

UNDERSTANDING BREAST CANCER: INFORMATION FOR CARERS OF A PERSON WITH A DISABILITY

FACT SHEET

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This fact sheet was produced by Breast Cancer Network Australia

This fact sheet provides a basic understanding of breast cancer for carers of a person with a disability. It also provides information on some of the ways that your role might change when the person you are caring for has been diagnosed with breast cancer.

Building your knowledge about breast cancer as a carer may help you to feel more confident and better placed to offer support and care.

About breast cancer

Breast cancer is the most common cancer affecting Australian women. It is important to understand that most people survive breast cancer and Australia has one of the highest survival rates in the world.

Following a diagnosis of breast cancer, as a carer, you may experience feelings of shock, fear, disbelief or uncertainty – this is normal. You may also feel overwhelmed with all the information about breast cancer as well as new treatment and medical terminology.

As a carer of a person living with a disability who has also been diagnosed with breast cancer, it is important that you consider how treatments for breast cancer may impact their disability, and also how the disability may impact their treatment and follow-up care.

Getting the right information

Knowing where to go to find credible information is helpful for both you and the person you are caring for. Access to appropriate breast cancer information can give you and the person you are caring for a greater sense of empowerment and autonomy in their health care decisions.

It is important to be aware that while there is a lot of information about breast cancer on the internet, some information may be unhelpful, inaccurate or scary.



For a list of credible websites about breast cancer, refer to BCNA's fact sheet *Beware Dr Google: a guide to reliable breast cancer information on the internet*.

BCNA also has a range of breast cancer information resources available in Easy English, HTML, audio and video formats.

How breast cancer is found

Breast cancer can be found in a number of different ways. The person you are caring for or their doctor may have noticed a change in the breast, or cancer may be found following a routine mammogram.

A range of tests will be completed to find out if the change in the breast is due to cancer. These tests may include a physical examination, imaging tests (for example a mammogram, ultrasound or MRI) and one or more biopsies.

If a biopsy is performed, a pathologist will look at the tissue which has been removed to see if it is normal or affected by breast cancer.



Pathology testing for breast cancer

It is important to remember each diagnosis and experience of breast cancer is different.

If breast cancer is found, a surgeon will usually remove the breast cancer and some healthy tissue around it – this is called the ‘surgical margin’.

The surgeon will then send this tissue to a pathologist, who will look at the tissue and write a pathology report. The pathology report will usually be sent directly to the surgeon and/or a medical oncologist.

The pathology report has a lot of information about the breast cancer, including how big it is, how fast it is growing and whether or not it has spread to the lymph nodes. BCNA’s *Breast cancer pathology* fact sheet can help you to understand this report.

The surgeon and/or medical oncologist will use the information in the pathology report to determine how likely it is that the breast cancer may come back, or spread to other parts of the body. This helps them to decide what the best treatment options are for the person you are caring for.

Understanding treatment options

All breast cancers are different. Not everyone has the same treatment.

Treatment will depend on:

- the type of breast cancer and how quickly it is growing
- the age and general health of the person with breast cancer
- what treatments the person would prefer.

The doctors involved in the treatment of the person you are caring for may include a surgeon, a medical oncologist and a radiation oncologist.

The doctors will talk about the treatments that will be best for the person you are caring for. The person you are caring for will have time to discuss treatment options with you and/or others before a decision is made about treatment. Having the treatment the doctors recommend will give the person you’re caring for the best possible outcomes.

It is important to ask the doctor questions about anything you or the person you are caring for do not understand. Sometimes this can be hard and you may not know which questions to ask. It can help to write down questions before your visit.

The person you are caring for may see more than one doctor or nurse during their treatment. Some hospitals will have a breast care nurse.

If the person you are caring for needs an interpreter, let the doctor or nurse know when you make their appointments.

Remember that it is okay for the person you are caring for to seek a second opinion, or talk to a GP or a nurse if they are still unsure about treatment options.

