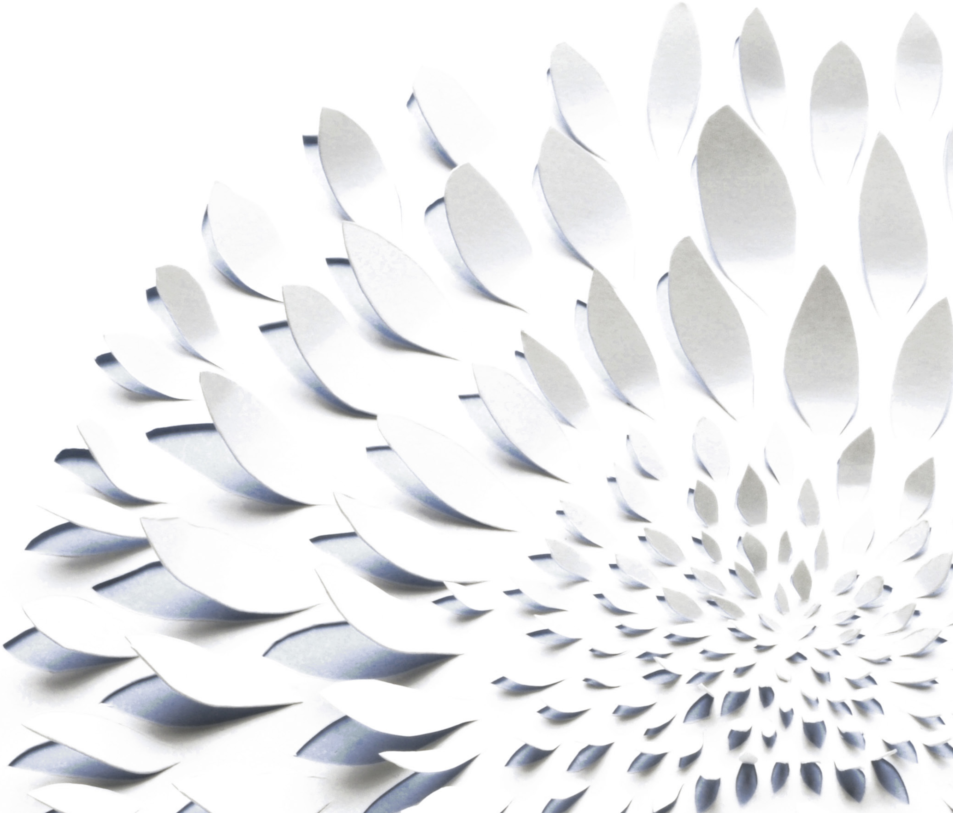
hope &hurdles

HER2-positive metastatic breast cancer



Contents

Introduction

In this booklet you will find information about the treatment recommendations for your subtype of metastatic breast cancer — **HER2-positive metastatic breast cancer**. It also has information for people whose breast cancer is hormone receptor positive as well as HER2-positive.

> *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

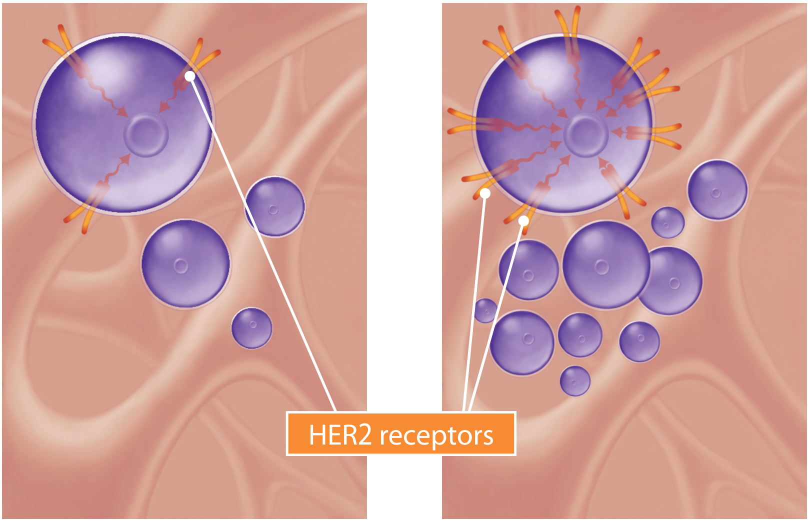
Hormone receptor (HR) positive cancers have what are called Oestrogen Receptors (ER) and/or Progesterone Receptors (PR) on the surface of the cancer cells. This means that hormones (mainly oestrogen) and hormone blocking treatments can directly influence the activity of these cancer cells via the receptors. 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.



