

Fear of Cancer Recurrence (FCR) Pathway

General Overview and Management

Most cancer survivors experience FCR, with approximately 49% experiencing moderate to severe levels. For more information click here: [▶](#)

General steps to take in Primary Care:

- Normalize the presence of FCR for patients
- Provide suggestions for coping, with specific instructions and/or resources. Click here for patient self-management resources: [▶](#)
- Educate patients about habits that may seem helpful in the short-term but actually make FCR worse long-term, such as:
 - Avoiding medical appointments
 - Checking for signs of recurrence too much or too little, outside of recommended guidelines
 - Excessive online searching about their cancer and recurrence

Assessment

FCR can be assessed by using the validated 9-item severity subscale of the Fear of Cancer Recurrence Inventory (FCRI) tool ^(3,4). [▶](#)

Levels of Severity

Low to Moderate: Score of 0-15 on FCRI	High: Score of 16-21 on FCRI	Clinically Significant: Score of ≥ 21 on FCRI
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Managing Low to Moderate Levels of FCR

- Assist patient in identifying when FCR is experienced and its triggers (e.g., medical settings, hearing of others with cancer).
 - Ask patient what specifically they are fearing about recurrence (e.g., treatment, side effects, death, impact on loved ones)?
- Provide information to patient about the after treatment stage, such as the surveillance test schedule, and what to expect in their follow-up care. [▶](#)
- Clarify the role of the patient's primary care provider versus their cancer care provider and the types of concerns they would bring to each. [▶](#)

Click for more information about managing low/moderate levels of FCR [▶](#)

Managing High and Clinically Significant Levels of FCR

- Communicate that although FCR is normal in patients, high or severe levels negatively impact patients' health and activities of daily living.
- Refer to professionals specializing in psychosocial cancer care. Click here for AHS CCA referral information. [▶](#)
- If the primary care provider is part of a Primary Care Network (PCN), the patient can also be referred to the PCN's behavioural or mental health professionals.
- There can be high wait times for specialized psychosocial care services. For more immediate (24/7) phone support while awaiting access to such services, patients can call:
 - Mental Health Helpline: 1-877-303-2642
 - Distress Centre: 211
 - > Online Mobile Chat: <https://ab.211.ca/>

Click for more information about managing high/clinically significant levels of FCR [▶](#)

Overview of Fear of Cancer Recurrence (FCR):

General Overview:

- Fear of Cancer Recurrence (FCR) is generally defined as: “Fear, worry, or concern relating to the possibility that cancer will come back or progress.” (1)
- It is a normal response in many patients who have had cancer treatment and are in the survivorship stage, and for those patients who may have an advanced, chronic, or metastatic cancer that they fear will progress.
- It is estimated that an average of 49% of overall cancer survivors experience moderate to severe levels of FCR (2).

From Butow et al (2), FCR may happen in any patient who has had cancer, but may be more common in:

- patients who are younger
- patients who have had more severe side effects
- patients with a cancer that may be more likely to recur
- patients who have an existing anxiety condition

Steps to Take in Primary Care

Assessment:

- FCR can be assessed by using the validated 9-Item severity subscale of Fear of Cancer Recurrence Inventory (FCRI-SF) tool (3) (4):

https://www.cfp.ca/content/cfp/suppl/2020/09/14/66.9.672.DC1/672_Fear_of_Cancer_Recurrence_Short_Form.pdf

- Low to moderate levels of FCR are scored at 0-15
- High levels are scored at 16-21
- Clinically significant severe levels are scored at ≥ 21

More information about how to assess for Fear of Cancer Recurrence can be found here:

[Assessing and managing patient fear of cancer recurrence | The College of Family Physicians of Canada \(cfp.ca\)](#).

Please note: If you suspect that the patient may not have FCR, but instead General Anxiety Disorder (GAD), you can complete one of the GAD pathways below.

