

Metastatic breast cance in the bone



I believe in the old saying 'one day at a time', which is really all anybody can live by. Since I was diagnosed with metastatic breast cancer in my bones, over two and a half years ago, my cancer has been pretty stable and I am getting on with life and living well. – Sylvia

This booklet is for people who have been diagnosed with metastatic breast cancer in the bone (also called bone metastases). It is designed to be read in conjunction with the *Information Guide* included in *Hope & Hurdles* and the systemic treatment booklet relevant to your 'subtype' of breast cancer. The three subtypes of breast cancer described are hormone receptor positive (with oestrogen and/or progesterone receptors), HER2-positive (with over-expression of HER2 receptors) and triple negative (none of these receptors present).

If you have been diagnosed with metastatic breast cancer in the bone, it means that breast cancer cells have travelled from the original cancer in your breast to one or more sites in your bones. These cancer deposits are called bone metastases or bone secondaries. This is not the same as having cancer that starts in the bone. Bone is the most common site for metastases; other sites can include the lungs, liver and, less frequently, the brain. Booklets on these types of metastatic breast cancer are also available as part of *Hope & Hurdles* (see back cover).

The diagram opposite shows breast cancer that has spread from the breast to the bone (figure 1).

When metastatic breast cancer spreads to the bone, it is most commonly found in the spine, skull, pelvis and upper bones of the arms and legs.

Metastatic breast cancer in the bone can be treated and may be controlled for long periods of time. While it can't be cured, many people with bone metastases live for many years and enjoy a good quality of life.



What happens in the bones?

Bone contains two types of living cells, osteoclasts and osteoblasts, as well as calcium, other minerals and proteins. Within the bone centre is the bone marrow, where blood cells are made.

Osteoclasts destroy and remove small amounts of old or damaged bone and osteoblasts build new bone to replace it. In healthy bone,

these two activities are in balance and our bones are constantly being broken down and rebuilt.

In metastatic breast cancer, the cancer cells that have spread to the bone produce chemicals that disrupt the balance between the osteoclasts and osteoblasts. There are two types of metastases that affect bones: osteolytic tumours break down bone and can create holes, while osteoblastic tumours cause new bone to form abnormally. Both leave the bone weak and fragile.

Cancer cells may also fill up the bone marrow, making it harder for blood cells to be made in good numbers (figure 2). This can lead to low blood counts (red blood cells, white blood cells and platelets, which stop bleeding). Once treatment starts to be effective and the amount of cancer filling up the marrow decreases, blood counts can start to return to normal.



Symptoms of bone metastases

Symptoms vary depending on the location and size of the metastases. You may experience one or more of the following symptoms or none at all.

Bone pain

Often, the first symptom of bone metastases is bone pain. It can be difficult to know what is causing pain as it could be muscular or the result of arthritis. However, pain from cancer in the bone commonly develops into a constant ache which may be worse when you are active. It generally doesn't go away at night, so you could find it difficult to sleep.

Fracture (broken bone)

Cancer in the bone can erode and weaken bones and cause them to fracture or break. This will often cause a sudden, severe pain at the site of the break.

Numbness or weakness in the legs

This can be a sign that there is cancer in the vertebrae of the spine that is pressing on a nerve or the spinal cord.

Bladder weakness

Problems passing urine, such as difficulty controlling your bladder, passing very little urine or passing none at all, could also be an indication that there is cancer in the vertebrae of the spine, which is pressing on a nerve or the spinal cord.

Changes in blood cells

Low red cells (anaemia), low white cells (infection fighting) or platelets (bleeding) may be picked up on a blood test if the bone marrow is affected.

High levels of calcium in the blood

This is called hypercalcaemia and may be associated with bone metastases. Symptoms of hypercalcaemia may include loss of appetite, nausea, constipation, increased thirst and frequent urination, and confusion. For further details see page 21.

