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, in particular, those who contributed to BCNA's 2015 report (involving 579 women and three men), The support and information needs of women with secondary 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.

Hope & Hurdles 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
- The Royal College of Pathologists of Australasia
- The Royal Australian and New Zealand College of Radiologists.

Published by Breast Cancer Network Australia
293 Camberwell Road
Camberwell Victoria 3124
Telephone: 1800 500 258
Email: beacon@bcna.org.au
Website: bcna.org.au

Design: Liz Grant, Designgrant

Hope & Hurdles comprises the Hope & Hurdles Information Guide and other resources.

ISBN 978-0-9752053-5-8
© Breast Cancer Network Australia 2016

No part of Hope & Hurdles may be reproduced without the permission of the publisher. People with breast cancer and their families and friends may reproduce materials from Hope & Hurdles for their own personal use.

Hope & Hurdles is a trademark of Breast Cancer Network Australia.
Contents

Who is Breast Cancer Network Australia?
A personal message to you
With thanks
Resources

Metastatic breast cancer
What is metastatic breast cancer?
What does it mean for me?
Finding out
Dealing with your diagnosis
Breaking the news
Maintaining hope
Resources

Treatment and side effects
Symptoms you may experience
Choosing your treatment and care team
Treatment for metastatic breast cancer
How might new drugs be available to me?
Demystifying palliative care
Planning ahead
How will I know if the treatment is working?
Concerns about your care and getting a second opinion
Managing symptoms and side effects
Complementary and alternative therapies
Taking a break from treatment
Emergencies
Resources

Living well
The people in your life
Single or dating
Partners
Family and children
Friends and colleagues
Caring for you
Practical support
Emotional support
Caring for your body
Exercise
Resources

Financial and practical matters
The financial cost of breast cancer
Federal government assistance
Making the most of your GP
State government assistance
Other sources of financial help
Superannuation and insurance
Employment
Resources

Metastatic breast cancer in young women
Introduction
Emotional wellbeing and caring for yourself
Building your support network
Relationships
Talking to your children
Employment and returning to work
Child care
Financial and practical support
Resources

Metastatic breast cancer in men
Getting information
Dealing with a diagnosis
Getting support
Treatment
Further information
Resources

Metastatic breast cancer from the start
The basics
Breast cancer: a brief overview
Finding out you have metastatic breast cancer
Feelings
What happens next?
Treatment
Role of breast surgery
How can I find more information?
Talking to others

Breast cancer drugs
Glossary of terms
Who is Breast Cancer Network Australia?

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We work to ensure they receive the very best support, information, treatment, and care possible.

We support, inform, represent and connect people and Australians diagnosed with breast cancer.

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 beacon@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.

*Hope & Hurdles* 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.

*Hope & Hurdles* is a tailored resource and while it has been designed for women, BCNA recognises that men get breast cancer too. While *Hope & Hurdles* uses language and stories that focus on women’s experiences, much of the information is also relevant for men.

BCNA is committed to ensuring that men with breast cancer have access to the best information, treatment and support available to them. We have included a new section in this *Information Guide* for men who have been diagnosed with metastatic breast cancer in recognition that the mental anguish of being diagnosed with metastatic breast cancer and the need for up-to-date high quality information is the same for any person, regardless of gender.

In developing *Hope & Hurdles*, we sought input from senior clinicians who are caring for people with metastatic breast cancer, and from people living with metastatic breast cancer themselves. We ran focus groups, talked to women and men, and took into account feedback from letters, emails and phone calls. We also drew from the findings of our 2015 report *The support and information needs of women with secondary breast cancer*, which involved 579 women and three men.

People shared with us their own experiences, lessons they have learnt, practical strategies to help you get through the tough times and ways they have learnt to focus on living well.
Through all of this feedback we found a common thread: there may be many hurdles ahead but hope is vital and support is available.

Today, new treatment discoveries and scientific advances mean that some women and men are living with metastatic breast cancer for many years. For those who respond well to treatment, metastatic breast cancer can be managed like a chronic disease, with extended periods of wellness in between episodes of being unwell.

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

This resource has a range of additional items that may be relevant to your individual diagnosis and needs. These are outlined on our website bcna.org.au. Your treating team can help you decide which might be most appropriate for you. You can order these additional items free of charge from our website bcna.org.au or by phoning 1800 500 258.

We hope Hope & Hurdles 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
With thanks

This edition of *Hope & Hurdles* would not have been possible without the contributions of many people from around Australia living with metastatic breast cancer.

Thanks to those who generously gave their time to participate in interviews, completed our surveys, provided valuable suggestions and ideas, and to those who reviewed drafts of this resource.

We are especially grateful to the women and men who provided photographs, quotes and messages of support and hope.

We also thank the health professionals and others who collaborated with us on this third edition of *Hope & Hurdles*, especially our Reference Group members: Professor Fran Boyle AM, Dr Steven David, Associate Professor Prue Francis, Dr Briony Jack, Pauley Kessel, Gillian Kruss, Dr Carrie Lethborg, Ms Meron Pitcher, Dr Andrew Redfern, Dr Magda Simonis, Karen Sprigg and Gillian Tong.

Thanks also to Associate Professor Jacquie Chirgwin for assistance with developing new booklets on the subtypes of breast cancer to help personalise information about likely treatment recommendations.

Some of the content of this *Hope & Hurdles Information Guide* is drawn from the Cancer Australia publication *Guide for women with secondary breast cancer*. For more information, see the Cancer Australia website, canceraustralia.gov.au.

We thank Cancer Australia for its support and guidance in developing this resource.

*Hope & Hurdles* has been produced with funding from the Australian Government through Cancer Australia – Australia’s peak government body that works towards reducing the impact of cancer on all Australians.

We also thank our corporate partners:
Resources

Many women 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 sit on grey pages (see the example below) and each has an accompanying symbol to indicate its type, such as book, CD or website.

More from BCNA

BCNA has a comprehensive range of information resources for people affected by breast cancer. Hope & Hurdles is our key resource for people with metastatic breast cancer.

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

**BCNA’s website** bcna.org.au includes a metastatic breast cancer section containing additional information.
The Inside Story, a supplement to BCNA’s free quarterly The Beacon magazine, is designed for women with metastatic breast cancer. In The Inside Story you will find information about the latest treatments and supports available, as well as personal stories from Australians living with metastatic breast cancer. It is also a way that you can share your story with others.

If you would like to receive The Beacon and The Inside Story, phone BCNA on 1800 500 258, email beacon@bcna.org.au or visit bcna.org.au.

BCNA produces additional booklets and fact sheets that you may find useful. The Hope & Hurdles suite contains optional items that you can order at any time if your circumstances change.

To see a list of the latest resources available visit the Resources section of the BCNA website bcna.org.au, or phone BCNA on 1800 500 258.
One:

Metastatic breast cancer

A diagnosis of metastatic breast cancer is not the end of the road, it is the start of a new journey. Some days you will be filled with fear and uncertainty, this is to be expected. Honour your feelings, they are valid; and always remember tomorrow is another day. Do not let anyone take away your hope. Remember you are not a statistic or a number, but a woman alive and kicking.

– Judy
Metastatic breast cancer

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. – Kate

Section overview

This section provides information on:

> What is metastatic breast cancer?
> What does it mean for me?
> Finding out
> Dealing with your diagnosis
> Sharing the news with the people you love
> Maintaining hope for the future
What is 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, secondary cancers, 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 ‘primary’ or ‘early’ breast cancer.

*For me the term metastatic, secondary, advanced doesn’t matter. What really matters is being able to communicate to others what I am experiencing and help them to understand what I am going through and what support I need.* – Gillian

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. It may also affect more than one location at the same time.

Some things that sound like metastatic breast cancer are not, and this can be confusing. For example, if cancer cells are found in the lymph nodes in your armpit (axilla) but have not spread beyond those lymph nodes, this is not metastatic breast cancer; it may be defined as early breast cancer or locally advanced breast cancer depending on the pathology results. Breast cancer that has spread to other lymph nodes near the breast or to tissues around the breast (for instance, the chest wall, pectoral muscle or skin) is also not usually described as metastatic breast cancer, but locally advanced breast cancer, or local or regional recurrence.

Wherever metastatic breast cancer is found in your body, it is still breast cancer. Metastatic cancer in the liver, for example, does not contain liver cancer cells; the cells are breast cancer cells.
Women often want to understand why they have developed metastatic breast cancer, especially if they have previously had treatment for early breast cancer. Unfortunately, even the best treatment for early breast cancer does not always remove every cancer cell. Most commonly, metastatic breast cancer develops from cells that have escaped.

Sometimes, cancer cells have already started to travel around the body when cancer in the breast is found. If there is already cancer outside the breast that is 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.

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.

What does it mean for me?

As yet, metastatic breast cancer cannot be cured. However, advances in treatment mean that some women with metastatic breast cancer are now living for many years.

Some people with metastatic cancer are now able to manage their disease in a similar manner to living with a chronic illness – with ongoing treatments providing periods of wellness between periods of ill health.

Living with chronic illness is an optimistic term I like rather than terminal or stage 4.

How you respond to your diagnosis is individual to you, there is no right or wrong way for you to feel. Not all women and men diagnosed with metastatic breast cancer want to talk about their cancer as if it were a chronic illness. For them, an incurable cancer is more than a chronic disease. For others, accepting this approach can provide optimism and hope for the future.
Finding out from my oncologist and GP and by reading Hope & Hurdles that metastatic breast cancer isn’t the immediate death sentence that 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.

When you are diagnosed with metastatic breast cancer it is natural to wonder how long you have to live. This is a difficult question to answer because no two women and no two cancers are the same. A number of factors will influence survival times for women with metastatic breast cancer, including the subtype of breast cancer (hormone receptor positive, HER2-positive and triple negative), the site of metastases, response to treatment, time since treatment for early breast cancer and the presence of other health issues not related to cancer.

Clinical trials can indicate the average survival time of women trialling a new treatment. However, women who participate in trials are not always representative of women being treated outside trials, and the data is usually summarised in a way that has little meaning for individuals. Research has shown that it is better for doctors to talk with you about survival times as a range of possible scenarios, including best-case, most likely and worst case scenarios. Everyone is different, and what one person wants to know about their prognosis may differ greatly from another.

If you wish to talk to your specialist about the likely progress of your disease, you have a right to clear and honest answers. Having a good relationship with your treatment team, where you can communicate openly and honestly, is important as you approach these sorts of conversations. Before you ask about your prognosis, you need to consider the impact of receiving this information.

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. Eight years down the track, I have learnt to live in the moment and enjoy what each new day brings rather than live in fear of what might be taken from me in the future.

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 is 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. – Christine

Most women feel devastated when they are told they have metastatic breast cancer. Many will have lived through the trauma of being diagnosed and treated for early breast cancer and may have believed they were cured. As you struggle to come to terms with the fact that a cure may no longer be possible, you might feel shocked, angry, overwhelmed, afraid, disbelieving or even guilty. You may experience powerful swings in mood. Your anger may spill over into the way you react to other people, even those you love, or the doctor who told you the bad news. You will almost certainly find yourself worrying about what lies ahead, both for you and your family and friends. Anxiety can make it difficult to think clearly – you may feel overwhelmed by the prospect of making even the smallest decision.
If you think back over your life, cancer won’t be the only experience that wasn’t welcome. You’ve learned to live with each of these experiences. You’ve grown, you’ve laughed, you’ve cried, you’ve still been a friend, partner, mother, lover, etc. You’ve still been a valuable and precious human being. This news doesn’t change any of that. It may alter the way you express who you are, but it doesn’t change who you are as a woman. – Liz

At first, you may not be able to imagine ever feeling happy or calm again. You may find it hard to believe that many women have lived through this turmoil and gone on to gain control and peace in their lives. But they have been able to do so – and it is worth trying to remember this if, sometimes, you feel trapped in the dark.

You will have black moments but those moments will pass – it might be in one day, three days or a month, but it’s important to remember it will pass. – Franca

I think you have to be strong and take control. The treatments can seem overwhelming at times but once the urgency of immediate care is over, it is critical to get on with life and actively seek to be as healthy and fit as possible.

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 women have told us that they experience feelings of guilt and wonder if they had picked up their breast cancer earlier, or done something differently they may not have presented with metastatic breast cancer. They may wonder whether the treatments they decided to have, or not have, may have influenced their cancer returning.

Some women 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.

The truth is that it is almost always no one’s fault, and you should not blame yourself. Sometimes it is just the fast-growing nature of a person’s cancer that is the reason it has metastasised, but that does not mean that there is not effective treatment available to help you.

Unfortunately, some breast cancers will spread whatever treatment a woman has received and whatever lifestyle changes she has made. It helps some women to understand that, unlike primary breast cancer, finding metastatic breast cancer early doesn’t usually affect treatment outcomes.

Making choices

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

Women react to discovering that they have metastatic breast cancer in different ways. Some prefer to carry on with something as close to their daily routine as possible. Some want to transform their life completely. It is probably best to give yourself time to get over the initial shock before you make any dramatic changes. Professional support 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, even though it was an*
added expense that I didn’t need. She helped me to think more logically and to think about things in different ways. – Alisha

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 to you, and things that make you feel good. That might mean pursuing something you’ve always wanted to do, such as travelling or taking up a creative hobby like painting or music.

We were going to buy a caravan and travel around Australia and we didn’t because I was diagnosed, but now three years on, I think we could have bought that caravan because here I am. – Catherine

You may just want to spend more time with your family and friends, or enjoy simple pleasures like being outdoors, watching movies or listening to music. You could also find that placing more focus on your general health by eating well, meditating and doing regular exercise helps you to feel better emotionally as well as physically.

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. – Amina
Managing uncertainty

It is hard when everyone else is saying they have finished their treatment when you know yours is ongoing. The emotional issues are the same, the fear of it returning, and also the fear of it spreading even further and not being able to stop it.

I asked my oncologist if I should buy a season ticket to the opera or a single performance. She was encouraging. Seven years later I still ask her, just for fun!
– Moya

Generally, we like to know what to expect in life, so uncertainty can make us feel uncomfortable or anxious. We like to plan, to feel secure, to imagine that we have control over how our lives will play out. In reality, there is very little we can be sure of. If you look back at the most memorable moments in your life – good and bad – you will probably see that few could have been predicted and planned for.

Having metastatic breast cancer adds a new and complex dimension to the uncertainty, but many women 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. – Marlene

Put your seatbelt on and try to keep positive. You will feel like you are on a roller coaster - up days, down days.
– Sandra

For some, knowing all about the disease and how it is likely to be treated reduces some of the anxiety. If you feel that having more information would help, don’t hesitate to ask your doctor or a health care professional.

Many women find that they gradually learn to focus on the things they can control, and then deal with things they can’t control as they arise. Relaxation, meditation or prayer may help with this.
The people around you

You may find you are not only trying to manage your own uncertainty but also the fears of people around you. This can bring additional pressure, as it is 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 are you able to be. 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 is 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.

How else could she possibly know? Making your feelings known is not being rude or selfish; it is helping both of you to make the most of your relationship.
Dealing with your diagnosis

Being diagnosed with metastatic breast cancer is never easy. The first few weeks can seem like a bad dream. The intense distress you feel at first generally eases over time — hard to believe, but true. After the initial shock you will gradually start to think a little more clearly and realise that there are things you can do to cope with the situation.

> It generally helps to be informed. Sometimes the information may not be what you want to hear, but at least when you know about your situation you can start thinking about how you will adapt. Avoidance can lead to uncertainty and, in the long run, make it harder to cope.

> Open communication with a partner and those closest to you can also help, even though it is natural to try to protect those we love from distress. Research has shown that putting on a brave face and not talking about your metastatic breast cancer is usually unhelpful in the long run — both for you and for those around you. Sharing your thoughts and feelings with your partner generally leads to increased closeness and takes away the burden of trying to keep a lid on things.

> If you have young children, it is important to think about how to talk to them. Again, honesty is best, but remember that you have time to gather your thoughts and discuss how to do this with your partner, friend and others whose support is helpful. Think about this as a series of conversations that can develop over time, rather than an emergency.

For more information on talking with children, see Section 5: Metastatic breast cancer in women.

> Learning how to do some ‘self-talk’ can be helpful. Anxious thoughts will often pop up and can gain momentum. Being able to challenge unhelpful thought patterns takes practise, but is very worthwhile. For example, if test results aren’t available when you are expecting them, you might feel distressed because you assume this means bad news. It would be less distressing, and probably more realistic, to think that they were held up because of a particularly busy time at the lab. If you have trouble managing your anxious thoughts, you might like to seek professional help with learning some techniques. 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.

*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 have no family. I found my medical team focused on the medical side, which is a barrage of information, and I had to find an external psychologist myself which in itself is daunting. I was not given access to the hospital psychologist until about six months into diagnosis, which I think is too late.* – Michelle

> It is 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 or health professionals. BCNA provides a professional telephone counselling service that offers free, confidential counselling support to women and men with metastatic breast cancer and their families.

For more information on BCNA’s telephone counselling service see Section 3: Living well.

> Experiencing intense emotion is normal. You will probably find that you are given advice to ‘be positive’ – feel free to ignore this! There is no good evidence that being positive affects your cancer outcome. Of course, at the other extreme are those who are full of doom and gloom – feel free to ignore them too!

> 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 is exhausting. Allow yourself to be the centre of your world. Choose who you want to see, and when.

> If you don’t have anyone close you can talk to, you may find it helpful to talk to a member of your medical team or to other women online. BCNA’s online network has an active public discussion area for anyone affected by metastatic breast cancer. There is also a private group for people with metastatic breast cancer where only members of the group can read the discussions.
To join the online network go to BCNA’s website bcna.org.au.

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 and what it is. – Nina

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 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 is 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 are not easy to talk about, but the more you communicate, the better your chances of feeling like a team. It can often be helpful for you 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 Section 2: Treatment and side effects.
Telling your parents

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

It is devastating for a parent to hear that their adult child has a potentially life-threatening illness, and could die before them; it is 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. – Becky

Your parents do not have to be told about your diagnosis immediately – it is not 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 is 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 was not 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 about this 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 over the years, and that some women can live for many years.
- Give them copies of BCNA brochures such as *She has secondary breast cancer – how can I support her?*.
- 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 women, 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 is 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 with children see Section 5: Metastatic breast cancer in young women.

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.* – Hui-Lin

Even when you are talking to adults, you may not always get the reaction you hoped for when you tell them that you have metastatic breast cancer.

Worrying about what is 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
You may need 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 are struggling with your own, but once they see that you are not your cancer, that you are 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!

Family and friends sometimes would like me to participate in something that I just don’t have the energy for. It’s hard for me to explain this to them without them starting to worry about me. Except for the walking stick, I look pretty okay, which makes it difficult sometimes. Some people just don’t get it.
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 have to 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.

Acknowledging that it is a roller coaster of hope and despair. I try to look at my life as a glass half full, not half empty. Cancer does not define me. I am still very useful to the world and to those around me that I love.

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.
- Mei-Ling

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.’
- Sue

It felt like the rug had been pulled out from under me and it took me weeks before I was given any hope. Women need to know that a metastatic breast cancer diagnosis doesn’t mean you are going to be dead in weeks or months. – Anna

Over time, most women 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. – Christine

A normal response

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.

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 5 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!
– Fairlie
When to seek help

Being preoccupied with negative thoughts can be a sign of depression. Other signs include feeling low for most of the day, every day; feeling guilty or worthless or a burden on your family; and not being able to enjoy things that normally give you pleasure. Depression can also cause physical symptoms such as poor appetite, tiredness and not sleeping well. Like all health issues, depression needs professional help. Your GP will be able to refer you to someone and treatment is usually very effective.

Many women with metastatic breast cancer seek professional help with managing depression, anxiety or stress. You should not feel embarrassed about telling your doctor if you are struggling to cope emotionally or if you think you need help. You are experiencing a life-changing situation and it is normal to need support while you are coming to terms with your diagnosis and getting your thoughts in order.