- Specialist Link (Calgary and area) pathway:
https://www.specialistlink.ca/assets/pdf/CZ_Anxiety_pathway.pdf
- Connect MD (Edmonton and area) pathway:
<https://pcnconnectmd.com/wp-content/uploads/2022/09/Anxiety-Primary-Care-Pathway-Edmonton-Zone.pdf>

Management:

Recommendations from Mutsaers et al (4), Galica et al (5), and CCA Supportive Care include:

Patients with low-moderate FCR:

- Normalize the presence of FCR for patients.
- Assist in the identification of when FCR is experienced and the triggers for FCR (e.g., medical settings, feeling certain symptoms, hearing about others with cancer).
 - Ask what exactly they are fearing about recurrence (i.e., treatment, side effects, death, impact on loved ones)?
- Provide information to patients about the post-treatment stage, such as their surveillance test schedule, and what they may expect in their follow-up care.
- Clarify the role of the primary care provider versus cancer care provider and the sorts of concerns they would present to you (PCP) vs. their cancer care providers.
- Provide suggestions for coping, like exercise, meditation, socializing, journaling.
- Share specific instructions and/or resources (e.g., handouts websites, phone apps). Examples of specific resources are found in [Patient Self-Management Resources](#).
- Educate patients about habits that may seem helpful in the short-term but could make FCR worse in the long-term, like avoiding medical appointments, checking for signs of recurrence (e.g., scanning and checking the body) too much or too little outside the recommended guidelines for their age and health history, and excessively searching topics related to their cancer and recurrence online.

Patients with high and clinically significant severe levels:

- Normalize the presence of FCR for patients; however also communicate that at high and severe levels, negative impacts on their activities of daily living occur.
- [Refer](#) to professionals specializing in psychosocial cancer care (cancer-related counseling, classes/groups, spiritual care, psychiatry, nurse navigation, sexual health consultation). AHS CCA supportive care referral information can be found [here](#).
- If the primary care provider is part of a Primary Care Network, the patient can be referred to the PCN behavioural or mental health professionals, as they would have the skillset to support patients.
- There can be high wait-times for specialized psychosocial care services. For more immediate (24/7) phone support while awaiting access to such are, patients can call:
 - Mental Health Helpline at 1-877-303-2642
 - Distress Centre at 211
 - Or online mobile chat <https://ab.211.ca/>
- Provide suggestions for coping, like exercise, meditation, socializing, journaling. Share specific instructions and/or resources (e.g., handouts websites, phone apps). Examples of specific resources are found in [Patient Self-Management Resources](#).
- Educate patients about habits that may seem helpful in the short-term but could likely make the FCR worse in the long-term, such as avoiding medical appointments, checking for signs of recurrence (e.g., scanning and checking the body) too much or too little outside the recommended guidelines for their age and health history, and excessively searching topics related to their cancer and recurrence online.

How to Refer to Counselling and Supportive Care:

Referral to CCA Psychosocial Oncology:

- Patients can self-refer to Psychosocial Oncology.
 - The phone numbers for the closest/easiest location to access can be found in [this brochure](#).
 - Services offered to patients include group classes, counsellor-led support groups, one-on-one counselling, and psychiatry services. More information can be found in [this one-page document](#).
- If patients are reluctant to self-refer, you can refer directly through the [Alberta Referral Directory](#).
 - Search 'psychosocial oncology' on the website to see the services and referral forms.
 - Please note, if the health professional completes the referral, patient consent for referral is an eligibility requirement.

Community-Based Treatment:

- If you are part of a Primary Care Network, the patient can be referred to the PCN behavioural or mental health professionals for support.
- There can be high wait-times for specialized psychosocial care services. For more immediate (24/7) phone support while awaiting access to such are, patients can call:
 - Mental Health Helpline at 1-877-303-2642
 - Distress Centre at 211
 - Or online mobile chat <https://ab.211.ca/>

Additional Resources:

Alberta:

[Cancer Care Alberta Supportive Care Framework](#)

[Wellspring Programs and Services](#)

Canada:

[Canadian Cancer Society Fear of Recurrence information](#)

North America:

[Coping with the Fear of Cancer Recurrence \(cancer.org\)](#)

[Cancer.net Fear of Recurrence](#)

International:

[Cancer Australia Guidelines](#)

References:

1. Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, et al. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Support Care Cancer*. 2016 Aug;24(8):3265–8.
2. Butow P, Sharpe L, Thewes B, Turner J, Gilchrist J, Beith J. Fear of Cancer Recurrence: A Practical Guide for Clinicians. *Oncol* 08909091. 2018 Jan;32(1):32–8.
3. Simard S, Savard J, Simard S, Savard J. Fear of Cancer Recurrence Inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. *Support Care Cancer*. 2009 Mar;17(3):241–51.
4. Mutsaers B, Rutkowski N, Jones G, Lamarche J, Lebel S. Assessing and managing patient fear of cancer recurrence. *Can Fam Physician*. 2020 Sep 1;66(9):672–3.
5. Galica J, Maheu C, Schroeder D, Lebel S. Understanding Fear of Recurrence. In: *Adult Cancer Survivorship: A Self-Learning Resource for Nurses*. Canada: Canadian Association of Nurses in Oncology; 2020. p. 110–40.

