjourney.org.au** to sign up.

BCNA's online network

Australia
bcna.org.au or phone **1800 500 258**

BCNA's online network is a good place to go if you think that talking about your thoughts and feelings online 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 exclusively for young people with metastatic breast cancer where only members of the group can read the discussions. If you need help to access the private group please call BCNA for support.

Breast cancer and sexual wellbeing booklet

bcna.org.au or phone **1800 500 258**

This booklet outlines different strategies to help women manage a range of sexual wellbeing issues, including how to build intimacy with your partner, a loss of desire and the physical symptoms of menopause.

Breast cancer in young women

breast-cancer-in-young-women.canceraustralia.gov.au

This website, developed by Cancer Australia, provides information for women diagnosed with breast cancer under the age of 40 and includes information on metastatic breast cancer.

Young Survival Coalition

US
youngsurvival.org

Young Survival Coalition is an international organisation focused on the needs of young women with breast cancer. Their website includes a bulletin board for support along with a detailed navigator booklet specifically for young women with metastatic breast cancer, called Metastatic Navigator: A Young Woman's Guide to Living with Metastatic Breast Cancer. The booklet contains information on treatment options, emotional and practical needs, relationships, self-care, sexual wellbeing, sharing your diagnosis with others and more.

'Let's Talk About It' video series for young women Living Beyond Breast Cancer

US
lbbc.org

This US-based breast cancer organisation has developed a series of helpful videos, with stories from young women affected by breast cancer. There are a number of videos within the series that focus specifically on issues for young women with metastatic breast cancer. The short YouTube videos feature young women with lived experiences of metastatic disease.

Work After Cancer website

Australia
workaftercancer.com.au

This website is a resource to support work during and after a cancer diagnosis. It's for people diagnosed with cancer, health care providers and employers.

Cancer, Work & You – a guide for people with cancer and their family and friends

cancer.org.au or phone **13 11 20**

Cancer Council has produced a booklet, Cancer, Work & You, to support cancer patients and their carers, and educate their colleagues and employers about their situation. The information may be helpful to you if you decide to work during treatment or want to make changes to your current work arrangements. The resource outlines options you may want to consider, such as flexible working arrangements, along with some of your rights and entitlements.

Resources for children, teens and parents

Talking to kids about cancer

cancer.org.au or phone **13 11 20**

Produced by Cancer Council Australia, this booklet describes ways to talk to children about cancer, with specific suggestions for age groups from infancy to 18 years. Cancer Council also provides a list of books about cancer.

Medikidz comic: Understanding metastatic breast cancer (8-12 years)

bcna.org.au or phone **1800 500 258**

The Medikidz comic explains metastatic breast cancer through comic adventures and helps both children and parents understand a difficult topic in an engaging way. This resource is available in hard copy and can be ordered from the BCNA website or by calling **1800 500 258**.

Parenting through cancer - A guide for parents of adolescents and young adults dealing with cancer in the family

canteen.org.au or phone **1800 226 833**

Developed by CanTeen, this booklet is designed for parents affected by cancer who have adolescent or young adult children. It provides insights into common questions and issues that many parents with cancer face.

Kids Helpline

Australia
kidshelpline.com.au or phone **1800 551 800**

A 24-hour telephone and online counselling service for five to 25-year-olds.

CanTeen

Australia
canteen.org.au or phone **1800 226 833**

CanTeen not only supports young people aged 12 to 25 living with cancer, but also young people whose parents have cancer, including free online and phone counselling.

Headspace

Australia
headspace.org.au or phone **1800 650 890**

Run by the national Youth Mental Health Foundation Headspace provides mental health services to people aged 12-25 years.

Young Carers Network

Australia
youngcarersnetwork.com.au

Young Carers Network provides information and support for people under 25 who care for someone with an illness, disability or mental health issue.

youthbeyondblue

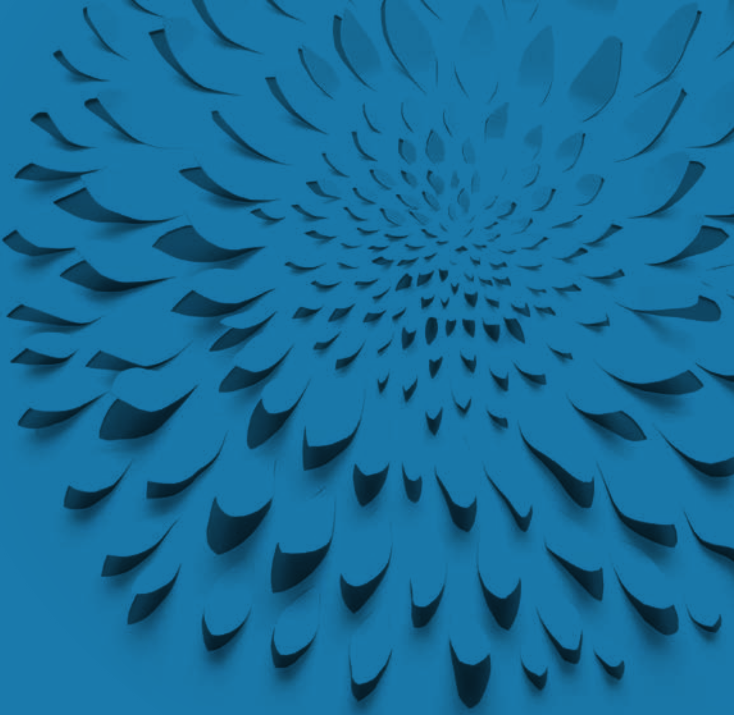
Australia
youthbeyondblue.com or phone **1300 224 636**

Supports young people aged 12-25 dealing with depression, anxiety or mental health problems.

Griefline

Australia
grief.org.au or phone **1800 642 066**

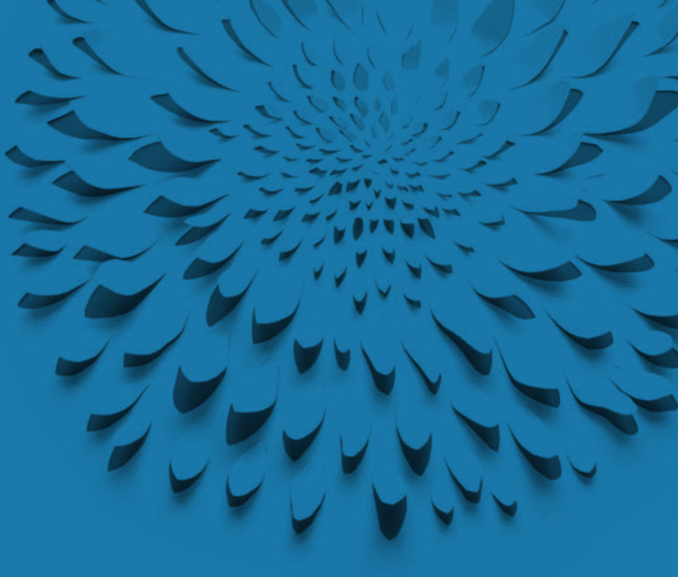
Griefline offers phone and online counselling.



SECTION 7

METASTATIC BREAST CANCER IN MEN

There will be hurdles along the way, but never give up hope.
– Matthew



SECTION OVERVIEW

This section is for men who have been diagnosed with metastatic breast cancer and includes information on:

- recognising that men can get breast cancer too
- dealing with a diagnosis of metastatic breast cancer
- getting support and connecting with others
- where to find more information
- questions you might like to ask.

METASTATIC BREAST CANCER IN MEN

Most people, men and women, feel devastated when they're told they have metastatic breast cancer. You may have lived through the trauma of being diagnosed and treated for early breast cancer and believed you were finished with the disease. Or your diagnosis might be your first experience of breast cancer.

For men, this diagnosis can be particularly confronting and bring with it many different challenges. These may include difficulty finding breast cancer information tailored to your needs, stigma around having what is seen to be a 'woman's disease', and feelings of isolation and being on your own.

This chapter is written to help you understand you're not alone. We hope that Hope & Hurdles provides helpful information and support.

