Metastatic breast cancer in the brain

hope &hurdles

Since being diagnosed with brain metastases I have become a grandmother, twice. My partner and I have married, plus I have walked my daughter down the aisle at her wedding. All of these are moments I didn't think I would get to enjoy and I treasure every one of them. Seven years after diagnosis I am beginning to stop pressuring myself to do what I used to be able to do, and instead accept my new 'normal'. This is allowing me to be calmer and to enjoy my life more. – Gillian

This booklet is for people who have been diagnosed with metastatic breast cancer in the brain. 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 brain, it means that breast cancer cells have travelled from the original cancer in your breast to one or more sites in your brain. These cancer deposits are called brain metastases or secondaries. This is not the same as having cancer that starts in the brain, which is often referred to as a brain tumour.

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

Other sites to which breast cancer can spread include bone, the liver and lungs. Booklets on these types of metastatic breast cancer are also available as part of *Hope & Hurdles* (see back cover).

When breast cancer spreads to the brain it can be treated although it cannot be cured.

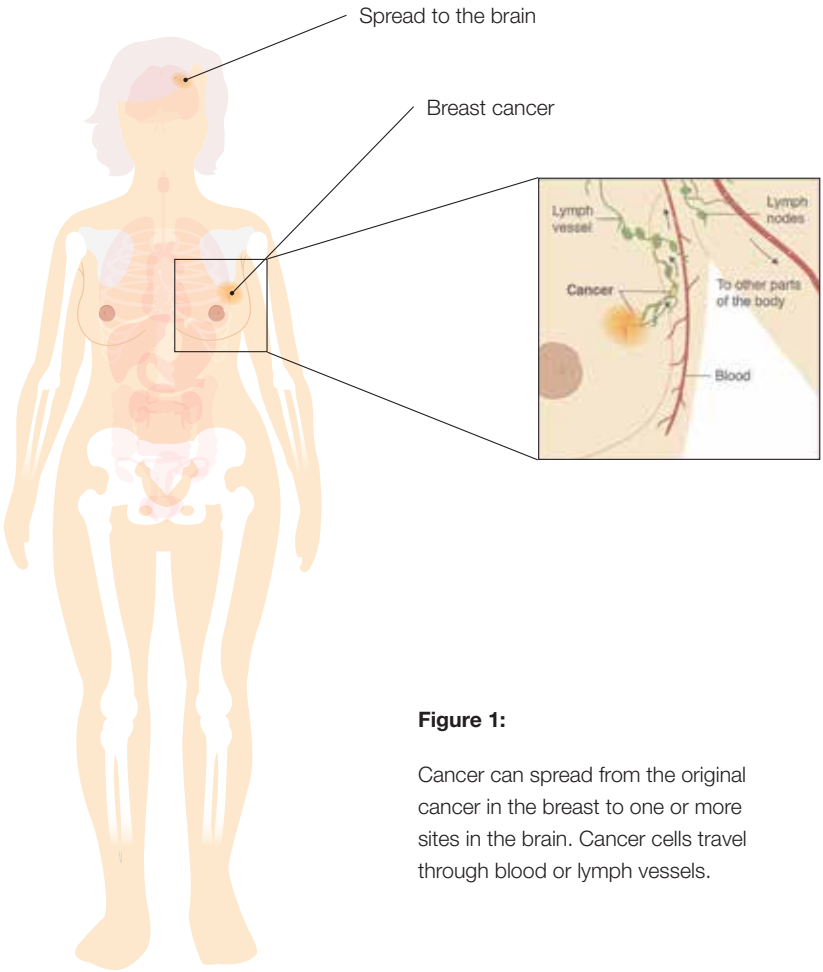

Figure 1:

Cancer can spread from the original cancer in the breast to one or more sites in the brain. Cancer cells travel through blood or lymph vessels.

Cancer deposits can also occur in the lining covering the brain and spinal cord (the meninges), as well as the fluid surrounding the brain and spinal cord (the cerebrospinal fluid). This is called meningeal carcinomatosis or leptomeningeal disease but is less common than other brain metastases.

Symptoms of metastatic breast cancer in the brain

Certain areas of the brain are responsible for different functions of the body so symptoms will vary according to the site/s of the metastases. For instance, they could include:

- loss of balance
- seizures (fits)
- weakness, numbness or tingling affecting one part of the body
- difficulty with speech or memory.

