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Fear of Cancer Recurrence Guideline

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- Cancer Care Ontario Person-Centred Care Guideline: Endorsement and Adaptation of CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. 2015 May 2015. Person-Centred Care Program
- Li M, Kennedy EB, Byrne N, Gerin-Lajoie C, Green E, Katz MR, et al. The management of depression in patients with cancer. Toronto (ON): Cancer Care Ontario; 2015 May 11. Program in Evidence-based Care Guideline No.: 19-4.

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Fear of Cancer Recurrence Guideline

Recommendations

GUIDELINE OBJECTIVES

To make recommendations based on evidence-based strategies and/or interventions to screen, assess, and manage fear of cancer recurrence (FCR) in adults living with cancer and their care partners/family members to improve patient outcomes.

TARGET POPULATION

Adults living with cancer and care partners/family members (≥18 years)

- Includes adult survivors of childhood cancer,
- Includes people currently in treatment and post treatment for cancer,
- Care partners include family members and other support people (i.e., friends) who provide unpaid care to cancer survivors.

INTENDED USERS

The intended users of this guideline include oncology professionals, primary care providers, healthcare professionals working with cancer patients, psychosocial oncology professionals, and decision and policy makers in hospitals, clinics, and health systems in the province of Ontario.

PREAMBLE

FCR presents on a spectrum of severity [1]. The definition of FCR is the fear, worry, or concern relating to the possibility that cancer will come back or progress [1]. The definition of clinical FCR, based on a Delphi study of FCR experts, stipulates that clinical FCR occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is accompanied by distress or impairment [2]. Moderate FCR is described as subclinical presentation of FCR determined by the presence of some but not all the symptoms of clinical FCR [3,4]. Low FCR is indicated by a patient having occasional or transient thoughts or worry about FCR accompanied by minimal distress or impairment [1].

There is strong evidence for the efficacy of high-intensity intervention for people with high levels of FCR. Specifically, interventions that directly target FCR have shown better results at reducing FCR than general broad band interventions aimed at improving distress and coping [5,6]. Modest evidence is available for those with moderate FCR, and weak evidence concerns people with low FCR. A matched care approach matches the intensity of intervention to the severity of FCR. A person with high or clinical FCR would be offered a high-intensity intervention and a person with low FCR would be offered a lower intensity intervention. Additional studies are necessary to support specific interventions for patients with moderate or low FCR.

Attention to preferences for intervention types and delivery options must also be considered when recommending available interventions to people with FCR.

The glossary that follows this preamble provides definitions for terms used throughout the guideline.

The supplemental information section that follows the recommendations provides links to webpages with tools to help with communication, interventions and programs that may be used with patients and care partners with FCR.

Glossary

Common Terms

Care partner

An individual who provides unpaid essential and on-going personal, social, psychological and/or physical support and care, as deemed important to the person requiring care. This can include support in decision-making, care coordination, care delivery and continuity of care. The term implies a two-way relationship with a shared purpose, and it includes people who are identified as family, chosen family, an informal caregiver, or a friend.

Clinical or high FCR

Clinically significant FCR that occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is accompanied by distress or impairment [2].

Subclinical or moderate FCR

Described as subclinical presentation of FCR determined by the presence of some but not all of the symptoms of clinical FCR.

Minimal or low FCR

Indicated by a patient having occasional or transient thoughts or worry about FCR accompanied by minimal distress or impairment.

FCR screening

Questionnaires to identify FCR in patients or care partners to indicate a need for further assessment. Screening questionnaires are usually brief and may consist of only one question.

FCR assessment

Questionnaires and/or clinical interview to quantify and evaluate the severity of FCR in patients or care partners.

FCR Intervention

Programs or processes to reduce the severity of FCR in patients or care partners.

Interventions and Organization

Matched Care Approach for Intervention Organization

The matched or stratified approach is a way to deliver care and intervention to patients and care partners. This approach tailors the FCR interventions to match with the severity of FCR [7]. Those deemed to have mild levels of FCR are referred to minimal interventions, those with moderate levels of FCR are referred to intermediate intensity interventions and those with high FCR are referred to high intensity interventions.

Cognitive Behavioural Therapy

Cognitive behavioural therapy (CBT) interventions, including mindfulness-based stress reduction, acceptance and mindfulness, commitment therapy and compassion-based interventions [8].

Traditional CBTs focused on the contents of thoughts and aimed to identify and modify people's negative thoughts or biases to reduce dysfunctional emotions and promote psychological adjustment, whereas contemporary CBTs focused on mental processes and aimed to modify how people relate to their inner experiences [9].

