

FEAR OF CANCER RECURRENCE

Questions to Ask Your Care Team

Fear of cancer recurrence (FCR) is defined as *fear, worry or concern relating to the possibility that cancer will come back or progress*.¹ It can present in varying levels of severity, from occasional bouts of cancer-related anxiety to more intense, regular feelings of distress.

This document can help initiate proactive discussions between patients and their health team about FCR. Communication between patients and healthcare providers – including oncologists, haematologists, other doctors, nurses and allied healthcare professionals – can have an important impact on a patient's psychosocial well-being and help to reduce and address FCR.

PREPARING

Before meeting with your healthcare provider about FCR, there are several ways to prepare to make sure your questions are answered, and the information provided is retained:

- Write down your list of questions before the appointment. Also, prioritise the most important questions in case you run out of time during the appointment.
- Make sure you have a way to record the answers. Write them down in a notebook, take notes on a tablet or consider asking the healthcare professional if you can record the conversation to reference it later.
- Bring a family member or friend to the appointment so there is another person there for the conversation. They can help ask questions, record the answers and will also provide support during the discussion.
- You will need to speak openly with your doctor about your questions, concerns, and needs. Do not feel embarrassed to ask your doctor to repeat or further explain something.

QUESTIONS TO ASK

Use this list of questions as a guide as you prepare for your discussion about fear of cancer recurrence.

1. What is fear of cancer recurrence?
2. Are there specific signs and/or symptoms to be aware of? When should I talk to my doctor or healthcare provider?
3. Is FCR normal? Do a lot of people experience FCR?
4. Are there different types of FCR? Is it the same for everyone?
5. Can FCR be treated?
6. Are there programs at this hospital / cancer centre that address FCR?
7. Can you refer me to a therapist or program that addresses FCR?
8. Is there a patient organisation / support group that can help with FCR?
9. Is there anything I can do at home to help address FCR?
10. Are there any other activities I can do that can help?
11. What can caregivers, friends or family do to help?
12. Is FCR something that will affect me for the rest of my life?

¹ Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, Dinkel A, Butow P. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Supportive Care in Cancer*. 2016 Aug 1;24(8):3265-8.

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.

10

Will FCR go away over time? Will it go away with a change in attitude?

If you think you are experiencing FCR at any severity, it is important to speak to your healthcare team to discuss an assessment, and treatment and support options. While severe FCR is unlikely to resolve itself without clinical intervention, treatment and support can also help alleviate mild or moderate FCR.

Though FCR is normal and expected, if it is distressing you, you should do something about it. There are things your care team can suggest to help you understand and manage your FCR.

11

Is this about getting back to normal or having a positive attitude?

No. FCR is a recognised and common psychosocial issue for cancer patients and survivors. Individuals may have to develop a new 'normal' that includes their cancer experience into their lives.

However, there are behavioural therapies and psychotherapies that can help reduce and treat the effects of FCR. If you think you are experiencing FCR, speak to a member of your health team to find out more about available support and resources.

- i. Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, Dinkel A, Butow P. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Supportive Care in Cancer*. 2016 Aug 1;24(8):3265-8.
- ii. Mutsaers B, Jones G, Rutkowski N, Tomei C, Leclair CS, Petricone-Westwood D, Simard S, Lebel S. When fear of cancer recurrence becomes a clinical issue: a qualitative analysis of features associated with clinical fear of cancer recurrence. *Supportive Care in Cancer*. 2016 Oct 1;24(10):4207-18.
- iii. Gretchen Dawson MS. Interventions to manage uncertainty and fear of recurrence in female breast cancer survivors: a review of the literature. *Clinical Journal of Oncology Nursing*. 2016 Dec 1;20(6):E155.
- iv. Lymphoma Coalition. 2018 Global Patient Survey. lymphomacoalition.org/global-information/global-patient-survey/2018

FEAR OF CANCER RECURRENCE Fact Sheet

WHAT IS FEAR OF CANCER RECURRENCE?

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

Created in 2015 by a group of expert researchers, policy-makers and patient advocates from around the world, this definition suggests FCR can affect both patients with a curable disease who fear the cancer coming back, as well as patients with advanced disease who fear progression. This definition is widely recognised and is accepted for use in current research studies.

WHAT ARE THE SYMPTOMS OF FCR?

Fear of cancer recurrence is a unique and significant mental health issue. It can impact an individual's quality of life and is associated with anxiety, depression and isolation. FCR can also hinder the ability to plan for the future.

FCR can present itself in varying levels of severityⁱⁱ:

- Mild FCR – Occasional thoughts about cancer with peaks of anxiety that are resolved after a few days. These occasions are triggered by external factors like follow-up medical appointments.
- Moderate to severe FCR – More frequent thoughts about cancer without external triggers (one or more time per week), a perceived inability to control these thoughts, and a strong feeling of related distress.