Normal breast cells

HER2-positive breast cancer cells

In normal breast cells, HER2 receptors send signals telling cells to grow and divide at a normal rate.

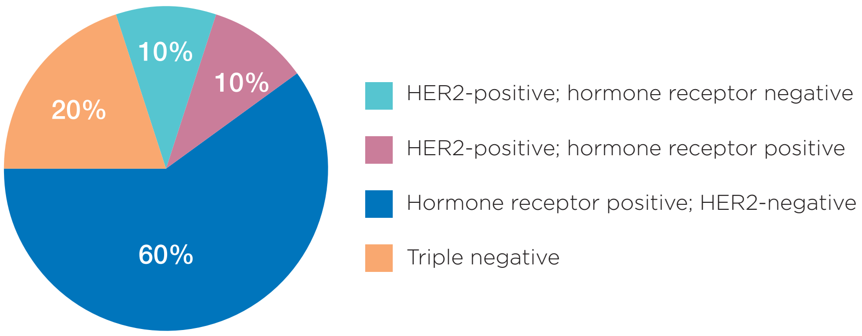
In some breast cancers, higher than normal number of HER2 receptors send many signals causing the cells to grow and divide at a faster rate than normal.

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 new targeted treatments that are being tested in clinical trials, 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 HER2-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 HER2-positive metastatic breast cancer

The backbone of treatment for HER2-positive metastatic breast cancer is ‘anti-HER2’ treatment. This includes drugs such as:

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

Anti-HER2 treatment targets the HER2 receptors on the surface of breast cancer cells, which blocks growth factor signals normally transmitted by these receptors, which in turn prevents the cancer from growing. Anti-HER2 treatment works best when combined with chemotherapy, although once the cancer is controlled, continuing the anti-HER2 treatment alone can keep the cancer under control for long periods of time — often for years. Provided anti-HER2 treatment is well tolerated, it will be continued long term. This is further explained in the section on page 22, *Can anti-HER2 treatment be stopped?*

Approximately half of HER2-positive metastatic breast cancer cases are also hormone receptor positive. This is sometimes called ‘Triple Positive’ metastatic breast cancer. If your cancer is triple positive, hormone therapies will be recommended in addition to the anti-HER2 treatment and chemotherapy, although not in combination with chemotherapy. Please see page 24 of this booklet for more information about how hormone therapies may be used in your treatment if you have HER2-positive and hormone receptor positive metastatic breast cancer.

Initial treatment

An initial course of anti-HER2 treatment plus chemotherapy will be recommended for people with HER2-positive metastatic breast cancer. This is called ‘first line’ treatment, which will usually start within a few weeks of the diagnosis of metastatic breast cancer. It may be delayed a short time if radiotherapy or surgery is needed. The anti-HER2 treatment is usually given every three weeks and the chemotherapy is given in cycles of three to four weeks, depending on the drug(s) used. This will continue until it is either causing excessive side effects or it is thought to be no longer beneficial in terms of controlling the cancer. Usually between four and eight cycles of chemotherapy are given to make up a single course of treatment.

At this point, provided the cancer is under good control, the anti-HER2 treatment will be continued without further chemotherapy.

When treatment might change (second and subsequent lines)

If the cancer stops responding to treatment, or new cancer is found (the cancer progresses), a change in treatment will be required. This will be ‘second line’ treatment. Which treatments are recommended will depend on several factors, including what treatments you have already received. However, anti-HER2 treatment will be continued.

Further changes in treatment will be considered each time the cancer progresses; you may proceed to third, fourth, fifth line treatments. However, the backbone of anti-HER2 treatment is always continued where possible and will be partnered by different chemotherapy or hormone treatments (if triple positive) 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.

In summary, you will receive a sequence of treatments over time, each adding a period of cancer control (see page 15). Where possible, you will have chemotherapy-free periods between different treatments, although anti-HER2 treatment will continue throughout. The choice of chemotherapy courses will take possible side effects into account.

How anti-HER2 treatments are given

Trastuzumab is given every three weeks either intravenously or as a subcutaneous (under the skin) injection. Pertuzumab and TDM-1 are given intravenously every three weeks. All will be given at the oncology day unit in the hospital or in some centres via a hospital in the home service. Lapatinib is an oral treatment taken daily on a continuous basis.

The ‘standard’ treatment recommendations are as follows:

First line treatment

trastuzumab + pertuzumab + taxane chemotherapy (paclitaxel or docetaxel). The chemotherapy is usually only given for approximately 6 cycles, with anti-HER2 treatment (trastuzumab and pertuzumab) continuing until the cancer progresses (grows again). This may be many years for some women.