Diagnosing bone metastases

If you develop any symptoms of metastatic breast cancer in the bone, your doctor will carry out a physical examination and may order tests to determine whether the breast cancer has spread to one or more bones.

The tests will depend on your symptoms and the bones involved and they may include the following.

X-ray

This is painless, takes only a few minutes and does not require any pre-test injections. It is not the most sensitive test for picking up bone metastases but is useful for detecting fractures.

Bone scan

This is a more sensitive test for bone metastases. A bone scan scans all your bones. Prior to the scan, a small amount of radioactive material is injected into a vein, usually in the arm. The scan is taken two to three hours later when the radioactive material has had time to circulate through your body and be taken up by the bone cells (osteoblasts). There will be increased uptake of the radioactive material where the bone is damaged and the osteoblasts are more active. These will show as 'hot spots' on the scan (figure 3).



Damage to bones (from cancer or other causes) shows up as dark 'hot spots' on a bone scan.

Hot spots are caused by any damage to the bone, including old or new fractures and arthritis as well as cancer.

The pattern of hot spots can give a good indication of the cause but other tests may be needed to clarify this.

After treatment begins, bone scans can look worse ('flare') before they look better, due to an increase in osteoblast activity as part of the healing response. If other factors suggest improvement (pain improving, tumour markers improving) your doctor may suggest deferring the first follow up bone scan for six months or so.

CT/CAT scan

Computerised tomography (CT) combines X-rays with sophisticated computer imagery to provide a cross-sectional image or images of the area being studied. Sometimes a contrast material may be injected into a vein, usually in the arm, to help show any cancer deposits more clearly. Let your doctor know if you are allergic to iodine or seafood. The scan itself is painless but the contrast material may cause you to feel hot or flushed and you need to lie very still for approximately 30 minutes.

PET scan

Positron emission tomography (PET) uses the detection of gamma rays (radioactive waves similar to those used in bone scans) to create a three-dimensional picture of your body. You will require an injection of radioactive material 90 minutes before the scan.

The scanning takes approximately 30 minutes and is painless. PET scans are not routinely used to look for bone metastases and are not usually covered by Medicare. They are sometimes useful for distinguishing a fracture from a metastasis, and monitoring response to treatment.

MRI scan

Magnetic resonance imaging (MRI) uses magnetic waves to scan areas of your body. An MRI is not painful but it does require you to lie still in a cylinder for 30-45 minutes. Let your doctor know if you have claustrophobia so that you can discuss whether it may be helpful for you to have some sedation. You may be given an intravenous injection of contrast material prior to the scan to help show any cancer deposits more clearly. Your kidney function will be checked through a blood test arranged by your oncologist before deciding if the contrast can be given. The MRI machine is noisy and you may be given headphones to wear while you're having your scan. You may be able to take your own music if you prefer. MRI is not performed if you have any metal in your body, for instance some cardiac pacemakers or a breast tissue expander with a magnetic port. This scan is most often used if it is suspected that the cancer in the bones is pressing on a nerve or the spinal cord.

Bone biopsy

If cancer is found in one or more of your bones, a biopsy may be used to confirm the pathology. A biopsy can determine whether the abnormality is due to a metastasis from breast cancer or another cause. It is also useful for your doctor to re-check the receptors (ER, PR and HER2) as these can be different from your primary breast cancer and they're important in determining the best treatments for you. Biopsies are performed under local anaesthetic using either ultrasound or a CT scan for guidance.

Blood tests

Blood tests will assess the red cells, white cells and platelets which are made in the bone marrow. If you have a metastasis in your bone, serum alkaline phosphatase may be elevated. This may be an indication of bone damage from the cancer (it can also be elevated with liver conditions and when there are other reasons for bone damage). Calcium levels may also be elevated (hypercalcaemia) when there are bone metastases and should be checked regularly. As adequate levels of vitamin D can optimise bone health, these may also be checked.