GETTING INFORMATION

There was just no information. There was nobody really to talk to, and to be honest I felt like I didn't belong anywhere. That was really hard. — **Ross**

As a man diagnosed with metastatic breast cancer, you'll look for information and support tailored to your needs. While this Information Guide is written primarily for women, much of the information is relevant for men and we hope this chapter will meet some of your specific needs.

BCNA's booklet *Men get breast cancer too* may also be helpful. Written for men diagnosed with early breast cancer, it includes some basic information about breast cancer, including metastatic breast cancer, and ways to deal with some of the challenges men may face after a diagnosis. The booklet also lists other resources and counselling services available for men. Visit BCNA's website **bcna.org.au** to download a copy.

DEALING WITH A DIAGNOSIS

In terms of breast cancer, my perception is that it's still perceived as being a female disease, and if a man gets it there's got to be something wrong. Many men are totally reluctant to tell people about it. — **Eric**

As a man who has been diagnosed with metastatic breast cancer, you probably have a strong sense of disbelief and shock. There is little awareness of male breast cancer in the general population so men are often surprised by their diagnosis. They can also feel isolated and even stigmatised by their disease. Having breast cancer can change how you feel about your body and about who you are – your sense of identity.

You may feel embarrassed telling other people about your diagnosis and, sometimes, people may react with discomfort or disbelief. Telling family and a few close friends first may help you become familiar with people's reactions. Taking the lead and talking openly about your cancer can give the message that you're comfortable discussing it and that there is absolutely nothing to be ashamed of. It can be challenging for men to find others to connect with in a similar situation, so it's important to know that help and a range of supports are available to you.

Some men are diagnosed with metastatic breast cancer from the start. This is called 'de novo' breast cancer.

For more information about de novo breast cancer see Section 8: Metastatic from the start

It never bothered me at all that breast cancer was somehow not a 'masculine thing'. I knew it was uncommon amongst males, but it never bothered me. I shared my story from the beginning. — **Ross**

GETTING SUPPORT

The family support, the dog, the neighbours and the Dragons Abreast ladies – it was all a significant contribution to my welfare. Support networks are beyond value for cancer survivors. If you haven't got it, I really think you're up against it. Nobody has to be alone in the world.
— Richard

As a man with metastatic breast cancer, you should receive the same level of support you would for any other type of cancer. But, because it's so uncommon, even health professionals can struggle to understand what support you really need. Fortunately, following an increased focus on the needs of men with breast cancer by organisations such as BCNA, this is beginning to change.

Looking after your wellbeing is easier if you have a strong support network including friends, partners and family. Some men also find professional counselling helps.

Finding support

- Your GP may be able to refer you to a counsellor and provide you with a mental health care plan which entitles you to a number of Medicare-subsidised appointments with a psychologist or other mental health care professional.
- If you're still working, your employer may provide some free, confidential counselling sessions through an employee assistance program.
- In some states and territories, you can access counselling through Cancer Council **13 11 20**.

You can have lots of resources and information and pamphlets and stories and newsletters, but the most powerful thing for me, to be honest, has been my friendship with other men who have been diagnosed. That has meant the world to me in terms of being able to share things that only we 'get'! — **Ross**

Some men find it valuable to connect with others who are living with metastatic breast cancer. However, it can be difficult to find support groups tailored to your needs where you feel included and comfortable. You may like to ask your breast cancer specialist, breast care nurse, GP or social worker whether they know of other men you could contact or suitable support groups. You could also gain support from other cancer groups.

What really made an impression on me with my support group was the way they just listened. I cannot tell you how empowering it was for me. It was like this huge emotional weight had been lifted off my shoulders.

You may find it easier to connect through online groups, including BCNA's online network. There are also overseas websites designed for male breast cancer survivors but, as these groups aren't always professionally facilitated, some of the posts may not align with your own views and you may not be able to access all of the resources referred to from Australia. A list of online support groups and male breast cancer resources can be found in the resources section.

Anxiety and depression

Being diagnosed and living with breast cancer can take its toll on both your physical and emotional health. It's common to experience a range of emotions, including stress, sadness, worry and anger.

Some men experience these feelings intensely and for long periods of time. They can find it difficult to function each day and may be reluctant to participate in activities they once enjoyed. If this is happening to you, you may be experiencing anxiety or depression. While anxiety and depression are common after a breast cancer diagnosis, they are often overlooked and undertreated. They are, however, very treatable.

If you feel sad or worried for long periods of time, or find it difficult to function each day, you may like to speak with your GP, who can discuss treatment options that might be helpful to you. The strategies recommended will depend on your personal situation and may include counselling, exercise and spending more time doing the things you enjoy. Antidepressant medications can also be prescribed in some cases.

For more information on counselling, anxiety and depression see Section 4: Living well.

TREATMENT

Treatment for metastatic breast cancer aims to stop the cancer from growing or slow its growth as much as possible, and to control pain, discomfort and any other symptoms.

There have been very significant advances in treatment in recent years as research has provided a better understanding of breast cancer. There has been no research specifically for men with metastatic breast cancer but men can benefit from the new treatments.

Men usually have the same treatments as women and those recommended for you will be influenced by a range of things, including the pathology or ‘subtype’ of your breast cancer. There are currently three main breast cancer subtypes that guide treatment recommendations:

- hormone receptor positive
- HER2-positive
- triple negative.

Most men with breast cancer have the hormone receptor positive subtype.

ℹ **For more information about treatment see Section 3: Treatment for metastatic breast cancer.**

QUESTIONS YOU MIGHT LIKE TO ASK

Men have told us they found it useful to ask these questions when they were diagnosed with metastatic breast cancer. Add any others you think of to the list before you go to appointments.

- What will my treatment involve?
- What side effects should I expect from the treatment?
- Is there a clinical trial suitable for me? What are the advantages or disadvantages of joining a trial?
- Who do I contact if I have any concerns about treatment or its side effects?
- Who can I talk to about how I am feeling?
- What support is available for men with breast cancer at my treating centre?
- Are there any men's support groups or organisations that provide support for men affected by breast cancer?

RESOURCES FOR MEN

- See BCNA's Men with breast cancer webpage at **bcna.org.au**. You can also connect with other men through a private group on the online network.
- Cancer Council can put you in touch with counselling and support groups. Call **13 11 20** or visit **cancer.org.au**.

You can also access general information and resources on the following websites.

Cancer Australia

Breast cancer in men website
breastcancerinmen.canceraustralia.gov.au

Breast Cancer Now

UK
Men and breast cancer webpage and booklet

breastcancernow.org

Cancer Research

UK
Breast cancer in men webpage

cancerresearchuk.org

American Cancer Society

USA
Breast cancer in men website

cancer.org/cancer

Breastcancer.org

USA
Male breast cancer webpage

breastcancer.org

Breast Cancer Network Australia (BCNA)

bcna.org.au or phone **1800 500 258**

BCNA's My Journey online tool has up-to-date information about metastatic breast cancer treatment and care. It also has information on supports available for men, including webcasts and podcasts addressing a variety of issues. Go to **myjourney.org.au** to sign up.

Men get breast cancer too

bcna.org.au or phone **1800 500 258**

BCNA's booklet *Men get breast cancer too* may be helpful. Written for men diagnosed with early breast cancer, it includes some basic information about metastatic breast cancer and information on ways to deal with some of the challenges men may face after a diagnosis. The booklet also lists other resources and counselling services available for men. Visit **bcna.org.au** to download a copy or phone **1800 500 258**.

Male Breast Cancer: Taking Control

BC Publishing, Australia
breastcancertakingcontrol.com.au

Written by prominent Sydney radiation oncologist Professor John Boyages, this book provides a wealth of information on everything from diagnosis and treatment options for men to tips on getting access to the right information, and practical and emotional supports. The book has helpful take-home messages at the end of each chapter, and features inspiring stories from men. Visit the above website for more information on how to order the book and other publications in this series or call BCNA to request a copy.

Cancer Australia

breastcancerinmen.canceraustralia.gov.au

Cancer Australia's Men can get breast cancer too website includes information about breast cancer treatment and care, as well as information on depression and anxiety, fatigue, loss of libido, issues with self-esteem and body image, impact on family and friends, how to tell others about your diagnosis, and the impact your diagnosis may have on your work.

