

### CANCER-RELATED FATIGUE

# Questions to Ask Your Care Team

Cancer-related fatigue (CRF) is one of the most common symptoms experienced by patients with, and survivors of, cancer. It is more severe, more distressing and less likely to be relieved by rest than the tiredness or fatigue of daily life.

Treating fatigue as early as possible, either following diagnosis or at the beginning of cancer treatment, can help prevent CRF from becoming a long-term issue.<sup>1</sup> Though fatigue is common for patients with and survivors of cancer, it is not an unavoidable part of the disease experience. It is often possible to lessen fatigue. However, before anything can be done to help the patient, the cancer care team must know about the level and severity of fatigue.

Patient's willingness to speak up about their fatigue is essential to early detection, assessment and treatment. The 2018 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL found that less than 20 percent of patients with fatigue spoke to their doctor about how fatigue was impacting their life.

This document can help initiate proactive discussions between patients and their health team – including oncologists, haematologists, other doctors, nurses and allied healthcare professionals.

#### PREPARING

Before meeting with your healthcare provider about CRF, there are several ways to prepare to make sure your questions are answered, and that 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 cancer-related fatigue (CRF).

1. What is cancer-related fatigue? \_\_\_\_\_
2. Are there specific signs and/or symptoms to be aware of? When should I talk to my doctor or healthcare provider? \_\_\_\_\_
3. Is CRF normal? Do a lot of people experience CRF? \_\_\_\_\_
4. What causes CRF? \_\_\_\_\_
5. Is CRF related to how much sleep I get or my activity level? \_\_\_\_\_
6. What is the difference between CRF and being tired? \_\_\_\_\_
7. Can CRF be treated? \_\_\_\_\_
8. Are there programs at this hospital / cancer centre that address CRF? \_\_\_\_\_
9. Can you refer me to a therapist or program that can help me manage CRF? \_\_\_\_\_
10. Is there a patient organisation / support group that has information or support for CRF? \_\_\_\_\_
11. Do you know of any online tools to help manage CRF? \_\_\_\_\_
12. Are there any other activities I can do to help? Or things I should not do? \_\_\_\_\_
13. Are there any precautions I should take to help minimise CRF? \_\_\_\_\_
14. What can caregivers, friends or family do to help? \_\_\_\_\_
15. Will it go away? Is this something that I will always live with? \_\_\_\_\_

i. Kuiper B. Cancer-related fatigue the problem and a digital solution. Lecture presented at: HNHCP Educational Conference; February 1, 2019; Zurich, Switzerland.

### CANCER-RELATED FATIGUE

## Frequently Asked Questions

#### 1 What is cancer-related fatigue?

Cancer-related fatigue (CRF) is one of the most common symptoms experienced by patients with, and survivors of, cancer. It is more severe, more distressing and less likely to be relieved by rest than the tiredness or fatigue of daily life.

CRF is defined as *a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.*<sup>i</sup>

CRF is a symptom of cancer itself, as well as a side effect of the therapies used to treat it. It can affect all aspects of a patient's quality of life, including physically, mentally, emotionally or socially.

#### 2 Is CRF different than being tired?

Yes. Unlike being tired, CRF is usually not related to the amount of rest or sleep, activity levels or exertion. It is a debilitating state of exhaustion that can come on quite unexpectedly and keep the individual from participating in life's activities.

#### 3 What are the signs of CRF?

The following are known signs of CRF<sup>ii</sup>:

- Feeling tired and it does not get better with sleep or rest, it keeps coming back, or it becomes severe
- Feeling more tired than usual during or after activity
- Feeling tired and it is not related to an activity
- Arms and legs feel heavy and hard to move
- Having no energy and/or feeling weak
- Spending more time in bed and/or sleeping more and/or having trouble sleeping
- Having trouble concentrating or becoming confused
- Experiencing tiredness that disrupts work, social life or daily routine

## 4 Are there emotional or psychosocial effects of CRF?

Yes. In fact, CRF can be caused by and perpetuate negative psychological, social and behavioural factors. Anxiety, fear of cancer recurrence and depression are a few of the factors known to have a compounding effect on CRF. In addition, when patients are experiencing fatigue, they are often unable to fully participate in their work, home and social lives. This can lead to social isolation or changes in relationships, which can cause or worsen anxiety and depression, and in turn worsen CRF. This puts people in a vicious cause-and-effect cycle.