Tumour markers

Tumour markers are substances, usually proteins such as CA15-3 and CEA, which are produced by the body in response to cancer or by the cancer tissue itself. If the levels are higher than normal, this can help to determine whether metastases are present. However, they are most frequently used to determine whether or not the cancer is responding to treatment. It is important to remember that tumour markers are not always reliable – for example, your tumour markers may increase even though there is other evidence that the cancer is responding – and some breast cancers do not produce tumour markers at all. Some medical oncologists don't check tumour markers for this reason. Others use them as just one of a number of measures to help determine whether the cancer is responding to treatment.

Other tests

The presence of metastases in the bone indicates that the breast cancer has spread from your breast into your body via the blood stream. Other organs may also be affected, so your doctor will recommend other tests. These tests are called 'staging' tests and will provide a more accurate picture of the extent of spread of the cancer so that treatment recommendations can be made. The number and type of tests advised will depend on your symptoms, the results of a clinical examination and your general health and wellbeing.

Treating metastatic breast cancer

The overall aim of treatment for metastatic breast cancer is to control the cancer for as long as possible and ensure the best possible quality of life with control of symptoms. This is done by regularly assessing the activity of the cancer and any problems it is causing, and treating accordingly. This means you may require regular blood tests and scans.

Anti-cancer treatments are generally used in sequence, sometimes with breaks between them when no treatment is required. For instance, for women with hormone positive breast cancer (ER+ and/or PR+), hormone treatments are used until they are no longer working and then a new treatment, often a different hormone treatment, is used.

Chemotherapy may be given for a short period of weeks to months, or continued indefinitely until the cancer starts to grow again. Tablet based (oral) chemotherapies may also be an option. Ongoing chemotherapy needs to be balanced against the side effects of treatment; if you have a problem with side effects, or have a special occasion or holiday coming up, you may be able to take a break from treatment.

For information about taking a break from treatment, see the 'Treatment and side effects' section of the *Hope & Hurdles Information Guide*.

Treating metastatic breast cancer in the bone

Treatments for bone metastases are often very effective at stopping the growth and/or decreasing the size of the cancer deposits in the bones. The treatments recommended for you will depend on:

- which bones are affected
- whether they have been weakened and are either in danger of breaking or have already broken
- the pathology of the cancer (for instance, whether it is ER, PR, or HER2 receptor positive)
- the treatments you have had in the past
- your general health
- your personal preferences.

Your treatment may be managed by a multidisciplinary team and you will probably see a number of different health professionals at different times. These could include any or all of the following:

- medical oncologist
- radiation oncologist
- palliative care physician
- GP
- oncology nurse or breast care nurse
- psychologist
- social worker
- allied health practitioners, such as a physiotherapist or occupational therapist.

Other health professionals who may be involved in your care include:

- an orthopaedic surgeon if there is a fracture or risk of fracture
- a neurologist or neurosurgeon if cancer in the vertebrae is pressing on a nerve.

Your dentist should also play an important role by helping maintain the health of your teeth, gums and jaw. This is particularly important if you are treated with bone strengthening treatments such as bisphosphonates or denosumab (see page 14).

Treatment for metastatic breast cancer in the bone can help to relieve symptoms, especially pain; heal bone damaged by metastases; delay the progression of the bone metastases; and prevent complications such as bone fractures and hypercalcaemia.

There are three types of treatment for bone metastases.

- systemic treatment, which treats the whole body, e.g. chemotherapy and hormone therapy
- bone strengthening treatment (bisphosphonates or denosumab)
- local treatment, which treats a single bone or part of the body, e.g. radiotherapy.