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DISCLAIMER: The evidence-based information and recommendations provided in this pathway and resource are intended to assist Primary Care Providers with supporting patients who may be experiencing fear of cancer recurrence. These recommendations are not intended to be a substitute for clinical judgment.

Patient Self-Management Resource Fear of Cancer Recurrence (FCR)

FCR is generally defined as: “Fear, worry, or concern relating to the possibility that cancer will come back or progress.” (1). It is a normal response in many patients who are in the after treatment stage, and for those patients who may have an advanced, chronic, or metastatic cancer that they fear will progress. Activities like exercising, meditating, journaling may help you manage your FCR. To access the resources and tools below, you can use the weblinks provided, or use your mobile phone’s camera to capture the accompanying QR code. Also attached are the pages about managing FCR from the CCA After Treatment book.

Resources:

Please Note: bit.ly links are case sensitive

After Treatment Book— <https://bit.ly/CCAatb>

A comprehensive 48-page PDF resource for patients who are finishing treatment. The booklet covers common concerns and includes information to help patients set priorities and take action.



Australian Cancer Survivorship Centre Factsheet — <https://bit.ly/ACSCfcr>

2-page PDF resource that provides information on FCR.

CCA FCR Video — <https://bit.ly/CCAfcr>

Video by CCA Psychosocial Oncology about emotions, including fear. This link starts at 15:29 of the video and focuses on fear. The speaker talks through common concerns, how to self-manage, and when to connect with a health professional.



Wellspring FCR Video — <https://bit.ly/WSfcr>

Comprehensive 54-minute video broken into sections and includes content on recognizing and managing symptoms, and tips about managing FCR during the COVID-19 pandemic.

1) Lebel S, Ozakinci G, Humphris G, Mutsaers B, Thewes B, Prins J, et al. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. Support Care Cancer. 2016 Aug;24(8):3265–8.

Tools:

Please Note: bit.ly links are case sensitive



Alberta Cancer Exercise Study — <https://bit.ly/aceStudy>

Free, 12-week, community-based exercise program for people undergoing or recovering from cancer treatment. If you enroll in this program, you will also be asked to complete fitness assessments and study questionnaires.

Exercise for Cancer to Enhance Living Well Study — <https://bit.ly/EXCELstudy>

Free, 12-week, online exercise program for people undergoing or recovering from cancer treatment who are living in rural and remote regions in Canada.



UCLA Mindful App — <https://bit.ly/uclaMindful>

Free University of California, Los Angeles (UCLA)- developed app for mindfulness and meditation. Contains basic and wellness meditations, videos, and weekly podcasts. **NOTE:** meditations are designed for educational purposes and are not clinical treatments.

Government of Western Australia, Centre for Clinical Interventions Self-Help Workbook for Health Anxiety — <https://bit.ly/ccliHANx>

PDF resource with 9 modules about how health anxiety develops, how to reduce the anxiety, how to adjust health assumptions, and healthy living and self-management tips.



This resource can be found on pages 30-31 of the **Cancer Care Alberta After Treatment Book (2022)**. You can find the most updated version of the After Treatment Book at <https://www.albertahealthservices.ca/assets/info/cca/if-cca-after-treatment-for-cancer.pdf> or by scanning the QR code.



Explore ways of managing fear and uncertainty

After cancer treatment finishes people sometimes find their fear can be overwhelming and other times find it more manageable. This is normal! The anniversary date of diagnosis or follow-up appointments can cause fear and anxiety. There are things you can do to help manage these feelings and live your life the way you want to.

? I worry about the cancer coming back like when I have aches or pains. What will help?