Cancer in the brain also causes swelling, which in turn increases pressure within the skull (raised intracranial pressure). This is a more common cause of symptoms, which include:

- headache
- nausea and vomiting
- double vision or blurred vision.

Headache is the most common symptom. A headache caused by metastatic breast cancer in the brain has different characteristics from headaches you may have suffered in the past. It is often present much of the time, and may only be a dull ache. It tends to be worse first thing in the morning when you wake up, and may feel worse when you lie down or cough.

Diagnosing metastatic breast cancer in the brain

If you develop any symptoms that suggest metastatic breast cancer in the brain your doctor may carry out a physical examination to check your vision, balance, sensation and strength in your arms and legs. You are then likely to be referred for a brain scan.

Your doctor may order a number of the following tests to confirm the diagnosis.

MRI scan

Magnetic resonance imaging (MRI) uses magnetic waves to scan your brain. It is more sensitive than a CT scan (see page 6) and provides very detailed cross-sectional views of the brain.

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. 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 to listen to if you prefer. MRI is not performed if you have any metal in your body, for instance a cardiac pacemaker or a breast tissue expander with a magnetic port.

CT/CAT scan

Computerised tomography (CT) uses X-rays to build up a three-dimensional picture of the brain. Before the scan, 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. Your kidney function may need to be checked through a blood test before deciding if the contrast can be given. The scan itself is painless but you need to lie very still for approximately 30 minutes.

Biopsy

Usually the MRI or CT scan will provide enough information for a diagnosis. However, sometimes a biopsy is necessary and, for this, you would need to be referred to a neurosurgeon.

Lumbar puncture

If your doctor suspects meningeal carcinomatosis (see page 3) a lumbar puncture will be arranged for you. Under local anaesthetic, a needle is passed through the gap between two vertebrae in the lower back and into the fluid-filled space (the sub-arachnoid space) that surrounds the spinal cord. A small amount of cerebrospinal fluid (CSF) is removed and sent to pathology to check for the presence of cancer cells. You will need to lie flat for a time afterwards.

Other tests

The presence of metastases in the brain indicates that the breast cancer has spread from your breast into your body via the blood stream or lymphatic system. 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+), a hormone treatment is used until it is 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. 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 brain

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

- your symptoms
- whether there is cancer in other parts of the body
- how many brain metastases there are
- 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
- surgeon
- palliative care physician
- GP
- neurosurgeon
- oncology nurse
- breast care nurse
- psychologist
- occupational therapist
- physiotherapist
- social worker.

Treatment for metastatic breast cancer in the brain has several aims, including relieving symptoms and preventing or delaying the progression of the brain metastases.

There are two types of treatment for brain metastases:

- **local treatment**, which treats a single part of the body, e.g. radiotherapy and surgery
- **systemic treatment**, which treats the whole body, e.g. chemotherapy and hormone therapy.

Local treatment

Surgery

Surgery may be an option to remove a single or small number of metastases (up to three), depending on their size and location in the brain. Radiotherapy may also be used after the surgery to destroy any remaining cancer cells.

Whole brain radiation therapy (WBRT)

Whole brain radiotherapy is a common treatment for metastatic breast cancer in the brain. It is given in daily doses over five to 10 days. Sometimes the radiotherapy can cause a temporary increase in symptoms such as headaches and nausea. This can be controlled using steroid medication (dexamethasone).

Possible side effects of whole brain radiotherapy include temporary hair loss, fatigue, skin irritation and blocked ears. Women who have had high doses or repeated courses of treatment may have problems with memory, speech, concentration and balance. If these symptoms occur, they most often do so many months after treatment has finished and may improve with time. If you are concerned about how possible side effects of whole brain radiotherapy may impact on your quality of life, talk with your radiation oncologist about what is important to you.

Some advanced radiation delivery methods have been developed that can avoid damage to important areas of the brain that are essential for cognitive function and at low risk of harbouring cancer cells. One of these areas is called the hippocampus. Your radiation oncologist will be able to talk to you about whether hippocampal sparing whole brain radiotherapy is appropriate for you.

> *I would have liked more information before making a decision about radiation therapy, especially about the way it would affect my memory, concentration and the general malaise that resulted.*

Localised radiation therapy treatments

Localised forms of radiotherapy may be appropriate where there are only a few brain metastases, or where they recur after whole brain radiotherapy or previous surgery. Localised forms of radiotherapy involve a single or short series of very high doses that are accurately focused on the cancer and therefore result in minimal damage to surrounding tissue. These treatments are usually delivered as an outpatient procedure. Most people can leave hospital just a few hours after the procedure.