Mind-body interventions

Mind-body interventions include meditation, relaxation techniques, the use of the creative arts, mindfulness-based stress reduction (MBSR) and may also include elements of CBT [10].

Psychoeducational Program

Psychoeducation refers to the process of providing education and information to those seeking or receiving mental health services, experiencing psychological symptoms or seeking medical care services and may combine the elements of CBT, group therapy, and education.

Non-mental Health Specialist

Interventions delivered by non-mental health specialists including doctors, nurses, and radiation therapy technologists for FCR within the context of routine medical oncology follow-up clinics [11].

Telecoaching

Telecoaching is the use of motivational interviews delivered over the telephone.

Screening and Assessment Tools Descriptions

Fear of Cancer Recurrence Inventory (FCRI)

The FCRI is a 42-item self-report scale for assessing the FCR. Higher scores indicating greater fear of recurrence. The FCRI consists of seven subscales: Triggers, Severity, Psychological Distress, Coping Strategies, Functioning Impairments, Insight, and Reassurance. There is no evidence for a cut-off score for the FCRI [12].

Fear of Cancer Recurrence Inventory Short Form (FCRI-SF)

The FCRI-SF is a short form of the FCRI that is the eight items of the severity subscale. A cut-off score of 13 or above indicates the possibility of clinical level FCR [13], a score of 16 or above indicates the likely presence of clinical level FCR and a score of 22 or above indicates a clinical severity of FCR that needs specialized intervention [4].

Fear of Cancer Recurrence Inventory-Caregiver (FCRI-Caregiver)

The 42-item FCRI-Caregiver was revised from the FCRI (patient version) and examined seven general areas: triggers, severity, psychological distress, functional impairment, insight, reassurance, and coping strategy. Each question was rated on a Likert scale ranging from 0 (not at all or never) to 4 (a great deal or all the time), with a higher score indicating a greater FCR [14].

Fear of Progression Questionnaire (FoP-Q)

The FoP-Q is a 43-item questionnaire to measure the fear of progression in chronically ill patients. The scale comprised five factors: affective reactions (13 items), partnership/family (7 items), occupation (7 items), loss of autonomy (7 items) and coping with anxiety (9 items) [15]. There is no evidence for a cut-off.

Fear of Progression Questionnaire - Short Form (FoP-Q-SF)

Consists of 12 items with four of the five subscales (excluding coping) from the original FoP-Q scale. The items are scored on a five-point Likert scale, ranging from 1 ("never") to 5 ("very often"). The resulting sum score of the FoP-Q-SF ranges from 12 to 60. A cut-off of 34 or over 34 for dysfunctional FoP has been derived in adult cancer patients [16].

Fear of Progression Questionnaire Short Form Parent (FoP-Q-SF/PR)

The FoP-Q-SF represents four of the five subscales of the long form (affective reactions, partnership/family, occupation, and loss of autonomy). The items are scored on a five-point Likert scale, ranging from 1 ("never") to 5 ("very often"). The resulting sum score of the FoP-Q-SF/PR ranges from 12 to 60. A cut-off of ≥34 for dysfunctional FoP has been derived in adult cancer patients [17].

RECOMMENDATIONS, KEY EVIDENCE, AND JUSTIFICATION

The following recommendations are based on the expertise and opinion of the Working Group, informed by the available research evidence. There is a flow chart following the recommendations that summarizes the steps for screening, assessing, and managing FCR.

Recommendations for Screening Fear of Cancer Recurrence

Recommendation 1.1 - Patients

It is recommended that a single-item screening tool be given to patients routinely to scan for FCR. Specifically recommended is the Fear of Cancer Recurrence 1 Item Screening Tool revised (FCR-1r) with a cut-off of five or more out of 10 signaling the potential presence of at least moderate FCR thus indicating a further need for FCR assessment.