Second line treatment

trastuzumab emtansine (TDM-1). TDM-1 is trastuzumab with a chemotherapy (emtansine) attached to it which is delivered very specifically to the cancer cells in conjunction with the trastuzumab. No additional chemotherapy needs to be given with it. It is continued until the cancer progresses. Again this may be many years for some women.

Later lines of treatment

There are a number of further treatments that will be given in sequence as considered appropriate. These include lapatinib (oral anti-HER2 treatment) plus capecitabine (oral chemotherapy) and trastuzumab plus chemotherapy. Various different trastuzumab plus chemotherapy combinations are effective.

Tests and monitoring

Throughout your treatment you will be monitored carefully and will have regular appointments with your medical oncologist. When you are receiving chemotherapy, monitoring will be more intense. You will see your medical oncologist before each cycle of chemotherapy (every three or four weeks depending on the chemotherapy course). 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
- 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.

During breaks, it is usual to continue the anti-HER2 treatment if possible. If you are planning a trip it is often possible to arrange to have the anti-HER2 treatment at another oncology centre (even internationally).

> *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

Checking the effects on your heart

Anti-HER2 treatments can occasionally weaken the heart muscle. For this reason your heart function will be checked regularly.

There are two ways of checking the heart function:

- Echocardiogram: this is an ultrasound of the heart, usually done in the cardiology department.
- Gated Blood Pool Scan: this is a nuclear medicine scan and requires an intravenous injection of contrast. It is done in the radiology department.

The first heart test will be done prior to starting anti-HER2 treatment. It will then be done every three months. Once you have been stable with these tests for more than a year, it may be possible to reduce the frequency of the tests. Your medical oncologist will discuss this with you.

Tests during periods of time when chemotherapy is given with HER2 therapy

Blood tests will usually be done every few weeks when you are receiving chemotherapy 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 at the start of therapy) will usually be done with each cycle. 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 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.

Test during periods of time when HER2 therapy is given without chemotherapy

During the periods of time when you are receiving only anti-HER2 therapy (and no chemotherapy) it is likely that your health will be very stable and you will require less frequent tests and visits to your medical oncologist. Appointments might be spaced every 6-12 weeks, with a blood test. Scans to check how well the cancer is controlled will be done regularly, but also may be able to be spaced quite far apart — perhaps even six monthly. Some people do extremely well on these treatments and remain stable for years — then perhaps a yearly scan may be sufficient.

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.

Assessing how well treatment is working

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 and scans.

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

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 feel about continuing with chemotherapy
- whether there are any specific commitments you have — such as a planned holiday or special event.

In other words, it is a very open-ended decision and involves some discussion between you and your medical oncologist.

Generally, however, as long as the cancer is responding to treatment, aiming for six cycles of treatment is appropriate. Sometimes it may be worth continuing the chemotherapy for longer than this, but as the anti-HER2 treatment will be ongoing, this may be enough to keep the cancer controlled without the need for further chemotherapy for some time.

If you do continue chemotherapy for longer, it is important not to do so in the face of side effects that interfere with your ability to live well. However, some chemotherapies, especially oral ones can, at times, be continued for long periods (12 months and more) with good cancer control.

Factors that influence which chemotherapy treatment is recommended

The treatment of HER2-positive metastatic breast cancer is quite complex and depends on many individual factors. It is expected that most people with HER2-positive metastatic breast cancer will receive a sequence of treatments (as described on page 12) and your medical oncologist will work with you regarding the best choice of treatment for you at any given time. You may talk with other women who have a similar diagnosis to you but may have received a different pattern of treatment. Different oncologists will have different treatment preferences. There are however some guiding principles and government regulations that influence choices. Your oncologist is the best person to discuss this with.

The main factors that influence treatment options are:

- Pharmaceutical Benefits Scheme (PBS) regulations. The PBS is the Australian Government scheme which subsidises the cost of most drugs used in the treatment of metastatic breast cancer. The rules are very strict regarding the use of anti-HER2 treatments, including what order they can be given in.
- Previous treatment you have received:
  - If metastatic breast cancer was your first breast cancer diagnosis, or if any anti-HER2 treatment you received for early breast cancer was given more than 12 months ago, you will be recommended ‘standard’ treatment, starting with first line treatment (see page 15).
  - If you have received anti-HER2 treatment for early breast cancer within the previous 12 months, you will be recommended to receive treatment as per the standard recommendations, but starting from the second listed treatment (TDM-1).

Several other factors will be considered in determining treatment choices:

- choice of chemotherapy will take into consideration ongoing side effects from previous treatment, such as nerve ending damage, skin problems, effects on the heart etc.
- your preference for oral or intravenous chemotherapy and any opinions you have about other side effects such as hair loss

- your heart function
- whether you have brain metastases – lapatinib plus capecitabine may be a good option in this situation.