Systemic treatment

Treatment will depend on which drugs have been used previously, including when you were first treated for breast cancer, and whether your cancer is hormone receptor positive and/or HER2-positive, or triple negative. It will also be influenced by the extent of the bone metastases and whether other parts of your body are also affected by metastatic breast cancer. Generally, if the cancer is hormone receptor positive and not causing a lot of symptoms or affecting vital organs such as the liver, it may be possible to use hormone treatment. Where the cancer is causing more significant problems and other organs are also affected, chemotherapy may be the best approach. Systemic treatments recommended for you will depend on the type of breast cancer you have. These include hormone therapies, chemotherapy and targeted therapies. For information on systemic treatments see the *Hope & Hurdles* booklet on your on the subtype of breast cancer (hormone receptor positive, HER2-positive, triple negative).

Bone strengthening treatment

Bisphosphonates

Bisphosphonates reduce the breakdown of bone and also strengthen bone, reducing bone pain and the risk of fracture and also correct or prevent hypercalcaemia. These drugs may also act directly on the cancer cells. An example of a bisphosphonate is Zometa. Zometa (intravenous infusion) is commonly given every three months.

Bondronat and Bonefos are also bisphosphonates and are taken as an oral tablet daily.

Side effects of the intravenous bisphosphonates can include flu-like symptoms, nausea, vomiting, renal toxicity and, rarely, osteonecrosis of the jaw (ONJ) (see page 17).

Oral bisphosphonates can also cause gastro-intestinal symptoms such as heartburn and diarrhoea and, again, may be associated with ONJ.

Biologic agents

Xgeva (denosumab) is a human monoclonal antibody that corrects the imbalance between the osteoblasts and osteoclasts, reducing bone loss caused by cancer. Its benefits are similar to bisphosphonates in reducing bone pain and the risk of fracture and controlling hypercalcaemia. Initially it is administered every four weeks by subcutaneous (under the skin) injection and can be given by an oncology unit nurse, your medical oncologist, your GP or a GP practice nurse. Once you have been on this treatment for more than a year, and your cancer is under control, your doctor may suggest reducing the frequency of the injections.

Some women find it more convenient to have their bone strengthening treatment as a subcutaneous injection rather than an intravenous infusion as it can reduce the amount of time spent in hospital. The option of having Xgeva through your GP or GP practice nurse can also mean you may be able to avoid having to travel for treatment. This may be particularly helpful if you live in a rural or regional area. Talk to your medical oncologist if you would like to know more about whether having your GP involved in this part of your treatment is an option for you.

Side effects of Xgeva may include hypocalcaemia and, very rarely, ONJ. It is usually better tolerated than the bisphosphonates.

Possible side effects of bone strengthening treatments

Hypocalcaemia

Hypocalcaemia is the term used for low levels of calcium in the blood. If you are being treated with a bisphosphonate or Xgeva, the level of calcium in your blood can fall, resulting in hypocalcaemia. This can cause tingling and numbness of the fingertips and perioral (mouth) area, muscle cramps, twitching or spasm, anxiety and irritability, or seizures. If you experience any of these symptoms you should contact your oncologist or go to the emergency department as you may need urgent treatment to restore the level of calcium in your blood.

To reduce the risk of hypocalcaemia, it is important that you have adequate levels of vitamin D and calcium in your blood. Having low levels of calcium or vitamin D before bone strengthening treatment starts increases your risk of developing hypocalcaemia. Your medical oncologist will arrange for you to have a blood test before starting treatment to correct any deficiencies you may have. You will also need regular monitoring of your vitamin D and calcium levels while you remain on bone strengthening therapy. Your GP will need to arrange this for you if you are being treated with Xgeva through your local clinic, in between seeing your medical oncologist.

Most women will also be recommended to have vitamin D and calcium supplements during bone strengthening therapy. Your doctor will prescribe these for you and it is important that you take the supplements every day.

Osteonecrosis of the jaw

Osteonecrosis of the jaw (ONJ) is a **rare** dental condition that can occur when the bone in the jaw is exposed and does not heal. It can follow dental procedures such as an extraction, tooth implant surgery or a tooth abscess or infection, and it can cause ongoing pain, loss of sensation or a chronic abscess. It does not cause the jaw to disintegrate. It is important to have a thorough dental examination and any necessary dental work prior to intravenous bisphosphonate therapy. This approach, together with ongoing good oral health care (including regular brushing and flossing and a visit to the dentist every six months to have your teeth cleaned), and timely attention to any decay, goes a long way towards preventing ONJ altogether.