The most widely available localised form of radiotherapy is referred to as stereotactic radiation therapy or stereotactic radiosurgery. This system uses standard linear accelerator radiotherapy machines to deliver precisely focused radiation to the cancer guided by radiological imaging (scans). This treatment provides a single, or several, radiation treatments of the brain or spine. It is a complex procedure that requires a team of expert specialists including a radiation oncologist and a neurosurgeon. Stereotactic radiotherapy may not be available in all centres, so speak to your radiation oncologist if you would like to know more about this treatment and whether it is appropriate for you.

You may also hear about a localised form of radiotherapy called Gamma Knife radiosurgery. This is a sophisticated system that delivers precisely

focused radiation, useful for the treatment of small lesions. At this time, there are only two sites in Australia that offer Gamma Knife radiosurgery. Only one of these (in Brisbane, Queensland) is a publicly funded service. If you want to learn more about this treatment and whether it is appropriate for you, speak to your radiation oncologist.

> *I believe in the mind–body connection. Athletes use visualisation and imagery before they compete, and I try to do the same. When I had radiotherapy to my brain, I imagined little workers in my head with little drills destroying the cancer and imagined the cancer disappearing. This imagery helped me get through the treatment.* – Amina

Systemic treatment

Generally, systemic treatment is not used to treat brain metastases, because of something called the blood-brain barrier. This is a protective network of blood vessels and cells that filters blood flowing to the brain, protecting it from potentially harmful chemicals. Many cancer treatments are unable to cross this blood-brain barrier. However, there are a few cancer treatments that can cross the blood-brain barrier which may be helpful in your treatment.

You may be recommended systemic treatment to treat metastases elsewhere in the body. Which treatments are recommended for you will depend on the subtype of your breast cancer. Systemic treatments include hormone therapies, chemotherapy and targeted therapies. For information on systemic treatments see the *Hope & Hurdles* booklet on your subtype of breast cancer (hormone receptor positive, HER2-positive, triple negative).

Managing the symptoms of metastatic breast cancer in the brain

The most common symptoms of brain metastases are a result of raised intracranial pressure (increased pressure in the brain) – headache, nausea and fatigue. These symptoms are most effectively managed with steroids such as dexamethasone.

Steroid medications reduce the swelling in the brain and can relieve symptoms such as headache and nausea. If symptoms of brain metastases occur, steroids may be prescribed before investigations are completed because they can act quickly. Dexamethasone is most commonly used. Steroids are usually given in higher doses initially and then reduced promptly once other treatments such as radiotherapy have taken effect.

Side effects of steroids can include increased appetite, indigestion if you take them on an empty stomach, disturbed sleep if you take them late in the day, oral thrush (candidiasis), mood swings and muscle weakness. It may also increase blood sugar levels, and in some cases may bring on diabetes. If you are diabetic it will be important to carefully monitor your blood sugar levels.

It is best to take the medication with food and early in the day. If you are likely to be on dexamethasone for longer than a week, you may also be given medicine to help prevent stomach ulceration/indigestion, and medication to help you sleep.

If you are having trouble sleeping, make sure you discuss this with your specialist at your next appointment. Steroids can also cause puffiness of the face and weight gain, but this is a temporary side effect and should improve once you are no longer taking the steroids.

Headache

Headaches can also be controlled by pain relieving drugs (analgesics). Paracetamol is effective for mild pain and is most effective if you take it regularly rather than waiting until the pain returns or worsens. Anti-inflammatory medications such as aspirin and ibuprofen (Nurofen) are also effective for mild pain but should not be used with dexamethasone. Codeine-containing analgesics such as Panadeine and Panadeine Forte are effective for moderate pain while morphine-based drugs such as MS Contin and Oxycodone can control more severe pain.

Nausea

In addition to dexamethasone, nausea is managed with anti-nausea drugs called antiemetics. They can be taken in tablet form, as a suppository or injection, and different drugs may be more effective for different people.

Fatigue

Gentle exercise, such as walking, can improve fatigue but it is important to pace yourself and have adequate rest. Anaemia can contribute to fatigue. If your doctor suspects that you may be anaemic, you will need blood tests. Poor nutrition can aggravate both fatigue and anaemia. Steroid drugs can boost energy and appetite.

