



Cancer survivorship information for survivors and carers

Coping with the fear of cancer coming back (fear of cancer recurrence)

Fear about cancer coming back or worry about the future is common for people who have completed treatment and for people who are receiving ongoing therapy. More than 70% of people who have had cancer say they have experienced this at some stage.

This fact sheet explains what fear of cancer recurrence is and suggests ways to cope with the fear of cancer coming back.

Key Messages in coping with fear of cancer coming back

- Fear of cancer recurrence is common
- Fear of cancer recurrence can reduce over time
- Speak with your doctor or health care team if fear of cancer recurrence is concerning you
- Health care professionals can offer specialist support

What is fear of cancer recurrence?

Fear of cancer recurrence is commonly referred to as 'the fear or worry that the cancer will return or progress in the same part of the body'. It can also refer to fear of being diagnosed with a new cancer. The fear can relate to a number of things such as: Fear of needing further treatment, more life disruptions, or fearing how further cancer might effect the survivor's family or their ability to raise their children. Fear of recurrence does not necessarily relate to a person's actual risk of the cancer coming back.

Common worries or fears

People may experience fear or worry during or after treatment. You may find it helpful to know that worry is a common feeling and that your health professional team can provide you with useful strategies to cope.

You may feel worried about one or more of the following:

- how likely it is that your cancer will come back
- what symptoms to watch out for
- how your body looks and feels
- follow-up appointments
- significant events or dates that remind you of your cancer diagnosis
- getting another type of cancer.

For some people, these fears (especially of the cancer coming back) are so strong that day-to-day life can become a big struggle, making it difficult to move on from the cancer experience. Some survivors describe their feelings as:

- being fearful of planning ahead; one survivor said 'I feel too scared to live... too scared to die'
- life has 'stalled' or been 'put on hold' with no way of knowing how to 'get started' or 'move forward' again.

Although it can take time, it doesn't need to always feel this frightening. By acknowledging fears and taking control of them, most survivors find they can enjoy life again.

**'It is always on your mind.
Every innocent cough strikes
at your heart.'**

Worrying about symptoms

At first you may worry that every ache, pain or feeling of sickness might mean that your cancer has come back. You may worry so much that you find yourself at your GP's office more than usual.

Maybe you did not have symptoms when you were told your cancer diagnosis. The cancer may have been picked up during a regular screening test for example. So how will you know if your cancer has come back?

Whatever your situation, it can be frightening. Although your cancer doctor or nurse can help with many of your concerns, there are steps you can take to help lessen your fears. Most survivors say that over time, their confidence builds up and they think less about their cancer coming back.





Coping with the fear of your cancer coming back

Practical tips to help you cope

- Acknowledge and talk about your fears. Be honest with yourself, your family, friends, doctors and other support people about how you really feel. Family and friends can be a good source of support. Speak to them about how they can help you when you are feeling fearful or anxious. If you find this hard, try writing your feelings down in a journal first.
- Be aware of which symptoms might mean a cancer recurrence. Your doctor or nurse may have provided you a list of symptoms to look out for and report in a survivorship care plan. Don't be afraid to make an appointment to see your doctor if you have a symptom that concerns you between follow-up appointments.
- Participate in your regular cancer screening programs to detect bowel, breast and cervical cancer. If you have concerns about cancers not routinely screened for, see your GP for advice.
- Attend your follow-up appointments. Some survivors find follow-up appointments and the time leading up to them stressful. Write down what you want to discuss with your doctor before you go. For example, symptoms you may have, fears of recurrence, problems with side effects and advice about how to prevent another cancer. Using the fact sheet 'Questions you may wish to ask about the time after cancer' may be helpful. www.petermac.org/sites/default/files/ACSC_FactSheet_Questions%20prompt%20sheet%20WEB.pdf
- Look after yourself. This means taking care of your mind and body. Making healthy lifestyle choices to stay well may help you feel more in control of your health. Try to eat a well-balanced diet with lots of fresh fruit and vegetables. Exercise regularly, maintain a healthy weight, and get plenty of sleep. Avoid too much alcohol. Lack of sleep, a poor diet, alcohol and recreational drugs can worsen fears and anxiety.
- Reduce the stress in your life. Some people find relaxation and meditation classes helpful. There is emerging evidence that 'Mindfulness meditation' can be useful. Your GP can provide advice on where to begin.
- Continue with your hobbies or take up new ones. Staying busy doing things that you enjoy can help you cope better with your fears.
- Do things in your own time. Not everyone wants to know about the risk of their cancer coming back or survival statistics. Don't feel you have to find out, even if those close to you want the answers. If you do want detailed survival statistics your doctor will be able to give you these answers based on what they know about you and your cancer.
- There may be times when it is helpful to have support that does not involve family or friends. Support from a professional experienced in survivorship issues may be more suitable. Knowing who to contact for further help can be a great relief to many cancer survivors. If you are unsure about where to go for help you can call the Cancer Council Information and support line on 13 11 20 and speak with a cancer nurse. They can give you further information about coping with survivorship, counselling, joining a support group and getting help with any practical issues you may have (e.g. financial concerns).

For some survivors, following these tips may seem like hard work. You may need to try more than one approach. Take your time and find what works best for you. Many survivors say that following these tips helped them cope with the fear of cancer coming back and to feel in control. If you are struggling to manage your fears, speak to your GP or your treatment team. They will assist you to get the most suitable support.

Last reviewed: July 2017

Acknowledgment

Thank you to the health professionals and survivors who reviewed this document

Further information

- The Australian Government Department of Health and Ageing offers information about government screening programs: Call BreastScreen (13 20 50), the national cervical screening program (13 15 56) or the bowel screening helpline (1800 118 868).
- Through the Cancer Council Information and support line (131120) Cancer council booklets include 'Living well after cancer' www.cancer.org.au
- Contact the ACSC (Australian Cancer Survivorship Centre)

www.petermac.org/services/support-services/australian-cancer-survivorship-centre/cancer-survivors or the Cancer Council Information and Support line (13 11 20) to find out about 'Wellness and life after cancer forums'.

All of these services may be accessed through their website.

This overview has been prepared with reference to:

- Cancer Australia. Recommendations for the identification and management of fear of cancer recurrence in adult cancer survivors. Cancer Australia, Sydney. 2014
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women's fears about the possibility of breast cancer recurrence. *Annals of Behavioral Medicine*, 25(1), 16-24.



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