A number of health professionals may be able to help you work through these issues including your GP, clinical psychologists, social workers and psychiatrists. If you feel some ongoing counselling would be of benefit, your GP can refer you to an appropriate person and arrange for you to have up to 10 Medicare-subsidised appointments through the GP mental health treatment plan.

BCNA’s Anxiety, depression and breast cancer fact sheet has more information about the symptoms of anxiety and depression and how to seek help. You can download or order a copy from BCNA’s website, bcna.org.au.

To find out how to access Medicare-subsidised professional counselling, refer to BCNA’s GP mental health treatment plan fact sheet, which you can download from the BCNA website; or talk to your GP.

For more information about managing emotions, see Section 3: Living Well.
Resources

Organisations

Breast Cancer Network Australia (BCNA)
bcna.org.au or phone 1800 500 258

In addition to this Hope & Hurdles pack, BCNA provides a range of information and support programs for people diagnosed with metastatic breast cancer.

- BCNA’s Helpline provides support and information about breast cancer for women and men living with breast cancer and for their family members and friends. You can contact our Helpline team on 1800 500 258 between 9.00 am and 5.00 pm (Eastern Standard Time). You can also contact us by email on beacon@bcna.org.au

- Free telephone counselling service for people diagnosed with metastatic breast cancer, their family and supporters

- The Beacon magazine and The Inside Story supplement (specifically for people diagnosed with metastatic breast cancer)

- Lists of BCNA-affiliated support groups across Australia

- Online network

- A range of booklets and fact sheets

- Information forums on metastatic breast cancer

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 ‘advanced’ 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. Services vary between states and territories, which have a range of brochures, booklets and fact sheets on many topics related to metastatic breast cancer.

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. Staff can provide information and materials depending on the needs of you and your family.

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

Online resources and publications

BCNA’s online network
onlinenetwork.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 is an active, public discussion area for anyone affected by metastatic breast cancer. There is also a private group for people with metastatic breast cancer, where only members of the group can read the discussions. If you need help to access the private group, please call BCNA for support.
Guide for women with secondary breast cancer
Australia 2010
Cancer Australia
canceraustralia.gov.au

This comprehensive guide is for people who have been diagnosed with metastatic breast cancer. It contains information to help you understand your diagnosis and options for treatment and care.

Finding the words – starting a conversation when your cancer has progressed
Australia 2016
Cancer Australia
Download from the Cancer Australia website:
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.

She has secondary breast cancer: how can I support her?
Australia 2012
Breast Cancer Network Australia
bcna.org.au or phone 1800 500 258

This booklet is for family, friends and partners of anyone diagnosed with metastatic breast cancer. It explains the diagnosis of metastatic breast cancer and suggests ways that partners, family members and friends can provide support.

When the woman you love has advanced breast cancer
Australia
Podcast section of the Cancer Australia website
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.
Anxiety, depression and breast cancer
Breast Cancer Network Australia and
beyondblue: the national depression initiative
bcna.org.au or phone 1800 500 258

This 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.
Two:

Treatment and side effects

Don’t be afraid to say, ‘I’m sorry I don’t understand what you have just told me, can you please explain it again?’ Keep on asking until you do understand it at your level.

– Ella
TREATMENT AND SIDE EFFECTS
Treatment and side effects

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:

- Symptoms you may experience
- Health professionals who may be involved in your care
- Types of metastatic breast cancer
- Types of treatment you may be offered
- How might new drugs be available to you?
- Demystifying palliative care – understanding what it is and how it might help you
- Planning ahead
- Managing symptoms of metastatic breast cancer and side effects of treatment
- Complementary and alternative therapies
Symptoms you may experience

Every person’s experience of metastatic breast cancer is different. The type of symptoms you may experience will depend on the extent of the cancer and the part of the body affected, as well as any other health issues that you may have. Some women will experience many symptoms while others will experience very few or none at all.

Some women with metastatic breast cancer will have general symptoms such as feeling more tired than usual, feeling generally unwell and having a reduced appetite. These could be caused by many things such as colds and flu or other medical problems; if they persist you may want to discuss them with your doctor.

Metastatic breast cancer in the bone

One of the main symptoms of metastatic breast cancer in the bone is bone pain. This could feel like a nagging ache, which you might be aware of day and night and that may increase when you are active and moving around. It may be caused by damage to the bone by cancer, or cancer in the bone that presses on the nerves.

Metastatic breast cancer in the bone may gradually damage and weaken the affected part of the bone, which could cause the bone to fracture.

Metastatic breast cancer in the bone can be treated with medication, radiotherapy or surgery. There is also medication that can strengthen bone, reduce pain and help prevent fractures. As treatment can help by preventing problems or addressing them early, before fractures or further weakening occurs, it is always a good idea to discuss any ongoing pain or changes with your doctor.

For more information, see BCNA’s booklet *Metastatic breast cancer in the bone.*
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 women with metastatic breast cancer in the liver feel tired, generally unwell and have less energy. They may also feel nauseous, lose their appetite and lose weight.

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 therapies such as tamoxifen and aromatase inhibitors may be used if the cancer is hormone receptor positive.

☞ For more information, see BCNA's booklet Metastatic breast cancer in the liver.

Metastatic breast cancer in the lungs

Metastatic breast cancer in the lungs may affect the lung tissue or the lining of the lungs, which is known as the pleura. Symptoms include a persistent cough, pain in the chest and shortness of breath.

General breast cancer treatments such as chemotherapy or hormone therapy can help to prevent and treat symptoms. If fluid builds up in the pleura – called 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.
Metastatic breast cancer in the brain

It is much less common for breast cancer to spread to the brain than the other organs listed above. 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 radiotherapy techniques have fewer side effects than radiotherapy treatments used in the past.

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

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.

Other sites

While the sites discussed above are the most common areas for metastatic breast cancer, there is potential for breast cancer to spread anywhere in the body. This may include skin nodules, lymph nodes other than in the local breast area or axilla or, less commonly, the abdominal cavity and the ovaries.
Choosing your treatment and care team

Although metastatic breast cancer is not currently considered curable, it is very treatable, and for most people it 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 is 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.

Seeking a second opinion

It is okay to seek a second opinion and/or choose a different team from the one that treated you in the past if you had an early breast cancer.

If you would like a second opinion, you have a number of options. You can ask your medical oncologist for a referral to someone suitable. Most oncologists are very happy to give referrals to patients for a second opinion. If you feel uncomfortable discussing this with your oncologist, you can 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 the new oncologist better suits your needs, 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 is important to take as much information as possible with you when you meet a new oncologist, including what drugs you have had in the past, and when you started and stopped them. In order to make the most of the appointment you have for a second opinion, spend time putting all of your treatment records together. This can seem tedious, but will mean that you can have an informative and worthwhile discussion that can help you decide whether you are comfortable with your current care or would prefer to see a new team.
Your medical oncologist must be your number one companion during this journey. If you don’t like your oncologist, then change. – Lisa

People on your treatment and care team

Multidisciplinary care

The management of metastatic breast cancer is complex, and therefore involvement of all appropriate specialists in a multidisciplinary team is important. Team members may include medical oncologists, surgeons, radiation oncologists, imaging experts, pathologists, nurses, clinical trial research staff, social workers, psychologists and palliative care specialists as well as other health professionals involved in your care.

The number and kinds of people treating you at any one time will depend on the details of your cancer, where you live and where you are being treated. In some treatment centres a multidisciplinary team of people involved in your care will meet to discuss your progress from time to time and make treatment recommendations that might be helpful for you. You can ask any of your treating team to advise you when this happens so that you are aware of any recommendations that are made that you may want to consider.

This model encourages good communication, treatment and care. However, not all women with metastatic breast cancer have access to a multidisciplinary team, particularly those who live in a regional or rural part of Australia.

I was concerned that I did not get treated by a multidisciplinary team and so asked my GP about how I could get access to such team-based management.

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! – Sylvia
General practitioner

Your GP is a good person to remain involved in your care. Not all of the symptoms you experience will be cancer-related. Your GP can assess each problem and, if you do need to be seen by your medical oncologist, can help to arrange an urgent appointment.

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 women 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 not 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 diagnose and treat cancer using chemotherapy, hormone therapy and other targeted therapies. They are doctors who have completed many extra years of training in order to specialise in looking after people with cancer. Your medical oncologist will probably be your main medical caretaker, referring you to other specialists when required and often coordinating your treatment and care.

Radiation oncologist

Radiation oncologists specialise in treating cancer using radiation. 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 breast care team, and usually work closely with medical oncologists.
**Psychologist**

Many women 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 anything that is worrying you. Managing relationship issues, coping with anxiety and fear, working through loss and grief; and understanding the effects your illness might have on you and your family can help you to focus more on the pleasures in life. Some psychologists specialise in supporting people who have had a diagnosis of cancer. This field is known 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 or liver to reduce its effect, for instance if it is causing a blockage, discomfort or other complications. If metastatic breast cancer is your first diagnosis of breast cancer, surgery on the breast may be considered to provide control of the cancer in the breast after initial drug treatment. However not all women with metastatic breast cancer as a first diagnosis will require surgery to the breast.

**Oncology/chemotherapy nurse**

Oncology nurses administer chemotherapy and other anti-cancer treatments and help with radiotherapy. They can also help you to manage pain, nausea or other symptoms. An oncology nurse can be a good person to talk to if you are having difficulty managing side effects of treatment.

**Patient navigator or cancer care coordinator**

A patient navigator is a person who can help guide you through the complex information and difficult decisions that may arise during your treatment. The best person to do this is a specialised breast care nurse or specialised oncology nurse, who is part of the team of experts managing people with metastatic breast cancer. However, a different team member who is qualified to help you may also take on this role — it depends on the health care centre where you receive your treatment.
If you are interested in finding out whether a patient navigator can be part of your care, talk to your oncologist or your nurse and ask them whether this service exists in the hospital you are being treated in.

**Breast care nurse**

A breast care nurse can provide information, counselling and support, and can help to coordinate your care.

Most breast care nurses work with surgeons and surgical wards at hospitals, and so mainly support women with early breast cancer. Many women diagnosed with metastatic breast cancer tell us that they do not have a breast care nurse as part of their treatment team. Sometimes women can feel disappointed that this aspect of their care is not the same as when they had treatment for early breast cancer.

> *I didn’t see her, as it was a different process and I was diagnosed in a different setting. I have seen her in passing when going to oncology, but we haven’t actually talked yet. This is after 18 months of various treatments.*

If you would like to see a breast care nurse, ask your medical oncologist or GP to refer you to one. If you had an early breast cancer diagnosis and a breast care nurse was part of your care, make contact and let them know that you would like to have her support once again. The McGrath Foundation has nurses throughout Australia who can support women diagnosed with breast cancer, including 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](http://mcgrathfoundation.com.au)) has a search function that you can use to find a McGrath breast care nurse in your area – just enter your postcode in the form provided.

Not all breast care nurses are experienced in the management of metastatic breast cancer. However, specialised metastatic breast cancer nursing roles are starting to emerge in Australia. Nurses working in these roles have the experience and training to specifically provide support and coordinated care to people with metastatic breast cancer.
BCNA is committed to advocating for an increase in the number of specialised breast care nurses who are knowledgeable in the treatment and care of metastatic breast cancer. If you are unable to access a breast care nurse, or find one who has specific knowledge about metastatic breast cancer, we are interested in hearing from you. You can contact us at policy@bcna.org.au.

Specialist palliative care providers

Many people think that palliative care services only provide end-of-life care. This is not the case. Specialist palliative care providers include doctors, nurses, social workers and others who have specific skills, and work as a team to help in a number of ways from soon after diagnosis. For instance, they can help take pressure off family members by providing specialist support. They can assess and manage physical symptoms, such as pain and poor appetite, and help to ensure that your home environment is safe and comfortable. They can also provide specialised care for your social, emotional, cultural and spiritual needs and those of your family. You can take advantage of 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 palliative care can help, see Section 2: Treatment and side effects.

Social worker

Social workers can help you and/or your family to cope with the impact metastatic breast cancer has on emotional, psychological and practical issues. 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 provide you with information and assistance about employment, finances, accommodation and legal matters. They can also provide information and links to any practical help and services that may be available to you, including 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 arrange any care that you may need at home and to plan your discharge.
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 find more joy in life.

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 are 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 4: Financial and practical matters.

Pharmacist

Your pharmacist can help by explaining how to take your medication and possible side effects of any medications prescribed for you and suggesting ways to alleviate some of them.

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

Allied health professionals

Allied health professionals are health care workers who can assist you to manage a range of symptoms and concerns that you may experience. You may be eligible for some Medicare-subsidised appointments with a range of allied health professionals. Your GP can help you to make a plan that can 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.
Physiotherapist

Physiotherapists can help you to manage some of the side effects of metastatic breast cancer and its treatment. They can help to relieve pain without medication, teach you breathing and coughing techniques, help you to become mobile after a bone fracture, and find appropriate ways for you to exercise and stay active. They can also help you to manage lymphoedema (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. An AEP 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.

For more information about exercise and how to find an exercise physiologist, see Section 3: Living well.
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 that would 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 that will improve your quality of life.

Nutritionist or dietitian

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

For more information about health care teams, see Cancer Australia’s Guide for women with secondary breast cancer.
Choosing a medical oncologist

Some women 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. Some questions for you to consider include:

- Does the medical oncologist have a special interest and experience in managing metastatic breast cancer patients?
- Do they work within a multidisciplinary team?
- 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 page 58 for more information about clinical trials.)
- 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?
Communication is the key

*Ask lots of questions and remember, ‘knowledge is power.’ – Judy*

Whichever team you choose or have provided for you, you can’t expect them to read your mind. Don’t be afraid to talk to them and ask questions until you’re sure you understand the answers.

*Don’t be afraid to say, ‘I’m sorry I don’t understand what you have just told me, can you please explain it again?’ Keep on asking until you do understand it at your level.*

– Ella

You may want to ask your medical team how they prefer to communicate. The options could include email, face-to-face appointments, video conferencing if you live in the country, and 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. During your appointment, you may want to take notes or have a family member or friend with you to listen and/or take notes. Taking a partner, family member or friend with you to appointments has many advantages so you may like to consider who might be the best person to attend with you on a regular basis.

Some women find it helpful to record their conversations, but you will need the doctor’s permission to do so.

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

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 way to give them an opportunity to be involved in your care.
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 women who have been living many years with advanced breast cancer. – Xuan

I have a good oncologist who explained the diagnosis perfectly. He said the diagnosis meant there is no cure but it didn’t mean there is 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. – Naomi

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. Some treatments will treat the cancer and may relieve the symptoms very quickly. Others take longer to work and some may not work at all. If one type of treatment doesn’t work for you, there will usually be others to try.

There have been very significant advances in the treatment of metastatic breast cancer in recent years due to research providing a better understanding of breast cancer. This has led to the recognition of three main breast cancer ‘subtypes’, which are now the main guide for treatment recommendations. Many treatments target specific features of particular breast cancer types and are already making a real difference for many people with metastatic breast cancer. They have led to better control of the cancer for longer and longer periods, and improvements in quality of life.
Types of breast cancer

While currently three main types of breast cancer have been identified, it is expected that in the future these will be further divided as understanding of the inner (‘molecular’) workings of each type of breast cancer expands. Consequently treatment will become more and more specific to an individual cancer. Developing this ‘personalised’ treatment is the main goal of current research.

The three subtypes of breast cancer that guide treatment options are:

- hormone receptor positive
- HER2-positive
- triple negative.

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

A pathologist will test your breast cancer in the laboratory to determine whether it has hormone receptors (hormone receptor positive) and whether it has an over-expression of HER2 receptors (HER2-positive). Based on these tests, your specialists will explain to you what type of breast cancer you have. It may be hormone receptor positive and HER2-positive. Around 10 per cent of breast cancers have no receptors and are classified as triple negative breast cancers.

These tests will have been done on your original breast cancer if you had an early breast cancer prior to the diagnosis of your metastatic breast cancer. If it is possible, a biopsy of the metastatic breast cancer will be done to confirm whether the receptor results have remained the same as the original cancer or not. Sometimes a biopsy is not possible, and the results from the initial cancer will be used.

If you have presented with metastatic breast cancer without a previous early breast cancer diagnosis, this is called ‘de novo’ metastatic breast cancer. A biopsy will need to be performed, both to confirm that the diagnosis is metastatic breast cancer, and to check the receptor results.

For more information about having metastatic disease as your first diagnosis see Section 7: Metastatic from the start.
Talking with your treating team about the pathology of breast cancer can be a complex discussion, especially if metastatic breast cancer is your first diagnosis of breast cancer. It is okay to keep asking questions until you understand the type of cancer you have, and what that means for your treatment options.

BCNA has developed booklets on the three different subtypes of breast cancer. They are designed to help you understand your specific subtype of breast cancer and help you to think about questions to discuss with your specialist.

To order these booklets contact BCNA on 1800 500 258 or visit the BCNA website bcna.org.au.

When you are told you have metastatic breast cancer, you don’t usually have to make a decision about treatment right away. You may want to take time to gather information, find out what treatments are available to you, explore clinical options, speak with your family and close friends, and think about what other things going on in your life might influence the decisions you make.
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 different women can respond differently to the same treatments. This is why treatments are tailored to individual women. Factors like your age, menopausal status, prior treatment, medical history, general health, work situation, life goals and personal preferences all need to be taken into account.

You will find that different doctors have different approaches to treatment and care. You may meet with or talk to other women online who are having different treatments to you. This is nothing to worry about. However, if you are concerned you can ask a member of your treating team why one treatment has been recommended to you over another. It is also okay to ask for a second opinion if that will help you feel more secure in the team and treatment you choose.

The most common treatments for metastatic breast cancer are hormone therapy, chemotherapy, targeted therapy, radiotherapy and, less frequently, surgery. These may be used individually or in combination.

The overall approach to treating metastatic breast cancer is to regularly assess the activity of the cancer and any problems it is causing, and treat accordingly. This means you may require regular blood tests and scans to monitor the activity of your cancer.

BCNA’s booklets on the subtypes of metastatic breast cancer provide comprehensive information on treatment pathways that may be recommended for you according to the pathology of your disease.

› Contact BCNA on 1800 500 258, or visit bcna.org.au for information on how to order these booklets.
Types of treatment

Hormone 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 (endocrine) therapy

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 that have 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 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 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 therapy is working. If it isn’t, or if it stops working after a time, there are generally other hormone therapies or treatments to try.

Some cancers, known as ‘hormone receptor negative’ or ‘hormone unresponsive’, have very few or no oestrogen or progesterone receptors and are not expected to respond to hormone therapy. If your cancer is hormone receptor negative, hormone therapy will generally not benefit you and will not usually be included in your treatment.

There are many different types of hormone therapy, including anti-oestrogens, aromatase inhibitors, progestins, ovarian suppression agents and surgical removal of the ovaries.

For more information on hormone therapy, refer to BCNA’s Hormone receptor positive metastatic breast cancer booklet.
Chemotherapy

Chemotherapy uses drugs known as cytotoxics to kill cancer cells or disrupt their growth.

There are many different types of chemotherapy; your doctor or oncology nurse will be able to explain the possible benefits and side effects of the drugs prescribed for you.

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, bone marrow and digestive system, which is why side effects such as low blood counts and hair loss may occur.

Not everyone has significant side effects, and most side effects stop when the treatment stops. You should talk to your medical oncologist or oncology nurse if you are concerned about any side effects that you experience.

For more information on managing side effects of treatment, see Section 2: Treatment and side effects.

Chemotherapy is most commonly delivered by drip, known as intravenous infusion, or in tablet form.

For more information about different chemotherapy drugs and how they are administered, see Section 8: Glossary of terms.

Chemotherapy drugs may be used on their own or in combination. When used in combination, the first letter of the name of each drug is used to describe the particular regime – for instance, AC is a combination of the drugs Adriamycin and cyclophosphamide.
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?
• Is there medication to help if I experience side effects such as nausea?
• How often will I need chemotherapy?
• What are the possible side effects?
• 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?
How can I avoid having sore 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.