Cancer Australia's fact sheet Understanding breast cancer in men provides a brief overview of breast cancer in men. It can be ordered or downloaded from the publications section of **canceraustralia.gov.au**.

Look Good ... Feel Better for Men

lgfb.org.au

This is a free workshop-based program that teaches men diagnosed with cancer to manage some of the appearance-related side effects of their treatment. It aims is to help improve people’s confidence and body image.

Cancer Council 13 11 20

cancer.org.au

This is a free telephone information and support service run by Cancer Councils in each state and territory. Trained health professionals are available to speak with you about breast cancer. They can also arrange for you to speak with a counsellor.

Breast Cancer in Men

USA
lbbc.org/infocusmen

This comprehensive information booklet from USA-based organization Living Beyond Breast Cancer provides excellent information on the emotional and support needs of men who are diagnosed with breast cancer, including a focus on gender identity issues, stories from men, and representative images of men who have undergone mastectomies. The final section of the booklet provides a good overview of available resources for men, although it’s mostly written with a US focus.

Male Breast Cancer Coalition

USA
malebreastcancercoalition.org

The Male Breast Cancer Coalition (MBCC) is a USA-based not-for-profit advocacy organisation. Its aim is to educate and promote awareness about breast cancer in men, and provide information and support resources. It includes stories of male breast cancer survivors from around the world. It also features plenty of resources for men and their families on topics such as treatment options, male breast self-examination.

HIS Breast Cancer Awareness

USA

hisbreastcancer.org

This is a USA-based organisation created to provide education and raise awareness on the causes, treatment(s), emotional experiences and stigma encountered by men who are living with breast cancer. The organisation also publishes a blog.

MaleBC.org

Australia

malebc.org

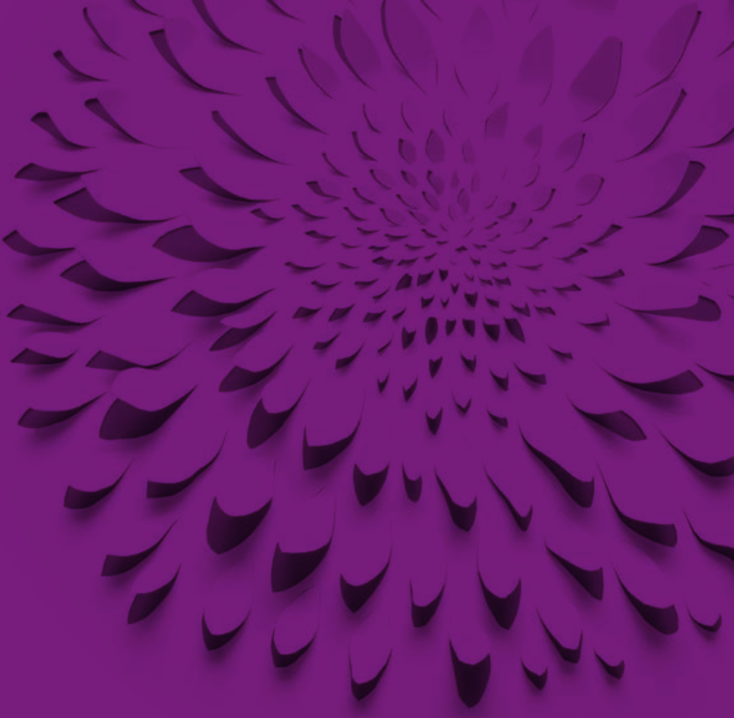
This Australian website is an information and awareness hub, which has been established by an Australian male breast cancer survivor.

Entering a world of pink

USA

malebreastcancerblog.org

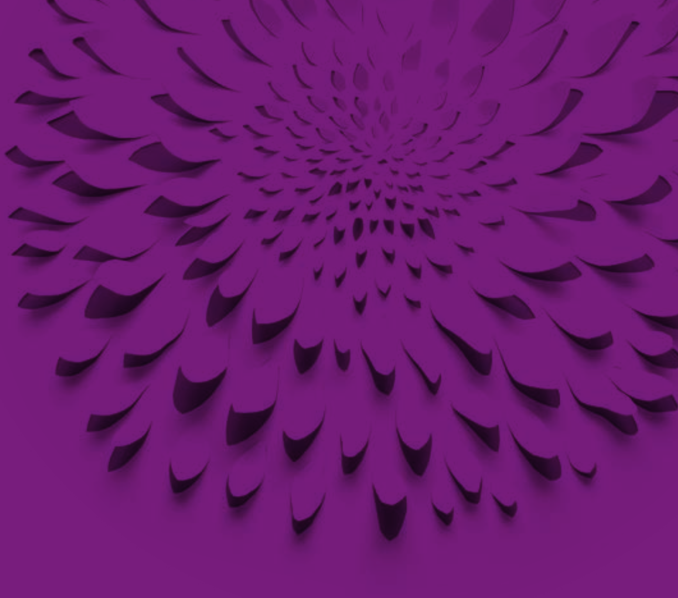
Entering a World of Pink is the personal blog of an American man diagnosed with breast cancer. In the blog, he shares his experiences with his diagnosis, treatment, and the latest research.



SECTION 8

METASTATIC BREAST CANCER FROM THE START

My biggest frustration was getting people to understand. People make an assumption that I had breast cancer a first time but I had no understanding about any of it, including the treatment or how I would cope.



SECTION OVERVIEW

This section is for people whose first diagnosis of breast cancer is metastatic and includes information on:

- how having metastatic breast cancer from the start might influence treatment
- the role of breast surgery
- where to find more information and support
- questions you might like to ask when diagnosed with de novo metastatic breast cancer.

Despite having an amazing medical oncologist and family support, I really struggled in those first few months after being diagnosed de novo. A good friend diagnosed with early breast cancer just six months before me and treated at the same cancer centre had assured me of the amazing supportive care I'd receive from the many breast care nurses at the centre, yet I never saw one. My friend told me about the fantastic workshops and information sessions that the hospital ran yet, when I asked about them, I was told that they weren't suitable for people like me. But I was struggling with the side-effects of chemo, with hair loss, with fatigue and anxiety. I felt so out of my depth and just wanted to connect with others going through what I was going through. What saved me was the metastatic breast cancer support group that I was eventually hooked up with. It took several months, but I had finally found a group of people who understood what I was going through and could provide the support I so desperately needed.

Being diagnosed as metastatic from the start can feel totally overwhelming - and like a double blow. Not only are you dealing with finding out you have breast cancer, you're also dealing with the fact that the cancer has progressed to such a point that it can't be cured. It's natural to feel devastated by the seriousness of the diagnosis, to feel confused by why the cancer has spread so quickly, and to feel angry that it wasn't picked up earlier.

You may feel you've been plunged into the metastatic breast cancer world without the knowledge and experience that comes with a prior diagnosis of early breast cancer. People with metastatic breast cancer have reported feeling excluded from the wider breast cancer support community. This is often exacerbated in those diagnosed de novo as some information sessions or support groups may only be available to those who have an early, not metastatic, diagnosis. Yet people with a de novo diagnosis typically know very little about breast cancer and are struggling to understand what's happening to them. This information and supportive care gap can make a diagnosis of de novo metastatic breast cancer even harder. If this has happened to you, you might feel overlooked, that your needs are not recognised, or that you have been excluded or even stigmatised.

The information in this section is designed to help you make sense of all the information you're receiving. It has been written with the input of people who, like you, have been diagnosed with metastatic breast cancer from the start. They've told us how important it is to share messages of hope, and reassurance that many people with metastatic breast cancer live for years with their cancer under control.

It's also important for you to know that, as we gain a better understanding of the needs of people with metastatic breast cancer, more metastatic breast care nurses are being trained to address the gap in supportive care. In the meantime, both information and some support groups have been tailored to meet your specific needs. Ask your treating team what's available for you.

This section also contains tips to help you navigate the health care system and learn about how other people have coped so you feel less alone. You'll find more general information about treatment, living well and financial matters in the other sections of this *Information Guide*.

