



FEAR OF CANCER RECURRENCE

FACT SHEET

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This fact sheet was produced by Breast Cancer Network Australia

Sometimes I think that fear of recurrence is the biggest challenge to face after a breast cancer diagnosis and treatment. It affects us all differently, at different times. – Di

This fact sheet provides information on fear of cancer recurrence for people who have been diagnosed with early breast cancer; their partners, families, friends, and colleagues; and others who support people with early breast cancer.

If you have been diagnosed with metastatic breast cancer, you may like to order a *Hope & Hurdles* information pack from Breast Cancer Network Australia (BCNA).

What is fear of cancer recurrence?

Many people who have had breast cancer worry that their cancer may one day come back (recur). This is a very normal response to a cancer diagnosis. It is called fear of cancer recurrence: the fear or worry that cancer could come back or progress. It can be a fear of cancer coming back in the same breast, in the other (unaffected) breast, or to another part of the body. Most people who have had cancer worry that it might one day come back.

It may be helpful for you to know that most breast cancers do not come back. Australia has one of the highest breast cancer survival rates in the world, with around 90 per cent of those diagnosed alive five years after their diagnosis. New and emerging treatments mean that survival rates continue to climb.

It may also be helpful for you to know the following about fear of cancer recurrence:

- it is the most common fear in the first year after breast cancer treatment
- between 40% and 70% of people who have had cancer experience fear of recurrence that causes them significant challenges in living their day-to-day life
- the majority of people who experience fear of recurrence find that it reduces with time as they adjust to their life with and after cancer.



Signs that you may be experiencing fear of cancer recurrence

Everyone will feel fear that breast cancer may return differently, and if and how you experience it will depend on your own personal circumstances. It might be fears around:

- **having to go through treatment again:** worries about pain and treatment side effects, time off work or away from things you would normally be doing, and the costs of treatment
- **more disruptions to your life and the lives of your family and friends:** worries about the stress and upset cancer may cause for the people close to you, and the effect on the lives of others who are important to you
- **what it might mean for your family, especially children:** worries about their distress, concerns for how a cancer recurrence may affect their schooling or other activities, and thoughts about how your family and children would cope if you were to experience cancer again
- **uncertainty:** thoughts around not being able to know what the future will be like, and anxiety about not being able to know for certain that your cancer will not return
- **the possibility of death:** thinking about whether cancer coming back may mean that you might die.



Being fearful that your cancer might return can affect:

- **quality of life:** anxious thoughts and worries can make it hard to live a full and enjoyable life, and take you away from enjoying the present moment
- **relationships:** worries about cancer coming back can add pressure to relationships with your partner, a new partner, family, friends and others who you are close to
- **how you manage your follow-up care and your relationship with your medical team:**
 - Some people ask their doctor for more checks and tests than they need, to try and reassure themselves that the cancer has not returned. Most doctors will not order additional tests on the basis of anxiety around fear of recurrence. Sometimes this can be challenging to understand.
 - Other people avoid routine examinations, mammograms or follow up appointments because their fear is overwhelming and they are uncertain how to communicate that to their doctor.
- **thinking about, and planning for, the future:** you might find thinking about long term plans difficult or distressing if you cannot exclude worries that your cancer might one day return.

Why does fear of cancer recurrence happen?

Almost everyone who experiences a cancer diagnosis will describe it as a shock. Research shows cancer is a major trauma and can change your life significantly. People need to have some sense of predictability and control in their lives. A cancer diagnosis shows that life is not predictable, which is why shock is a common response.

We know that our expectations of the future are shaped by our past. Because of this, a past cancer diagnosis means that it is normal to have thoughts and worries about it happening again.

Currently, there is no test that shows you are 'cured' of breast cancer. No one can say for certain whether the cancer is gone for good. There are no certainties in life.

Just like other areas of life where we don't know for sure what will happen, it is this uncertainty that creates a space for fear; in this instance, fear of cancer recurrence.

How can I reduce my fear of cancer recurrence?

Fear of recurrence can affect anyone who has had cancer, but there are some people who may be more at risk of experiencing higher levels of worry and distress.

Research tells us that younger survivors and those with more treatment side effects (such as pain and fatigue) are more likely to have greater worries about cancer coming back.

Research also shows that people who don't feel well supported, or have unmet needs, are more likely to experience fear of recurrence that significantly affects their life.

Unmet needs might be things like not getting social support from friends and family, or not getting the right medical information in a way that lets you feel informed about your condition and treatment.

Having the following supports throughout your treatment for cancer and beyond may make you less likely to experience high levels of fear that the cancer may return:

- social support – having someone to talk to or to keep you company when you need it
- financial support – having enough money to cover your expenses
- employment – being part of a workplace that helps you look after yourself
- medical information – understanding your medical condition and treatment
- transport – being able to get to and from the places you need to be easily
- sexuality – being able to get help and support for any sexual problems caused by your cancer treatment
- home environment – making your home suitable for your changing needs.