Can anti-HER2 treatments be stopped?

Anti-HER2 treatments may need to be stopped for a while if the heart function is affected. However, this is usually only temporarily as medication is usually able to bring the heart function back to normal. There are very few other side effects of anti-HER2 treatment that would lead to the treatment having to be stopped.

How long can anti-HER2 treatment be given for?

There are some women who have taken anti-HER2 treatment (trastuzumab) for a number of years, without any progression of their cancer. In this situation there may come a time when a woman and her oncologist might have a discussion around whether anti-HER2 treatment needs to be continued. There are some women who have stopped trastuzumab after three to five years of treatment for metastatic breast cancer who have not had further relapse after several further years of follow up. However, whether it is safe to do this is currently unknown. There is currently no research to guide duration of trastuzamab therapy in people who are disease free after many years of treatment.

As a general rule, it is therefore likely that you will be strongly encouraged to continue your anti-HER2 therapy without any major breaks, long term or indefinitely. The concern is that stopping the treatment 'takes the brakes off' and could let the cancer's growth accelerate.

Side effects of anti-HER2 treatments

- Generally anti-HER2 treatments do not result in many day-to-day side effects. They may be associated with increased fatigue, headaches and skin rashes and, occasionally, reduced heart function.
- Trastuzumab emtansine sometimes causes abnormalities in liver function and reduction in platelets (blood cells responsible for clotting).
- Lapatinib is associated with more side effects than the other anti-HER2 treatments. These include diarrhoea, nausea, mouth ulcers and troublesome skin rashes.

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*.

If your breast cancer is also hormone receptor positive

This information is for people with breast cancer that is both HER2-positive and hormone receptor positive. The information in this section is not relevant if your cancer is hormone receptor negative.

Hormone therapies

If your cancer is hormone receptor positive, hormone therapies will usually be included as part of your treatment, although the anti-HER2 treatments and chemotherapy will be the most effective part of your treatment. Hormone therapies are most often used in conjunction with trastuzumab, between courses of chemotherapy and usually NOT in combination with chemotherapy.

Hormone therapies block the effect of oestrogen on the 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), letrozole (Femara), exemestane (Aromasin)
- Progestins: medroxyprogesterone acetate (Provera), megestrol (Megace)
- Ovarian suppression: goserelin (Zoladex)

Each treatment chosen is continued until it is no longer effective or side effects are sufficiently troublesome to prevent its use. A sequence of these treatments can be used in conjunction with trastuzumab, between different chemotherapy treatments.

Treatment used 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. The chemotherapy you have already received for your breast cancer may have stopped your ovaries from working although the ovarian function may recover with time, so a regular check of your

hormone levels may be needed until it is clear that you have become permanently postmenopausal.

- 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.

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. Every woman is different and also each treatment may be different in the side effects it causes. The most common side effects include:

- 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 chemotherapy 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.

Hormone therapy options

This section is for those who are interested to further understand the hormone therapy options available and which treatments are appropriate in different situations. If you want to know more about any of the treatments listed here, or if you have additional questions, talk to your medical oncologist.

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 is called ‘first line’ hormone 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 25.

This ovarian treatment 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 will become premenopausal again.

Sometimes, if your cancer is very slow growing and causing minimal problems for you, you may not require ovarian suppression. Usually you would be offered tamoxifen, although occasionally the drug 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 are:

- 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 in the past, such as deep vein thrombosis or a clot in the lungs, it may not be appropriate for you to receive tamoxifen. You should discuss this with your medical oncologist

- fulvestrant: this is less commonly used as it is not 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

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 hormone treatment until the cancer progresses, or side effects are troublesome enough that you can't continue it. Usually, you will 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 of hormone therapy treatment as for first line treatment. It may be possible to offer a third line of 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 in combination with your anti-HER2 therapy. It is very likely that you will be treated with most of them over a period of time — usually quite a number of years.

Role of clinical trials

New targeted treatments are being developed for HER2-positive metastatic breast cancer so you may have the opportunity to enrol in a clinical trial. 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, 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*.

Making a decision to stop treatment altogether

Provided treatment is working well for you and you are coping with it, it is not unreasonable 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 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. Sometimes, it might be appropriate to stop chemotherapy and hormonal therapy but to continue anti-HER2 treatments.

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 subtype 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

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*
- *Hormone receptor positive metastatic breast cancer*
- *Triple negative metastatic breast cancer*
- *Planning ahead (formerly called Getting your affairs in order)*

hope
&hurdles

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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.

Breast
Cancer
Network
Australia

bcna.org.au
1800 500 258
beacon@bcna.org.au