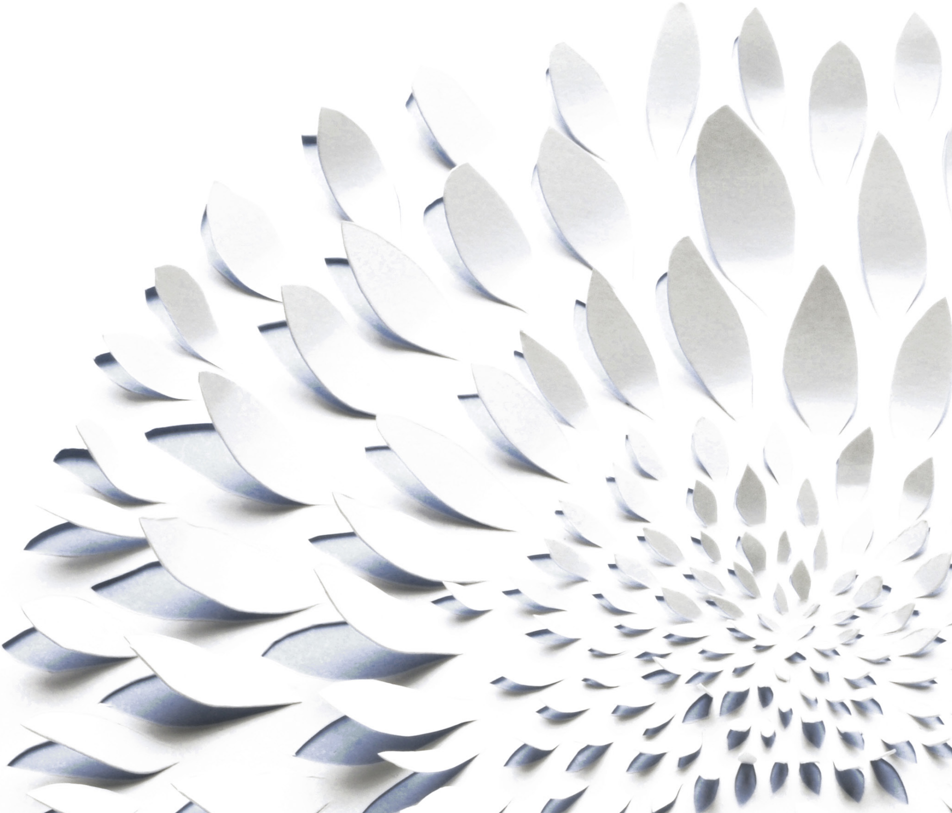
hope &hurdles

Hormone receptor positive metastatic breast cancer



Contents

Introduction

In this booklet you will find information about the treatment recommendations for your subtype of metastatic breast cancer — **Hormone receptor positive metastatic breast cancer.**

> *It has taken me a while to get my head around the diagnosis and the fact that nearly every case is different in its state and treatment options. People need simpler, clearer explanations in the initial diagnosis phase around why their cancer is being treated in a certain way. If we had more personalised information it would go a long way to helping to absorb the facts and come to terms with what is ahead.* — Leanne

There have been significant advances in the treatment of metastatic breast cancer in recent years, due to a deepening understanding of breast cancer biology. 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 the breast cancer subtype and are already making a real difference for many people with metastatic breast cancer. As a result, cancer can be controlled for longer and longer periods, leading to improvements in quality of life.

Subtypes of breast cancer

Three main subtypes of breast cancer have been identified, although in the future it is expected that these will be further divided as understanding of the inner (‘molecular’) workings of each subtype 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:

1. Hormone receptor positive metastatic breast cancer

Hormone receptor (HR) positive cancers have what are called Oestrogen Receptors (ER) and/or Progesterone Receptors (PR) on the surface of the cancer cells. This means that hormones (mainly oestrogen) and hormone blocking treatments can directly influence the activity of these cancer cells via the receptors. When oestrogen attaches, or binds, to the receptors this signals the cell to grow and divide, producing new cells. Hormone treatments work either by attaching to the receptors and blocking oestrogen from binding to them, or by preventing the production of oestrogen in the body. Both of these effects prevent oestrogen from stimulating growth of the cancer cells.

Around 70% of metastatic breast cancers are hormone receptor positive, with 10 per cent of these also being HER2-positive.