Studies indicate that patients often perceive fatigue to be the most distressing symptom associated with cancer and its treatment.<sup>iii, iv</sup>

## 5 How common is CRF? Do a lot of people experience it?

If you are experiencing CRF, you are not alone. It is one of the most common symptoms patients with cancer and survivors of cancer experience. Specific to lymphomas, the 2018 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL found that 72 percent of patients experienced life-impacting fatigue.<sup>v</sup>

## 6 Does CRF only affect people with lymphoma?

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

## 7 Does fatigue vary by stage of lymphoma or subtype?

It can. The 2018 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL (LC 2018 GPS) found the prevalence of CRF varied according to lymphoma subtype and the stage of the cancer experience. There was a greater prevalence of CRF reported by patients in the later stages of lymphomas – relapse, remission and disease transformation – indicating that fatigue may get worse rather than better over time.

It is important to note that while these trends exist, the LC 2018 GPS showed fatigue was the most reported physical issue affecting patient quality of life at every step in the patient experience, from those newly-diagnosed to being in remission.

More details can be found in Lymphoma Coalition's report on Cancer-Related Fatigue found at [lymphomacoalition.org/images/Cancer\\_Related\\_Fatigue\\_Report\\_2020.pdf](https://lymphomacoalition.org/images/Cancer_Related_Fatigue_Report_2020.pdf).

## 8 What factors contribute to CRF?

There are two main categories of factors that contribute to CRF:

- The biological effects of cancer on the body, including, inflammation, changes to immune and stress responses, and impaired hormone and energy production.
- Patient-related factors, including age, other medical conditions and treatment, side effects of different therapies used to treat cancer, and other comorbidities.



## 9 Can CRF be treated?

Treating fatigue as early as possible, either following diagnosis or at the beginning of cancer treatment, can help prevent CRF from becoming a long-term issue.<sup>i</sup>

Patients with mild CRF should receive education and counselling related to CRF. As well, general fatigue management strategies, such as monitoring fatigue and conserving energy, have shown to be helpful.

In addition to education and counselling, patients with moderate to severe fatigue should be assessed to identify and treat any conditions or contributing factors, such as pain, anxiety, sleep disturbances, or other side effects of cancer treatment. If there are not any treatable factors, or if treatment is not working, patients should be referred to one or a combination of CRF-specific therapies based on their health status. These may include:

- Physical activity
- Nutritional consultation and counselling
- Psychoeducation
- Cognitive behavioural therapy (CBT)
- Mindfulness-based cognitive therapy (MBCT) or stress reduction (MBSR)
- Mind-body interventions (yoga)
- Bright white light therapy
- Medications or supplements

After any therapy is introduced, patients must be re-screened and re-evaluated for the presence and severity of fatigue.

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

## 10 If I think I'm experiencing CRF, should I speak to my health team? Who specifically should I talk to?

If you think you are experiencing CRF, it is important to speak to your healthcare team to discuss an assessment and treatment options. 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 well-being and help reduce CRF. Treating fatigue as early as possible can help prevent CRF from becoming a long-term issue.<sup>i</sup>

## 11 Where else can I seek support?

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

You may also find digital resources that can help manage CRF. For example, *Untire* is a mobile app that uses scientifically proven methods to reduce cancer-related fatigue and improve energy.

- Kuiper B. Cancer-related fatigue the problem and a digital solution. Lecture presented at: HNHCP Educational Conference; February 1, 2019; Zurich, Switzerland.
- What Is Cancer-Related Fatigue? Cancer.org. [cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue/what-is-cancer-related-fatigue.html](https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue/what-is-cancer-related-fatigue.html). Published 2019. Accessed June 4, 2020.
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### CANCER-RELATED FATIGUE

## Fact Sheet

#### WHAT IS CANCER-RELATED FATIGUE?

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CRF is defined as *a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.*<sup>i</sup>

CRF is a symptom of cancer itself, as well as a side effect of the therapies used to treat it. It can affect all aspects of a patient's quality of life, including physically, mentally, emotionally or socially.

#### WHAT ARE THE SIGNS OF CRF?

Cancer-related fatigue can be quite severe and often comes on suddenly. It is not usually a result of a person's activities or their level of exertion. Some people describe it as feeling weak, drained or washed out.