Aches and pains can be normal as we age. If you have a new, unexplained pain that will not go away or gets worse, talk to your doctor. For other worries:

try these

- Practice a healthy lifestyle (physical, psychological, emotional, and spiritual wellness)
- Maintain a good relationship with your healthcare provider
- Try to keep a sense of hope, optimism, and humour
- Find support from family, friends, support programs, and professionals

? What can I do about fear and uncertainty?

try these

Express your feelings – including the unpleasant ones like fear, anxiety, uncertainty, sadness, or frustration. There are lots of ways to do this:

- Share your feelings with a trusted friend or family member
- Attend a support group, or try www.cancerconnection.ca
- Meditate or pray
- Go for a walk or get some exercise



Manage your medical concerns

If you feel like your cancer follow-up is being managed well, you may feel less anxious about the future and you may worry less about the cancer coming back.

- Talk with your oncology team or family doctor about what you should watch for and what tests you will need and when.
- See your family doctor for regular check-ups, and your medical concerns.
- Find out more about how to take care of yourself after cancer, including activity and eating well after cancer.



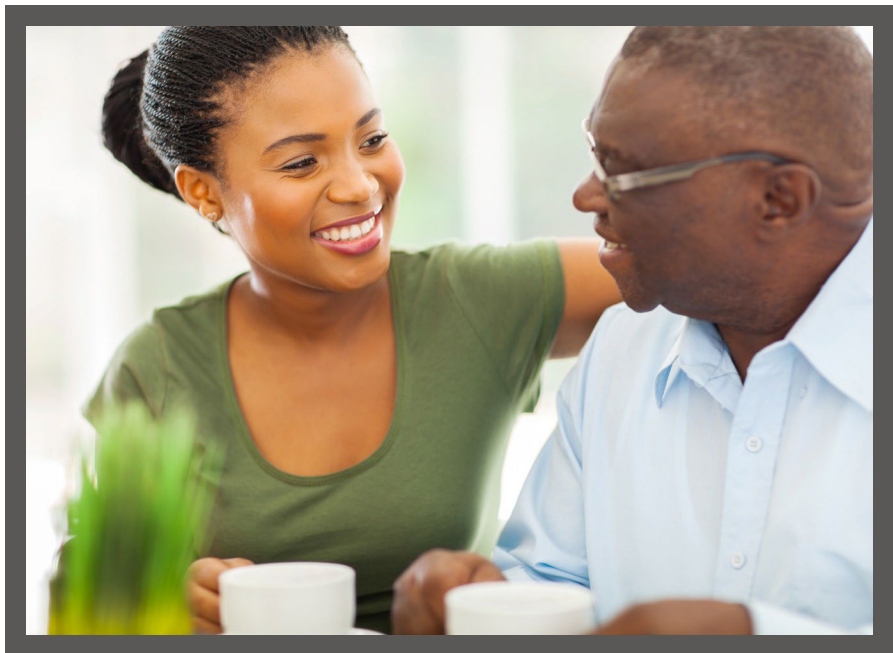
Focus on the positive. This does not mean you should be positive all the time – that is not realistic or healthy. It just means taking the time to focus on something positive to help you feel better.

- Focus on living each moment and day as it comes instead of thinking about what comes next.
- Look for positive things in your day or your life and practice feeling grateful for them.
- When you do feel fear, try changing activities. Do not let the fear take over. Sometimes just doing something else can help your mind think about other, more positive things.
- Look for ways to relax and manage your stress. Laugh, go to a movie, get outdoors, or do an activity to help you relax.
- Find something that brings a sense of purpose or meaning to your life.
- Ask yourself if there is something you can do to deal with your fear, like getting more information, talking to someone or seeing your doctor. If there is, take action.

Get support

Having people around you who can give you support may help you manage your fear and uncertainty.

- Being honest with trusted loved ones is worth trying. Telling some loved ones about how you feel, including your challenges and concerns may get you understanding and support.
- Make plans with people who make you feel better rather than worse.
- Ask for the kinds of support you need in a clear and direct way.



People often want to help but are not sure how. Try asking for specific things like “Can you pick my daughter up from school today?” or “Can you bring something over for dinner on Saturday?”

- Talk to, or read about people who have had similar experiences. You can look at online and in person support groups, discussion forums as well as blogs or books written by cancer survivors.