Edmonton Symptom Assessment System Fear of Cancer Recurrence Question:
Please circle the number that best describes how you feel now:
(FCR = fear that your cancer might come back or get worse)

0 No FCR	1	2	3	4	5	6	7	8	9	10 Worst possible FCR

Qualifying Statements for Recommendation 1.1

- This item is similar in wording to the Edmonton Symptom Assessment System (ESAS) questions and is designed to be embedded into the ESAS, which is routinely used at every visit to cancer centres in Ontario. Being screened at each visit would allow for fluctuations in individual variability [18].
- Completing a screening tool may make it easier for patients to have a conversation regarding FCR that they may otherwise be reluctant to have with their oncologist.
- Evidence has shown that screening for FCR had similar consultation times to regular follow-up appointments.
- Additional studies need to be conducted to establish the optimum cut-off score to use.
- Although overall FCR levels tend to be stable over time [19], clinicians should be aware that a visit to the cancer centre, and waiting for test results or documents are triggers that will elevate FCR in most patients, including those with low FCR, and therefore elevated scores on the screener need to be followed by a more in-depth questionnaire or clinical interview.

Recommendation 1.2 - Care partners

Care partners would benefit from FCR screening in the opinion of the Working Group and the existing literature.

Qualifying Statements for Recommendation 1.2

- More research needs to be conducted to create validated measures specific to care partners.

Recommendations for Assessment of Fear of Cancer Recurrence

Recommendation 2.1 - Patients

There is a systematic review pending publication that will be used to inform recommendations for the selection of assessment tools (questionnaires) of FCR in patients when fully published and this document will be updated at that time.

Recommendation 2.2 - Care Partners

It is recommended that the FoP-Q-SF/PR and the FCRI-Caregiver be used to measure FCR in care-partners, until care-partner-specific measures are developed.

Recommendations for Interventions for Fear of Cancer Recurrence

Recommendation 3.1

Low-Intensity Interventions for Minimal or Low FCR

3.1.1 An online (completely self-led or self-led with assistance when needed) FCR-specific intervention (e.g., CBT) should be offered for people with low-to-moderate FCR.

3.1.2 Low-intensity interventions that are not specific to FCR, such as exercise programs, could be offered to people with low FCR.

Qualifying Statements for Recommendation 3.1

- There is insufficient evidence to determine the optimum timing for FCR interventions (i.e., during or post treatment).
- Providing a general medical informational booklet on survivorship care to people with low-to-moderate FCR is not sufficient.
- Guidance and/or coaching in conjunction with self-led interventions can lead to better attendance and adherence to a treatment or follow-up protocol as well as increased participant satisfaction.
- Communication therapy with patients (i.e., teaching patients how to ask medical questions to the oncology team) does not appear to influence patient FCR. However, teaching oncologists how to introduce, discuss, validate, and respond to FCR may have a beneficial effect on the patients' concerns around FCR.
- In the absence of more studies, patients could be offered exercise programs that meet the suggested Canadian 24-Hour Movement Guidelines.
- Patients should be asked about their preferences for intervention types and delivery options.

Recommendation 3.2

Intermediate-Intensity Interventions for Moderate FCR

3.2.1 Those with moderate FCR could be offered a moderately intensive, general intervention, preferably in group format. Specifically, participation in either a psychoeducational program, relaxation training and/or professionally led support group is suggested for people with moderate FCR, although there is limited evidence on effectiveness at this time.

Qualifying Statements for Recommendation 3.2

- There is insufficient evidence to determine the optimum timing for these interventions (i.e., during or post treatment).

- Psychoeducational programs and support groups could be delivered by a range of mental health professionals with experience in oncology care.
- Psychoeducational programs should offer information regarding cancer management, survivorship, and symptoms surveillance, and could include information on FCR.
- Patients should be asked about their preferences for intervention types and delivery options.

Recommendation 3.3
High-Intensity Interventions for high FCR

3.3.1 Participation in an individual or group FCR-specific CBT or mind-body interventions (MBI) program, led by mental health professionals with experience in oncology care is indicated for people with high FCR (i.e., FCR occurs regularly outside of predictable triggers such as annual visits to the cancer centre or waiting for test results, lasts a minimum of three months, and is associated with impaired functioning or significant psychological distress).

3.3.2 A face-to-face or a blended format intervention (combination of face-to-face and video conferencing), with an average of six to seven sessions, is recommended.

Qualifying Statements for Recommendation 3.3

- Due to the absence of comparative studies, we cannot recommend one approach versus another; however, the evidence was strongest for various CBT and mindfulness-based approaches. Studies used several intervention strategies so we cannot comment on the usefulness of specific strategies.
- Studies have yet to report on the efficacy of interventions that are delivered entirely by video conferencing.
- No difference in FCR has been observed between sessions held during treatment compared with post treatment.
- There is insufficient evidence to show a benefit of high-intensity FCR interventions when delivered by a non-mental health specialist.
- Patients should be asked about their preferences for intervention types and delivery options.