A central venous access device, also known as a port-a-cath, infusaport or simply a port 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.

An alternative to a port is a peripherally inserted central catheter (PICC) line, which can also be called a PICC. 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 is 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 and 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. – Veronica

The advantages of having a port or PICC line are that it can spare your veins from the frequent ‘needle sticks’ associated with chemotherapy and blood tests. It can also spare your veins and blood vessels from the irritating effects of intravenous medications, which over time can make your veins sore and scarred, so they can no longer be used.
The advantages of a port are that, because it is under the skin, it is less susceptible to infection and does not require dressings. As it is not visible, other than as a minor swelling under the skin, it is also less intrusive than a PICC line. You are able to go swimming with a port in place. The disadvantages might be that it means another hospital procedure and another scar. Also, even if you are not having treatment, a port will need to be flushed with an anti-clotting agent at least once every six weeks.

The advantage of having a PICC is that it may be easier for your medical team to arrange for you to have this close to the time that you need to start your chemotherapy. PICC lines can be put in place in the radiology department at the same time that you have your chemotherapy.

Disadvantages of having a PICC include that it is held in place by a dressing that needs to be changed at least once per week. There is also a risk of infection associated with the external component of the catheter that enters the skin. The line will need to be flushed at least once per week to keep it from becoming blocked – the oncology nurse will do this for you. You may also be able to have a nurse visit you at home to do this if your treating centre offers this service. If you like to swim, a PICC line might not be the best option for you because of the increased risk of infection.

Questions you may like to ask if your doctor suggests a PICC line or port:

- Where can it be inserted?
- How do they work?
- Which option is better for my lifestyle?
- Will I be able to see it?
- How do I care for it?
- Will I need a general or local anaesthetic?
- How often will it need to be flushed, and who will do that for me?
- Can it be used for scan contrast injections?
- How often will it need to be replaced?
- Can blood be taken from it for tests?
- How will I know if it gets infected?
**Port**
A port is implanted under the skin of the chest. It is a very slender, flexible tube that feeds directly into one of the major veins near the heart.

**Peripherally inserted central catheter (PICC) line**
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 therapy, there are newer treatments that can attack specific breast cancer cells without harming normal cells. These therapies are called targeted therapies. Targeted therapies are drugs that block the growth of breast cancer cells in specific ways.

The best known targeted therapies are the hormone therapies targeting the oestrogen receptor. HER2 therapies (Herceptin, Perjeta, Kadcyla and Tykerb) that block the action of HER2 receptors on cells are the best known newer targeted therapies. Breast cancers that are HER2-positive have excessive numbers of HER2 receptors 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.

For more information about HER2 therapies, see BCNA's HER2-positive metastatic breast cancer booklet.

New targeted therapies that block other pathways within cancer cells are currently in development. These targeted therapies are sometimes called biological therapies. For more information about some of these, see BCNA’s subtypes of metastatic breast cancer booklets.

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/detect cancer cells or by adding components to a person’s immune system such as man-made immune system proteins. The development of immune therapies for cancer has taken off in recent times, especially in the treatment of melanoma skin cancers. It appears that triple negative breast cancer is one of the subtypes of breast cancer most likely to respond to these treatments. Trials are underway in triple negative metastatic breast cancer, and also in HER2-positive metastatic breast cancer, to test the effectiveness of immunotherapy drugs.
Local treatment

Radiotherapy

Radiotherapy uses X-rays and other forms of radiation, such as high-energy electrons, to destroy cancer cells. It is 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. While it may be some weeks before pain in the bone eases after radiotherapy, most women 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 Section 2: Treatment and side effects.

BCNA’s suite of metastases booklets has information about radiotherapy for different areas of the body where breast cancer has spread.

Surgery

Surgery is a less common treatment for women 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 ureter. New surgical options are also emerging for solitary (single) liver metastases.

For more information on breast cancer treatment, go to Cancer Australia’s website: canceraustralia.gov.au.
How might new drugs be available to me?

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. – Astrid

I was fortunate to participate in two clinical trials and this treatment has been very successful for me. On both occasions they have worked. Cancers have decreased in size and in some cases, cancers have gone. – Julie

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 best existing treatment. While we tend to think of trials in terms of new drugs, 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.

Many people have the impression that clinical trials are using you as a guinea pig. This could not be further from the truth. When you have advanced disease, it quickly becomes evident that the treatment given to you is to maintain the best quality of life. – Luba

I was glad to be able to access the trial of a new drug. If I had not been able to participate, I would have always wondered if this treatment may have changed the course of my disease. – Ann
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 upon information gained from the previous phases. Participants in any phase trial are watched closely to see if any serious side effects develop. Treatment is stopped if side effects appear to be problematic.

*Phase I trials*

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

*Phase II trials*

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

*Phase III trials*

Phase III trials compare a new drug to existing treatments that are standard of care. They are usually large and can involve thousands of people. Phase III trials are usually the last step before the government approval process of enabling a drug to become available for sale in Australia.

Participants in Phase III studies will usually be randomised to either the new drug treatment or to standard treatment. This means that 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 are usually conducted after a drug has been approved for use and are less common than Phase I, II or III trials.

Benefits of clinical trials

Participating in a clinical trial could give you early access to a new type of treatment or a new way of receiving treatment that may otherwise not be available to you and which may result in longer survival. This might be important if existing treatments are not working well or if a new treatment has been developed that is showing some benefits for your particular subtype of cancer. Some participants 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.

Another benefit of participating in a clinical trial is that you will be closely monitored by breast cancer specialists, research nurses and other cancer experts. Research shows that patients who are treated in a clinical trial often do better than those who are not, as a result of this very closely monitored care. You will also be helping researchers to develop new treatments for metastatic breast cancer that will help other women in the future.

Nevertheless, a clinical trial is not for everyone.

In the first instance, 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.

You may feel that, on balance, the negative aspects outweigh any possible benefits. You may need to set aside extra time for appointments, or visit the clinic more often than if you were on the standard treatment, for example. Or you may have additional out-of-pocket costs for travel to the trial site. Not all medical oncologists and oncology centres offer all trials, so you may need to be referred to another oncologist for the period of the trial.
You may also need to consider that 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 are free to leave the trial at any time.

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. However, if you are interested, it is always worth asking whether there are any trials that may be available to you.

These trials do not have to be in your treating centre. You can ask your oncologist if there is a trial at another centre that might be of benefit to you. In this instance you will need to weigh up the potential benefits of participating in a clinical trial with the challenges associated with travelling for treatment and seeing a different oncologist.

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 are 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 is 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 is no need to rush into this. Take the time to make sure you understand everything that you are 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.

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

> australianclinicaltrials.gov.au
> Australia and New Zealand Breast Cancer Trials Group anzbctg.org.au
> Victorian Clinical Trial Link (VCTL) cancervic.org.au
> Cancer Australia’s website canceraustralia.gov.au

You can also read more information in:

> BCNA’s website
> BCNA’s Clinical trials fact sheet
> Cancer Australia’s website canceraustralia.gov.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 10 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 in time you may reach a stage where there are no new government-subsidised treatments available to you. You might also face a time when your oncologist talks to you about a drug that might benefit you but is not yet available to Australian women. Or you may hear about such a drug through the media or from other women. This can cause real heartache for you and your family.

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 is a new drug available that may be beneficial for you, but you cannot 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 are even approved for sale in Australia. We have listed a number of avenues here. Be wary of other methods 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 schemes are offered at the discretion of the pharmaceutical company, and the drugs are provided to individuals on a case-by-case basis. These 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 rest, or some, of your treatments until either the drug is listed on the
PBS or it stops working for you.

Your medical oncologist will have to apply to the pharmaceutical
company on your behalf. You can talk to your medical oncologist about
whether there are any treatments suitable for you that may be available
through one of these schemes.

**Compassionate grounds**

Sometimes, although it is rare, a pharmaceutical company will provide
a drug free of charge on compassionate grounds. If you are unable
to meet the cost of a new drug, talk to your medical oncologist about
whether there may be a case to apply for the drug to be provided to
you on compassionate grounds.

**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, you may like to ask your insurance company if you are
able to claim benefits towards the cost of a particular drug. It is unlikely
that your insurer will cover all of the costs, so make sure you get a
quote in writing before you go ahead and pay for a treatment for which
you will seek reimbursement from your insurer.

**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 fundraising 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 is a process for this, and it is advisable to 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 permit their staff to administer them to you.

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 that are not yet registered for use in Australia. To ensure the drugs they offer are legitimate, TheSocialMedwork only supplies drugs 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 is important to remember that even when new drugs have good results in clinical trials, they do not work for everyone. It is possible that you may pay thousands of dollars for a drug that does not benefit you. For this reason, we encourage you to have a very carefully considered discussion with your oncologist and your family before considering this option. 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. Discuss this with your oncologist.
Changes to the approval process for new cancer drugs announced by the Australian Government in September 2016

In September 2016, the Australian Government announced that the Australian drug regulatory authority, the Therapeutic Goods Administration (TGA), will be able to fast-track the approval and sale of new medicines that have been listed by reputable overseas drug regulatory authorities such as the US Food and Drug Administration and the European Medicines Agency. It is hoped that the proposed changes will mean that Australians with cancer who want access to medicines newly available in the USA and Europe will no longer have to obtain them from an overseas supplier.

This should also mean that new medicines are available for purchase in Australia sooner. While this is a good outcome, it is important to understand that there will still be a delay before these medicines are listed on the Pharmaceutical Benefits Scheme (PBS) and available for the cost of the PBS script fee. There is a separate process for having medicines listed on the PBS, and unfortunately this can take up to three years in some cases. Some medicines may never be listed on the PBS at all. This means that new medicines available in Australia may be still be very expensive for a period, and so may be unaffordable to many people who might benefit from them.

Despite this, it is expected that the proposed changes will help some Australians who are willing to pay for new cancer medicines by reducing some of the complexities and costs around purchasing them from overseas.

If you would like to know more about these changes you can contact the policy team at BCNA at policy@bcna.org.au or talk with your medical oncologist.
Demystifying palliative care

Many people are concerned when they hear the words palliative care. You might think it will only be offered to you when you are in your last weeks or months of life. You might think it means you can no longer receive treatment aimed at controlling your cancer and prolonging your life. You might think it means you won’t see your oncologist, breast care nurse or other members of your treating team. This is not the case.

When told what palliative care services can actually provide, many people are much more comfortable with the idea.

My palliative care team, which I only accessed a couple of months ago, has been amazing. They linked my family with services and support that would have been great to know about three years ago when I was first diagnosed with metastatic breast cancer.

How palliative care can help you

Palliative care helps people live as fully and as comfortably as possible when living with a serious illness that cannot be cured, such as metastatic breast cancer.

I’m having palliative care now and I’m not at the end of my life ... I am 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. It is there not just for you, but for your family and friends as well. This means that your family and carers can receive practical and emotional support, as well as physical support. Many women find that support for their family is as valuable as the direct support they receive.

I always thought of it (palliative care) as something for me, but hadn’t thought it was there to support my family. – Kate
The benefits

Palliative care can identify and help you manage your physical symptoms, such as pain, and it can also help with your emotional, spiritual and social concerns. Because palliative care is based on your individual needs, the services offered will differ for each person, and may include:

- relief of pain and other symptoms (e.g. vomiting, shortness of breath)
- provision of equipment needed to help you live as independently as possible at home (e.g. wheelchairs, special beds, shower chairs)
- assistance for families to come together to talk about sensitive issues (e.g. counselling for your children)
- links to other services (e.g. home help, financial support)
- support for people to meet cultural obligations
- support for emotional, social and spiritual concerns
- 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, knowing that you will be well cared for.

Palliative care is provided where you and your family want to receive the care, wherever possible. This may include:

- 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 the diagnosis of metastatic breast cancer can help make you feel more comfortable in seeking their support at a later time 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.

You might also find it reassuring to hear about the extent of the support available to you.

I see a (palliative care) nurse practitioner regularly about prevention; deep breathing to prevent pneumonia, for instance. – Vanessa
Early access to palliative care can also ensure that you have all the supports you need to maximise the quality of your life and your mobility for as long as possible.

*The wheelchair and shower stool are strategies to manage my energy reserves in the way I want to. I use it (my energy) to be with my kids, not to stand up in the shower.* – Vanessa

Not feeling your best and needing to use health services can be depressing, so having other people who can assume roles and responsibilities and advocate on your behalf, as your palliative care team can do, can be empowering. Your palliative care team can also help interpret your medical reports and even attend oncology appointments with you.

🔗 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 is good to think ahead and talk to them about the care that 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 women 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 am able to do ... Empowerment is important for me. – Maya*

One useful tool to help you reflect on your values and preferences for care is the Dying to Talk Discussion Starter dyingtotalk.org.au. This useful tool walks you through a personal reflection, and then provides some tips for talking with your family and doctors about your preferences for care.

After you have thought about the care that you want, you might like to 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. This is important because in the future you may 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 help 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 at the time and place it is needed.

Planning ahead can be difficult, but once you have 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 that it was what you wanted. Over three quarters of people who had talked to a family member about their health care wishes found it helped them make decisions about their care.

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 fullest and continue to do the things I had planned to do prior to my diagnosis.

The Hope & Hurdles Planing ahead (formerly Getting your affairs in order) booklet provides more details around planning ahead. You can order it from the BCNA website bcna.org.au or by phoning 1800 500 258.
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 (‘progressing’), but being tested, waiting for results and perhaps hearing that a treatment is no longer working can be stressful and upsetting. It is important to be aware of this and to think about ways of managing this stressful time. If you are being tested or scanned to determine the cancer’s response to treatment it can sometimes be helpful to talk with your oncologist beforehand about what treatment changes may be recommended if the results are not good news. It may be reassuring to know that even if the cancer has not responded or if it has in fact started to increase, there are other treatment options that can be commenced.

*Waiting for test results is one of the most worrying times; days turn into weeks. Finally 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.* – Alana

Scheduling your scans as close as possible to the review appointment with your oncologist will mean you don’t have to wait as long for the results, although enough time needs to pass to ensure all of the test results are available when you meet with your oncologist.

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), and blood tumour marker tests. Scan results are not usually considered in isolation. Other factors will help to provide a more complete picture about 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 are 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 is okay to get a second opinion. You are not being disrespectful or disloyal to your doctor, you are just checking things out. Your doctor would do the same. – Jenny

If you are uncertain about or unhappy with the care you are receiving, either from your doctors or through the health care system, it is important to voice your concern.

You may decide to raise the issue yourself by explaining your feelings to the health care professional in question. If you do, you might want to arrange an appointment where you focus specifically on your concerns. You may find it helpful to take someone with you who can help you explain your concerns and take the emotion out of the discussion. Communication is important and you need to feel that your treating team listens to you and responds to your needs and concerns. Treatment for metastatic breast cancer is ongoing, and your relationship with your treating team will be an integral part of your care, so this is not the time to see someone who you find it difficult to communicate with.

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 Section 2: Treatment and side effects.
Managing symptoms and side effects

You may have experienced only a few symptoms in the lead-up to your diagnosis and it may be a long time before any symptoms develop that impact on your quality of life and ability to live well. 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 on the type of symptoms and side effects that you experience will be the sites your cancer has spread to and the type of treatment you are having. Other factors such as your general health and wellbeing will also play a part in how your symptoms may affect you.

The following section provides information on managing a wide range of symptoms and side effects. Remember, everyone is different and you are unlikely to experience all of these symptoms or side effects. Some people experience very few or have only mild side effects or symptoms. Others experience more serious side effects or symptoms that can interfere with their quality of life. You may also experience side effects that are not covered in the following section.

You may not want to read all of this section right now. Some of the side effects described may not be relevant to the treatments you are having. It may be helpful to come back to this section at a later time if you start a new treatment or are concerned about how to manage a symptom that is bothering you.
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 women believe that pain associated with metastatic breast cancer is inevitable; this is often one of women’s greatest fears. However, some women experience no pain at all and others very little.

It is 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. There are also 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 and prescription drugs can be helpful to reduce or eliminate pain. 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. Anti-inflammatory medications such as aspirin and ibuprofen (Nurofen) are also effective for mild pain. Codeine-containing analgesics such as Panadeine can also be purchased without a prescription and can be effective for moderate pain.
Prescription medications for pain

Panadeine Forte is a stronger codeine-containing analgesic, but you will need a prescription from your oncologist or GP to purchase it.

The opiate painkillers are the prescription drugs that provide the backbone of managing moderate or more severe pain. There are quite a number of different versions of opiate painkillers, and new ones are introduced from time to time. The usual approach is the use of a slow-release form – these are either oral medications or patches that are placed on the skin and renewed every few days. Examples are:

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

You may also be able to use fast acting (as opposed to slow-release) pain medication for what is called ‘breakthrough pain’ – pain that occurs despite the slow-release pain 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, such as bone or liver metastases.

Radiotherapy for pain relief

Radiotherapy can be a very effective way of reducing bone pain in women who have bone metastases.
Who can help me control my pain?

It should be possible to achieve good control of your pain. It is important for you to let your treating team know if you are having a lot of pain, as a change in dose or use of different drugs may be helpful. Sometimes, your oncologist may 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 is important to talk with your treating team about any pain you may be experiencing. The more accurately you can describe the pain, the easier it will be for your doctor to prescribe the most effective treatment. Keeping a diary noting the following could help.

- 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 or more like 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 may become dependent on it. Or you may find yourself worrying that increasing the amount of pain medication you are using means that your cancer is getting worse. There are many myths about pain-relieving agents and cancer, particularly morphine.
Myths around morphine

Myth 1 – If I take morphine I will 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 that means my cancer is getting worse.

If your doctor recommends morphine it is 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 will 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 am taking other medication.

While morphine can be effective on its own it is quite commonly used in combination with other pain medication like paracetamol. As some antidepressant medications work to increase the pain-relieving benefits of morphine, 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.

A free DVD, Overcoming Cancer Pain, is also available in some states and territories. Contact your local Cancer Council for details.
Non-medical pain relief

Complementary therapies may be helpful 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 Section 3: Living well.

Research shows that acupuncture can relieve pain, and 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 that can protect you from the weight of your bedding. Back supports may make sitting more comfortable and there are other devices to 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 (or 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 of the intravenous chemotherapy drugs, including the family of drugs called taxanes, and eribulin, can cause neuropathy, which for
some people can be significant. Some oral forms of chemotherapy, such as Xeloda (capecitabine) and Navellbine, and some of the targeted therapies can also cause neuropathy.

Chemotherapy-associated neuropathy can start any time after treatment begins, and it 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 sensations
- loss of touch sensation
- trouble using hands/fingers to pick up objects, fasten clothing, type on a keyboard or a mobile device.

Neuropathic pain can also occur from cancer damaging nerves.

**Treatment for neuropathy**

There are medications that can help reduce the pain and discomfort associated with neuropathy. This includes Lyrica (pregabalin), Neurontin (gabapentin), Tegretol and Endep.

Sometimes having a rest from chemotherapy drugs that cause nerve damage can help improve symptoms. Your oncologist may be able to switch your treatment to a drug that does not cause neuropathy. If you are someone who likes to do artwork/needlework/craftwork (knit, embroider, sew, paint, etc.), or you use your hands constantly for keyboard work, let your oncologist know that avoiding neuropathy may be important for your quality of life.

**Joint pain**

Any treatments that result in menopause may cause joint pain as a side effect. In particular, if you are taking an aromatase inhibitor (anastrazole, letrozole, 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 more. Some women find that gentle
exercise and stretching helps, such as hydrotherapy (exercise in water), swimming, tai chi and yoga.

If you want to try exercise, or if exercise is new to you, see Section 3: Living well for some suggestions on how to get started.

Over-the-counter drugs such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs) such as Nurofen or Voltaren may help. Your doctor or pharmacist can give advice about what option may be best for you.

Acupuncture has also been shown to help joint pain for some women, and research trials are continuing in this area. Glucosamine and fish oil can also be helpful.