The following are signs of CRF<sup>ii</sup>:

- Feeling tired and it does not get better with sleep or rest, it keeps coming back, or it becomes severe
- Feeling more tired than usual during or after activity
- Feeling tired and it is not related to an activity
- Arms and legs feel heavy and hard to move
- Having no energy and/or feeling weak
- Spending more time in bed and/or sleeping more and/or having trouble sleeping
- Having trouble concentrating or becoming confused
- Experiencing tiredness that disrupts work, social life or daily routine

## HOW COMMON IS CRF?

Cancer-related fatigue is one of the most common symptoms patients experience, and it affects people with all types of cancer. It can be experienced before and after diagnosis, as well as when a patient is in treatment, has relapsed, or is in remission.

Specific to lymphomas, the 2018 Lymphoma Coalition Global Patient Survey on Lymphomas and CLL found that 72 percent of patients experienced life-impacting fatigue.<sup>iii</sup> The survey also revealed a greater prevalence of CRF in the later stages of lymphomas – relapse, remission and disease transformation – indicating that fatigue may get worse rather than better over time.

## WHAT CAUSES CRF?

The causes of CRF are still not fully understood because CRF is a symptom of the cancer itself, as well as a side effect of many of the therapies used to treat it.

Currently, CRF is thought to be caused by a combination of biological and patient-related factors. Cancer and/or its treatment bring on a series of biological changes that lead to CRF. A patient's own characteristics can also contribute. For example, patients who are older, have an advanced stage cancer, or have had more than one type of treatment are more likely to experience long-term fatigue. Many people also have medical conditions or take medications that are unrelated to cancer but may add to their fatigue.



## CAN CRF BE TREATED?

Treating fatigue as early as possible, either following diagnosis or at the beginning of cancer treatment, can help prevent CRF from becoming a long-term issue.<sup>i</sup>

Patients with mild CRF should receive education and counselling related to CRF. As well, general fatigue management strategies, such as monitoring fatigue and conserving energy, have shown to be helpful.

In addition to education and counselling, patients with moderate to severe fatigue should be assessed to identify and treat any conditions or contributing factors, such as pain, anxiety, sleep disturbances, or other side effects of cancer treatment. If there are not any treatable factors, or if treatment is not working, patients should be referred to one or a combination of CRF-specific therapies based on their health status. These may include:

- Physical activity
- Nutritional consultation and counselling
- Psychoeducation
- Cognitive behavioural therapy (CBT)
- Mindfulness-based cognitive therapy (MBCT) or stress reduction (MBSR)
- Mind-body interventions (yoga)
- Bright white light therapy
- Medications or supplements

After any therapy is introduced, patients must be re-screened and re-evaluated for the presence and severity of fatigue.

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

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- ii. What Is Cancer-Related Fatigue? Cancer.org. [cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue/what-is-cancer-related-fatigue.html](https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue/what-is-cancer-related-fatigue.html). Published 2019. Accessed June 4, 2020.
- iii. Lymphoma Coalition. 2018 Global Patient Survey. [lymphomacoalition.org/global-information/global-patient-survey/2018](https://lymphomacoalition.org/global-information/global-patient-survey/2018).



# Lymphoma Learning Centre

## EXPERT PATIENT EDUCATION SERIES

### CANCER-RELATED FATIGUE Hosting an Educational Event

Consider hosting an event dedicated to educating your community about cancer-related fatigue (CRF). An event creates an interactive opportunity for patients, caregivers and members of the lymphoma community to learn more about CRF, have their questions answered, and perhaps most importantly, see that they are not alone in their concerns or the way they feel.

#### EVENT FORMAT

When choosing your event format, consider what objective you're trying to achieve, as well as the resources available. Online-based events are becoming more and more common. They are cost-effective and provide an opportunity to reach many more people than just those in your geographical location. Questions can be submitted in advance or through the chat function during the online event. It is also possible to record the event and post to your website for future reference.

#### Expert Seminar

Work with a local expert to host an informative session that provides an overview of CRF, including what it is, the signs and symptoms and treatment. Experts to consider include physicians, psychiatrists, psychologists or nurses with direct experience related to CRF.