THE BASICS

When breast cancer comes back after an early breast cancer, doctors call it a recurrence. It happens when a small number of cancer cells survive the initial treatment and travel to other parts of the body, growing into new cancers called metastases, or metastatic breast cancer. Once metastases occur, although treatment is often very effective in controlling the cancer, the cancer is generally not curable. However, recent treatment innovations have meant that some people are now able to manage their disease as if they were living with a chronic illness, with ongoing treatment providing periods of wellness between periods of ill health.

Sometimes people are found to have metastatic breast cancer when they're first diagnosed. This is called 'de novo' metastatic breast cancer. This isn't common. It only occurs in about 5-10 per cent of diagnoses, and is more frequent in men than women.

When people hear you have breast cancer, they may assume you'll just have some treatment then be okay. If they know people who have had this experience they may not understand that yours will be different. They might ask about your treatments before you know the answers yourself, which can make conversations challenging and frustrating.

It can be really hard to come to terms with the fact that you had a normal life yesterday but now you're wondering how you're going to get through each day. However, in time this early phase will pass. Take your time to deal with your news.

BREAST CANCER: A BRIEF OVERVIEW

Basic information is what's needed when you first hear the news. What is breast cancer? What are the different types of treatment for my specific diagnosis? Will the treatment be continuous from now on, or will there be breaks? What tests will be needed?

Cancer is a malignant growth or tumour resulting from an uncontrolled division of abnormal cells in a part of the body. Breast cancer is cancer that starts in the breast tissue.

Breast cancer can start in the ducts or lobules of the breast. Sometimes cancer cells stay in the ducts and lobules. This is called non-invasive breast cancer – ductal carcinoma in situ (DCIS) and lobular carcinoma in situ (LCIS). If the cancer cells grow into the surrounding breast tissue, this is called invasive breast cancer. The site where the cancer starts is called the primary cancer. Breast cancer cells may travel in the lymphatic system to lymph nodes in the armpit (axilla). Breast cancer confined to the breast or breast and axilla is referred to as early breast cancer and treatment is given with the intent of cure.

When breast cancer cells travel through the bloodstream to other parts of the body such as the bones, lungs or liver, it's called metastatic breast cancer. Metastatic breast cancer can be treated with the expectation of controlling, but not curing, the cancer.

Doctors seldom know why one person develops breast cancer and another doesn't, and most people who have breast cancer will never be able to pinpoint an exact cause. What we do know is that breast cancer is always caused by damage to a cell's DNA.

People with certain risk factors are more likely than others to develop breast cancer. A risk factor is something that may increase the chance of getting a disease. Some risk factors (such as drinking alcohol, postmenopausal obesity and lack of exercise) can be avoided. But other risk factors (such as ageing and having a family history of breast cancer) can't. Some people with risk factors will never develop breast cancer.

ⓘ **For more information about breast cancer and risk factors, go to BCNA's website bcna.org.au.**

The Glossary on p.266 provides definitions for commonly used breast cancer terms that you may hear about or come across if you're researching breast cancer online. If there are any terms you're unsure of, make a note and ask your medical oncologist or cancer nurse to explain them to you.

It's normal to feel overwhelmed as you and your family try to learn not only about breast cancer, but also metastatic breast cancer. You're likely to be given a great deal of information which is completely new to you.

I couldn't make sense of it, none of it. It took a long time to get my head around what it all meant.

FEELINGS

Finding out you have metastatic breast cancer brings up different feelings for different people. Some tell us they're relieved to finally get a diagnosis and a treatment plan after undergoing many test and scans. Others say they experience feelings of guilt about their diagnosis. They wonder whether they would have still developed metastatic disease if their breast cancer had been detected earlier or they had done something differently. Others feel angry that their cancer wasn't detected earlier.

The truth is that it's rarely anyone's fault. You shouldn't blame yourself, or waste your energy trying to change things you can't. Sometimes the cancer simply grew too fast to be detected before it metastasised but, even then, there will be treatments to help you.

If you have been diagnosed with metastatic breast cancer from the start, you may feel a sense of isolation from the broader breast cancer community because your experience of being diagnosed and the treatment that follows will be different. At first, you might find it hard to find the support you need but it's important to know that support is available.

Take your time to make decisions and, if you can, nominate someone you trust to deal with all of the questions from family and friends in a pragmatic way that gives the facts without getting too emotional. It can really take the pressure off and avoid the exhaustion of having to explain things over and over.

WHAT HAPPENS NEXT?

I wanted more information about the types of test and scans and what each one did.

What happens after your diagnosis depends on how the metastatic breast cancer was found and what tests have already been done. When metastatic breast cancer is suspected, you will be referred to a medical oncologist who will become the lead provider for the management of your cancer.

If your breast surgeon made the diagnosis, the primary cancer in the breast will probably have been biopsied or removed and analysed in pathology. If the surgeon has concerns that the cancer has spread from the breast to more distant parts of the body, you will need to have scans and other tests. If abnormalities are found on the scans, a biopsy of the abnormality may be undertaken to determine if it's metastatic breast cancer. While a biopsy is ideal, it's not always possible due to the site or position of some abnormalities.

If your symptoms have been investigated by your GP or another doctor and results suggested cancer, your medical oncologist will arrange for the necessary tests and scans.

In either scenario, a biopsy is required to confirm a diagnosis of metastatic breast cancer and to determine its subtype by analysing the receptor results. Receptors are proteins on cancer cells that hormones or other proteins can attach to and stimulate cancer cells to grow. These results will influence the type of treatment recommended for you.

In de novo metastatic breast cancer, if the cancer in the breast (the 'primary' breast cancer) has already been biopsied or removed, the pathology results will have confirmed the diagnosis of breast cancer and the subtype. Your oncologist will want to confirm that another area of concern is a breast cancer metastasis and that the receptors are the same as the cancer in the breast. This isn't always possible because of the position of the metastasis – most commonly, if it's in the bone. In this case, your oncologist may have to rely on other test results to determine whether you do have metastatic breast cancer. Often scans and tumour marker blood tests are enough to confirm that there are metastases present so a biopsy of the area may not be required.

Some people find themselves in a rare situation where it's unclear whether a metastasis is from breast cancer or another type of cancer. Here, the approach is to monitor the situation and repeat relevant tests.

When metastatic disease is found through investigation of symptoms, rather than a breast lump, a biopsy of the abnormality is usually the way the diagnosis is made. If the biopsy suggests that the primary site may have been in the breast, investigations will be undertaken to determine if this is the case – such as mammograms, breast ultrasounds and breast biopsy.

For more information on tests and scans, including mammograms and ultrasounds, see Section 9: the Glossary.

TREATMENT

Treatment for people with de novo metastatic breast cancer follows the same general principles as for those who have had a previous early breast cancer diagnosis. For most people the backbone of treatment is systemic therapy such as hormone-blocking therapy, targeted therapy or chemotherapy. Treatment is guided by the subtype of breast cancer.

Clinical trials

When you're diagnosed with metastatic breast cancer, your oncologist might talk to you about a clinical trial that may be beneficial for you.

Participating in a clinical trial could give you access to a new type of treatment or a new way of receiving treatment, which could be important if a new treatment is showing some benefits for your particular subtype of cancer.

For more information about treatment including clinical trials, see Section 3: Treatment for metastatic breast cancer.

How having metastatic breast cancer from the start might influence treatment

There are some advantages for people diagnosed with de novo metastatic breast cancer compared with people who have progressed following an early breast cancer. The main advantage is that their cancer is ‘treatment naïve’, meaning it hasn’t previously been exposed to any anti-cancer treatments and is therefore likely to be more responsive. In fact, there have been reports of small numbers of people in this situation with no evidence of metastatic breast cancer following treatment. In addition, there are more treatment options available than for those who have already ’used up’ some of their options.

The one positive was that my oncologist said that he more or less had an open book of treatments that he could offer me.

Another positive some people describe is that they can feel the cancer in their breast getting smaller once treatments starts. Mammograms and breast ultrasounds may be used to check that the cancer in the breast is responding to treatment. It can be reassuring to know that treatment is working.

