

A young woman with curly brown hair, wearing a white lab coat, is looking towards an elderly man with grey hair and glasses. The man is seen from the back, holding a mobile phone to his ear. The background is a bright, out-of-focus indoor setting.

COPING

WITH FATIGUE

A guide for

LYMPHOMA AND CLL PATIENTS



LYMPHOMA
CANADA

One of the many side effects of having or getting treated for lymphoma or chronic lymphocytic leukemia (CLL) is chronic fatigue. It is essential to understand that cancer related fatigue is very different from normal tiredness as it does not necessarily go away with more rest or sleep. **Each patient experiences fatigue differently, but it may feel like:**

- + Extreme tiredness or a constant feeling of low energy
- + Difficulties with memory or concentration
- + Difficulty completing tasks that were previously easily accomplished
- + Not having energy or enthusiasm like you used to
- + Overwhelming feeling of exhaustion

You may experience fatigue prior to diagnosis. It could begin during or after treatment, lasting months to years after treatment, which can impact day to day life and relationships significantly. To help lymphoma patients and their family members navigate through this incredibly challenging condition, this guide aims to identify coping strategies that can be implemented to optimize energy levels and manage chronic fatigue. **This resource will further identify:**

- 1 What is fatigue and why does it occur? (physically and psychologically)
- 2 What does fatigue look like? (symptoms)
- 3 When does fatigue occur for lymphoma/CLL patients?
- 4 Strategies to increase energy and combat fatigue

This guide is for people who experience fatigue associated with, or as a result of, their lymphoma/CLL diagnosis, its treatment, and/or as a long-term side effect. This information is intended for patients and their caregivers and does not replace advice from your health care team. Check with your health care team before starting a new exercise program or when changing your diet.

Remember – You're Not Alone. Lymphoma Canada offers help and support to anyone affected by any subtype of Hodgkin lymphoma, Non-Hodgkin lymphoma and Chronic Lymphocytic Leukemia. Visit our website for additional resources at www.lymphoma.ca

WHAT IS FATIGUE AND WHY DOES IT OCCUR?

Fatigue is a common symptom in the general population and is even more frequently found in patients with lymphoma and CLL. The cause of fatigue is due to a combination of factors related to the individual, cancer and its treatments. It can involve physical (feeling weak), emotional (low mood or motivation), or even mental (poor memory and concentration) effects. The fatigue you are experiencing could be mild, moderate, or severe. As recommended by Cancer Care Ontario, use the table below to help you describe to your health care team the degree of fatigue you are suffering from.

TYPE OF FATIGUE	SIGNS
Mild	Have some symptoms of fatigue but are able to do regular activities like caring for yourself, cooking, cleaning, or working
Moderate	Your fatigue causes you moderate stress and worry You have trouble doing regular activities like caring for yourself, cooking, cleaning, or working, and have trouble walking or climbing stairs
Severe	Your fatigue is strong and causes you high levels of stress and worry You want to sit, lie down, or sleep all day You are not able to do regular activities like caring for yourself, cooking, cleaning, or working When resting, you may feel sudden fatigue and/or shortness of breath, rapid heart rate, and/or have low blood count

If you have moderate to severe fatigue, your health care providers may need to conduct an assessment to better understand what may be causing the fatigue and to assess how best to help you.

Fatigue can be more common depending upon the lymphoma subtype you have, other medical conditions and the treatments you receive. Chronic fatigue can last for weeks or months after treatment and can be exacerbated by physical and psychosocial issues.

From a physical perspective, fatigue can result from numerous causes, including:

- + **Anemia:** Low red blood cell levels impacting the body's oxygen levels.
- + **Reduced thyroid gland function:** A gland in your body that makes a metabolism-controlling hormone.
- + **Deconditioning:** Reduced physiological function after a period of reduced physical activity.
- + **Muscle loss:** Very common after cancer related weight loss and made worse with steroids.
- + **Nutritional deficiencies**

Lymphoma and CLL can also reduce the number of healthy white blood cells in your body, which are essential when it comes to fighting infections. With fewer white blood cells, you are more prone to infections, which take additional energy to fight, ultimately contributing to fatigue. However, once CLL or lymphoma has been treated, you may feel a dramatic lessening of fatigue as the disease burden has been reduced.