Types of treatment and side effects

Your carer role might be influenced by the type of cancer and treatment. For example, treatment for early breast cancer typically lasts for approximately 12–18 months, whereas treatment for metastatic breast cancer (also called secondary or advanced cancer) will be ongoing. No matter the scenario, your support will contribute to overcoming hurdles, and help the person you are caring for to live well.

Treatment options will depend on the type of diagnosis. Treatments do not necessarily occur in the order below, and the person you are caring for will not necessarily need all treatments.

Some breast cancer treatments have side effects. Everyone is different – the person you are caring for may experience side effects or they may not. The doctor or nurse can provide information about side effects that may be experienced. They can also help to manage side effects and make things more comfortable.

Some disabilities may have an impact on treatment options and side effects. Sometimes treatments and side effects may also have an impact on someone’s disability.

It is important that the medical team and the person you are caring for are aware of these impacts so these can be factored in to the treatment decisions.

For more information about side effects, visit bcna.org.au.



Surgery

The main types of surgery are:

- mastectomy – removal of one or both breasts
- breast conserving surgery (also known as lumpectomy, partial mastectomy or wide local excision) – removal of the cancer and some healthy tissue around it
- removal of one or more lymph nodes from the armpit.

Depending on the type of surgery, the person you are caring for may develop side effects such as pain, swelling and discomfort. It is important that you discuss these with the doctors and the person you are caring for.

Chemotherapy

Chemotherapy drugs treat the whole body, not just the area where the cancer was found. It aims to kill any cancer cells that may have spread outside the breast and armpit areas that cannot be seen or found.

There are a number of chemotherapy treatments and each type has different side effects. Everyone experiences side effects differently. Some of the most common side effects of chemotherapy are:

- feeling sick (nausea) or vomiting
- becoming very tired (fatigue)
- temporary hair loss
- finding it hard to think (sometimes called 'chemo brain')
- periods stopping (menopause).

It is helpful for the person you are caring for to have an opportunity to discuss side effects prior to the commencement of chemotherapy. This includes how the person may be able to manage these side effects, especially once they return home.

Depending on the disability experiences of the person you are caring for, there may be additional modifications that are required around the home to manage treatment side effects.

To meet these needs, the treating team may need to make a referral to an allied health professional, such as an occupational therapist.

Radiotherapy

Radiotherapy uses X-rays to kill any cancer cells that may be left in the breast or armpit area after surgery. Before the person you are caring for starts radiotherapy, they will meet with:

- a radiation oncologist to plan their treatment
- a radiation therapist who will explain what will happen.

Once radiotherapy starts, the person will usually have treatment once a day, five days a week, for three to six weeks. They will be given an appointment time for each of their visits. Each treatment usually only takes a few minutes.

Radiotherapy is usually painless, but there may be some side effects. The most common side effects are:

- the skin of the breast can become red and dry like sunburn
- the skin can become darker (and may stay that way for a few months)
- feeling more tired than usual during treatment and for a few weeks after treatment is over.

There are other side effects, which are less common. Radiotherapy or nursing staff are helpful in providing information on ways to manage the side effects or other concerns that you or the person you are caring for may have. If the person you are caring for has restricted mobility, it is important that this is discussed with the radiotherapy team prior to their appointment, as it may impact their treatment.

Hormone therapy

One of the tests the pathologist performs is identifying whether the breast cancer has receptors to the two main female hormones, oestrogen and progesterone, on its cells. If receptors are present, the breast cancer is referred to as oestrogen receptor positive (ER+) and/or progesterone receptor positive (PR+).

About two-thirds of women with breast cancer have hormone receptor positive breast cancer, and may require hormone therapies.

Hormone therapies stop cancer cells from growing. They lower the amount of oestrogen in the body, or stop the oestrogen from getting into the cancer cells.



The type of hormone therapy recommended for the person you are caring for will depend on whether or not their periods have stopped (menopause). Hormone therapies are tablets that are taken every day, usually for five years or more.

How your role may change

Your role as a carer may change because of the person's breast cancer diagnosis. You may need to offer them additional practical support and take on extra responsibilities, either for a while or in an ongoing way.