For more information about coping with the emotional impact of metastatic breast cancer, see Section 4: Living well.

ROLE OF BREAST SURGERY

Surgery to the breast is considered a local therapy, meaning it only removes the cancer in the breast tissue. Surgery to remove a cancer in the breast is usually not recommended when a person has metastatic breast cancer, or at least not initially. Treatments that work systemically to destroy cancer cells anywhere in the body will usually be recommended first. These treatments work simultaneously on the cancer cells in the breast and the metastases.

At the moment, there's no clear evidence to suggest that removing the cancer in the breast tissue will lead to a better outcome. However, surgery is usually recommended if there's a risk the cancer could cause troublesome local problems in the future, such as ulceration through the skin. Alternatively, your oncologist might recommend radiotherapy to the breast to shrink the cancer and control its growth. In this case, you'll be referred to a radiation oncologist who can talk to you about potential benefits. For some people there may be psychological value in having the primary cancer in the breast removed.

Decisions about surgery to the breast (mastectomy to remove the whole breast or lumpectomy to remove just the lump and some surrounding tissue) will be individualised and should be a joint decision between you and your medical team. Some people may also want to discuss whether breast reconstruction is possible if mastectomy is recommended. If you're concerned about whether breast surgery should be part of your treatment plan, ask your oncologist what options are available for you.

If you saw a breast surgeon when you were first being tested for breast cancer, you may want a referral for a second opinion on the role of breast surgery in your particular situation.

If you're being treated in a centre that offers multidisciplinary care, your surgeon will remain part of your multidisciplinary team and will be up to date with the treatment you're receiving.

HOW CAN I FIND MORE INFORMATION?

Many people tell us they sought online information when they were first diagnosed with metastatic breast cancer. It can be hard to know where to start, especially when you don't have previous experience of breast cancer. If you're going to search online, you may first want to think about how the information might make you feel. If you think it might be distressing, it could be a good idea to ask someone you trust to do the research for you and then explain it in a less worrying way.

Don't go onto the internet – it's overwhelming and may not have the right information relevant to your personal situation.

BCNA's fact sheet *Getting the most from the web: a guide to reliable breast cancer information on the internet* outlines some of the pitfalls around researching online. It also provides some information about sites that are reputable and may be of assistance to you. You can download it from bcna.org.au.

Other ways to find information

A breast care nurse may be able to help you make sense of all of the information you're receiving. A breast care nurse has specialist knowledge about breast cancer and can provide information, counselling and support as well as help to coordinate your care.

You may have met a breast care nurse if you were referred initially to a surgeon. Many breast care nurses work closely with breast surgeons, caring for people in the lead-up to, and recovery from, breast cancer surgery. Even if you're not having breast surgery, you can ask your specialist or GP to refer you to a breast care nurse, preferably one who is experienced in supporting people with metastatic breast cancer. You can also contact a breast care nurse directly if there's one working in your local community – you don't need a referral.

Try and get access to a breast care nurse if you can. Talk to your oncologist or GP or look up a nurse in your area on the McGrath website.

The McGrath Foundation website (**mcgrathfoundation.com.au**) has a search function you can use to find a breast care nurse in your area – just enter your postcode in the form provided.

You may also find it helpful to make regular visits to your GP. A GP can clarify information for you, help with advice and counselling, and refer you to other health professionals who may be able to help such as dietitians, social workers or exercise physiologists. A good GP will see you when you need to be seen and visit you at home if the need should arise.

Many people with metastatic breast cancer find they have more contact with their GP than any other health professional apart from their medical oncologist. If you don't already have a good GP, finding one could make a big difference to your care.

Connect in with your GP and keep them involved as a key member of your team. They can help connect you in with local services, especially of you live rurally.

ℹ **For more information on multidisciplinary care, see p.54, Section 2: Metastatic breast cancer: the facts.**

Questions to ask

You're likely to have a lot of questions and writing a list can help you feel less overwhelmed. When you're first diagnosed even your doctors may not have all the answers but this will probably change once you start your treatment and they can see how you respond.

Write down your questions and take them to your oncologist, keep asking questions until it makes sense and you understand.

Discussing prognosis with your oncologist

When you're first diagnosed with de novo metastatic breast cancer, it's normal to wonder about how long you may have to live. Many people have talked to us about how challenging these conversations can be, especially in the early days.

Statements about prognosis at the time of diagnosis are not helpful in the beginning. How long is a piece of string – everyone is so variable.

A number of factors will influence survival times for people with de novo metastatic breast cancer. It's therefore not helpful to give an answer based on a statistical average. This single figure doesn't take into account your individual circumstances or how well you will respond to treatment.

ℹ **See p.45, Metastatic breast cancer: the facts for further information on ways prognosis can be addressed in a meaningful way.**

If you're struggling with how best to manage your concerns around prognosis, you may find it helpful to talk to someone such as an oncology counsellor or social worker.

ℹ **Find out more about how to get support from a professional counsellor in Section 4: Living well.**

Talking to others

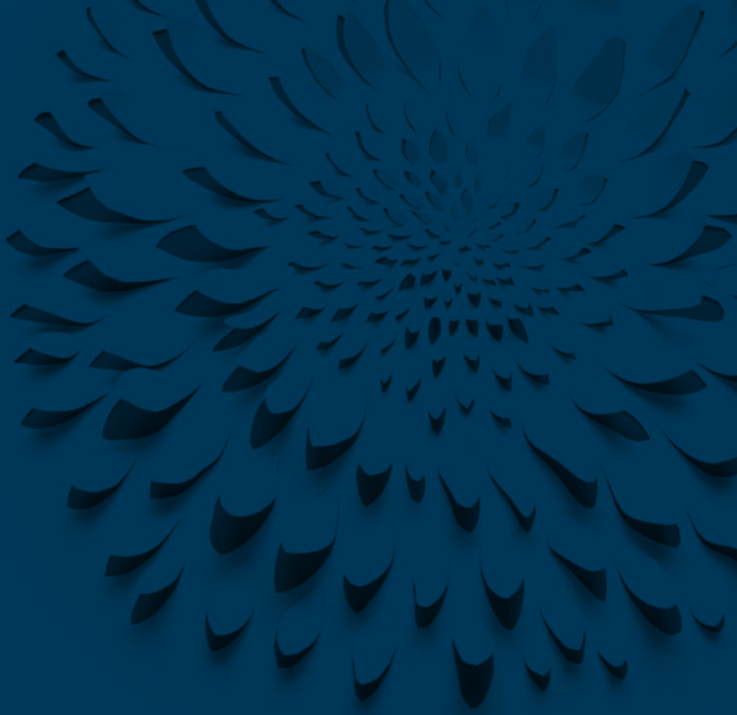
Reach out to other people, either online or face-to-face, and read the messages of hope and support in the BCNA brochures. The most important thing out there is to read the number of years people have lived for. It gives hope and reinforcement that you can do well too.

BCNA's online network has a private group for people with metastatic breast cancer. Some of the people in this group will, like you, have been diagnosed with metastatic breast cancer from the start. If you would like more information about how to join the online network, visit the BCNA website at **bcna.org.au** or phone BCNA on **1800 500 258**.

QUESTIONS YOU MIGHT LIKE TO ASK

People have told us they found these questions useful to ask when they were first diagnosed with de novo metastatic breast cancer. Add any others you think of before you go to appointments and, if you can, take someone with you to take notes. The questions at the end of each section of the guide could also help you.