Fatigue can be accentuated by underlying health issues such as:

- + Diabetes
- + Low testosterone in men

- + Menopause in women
- + Lung, kidney, or heart disease
- + Anxiety or depression
- + Poor sleep or sleep disorders such as obstructive sleep apnea

From a psychosocial perspective, during treatment, your body is in a heightened “fight-or-flight” state to “attack” and “battle with” your lymphoma. However, once treatment stops, your mind and body begin to relax and you feel the symptoms of fatigue.

Other social stressors may arise during this time as a result of financial concerns from treatment, stress while transitioning back into work, or the withdrawal of physical/emotional support from friends and family. As you become more independent, those in your support circle may perceive that you are now able to cope on your own. These added stressors combined with the withdrawal of support may lead to other issues such as difficulty sleeping, depression, and anxiety, which can further worsen your symptoms of fatigue, and have a serious impact on your quality of life.

Diagnosing the exact cause of fatigue can be a challenge, since it can be caused by any number of factors.

WHAT DOES FATIGUE LOOK LIKE?

As a result of your fatigue, some symptoms you may experience may include, but are not limited to:

- + Feeling too tired to participate in daily work or school activities
- + Too exhausted to spend time with friends or family (tension or conflict as a result of social withdrawal)
- + Mood changes that can result in memory problems and confusion/mental fog

- + Difficulty in retaining concentration in a particular task
- + Feeling irritable or in a depressed mood
- + Experiencing forgetfulness
- + Still feeling tired after a good night's sleep

What symptoms do you experience as a result of your lymphoma/CLL fatigue?

WHEN DOES FATIGUE OCCUR FOR LYMPHOMA/CLL PATIENTS

Fatigue is one of the most common symptoms experienced by lymphoma and CLL patients. Many patients will experience fatigue prior to receiving a diagnosis. While this can be a result of various factors, one reason may be that you are suffering from anemia, which causes tiredness and breathlessness. The risk of experiencing fatigue is greater when having an advanced stage (stage 3 or 4) of lymphoma, in comparison to an early stage (stage 1 or 2) of lymphoma. Fatigue is known to increase during treatment as a result of surgery, radiation, chemotherapy, or immunotherapy. Overall, the duration of the fatigue experienced varies from person to person, depending on the type of lymphoma or CLL, and the treatment plan. For some, it may last for only a few months, while for others, it may persist for years after the cancer treatment ends and even worsen over time.

How long have you been experiencing lymphoma/CLL related fatigue?

WHEN SHOULD I TALK TO MY HEALTH CARE TEAM ABOUT MY FATIGUE?

If you are experiencing fatigue that is impacting your quality of life, you can reach out to your health care team at any point during or after diagnosis and treatment. It is often the case that fatigue will slowly increase. Over time you may feel less energetic, take more naps during the day than you used to, and find you tire more easily than before. Take written notes of these changes as you notice them, so that when you see your health care team, you can describe the fatigue you are feeling and its impact on your life. **Cancer Care Ontario recommends you contact your health care team right away if you have the following symptoms:**

- + dizziness, loss of balance or falls
- + fatigue that is suddenly much worse
- + sudden shortness of breath or a fast heartbeat
- + unexplained bleeding or bleeding that does not stop
- + anxiety, depression, or feelings of not coping well

STRATEGIES TO INCREASE ENERGY AND COMBAT FATIGUE

There are various strategies to help manage your fatigue, including:

- 1 Physical Activity and Exercise
- 2 Developing Better Sleep Habits
- 3 Mental Well-Being/ Mindfulness Based Interventions
- 4 Nutrition – Based interventions
- 5 Medical Treatment