#### Panel Discussion

A panel discussion offers multiple perspectives from a variety of experts on the same topic. A panel focused on CRF could include a physician, a nurse, a mindfulness expert (or other psychotherapist) and a person with lived experiences related to CRF. A panel discussion also benefits from a well-informed moderator who guides the discussion and manages questions from the audience.

Either format can be hosted live or online, with questions from the audience.





# EVENT PLANNING TIPS

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.

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### Location, location

For in-person events, think about rental fees, A/V needs, catering availability or restriction and accessibility to public transit and parking for attendees.

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### Tech check

For online events, test the platform you are using with your speaker(s) at least a day or two before your event to ensure everyone can be seen and heard and knows how to show and advance slides, etc.

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### Spread the word

Look for cost-effective ways to let people know about your event. Share information via email and on social media. Also, consider advertising in the hospital newsletter and putting up posters in the hospitals and cancer clinics.

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### 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.

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### Stay in touch

Through registration and 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. Also, consider a short survey to gather participants' feedback regarding the event.

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### CANCER-RELATED FATIGUE

## Treatment Overview

Cancer-related fatigue (CRF) is one of the most common symptoms experienced by patients with, and survivors of, cancer. It is more severe, more distressing and less likely to be relieved by rest than the tiredness or fatigue of daily life.

Despite the common idea that fatigue is an inevitable part of cancer treatment, addressing fatigue as early as possible can help prevent CRF from becoming a long-term issue.<sup>i</sup>

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

#### PATIENT-HEALTHCARE PROVIDER COMMUNICATIONS

Treating fatigue is an important part of care for the patient and their family and it is often possible to lessen fatigue. However, before anything can be done to help the patient, the care team must understand the fatigue and the level of severity.

Members of the healthcare team should proactively discuss fatigue at the time of diagnosis to help patients know what to expect and regularly screen and assess patients throughout treatment and into survivorship.

Patients with cancer who experience CRF often underreport the way they feel, which has a role in CRF being underdiagnosed and undertreated. Specific to lymphomas, the Lymphoma Coalition 2018 Global Patient Survey on Lymphomas and CLL found that less than 20 percent of patients with fatigue spoke to their doctor about how it affected their life.<sup>ii</sup>

Patients may avoid bringing it up because they think it is an inevitable part of having or treating cancer, or they fear the strength of their treatment will be reduced if they reveal they are experiencing fatigue. Patients are urged to discuss their CRF and its true impact on their lives with their healthcare team.

## SCREENING AND ASSESSMENT

Healthcare professionals should screen patients with cancer and survivors at every point of contact for the presence and severity of fatigue using a quantitative or semi-quantitative measurement tool.<sup>iii,iv,v</sup> Because fatigue is subjective, assessments rely on a patient's ability to accurately describe the way they feel, which can be done using numeric scales (0 meaning no fatigue to 10 meaning worst fatigue imaginable) or descriptive words (mild, moderate, severe).

It is important that patients understand the context of the questions. For instance, clarity is needed to understand if answers about their fatigue levels should be compared to pre-cancer life or based on their fatigue levels since their last medical appointment.

Patients who are experiencing moderate to severe fatigue should be further evaluated to understand the physical, emotional, and cognitive effects they are experiencing. This should include reviewing different aspects of the fatigue including its onset, progression, patterns, how it is alleviated and how it interferes with the individual's life.<sup>iii,iv,v</sup> In addition, symptoms and contributing factors associated with fatigue should be evaluated, including depression, pain, emotional distress, poor sleep, poor nutrition, activity levels, alcohol or substance use, medication side effects, other chronic illnesses and the effects of cancer treatments.<sup>iii,iv,v</sup>

## TREATING CRF

Patients with mild CRF should receive education and counselling related to CRF. As well, general fatigue management strategies, such as monitoring fatigue and conserving energy, have shown to be helpful.

In addition to education and counselling, patients with moderate to severe fatigue should be assessed to identify and treat any conditions or contributing factors, such as pain, anxiety, sleep disturbances, or other side effects of cancer treatment.

If there are not any treatable factors, or if treatment is not working, patients should be referred to one or a combination of CRF-specific therapies based on their health status and age. These may include:

### Psychoeducation

A means of providing education and information to those seeking or receiving mental health services, such as people diagnosed with mental health conditions or life-threatening/terminal illnesses and their family members. The information and support focuses on improving understanding and helping patients and their families cope with the illness or condition.

