

FEAR OF CANCER RECURRENCE

Frequently Asked Questions

1 What is fear of cancer recurrence? How does it affect patients?

Fear of cancer recurrence (FCR) is defined as *fear, worry or concern relating to the possibility that cancer will come back or progress.*ⁱ

FCR is a unique and significant mental health issue. Mild FCR is associated with occasional thoughts about cancer with peaks of anxiety that are triggered by things like follow-up appointments and resolve after a few days. Moderate to severe FCR is more frequent thoughts about cancer without external triggers. Severe FCR is considered clinically significant FCR and is associated withⁱⁱ:

- Death-related thoughts
- Feeling alone
- Believing that the cancer will return
- Experiencing uncertainty
- Having cancer-related thoughts and imagery that are difficult to control
- Daily and recurrent thoughts
- Thoughts that last 30 minutes or longer
- Experiencing distress
- Experience of increased distress over time
- Impact on individual's daily life

Clinically significant FCR is unlikely to resolve itself without clinical intervention.

2 Can FCR be treated?

While evidence-based strategies are not yet widely available, in recent years there have been many studies evaluating FCR interventions for cancer survivors. Interventions that help manage FCR includeⁱⁱⁱ:

- Being mindful
- Addressing fears
- Managing uncertainty
- Gaining control
- Improving patient-healthcare provider communications
- Handling stress through counselling

For more information about treating FCR, speak to your healthcare team.

3 How does FCR affect a person's quality of life?

FCR can impact an individual's quality of life and is associated with emotional distress, anxiety, depression and isolation. FCR is associated with a decreased ability to participate in work, social activities, and relationships with partners and family. It can also affect a person's ability to make plans for the future.

4 How common is FCR? Do a lot of people experience it?

If you are experiencing FCR, you are not alone. It is among the most commonly reported psychosocial issues for cancer survivors. Specific to lymphomas, the 2018 Lymphoma Coalition Global Patient Survey on Lymphomas & CLL found that 43% of respondents experienced FCR during treatment and 72% experienced FCR after treatment.^{iv}

5 When does FCR most commonly happen?

Research shows that FCR most commonly occurs after treatment. This is when the individual begins to have less frequent contact with their health team, fewer appointments and less frequent touchpoints. The Lymphoma Coalition Global Patient Survey on Lymphomas & CLL showed that 72% of respondents experienced FCR after treatment, compared to 43% who experienced it during treatment.

However, it is recommended to talk about the psychosocial effect of a cancer diagnosis early and tell patients and families about the possibility of FCR. Additionally, because FCR can occur in waves, and change in severity over time, it is important to tell patients to note these patterns and discuss any changes with their care team. Normalising FCR and encouraging patients to discuss it can help reduce its effects and identify when therapy is needed.



6 Does FCR only affect people with lymphoma?

No. FCR is something that can affect people with all types of cancer.

7 If I think I'm experiencing FCR, should I speak to my health team? Who specifically should I talk to?

If you regularly have worries about your cancer coming back, talking with a member of your health team is a very good step to take. FCR can be experienced in several ways – from bouts of worry to emotional distress – and it can vary in severity. In fact, severe FCR is unlikely to resolve itself without clinical intervention.

All of the members of your health team – including haematologists, oncologists, nurses, allied healthcare professionals and your family doctor – can have an important impact on psychosocial well-being and help reduce FCR. Speak to a member of your team with whom you feel most comfortable and ask about treatment options and support resources.

8 Where else can I seek support for FCR?

Your local lymphoma patient group may have support programs for FCR. Find out if the organisation offers one-on-one counselling, education or support sessions or peer-support programs.

9 Why haven't I heard about FCR before?

As there have been advances made in cancer detection and treatment, many more people are surviving or living with cancers for many years. While improved cancer survival is a very good thing, it has resulted in these survivors living their lives concerned their cancer will come back. Unfortunately, research and understanding relating to quality of life issues associated with survivorship, or living with more chronic cancers, has not advanced as quickly.

FCR is a very common experience for which cancer survivors seek professional help or support, yet it is also one of the most frequently cited unmet needs. Though improving, the process of translating FCR knowledge and research into effective patient services and support is still slow.