**Low blood counts and risk of infection**

Chemotherapy, particularly the anthracycline and taxane groups of drugs, 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 it 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 contribute to fatigue, leaving 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 are 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) so try to include some light exercise, such as a walk, into every day.

- Adequate rest is vital, but too much can leave you feeling more exhausted. Try 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 that you can feel a sense of satisfaction from even 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 painkillers. It can also be a symptom of constipation. Anxiety can worsen the feeling of nausea.

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 under the tongue lozenges or wafers. Steroids can also help control nausea caused by chemotherapy and liver and brain metastases.

Modern-day anti-nausea drugs mean it is much less likely for people to experience excessive vomiting. However, talk to your doctor if you are experiencing vomiting.

Complementary therapies, such as relaxation therapy, hypnosis and acupuncture, can 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.
- Take the antiemetic schedule recommended to you by your oncology support team.
- Ask your oncologist for additional medications you can take if you feel nauseated in 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 is very common in women 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 coloxy or senna. Fibre supplements such Fybogel or Metamucil are not recommended for constipation related to medicines or cancer, as they are 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. 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 also be caused by an infection or drugs used to treat constipation.

Diarrhoea can be an unwanted minor side effect of treatment, but can sometimes be more serious. If you are not in regular contact with an oncology nurse or are only seeing your oncologist once a month or less, it can be difficult to know when to report diarrhoea. If you are 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 to your diet or diarrhoea medications, it is 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 heart beat.

As well as losing fluid from your bowel you can also lose salts such as sodium and potassium. Rehydration fluids such as Gastrolyte will replace both the water and salts. You can purchase this over the counter at your pharmacy. Medication that can be purchased over the counter, such as Imodium or Gastro-Stop (loperamide) can be used 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 are struggling to eat well, or seek advice from a dietitian. The more you can let her/him know about the changes in your appetite, the better your chances of managing the problem. You might like to keep a note of any weight you have lost or gained, when your appetite is better or worse, and whether it is 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 are 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 are 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 are 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. Your doctor, pharmacist or dietitian will be able to help you find the most appropriate ones for you.

🔗 For more information, see Nutrition and cancer: A guide for people with cancer, their family and friends. Contact Cancer Council 13 11 20 to order a copy.
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.

– Savannah

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 is 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 all women with metastatic breast cancer lose weight. Some women 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. 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. Women who are taking a steroid also often notice that their face looks more puffy than normal. This will subside when you no longer need to take the steroids for the chemotherapy treatment.

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

Most women 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, to issues at home and with relationships. It is quite normal to feel great one day and pretty ordinary the next. But if you find that you’re low for more than a couple of days at a time, that you can’t enjoy the things you normally would, or you feel overwhelmed and unable to move forward, you may be depressed.

Depression is common in women with metastatic breast cancer. Being depressed is not a sign that you aren’t trying hard enough. There are very effective treatments, including non-pharmaceutical strategies so talk to your medical oncologist or GP about what can be done to help you.

For more information about managing depression, see Section 3: 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 why you may have difficulty sleeping when you have metastatic breast cancer. 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 that you enjoy such as malted milk, milk with honey, or chamomile tea.
> Reduce caffeine intake during the day, preferably no more than two coffees per 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 pain doesn’t wake you.

> Practise relaxation techniques – relaxation exercises such as yoga, mindfulness, meditation and tai chi may lessen worry and stress. Slow, deep breathing can help with relaxation.

If these don’t help, you may consider asking your doctor to prescribe sleeping tablets. Formulations have improved and they are now far less likely to leave you feeling drowsy the following day than they did in the past.

BCNA’s Sleepless nights fact sheet includes tips and strategies that may be helpful if you are having trouble sleeping. It also describes resources and supports that are available. Visit bcna.org.au or phone 1800 500 258 to have a copy sent to you.

Hair loss

If metastatic breast cancer is your first diagnosis of breast cancer, you may 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 like you have lost your sense of identity. It can also mean that you have less privacy around your diagnosis. You may feel that the whole world can see you are undergoing treatment for cancer. It is perfectly normal to feel distressed at the thought that your hair might thin or fall out completely.

Women from many cultures and backgrounds find that hair loss affects their self-esteem and how they view their bodies and femininity. On the other hand, some women are less concerned about hair loss and can see it as a sign that they are 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 about treatment options that may result in less significant hair loss. Some chemotherapy drugs are more likely to cause hair loss than others, particularly the anthracyclines and the taxanes, so it may be possible to have a chemotherapy that is less likely to make you lose your hair if that is important to you.

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 the hair will grow back several months after completing radiotherapy. 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. – Di

Use of cold caps

To help prevent or reduce hair loss from chemotherapy, some oncology day centres offer cold caps (scalp cooling) to women receiving certain types of chemotherapy. A cold cap is usually a strap-on cap through which cold liquid circulates while you are having chemotherapy. The cooling effect of the cap is thought to prevent or reduce hair loss by putting the hair follicles into hibernation. Some women find cold caps uncomfortable to use, and they increase the time spent in the chemotherapy unit as you need to wear them for a time before and after the chemotherapy infusion, as well as during the infusion. They need to be used with each chemotherapy treatment. Cold caps are not available at all chemotherapy centres. Trials on cold caps have been mostly in the early breast cancer setting but they are starting to be used more for women with metastatic breast cancer. There have been good results for women with metastatic breast cancer who are having the
taxane chemotherapy drugs. If you would like to learn more about cold caps and whether they would be suitable for your situation, you may like to talk to your medical oncologist or oncology nurse.

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 or phone 1800 500 258 and we will send a copy to you.

**Mouth ulcers**

Mouth ulcers can occur with chemotherapy and some targeted therapies, usually appearing five to 10 days after the start of each treatment cycle and clearing 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 that has been particularly designed 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, can also help avoid complications from mouth ulcers associated with chemotherapy. It may be helpful to suck ice chips or an icy pole during your chemotherapy infusion and for a time afterwards (similar mechanism as for cold caps).
Talk to your doctor before using a proprietary mouth wash such as Listerine; some commercially available mouth washes contain alcohol, which can aggravate symptoms, and others can 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 are someone 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
> using a topical antiseptic cream such as Savlon if your nails split or break, to avoid infection.

If these tips don’t help and you’re feeling distressed by these side effects, you may want to talk to your oncology nurse. It may also be worth considering ice gloves. 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’.

It is not clear exactly what causes these memory and concentration problems in people with cancer, so calling them ‘chemo brain’ may not be accurate. Mild cognitive impairment (MCI) is a more accurate description used by doctors. Another term is cognitive dysfunction.

People use the word cognitive or cognition in different ways. Most people who have cognitive changes are able to do everyday things. But they may notice they aren’t 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 better understand how best to manage the symptoms of cognitive impairment related to chemotherapy. There are some strategies that have been suggested that might be helpful, including:

- Mindfulness – any kind of yoga or mindfulness practices such as sitting or walking meditation can help you develop your ability to pay attention, and could lead to better memory retention.
- ‘Brain exercises’ or ‘brain training’ including activities, such as word puzzles or maths quizzes.
- Physical exercise – memory and executive function (decision-making abilities, basically) have been shown to 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.

> Work on your strengths, rather than focus on your weaknesses – try doing 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 talk to your oncology nurse before you buy them, as not all over-the-counter preparations are suitable. Wearing sunglasses to protect your eyes from bright light and wind can help, as can saltwater eye baths.

Taxotere (docetaxel) can cause watery eyes. An ophthalmologist (specialist eye doctor) will be able to treat this effectively for you. Talk with your medical oncologist if watery eyes is an ongoing problem so that a referral to an eye specialist can be arranged.

**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 in the feet and ankles is more common than elsewhere 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

Some types of chemotherapy can cause dryness, itching, redness or peeling of the skin; non-perfumed moisturisers may help. Some drugs make your skin more sensitive to the sun, so it is important to cover up outdoors and use sunscreen.

When you are 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 non-scented cleansers and moisturisers, such as MooGoo, that you can purchase over the counter from most pharmacies.
> Wear sun-protective clothes and sunscreen over the treated area when you are outdoors.
> Avoid damaging the skin in the treated area and keep skin folds dry.

Breathing problems

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

Breathlessness doesn’t necessarily mean that 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 be helpful. 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 that you cannot explain, seek medical advice to rule out the possibility of a blood clot that may require 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 anti-nausea medication side effects. More rarely, headaches that continue and do not respond to medication may be a symptom of secondaries in the brain, so seek medical advice if you are concerned.

It is 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 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 are 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 you are experiencing severe menopausal side effects that are impacting your quality of life, talk with your oncologist about medications available to 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 Breast cancer and early menopause: a guide for younger women. More information on managing the side effects of breast cancer treatment is available from the Cancer Australia website 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 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 to improve wellbeing. There are many different types of complementary therapies, most of which work on the whole body. They can be helpful in managing some of the side effects of metastatic breast cancer and metastatic breast cancer treatments, including anxiety, fatigue and pain.

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

Complementary medicines are products that are sometimes used in addition to conventional medical treatments to help improve wellbeing. These include vitamin and mineral supplements, herbal medicines (including Chinese and Ayurvedic [Indian] medicines) and homeopathic remedies.

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.

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 is no credible evidence they are effective in treating metastatic breast cancer.

For more information about complementary therapies and medicines, see Section 3: 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.
– Nicola

Many women 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 be able to enjoy yourself without having to manage treatments and their side effects.

Sometimes you may be looking 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 to do.

Your medical oncologist or treating doctor will be able to talk to you about your options. Tell your doctor how you feel and about your goals in life so that, together, you can work out a treatment plan that suits you. You may be able to have a rest from your normal treatments or use a gentler treatment that has fewer side effects.

Sometimes a break from treatment will allow your body to rest and recuperate. However, if you are 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.

You may also want to discuss longer-term options, such as limiting or stopping treatment. For example, 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.
Emergencies

From time to time, women with metastatic breast cancer develop new or persistent symptoms that require urgent medical attention.

It is important that you know who you will contact if you should need urgent help and that you have a plan in place to manage this situation. The plan will depend on whether you are 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 so that you can develop the plan together.

It may also be helpful to 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 are at risk of developing a potentially life-threatening bacterial infection or sepsis. If, while you are 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 your white cell count checked. You may require hospital admission for intravenous antibiotics.

Spinal cord compression

If cancer has spread to the bones in your spine, sometimes 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 that 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, treatment can be most effective if it is given early.

🔗 For more information on spinal cord compression, refer to the BCNA *Metastatic breast cancer in the bone* booklet.
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 order the booklets appropriate for you by visiting the BCNA website, or by phoning BCNA on 1800 500 258.

- 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 (formerly called Getting your affairs in order)

BCNA's online network

Australia

*onlinenetwork.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 is an active, public discussion area for anyone affected by metastatic breast cancer. There is 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 'advanced' 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 Australia, their partners, family members and friends.

Breast Cancer Care
UK
breastcancercare.org.uk
The website has a wide range of information on metastatic breast cancer, including a chat room for women 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 women share their experiences of metastatic breast cancer. It has input from women and health professionals. Australian women are able to participate.
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.

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.

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

Australian guidelines for the management of women with advanced breast cancer, primarily intended for use by health professionals.

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 is updated daily.

Australia and New Zealand Breast Cancer Trials Group
anzbctg.org

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

Cancer Council
cancer.org.au or 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 is 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 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 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.
Hair loss

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

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

BCNA telephone counselling service
Phone 1800 500 258

BCNA's professional telephone counselling service that offers free, confidential counselling support to women and men with metastatic breast cancer and their families. To make an appointment to speak with an experienced professional oncology counsellor in the privacy of your own home or other preferred place, phone BCNA on 1800 500 258.

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.

beyondblue: the national depression initiative Australia
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.

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

The Lifeline website has information about its 24-hour telephone counselling service, their information service and a ‘service finder’ directory.

Depressionet website
Australia
depressionet.com.au

The website provides information about depression and counselling services.
Three:

Living well

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. I laugh with my family and doctors and nurses. Often we try to be strong all the time so that we can protect our family and friends.

– Jill
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. - Lyn

Section overview

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

- Managing relationships with others
- Talking with family and children
- Talking with friends and work colleagues
- Caring for yourself emotionally
- Caring for yourself physically
I live with metastatic breast cancer, but I do not let it control my life.– Judith

Be kind to yourself. You are not to blame. It was just bad bloody luck. – Fairlie

Many people measure life by length of time. Life is not a competition, it’s not about how long you live, but how well you use the time you have. – Yvonne

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. – Marlene

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 is not unusual if you find yourself thinking about what it means to deal with more uncertainty in your life.

Many women 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 is 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. – Barbara

Other changes may be thrust upon you — for instance, if fatigue or pain limits your mobility and independence. In this case you are 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.
Your greatest support, your greatest strength and the aspect you have the most influence over is your attitude — the way you think about your experience. Your thinking will influence your journey. I’m not for a second saying that you always have to be happy and jolly — that would be to live a phony life. Just be real. Enjoy the good days; continue to love yourself on the not-so-good days. Be alert or aware of how you’re thinking, your attitude influences your experience. Above all, listen to yourself, love yourself, accept yourself. Know deep within that whether you have cancer or not, whether you are well or not, you are lovable and acceptable. – Liz

Many women 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.

Take the good days and grasp them, because there will be bad days. Make the most of all your opportunities.
- Jane

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. I laugh with my family and doctors and nurses. Often we try to be strong all the time so that we can protect our family and friends. – Jill
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 tell the people around you about your diagnosis. 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 are 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.

For anyone you are close to, you may want to suggest that they read the booklet enclosed with this pack, *She has secondary breast cancer: how can I support her?* This booklet has been written for partners, family, friends and colleagues of women newly diagnosed with metastatic breast cancer. It includes information on breast cancer treatment and care, as well as practical tips to help partners deal with some of the common challenges they may face.

Single or dating

If you are 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 is 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 ‘gift’ with which you allow others to 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.
If you are single, the thought of entering a new relationship may be daunting. There are many questions that might be 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 is 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.

Having a partner is not just about intimacy and romance. A partner can provide emotional and practical support, although sometimes there is a gap between what a partner offers and what you might feel that you need or would like. If you are single, sometimes it can feel exhausting to have to organise and plan everything yourself. But, the more organised and efficient you appear to be, the less likely it is that others will think you need help!

**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.*

– Peta

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 therefore vary enormously.

Research has shown that partners can feel as overwhelmed or depressed as the person with cancer. Partners can sometimes benefit from professional support or going to a support group. While there are increasing numbers of resources for male partners, female partners may
face the added grief of feeling isolated and disconnected, and feel that their needs are not acknowledged.

Whatever the nature of your relationship, at least some of the following will almost inevitably 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 *She has secondary breast cancer: how can I support her?* has been written to help partners, family, friends and colleagues understand your needs.
**Same-sex couples**

Most cancer treatments and support services are aimed at heterosexual couples, which can make things more difficult for same-sex couples. It can be helpful to seek care from a medical team that is sensitive to your situation, respects your privacy and encourages both you and your partner to be involved in your health care. If you feel that your medical team is not supportive, then it is probably a good idea to look around for other health professionals. Some couples also find it helpful to talk to a counsellor or join a same-sex support group.

- If you are unsure where to start, the Australian Lesbian Medical Association (ALMA) has a list of health professionals who are recommended by lesbian women. Visit almas.org.au.

If you are 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.
- Your local Cancer Council (13 11 20) may have contacts with counsellors or support groups who will be sensitive to your needs.
- beyondblue has information on depression and anxiety, and where to get help. Visit beyondblue.org.au.
Things you can do to help your partner

• Be open and honest in communication. Trying to keep strong feelings to yourself is hard work, and sharing them can feel liberating. Remember that relationships are like ballroom dancing; if one person takes the lead, the other usually follows. Opening up the discussion allows you and your partner to share a real closeness rather than using energy to keep a lid on things.

• Be honest about your needs and be prepared to ask. Don’t expect your partner to be a mind-reader, and don’t react angrily when your partner does not respond in the way you would like or expect (including thoughts like, ‘If they really cared, they would offer to do this for me’).

• Let them know that you need them to listen, to share the space with you, and that they don’t have to 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 section Section 3: Living well.)

BCNA’s telephone counselling service for people affected by metastatic breast cancer offers free telephone counselling support to partners and family members. Phone 1800 500 258 to find out more or make an appointment.
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.

– Tracey

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 – all of these things or more. You may also face sexual problems due to tiredness, a lowered libido, being in pain, vaginal dryness due to chemotherapy or other medications, 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 is 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 also of avoiding painful misunderstandings. For instance, you may believe that your partner no longer finds you attractive when in fact they are just reluctant to touch you for fear of hurting you. Some couples find it helpful to talk to a counsellor together.

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. You can download or order a copy of the booklet from the fact sheets and booklets page on the BCNA website, or by calling 1800 500 258. The booklet is also available through Relationships Australia.
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 are going to handle any changes and challenges that come your way with their help and understanding. – Julie

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. It’s not because they don’t love me. Don’t blame them – we’re all stressed and we’re all trying to cover it up. – Astrid

My younger sister and I now share a deep and loving relationship which prior to my metastatic diagnosis had been tenuous. It has brought our family together. – Margot

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. Women often tell us about different resources that they have found helpful in communicating with children and teenagers about what is going on or what might happen in the future.

🔗 For information about talking to young children and teenagers, see Section 5: Young women.
If there is 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 did not 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. I now have a good network of friends. Some offer help by listening, being a shoulder to cry on or just being there when I need them. I found other friends preferred to be able to assist with the practical things, taking me to the doctor, vacuuming, making meals, etc. These friends don’t understand what it is like to live with this prognosis on a daily basis, but I found I shouldn’t expect them to understand. They still want to help as much as they can. – Cynthia

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, sometimes people can offer unrealistic or unhelpful opinions, ideas and suggestions. 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. Those who offer information about the latest treatment or cure may not realise that it is generally not helpful.

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. I went to a little drinks party last Saturday night and I was quite depressed and I thought, ‘Oh bugger it, I’m going to tell them’. So someone asked me, ‘How are you?’ and I said, ‘Well actually I’m really
People don’t really want to know all the time. 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 are you, you think, do they really want to know or are they just being polite? – Delia

You may find that after a diagnosis, some friendships do not provide the level of support and understanding that you need. Some friends or colleagues may be able to support you or keep your spirits up. Others might not know what to say, or may say things that are well meaning but unhelpful. Concentrate your energy on being with friends who are there for you.

Discard negative people and situations. Talk about your condition and how you feel openly with friends and family. They will react to your lead. If you are silent, so will they be. – Irene

I find it hard to be tolerant when my friend complains about what seem to be small problems, when I feel like I’m dealing with huge problems. – Min

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. – Shirley

Friends or colleagues of women with metastatic breast cancer can phone Cancer Council 13 11 20 to find information, talk to someone 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 is 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 women with metastatic breast cancer are the same. For each woman, 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. So every woman will handle her situation differently. There is no rule for how to handle emotions. You have 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 is impossible to be positive all the time. When I am feeling low I cry. When I am feeling good it is like walking on air. I believe in being authentic and not pretending to feel something that I don’t. I usually find after a great big cry that I feel so much better and the well is ready to be filled with good stuff again. – Amanda

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. Friends and family often can’t be honest in a way that a stranger can be. – Jenny

For most women 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. Or, even worse, they might trivialise your concerns with comments like ‘Well, I could be hit by a bus tomorrow’.

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. And, perhaps most important of all, they will listen; they won’t ‘compete’ by telling you about their own problems!

For more information on counselling see the references and resources pages at the end of this section.
Anxiety and depression

Your diagnosis may result in a range of emotions including stress, sadness, fear and anger. If you are feeling these emotions intensely and for long stretches of time, you may be experiencing depression.

Anxiety and depression are common for people with metastatic breast cancer.