2. HER2-positive metastatic breast cancer

HER2-positive cancers have what are called HER2 receptors in excess of normal on the surface of the cancer cells. These receptors allow growth factors to stimulate the growth of the cancer cells. Treatments that block the HER2 receptors prevent this growth stimulation, in turn controlling the cancer.

Around 20% of metastatic breast cancers are HER2-positive. Around half of these cancers are also hormone receptor positive.

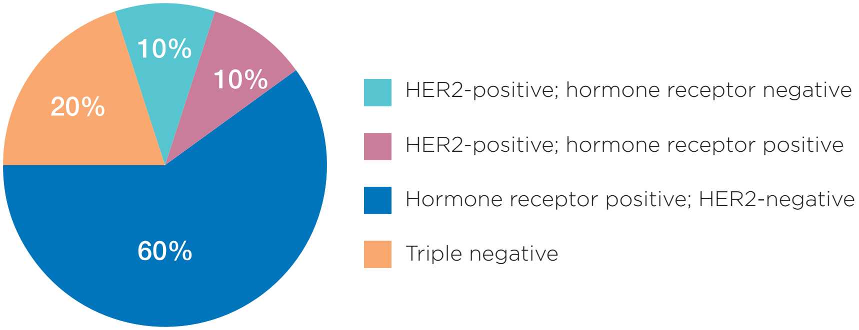
3. Triple negative metastatic breast cancer

Triple negative breast cancers have none of these receptors (oestrogen, progesterone or HER2) on the surface of the cancer cells. This means that they do not respond to treatments that block these receptors. However, they are particularly responsive to chemotherapy, and this is the backbone of treatment for these cancers.

Research is focusing on identifying receptors and other targets in these triple negative breast cancer cells to allow additional treatment options; some of these are just beginning to become available.

Around 20% of metastatic breast cancers are triple negative.

Subtypes of metastatic breast cancer



Identifying the different subtypes of breast cancer

A pathologist will test your breast cancer in the laboratory to determine whether it has hormone receptors and whether it is HER2-positive.

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, however, a biopsy of the metastatic breast cancer will be done to confirm whether the receptor results have remained the same as originally 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, 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 of the *Hope & Hurdles Information Guide.*

Talking with your treating team about the pathology of your 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 about the type of cancer you have.

These booklets are designed to help guide your understanding and help you to think about the questions you can ask your specialists. You are not expected to understand all of the treatment pathways that may be available to you, particularly when you are first diagnosed. Over time you are likely to have a much better understanding of your subtype of metastatic breast cancer. As you read through the information in this booklet you may want to take notes and add them to the back section of this booklet. You can then take those notes along to your specialist to answer your questions.

What does it all mean and how will the subtype of breast cancer influence my prognosis?

One of the first things that people often ask when told the news that their breast cancer has spread is, ‘How long do I have to live?’ You may wonder how the subtype of your breast cancer might influence your prognosis.

It is very common for people who are diagnosed with metastatic breast cancer to be fearful of their prognosis and believe that their lifespan will be very short. Friends and family often want to know about prognosis and ask questions that lead to a lot of stress and anxiety for everyone. Regardless of the subtype of breast cancer, it is often the case that reality is so much better than what people predict for themselves.

Although metastatic breast cancer is not currently considered curable it is very treatable, and for most people it can be controlled for several years. There have been a small number of women whose metastatic breast cancer has been in remission so long, it is thought they may be cured. It is hoped that with increasingly effective treatments in coming years, this will not be such a rare occurrence.

The prognosis in metastatic breast cancer varies widely based on many individual factors and characteristics of the disease. If you wish, an estimate can be made for you based on the details of your case but it is important to remember it is just an estimate. The most useful way to look at a prognosis is to understand what the average is for your situation, as well as the worst and the best case scenarios. Whether (and when) you want to discuss this with your doctor is entirely up to you.

However, it is important that you understand in broad terms what your doctor expects for you, so you are able to be realistic — and in particular not imagine the very worst, as it is quite likely that treatment will control the cancer and help maintain your quality of life for some years.

You may find survival figures quoted for the different subtypes of breast cancer, but such figures are generalisations and will be unlikely to accurately describe your situation.