Recommendation 3.4
Caregiver Interventions

3.4.1 There is insufficient evidence at this time to make recommendations about interventions for care partners. It is the opinion of the Working Group that care partners would benefit from existing interventions adapted to care partners.

3.4.2 More research needs to be done to develop and evaluate interventions for care partners with FCR given the evidence of almost 50% of care partners having moderate to high FCR.

Qualifying Statements for Recommendation 3.4

- Preliminary evidence has found that care partners have different experiences with FCR than patients and that proper adaptations of patient interventions for use with care partners can be satisfactory and acceptable to care partners.
- Care partners should be asked about their preferences for intervention types and delivery options.

IMPLEMENTATION CONSIDERATIONS

The identification and treatment of FCR recommendations are very important to all patients and care partners. Patients have identified FCR as one of the top unmet needs [10] and the Working Group believe that these recommendations are acceptable and flexible and allow for conversations with the care provider so that the patients' treatment preferences will be known and met.

Asking the patient FCR screening questions at each follow-up visit would be easy to implement and has been shown to not add additional time to appointments [19]. (See Resource section for brief FCR intervention for oncologists [CIFeR]). Asking all patients at each visit will allow for the opportunity for more equitable identification and treatment of FCR. Screening care partners, while beneficial, would require more implementation efforts. Proper infrastructure for documenting personal health information of care partners (i.e., if a care partner is already in the care of a psychosocial oncology clinician and has their own chart) is necessary to be able to collect screening information for care partners. Additional resources may be needed to address the needs of care partners at some centres.

Adding a FCR screening question to the Ontario web-based ESAS platform will take some effort but may soon be achievable. Adding clearer pathways to interventions will allow providers to refer patients and care givers to the appropriate resources.

Some moderate-intensity interventions might already be available at some cancer centres, e.g., professionally led support group or psychoeducational group interventions such as survivorship classes.

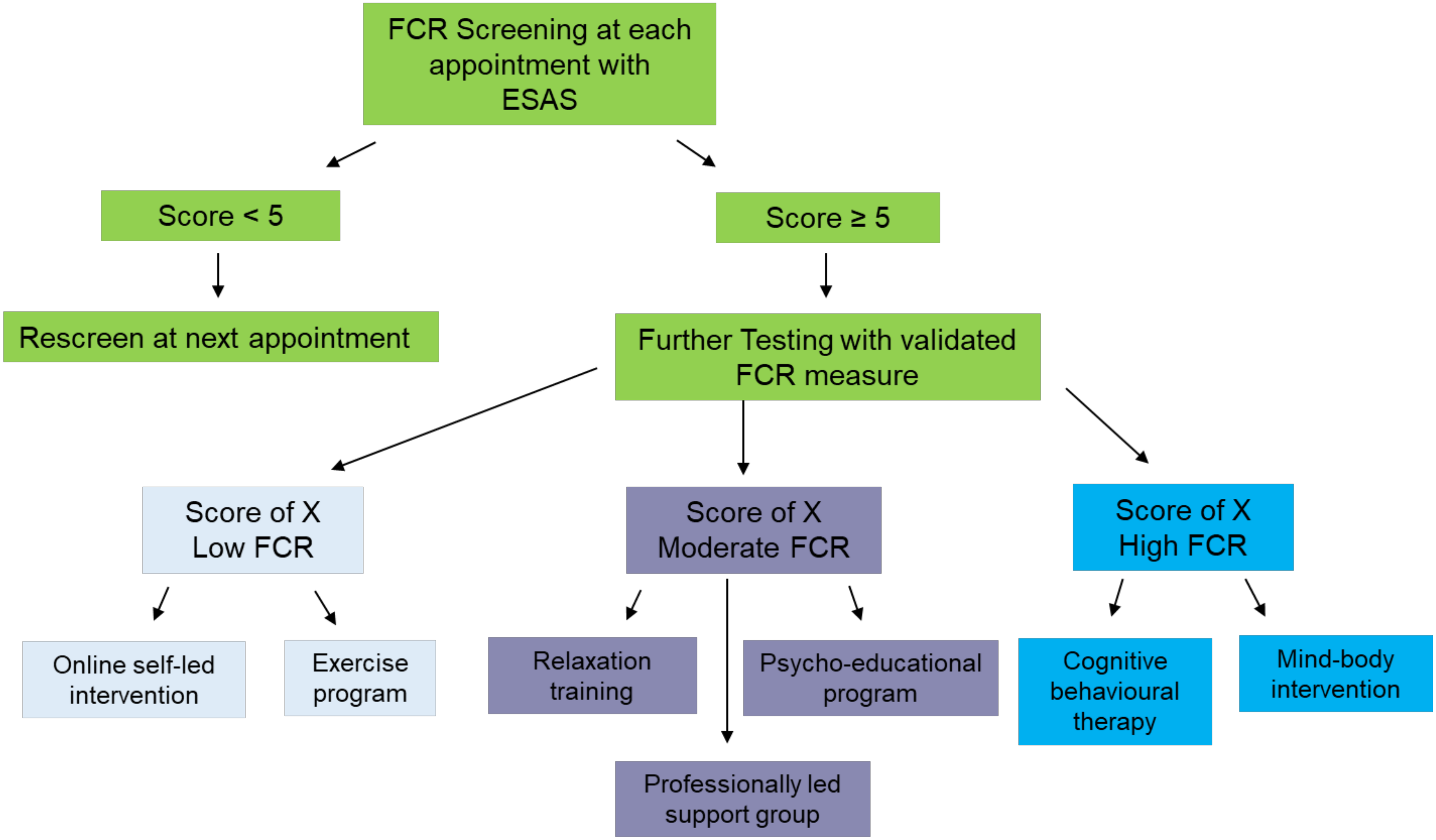
There are a growing number of evidence-based high-intensity FCR interventions that have been empirically established, including some with training material available for clinicians to readily implement (see Resources section). Promising online FCR interventions have already been tested in different countries and could be implemented in Ontario.