**Anxiety** is more than just feeling stressed or worried, which are normal feelings 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
> trouble 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. Depression affects how you feel about yourself. You may lose interest in work, hobbies and doing things you normally enjoy. You may lack energy, have difficulty sleeping or sleep more than usual, feel anxious or irritable, or find it hard to concentrate. Just like a physical illness, depression is treatable.
Some common symptoms of depression include:

- not going out anymore; loss of interest in enjoyable activities
- withdrawing from close family and friends
- being unable to concentrate and not getting things done at work or home
- feeling overwhelmed, indecisive and lacking in confidence
- increased alcohol and/or drug use
- loss or change in appetite and significant weight loss or gain
- 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 your recovery will be. If you are 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 psychologist, social worker, counsellor or psychiatrist. Talk to your doctor about whether you are eligible for treatment under a GP mental health treatment plan. This will entitle you to up to 10 Medicare-subsidised appointments with a clinical psychologist, appropriately trained GP, social worker or clinical occupational therapist.

For further details about GP management plans or team care arrangements, talk to your GP or visit the Department of Health and Ageing website at health.gov.au.

BCNA provides a professional telephone counselling service that offers free, confidential counselling support to people affected by metastatic breast cancer and their families. Phone 1800 500 258 to find out more or make an appointment.

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. It’s available from BCNA’s website bcna.org.au or by phoning 1800 500 258. For more information on both anxiety and depression, go to the beyondblue website beyondblue.org.au.

> *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.

Fact sheets can be ordered or downloaded from the BCNA website bcna.org.au or by phoning 1800 500 258.
Other things that can help you:

> Spend time with people who make you feel good.
> Relax and do things that you enjoy.
> Say no to invitations or activities that you don’t feel up to doing.
> 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 our online network, or a face-to-face breast cancer support group, where you can talk to other women whose experiences are similar to yours.
> Talk to your doctor if you are worried about how you are feeling.
> Relaxation or meditation can help to keep your emotions in balance.
> Give yourself time to do things you enjoy, such as reading, listening to music or spending time in the garden.
> Consider treating yourself to regular things that give you joy, such as facials, visits to the cinema or galleries.
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._ – Amanda

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.

Your GP may be able to give you a referral for Medicare-subsidised counselling sessions. Psychiatrists also offer counselling – the idea that they only prescribe medication is a myth. If you would like to see a psychiatrist, you will need a referral from your GP. Some social workers, psychologists and psychiatrists specialise in working with people affected by cancer.

**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 sounds trite, but simply ‘sharing the space’ can be liberating. 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.

There is no formula for what works. Some find that seeing a counsellor a couple of times a week helps them to feel that they have created ‘space in their head’ to handle their emotions. Others prefer to use
a counsellor as a safety net – someone they can turn to if there are
problems but are of no real value when things are going okay. Some
people use counselling sessions to talk about issues other than cancer,
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 is important to feel that you can work
together as a team.

Many women also tell us it is important to see a counsellor who is
experienced in working with people with cancer. One of the benefits
of BCNA’s counselling service is that our counsellors are highly
experienced in managing issues that impact on women with metastatic
breast cancer.

Of course, having the five free sessions with such a
qualified person is a great financial relief for us and
something I could not otherwise access.

The telephone counselling method can work well for people who find
the thought of a face-to-face counselling session a bit intimidating.

Not being face to face was ideal for my personality ...
I was able to ‘unload’ without anyone ‘seeing’ and so
made me more honest and less stoic!

It is also particularly helpful for people who live rurally or remotely who
may not have access to local services.

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

Especially for those in country areas where support
is limited.
Counselling resources and services

> Some hospitals have specific psycho-oncology services that includes counsellors who work closely with other oncology health professionals who may be caring for you. Talk to your oncologist or nurse to see if there is a service at your hospital that is available for you.

> Your GP may be able to give you a referral for a mental health plan – a Medicare-subsidised set of counselling sessions with a psychologist.

> If you are still working, your employer may also provide a small number of free confidential counselling sessions through an employee assistance program.

> BCNA provides a free confidential, telephone counselling support service for people affected by metastatic breast cancer. To make an appointment to speak privately with an experienced professional oncology counsellor, phone BCNA on 1800 500 258 or email beacon@bcna.org.au.

> In some states, you can access counselling through Cancer Council 13 11 20.
Building your support network

Work out which friends give you which kind of support: who makes you laugh, who makes you cry, who listens, who shares values, who will give you a hug when you need it! – Li

I felt confused at first. I didn’t know who to speak to. I didn’t know who to ask for support. I then luckily met another woman. I went to a stretch class and she invited me somewhere and I said, ‘I’m sorry, I can’t do that, I have advanced disease’. She said, ‘I have too’. I nearly kissed her it was so nice. It was a lifeline to see a real living person who can go about life and someone you can ask all your questions. It was marvelous. – Kay

I have had lots of help and support from friends – often for walks, phone calls, invites to films, plays, etc. I find having something (no matter how small) to look forward to is great therapy. – Helen

Without a doubt friends saved me. Some I knew I had – some I didn’t know I had. – Sharon
Practical support

Sometimes it seems there is a lot of support/information about breast cancer available but the practical assistance is somewhat more limited. It can be hard to know where to find help.

Looking after your wellbeing is easier if you have a strong support network. Many women say it can be hard to get practical support, especially if there aren’t many support options around in your local area.

A third party can be very helpful. For instance, if you can find an opportunity to explain your needs to one person in your social club, their contribution can be spreading the word on your behalf. Or your doctor may know of people in the area who would be glad to do something for you. Once the door has been opened, you may find that people approach you.

Friends and family can be an important source of practical support. At the same time, it’s not easy to walk up to an acquaintance and ask them to do something for you. People may also be shy about offering help, or just not think about it, simply because they’re not sure about your situation. But there are ways of letting your needs be known without embarrassment.

One close friend organised to pick up my daughters and had dinner ready for all of us when I came back from appointments. I don’t know how I would have coped without her. – Tracey

I have a disabled sticker for my car so I don’t have to walk too far — I take it with me if my daughters take me out. I don’t push my body if it says rest, I rest. My husband does the vacuuming and washing when I’m having a bad day — not often now. – Julie
Saw a fabulous counsellor who said she will organise everything. Got home at 3 pm, by 5 pm had an occupational therapist assessing the house. We need lots — bars, rails, elevated bed, new wheelchair, raised toilet seat, completely modified shower. Some bloke has turned up this morning about in-home assistance. There really is lots of help available. – Lisa

For more information on finding practical assistance and support, see Section 4: Financial and practical matters.

**Emotional 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.

> I believe in a support group – it fills the need for meeting other people with a similar diagnosis and the sharing that goes on, the exchange of information. I hear about websites and how different people are coping with medications and it’s very valuable. – Helena

> It’s a tough time, but there are people out there for you to talk to. You can’t beat talking to people who have experienced this illness. – Tracey

> The women I met were the most important source of information, encouragement, discussion, sharing, crying, laughing. – Nicola

In some parts of Australia, it can be difficult to find a local group that supports women with metastatic breast cancer. Many women 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. This group was set up by, and is run by, people with metastatic breast cancer. Visit bcna.org.au to find out more or to join the online network.
I was diagnosed with metastatic breast cancer in 2005. I found it extremely difficult to locate other women my age who also had secondaries. The breast cancer support groups would either be on days I worked or they felt that they could only cater to my needs for a short time and then they would not be able to go any further for me. 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. – Tracey

My greatest inspiration has come from the friendships with other women living with breast cancer, particularly metastatic breast cancer. There are low times, we acknowledge this; we can’t be ‘inspirational’ all the time, and we certainly don’t aspire to martyrdom. 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. – Judy
Travel

For some women, knowing they have metastatic breast cancer sparks a desire to fulfil lifelong dreams of travel. For others travel is a longer-term goal that people look forward to working towards. If you are thinking about travelling, you will have a few extra things to consider.

Domestic travel

If you are 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.

*My husband says ‘let’s do that trip around Australia we’ve always talked about’ but I’m scared in case something happens. I need to be close to hospitals and family and all that support. But the thing is I’m well now and maybe we should be taking advantage of that.*

– Agnes

*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.*

– Doreen

Domestic travel tips

> If you are booking airfares that have to be pre-paid, try to book a fare that is flexible in case you have to make last minute changes or delay your trip.

> Check the cancellation policy of the accommodation that you are booking to make sure you can have as much leeway as possible should your travel plans need to change around your health.
International travel and travel insurance

International travel is more complicated because you’re not covered by Medicare once you leave the country and it is unlikely that your private health insurance will help with any medical costs.

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 humanservices.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. – Peta

Most international travellers take out travel insurance to cover things like lost luggage, accidents and medical cover. There are some travel insurance policies that will cover you for these incidentals but unfortunately you are unlikely to be able to obtain cover for medical costs related to your cancer. This is because it is viewed as a ‘pre-existing condition’.

Sometimes women decide to travel without insurance to countries that don’t have a reciprocal agreement. This is a personal decision and, for many women, it is a matter of weighing up the risk of needing medical attention against the possible cost.

Some travel insurance companies may be more flexible about covering people with breast cancer. You may need to consult a travel agent or specialist travel insurance consultant to find out what is 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. – Margaret
International travel tips

➤ If you are planning an overseas trip, talk with your medical oncologist before you make any payments. It may be better to hold off on making payments on a trip until as late as you can.

➤ When travelling overseas, make sure you take a letter from your oncologist detailing any medications you are carrying and the reasons you have them and keep your medications in their original packaging.

➤ Make sure you have enough of your prescription medication to cover you for the entire time you are away.

➤ Ask your oncologist to also provide you with a brief summary of your breast cancer history, and treatments you have 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 are suddenly new that might come up before you head away.

Travelling overseas can be complicated but with some forward planning you can reduce your risks of having an experience that leads to trouble when you are 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. – Barbara

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. As it turned out I did need treatment while I was away. I did not have to pay a cent for this treatment or medication and I was treated with the utmost care and consideration. The small hiccup of my stay in an Edinburgh hospital pales into insignificance when compared with the memories of our time in Europe and the UK, which will stay with us for the rest of our lives. – Julie
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 women with metastatic breast cancer.

**Compare Travel 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**
cancer.org.au or 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 free retreats in selected locations, available free of charge for women with breast cancer. Located in VIC, 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.

**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.
Caring for your body

Nutrition

I enjoy being proactive with my eating regime. Having been educated by professional people, I am able to make informed choices on the most beneficial foods for my condition. 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. – Margot

Some people choose to make fairly drastic changes to their diet after a diagnosis of metastatic breast cancer. 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 2–3 times a week, and limit your intake of red meat to 500 g 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 around 6–8 250 ml glasses daily (a total of around 1.5–2 L).

It is also recommended that you cut back on:

> 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 like biscuits, fruit juice and soft drink.
Alcohol – it is recommended that you avoid alcohol if possible, or aim for no more than four standard drinks per week and include two alcohol-free days per week. For women who have liver metastases, the cancer can impair the ability of the liver to break down alcohol. You oncologist will be able to give you specific advice around safe levels of alcohol consumption.

An accredited practising dietitian (APD) can greatly assist you to manage your dietary intake and ensure you are meeting your nutritional requirements. An APD near you can be found on the Dietitians Association of Australia. Visit daa.asn.au > For the Public > Find an accredited practising dietitian.

If you have a GP Management Plan and Team Care Arrangement, you may be eligible for a Medicare rebate for these appointments.

The Australian Guide to Healthy Eating is a handy visual guide showing you 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 soy beans and soy products — including tofu, tempeh and soy milk. There are a lot of myths and conflicting evidence around the role of phyto-oestrogens in breast cancer. However, the evidence regarding their impact is mixed. Soy products can be consumed in moderation as part of a balanced diet. However, Cancer Council Australia recommends that women with breast cancer (early or metastatic) be cautious about consuming large quantities of soy foods, high-concentrated soy products such as vegetarian protein powders, or phyto-oestrogen supplements. Soy supplements include soy protein isolates and isoflavone capsules.
Weight management

It is important to try to achieve a healthy weight and maintain your weight. If you are underweight you should see an accredited practise dietitian to assist you to gain or maintain weight as you could be at risk of poor nutrition due to treatments you are having or your illness. This can significantly impact the way you feel, your recovery from any treatments and energy levels.

If you are overweight, you could aim to lose weight in a healthy manner with the assistance of an accredited practising dietitian. 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.

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 density loss. This can be especially important if you are 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 all people, 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 are struggling to maintain or gain weight.

It is 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 are already using a complementary medicine, it may help to 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.

🔗 For more information on complementary therapies, see Cancer Australia’s Guide for women with secondary breast cancer.
Alternative therapies

Trust yourself, as friends will press all sorts of quack treatments on you out of love and concern. – Nicola

In cancer treatment, alternative therapies are products or treatments that are used instead of conventional medical treatments such as chemotherapy and hormone 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 is no evidence that these treatments have any anti-cancer benefit. When a treatment is shown to be of value, it is no longer deemed ‘alternative’. If you are contemplating alternative therapies, you need to give careful consideration to what you might miss by avoiding conventional treatment.

Some women 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 having no scientific evidence that they work in any way to control cancer. Beware of testimonials and quick-fix promises. If an alternative treatment was as good as it was promoted to be, 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 is another form of meditation and you get the fitness benefits too. – Amanda

I exercise on a treadmill as I find it kinder on my body than uneven ground. My muscles feel stronger, I feel good and have less pain – it’s great! – Inka

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.
Swimming or walking in a warm pool can help with joint pain.

Many people also 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 life.

*I have found walking daily to be an outstanding way in helping me feel more in control of this disease.* – Lisa

Exercising with a friend provides a great opportunity to catch up and have a chat, and can help to keep you motivated.

The physical and psychological benefits of exercise are many, but many women say that it is better to listen to your body and pace yourself rather than overdo it if you start to feel weary.

**Exercise and safety**

We recommend that you discuss exercise with your doctor and gain medical clearance before starting. You might need to consider issues like compromised immunity, your bone health or lymphoedema when talking to your health professional about an exercise program.

Until recently exercise was thought to be ‘too dangerous’ for women with bone metastases. However, the good news is that in recent years research has shown that some exercise can be safe and effective. Certain exercises will be better than others to avoid putting too much stress on affected bones. The best person to develop and supervise an exercise program for you is an Accredited Exercise Physiologist (AEP) who has cancer management expertise.

You can access Medicare rebates for exercise physiologists through a GP chronic disease management care plan.

☞ You can learn more about these care plans by downloading the fact sheet on BCNA’s website bcna.org.au.

☞ 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.
Benefits of exercise for lymphoedema

Lymphoedema, or swelling of the arm, hand or breast, sometimes develops in women 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. It can also help you to manage lymphoedema symptoms if you already have it.

You can find more information about how to reduce your risk of lymphoedema on the lymphoedema page of the BCNA website bcna.org.au.

*Aqua aerobics has really helped the lymphoedema in my arm. The water acts like a gentle massage.* – Ann

Where to go for help

Seek professional advice from an accredited exercise physiologist or a physiotherapist, who are trained to design individual exercise programs. You may be eligible for a GP care plan or for rebates through your health insurance to help pay for these services.

Accredited exercise physiologists (AEPs) are accredited 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 to help with recovery after treatment. You can search online for an AEP in your area by visiting 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. You can search for a physiotherapist in your area by visiting physiotherapy.asn.au.
Touch therapy

Research has found that the use of touch therapy, particularly massage, can help to reduce pain and physical and emotional distress, and also 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

It can be beneficial to go to a specialist oncologist massage therapist. These are massage therapists who 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.

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). – Xin

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. – Judy
What do you want to do with your time? It is okay to take some time for yourself and do the things you want to do; in fact, many people say it is essential! So that you can be sure of making the most of things you enjoy, you may want to make a list of everything, large or small, that gives you pleasure. Then, if you’re feeling down or simply have some time on your hands, you can refer to your list for inspiration.

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. – Marlene

Be selfish and do what you need to do to feel better. Find your outlet or your distraction, like music. I used to drive out to the Dandenongs and just sit and take in the view or have a coffee in a little coffee shop. – Mia

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.

Keep focused on the short-term goals, find good things to do every day, have a plan – coffee, sewing class, painting, video – anything to keep the demons away. Take a rest, try not to overdo things. Things cannot be the same while you’re being treated – chemo, radiotherapy and surgery take a lot of strength away. – Susan

Learn to say no. If you are 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. – Julie

I found art therapy very helpful – run by a professional artist. It’s a real creative outlet which I now do at home. – Thea
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. – Pamela

I find walking, practising breathing exercises, relaxation, affirmations, and documenting what has gone on get me through. – Margot

The bottom line

Handling metastatic breast cancer is tough. There are a lot of things about your situation that 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 just because you can’t see your feelings doesn’t mean that they aren’t real and don’t need looking after.

Have heart but do not be afraid to fall apart a little and accept whatever help is offered or available. – Kala
BCNA’s online network

onlinenetwork.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 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.

BCNA’s breast cancer and sexual wellbeing booklet

Australia 2011
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.

BCNA telephone counselling service

Phone 1800 500 258

BCNA’s professional telephone counselling service that offers free, confidential counselling support to women and men with metastatic breast cancer and their families. To make an appointment to speak with an experienced professional oncology counsellor in the privacy of your own home or other preferred place, phone BCNA on 1800 500 258.

Palliative Care Australia

Australia
palliativecare.org.au 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.
**Finding the words – starting a conversation when your cancer has progressed**
Australia 2016
Cancer Australia
*Download from the Cancer Australia website 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.

**Partners and carers**

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

Cancer Australia has a number of resources for partners of women 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.

**When the Woman You Love has Advanced Breast Cancer**
Podcast section of the Cancer Australia website canceraustralia.gov.au

In this podcast series (also available to be ordered as a CD) men speak openly about the challenges they face as partners, parents and carers of women with metastatic breast cancer. Health professionals provide advice and information to men on how to deal with their own needs and feelings.

**Living with Advanced Cancer**
Australia 2000
Cancer Council NSW
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.
**When Someone You Love Has Advanced Cancer: Support for Caregivers**  
USA  
National Cancer Institute  
cancer.gov

This website includes information for those who care for people with metastatic breast cancer, including quotes from carers.

**Worse Things Happen at Sea**  
Australia  
William McInnes and Sarah Watt  
*Available from ABC Centres, shop.abc.net.au, or online bookstores, such as booktopia.com.au*

Australian actor and author William McInnes and animator and filmmaker Sarah Watt, who was diagnosed with metastatic breast cancer, speak about their relationship and family life.

**Intimacy and sex**

**Breast cancer and sexual wellbeing**  
Australia  
bcna.org.au or phone 1800 500 258

This BCNA information booklet includes strategies that can help you manage a range of sexual wellbeing issues, including building emotional and physical intimacy with your partner.

**Passionfruit – the Sensuality Shop**  
404 Bridge Rd, Richmond, Vic  
passionfruitshop.com.au or phone (03) 9421 3391

The Passionfruit Shop is a tasteful shop that offers a wide range of sexual and sensual products, including lubricants, videos and adult toys.
Wellness and hope

Creative Journal Writing: The Art and Heart of Reflection
Australia 2006
Stephanie Dowrick, Allen & Unwin
Available from stephaniedowrick.com

Many people living with secondaries find writing a personal journal helps their emotional journey. Based on her lifetime of writing, Stephanie Dowrick provides insights and confidence to inspire journal writing.

A Pocketful of Sequins: Words from the Heart
Australia 2006
Margaret Wright, Moonstone Media
Available from amazon.com

This book is a compilation of ‘words from the heart’ – quotes from Australians whose lives have been touched by breast cancer, celebrating their strength, courage, humour and spirit.

Can-Survive Australia
ucansurvive.org and a 24-hour support line (07) 5441 5730

Can-Survive provides practical and emotional support and survival skills for patients and their families facing, and living with, cancer or other life-threatening illnesses.

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.

Healthy eating and breast cancer
BCNA
bcna.org.au or phone 1800 500 258

This booklet provides general information to help you maintain a healthy diet. Developed in consultation with dietitians and other health professionals, it includes information on the types of foods that make up a healthy diet and tips to help you eat well when you’re feeling unwell. It can be downloaded free from the BCNA website or you can order a printed copy by phoning 1800 500 258.
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 1185

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.