### 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.

### Mindfulness-based cognitive therapy (MBCT)

An evidence-based group therapy approach to psychotherapy that combines cognitive behavioural therapy methods with mindfulness meditative practices and similar psychological strategies. It helps reduce depression, anxiety and stress.

### Mindfulness-based stress reduction (MBSR):

A program that helps teach on how to calm the mind and body to help you cope with illness, pain, and stress. MBSR teaches "mindfulness," which is a focus only on things happening in the present moment. MBSR encourages purposefully paying attention and being aware of your surroundings, emotions, thoughts, and how your body feels.

### Exercise

Exercise programs can include resistance training, such as lifting weights or strength training, and endurance training, including walking, jogging, cycling or swimming (applicable for non-cachectic patients).

### Mind-body regimens

Includes mindful activities such as yoga and reiki.

### Nutritional counselling

Working with a professional to assess nutritional intake and create a plan to optimise energy levels.

### Bright white light therapy

Also known as phototherapy, it consists of exposure to bright lights that mimic natural light in controlled circumstances. It is thought to affect the brain chemical linked to mood and sleep.

### Pharmacologic therapy

Medications recommended may include psychostimulants, antidepressants, steroids or supplements (such as ginseng or vitamin D).



# Have you heard of Cancer-Related Fatigue?

Unlike being tired, cancer-related fatigue (CRF) is usually not related to your rest or sleep, activity levels or exertion. It can be quite severe and distressing. It can also come on unexpectedly and keep you from participating in life's activities.

- Not having energy or feeling weak
- Sleeping more or having trouble sleeping
- Trouble concentrating or feeling confused

Do not let CRF control your life — it is possible to lessen CRF with treatment.

Addressing CRF early can help prevent a long-term issue. Speak to your healthcare team about an assessment and treatment options.

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For more information and resources, visit:



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**You are  
not alone.**

Cancer-related fatigue is one of the most common symptoms patients experience.

Research shows  
72% of patients  
with lymphoma  
experience  
life-impacting  
fatigue.<sup>1</sup>

1. Lymphoma Coalition 2018 Global Patient Survey.  
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For more information and resources, visit:

**LYMPHOMA  
COALITION** 



You are  
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Cancer-related fatigue is one of the most common symptoms patients experience.

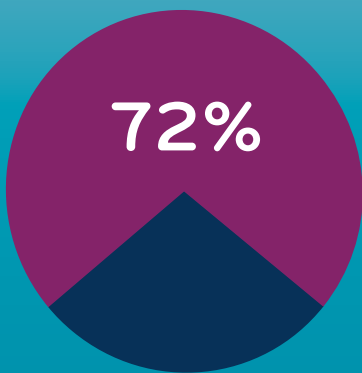
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### CANCER-RELATED FATIGUE

Cancer-related fatigue (CRF) is one of the most common symptoms patients experience. It is a state of exhaustion that can come on unexpectedly and keep you from participating in life's activities.

72% of patients with lymphoma reported life-impacting fatigue.



CRF is feeling tired without getting better with rest.

-  Feeling weak or drained
-  Sleeping more or having trouble sleeping
-  Not related to activity levels
-  Trouble concentrating or feeling confused

CRF affects the lives of people with lymphoma.

Ability to work  
**62%**

Intimate relationships  
**42%**

Independence  
**44%**

Activity levels  
**78%**

**Addressing CRF early can help prevent a long-term issue.**

Speak to your healthcare team about an assessment and treatment options.

Source: Lymphoma Coalition. 2018 Global Patient Survey. [lymphomacoalition.org/global-information/global-patient-survey/2018](http://lymphomacoalition.org/global-information/global-patient-survey/2018).



# Tiredness

VS

# Cancer-Related Fatigue



Can be resolved by a good night's sleep

Expected after certain activities

Lasts for a short amount of time

Happens to everyone



Doesn't get better with rest, comes back, or worsens

Comes on unexpectedly and not related to activity

Lasts for months to years

Happens to people with all types of cancers

Recognising the difference between tiredness and cancer-related fatigue is key to an early diagnosis and treatment.

**Speak to your healthcare team to learn more.** [lymphomacoalition.org](http://lymphomacoalition.org) | [@knowyournodes](https://twitter.com/knowyournodes)

### CANCER-RELATED FATIGUE Treatment Pathway