Knowledge of FCR, assessments and resources for all levels of FCR could come through education for health care specialists and patients. Education could come via online courses, webinars, and patient groups (see Resources section).

RELATED GUIDELINES

- Cancer Care Ontario Person-Centred Care Guideline: Endorsement and Adaptation of CG 138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. 2015 May 2015. Person-Centred Care Program
- Li M, Kennedy EB, Byrne N, Gerin-Lajoie C, Green E, Katz MR, et al. The management of depression in patients with cancer. Toronto (ON): Cancer Care Ontario; 2015 May 11. Program in Evidence-based Care Guideline No.: 19-4.

FCR Screening, Assessment, and Intervention Flow Chart



Resources for Patients\Care Partners and Health Professionals

Patient/Care Partners

Canadian Cancer Society

- Fear of cancer recurrence during COVID-19
- https://cancer.ca/en/cancer-information/resources/webinars/2020/fear-of-cancer-recurrence-during-covid-19

- Worrying that cancer will come back
- https://cancer.ca/en/living-with-cancer/life-after-treatment/worrying-that-cancer-will-come-back

- Community Services Locator
- https://cancer.ca/en/living-with-cancer/how-we-can-help/community-services-locator

- Talk to an Information Specialist
- https://cancer.ca/en/living-with-cancer/how-we-can-help/talk-to-an-information-specialist

- Spirituality
- https://cancer.ca/en/living-with-cancer/coping-with-changes/spirituality

Canadian Association of Psychosocial Oncology

- Coping with Cancer
- https://www.copingwithcancer.ca/

Canadian Cancer Survivor Network

- Educational activities for cancer survivors, patients and care partner
- https://survivornet.ca/news/did-you-miss-our-webinar-fear-of-cancer-recurrence-5-ways-to-lessen-your-anxiety/

OH (CCO) Managing Symptoms

- Talk to your oncologist and nurses to find close places for help near you
- OH (CCO) Recommended resources for anxiety: https://www.cancercareontario.ca/en/symptom-management/3981

Wellspring Cancer Support

- Resources, programs, brochures and community links for emotional, physical and practical challenges for cancer patients and care partners
- https://wellspring.ca/online-programs/programs/all-programs/

Mindfulness Based Cognitive Therapy for Cancer

- Mindfulness based courses available for people with cancer. Includes links to courses and on-line mindfulness recordings and practices.
- https://www.inspirationsolutions.com/mindfulness.html

Alberta Health Services
- After Treatment: Information and Resources to Help You Set Priorities and Take Action
- https://www.albertahealthservices.ca/assets/info/cca/if-cca-after-treatment-for-cancer.pdf

Peter MacCallum Cancer Centre
- Coping with the fear of cancer coming back (fear of cancer recurrence)
- https://www.petermac.org/sites/default/files/media-uploads/ACSC_Factsheet_FearOfCancerComingBack.pdf