> *My psychologist advocates to learn to 'live in the moment' which has helped me to enjoy what each new day brings instead of living in fear of what might be taken from me in the future.* — Denise

> *After being diagnosed with metastatic breast cancer, I thought my life was over. But now I see things very differently. I've been living with this diagnosis for over two years now and with the wonderful support of family and friends, my medical team, and the team from BCNA, I'm beginning to accept what I have and move forward a little bit everyday.* — Sonia

Aim of treatment

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

Treatments may include:

- anti-cancer therapies, including:
  - localised treatments, such as radiotherapy and surgery
  - systemic treatments, such as chemotherapy and hormone therapy, which treat the cancer wherever it is in the body
- treatments to control symptoms
- other supportive care measures to improve quality of life.

This booklet focuses only on the systemic anti-cancer treatments that are appropriate for hormone receptor positive metastatic breast cancer.

For more information on **localised cancer treatments**, see BCNA's booklets on the specific sites of metastatic breast cancer.

For information on **symptom management** and supportive care, see the 'Treatment and side effects' section of the *Hope & Hurdles Information Guide*.

Treatment for hormone receptor positive metastatic breast cancer

Treatment will start with hormone therapy given in the form of oral tablets in most cases. Occasionally, if there is concern that your cancer may cause serious problems for you in the near future (for example, if you are having a lot of symptoms from your cancer, have liver metastases, or if your calcium level has been above normal [hypercalcaemia]) you may be advised that a course of chemotherapy be given first to gain control quickly. Following this you will usually be able to proceed with hormone therapies to keep the cancer controlled. Chemotherapy may also play a role in your treatment at different times.

Hormone therapies

Hormone therapies block the effect of oestrogen on cancer cells. There are several different medications that can be used which include:

- Anti-oestrogens: tamoxifen (Tamoxifen), fulvestrant (Faslodex), toremifene (Fareston citrate)
- Aromatase Inhibitors: anastrozole (Arimidex, Anastrozole FBM), letrozole (Femara, Letrozole FBM), exemestane (Aromasin)
- Progestins: medroxyprogesterone acetate (Provera), megestrol (Megace)
- Ovarian suppression or ablation: goserelin (Zoladex)

Once started, each treatment is continued until it is no longer effective, or side effects are sufficiently troublesome to prevent its use. Often a sequence of these treatments is able to control the cancer for a number of years.

There are now also several targeted treatments (see the section on Targeted treatments on page 20) that can be added to extend the length of control by hormone therapies, although only one, everolimus (Afinitor), is available for use in Australia at the time of writing (2017).

Be aware that treatment is individualised. You should ask questions of your medical oncologist if you want to understand why a certain treatment option is being recommended for you.

Which treatment should be used?

This will depend on a number of factors:

- what breast cancer hormone therapies you have taken previously — for instance following an early breast cancer diagnosis
- whether you were still taking a breast cancer hormone therapy when metastatic breast cancer was diagnosed
- whether you are premenopausal — i.e. still having periods or, if you have had a hysterectomy, blood tests show your ovaries to be producing oestrogen
- whether you are postmenopausal — i.e. your periods have stopped and your ovaries are no longer producing oestrogen. If you have had a hysterectomy, you may need a blood test to determine whether you are premenopausal or postmenopausal.

De novo metastatic breast cancer

If your breast cancer was metastatic when you were first diagnosed (de novo metastatic breast cancer), the main factor influencing the choice of hormone therapy is whether you are premenopausal or postmenopausal. If you have been using hormone replacement therapy or a hormonal contraceptive, then this will need to be permanently ceased.

First line hormone therapy

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

Treatment if you are premenopausal

You will most likely be recommended to receive treatment to ‘shut down’ the ovaries (ovarian suppression or ‘ovarian treatment’) and bring on menopause in addition to one of the hormone therapy medications mentioned on page 11.

This ovarian supression can be achieved in one of three ways:

- surgical removal of ovaries (oophorectomy usually performed via keyhole surgery)
- monthly injection under the skin (goserelin [Zoladex])
- radiation treatment to ovaries (this is used infrequently)

The reason to recommend treatment to make you postmenopausal is to take away most of the oestrogen in your body, as hormone receptor positive breast cancer ‘feeds’ on oestrogen. Another reason why this is recommended is because the hormone therapies called Aromatase Inhibitors and fulvestrant are only effective if your ovaries are not producing oestrogen (i.e. you are postmenopausal).