Local treatment

Radiotherapy

Radiotherapy uses X-rays to destroy cancer cells in the bone. It is used to reduce pain and help prevent fractures. Treatment may be given as a single dose or as a course of up to 12 doses. Treatment is generally very well tolerated with few side effects. The side effects will depend on the area that is being treated. In general it takes two to four weeks to get the maximum benefit from the radiotherapy.

For information about the side effects of radiotherapy and how to manage them, see the 'Treatment and side effects' section of the *Hope & Hurdles Information Guide*.

Surgery

Surgery can be used to fix a bone that has fractured due to the cancer, to stabilise a bone that has become weakened by the cancer or to help prevent a fracture (see page 20).

Managing symptoms of bone metastases

Pain

It is important to know that pain can almost always be controlled. Many of the treatments for metastatic breast cancer in the bone are aimed at reducing or eliminating bone pain. There are also many different pain relieving drugs (analgesics) that can be used singly or in combination.

Paracetamol is effective for mild pain and is most effective if you take it regularly rather than waiting until the pain returns or worsens. Antiinflammatory medications such as aspirin and ibuprofen (Nurofen) are also effective for mild pain. Codeine-containing analgesics such as Panadeine and Panadeine Forte are effective for moderate pain while opioid-based (morphine related) drugs such as Oxycontin, Targin, and Endone (containing oxycodone) and, MS Contin, or Kapanol (containing morphine) and Jurnista and Dilaudid (containing hydromorphone) can control more severe pain.

The opioid pain killers provide the backbone of managing moderate or more severe pain. There are quite a number of different versions of opioid pain killers, and new ones are introduced from time to time. The usual approach is to use 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, MSContin, Jurnista (tablets)
- Fentanyl (Durogesic) patches.

You will also be able to take a dose of 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 (fentanyl lozenges)
- Abstral (fentanyl tablets).

The steroid medication dexamethasone can sometimes be very helpful for the pain associated with bone metastases.

It should be possible to achieve good control of your pain. It is very important for you to let your treatment team know if your pain is not well controlled as a change in dose or use of different drugs may be very helpful. Sometimes, your oncologist may suggest input from someone who specialises in cancer pain management (palliative care physicians usually provide this advice in a cancer treatment team).

Complementary therapies such as relaxation therapy, acupuncture, gentle massage and hot or cold packs may also be helpful.

Radiotherapy is a very effective way of reducing bone pain and it can also reduce the risk of bone fracture. It is most likely to be used when there is one or a limited number of bone metastases.

Pain can also affect on your sleep. If you are having trouble sleeping, make sure you raise this with your specialist at your next appointment.

For more information on managing pain, see the 'Treatment and side effects' section of the *Hope & Hurdles Information Guide*.

Cancer Council has a free booklet and DVD *Overcoming cancer pain*, which provides information and strategies to help manage pain caused by cancer. You can order a copy by phoning 13 11 20 or download a PDF from your local Cancer Council website.

Fracture (broken bone)

The growth of cancer cells can cause bones to become so weak that it takes very little impact to break them. Weight-bearing bones such as the leg or spine are at the highest risk, though arm fractures can also be caused by lifting heavy weights or a fall. Sometimes fractures occur without any trauma at all.

The most common symptom of a fracture is pain at the site of the break.

If you have a fracture in a major bone, you are likely to need surgery to repair it. An orthopaedic surgeon can secure the bone with a screw or plate, or replace a joint such as a hip that has been affected by cancer. Bisphosphonates and radiotherapy may help prevent new fractures.