Fred Hutchinson Cancer Research Centre
- How to deal with FCR – patient treatment and support
- https://www.fredhutch.org/content/dam/www/research/patient-treatment-and-support/survivorship-program/survivorship-health-links/Fear%20of%20Recurrence.pdf

Maggie's - Everyone's home of cancer care
- Fear of cancer returning
- https://www.maggies.org/cancer-support/managing-emotions/fear-cancer-returning/

Dana Farber Cancer Institute
- Your emotions after treatment – Dana Farber Cancer Institute
- https://www.dana-farber.org/for-patients-and-families/for-survivors/caring-for-yourself-after-cancer/your-emotions-after-treatment/

Mayo Clinic: Adult Health
- Cancer survivors: managing your emotion after cancer treatment
- https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20047129

- Connect with other patients who have fear of cancer recurrence
- https://newsnetwork.mayoclinic.org/discussion/connect-with-other-patients-who-have-fear-of-cancer-recurrence/

- Consumer Health: Life after cancer
- https://newsnetwork.mayoclinic.org/discussion/consumer-health-life-after-cancer-2/

Cancer Council Victoria
- Life after treatment – fear of the cancer coming back
- https://www.cancervic.org.au/living-with-cancer/life-after-treatment/fear-of-the-cancer-coming-back

American Cancer Society
- Life after Cancer
- https://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/life-after-cancer.html

- Preventing cancer, signs and symptoms, and coping
- https://www.cancer.org/cancer/survivorship/long-term-health-concerns/recurrence/can-i-do-anything-to-prevent-cancer-recurrence.html#:~:text=Eating%20right%2C%20exercising%2C%20and%20seeing,be%20as%20healthy%20as%20possible.

Fox Chase Cancer Center

- ‘Is My Cancer Coming Back?’ How to Cope with the Fear of a Recurrence
- https://www.foxchase.org/blog/2018-03-23-how-to-cope-with-the-fear-of-a-cancer-recurrence

Cancer*Care*

- Coping with fear of cancer recurrence
- https://www.cancercare.org/publications/253-coping_with_the_fear_of_recurrence#

Breast Cancer Network Australia

- FCR – Fact sheet
- https://www.bcna.org.au/resource-hub/articles/fear-of-breast-cancer-recurrence/

Cancer.Net: Coping with Fear of Recurrence

- Coping with fear of cancer recurrence, knowing when to seek help and prompting questions to ask healthcare team.
- https://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence

Harvard Health Blog

- Fear of cancer recurrence: Mind-body tools offer hope
- https://www.health.harvard.edu/blog/fear-of-cancer-recurrence-mind-body-tools-offer-hope-2019030716152

- Mindfulness apps: How well do they work?
- https://www.health.harvard.edu/blog/mindfulness-apps-how-well-do-they-work-2018110615306

Cleveland Clinic

- Coping With Fear of Cancer Recurrence
- https://health.clevelandclinic.org/fear-of-cancer-recurrence/

Health Professionals

CIFeR

- Clinician Intervention Fear of Cancer Recurrence: CIFeR is a short eight-minute doctor-led intervention to help you to address fear of cancer recurrence when seeing your breast cancer patients in clinic.
- https://cifer.thinkific.com/courses/2021

FORT
- Fear of Recurrence Therapy resources and manuals
- https://drive.google.com/drive/folders/1cn_oK0loAhJzp-sTP0CiFg2FUJXiRKVv?usp=share_link

CANO/ACIO
- Adult Cancer Survivorship Manual — A Self Learning Resource for Nurses
- https://www.cano-acio.ca/page/survivorship_manual

Cancer Network
- Fear of Cancer Recurrence: A Practical Guide for Clinicians
- https://www.cancernetwork.com/view/fear-cancer-recurrence-practical-guide-clinicians

User Manual
- Treating Fear of Cancer Recurrence with Group Cognitive-Behavioural Therapy: A Step-by-Step Guide
- https://link.springer.com/book/10.1007/978-3-031-07187-4

Alberta Health Services
- Fear of Cancer Recurrence (FCR) Pathway
- https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-primary-care-fcr-pathway.pdf

Cancer Nurses Society of Australia
- **Online Webinar**
- https://www.youtube.com/watch?v=1Ud5qIKmiMI

Psycho-oncology Co-operative Research Group
- Fear of Cancer Recurrence: Resource Hub
- https://www.pocog.org.au/content.aspx?pagetype=public&page=fcrhub&version=1&search=*

Articles
- Primer for primary care providers: Assessing and managing patient fear of cancer recurrence
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7491663/

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