If you undergo oophorectomy or radiation treatment to your ovaries, you will become permanently postmenopausal and your hormone therapy will be as for postmenopausal women.

Goserelin injections result only in a temporary menopause: while you continue the injections you are postmenopausal and can receive hormone therapies suitable for postmenopausal women, but if you cease the injections you may become premenopausal again.

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

Treatment if you are postmenopausal

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

If you were not taking hormone therapy

Aromatase inhibitors are generally the first choice for treatment if you have not received one before, or if it is more than 12 months since you last took one. The reason for this is because they are considered the most effective hormone therapies. Anastrozole and letrozole are considered equivalent and either one may be recommended. Occasionally, tamoxifen will be recommended as an alternative, usually because of a personal preference (yours or your medical oncologist's) or because of concerns regarding possible side effects.

If you were taking an aromatase inhibitor

The three options available include:

- exemestane: although this is also an aromatase inhibitor it has quite a different chemical structure and can work after anastrozole or letrozole has stopped working.
- tamoxifen: this is also a good option, especially if you have never taken it before or it is some years since you were on it. However, if you have had a blood clot (deep vein thrombosis [DVT] or a clot in the lungs [PE]) in the past, it may not be appropriate for you to receive tamoxifen. You should discuss this with your medical oncologist
- fulvestrant: this is rarely used as it is not yet subsidised on the PBS (Pharmaceutical Benefits Scheme that subsidises most medications for breast cancer treatment), but it is an effective option.

If you were taking tamoxifen when metastatic breast cancer was diagnosed

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

If metastatic breast cancer was your first breast cancer diagnosis

If your first breast cancer diagnosis was metastatic breast cancer, the main factor influencing the choice of hormone therapy is whether you are pre- or postmenopausal. If you have been using hormone replacement therapy or a hormonal contraceptive, then this will need to be permanently ceased.

How long can you continue on first line hormone treatment

You will continue to take your first line treatment until it is no longer working, or side effects are troublesome enough that you can't continue it. Usually, you will then be able to go onto an alternative 'second line' hormone therapy.

Second line hormone therapy

If your cancer progresses or treatment side effects are concerning you to the point that they are interfering with your quality of life, your medical oncologist may change you to a different hormone therapy.

Which medication you are recommended will again depend on what you have taken previously.

You will continue on your second line treatment as for first line treatment. It may be possible to offer a third line of hormone treatment once the second line treatment is not effective, and later, sometimes even a fourth line.

Overall, your oncologist will try and continue hormone therapies for as long as possible. It is very likely that you will be treated with most of them over a period of time, usually quite a number of years.

Tests and monitoring

During the time you are on hormone therapy you will be monitored regularly. To begin with you will probably see your medical oncologist about once every month or two. Your doctor will assess how you are getting on at each visit in terms of possible side effects from your medication, and whether the cancer is responding to treatment.

Blood tests: Usually you will have a blood test prior to each appointment which may include tumour marker blood tests (if above normal at the start of therapy). Tumour markers are proteins found in the blood, such as CA15-3 and CEA, which are produced in the body in response to cancer or by the cancer itself. They can be useful in monitoring response to the treatment, although they are not always helpful.

Scans: After two to four months scans will be done to assess the response of the cancer to treatment.

Once it is clear you are doing well on the treatment your doctor may reduce the frequency of visits, blood tests and scans. At each visit you should expect to go away with a plan for when to come back for your next visit, and when your next blood test and scans are to be done. Sometimes, when your cancer has been stable for more than a year, you may not need to see your medical oncologist more often than every four to six months.

Times that additional tests might be needed

It is always important to consider making an earlier appointment to see your medical oncologist if you are not feeling well and especially if you develop symptoms that make you think the cancer is becoming more active again. You might like to see your GP to help decide if you need an early appointment with your oncologist.

Sometimes it can be difficult to determine if your cancer has worsened or progressed, because scans cannot show everything.

Your medical oncologist will base their assessment on a combination of factors:

- how you are feeling generally
- whether you have any specific symptoms
- results of your blood tests, including tumour markers if they are useful in your case
- findings on physical examination
- scans.

If after careful assessment your oncologist considers the cancer has progressed, a new treatment will be recommended.