Seizures

Anti-epileptic drugs may be recommended if you have had a seizure, or to prevent seizures if it is thought these could occur. They may also cause drowsiness.

Managing side effects of radiotherapy

Fatigue

Radiotherapy may worsen fatigue during treatment and for a few weeks afterwards. Light exercise, such as walking, can help.

Skin changes

The treated area of the head may become reddened, dry and itchy. To reduce skin reactions:

- wash your hair with a gentle, non-scented shampoo
- avoid chemicals that can irritate the skin, such as hairsprays
- wear a hat when you're outdoors.

Radiotherapy staff will be able to help you with other recommendations.

Hair loss

Radiotherapy to the brain, especially whole brain radiation therapy, can cause your hair to fall out. This is rarely permanent. Your hair will usually grow back several months after completing radiotherapy. When it grows back it may be thinner and have a different texture.

Blocked ears

Blocked ears are temporary and the problem will resolve itself.

Living with metastatic breast cancer in the brain

> *In 2013, I was found to have brain mets. It hasn't always been an easy road but I am still here. I am currently living with a couple of tiny brain lesions, but so far they have not caused any significant side effects. You never know what curve balls life is going to throw at you, but I have learnt to cope with them and if my 'normal' changes, it changes. Three years later I am still living strong and well.* – Karen

It is quite normal to experience a range of intense emotions when you learn that you have metastatic breast cancer in the brain. You may worry about what it means for you and how it will impact on your ability to concentrate, to remember things, to be able to continue to work if that is important for you and to maintain your quality of life. 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 also refer you to a counsellor or psychologist. 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 other people with metastatic breast cancer. There is an active group on the network who will welcome you into their fold 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 that they found it a wonderful way to connect with others and share their experiences.

Driving

Usually, people diagnosed with brain tumours are required to stop driving as soon as they receive the diagnosis.

The medical standards for drivers on Australian roads state that if a driver's memory, concentration, vision, strength or hearing is affected, he or she should stop driving until treatment has resolved the problem. The standards can be found on the Austroads website, austroads.com.au > Assessing fitness to drive.

If you are unsure about whether you should be driving, being assessed by a neurologist or occupational therapist may help. Seizures also make it unsafe to drive until they are controlled; again a specialist may help you to decide whether you are well enough to drive safely.

As well as safety concerns, there are important legal reasons not to drive if you are not medically fit. If you cause an accident when you are not medically fit to be driving, you will have committed an offence. Your insurance company may not cover you in this situation. The onus is on you to stop driving if you are not fit to drive; it is not up to licencing authorities to take away your licence.

You may be able to return to driving after the metastases have been treated, but will need to be reassessed prior to doing so. This may involve vision tests or on-road testing. A hospital social worker will be able to help you to determine alternative travel arrangements in the meantime.

Many people find that following on from treatment for brain metastases, they are able to resume a very good quality of life and return to normal activities, including work.

> *Modern advances in treatment for brain secondaries have substantially altered prognosis. Many patients who have surgery for brain secondaries are doing outstandingly well, with some women even having several surgical treatments for recurrent brain secondaries with excellent results. New radiotherapy treatments are also offering highly targeted radio-surgery not only in specialised research centres but also community radiation centres.* – Professor Michael Green, medical oncologist

More information

BrainMetsBC.org

brainmetsbc.org
This US-based website offers women with metastatic breast cancer and their families a place to learn about brain metastases from the woman's perspective. It provides the latest information and personal stories about being diagnosed and treated for brain metastases.

Cancer Institute NSW

cancerinstitute.org.au
Brain cancer fact sheets: 16 fact sheets about the thinking and behavioural changes people may experience after a brain tumour. They cover topics such as attention and concentration, being unable to find the right word, high level thinking and memory loss.

eviQ

eviQ.org.au
A free online service of the Cancer Institute NSW that provides evidence-based information on cancer treatments. You will need to register to use the site.

Cancer Australia

canceraustralia.gov.au
Clinical practice guidelines: Clinical guidelines for the treatment of central nervous system (CNS) metastases, including brain metastases.

Cancer Council

cancer.org.au or phone 13 11 20
Overcoming Cancer Pain: This free booklet explains treatment for pain caused by cancer and provides strategies for helping to manage pain. A downloadable PDF is available from the website.

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 bone*
- *Metastatic breast cancer in the lung*
- *Metastatic breast cancer in the liver*
- *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*)

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January 2017

Breast Cancer Network Australia

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.

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