Taking good care of yourself throughout your treatment and afterwards can help to lower your risk of developing a significant fear of recurrence.

Ask for the help and support you need, when you need it – it can be challenging to ask for help, but will benefit you in the long run.



Why am I more anxious at certain times?

Fear of the cancer coming back can happen anytime. However, some people find that certain events can make them worry more about their cancer returning.

Events people often find worrying include:

- routine follow-up tests such as mammograms and medical appointments
- anniversaries – the date of your diagnosis or end of cancer treatment, birthdays
- hearing about another person's cancer, a person whose cancer returned or a person who died from cancer – it maybe someone you know or a public figure
- unexplained physical symptoms, such as headaches or stomach pain
- persistent side effects of treatment – especially fatigue or pain
- a change in your health – weight loss, fatigue
- illness in another family member
- times of stress.

How can I manage my fear of recurrence?

There are many things you can try to help you manage unwanted fears about your cancer returning.

Think about what events make you feel fearful. Is it hearing about someone else's cancer? Is it the anniversary of your final chemo or radiotherapy treatment?

Many people find that once they know what is likely to make them feel especially worried, they can make a plan to deal with the associated fear and anxiety. For instance, if going for your routine follow-up mammogram causes you to worry, you may like to schedule it close to your follow-up appointment so that you are not waiting for too long to get the results.

You may also like to schedule something you enjoy – for example, coffee with a friend – after your mammogram to give yourself something to look forward to and to help distract you.

Some people have found the following things help ease their fear of cancer returning.

- Talking about it with friends, family or someone else you trust.

- Writing down what worries you. Sometimes getting thoughts out of your head and onto paper can be helpful.
- Focusing on looking after yourself. This may include:
 - doing things you enjoy
 - taking time out to do something nice for yourself
 - trying a mindfulness technique such as relaxation exercises or a mindfulness colouring book
 - addressing your spirituality needs through meditation, prayer or another practice that has meaning to you
 - attending your regular health screenings, such as your follow-up mammograms
 - making lifestyle changes so that you feel in better control of your health, which may include:
 - eating a healthy diet that includes:
 - plenty of vegetables, fruit and legumes
 - cereals, preferably wholegrain, such as bread, rice, and pasta
 - some lean meat, fish and poultry
 - reduced-fat dairy foods
 - plenty of water
 - reducing stress
 - limiting alcohol
 - exercising regularly
 - maintaining a healthy weight.

It is important to remember that everyone is different – what works for one person might not work for you. You might need to try a few different things to work out what is the best approach for you.

How do I know if it's time to get help?

Some fear and anxiety is normal, particularly around things you know make you worry, such as mammograms or follow-up appointments.

However, there are times when it is important to get help. It might be time to ask for help if:

- you have tried some of the suggestions above and you are still feeling very worried and anxious
- things that used to work well for you are no longer working
- anxiety or sadness over fear of the cancer coming back stops you doing the things that are important to you.



Who can help?

You can get help in a number of ways. A good place to start is your GP, who may be able to talk to you about your concerns or refer you to a counsellor, social worker or psychologist.

Other people who may be able to help include:

- your medical oncologist
- your breast care nurse
- a hospital-based social worker
- other women who have experienced breast cancer who can share their tips around how they manage fear of cancer recurrence.

How can family and friends help?

You may find that people who care about you want to help when you are feeling fearful or anxious about the cancer returning, but it can be hard to know how to start a conversation with them. You might like to use some of the following suggestions to get you started.

- 'It helps me when you let me talk about my fears and concerns about the cancer coming back.'
- 'When you listen, without trying to offer a solution straight away, it helps me to feel heard.'
- 'It would be great if you helped me with ideas to help me cope. Perhaps we could go for a walk together? I could use some company on the day of my appointment, it would be good if you could meet me for lunch afterwards.'
- 'If you see me struggling with my fear and anxiety, remind me that there is help available and I should talk to my doctor about it.'

What are the most important things I need to know about fear of recurrence?

- Fear that cancer may come back is normal.
- There are things you can try yourself to help manage your fears and worries.
- Professional help is available if worry about the cancer returning is affecting your life and stopping you doing the things you want to do.

Other supports available

Breast Cancer Network Australia (BCNA) has developed a series of short videos on fear of cancer recurrence.

The series includes information from a woman diagnosed with breast cancer about how she manages her fear of recurrence, an oncology social worker who supports people dealing with fear of recurrence issues, and a leading breast surgeon. You can watch the videos by visiting bcna.org.au.

BCNA's online network is a place where you can connect with people who have experienced breast cancer, share stories, and learn how others cope with fear of recurrence. Visit bcna.org.au to find out more or to join.