Side effects of hormone therapies

Most side effects of hormone therapies are menopause symptoms — meaning that they are symptoms that women may experience during menopause. Everyone is different and also each treatment may be different in the side effects it causes. The most common side effects are:

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

Please speak to your doctors or nurses about any side effects you experience as there are often ways to help you. Occasionally you may need to stop a treatment because of side effects.

Further information about side effects of hormone therapies can be found in the **Treatment and side effects** section of the *Hope & Hurdles Information Guide*.

Cancer Australia has produced a new information booklet called *Managing menopause after breast cancer - A guide for women*. This guide contains evidence based information about **managing menopause and its symptoms**. You can order this from canceraustralia.gov.au.

Targeted therapies

Targeted therapies are types of treatments using drugs that identify, and specifically attack, cancer cells while leaving normal cells largely unaffected. As a result, there are often fewer side effects than with chemotherapy.

Targeted therapies work in a variety of ways:

- by blocking the action of growth factors that accelerate the growth of cancer cells.
- by blocking the action of certain enzymes, proteins or other molecules involved in the molecular workings of cancer cells, preventing the growth and spread of cancer cells. CDK inhibitors (e.g. palbociclib) and mTOR inhibitors (e.g. everolimus) are examples of this type of targeted therapy.
- by helping the immune system kill cancer cells.
- by delivering toxic substances directly to cancer cells to kill them without affecting normal cells.

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

One of the challenges of treating hormone receptor positive metastatic breast cancer is that the cancer cells ultimately develop resistance to the hormone therapies.

New targeted therapies for hormone receptor positive metastatic breast cancer

Research is currently investigating a variety of drugs that target and block pathways in cancer cells responsible for this resistance to hormone therapies. As a result of this research there are now newer drugs that, when given in conjunction with hormone therapies, lengthen the duration of cancer control. Over time it is expected that more treatments in this area will be developed.

The next section gives examples of new targeted therapies for hormone receptor positive metastatic breast cancer.

Everolimus (Afinitor). This is an mTOR inhibitor that blocks a molecular pathway in cancer cells that is involved in resistance to hormone therapies. Therefore, when it is given with a hormone therapy, it can overcome the resistance a cancer cell may have developed to hormone therapy and essentially makes hormone therapy effective again. Everolimus, given in combination with the hormone therapy exemestane, has been shown to double the duration of cancer control, i.e. the length of time from starting treatment to progression (worsening) of the cancer is twice as long for people taking the combination of exemestane and everolimus, compared to those taking exemestane alone.

This combination treatment is subsidised by the PBS and may be useful when it appears that resistance to hormone therapy is developing. This treatment is often considered when other hormone therapies are no longer helping and chemotherapy looks like the next choice.

The drawback of everolimus is its possible side effects. These include mouth ulcers, diarrhoea, skin rash, fatigue, nausea, and occasionally pneumonitis (inflammation of the lungs). Unfortunately these side effects are quite frequent and may result in the need to reduce the dose or stop taking everolimus. Some interventions can help with some of the side effects (e.g. a special mouthwash for mouth ulcers containing steroids such as Dexamethesone) and may make it possible to continue. You should discuss any side effects that you experience with your medical oncologist.

Mouth care and everolimus

Everolimus can cause sores in the mouth, mouth ulcers and cold sores if you are prone to them. This can be managed, especially if it is treated early. It is important to look after your mouth, particularly in the first two months of treatment. The following are recommended:

- use a soft toothbrush and mild tasting toothpaste
- allow your toothbrush to air dry and replace it regularly
- frequently rinse your mouth with a bland mouthwash such as sterile water, normal saline or sodium bicarbonate solution
- floss your teeth daily
- avoid products containing alcohol, hydrogen peroxide, iodine and thyme
- drink plenty of water
- use an oral moisturiser (such as Biotene) and keep your lips moisturised
- avoid very cold and very hot foods and foods that are crunchy or spicy.

Let your medical oncologist know if you develop a sore mouth during treatment or have any other concerns.

CDK inhibitors

Our cells contain pathways that help to control when cells should multiply. A group of enzymes involved in this pathway are 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, ribociclib and abemaciclib), which prolonged cancer control in clinical trials when given in conjunction with hormone therapies. However these drugs are not yet available in Australia. It is hoped that TGA approval (making the drug available for sale in Australia) and PBS listing (making it affordable to purchase) of palbociclib will occur in 2017 or 2018. In the meantime, it may be possible to access these medications through clinical trials or through a patient access scheme. Tight eligibility criteria will apply and will be influenced by past treatments you have had, in particular chemotherapy treatments.