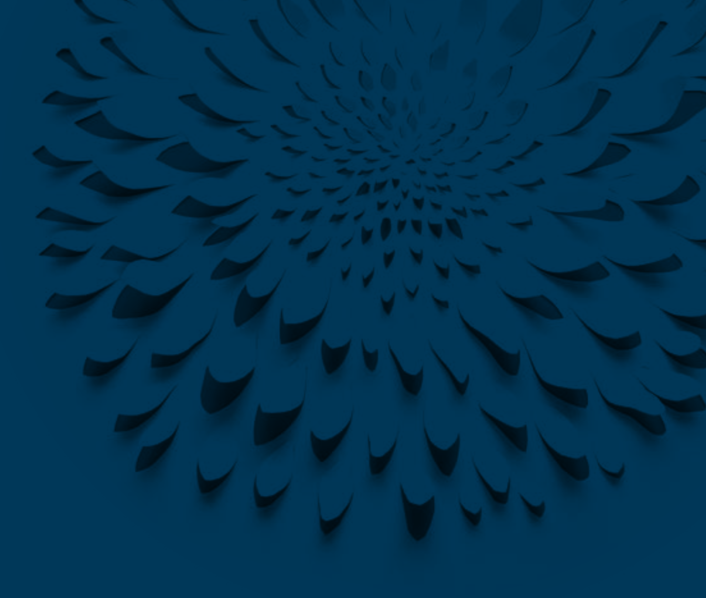
- What is breast cancer?
- Why had it spread to other parts of my body before it was found?
- What tests will I need and what does this involve?
- What will my treatment involve?
- What support is available to me?
- Can I speak to a breast care nurse?
- Are there any metastatic breast cancer support groups I can go to?



SECTION 9

APPENDIX A

Ask a lot of questions and remember knowledge is power



SECTION OVERVIEW

This section includes information on breast cancer drugs, plus a glossary

BREAST CANCER DRUGS

The table on the following pages lists the drugs most commonly used in the treatment of metastatic breast cancer. It's not a comprehensive list and it doesn't include all of the drugs being tested in clinical trials.

New drugs are constantly being developed, and some drugs will become available under new trade names as they come off patent – the exclusive rights by one company to sell a drug. Some drugs can be given in different ways, so talk with your oncologist about what might be best for you.

Key to table

Administration – medications can be given in different ways. This column shows how different types of medication are administered.

- Intravenous (IV) infusion: given slowly over time through an intravenous drip or via a faster bolus infusion push.
- Intramuscular (IM) injection: injected with a syringe into a large muscle such as the upper arm or thigh.
- Subcutaneous (SC) injection: injected just under the skin in areas such as the thigh or abdomen.
- Oral: taken by mouth as a tablet, liquid or capsule.

🟢 Chemotherapy

🔵 Hormone-blocking (endocrine) therapy

🟠 HER2 targeted therapy

🟣 Targeted therapy (other than Hormone and HER2 targeted therapies)

⚪ Supportive care

Drug	Trade name/s (not all may be listed here)	Drug type	Administration
abemaciclib	Verzenio	Targeted therapy – CDK 4/6 inhibitor (HR+, HER2-)	Oral
*alpelisib	Piqray	Targeted therapy (P13K mutation) (clinical trials HR+,HER2 -) (in clinical trials)	Oral
anastrozole	Arimidex, Anastrazole FBM, Anastole, Anastrazole, Anzole, Arianna	Hormone-blocking therapy – aromatase inhibitor	Oral
*atezolizumab	Tecentriq	Immunotherapy (PD-L1 positive triple negative) (in clinical trials)	IV
capecitabine	Xeloda	Chemotherapy	Oral
carboplatin	Carboplatin Paraplatin	Chemotherapy	IV
clodronate	Bonefos	Bisphosphonate	Oral
cyclophosphamide	Cycloblastin, Endoxan	Chemotherapy	IV or Oral
denosumab	Xgeva Prolia	Biologic agent	SC injection
docetaxel	Taxotere	Chemotherapy	IV
doxorubicin	Adriamycin, Doxorubicin	Chemotherapy	IV
doxorubicin liposomal	Caelyx, Doxil	Chemotherapy	IV
epirubicin	Pharmorubicin, Ellence	Chemotherapy	IV
eribulin	Halaven	Chemotherapy	IV
everolimus	Afinitor	Targeted therapy – mTOR Inhibitor (HR+)	Oral

Drug	Trade name/s (not all may be listed here)	Drug type	Administration
exemestane	Aromasin, Exaccord, Exemestane	Hormone-blocking therapy – aromatase inhibitor	Oral
fluorouracil	5-FU, Fluorouracil	Chemotherapy	IV
*fulvestrant	Faslodex	Hormone-blocking therapy	IM injection
gemcitabine	Gemzar, Gemcitabine, Gemaccord, Gemplan	Chemotherapy	IV
goserelin	Zoladex	Hormone-blocking therapy	SC injection
mitoxantrone	Novantrone, Onkotrone	Chemotherapy	IV
ibandronate	Bondronat	Bisphosphonate	IV or Oral
lapatinib	Tykerb	Targeted therapy (HER2+)	Oral
letrozole	Femara, Letrozole FBM, Letrozole, Femolet, Fera, Letara	Hormone-blocking therapy – aromatase inhibitor	Oral
medroxy-progesterone acetate	Provera, Premia, Ralovera	Hormone-blocking therapy – progestin	Oral
megestrol acetate	Megace	Hormone-blocking therapy – progestin	Oral
methotrexate	Otrexup, Rasuvo, Rheumatrex, Trexall	Chemotherapy	IV or Oral
mitomycin	Mutamycin	Chemotherapy	IV

Drug	Trade name/s (not all may be listed here)	Drug type	Administration
nab-paclitaxel	Abraxane	Chemotherapy	IV
*neratinib	Nerlynx	Targeted therapy (HER2+)	Oral
*nivolumab	Opdivo	Immunotherapy (PD-1 positive triple negative) (in clinical trials)	IV
*olaparib	Lynparza	Targeted therapy – PARP Inhibitor (BRCA mutations in clinical trials)	Oral
paclitaxel	Taxol, Anzatax, Paclitaxel, Plaxel	Chemotherapy	IV
palbociclib	Ibrance	Targeted therapy – CDK 4/6 inhibitor (HR+, HER2-)	Oral
pamidronate	Aredia, Pamisole	Bisphosphonate	IV
*pembrolizumab	Keytruda	Immunotherapy (PD-1 positive triple negative) (in clinical trials)	IV
pertuzumab	Perjeta	Targeted therapy (HER2+)	IV
ribociclib	Kisqali	Targeted therapy – CDK 4/6 inhibitor (HR+, HER2-)	Oral
tamoxifen	Nolvadex, Genox, Tamoxen, Tamosin, Tamoxifen	Hormone-blocking therapy	Oral

Drug	Trade name/s (not all may be listed here)	Drug type	Administration
*talazoparib	Talzenna	Targeted therapy- PARP inhibitor (BRCA mutation in clinical trials)	Oral
trastuzumab	Herceptin	Targeted therapy (HER2+)	IV or SC injection
trastuzumab emtansine (T-DM1)	Kadcyla	Targeted therapy (HER2+)	IV
*venetoclax	Venclexta	Targeted therapy-BCL-2 inhibitor (in clinical trials HR+, HER2-)	Oral
vinorelbine	Navelbine	Chemotherapy	IV or Oral
zoledronic acid	Zometa	Bisphosphonate	IV

* not listed on the PBS (Pharmaceutical Benefits Scheme) at the time of printing.

The EviQ website is an evidence-based national information resource for cancer treatments. Visit eviq.org.au.

GLOSSARY OF TERMS

Ablation – the removal or destruction of an area of tissue or part of the body, such as the ovary or lining of the uterus. This can be achieved by surgery or other means such laser, cryo or thermal therapy.

Advanced breast cancer – another term for metastatic breast cancer.

Alopecia – hair loss.

Alternative therapies – different from complementary therapies, these are treatments or products that claim to cure or remove cancer completely and that are used instead of the conventional cancer treatments such as surgery, chemotherapy, radiotherapy or hormone-blocking therapy. Where research has been done, there is no evidence that these treatments have any anti-cancer benefit.

Anaemia – a lower than normal number of red blood cells in the blood.

Antiemetics – drugs given to reduce feelings of nausea or sickness.

Arthralgia – pain in the joints.

Aromatase inhibitors (Arimidex, Aromasin, Femara + generic versions) – hormone-blocking drugs that may be prescribed for post-menopausal women who have hormone receptor positive breast cancer (i.e. ER+ and/or PR+). They work by stopping the body from producing oestrogen.

Ascites – the build-up of fluid in the peritoneal cavity, a membrane that forms the lining of the abdomen. It may be drained in order to relieve symptoms.