Severe FCR is considered clinically significant and is unlikely to resolve itself without clinical intervention. Clinically significant or severe FCR is associated with the followingⁱⁱⁱ:

1. Death-related thoughts
2. Feeling alone
3. Believing that cancer will return
4. Experiencing uncertainty
5. Having cancer-related thoughts and imagery that are difficult to control
6. Daily and recurrent thoughts
7. Thoughts that last 30 minutes or longer
8. Experiencing distress
9. Experience of increased distress over time
10. Impact on individual's daily life

HOW COMMON IS FCR?

Fear of cancer recurrence is among the most commonly reported psychosocial issues for cancer survivors. It affects people with all types of cancer, and it may continue long after treatments are completed.

Specific to lymphomas, the 2018 Lymphoma Coalition Global Patient Survey on Lymphomas & CLL found that 43% of patients experienced FCR during treatment and 72% experienced FCR after treatment.^{iv} FCR was also reported to continue for up to 8+ years after treatment by some individuals.

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 include :

- 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.

- i. Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, Dinkel A, Butow P. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Supportive Care in Cancer.* 2016 Aug 1;24(8):3265-8.
- ii. Butow P, Sharpe L, Thewes B, Turner J, Gilchrist J, Beith J. Fear of cancer recurrence: a practical guide for clinicians. *Oncology-New York.* 2018 Jan 1;32(1):32-8.
- iii. Mutsaers B, Jones G, Rutkowski N, Tomei C, Leclair CS, Petricone-Westwood D, Simard S, Lebel S. When fear of cancer recurrence becomes a clinical issue: a qualitative analysis of features associated with clinical fear of cancer recurrence. *Supportive Care in Cancer.* 2016 Oct 1;24(10):4207-18.
- iv. Lymphoma Coalition. 2018 Global Patient Survey. lymphomacoalition.org/global-information/global-patient-survey/2018
- v. Gretchen Dawson MS. Interventions to manage uncertainty and fear of recurrence in female breast cancer survivors: a review of the literature. *Clinical Journal of Oncology Nursing.* 2016 Dec 1;20(6):E155.

FEAR OF CANCER RECURRENCE The 5 Ws

1

WHAT is fear of cancer recurrence?

Fear of cancer recurrence (FCR) is a unique and significant mental health issue defined as *fear, worry or concern relating to the possibility that cancer will come back or progress.*ⁱ

It can impact an individual's quality of life and it is associated with emotional distress, anxiety, depression and isolation.

2

WHO is affected?

People with all types of cancer can experience FCR. It is among the most commonly reported psychosocial issues for cancer survivors.

Specific to people with lymphomas, 43% experience FCR during treatment and 72% experience FCR after treatment.ⁱⁱ

3

WHEN does FCR occur?

Most often when treatment is completed and the individual has less frequent contact, support or appointments with their health team, but FCR can happen at any point after the initial diagnosis. FCR can also change in severity over time or because of certain triggers.

It is recommended to talk to patients about the emotional impact of a cancer diagnosis and normalise the possibility of FCR early on.

4

WHY does FCR happen?

Better cancer detection and treatment have led to many more people surviving or living with cancers for many years.

It has resulted in these survivors living their lives concerned or even distressed their cancer will come back.

5

WHERE can I go for help?

If you think you are experiencing FCR at any severity, speak to your healthcare team to discuss an assessment, interventions and available resources to help reduce and treat the effects of FCR.

i. Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, Dinkel A, Butow P. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Supportive Care in Cancer*. 2016 Aug 1;24(8):3265-8

ii. Lymphoma Coalition. 2018 Global Patient Survey. lymphomacoalition.org/global-information/global-patient-survey/2018

FEAR OF CANCER RECURRENCE Referral Guide

Fear of cancer recurrence (FCR) is defined as *fear, worry or concern relating to the possibility that cancer will come back or progress.*¹ It can present in varying levels of severity from occasional bouts of cancer-related anxiety to more intense, regular feelings of distress.

The following helps to identify when a patient should be referred onto appropriate support or treatment for FCR.

WHEN TO REFER PATIENTS FOR FCR SUPPORT OR TREATMENT

1 PATIENT INTERACTIONS

Is the patient raising their concerns related to their cancer returning? Have they been examining themselves for physical signs of cancer, or attributing small changes to a possible recurrence? Have they shown any signs of increased anxiety or worry about the future? Have you asked them about their emotional well-being in an open-ended way? A patient may also be especially vulnerable if they are just finishing treatment.