You might:

- arrange and attend medical appointments with the person you are caring for
- keep a list and schedule of medications
- provide personal hygiene care
- provide extra help around the house as physical activities will be difficult for a while, especially after surgery or during chemotherapy – this may include garden maintenance, cooking, cleaning and washing
- go with them if they need to buy a wig or breast prosthesis
- assist with managing finances and paperwork, such as medical bills, Medicare claims and household expenses
- help to find support services and information.

It is important to be aware of the level of support and care required. You might find it helpful to put strategies in place to help you manage and prepare for any extra responsibilities if you need to take them on.

You may feel overwhelmed with extra roles and responsibilities, or you may feel worried about the person you are caring for. This is okay. Try talking with your friends or family and ask them for help, or call your local council or community health service and ask what help they may be able to provide.

I think it's important to realise that you're only human and you're doing the best you can and you can ask for help. Call the nurse, call your support networks and just say I can't remember and it's okay, we're not expected to be infallible. – Carer

It may be helpful to talk with your employer and discuss flexible working arrangements, especially if you are the main carer.

You can also discuss these extra roles and responsibilities with Centrelink, as you may be eligible for extra entitlements.

For more information about your health and wellbeing as a carer, and the supports and services you can use, refer to the BCNA fact sheet, *You're important too: looking after yourself as a carer*.

Life after active treatment for breast cancer

Many people with early breast cancer look forward to finishing treatment (surgery, radiotherapy or chemotherapy). However, for some people, the end of treatment can be a confusing or worrying time. Some people feel nervous or upset at the thought of no longer seeing members of their health care team regularly. Others feel worried about what the future holds.

For information about fear of breast cancer coming back, refer to BCNA's fact sheet, *Fear of cancer recurrence*.

You can also refer to BCNA's Easy English fact sheets *Life after breast cancer*, and *Keep breast cancer away*, or the audio versions, *Emotional wellbeing* and *Reduce your risk*.

Follow-up care and ongoing care

Follow-up care is recommended after treatment for breast cancer to check whether breast cancer has returned, to monitor side effects of treatment and to provide practical and emotional support. Follow-up care usually involves physical examinations and breast imaging tests such as mammograms and/or ultrasounds.

How often these tests are done will depend on the person's individual situation and how long it has been since they finished treatment. In general, the recommended timing for physical examination/history is:

- years 1–2 after treatment – every 3–6 months
- years 3–5 after treatment – every 6–12 months
- more than 5 years after treatment – every year.

If the person you are caring for finds a change in their treated breast (or chest wall if they had a mastectomy) or in their other breast between follow-up appointments, they need to see their GP or specialist as soon as possible. It is important that they do not wait until their next appointment.



Lymphoedema after breast cancer is a persistent swelling of the arm or breast, and can develop after treatment for breast cancer.

Lymphoedema develops due to a build-up of fluid after damage to or removal of lymph nodes from the armpit or breast area. There is no cure for lymphoedema but the symptoms can be managed.

For more information, refer to BCNA's fact sheet, *Lymphoedema*, which is also available in Easy English.

Living with metastatic breast cancer

For people living with metastatic breast cancer, there are ongoing treatment and support needs, which will depend on their treatment, with varying periods of illness and wellness.

Many people with metastatic breast cancer can have treatments that can manage and control their cancer, which allows them to live well for many years.

For those who respond well to treatment, metastatic breast cancer can be managed like a chronic illness, which might flare up from time to time, but offers extended periods of wellness in between.

Others will reach a stage where there are no further active treatment options available. Treatment and care they receive will then be aimed at keeping them comfortable. The support you provide may change depending on the level of care needed at different points.

For more information about living with metastatic breast cancer, refer to the BCNA *Hopes & Hurdles* pack.

More information and support

There are many organisations that can provide resources and support for carers of a person with a disability and breast cancer.

Visit bcna.org.au for a list of resources, or call BCNA's Helpline on 1800 500 258 for free and confidential information, support and referral.