These medications generally don't have severe side effects. The most common are reduced appetite, tiredness, nausea, diarrhoea and mouth ulcers, and are usually easily managed and often settle over time. Low white blood counts are common with the drug palbociclib but rarely lead to hospitalisation. Ask your medical oncologist about whether these options might be appropriate for you.

📖 For more information about **the availability of new drugs and how they are listed on the PBS**, see p.58 of the *Hope & Hurdles Information Guide.*

Chemotherapy

When to stop hormone therapy and move to chemotherapy

Most people are much more wary of chemotherapy treatment than hormone therapies and may not even want to change to chemotherapy at all. This is a personal decision, but when the suggestion comes up with your medical oncologist you should think about it carefully. Your oncologist also will be trying to avoid recommending chemotherapy for you for as long as possible, however there will come a time when it will be the best option.

Chemotherapy will be considered in the following situations:

- when it appears that hormone therapy options are exhausted — i.e. they are no longer controlling the cancer
- if the cancer is causing troublesome symptoms — a course of chemotherapy may be recommended; sometimes it may be possible to return to hormone therapies again afterwards
- if there are concerns regarding metastases in the organs (e.g. lungs or liver) or if you develop hypercalcaemia (high calcium levels in the blood).

For most people with hormone receptor positive metastatic breast cancer, chemotherapy will be an option at some point. Whether you proceed with chemotherapy will be your decision. You will also need to be medically well enough. There are at least ten different chemotherapy drugs that may be effective in hormone receptor positive metastatic breast cancer. It is most common to use these treatments individually, as single agents, although occasionally two may be used together in combination.

Overall scheme of chemotherapy treatment

An initial course of chemotherapy will be recommended. The chemotherapy is given in cycles of three to four weeks, or in other schedules such as every two out of three weeks. How frequently it will be given will depend on the drug/s used. Treatment will continue until it is determined that it is either causing excessive side effects or it is no longer controlling the cancer. Usually between four and eight cycles of treatment (4-6 months) are given to make up a single course (line) of treatment.

You may be able to have a break from chemotherapy when a course of treatment is completed. Sometimes a hormone therapy can be tried next, although it may be necessary to start another chemotherapy treatment. Either way you will be recommended to proceed with a new course (line) of treatment when it is clear that the cancer is active and worsening in terms of symptoms, scans or findings on physical examination. This next course of treatment will proceed just as for first line treatment. Subsequently, when the cancer is no longer responding, you may proceed to other types of chemotherapy as considered appropriate by your medical oncologist and you. Decisions will depend on how well the cancer responds to treatment, how well you tolerate the treatment and, importantly, your wishes about treatment.

It may be appropriate for you to receive further hormone therapy between lines of chemotherapy if you still have hormone therapy options available.

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

Tests and monitoring during chemotherapy treatment

Monitoring: Throughout your treatment you will be monitored carefully, and will have regular appointments with your medical oncologist. When you are receiving chemotherapy, you will see your medical oncologist before each cycle of chemotherapy (usually every three or four weeks depending on the chemotherapy schedule). Your doctor will assess how you are getting on at each visit in terms of how you are coping with the chemotherapy, any side effects you are experiencing , and whether the cancer is responding to the treatment. Sometimes at these visits your doctor may recommend a change in chemotherapy dose, a change in medication to control side effects, a break in treatment to help with side effects, or a change in chemotherapy if it is causing you excessive side effects or if it is not working. You can also discuss with your doctor having a rest from treatment for a while, or a break if you have a holiday or special event planned.

> *I have given myself permission to take a break from treatment. I have finally acknowledged that it is going to be ok to take that break; that my oncologist is right, my cancer won't get worse and I can have a rest for a while.*
> — Wendy

The types of test you may have include:

Blood tests: You will have regular blood tests to check your blood count levels (white blood cells that help fight infection, red blood cells that carry oxygen and platelets for clotting), liver function and kidney function.

Tumour marker blood tests: (if above normal) will also be monitered. Tumour markers are proteins found in the blood, such as CA 15-3 and CEA, which are produced in the body in response to cancer or by the cancer itself. They can be useful in monitoring response to the treatment, although they are not always helpful.