Living Beyond Breast Cancer
USA
lbbc.org

Living Beyond Breast Cancer (LBBC) is dedicated to assisting women – whether newly diagnosed, in treatment, having recently completed treatment, years beyond or living with advanced disease. It also provides information and support for family members, caregivers, friends and health care providers.

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.
Four:

Financial and practical matters

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.

– Robin
Financial and practical matters

I am still working out all the things I need to do. It is 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
> Accessing the public and private health system
> Federal government assistance (Centrelink)
> GP management plans and team care arrangements
> State government assistance
> Community supports
> Superannuation and insurance
> Employment and your work rights
The financial cost of breast cancer

For many women 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 are not able 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
> you are working and need to take time off or reduce your work hours
> you live in a rural area and need to travel for treatment
> you have a Centrelink Health Care Card or receive a Centrelink pension
> you 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. It means that 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, once you reach the threshold, you still pay the same amount upfront to your doctor. However, you may receive a higher Medicare benefit, making your out-of-pocket expenses much less.

The Medicare safety net covers a range of doctors’ visits and tests that you receive out of hospital. It does not 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 tests such as bone scans, CT scans, X-rays and ultrasounds
- Blood tests.

Medicare safety net thresholds are changed annually to account for inflation. There is 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 are 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 safety net for concession card holders and families eligible for Family Tax Benefit (A).

If you are concerned about gap fees associated with doctors’ appointments and tests, talk to your specialist about 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 talk to your specialist or service provider about whether they can claim the Medicare rebate on your behalf when you pay your full account so that you don’t need to submit a claim at all. Medicare will then pay the rebate to the provider so that 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 capped per prescription (at the time of writing) at $38.30 (general co-payment) and $6.20 concessional payment for people on a Health Care Card or for those on a pension.

Some breast cancer drugs that 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. For more information on accessing drugs outside the PBS, see Section 2: Treatment and side effects.

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. – Jenny Anne
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.

Accessing the public and private health systems

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

It is okay to ask your doctor for public health options that might be available to you when you are making treatment decisions.

You are entitled to be treated for your breast cancer as a public (Medicare) patient in a public hospital even if you have private health insurance. However, you must let your doctors know that this is what you want to do. In this case, you will be treated by doctors nominated by the hospital and you will not be charged for most of your treatment and care.

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

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

If you have private health insurance, you can be treated as a private patient in a public hospital. You will be able to choose your treating doctor and, in some public hospitals, will have no out-of-pocket expenses (the excess is waived). If you would like to consider this option, talk to your treating doctor and hospital about what they offer.
What might my out-of-pocket costs be if I access the private health system?

_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._ – Robin

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 does not matter what level of cover you have; medical needs take priority.

Sometimes people get disappointed and annoyed that they have been paying for private health insurance for many years, but find themselves faced with substantial out-of-pocket costs for their treatment. For instance, depending on the level of your 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 my journey continues and I am now on a disability pension, I get few out-of-pockets from surgeons. However, I recently had two urgent operations and found there were changes in the private system for ancillary services such as pathology that historically were at no cost but now attract a gap. Discovered that this is attached to the hospital outsourcing services. Also discovered that my ambulance was covered by the health insurance getting to the hospital as I was immobile but even though I was still immobile coming home, I was not covered._ – Karen
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.

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 is okay to ask for a second opinion if you feel that the fees quoted may be higher than you can afford or want to pay.

For more information on seeking a second opinion, see Section 2: Treatment and side effects.

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

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

> 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 tell you how much this would cost.
Federal government assistance

Centrelink payments

If you are 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 25 80) or contact the Financial Information Service (phone 13 23 00) for advice. It is best to do this as soon as possible, as there might be a waiting period before payments can start to be paid to you. If you are feeling too unwell to have this discussion, your partner or a family member can seek advice on your behalf. You can nominate your partner or a family member to represent you, so that Centrelink can deal directly with that person instead of you.

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 is important that you or your representative keep on asking questions until you are sure about your entitlements.

You may also want to ask your partner or a family member or close friend to help you keep track of all of 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. Getting family to help with the paperwork side of treatment is a really practical way that you can get family or friends to support you. – Jenny

There are a number of different Centrelink payments for which you and your partner may be eligible.

🔗 For more information about any of the services or payments overleaf visit a Centrelink office, or phone 13 27 17.
Sickness allowance

If you are 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 are 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 cannot use public transport. Your doctor will need to complete the Centrelink form confirming you cannot use public transport without help because of disability, illness, or injury. If you are 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 do not meet the financial criteria that is part of the standard Centrelink application.

You can find more information and download the forms from the Centrelink website humanservices.gov.au/centrelink.

Disability support pension

If you are 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 are not receiving a Centrelink payment but are on a low income, you may be eligible to apply 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. A carer allowance 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 are caring for.

The carer allowance is not means tested and is a non-taxable payment.

Financial Information Service

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.

Social work services

I saw the oncology social worker to determine my eligibility for financial assistance. – Margot

Social workers can help you if you are experiencing financial difficulty, are in need of 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 may be having in meeting your financial obligations or requirements.
You can contact a Centrelink social worker by:

- calling 13 28 50 and asking to speak to a social worker
- visiting your local Centrelink office and asking to be referred to a social worker.

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.

_I saw the social worker while in hospital to discuss my needs while I convalesce at home after my operations, and was directed to my local palliative care service, which is free. Also the occupational therapy staff at the hospital have provided a referral to the community health service to come out and do an assessment on my house with a view to obtaining a grant to have my bathroom retrofitted to suit my ongoing needs and allow me to be more independent._ – Karen

**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 be present for six months or longer.

There are two types of GP management plans your GP can prepare for you.

> a GP management plan (GPMP)
> team care arrangement (TCA).

GPMPs can help you by providing an organised approach to care.

A GPMP is a plan of action that:

> identifies your health care needs
> sets out the services to be provided by your GP
> lists any other health care and community services you may need
> lists the actions you can take to help manage your condition.

A TCA enables you to have access to other health care providers, including allied health workers, who may be able to provide treatment or services to you. These include physiotherapists, registered lymphoedema practitioners, dietitians, podiatrists, occupational therapists and exercise physiologists.

Having a TCA in place means that you may be eligible for Medicare rebates for the care provided by these health workers for up to five visits per year. However, the care must be directly related to your breast cancer. You may need to make a special appointment to discuss a TCA – your GP’s receptionist will be able to advise.

GP mental health plans

If your GP believes that 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 to up
to 10 individual Medicare-subsidised appointments and 10 group appointments with an allied health mental health service provider such as a clinical psychologist, specialist GP, social worker or clinical occupational therapist.

BCNA has fact sheets that provide 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 have to stay overnight at times. This can be expensive. All state and territory governments provide some financial assistance for these kinds of expenses through Patient Assisted Travel Schemes (PATS). The payment you receive will depend on the distance you need to travel, and you may only be eligible if you are attending the treatment centre closest to your home. While these payments will not cover all the costs of your travel for treatment, they can help and are worth investigating. BCNA’s PATS fact sheet provides information about each state and territory scheme, including what they pay and how you can apply.

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
Subsidies for lymphoedema compression garments provide people diagnosed with lymphoedema with financial assistance towards the costs of their garments. The schemes are run by state and territory governments, and cover some, or all, of the cost of compression garments.

There is no compression garment subsidy program offered by the South Australian Government. Some hospitals in South Australia
do provide compression garments free of charge. There is also an organisation in South Australia called the Louisa DaCosta Trust that may be able to provide financial assistance towards the cost of lymphoedema compression garments for people in South Australia. For more information on lymphoedema subsidies, see BCNA’s lymphoedema fact sheet downloadable from bcna.org.au or phone 1800 500 258.

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 (providing carers with 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.

For more information on where to find financial assistance, see Section 4: Financial and practical matters.
**Taxi concession programs**

State and territory governments have programs that provide access to discounted taxi fares for people who meet certain residential, medical and financial criteria.

Eligibility criteria 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 are 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, meaning you would only be charged $60. You will need a letter from your doctor to advise that your illness means that you cannot 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.

You can contact Cancer Council on 13 11 20 for information about:

- 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 cannot afford to pay for advice.

Phone Cancer Council 13 11 20 for more information about the pro bono program.

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.

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).

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 in your local area, visit redcross.org.au or contact your state or territory Red Cross office.

Dreams2Live4
dreams2live4.org.au

Dreams2Live4 is a national charity that helps make dreams come true for people living with metastatic cancer. The organisation was founded by Annie Robertson, who was, herself, diagnosed 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

To find out more information, visit dreams2live4.org.au, phone 0400 914 375 or email info@dreams2live4.org.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 aren’t at retirement age. If you don’t feel up to looking into it, 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

Generally you cannot 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 dependant 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 dependant with a terminal medical condition
> pay for expenses associated with a dependant’s death, funeral or burial.

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.

You will be required to have two medical specialists involved in your care complete forms that specify your life expectancy as less than two years. This can lead to great anxiety for many people. It is difficult for doctors to estimate life expectancy. It can be hard to predict how a particular cancer may respond to different treatments, and clinical trials may offer new beneficial treatments that are not 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 will not be required to repay the money, and there is no penalty, should you live longer than two years.

There are also no rules on how you can spend the money. You may need it for your medical care, but you can use it however you like; for example to pay off your mortgage, pay school fees for your children, or take your family on a holiday.

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.

I used my superannuation to pay for a wonderful family holiday. Mentally and physically it was the best thing we could have done. It is the best medicine. I would love to think that everyone with this disease could do that.
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 result in you losing insurance benefits that might be attached to your superannuation policy. This includes life insurance and disability insurances. If you receive a Centrelink payment, you should also discuss with Centrelink any impact it may have on this.

BCNA has developed a fact sheet on superannuation and insurance for people with a terminal illness. It provides information to assist you to make the decision that is right for you. You can download the fact sheet from the BCNA website bcna.org.au or phone 1800 500 258.

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 are no longer able to work. These insurance benefits are often attached to your superannuation account as a default option, which means that 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.

There are two types of benefits that you may be able to claim:

Total and Permanent Disability cover (TPD) – this provides you with a lump sum insurance benefit if you are totally and permanently ‘disabled’. Although definitions of TPD differ between insurers, the most common definition is that you cannot return to your usual job or any other job because of your injury or illness, taking into account your age, education and experience.

Total and Temporary Disability cover (TTD) – this is where you
are 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 you with a monthly payment for up to two years and longer in some cases.

There is often a waiting period before these payments commence.

**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 correct. Some death benefit policies attached to superannuation may be able to be claimed by people who are terminally ill when they withdraw their superannuation account balance.

You can find out more about insurances that may be attached to superannuation policies by reading BCNA’s Superannuation and insurance payments for people with a terminal illness fact sheet.

If you are 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

I have had to adjust my working schedule and change my career aspirations, but have found fulfilment with the work I do. A lot less stress has helped my body to respond positively to treatment. It has also enabled me to enjoy my life and develop relationships more deeply and positively. – Wendy

Keep working unless you don’t like it or it is too stressful, because that is one way to maintain a social network. – Linda

If you want to work, do so. It helps mental wellbeing and keeps your mind busy with many other things. – Judith

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 by adjusting your role.

It is 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. Cancer Council Australia produces a free booklet, Cancer, Work & You, which includes some useful information and suggestions – for instance, that you should keep a diary of meetings, tasks, important conversations and any leave you have taken so that you have an accurate record in case you need to negotiate new or more flexible work arrangements.
Through my experience I think it is important for anyone coping with a chronic illness to know their employment rights from the beginning. My employer was fantastic until a change in management when my affairs were handled very surreptitiously. If I had my time again, I would like to have been counselled about my rights. I would have handled things differently. No one in my situation should have to go to Equal Opportunity to fight for their rights. Most would find this too daunting to even try. – Karen

You can download a copy of the Cancer, Work & You booklet from the Cancer Council’s website cancer.org.au or phone Cancer Council 13 11 20 and ask them to send you a copy.

Most employers are supportive when an employee is diagnosed with breast cancer. However, if you are worried that yours may not be sympathetic or that you are 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. The website also has useful information about the rights and responsibilities of both employees and employers.

You may also consider talking to an employee representative or union representative in your workplace.

If you are 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 are receiving a Centrelink payment and decide to return to work, you are 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 women with breast cancer are volunteers and they say it helps them to feel ‘normal’ as well as being very fulfilling.

I am lucky to be able to do volunteer work and study as I am receiving a superannuation pension which replaces a lot of my income and I have amazing support from my family, friends and ex work colleagues.

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!
– Karen
Resources

Government assistance

**Centrelink**

[humanservices.gov.au or phone 13 27 17](https://humanservices.gov.au)

You can phone Centrelink, visit the website or visit a Centrelink office for more information about Centrelink payments and Health Care Cards.

More information about Centrelink payments is also available on BCNA’s website at [bcna.org.au](https://bcna.org.au).

Working with cancer

**Cancer, Work & You – a guide for people with cancer and their family and friends**

[cancer.org.au or phone 13 11 20](https://cancer.org.au)

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, and outlines some of your rights and entitlements.

Travel assistance

**Patient Assisted Travel Schemes (PATS)**

[bcna.org.au or phone 1800 500 258](https://bcna.org.au)

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](https://angelflight.org.au)

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

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

Provides free legal, financial and workplace assistance to people affected by cancer who cannot afford to pay for advice. This service is means tested, which means that you will need to pass a test in order to 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 are 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.
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.

Other 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 women 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 Sunshine Coast Private Hospital Cindy Mackenzie Breast Cancer Foundation
Qld
cmbcf.com.au or phone 1300 557 710

The Cindy Mackenzie Breast Cancer Foundation provides women diagnosed with breast cancer and living on Queensland’s Sunshine Coast with practical and financial support.

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.
Five:

Metastatic breast cancer in young women

I am 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.

– Kate
YOUNG WOMEN
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. – Mei

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
- Single and dating
- Talking to parents
- Talking to children
- How you can help your children cope
- Employment and returning to work
- Child care
- Financial and practical support
Introduction

There have been many challenges. Probably the biggest is learning to live with the reality of it all. – Chelsea

Although metastatic breast cancer is a life-changing illness for all women, young women can experience 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 are 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 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, or 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 is 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. And as a young woman, a diagnosis of metastatic breast cancer may feel especially frightening, confronting and isolating. You may be worrying about issues such as:

> 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?

These are all common thoughts and concerns, and this is a time to draw on as much support as you can. Although you may be experiencing a lot of worry and sadness, there are many resources that can help young women – and their family, partners and friends – to 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. – Rebecca

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 fear or anger at the diagnosis. As a young woman, you may feel a deep sense of 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 can feel sometimes like the cancer has robbed you of hope and a future, just when you have been starting out, or hitting your stride in life. These feelings are normal and understandable. The initial feeling – that everything is a disaster – can be hard to shake.

Over time, most people come to realise that hope hasn’t gone. Your hope may now centre on long periods of disease control and feeling well, or enjoying a trip or a special event, or quality time spent with family and friends.

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. – Charlotte

I am 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. – Louise
Understanding how to care for your emotional wellbeing can help you to feel more optimistic and in control.

**Counselling and managing emotions**

There is no rule for how to handle emotions. You have to listen to what your heart says is right for you. Being able to talk about emotions 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.

> Your GP may be able to give you a referral for a mental health plan – a Medicare-subsidised set of counselling sessions with a psychologist or counsellor who has a Medicare provider number.

> If you are still working, your employer may also provide a small number of free, confidential counselling sessions through an employee assistance program.

> BCNA provides free confidential, professional one-on-one telephone counselling support for people affected by metastatic breast cancer. To make an appointment to speak with an experienced professional oncology counsellor in the privacy of your own home or preferred place phone BCNA on 1800 500 258, or email beacon@bcna.org.au.

> In some states, you can access counselling by phoning Cancer Council 13 11 20.

Ξ For more information about counselling and other sources of emotional support, see Section 3: Living well.
Building your support network

*People with cancer can like to talk to other people who are going through similar things.* – Marie

Looking after your emotional wellbeing is easier if you have a strong support network. Friends, partners and family are a crucial part of that support network. Many women find that connecting with other young women living with metastatic disease is also very helpful.

*I am 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.* – Kate

*Support groups are fantastic; online and face to face.* – Breanan

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 that it is 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.

It is important to be mindful that these groups are not 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 you can connect with.

**Further information**

- You can connect with other young women through BCNA’s online network at onlinenetwork.bcna.org.au
- BCNA’s website has a metastatic breast cancer section that lists breast cancer supports at bcna.org.au
- Cancer Council’s Cancer Connect peer support program can put you in touch with someone who has experienced metastatic disease. Call 13 11 20 or visit cancer.org.au
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. Many like to put on a brave face.

– Kay

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 are feeling. You might find that some people don’t know what to say to you, or what they can do to help you. It is helpful to be open and honest about how you are going and what you need.

Communicating openly with trusted people in your life, and allowing them to help you where they can, can give you more energy for doing the things that matter and that give you pleasure.

It is really important to be self-aware and know when you need to reach out to talk to someone professionally, instead of putting on a brave face for everyone around you, that everything is fine. – Ros

Single and dating

If you are single, you may not have ‘one’ person you turn to 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 the comfort and support they need. Others so value their independence that they would rather not have to rely on parents for care and financial support. For independent young women, it can
be tempting to avoid asking close friends or family for help as you don’t want to feel like a burden. It can be helpful to think of others’ help as a ‘gift’, allowing others to show their support for you.

You may find that, after a diagnosis, some friendships do not provide the level of support and understanding that you need. Concentrate your energy on being with friends who are there for you.

When I need some help with feeling down or depressed, I like to have a chat with some of my close friends.
– Jasmine

If you are feeling up to it, it is nice to have regular catch-ups with close friends – even if someone just comes to visit for a chat at home. This can be something to look forward to, as it offers companionship and support.

As a single woman, new relationships are a challenge, especially having to manage information about my cancer to potential new partners. – Amy

If you are 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 you might find that if you are stressed or feeling down, it 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.*
- Georgia

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 own feelings about the situation. Sometimes partners can be afraid that talking about it will be too painful (with 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.

Communicating openly and honestly is usually the best way to keep your relationship healthy. You should both feel able to express your fears and discuss your individual needs and your needs as a couple or family. Trying to keep strong feelings to yourself is hard work.

Recognise that your partner will need space at times. Having some personal time will help your partner to have more energy to be there for you. It is also helpful to schedule some regular time out for yourselves as a couple. This will help to strengthen your communication and the quality of your time together.

There are many resources that can help you and your partner.

- Talk to your GP, social worker or oncologist about services and supports available to you and your partner.

- If you are in a same-sex relationship, it can help to seek out health professionals who are sensitive to and respectful of your situation. It is important that your partner is involved in your treatment and care. If you feel that your medical team is not supportive, then it is probably a good idea to look around for other professionals. Some couples also find it helpful to talk to a counsellor or join a same-sex support group.

> For more information on the impact of breast cancer on partners and family, see Section 3: Living well.

> If you are looking for a resource to help your partner in understanding your needs, see BCNA’s booklet *She has breast cancer: how can I support her?*
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. – Rose

Sexual wellbeing is an important part of life for every woman. Your sense of sexual wellbeing is unique to you, and it is shaped by factors such as desire, self-esteem and body image; your physical and emotional wellbeing, as well as your libido and levels of sexual satisfaction.

Sometimes you might find that physical side effects and symptoms can make it difficult to have interest in sex or to feel comfortable and confident in your body. This can include concerns such as 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 am an otherwise healthy, active 39-year-old woman but now I am menopausal. I still have a libido but I have symptoms from menopause that make sex less enjoyable and painful. – Amanda

Sometimes the emotional impacts of metastatic disease can also impact on your sexual wellbeing. You may feel a loss of confidence, have concerns about your body or appearance, or feel anxious or upset. Very often, it is a combination of different factors that impact on your libido and sexual intimacy. This can place a strain on existing relationships, or make it more challenging to establish new relationships.