Understanding the comorbidities linked to FCR can also help identify individuals at risk. FCR is associated with lower overall health-related quality of life, lower social functioning, anxiety and depression.

If interactions with a patient lead you to believe they are experiencing FCR, they should be referred onto appropriate support. These interactions can occur with healthcare professionals, patient organisation staff, family or friends.

2 SCREENING FOR FCR

It is recommended to screen cancer patients using a validated measurement tool to assess FCR. Screening for FCR is particularly important at the end of treatment and during follow up appointments, when individuals have less contact with their healthcare teams. Since FCR may fluctuate throughout a patient's experience, it is also important to repeat assessments.

Ideally, a validated FCR measurement tool should be used alongside verbal open-ended questions because some patients may be more likely to respond to direct questions.

Screening for FCR should be done by a healthcare professional. If FCR is detected at any severity, this information should be shared with the patient and their healthcare team and the patient should be referred onto appropriate support.

A sample screening tool can be viewed at lymphomacoalition.org/FCR

FEAR OF CANCER RECURRENCE

Local Resources

Please find below a list of local resources for patients and caregivers related to Fear of Cancer Recurrence.

HOSPITAL AND CANCER CLINIC RESOURCES		
ORGANISATION	DESCRIPTION	CONTACT INFORMATION

IN-PERSON SUPPORT SERVICES		
ORGANISATION	DESCRIPTION	CONTACT INFORMATION

ONLINE RESOURCES AND WEBSITES		
ORGANISATION	DESCRIPTION	CONTACT INFORMATION

Updated on

FEAR OF CANCER RECURRENCE

Hosting an Educational Event

Consider hosting an event dedicated to educating your community about fear of cancer recurrence (FCR). An event, either held in person or virtually via webinar, creates an interactive opportunity for patients, carers and members of the lymphoma community to learn more about FCR, have their questions answered, and perhaps most importantly, see that they are not alone in their concerns about their cancer coming back.

EVENT FORMAT

When choosing your event format, consider what objective you're trying to achieve, as well as the resources available.

Expert Seminar – Work with a local expert to host an informative session that provides an overview of FCR, including what it is, the signs and symptoms and treatment. Experts to consider include physicians, nurses and/or social workers with direct experience related to FCR.

Panel Discussion – A panel discussion offers multiple perspectives from a variety of experts on the same topic. A panel focused on FCR could include a physician, a social worker and a person with lived experiences related to FCR. A panel discussion also benefits from a well-informed moderator who guides the discussion and manages questions from the audience.

Live or Online Event – There are benefits to both formats. In-person events allow people the opportunity to connect. Online events can be cost effective and reach a broader audience. If your event will be hosted online, look for effective web-based services in your region. It is also often possible to record the event and post to your website for future reference.

EVENT PLANNING TIP

Below are several tips and things to consider as you plan your event.

Save the date – Think about the best time for the people you want to attend. Weekday or weekend? During the day or evening? Once you've decided, try to give people at least one-month notice about your event.

Location, location – When choosing your venue, things to think about include rental fees, A/V needs, catering availability or restriction and accessibility to public transit and parking for attendees.

Spread the word – Look for cost-effective ways to let people know about your event. Advertise in the hospital newsletter, online or internal TV monitors, share on social media and put up posters in the hospitals and cancer clinics.

Build momentum – Once registered for the event, stay in touch with attendees with periodic reminder emails. Also consider sharing advertising materials or social media assets for them to share with their friends, family and colleagues.

Stay in touch – At the event, collect participants' email addresses. Send a follow-up note after the event with a thank you and key learnings from the event, and encourage them to join your community, follow your social media pages and volunteer at upcoming events.

FEAR OF CANCER RECURRENCE Therapy Overview

Fear of cancer recurrence (FCR) is defined as *fear, worry or concern relating to the possibility that cancer will come back or progress.*¹ It can present in varying levels of severity from occasional bouts of cancer-related anxiety to more intense, regular feelings of distress.

The following overview examines ways to screen and assess, as well as reduce and treat FCR.

PATIENT-HEALTHCARE PROVIDER COMMUNICATIONS

Communication between patients and healthcare providers – including oncologists, haematologists, other doctors, nurses and allied healthcare professionals – can have an important impact on a patient's psychosocial well-being and help reduce FCR.

However, FCR is often left out of care planning and discussions between patients and healthcare providers. The 2018 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL found that only 45% of patients discussed their FCR with their doctor, and only 29% felt it helped alleviate their fear. Of those who discussed their FCR with their doctor, only 37% were referred onto further support.