Biopsy – removal of cells or tissue from the body for examination by a pathologist to determine whether or not they are cancer.

Biological therapies – another term for targeted therapies (see Targeted therapies).

Bisphosphonates (Aredia, Zometa, Bonefos, Fosamax) – drugs used in the treatment of metastatic breast cancer in the bone to help reduce the breakdown of bone and strengthen the bones.

Bone marrow – spongy, soft tissue in the centre of bones where red blood cells, white blood cells and platelets are made.

Bone metastases – cancer that has spread from its original site to the bones. Metastatic breast cancer in the bone develops when breast cancer cells travel from the original tumour in the breast to the bone.

Bone mineral density test – a test used to measure bone mineral density levels to determine whether the bones are at risk of fracture and osteoporosis. The most common bone mineral density test is the dual energy X-ray absorptiometry test (DXA/DEXA).

Bone scan – a test used to measure an increase or decrease in bone growth. It can help to identify any abnormalities such as cancer, infection or fractures.

Brain metastases – cancer that has spread from its original site to the brain. Metastatic breast cancer in the brain develops when breast cancer cells travel from the original tumour in the breast to the brain.

BRCA1 and BRCA2 genes – genes that normally prevent a woman from developing breast or ovarian cancer.

BRCA1 and BRCA2 gene mutations – changes or faults in genes indicating a higher than normal chance of developing breast and/or ovarian cancer.

Carcinoma – another word for cancer.

CDK 4/6 inhibitor (Kisqali, Ibrance, Verzenio) – drugs that block the function of CDKs (cyclin dependent kinases). Our cells contain pathways that help to control when cells should grow and divide. A group of enzymes involved in this pathway is the CDKs. These have been found to be overactive in some breast cancers.

Chemotherapy – treatment for cancer using drugs. They may be used on their own, or in combination with other chemotherapy drugs or targeted treatments. Common chemotherapies used to treat metastatic breast cancer include:

> **Anthracyclines** – Andriamycin (doxorubicin), Pharmorubicin (epirubicin) Taxanes – Taxol (paclitaxel), Taxotere (docetaxel)
>
> **Vinca alkaloids** – Navelbine (vinorelbine)
>
> **Antimetabolites** – Xeloda (capecitabine), 5-FU (5-fluorouracil), Gemzar (gemcitabine)
>
> **Alkylating agents** – Cycoblastin, Endoxan (cyclophosphamide)

Chronic disease – a disease or medical condition that lasts a long time and is generally not curable. Metastatic breast cancer is often considered a chronic disease.

Clinical trials – studies involving patients to see if a new treatment is better than an existing treatment.

Complementary therapies – different from alternative therapies, these are treatments or therapies used alongside conventional treatments to enhance quality of life and improve overall wellbeing. These might include massage, acupuncture, relaxation or meditation.

Core biopsy – a procedure when a needle is inserted into the breast to take a small sample of breast tissue from an area suspected to be cancer so that it can be sent to pathology for testing. A local anaesthetic is used to numb the breast being biopsied. Core biopsies can be performed under ultrasound guidance in the X-ray department or breast clinic or can be done in the surgeon's rooms or clinic without the use of ultrasound.

CT or CAT scan (computerised tomography scan) – a type of scan that uses X-rays to take a series of detailed pictures across the body.

Depression – a mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy and poor concentration.

DXA or DEXA scan (dual energy X-ray absorptiometry) – a type of scan that measures bone mineral density. It's one of the most accurate ways to diagnose osteopenia (low bone mineral density) and osteoporosis. People treated with tamoxifen or an aromatase inhibitor may be susceptible to bone loss.

Dyspnoea – shortness of breath or difficulty in breathing.

Early breast cancer – breast cancer that has not spread beyond the breast or lymph nodes under the arm, known as axillary lymph nodes.

Early menopause – menopause occurring in women under 45 years of age. Early menopause can be a side effect of some common treatments for breast cancer. It can be temporary or permanent.

Endocrine therapies – another term for hormone-blocking therapies (see Hormone-blocking therapies).

HER2 (human epidermal growth factor receptor 2) – a protein found in small amounts on normal breast cells. It is one of the proteins involved in the growth of cells. Some breast cancer cells have a lot more HER2 receptors than others. They are known as HER2-positive.

Hormone receptors – receptors in cells that attract and bind hormones such as oestrogen (ER) and progesterone (PR) that circulate in the blood. If the breast cancer cells have hormone receptors, oestrogen and/or progesterone will 'feed' the cancer cells, allowing them to divide and grow.

Hormone receptor negative breast cancer – breast cancer that doesn't have hormone receptors, i.e. the cancer cells don't require oestrogen or progesterone to divide and grow. A pathology report would report hormone negative breast cancer as ER- and PR-.

Hormone receptor positive breast cancer – breast cancer that has hormone receptors for oestrogen and/or progesterone, i.e. the cancer cells require oestrogen and/or progesterone to divide and grow. A pathology report would report hormone receptor positive breast cancer as ER+ and/or PR+.

Hormone-blocking therapies – use of drugs to treat people whose breast cancer is hormone receptor positive (ER+ and/or PR+). Common hormone-blocking therapies used in Australia include tamoxifen (Tamoxifen, Nolvadex, Genox, Tamoxen) and aromatase inhibitors (Arimidex, Aromasin, Femara).

Hypercalcaemia – a higher than normal level of calcium in the blood. Hypercalcaemia can affect people with metastatic breast cancer in the bone.

Hypocalcaemia – a lower than normal level of calcium in the blood. Hypocalcaemia can affect people who are being treated with a bisphosphonate.

Immunotherapy – treatment that uses certain parts of a person's immune system to fight diseases such as cancer. This can be done by stimulating the immune system to work harder or smarter to attack cancer cells or by adding components to a person's immune system such as man-made immune system proteins. It appears that triple negative breast cancer is one of the types of breast cancer most likely to respond to these treatments. Trials are underway in triple negative breast cancer and HER2-positive metastatic breast cancer testing the effectiveness of immunotherapy agents.

Intravenous infusion – the injection of fluids, such as chemotherapy drugs or other substances the body needs, directly into a vein.

Liver metastases – cancer that has spread from its original site to the liver. Metastatic breast cancer in the liver develops when breast cancer cells travel from the original tumour in the breast to the liver.

Local treatment – treatment confined to a specific area of the body, e.g. surgery or radiotherapy.

Locally advanced breast cancer – breast cancer that has spread to areas near the breast, such as the chest wall, muscle or skin.

Lung metastases – cancer that has spread from its original site to the lung. Metastatic breast cancer in the lung develops when breast cancer cells travel from the original tumour in the breast to the lung.

Lymph nodes – nodes or glands in the armpit and other parts of the body that filter and drain lymph fluid, trapping bacteria, cancer cells and any other particles that could be harmful to the body.

Lymphatic system – a filtering system for the blood that includes lymph nodes, lymph fluid and lymph vessels.

Lymphoedema – a condition that sometimes develops when lymph nodes have been removed during breast cancer surgery and the lymph fluid no longer drains freely, causing swelling in the arm or breast.

Mammogram – an X-ray image of the breast that is used to detect breast cancer.

Medical oncologist – a health professional who specialises in the systemic treatment of cancer using chemotherapy, hormone-blocking therapy and targeted therapies, and in managing cancer pain and other symptoms.

Metastases – the spread of cancer from one part of the body to another site. In breast cancer, these are most commonly the bone, liver and lungs and, less frequently, the brain or other areas of the body.

Metastatic disease (also called secondary, stage IV or advanced breast cancer) – breast cancer that has spread from the breast to other, more distant parts of the body, most commonly the bones, lungs, liver; less frequently the brain; and, very occasionally, other areas of the body.

MRI (magnetic resonance imaging) – a type of scan that uses magnets and radio waves to produce a series of cross-sectional images of the inside of the body.

mTOR inhibitors – a class of drugs that target a particular protein that helps control factors that stimulate cell growth and cell death. In certain cancers the mTOR pathway is more active, meaning cell growth may be faster than normal. Everolimus (Afinitor) is an example of an mTOR inhibitor that can help stop the cancer growing or slow down its growth by blocking the mTOR pathway.