Many women experience these kinds of concerns, and it can be reassuring to know that you are 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.** The changes that can occur as a result of metastatic breast cancer can lead to feelings of grief, loss, anger and sadness. Be kind to yourself, and give yourself time to process what you have experienced. There’s no ‘right’ way or time to process these experiences. Some women find it helpful to talk to their partner, friends or family, or to write down their feelings. It is different for every woman, and it is good to take your time and find what works for you.

> **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 hard to adjust and to feel confident and attractive. You might find it can give a sense of relief and comfort to treat yourself, such as visits to the hairdresser, buying lingerie or having 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 your relationship to be, and what level of intimacy you would like. If you feel you have lost interest in sex, remember that sex isn’t only about intercourse or foreplay. You and your partner can continue an intimate closeness. It may not be easy, but it is more important than ever to speak plainly and openly with your partner at this time.

> **Seek help if you are 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 with their sexual wellbeing during and after treatment. Topics in the booklet include practical strategies to help with building intimate relationships, the loss of desire, and dealing with physical symptoms like vaginal dryness.
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.
– Maddy

The thought of telling your parents about your diagnosis can be daunting and upsetting. To help in the process, you might choose to share 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 your parents about your diagnosis until you have all of the information you need. You need to do what feels right for you – and, of course, you may come to think about this differently over time. You might want to talk to a health professional such as a counsellor to get some help around talking with your parents about your illness.

Sometimes it may become necessary to move back with parents for a time so they can care for you and give some financial support. If you require additional assistance at this time, it can be helpful to connect with your GP or social worker who can 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.
– Hillary

If you have children, especially young ones, concern about their welfare and how they will take the news of your diagnosis can be the most distressing issue of all. You will undoubtedly worry about how they will understand and accept your diagnosis and treatment. It may be difficult for you to find the right words to say to them, 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’. – Amanda

Young children don’t understand chance or bad luck – they think that everything happens for a reason. It is normal for young children to believe in fairies and magic (think about making a wish when blowing out candles on a birthday cake), but this belief in magic extends to their believing that they can also make bad things happen. If you add these things together it makes sense that a young child might feel that 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.
So 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 message behind it; that it is 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 the ‘extra good’ 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.

*I tell my children that it is no one’s fault I got cancer – it just happened.*

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. Even though it is an effort to keep to the usual rules, 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. Then suddenly she wasn’t seeing him anymore. When I asked why, she said it was because I was better now (i.e. radiotherapy had finished and I was back at work!). 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. – Despina

From about eight to 12, children start to realise that sometimes things just happen, and that bad things aren’t necessarily their fault. One of the things that helps children of this age cope with difficulty is helping them to understand what is within their control and what is not. The cancer is not because of anything you did. It is not because of anything they did. You are trying to be well. Tell them it is 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 sports activities, but research shows that these sorts of activities help children to cope. Maybe you could ask a friend to take them to sports practice if this is something your children enjoy.

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 is going to die.’ Well-meaning family and friends may tell them to be brave and grown-up, 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 are okay with your child expressing their concerns, rather than being encouraged to ‘be brave’.

Feeling that they are helping out can really improve children’s confidence, so having a list of chores is generally a good idea. The challenge is to match the chores to the skill level of the child. Giving a child a task at which they are likely to fail doesn’t help anyone.
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.
– Karen

Adolescents are just starting to think in abstract terms, although their ability to think logically often fluctuates. This is the time when 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. Teenage boys can often be the height and weight of a man before the middle of high school – but their brain hasn’t necessarily caught up with the physical growth. Sometimes we need to remind ourselves that the adolescent brain is a work in progress – for boys and girls!

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. They do need to have ongoing social activities and opportunities to have fun – these are the things that will help them cope.

It is common for teenagers to have wildly fluctuating and conflicting demands and expectations of their family – if you don’t ask, you are selfish and don’t care; if you do, you are nosey. Emotions can be felt very intensely, and it is easy to feel isolated. Teenagers whose mother has metastatic breast cancer may feel on the 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.
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 diagnosis, your feelings are likely to be very intense. It is tempting to feel that keeping the situation secret from children will protect them from worry.

> Many women say they try not to cry in front of their children. It might be helpful to reflect on what this means for you and for them. Crying when we are sad is normal. The first, and often hardest, thing is to be honest. Children are often very good at picking up on things and will know when something is wrong.

*If you don’t tell them, some kid in the school yard will, and they will have no defences to deal with it. – Lauren*

> However upsetting, talking is essential, and it is 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 that they are also affected by the diagnosis. Of course you know this, but actually saying it makes a difference.

> 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. If your children know that you will always tell them what is happening, they will feel less worried about being away from you for a short time.

> Children may ask difficult questions. Think what your children’s questions might mean and find ways to encourage them to talk or share their feelings. It is okay for you all to share even very sad feelings, and it can also give you all 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 are 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 with them things that they can do in an emergency – for example, when they may need to call an ambulance or which neighbours or relatives they can ring.

> Consistency is important for children. This means keeping children to their normal routines as much as possible, and drawing on the support of your partner, family and friends to help out if you are feeling overwhelmed or need any extra help.

Women often tell us about different resources that they have found helpful in communicating with children and teenagers about what is going on or what might happen in the future.

For more information on resources that may help, see Section 6: Metastatic breast cancer in men.

My sons were 9 and 7 when I was diagnosed with early breast cancer. They both remember it being a frightening, long time with me being away from them – I had 4½ months in Melbourne participating in a clinical trial. I don’t think anything we could have done differently would have changed this perception. When I was again diagnosed and had to relocate to Melbourne for six weeks of radiotherapy they were 16 and 14. They moved in with my parents while I was away, but each weekend when I returned home they demanded that we move back into our own home where they would look after me. There was lots of spag bol and cups of tea! 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. – Marlene
Employment and returning to work

For many young women, work can be an important source of meaning, income and wellbeing. You may want to keep working for as long as you can because you enjoy your job or because it gives you financial security. Or you may want to give up work to concentrate on other things in life. Sometimes you may have to give up work because you are too unwell. Every person’s experiences and priorities are different.

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. – Ellen

It has been hard to give up my career to focus on treatment. – Dani

Planning to return to work

If you are planning to return or stay at work, your employer can help you by making adjustments to your work duties, or changing your hours. Although it may sometimes feel uncomfortable to disclose a diagnosis, the benefit of telling your employer is that they can assist you in making any adjustments that are needed to help you. It is important to communicate regularly with your employer, and to agree on a return to work plan if you are returning after a period of leave. It is 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 programs provide short-term counselling and emotional support, free of charge for employees.
Support with discrimination and other workplace issues

> Most employers are supportive when an employee is diagnosed with breast cancer. However, if you are worried that your employer is not understanding, or you are in danger of losing your job after disclosing your diagnosis, you can talk to an adviser at the office of Fair Work Ombudsman. They 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 by calling 13 13 94.

> If you are experiencing workplace bullying or harassment, you may want to 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 may 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 cannot afford to pay for advice.

♫ For more information phone Cancer Council 13 11 20.

Further information

Cancer Council has a free booklet, Cancer, Work & You, which includes some useful information on your rights, and practical tips and suggestions.

Cancer Council also has a suite of fact sheets, Supporting a Colleague with Cancer, which are designed to help colleagues who want to be supportive but are unsure of what they can do.

♫ You can download copies of these fact sheets from cancer.org.au or call Cancer Council 13 11 20 and ask them to send you a copy.
Child care

If you have young children, child care can be a complex issue. Cancer treatments such as chemotherapy involve periods where you are immune-compromised and your treating team will advise you to avoid exposure to possible sources of infection. Long Day Care or Family Day Care programs are not usually an option when you are in treatment, because there’s a risk of your child bringing home a virus or other form of infection. In-home care is a more appropriate option. Paying for in-home care can unfortunately be expensive and is often out of reach for many young women and their families.

If you have limited options for child care, you may need some extra assistance.

The Family Assistance Office, set up by the Australian Government, provides information on:

- any child care services in your local area that you may be eligible for
- privately operated and local government (council/shire) operated services
- government financial assistance for child care, such as the Child Care Benefit.

To find out more, visit humanservices.gov.au, or phone 13 61 50.
You can also visit the Australian Government’s website mychild.gov.au, which 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.

**Special Child Care Benefit**

*It is so difficult sole parenting young children with little to no support. Managing the day-to-day housekeeping and cooking has been challenging. – Zoe*

If you already receive Child Care Benefit (CCB), you might be eligible for extra hours under the ‘exceptional circumstances’ provision.

If your illness has caused hardship and you are having difficulty paying your child care fees, you may be eligible for up to 13 weeks of Special Child Care Benefit (SCCB). 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 are receiving treatment, you can contact the Child Care Access Hotline on 1800 670 305, or TTY Service 1800 810 586.

For more information on the Special Child Care Benefit, visit the Family Assistance Office website at humanservices.gov.au > Families > Child care or call 13 61 50.
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 allocation places, and to be eligible you must meet a set of criteria.

To find out more about your eligibility for the program, contact the Family Assistance Office: visit humanservices.gov.au > Families > Child care or call 13 61 50.

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. Support provided includes help with child care options, housecleaning and housekeeping, provision of meals, financial assistance, and food vouchers.

For more information, phone (07) 3162 8265 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. – Selina

Most young women find that their diagnosis affects them financially in some way. This includes costs not covered by Medicare, a loss or reduction of income, and ‘incidental’ costs associated with treatment such as parking, travel and child care. You may already be under financial pressure due to mortgage repayments, rent, university fees, and other financial commitments.

For a young woman, the out-of-pocket costs of cancer diagnosis and treatment can add to these financial pressures, especially if you have not had the opportunity or time to build up your savings.

The good news is that there are services and support available. Your hospital social worker, GP or breast care nurse can help you find services for which you may be eligible. This could include specific local support such as one-off payments to help with utility bills, and interest-free loans.

Discounted parking

Many women tell us that discounted parking at hospitals and clinics is a crucial financial need. To make sure you get the most out of available parking discounts, it is helpful to ask what policies and provisions are available at your hospital. It is also useful to call ahead to be familiar with the parking options, and to allow for extra time to find parking.

You can also consider applying for an Australian Disability Parking Permit, which allows you to park in disability marked spaces and for longer periods.

For more information about financial support, see Section 4: Financial and practical matters.
Resources

Breast Cancer Network Australia (BCNA)
Australia
bcna.org.au or phone 1800 500 258

BCNA's website has up-to-date information about metastatic breast cancer treatment and care, and information on supports available for young women. It includes information on treatment-related side effects as well as personal stories of young women diagnosed with breast cancer.

BCNA's online network
Australia
onlinenetwork.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 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
Australia
BCNA
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
Australia
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. Their website also contains 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. The videos cover topics including how to manage hard conversations, getting support, managing fatigue, and coping with other people’s reactions.

Work After Cancer website

Australia
workaftercancer.com.au

This website is a resource to support work during and after a cancer diagnosis. It is 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, and outlines some of your rights and entitlements.

Resources for children, teens and parents

Talking to kids about cancer

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

Produced by Cancer Council, this booklet describes ways to talk to children about cancer, with specific suggestions for age groups from infancy to 18 years.

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 24) living with cancer, but also supports young people whose parents have cancer.

When a parent has cancer: a guide to caring for your children
USA 1997
Wendy S. Harpham, Harper Collins
Available from bookstores
Drawing from her experiences as a physician and as someone who has had cancer, the author provides practical advice about caring for children of all ages during diagnosis and treatment. She also provides helpful insights into helping them cope with grief, loss, uncertainty and fear of death.
Six:

Metastatic breast cancer in men

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
BREAST CANCER IN MEN
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
> Overview of treatments that may be recommended to you
> Where to find more information
Most people, men and women, feel devastated when they are told they have metastatic breast cancer. You may have lived through the trauma of being diagnosed and treated for early breast cancer and may have believed you were finished with breast cancer. Or your diagnosis of metastatic breast cancer might be the first time you have experienced breast cancer.

For men, this diagnosis can be particularly confronting and may 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 are not alone. We hope that through *Hope & Hurdles*, you will find information and support to help you.

**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 will be looking for information and support that is tailored to your needs. *Hope & Hurdles* is a tailored resource and, while it has been designed for women and uses language and stories that focus on women’s experiences, much of the information in it is also relevant for men. Men usually have the same breast cancer treatments as women, with similar side effects for example. And the mental anguish of being diagnosed with a life-limiting illness is similar for any person, regardless of gender or disease type.

We encourage you to read *Hope & Hurdles* to find information that might be of interest to you. This *Information Guide* includes information on treatments and on practical, financial, emotional and physical support. It is designed so that you can dip in and out of it as you need it – you don’t need to read it from cover to cover.
The optional booklets on the sites of metastases (bone, lungs, liver and brain) and subtypes of breast cancer (hormone-positive, HER2-positive and triple negative) that you can order as part of Hope & Hurdles will also have relevant information for you. Talk to your medical oncologist or breast care nurse about which booklets are appropriate for you if you are not sure.

If you are looking for additional information that is tailored to men, 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’s website (bcna.org.au) to download a copy or to order a printed copy. You can also order the booklet by phoning BCNA on 1800 500 258.

Dealing with a diagnosis

_In terms of breast cancer, my perception is that it is 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. Men often want to understand why they have developed metastatic breast cancer, especially if they have previously had treatment for early breast cancer. Unfortunately, even the best treatment for early breast cancer does not always remove every diseased cell.

Some men may be 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 7: Metastatic from the start.
Men with breast cancer can sometimes feel very 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 seem to react with discomfort or disbelief when you tell them about it.

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 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

For more information on dealing with a diagnosis of metastatic breast cancer, see [Section 2: Treatment and side effects](#).
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

Men with breast cancer should receive the same level of support they would receive if they had any other type of cancer. But because it’s so uncommon, even health professionals can struggle to understand what support is needed. This is beginning to change, with the increased focus on the needs of men with breast cancer by organisations such as BCNA, but it can be frustrating at times to feel that there’s still not enough support out there. The good news is that there are resources that can help you.

Looking after your wellbeing is easier if you have a strong support network. Friends, partners and family are a crucial part of that support network. However, some men also find counselling is very helpful.

> BCNA provides free confidential, professional one-on-one telephone counselling for people affected by metastatic breast cancer and their family members. To make an appointment to speak with an experienced professional oncology counsellor in the privacy of your own home or preferred place, phone BCNA on 1800 500 258 or email beacon@bcna.org.au.

> Your GP may be able to refer you to a counsellor, and provide you with a GP 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 are still working, your employer may provide a small number of free, confidential counselling sessions through an employee assistance program.

> In some states and territories, you can access counselling through Cancer Council 13 11 20.

For more information on counselling, see Section 3: Living well.
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. Unfortunately, men tell us it is especially hard to find support groups that are tailored to their needs, and that help them to feel included and comfortable. You may like to talk to a member of your treating team to see if they know of other men or suitable support groups you could connect with. A counsellor, social worker or GP may also be able to connect you with local support services. You may also find it helpful to seek support from other, more general cancer groups where members have a range of cancers.

*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. It was perfect, it was just what I needed. I went for about four sessions to that support group. And then I felt fine, I didn’t need to go anymore.* – John

Some men find it easier to connect through online groups, including overseas websites designed for male breast cancer survivors. It is important to be mindful that these groups are not always professionally facilitated, so some of the posts may not align with your own views. A list of online support groups and male breast cancer resources can be found in the resources section.
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. Some treatments will treat the cancer and may relieve the symptoms very quickly. Others take longer to work and some may not work at all. If one type of treatment doesn’t work for you, there will usually be others to try.

There have been very significant advances in the treatment of metastatic breast cancer in recent years, due to research providing a better understanding of breast cancer. While research has not been undertaken specifically in men with metastatic breast cancer, men can benefit from new treatments developed.

The treatments 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.

Your oncologist will talk with you about the subtype of breast cancer that you have, but most men with breast cancer will have hormone-positive breast cancer.

For more information on treatment and treatment side effects, see Section 2: Treatment and side effects.

BCNA has developed booklets on each of the three subtypes of breast cancer. You can refer to the one relevant for your breast cancer subtype for specific information about treatments that may be recommended for you. You can order these booklets online or call 1800 500 258 and we will send a copy to you.
Further information

Where to start

> See BCNA’s Men with breast cancer webpage at bcna.org.au.
> See BCNA’s webpage listing of metastatic breast cancer resources and support services at bcna.org.au.
> You can connect with other men and women with metastatic breast cancer online, through BCNA’s online network at onlinenetwork.bcna.org.au.
> 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

> **Cancer Council SA**
  Australia
  Breast cancer in men webpage
  cancersa.org.au

> **Breast Cancer Care UK**
  UK
  Men and breast cancer webpage and booklet
  breastcancercare.org.uk

> **Cancer Research UK**
  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
Resources for men

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.

Cancer Australia
breastcancerinmen.canceraustralia.gov.au

Cancer Australia’s Breast cancer in men 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
phone 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 organisation 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 is 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 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.
Seven: Metastatic from the start

It can be really hard to come to terms with the fact that you had a ‘normal’ life yesterday and to know how you are going to get through each day. However in time this early phase will pass. Take your time to deal with the news that has been given to you.

– Ros
METASTATIC FROM THE START
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. – Vanessa

Section overview

This section is for people whose first diagnosis of breast cancer is metastatic breast cancer and includes information on:

> What is breast cancer?
> Finding out you have metastatic breast cancer
> An overview of treatments that might be recommended to you
> How having metastatic breast cancer from the start might influence treatment
> The role of breast surgery
> Where to find more information and support
If your first diagnosis of breast cancer is metastatic breast cancer, this has undoubtedly come as a huge shock to you. You may have seen stories in the media about the high numbers of women now surviving early breast cancer, and wonder why your breast cancer was not picked up earlier. You may be feeling devastated, confused and even angry. These feelings are normal. Many women describe this time as overwhelming, feeling they are being constantly bombarded with new information each time they go to hospital or see their doctors.

The information in this section is designed to help you make sense of all of the information being given to you. It is designed to provide you with a basic understanding of breast cancer and what it means when it has spread to another part of the body. It has been written with the input of women who, like you, have been diagnosed with metastatic breast cancer from the start. These women have told us the importance of providing messages of hope and reassurance that many people with metastatic breast cancer can live for years with their cancer under control.

This section also contains tips to help you navigate the health care system and learn about other ways that women have coped to help you understand that you are not alone. You will 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 with metastatic breast cancer are now able to manage their disease in a similar manner to living with a chronic illness – with ongoing treatment providing periods of wellness between periods of ill health.
Sometimes women are found to have metastatic breast cancer when they are first diagnosed with breast cancer. This is called ‘de novo’ metastatic breast cancer, meaning their breast cancer is metastatic from the start. This is not common – about one in 20 women diagnosed with breast cancer will have metastatic breast cancer from the start.

When people hear that you have breast cancer, they often ask questions about what treatment you will have and when it will finish. It is very likely that you will not have the answers to give them at this time. This can make conversations with the people around you challenging and frustrating.

People think that you will just have some treatment and then you will be okay, especially if they have known other women who have had breast cancer. They don’t understand that this is not going to be your experience.

It can be exhausting as you try to understand and make decisions on the treatments being recommended to you when you feel that overnight your world has been tipped upside down. Sometimes it can feel difficult to see the way forward.

It can be really hard to come to terms with the fact that you had a ‘normal’ life yesterday and to know how you are going to get through each day. However, in time this early phase will pass. Take your time to deal with the news that has been given to you. – Ros
Breast cancer: a brief overview

Basic information is what is 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 is 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 woman develops breast cancer and another doesn’t, and most women 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.
Women 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, post-menopausal obesity and lack of exercise) can be avoided. But other risk factors (such as being a woman and having a family history of breast cancer) can’t be avoided. Having a risk factor does not mean that a woman will get breast cancer. Many women who have risk factors never develop breast cancer.

For more information about breast cancer and risk factors, go to BCNA’s website bcna.org.au.