While FCR is associated with patients whose cancer is in remission, it is important to note that 43% of patients with lymphoma reported starting to experience FCR before their initial treatment was completed. Providing adequate information about prognosis, information about the signs and symptoms of a recurrence, and strategies for risk reduction inform and empower patients about their own health. Lymphoma Coalition research has demonstrated that confidence, which stems from information and support, plays a significant role in positive healthcare experiences and outcomes.

It is also important to talk about the psychosocial effect of a cancer diagnosis and tell patients and families about the possibility of FCR. Normalising FCR and encouraging patients to discuss it can help reduce its effects and identify when therapy is needed.

ASSESSING AND SCREENING

Fear of cancer recurrence affects the majority of cancer survivors. It has the potential to be severe and significantly affect a person's quality of life. For these reasons, screening using a validated measurement tool to assess FCR is recommended. Ideally, a validated FCR measurement tool should be used alongside verbal open-ended questions because some patients may be more likely to respond to direct questions.

If FCR is detected at any severity, it is important this information be shared with the patient and their healthcare team, and that the patient is referred onto appropriate support. Severe FCR is considered clinically significant and is unlikely to resolve itself without clinical intervention.

Understanding predictors that are more commonly associated with FCR can also help identify individuals who are at higher risk of FCR. These predictors include demographic features such as being younger, female, and of lower social-economic status; clinical features such as pain, fatigue, and a lack of well-being; and psychosocial features including depression, anxiety, and lower levels of optimism.

Screening for FCR is particularly important at the end of treatment and during follow up appointments, when individuals have less contact with their healthcare teams. Since FCR may fluctuate throughout a patient's experience, it is also important to repeat assessments. Specific to lymphomas, the 2018 Lymphoma Coalition Global Patient Survey on Lymphomas & CLL found that 43% of patients experienced FCR during treatment and 72% experienced FCR after treatment.ⁱⁱ Patients' report FCR peaked immediately following treatment (27%) and 3 - 5 years after treatment (22%).ⁱⁱⁱ

Find validated measuring tools at
lymphomacoalition.org/FCR

- i. Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, Dinkel A, Butow P. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Supportive Care in Cancer*. 2016 Aug 1;24(8):3265-8.
- ii. Lymphoma Coalition. 2018 Global Patient Survey. lymphomacoalition.org/global-information/global-patient-survey/2018
- iii. Ibid

TYPES OF THERAPY

Several behavioural therapies and psychotherapies have been adapted to address FCR in cancer survivors.

Acceptance and Commitment Therapy (ACT)

This therapy suggests that greater well-being can be achieved by overcoming negative thoughts and feelings. Often conducted one-on-one with a therapist, ACT promotes forms of coping including accepting cancer-related distress, reducing cancer-related avoidance, clarifying personal values and committing to behavioural change.

Cognitive Behavioural Therapy (CBT)

The goal of CBT is to change the patterns of thinking or behaviours that are behind the individual's difficulties. Usually conducted one-on-one with a therapist, CBT focuses on the individual's thoughts, images, attitudes or beliefs and how they relate to the way the person reacts or behaves.

Blended Cognitive Behavioural Therapy (bCBT)

Similar to CBT, this therapy employs both face-to-face sessions with a therapist and web-based sessions offering the individual continuous access to online interventions.

Cognitive Existential (CE)

In this setting, CE aims to improve mood and mental attitude towards cancer. Used in individual and group settings, themes related to oncology-focused CE include working through grief over losses, improving problem-solving, developing cognitive strategies to improve coping, body and self-image, sexuality and relationships.

Mindfulness-Based Stress Reduction (MBSR)

Usually in a group setting, this therapy employs mindfulness meditation, body scanning and yoga postures to help individuals become more aware of habitual reactions and find new ways to interrupt the cycle and create more choice. Key principles include non-judging, non-striving, acceptance, letting go, beginner's mind, patience, trust and non-centring.

Communication Skills Training (CST)

Also known as Survivorship Care Planning, CST programs are being developed for physicians to help them initiate survivorship-focused care plans that go beyond more common discussions of nutrition, exercise and rehabilitation, to include psychosocial issues and concerns.

Are You Experiencing Fear of Cancer Recurrence?

Feeling alone?

Believe the cancer will return?

Experiencing distress?

Trouble making plans for the future?

Experiencing uncertainty?

Death-related thoughts?

Fear of cancer recurrence (FCR) is a unique and significant mental health issue defined as fear, worry or concern relating to the possibility that cancer will come back or progress.¹

It impacts daily life and is associated with emotional distress, anxiety, depression and isolation.

Research shows that **43%** of people living with lymphoma experience fear of cancer recurrence during treatment and **72%** experienced it after treatment.



If you think you are experiencing FCR, you are not alone.

Help is available.

For more information and resources, visit:

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