Scans: such as CT scans and bone scans will be done every two to three cycles to help assess the response of the cancer to treatment.

Length of the chemotherapy course

How long you continue with a chemotherapy course depends on:

- how well it is controlling the cancer
- how well you are coping with side effects
- whether there are side effects that might cause longer term problems e.g. nerve ending damage
- how you are feeling about continuing the course
- whether there are any specific commitments you have — such as a planned holiday etc.

In other words, it is a very open-ended decision and involves some discussion between yourself and your medical oncologist. Generally, however, as long as the cancer is responding to treatment and side effects are acceptable, aiming for six cycles of treatment in the first instance is appropriate. Although there is evidence that longer duration of treatment can prolong the benefit of treatment, it is important not to continue in the face of side effects that are interfering with your ability to live well. Treatments, especially oral ones, can sometimes be continued for longer periods (12 months and more) with prolonged cancer control and have the added benefit of avoiding many hospital visits for IV drip treatments.

Side effects of chemotherapy

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

All chemotherapy treatments affect your blood counts making you more susceptible to infection. It is very important that you seek urgent medical attention for signs of infection, especially a temperature over 38°C.

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

Please also see the **Treatment and side effects** section of the *Hope & Hurdles Information Guide.*

Factors that influence which chemotherapy is recommended

There is no definite right and wrong about which chemotherapy to receive or when. It is expected that most people with metastatic breast cancer will receive a sequence of treatments as described on page 25 and your medical oncologist will work with you regarding the best choice of treatment for you at any given time. It is quite common to find, when talking with other women who have a similar diagnosis to you, that they have received a very different chemotherapy treatment. However there are some guiding principles and government regulations that influence choices. Your oncologist is the best person to discuss this with.

Making a decision to cease chemotherapy altogether

Provided chemotherapy is working well for you and you are coping okay with it, it is reasonable to continue to have successive lines of treatment. Some people may have more than six lines of treatment.

However, what is appropriate is very individual. Although stopping chemotherapy and other active treatment is a big decision, it is important that you feel free to have this discussion with your medical oncologist, and your family if that is important to you, and make this decision when it feels right for you.

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

Role of clinical trials

With the focus on developing new targeted treatments for hormone receptor positive metastatic breast cancer, you may have the opportunity to enrol in a clinical trial. Some chemotherapy trials may also be appropriate. Whether to participate in a clinical trial is an individual decision, and it is important that you understand the benefits and risks involved as well as the required time and practical commitments before making a decision.

Your participation in research will certainly benefit future patients with metastatic breast cancer, and although participation may benefit you personally, (including longer survival), this is not always the case. However, patients on clinical trials are monitored very carefully, so any risk to you is minimised, and there is research that suggests that just participating in a clinical trial results in improved outcomes for the individuals involved. Your medical oncologist would not offer you trial enrolment if they did not think this could be of value to you.

For more information on **clinical trials** see page 58 of the *Hope & Hurdles Information Guide*.

More information

Metastatic breast cancer is a complex disease and there is no single standard of care. Every woman's experience is different, meaning treatment is individualised based on multiple factors. A big part of treatment decision-making will be the type of breast cancer that you have and the ability to be prescribed treatments that target specific features of that cancer. Many other factors will influence treatment decision making including your personal preferences, your life stage and general health and wellbeing.

This booklet has been developed to give you specific information about medical treatment that your medical oncologist will discuss with you. We know that many other health professionals and supporters in your life will also be important to how you manage your cancer.

📖 For more information on **practical, emotional and financial supports** available, refer to BCNA's *Hope & Hurdles Information Guide*.

You can order a copy online from bcna.org.au or phone **1800 500 258**.

Notes

Notes

More information

More information is available in the *Hope & Hurdles Information Guide* and in the *Hope & Hurdles* booklets:

- *Metastatic breast cancer in the bone*
- *Metastatic breast cancer in the liver*
- *Metastatic breast cancer in the lung*
- *Metastatic breast cancer in the brain*
- *HER2-positive metastatic breast cancer*
- *Triple negative metastatic breast cancer*
- *Planning ahead (formerly called Getting your affairs in order)*

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This booklet was developed by Associate Professor Jacquie Chirgwin in collaboration with BCNA, women living with metastatic breast cancer and the *Hope & Hurdles* Advisory Group.

About 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 that people diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible.

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