PHYSICAL ACTIVITY AND EXERCISE

Research has shown that physical activity can help improve your energy levels, making it one of the most effective strategies in terms of managing your fatigue and boosting your quality of life. Exercise helps to improve muscle mass, cardiovascular fitness (improves oxygen supplementation in the body), and metabolic function (how your body produces and uses energy), while reducing inflammation. All of these benefits work to improve symptoms of fatigue. **Other benefits of physical activity include but are not limited to:**

- + Improved immunity
- + Relief of mental fog
- + Reduced feelings of depression and anxiety
- + Less stress and improved sleep
- + Improved physical fitness and functioning, making daily activities feel easier and less exhausting
- + Helping get your mind off your lymphoma/CLL diagnosis

It may seem strange that activities that usually make you tired can help with fatigue. The critical element is the amount and intensity of the exercise that you do: too much and you exhaust yourself, too little and you do not get the benefits.

Incorporating exercise into your routine may be difficult on some days (eg., when you are feeling ill or sick from your treatment). This is normal. The secret to alleviating fatigue through exercise is to listen to your body as you exercise. Even if you do not feel energetic at the start, you will find that your energy level increases once you have started an exercise session. When you start feeling tired or out of breath, **stop** to take a break. You can then decide to restart in a few minutes, later that day, or stop for the day.

While it has been recommended to aim for a duration of at least 30 minutes of exercise per day for 5 days a week, with time, you will learn to feel the level, duration, and intensity of exercise that is right for you. It is important to start slowly and to go at a pace that is comfortable for you, while remembering that some activity is always better than none! If 30 minutes of activity is too difficult, you can split it up into shorter sessions throughout the day (ex. 5-to-10 minute sessions). Over time, slowly increase how much and how hard you exercise, remembering to listen to your body and not to push yourself too hard. If your energy is particularly low and you have not been able to be as active as you would have liked, you can try exercises in which you are lying down such as ankle exercises, leg raises, knee flexion and extensions, or sitting exercises such as arm raises, sitting and standing, or breathing exercises.

Any type of physical activity at moderate levels of intensity (ex. walking, hiking, swimming, cycling, yoga, Pilates, and other mobility exercises) will help improve your fatigue. Trying a mix of activities is a great idea, as it helps keep you motivated and excited for your next workout! It may also be encouraging to keep a journal where you can set goals and keep track of your progress.

It is vital to stay safe while engaging in physical activity. Always keep in mind restrictions from your health care team as well as any injuries or treatments that may limit your ability to engage in select activities. If you are overly exhausted the day after you have exercised, then cut back on the length and/or intensity of exercise the next day. **As recommended by the Canadian Partnership Against Cancer, if you have any of the following symptoms, stop exercising and consult your doctor or healthcare team before proceeding:**

- + Unusual fatigue or muscle weakness
- + An irregular heart beat
- + Leg pains or cramps
- + Chest pain
- + Feeling sick or are sick during exercise
- + Vomiting within the last 2-3 days
- + Dizziness or blurred vision
- + Difficulty breathing
- + Numbness in your hands or feet

What are some physical activities you would like to incorporate into your day?

When is the best time for you to engage in physical exercise?

SLEEP STRATEGIES

Many people with lymphoma/CLL experience disrupted sleep schedules because of uncomfortable treatment side effects, symptoms (pain, itching, sweating, etc.), or anxious thoughts. Several sleeping problems observed include struggling to fall or stay asleep (insomnia), waking up earlier than desired, experiencing nightmares, feeling very tired throughout the day, or sleeping too much. Having a disrupted sleep schedule contributes to increased fatigue and can significantly hinder quality of life. To combat this, it is important to create new healthy sleep habits. **This includes:**

- + Setting a routine to wake up at the same time every day
- + Opening curtains to let light in or going to a brighter room after you wake up (this prepares your mind and body to get ready for the day)
- + Throughout the day, take short naps that are less than one hour long, primarily between 12 and 3 pm
- + Limit alcohol and caffeine consumption as these can act as stimulants that disrupt your sleep cycle
- + Before bed, dim the lights and try relaxation activities such as reading, listening to music, or taking a hot shower or warm bath
- + Turn off all electronic devices at least one hour before going to bed (blue light from screens restrains melatonin production – the hormone that controls your sleep-wake cycle- making it difficult for you to fall asleep)

- + Use your bed for sleep and intimacy only – conditioning the brain this way can help induce better sleep
- + Exercise during the day, or even during periods of insomnia at night, as this can improve the quality and quantity of sleep.