Spinal cord compression

Spinal cord compression is an **uncommon** complication of metastases in the spine, but one that requires urgent medical attention. A weakened vertebra can collapse and cause pressure on the spinal cord. Symptoms may include an increase in pain or tenderness in that area of the spine, sudden changed sensation such as pins and needles or numbness, weakness in the legs or loss of bladder control. Most often spinal cord compression is treated with radiotherapy, however, if these symptoms appear and progress rapidly, urgent surgery may be required to prevent permanent damage to the nerves or spinal cord.

Hypercalcaemia

Hypercalcaemia means that there are high levels of calcium in the blood.

Bone is a living tissue made up of calcium and proteins. Breast cancer cells growing in the bone alter the structure and, as a result, calcium is released into the blood. Breast cancer cells may produce a hormone that also contributes to high calcium levels by disrupting the calcium balance.

If calcium levels become too high they can cause a range of symptoms including:

- excessive thirst
- frequent urination
- constipation
- nausea and loss of appetite
- sleepiness, confusion or weakness.

If hypercalcaemia becomes very severe, it can cause loss of consciousness.

Hypercalcaemia is treated with intravenous fluids, which flush the calcium out of the body, and bisphosphonates or denosumab (see page 14), so you may need to be treated in hospital. Bisphosphonates or denosumab are also used to prevent hypercalcaemia.

Bone marrow problems

Cancer in the bone marrow can cause low red cells (anaemia), low white cells (infection risk) and low platelets (bleeding). These problems can be magnified by chemotherapy and radiotherapy, which can affect the marrow, and blood tests will be done regularly to monitor and adjust therapy. Controlling the cancer may improve the marrow function, but a blood transfusion might also be needed if anaemia persists.

Living with bone metastases

People diagnosed with metastatic breast cancer in the bone can feel well and have long periods of time without experiencing any symptoms. Some people live for many years with bone metastases and enjoy a good quality of life.

However, it is normal to experience a range of intense emotions when you learn you have metastatic breast cancer in the bone. If you have been treated for early breast cancer, you may feel angry that the breast cancer has spread despite that treatment. There may be times when you feel isolated or overcome by fear, sadness, depression or anxiety. For many people, living with the uncertainty that comes with a diagnosis of metastatic breast cancer can be very difficult.

You may find you can cope with these feelings on your own or with support from family members and close friends. However, many people seek additional support and there are many places where you can find help. If you have one, your breast care nurse, may be able to help you deal with some of these issues. Your GP is another good person to talk to and can refer you to a counsellor or psychologist if that would be helpful.

You'll find more information about finding support in the 'Living well' section of the *Hope & Hurdles Information Guide*.

Breast Cancer Network Australia's online network – bcna.org.au – is an excellent place to find support from others with metastatic breast cancer. There is an active group of women on the network and they will welcome you and answer any questions you may have. Many women tell us that they had never met another woman with metastatic breast cancer before joining the network, and found it a wonderful way to connect with others and share their experiences.

More information

Breast Cancer Network Australia

bcna.org.au 1800 500 258

In addition to *Hope & Hurdles* – BCNA's key information resource for people affected by metastatic breast cancer – BCNA produces a range of fact sheets and booklets on specific topics. These are available to order or download from BCNA's website bcna.org.au.

BCNA's telephone counselling service provides one-on-one telephone counselling support to women and men with metastatic breast cancer, their families and supporters. Phone 1800 500 258 for more information or to make an appointment.

BCNA's Helpline provides support and information about breast cancer and is available Monday to Friday from 9.00 am to 5.00 pm. You can phone 1800 500 258 or email contact@bcna.org.au.

The metastatic breast cancer section of BCNA's website is regularly updated as new information becomes available. Visit bcna.org.au.

BCNA's twice-yearly *The Beacon* magazine has information and stories about metastatic breast cancer.

More information

Breast Cancer Network Australia

bcna.org.au 1800 500 258

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

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



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 support, information, treatment and care possible.

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