Multidisciplinary care – a team of health professionals who work together to manage a person's treatment and care.

Neutropenia – a condition that occurs when the level of neutrophils (a type of white blood cell) falls below the normal range. Neutropenia can be associated with some forms of chemotherapy.

Oestrogen – a type of female hormone.

Palliative care – specialised care that focuses on symptoms rather than cure. Palliative care is much more than end of life care. It can help people live as fully and as comfortably as possible when living with a serious illness. Palliative care can help you manage any physical symptoms you may be experiencing, such as pain or nausea, and it can also help with your emotional, spiritual and social concerns. Palliative care is a family-centred model of care. It's there not just for you, but for your family and friends as well.

PARP inhibitor – a substance that blocks an enzyme in cells called PARP. PARP helps repair DNA when it becomes damaged. In cancer treatment, blocking PARP may help keep cancer cells from repairing their damaged DNA, causing them to die. PARP inhibitors are a type of targeted therapy also called poly (ADP-ribose) polymerase inhibitors. They are being tested in clinical trials including trials for people with hereditary BRCA1 and BRCA2 mutations who have metastatic breast cancer.

Pathology report – a summary of test results following a biopsy or surgery. The pathology report includes information about the cancer type, its size, how fast the cells are growing and whether there are any hormone receptors on the cancer. The results of the pathology report help doctors to determine the best treatment for the cancer.

PET (positron emission tomography) – a type of scan that produces a three-dimensional image giving details of the structure and function of organs or tissue being investigated.

Physical examination – an examination of a patient by a doctor to determine the presence or absence of physical symptoms. A typical physical examination may include the doctor looking at the body (examination), feeling the body with fingers or hands (palpation), listening to sounds (auscultation), and producing sounds by tapping on specific areas of the body (percussion).

Pleura – the membrane that lines the rib cage and covers the lungs.

Pleural space – the narrow, fluid-filled space between the pleural membranes that allows the lungs to inflate and deflate as we breathe. Also referred to as the pleural cavity.

Pleural effusion – a build-up of fluid in the pleural space. The fluid can be drained under local anaesthetic.

Progesterone – a type of female hormone.

Psycho-oncology – an area of health professional practice and research that focuses on the psychological responses of patients, their families and caregivers to cancer.

Psycho-social support – the process of meeting the emotional, mental, social and spiritual needs of cancer patients.

Radiotherapy – treatment for cancer using X-rays and other forms of radiation such as high-energy electrons that target a particular area of the body.

Secondary breast cancer – another term for metastatic breast cancer.

Subcutaneous injection – an injection into the fatty tissue under the skin.

Systemic treatment – drugs that treat the whole body, e.g. chemotherapy, hormone therapy or targeted therapy.

Targeted therapies – drugs that stop the signals that tell cancer cells to grow. Examples include trastuzumab (Herceptin), lapatanib (Tykerb), pertuzumab (Perjeta) and everolimus (Afinitor). Targeted therapies are also known as biological therapies.

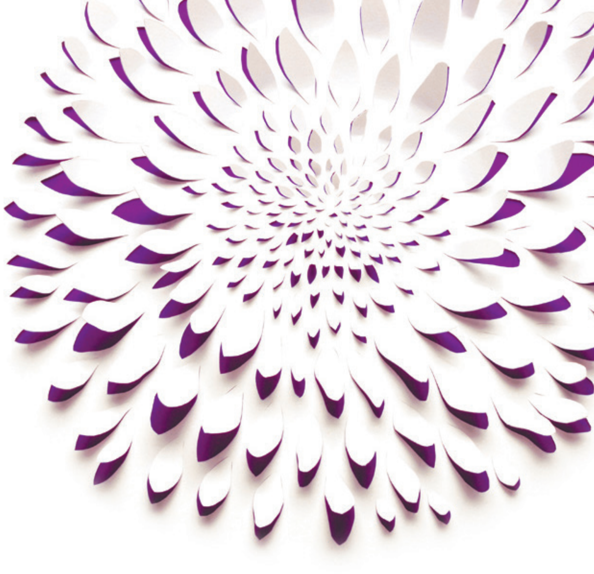
Thrombosis – the formation of a blood clot in a blood vessel.

Triple negative breast cancer – breast cancer that does not express receptors for oestrogen, progesterone or HER2 – i.e. the cancer cells do not require oestrogen, progesterone or HER2 to grow. In pathology terms, it is reported as ER-, PR- and HER2-.

Tumour markers – substances, usually proteins such as Ca125 and CEA, which are produced by the body in response to cancer, or by the cancer tissue itself. Blood tests can measure the level of these substances and, over time, tumour marker levels can be monitored.

Ultrasound – a scan that uses high-frequency sound waves to produce an image of an area in the body.

X-ray – a scan that uses high-energy radiation to take pictures of the inside of the body. In low doses, X-rays are used to diagnose diseases; in high doses, they can be used to treat cancer.



HOPE & HURDLES

ACKNOWLEDGEMENTS

BCNA acknowledges and thanks the many people diagnosed with breast cancer who contributed to the development of the *Metastatic Breast Cancer: Hope & Hurdles Information Guide*.

We also acknowledge and appreciate the many health professionals who supported its development.

Australian Government
Cancer Australia

This guide is a Cancer Australia *Supporting Women in Rural Areas Diagnosed With Breast Cancer* Program initiative, funded by the Australian Government.

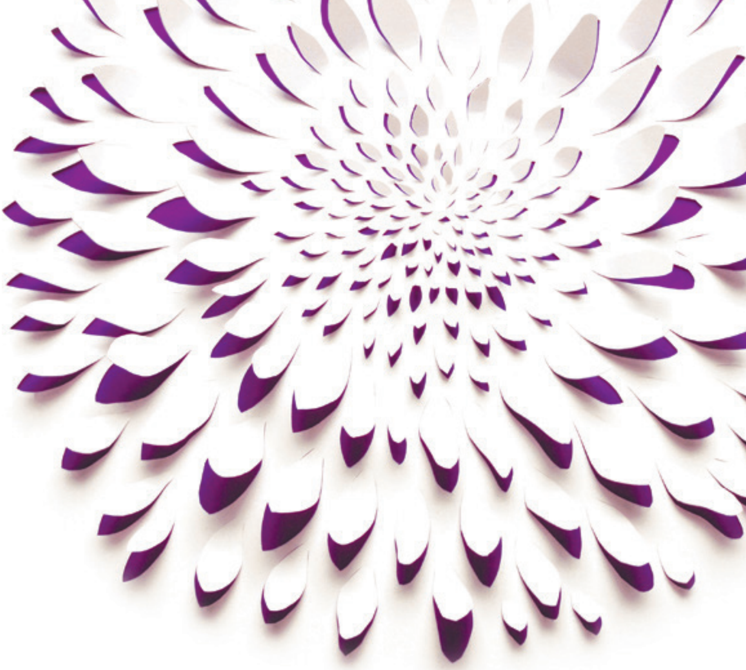
WE THANK OUR PARTNERS

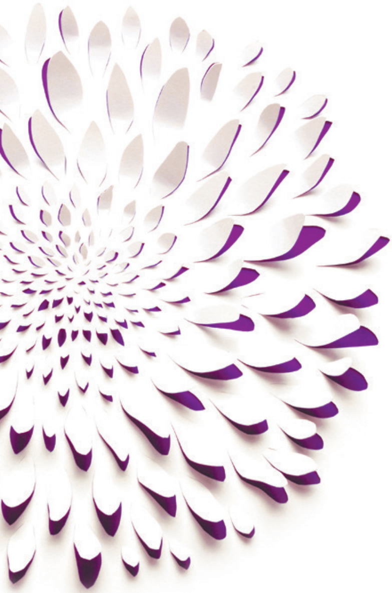
BCNA Foundation Partner

Bakers Delight

BCNA Major Partners

BERLEI
red energy
sussan
Reflex





Breast
Cancer
Network
Australia

bcna.org.au | 1800 500 258

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer.

We work to ensure that Australians diagnosed with breast cancer receive the very best care, treatment and support.