The Glossary provides definitions for commonly used breast cancer terms that you may start to hear about or come across if you are researching breast cancer online. If there are any terms you are unsure of, make a note and ask your medical oncologist or cancer nurse to explain them to you.
Finding out you have metastatic breast cancer

Everyone is different, and how you find out that you have metastatic breast cancer may also be different. Some women will find out their cancer has already spread as part of routine tests and scans for what was thought to be early breast cancer. For these women, who may be in the middle of making decisions on breast cancer surgery, or perhaps have already had surgery, it can be extremely distressing to learn from their doctor that the aim of treatment has suddenly changed and that control of the cancer is now the focus rather than cure.

You are likely to be referred to a number of other medical specialists for further tests and appointments, including a medical oncologist, who will be your main cancer specialist.

I had started to feel comfortable with my surgeon and trusted him to help me make the right decision around whether to have a mastectomy or not. Then all of a sudden he was sending me off to see someone else and I felt like I had to start all over again. – Brenda

A diagnosis of metastatic breast cancer may also be made following tests for symptoms you have been experiencing. At this time your GP may be the one coordinating your care. You may not have even considered that you have breast cancer. Sometimes, it takes a while and many tests before the doctors work out the diagnosis. This can be a distressing and frightening time, particularly as you become more concerned that something serious is wrong, and yet a diagnosis has not been confirmed.

It is normal to feel overwhelmed as you and your family try to learn not only about breast cancer, but also metastatic breast cancer. You are likely to be given a great deal of information, none of which may feel familiar 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.

It took a lot of time to take it all in and understand the diagnosis fully. Signing the chemo form made it sink in a little – knowing that it wasn’t meant to be a cure but a measure to extend life.
Feelings

Finding out you have metastatic breast cancer can bring up different feelings for different people. Some women tell us that they are relieved to finally get a diagnosis and a treatment plan after undergoing a large number of test and scans. Others tell us that they experience feelings of guilt about their diagnosis. They wonder whether they would have still developed metastatic breast cancer if their breast cancer had been detected earlier or they had done something differently. Others can feel angry that their cancer was not detected earlier. The truth is that it is almost always no one’s fault, and you should not blame yourself, or waste your energy trying to change things that you can’t. Sometimes it is just the fast-growing nature of the cancer that is the reason it has metastasised before being detected. But even if that is the case, it doesn’t mean that there is not effective treatment available to help you.

*I don’t waste my time thinking about the things I can’t change. I’m grateful for modern medicine and each day I make sure my family and friends know I love them and appreciate them.*

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 will follow will be different. It can sometimes be hard to find out where to get support that is right for you, but in time you will come to work out what is going to work best for you.

*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.* – Ros
What happens next?

I wanted more information about the types of test and scans and what each one did. – Gillian

What happens after your diagnosis depends on the scenario in which the metastatic breast cancer has been 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 the diagnosis has been made by your breast surgeon, it is likely that the primary cancer in the breast will have been biopsied or removed and the cancer will have been analysed in pathology already.

If the surgeon has concerns that the cancer has spread from the breast to other more distant parts of the body, you will need to have a number of scans and other tests. If abnormalities are found on the scans, a biopsy of the abnormality may be undertaken to determine if it is metastatic breast cancer. While a biopsy is ideal, it is not always possible due to the site or position of some abnormalities.

If you have been investigated for symptoms by your GP or another doctor and results have suggested cancer, the medical oncologist you are referred to will arrange for the different tests and scans that you may need.

In either scenario, a biopsy is required to confirm that the diagnosis is metastatic breast cancer, and to determine the subtype of the metastatic breast cancer 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. They are important because the receptor results will influence the type of treatment that will be recommended for you.

In the situation of 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 receptor results. Your oncologist will want to confirm that the area of concern on the scan is a breast cancer
metastasis and check that the receptors are the same as the cancer in the breast. However, sometimes this is not possible because of the position of the metastasis (this is more likely if it is in the bone), and your oncologist may have to rely on other test results to determine whether you do have metastatic breast cancer. Often the appearance on scans and tumour marker blood tests that are higher than normal are enough to be clear that there are metastases present, and a biopsy of the area may not be required.

Sometimes women may find themselves in the rare situation where it is unclear whether an abnormality in a particular area of the body is in fact a metastasis from breast cancer or a metastasis from another type of cancer. In this situation, the approach is to monitor over some months with repeated tests to see what is happening. In the end (and it may take 3–6 months), it will be possible to be certain one way or another.

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 the Glossary.
Treatment

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 different women can respond differently to the same treatments. This is why treatments are tailored to individual women. Factors like your age, menopausal status, medical history, general health, work situation, life goals and personal preferences all need to be taken into account.

For most women, the backbone of treatment for metastatic breast cancer (whether de novo or following a previous early breast cancer diagnosis) will be what is called ‘systemic’ treatment. This means treatment that travels throughout the whole body and treats the cancer wherever it is.

The results of the biopsy that you have had on either the primary cancer in your breast or the abnormality in another part of the body will influence the type of systemic treatment you may be recommended. This is because the biopsy will have identified the subtype of breast cancer that you have and the treatments that are the most tailored to stopping that subtype of breast cancer growing.

There are three main subtypes of breast cancer that will help guide treatment recommendations. They are:

- hormone receptor positive (oestrogen and/or progesterone receptor positive)
- HER2-positive
- triple negative.

The following information provides a general overview of the types of systemic treatments available, and may be helpful in giving you a basic understanding of the treatments that can be used for breast cancer.
Systemic treatment

Hormone therapy (endocrine therapy)

Hormones occur naturally within the body and control the growth and activity of some normal tissues in the body. However, hormones, and particularly oestrogen, can encourage the growth of breast cancers that have hormone receptors, known as ‘hormone receptor positive’ (ER+ and/or PR+) breast cancer.

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

Chemotherapy

Chemotherapy uses drugs known as cytotoxics to kill cancer cells or disrupt their growth. 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, bone marrow and digestive system, which is why side effects such as mouth ulcers and hair loss may occur.

Targeted therapy

In addition to chemotherapy and hormone therapy, there are newer treatments that can attack specific breast cancer cells without harming normal cells. These therapies are called targeted therapies. Targeted therapies are drugs that block the growth of breast cancer cells in specific ways. Hormone therapies were the first example of targeted therapies for breast cancer, targeting the oestrogen receptor that stimulates the cancer cells to grow.

The best known new targeted therapies are the HER2 targeted therapies (Herceptin, Perjeta, Kadcyla and Tykerb) that block the action of HER2 receptors on cells. Breast cancers that are HER2-positive have excessive numbers of HER2 receptors 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.

New targeted therapies that block other pathways within cancer cells are currently in development.

For more detailed information around systemic treatments, see Section 2: Treatment and side effects.

BCNA’s subtype of breast cancer booklets can provide you with more information on systemic treatments that are more personalised to your specific cancer. Your oncologist can help guide you to the booklets that may be most appropriate for your type of breast cancer.

Clinical trials

Clinical trials aim to find new and/or better cancer treatments or to see whether a new treatment is better than the best existing treatment. When you are 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 that may otherwise not be available to you. This might be important if a new treatment has been developed that is showing some benefits for your particular subtype of cancer. Some women 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.

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.

For more information about clinical trials, see Section 2: Treatment and side effects.
How having metastatic breast cancer from the start might influence treatment

There are some advantages for women diagnosed with de novo metastatic breast cancer compared to women who have progressed following an early breast cancer. The main advantage is that their cancer is ‘treatment naïve’, meaning it has not previously been exposed to any anti-cancer treatments and is therefore likely to be more responsive to treatment. There have been some reports of small numbers of women who may even be cured from metastatic breast cancer in this circumstance. In addition, there are more treatment options available than for those who have received previous treatment for early breast cancer who may 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 that women sometimes describe is that they can feel the cancer in their breast getting smaller once treatments starts. Mammograms and breast ultrasounds may be used as a way of checking that the cancer in the breast is responding to treatment. Many women find this reassuring, knowing that the treatment they are having is working for them.

For more information about coping with the emotional impact of metastatic breast cancer, see Section 3: Living well.
Role of breast surgery

Surgery to the breast is considered a ‘local therapy’, meaning it only removes the cancer that is in the breast tissue. Surgery to remove a cancer in the breast is usually not recommended when a woman has metastatic breast cancer, at least not initially. Treatments that work ‘systemically’ to destroy cancer cells anywhere in the body will usually be recommended first. These treatments will work simultaneously on the cancer cells in the breast and the metastases.

Sometimes women with de novo breast cancer question why they are not being recommended breast surgery. Evidence regarding the benefit of removing the primary cancer in the breast, in addition to systemic therapy for metastatic breast cancer, is incomplete. It was once thought that there was no value in treating the primary cancer unless it was causing local problems. Then evidence emerged suggesting that those whose cancers were removed had better outcomes. More recently, however, a study performed in India, where women were randomly allocated to either receive surgery or not, revealed no benefit in terms of length of survival from undergoing breast surgery. There remains substantial uncertainty, as this was not a big study and there may be benefits for some individual women, particularly those whose metastatic cancer is only in the bones. If there is a risk that the cancer may cause troublesome local problems, such as ulceration through the skin in the future, surgery is usually recommended. For some women there may also 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 women may also want to have a discussion around whether breast reconstruction is possible if mastectomy is being recommended. If you are concerned about whether breast surgery should be part of your treatment plan, talk with your oncologist and see what options may be available for you.

If you saw a breast surgeon when you were first being tested for breast cancer, you may like to ask for another referral to have a new discussion around the role of breast surgery for your particular situation.
If you are 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 that you are receiving.

For more information on multidisciplinary care, see Section 2: Treatment and side effects.

If there is concern that the cancer in the breast may cause problems if it is not removed, but surgery is not recommended, an alternative may be radiotherapy to the breast to shrink the cancer and control its growth. This may be something that your oncologist recommends you consider. In this case, you may be referred to a radiation oncologist, who can talk to you about whether radiotherapy may be of benefit to you.

How can I find more information?

The breast care nurse ordered me the My Journey Kit (BCNA’s resource for women with early breast cancer), but by the time it came in the mail, I had been diagnosed with stage IV cancer. I read it cover to cover but none of it applied to me. I just threw it against the wall and cried. – Brenda

Many women tell us that they turned to online information about breast cancer when they were first diagnosed with metastases. It can be overwhelming to know where to start, especially when you have not had a previous experience of breast cancer. If you are going to search online, it may be helpful to first think about how that information might make you feel. If the information you are reading makes you feel distressed, it may be worth asking someone you trust to do the research for you and then explain it to you in a way you can understand.

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 Beware Dr Google: A guide to reliable breast cancer information on the internet, outlines some of the pitfalls around
researching on line. It also provides some information about sites that are reputable and may be of assistance to you.

🔗 You can download it from the website bcna.org.au or phone BCNA on 1800 500 258 and we will send it to you.

**Other ways to find information**

A breast care nurse may be able to help you make sense of all of the information that is being given to you. A breast care nurse is a nurse with specialist knowledge about breast cancer who can provide information, counselling and support, and can 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 women in the lead-up to, and recovery from, breast cancer surgery. Even if you are 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 women with metastatic breast cancer.

You can also contact a breast care nurse directly yourself if there is one working in your local community – you do not 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._

McGrath Foundation has nurses throughout Australia who support women diagnosed with breast cancer, including 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 that you can use to find a breast care nurse in your area – just enter your postcode in the form provided.

🔗 For more information on breast care nurses, see **Section 2: Treatment and side effects.**

You may also find it helpful to regularly see your GP, who can clarify information for you, help with advice and counselling, and refer you
to other health professionals who may be able to assist you, 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 women 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.

*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 if you live rural.*

**Questions to ask**

You are likely to have a lot of questions that you need help answering. It can seem overwhelming at first, but making a list of questions about things that you don’t understand can be really helpful. Think about what is important to you and your family.

When you are first diagnosed it can be difficult for your doctors to have all of the answers you are looking for. Once you start on treatment, the way you respond to treatment can make it easier for your doctors to answer some of the questions you may have.

*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 are first diagnosed with metastatic breast cancer, it is normal to wonder about prognosis and how long you may have to live. Many women have talked to us about the challenges associated with having conversations with their oncologist about expected prognosis, especially in the early days and weeks after you first find out the news that you have metastatic breast cancer.

*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 women with metastatic breast cancer. It is therefore not helpful to base answers on statistics that give a single figure of expected survival times. Statistics do not take into account your individual circumstances or how well you will respond to treatment. Research with women with metastatic breast cancer has shown that it is much more helpful to talk about best case, most likely and worst case scenarios. Everyone is different and will have different needs around what may be helpful to know. Before you talk to your oncologist about your prognosis, you may want to think about how you might manage the information you will receive.

*If you are going to ask about prognosis you have to be ready for the answer that comes. Once you hear a number you can never ‘unhear’ it. It is much more helpful to talk about best case and worst case scenarios and know that many women are living well for long periods of time.* – Ros

If you are struggling with how to best manage your concerns around prognosis, you may find it helpful to talk to someone such as an oncology counsellor or social worker.

Find out more about how to get support from a professional counsellor, see Section 3: Living well.

Talking to others

*Reach out to other women, 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 women have lived for. It gives hope and reinforcement that you can do well too.*

BCNA’s online network has a private group for women with metastatic breast cancer. Some of the women in this group will, like you, have been diagnosed with metastatic breast cancer from the start. If you would like to know more information about how to join the online network, visit the BCNA website at [bcna.org.au](http://bcna.org.au) or phone BCNA on 1800 500 258.
Ask a lot of questions and remember ‘knowledge is power’.

- Judy

Section overview

> Breast cancer drugs
> Glossary of terms
Breast cancer drugs

The table on the following pages lists the drugs most commonly used in the treatment of metastatic breast cancer. It is not a comprehensive list. It does not include a list of all of the drugs that are 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 (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 many different ways. This column shows which routes of administration are used for the different types of medication you may be prescribed:

- 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 (endocrine) therapy

HER2 targeted therapy

Targeted therapy (other than Hormone and HER2 targeted therapies)

Supportive care
<table>
<thead>
<tr>
<th>Drug</th>
<th>Trade name/s (not all may be listed here)</th>
<th>Drug type</th>
<th>Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td>anastrozole</td>
<td>Arimidex, Anastrazole FBM, Anastole, Anastrazole, Anzole, Arianna</td>
<td>Hormone therapy – aromatase inhibitor</td>
<td>Oral</td>
</tr>
<tr>
<td>capecitabine</td>
<td>Xeloda</td>
<td>Chemotherapy</td>
<td>Oral</td>
</tr>
<tr>
<td>carboplatin</td>
<td>Carboplatin</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>cyclophosphamide</td>
<td>Cycloblastin, Endoxan</td>
<td>Chemotherapy</td>
<td>IV or Oral</td>
</tr>
<tr>
<td>denosumab</td>
<td>Xgeva</td>
<td>Biologic agent</td>
<td>SC injection</td>
</tr>
<tr>
<td>docetaxel</td>
<td>Taxotere</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>doxorubicin</td>
<td>Adriamycin, Doxorubicin</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>doxorubicin liposomal</td>
<td>Caelyx, Doxil</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>epirubicin</td>
<td>Pharmorubicin, Ellence</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>eribulin</td>
<td>Halaven</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>Everolimus</td>
<td>Afinitor</td>
<td>Targeted therapy – mTOR Inhibitor** (Hormone+)</td>
<td>Oral</td>
</tr>
<tr>
<td>exemestane</td>
<td>Aromasin, Exaccord, Exemestane</td>
<td>Hormone therapy – aromatase inhibitor</td>
<td>Oral</td>
</tr>
<tr>
<td>fluorouracil</td>
<td>5-FU, Fluorouracil</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>fulvestrant</td>
<td>Faslodex</td>
<td>Hormone therapy</td>
<td>IM injection</td>
</tr>
<tr>
<td>gemcitabine</td>
<td>Gemzar, Gemcitabine, Gemaccord, Gemplan</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>Drug</td>
<td>Trade name/s (not all may be listed here)</td>
<td>Drug type</td>
<td>Administration</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------------------------------</td>
<td>-------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>goserelin</td>
<td>Zoladex</td>
<td>Hormone therapy</td>
<td>SC injection</td>
</tr>
<tr>
<td>mitoxantrone</td>
<td>Novantrone, Onkotrone</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>ibandronate</td>
<td>Bondronat</td>
<td>Bisphosphonate</td>
<td>IV or Oral</td>
</tr>
<tr>
<td>lapatinib</td>
<td>Tykerb</td>
<td>Targeted therapy (HER2+)</td>
<td>Oral</td>
</tr>
<tr>
<td>letrozole</td>
<td>Femara, Letrozole FBM, Letrozole, Femolet, Fera, Letara</td>
<td>Hormone therapy – aromatase inhibitor</td>
<td>Oral</td>
</tr>
<tr>
<td>medroxyprogesterone</td>
<td>Provera, Premia, Ralovera</td>
<td>Hormone therapy – progestin</td>
<td>Oral</td>
</tr>
<tr>
<td>megestrol acetate</td>
<td>Megace</td>
<td>Hormone therapy – progestin</td>
<td>Oral</td>
</tr>
<tr>
<td>Methotrexate</td>
<td>Otrexup, Rasuvo, Rheumatrex, Trexall</td>
<td>Chemotherapy</td>
<td>IV, or Oral</td>
</tr>
<tr>
<td>Mitomycin</td>
<td>Mutamycin</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>nab-paclitaxel</td>
<td>Abraxane</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>*Olaparib</td>
<td>Lynparza</td>
<td>Targeted therapy – PARP Inhibitor*** (BRCA1 / BRCA2 mutations)</td>
<td>Oral</td>
</tr>
<tr>
<td>paclitaxel</td>
<td>Taxol, Anzatax, Paclitaxel, Plaxel</td>
<td>Chemotherapy</td>
<td>IV</td>
</tr>
<tr>
<td>*palbociclib</td>
<td>Ibrance</td>
<td>Targeted Therapy – CDK inhibitor**** (hormone positive)</td>
<td>Oral</td>
</tr>
</tbody>
</table>
**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.

***PARP inhibitors***
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 inhibitor. They are being tested in clinical trials including trials for women with hereditary BRCA1 and BRCA2 mutations who have metastatic breast cancer.

****CDK inhibitors****
Our cells contain pathways that help to control when cells should grow and divide. A group of enzymes involved in these pathways is the cyclin dependent kinases (CDKs). These have been found to be overactive in some breast cancers. A CDK inhibitor is any drug that inhibits the function of CDKs. There are new drugs being developed in this area including palbociclib, abemaciclib and ribociclib that are currently being tested in clinical trials around the world, including Australia.
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 by other means such as laser, cryo or thermal therapy.

**Advanced breast cancer** – another term for metastatic breast cancer.

**Alopecia** – hair loss.

**Alternative therapies** (different to complementary therapies) – 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 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 therapy 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 inhibitor – any drug that blocks 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. There are new drugs being developed in this area that are currently being tested in clinical trials around the world, including Australia.

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 is prolonged (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 to alternative therapies) – 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 that is suspicious for cancer so that it can be sent to pathology for testing. It is performed under a local anaesthetic to numb the breast that is 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 is one of the most accurate ways to diagnose osteopenia (low bone mineral density) and osteoporosis. Women 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 therapies (see Hormone 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 does not have hormone receptors, i.e. the cancer cells do not 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 therapies** – use of drugs to treat women whose breast cancer is hormone receptor positive (ER+ and/or PR+). Common hormone 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 women with metastatic breast cancer in the bone.

**Hypocalcaemia** – a lower than normal level of calcium in the blood. Hypocalcaemia can affect women 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 component’s to a person’s immune system such as man-made immune system proteins. The development of immune therapies for cancer has taken off in recent times, especially in the treatment of melanoma skin cancers. 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 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 in the bone, liver and lungs; and less frequently the brain or other areas of the body.

**Metastatic disease** (also called secondary 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 woman’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 is focused 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, but it can also help with your emotional, spiritual and social concerns. Palliative care is a family-centred model of care. It is 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 inhibitor. They are being tested in clinical trials including trials for women 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 on 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 to cancer, and that of their families and caregivers.

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.