Speaking with your healthcare team about your sleep disturbances (ex. as a result of anxiety or stress) can help address the root cause and lead to better sleep. Your healthcare team may recommend cognitive behavioural therapy specific for insomnia (CBT-I), which helps reset your sleep-wake cycle, to help improve your sleep and reduce overall fatigue.

What are some factors that prevent you from a good-night's sleep?

What new sleep habits would you like to incorporate into your day-to-day life to improve your sleep?

MENTAL WELL-BEING

Fatigue is often the result of emotional obstacles, including feeling anxious or depressed. Studies have shown that depression and post traumatic symptoms related to cancer diagnosis and treatment are significant factors in post lymphoma fatigue. Several approaches can

improve psychological well-being, including psychoeducation (education on cancer fatigue), cognitive-behavioural therapy (CBT), and behavioural-activation therapy.

Psychoeducation helps you better understand why you suffer from fatigue and teaches you ways to determine what activities are important to you, so that you can conserve your energy accordingly. Psychoeducation usually occurs in group settings, where you can interact with and learn from the experiences of others who have lymphoma/CLL. This can be a useful strategy in terms of easing anxiety, as you learn that you are not alone in your experience.

CBT helps you to identify how your thoughts and feelings could directly impact your behaviour, positively or negatively. Hence, CBT may help you overcome the cycle of negative and unhelpful thoughts related to your fatigue. This strategy is effective in instilling a sense of autonomy over one's thoughts and beliefs. Behavioural-activation therapy similarly substitutes negative behaviors with positive and rewarding ones, resulting in improved mood and energy levels.

There are also many mindfulness-based interventions that can help relieve stress or anxiety and improve fatigue. These include spiritual practices such as meditation, praying, journaling, or mind-body practices such as yoga or tai chi. Engaging in mindfulness-based activities may allow you to be present in the moment without additional stressors that exacerbate your fatigue.

How can you incorporate mindfulness-based activities into your daily routine?

NUTRITIONAL INTERVENTION

A lowered appetite or feeling full easily is a common symptom in lymphoma and CLL. Changes in appetite can result in anemia, fluid and electrolyte imbalances, a lack of vitamins, minerals, and other important nutrients, and unintentional weight loss or gain. All of these factors can contribute to fatigue.

It is essential to eat good foods to meet nutritional needs, stay hydrated (water or herbal teas) and intake enough potassium and sodium to prevent electrolyte imbalances. Some foods that have been recommended to maintain a balanced diet while reducing fatigue include a variety of fruits and vegetables, whole grains, and foods high in omega 3 fatty acids such as leafy vegetables, nuts/seeds (walnuts, flaxseeds, and linseeds), and oily fish (sardines, salmon, or mackerel). Additionally, a diet rich in vitamins (including vitamins D, B12, and iron), proteins, and other nutrients may help alleviate symptoms. This may also help reduce other uncomfortable symptoms experienced due to your diagnosis, such as digestive issues like abdominal pain, nausea, and diarrhea.

What changes can you make in order to ensure adequate nutrient intake?

MEDICAL INTERVENTION

If you are experiencing fatigue because of an underlying condition associated with treatment, medication may be prescribed to alleviate your symptoms. For example, medications are available if patients are suffering from moderate-to-severe depression or anxiety. Your health care team will decide which treatments are appropriate for you.

CONCLUSION

Overall, to help alleviate your symptoms of fatigue, it is important to:

- 1 Ask for help:** do not assume that your fatigue is not a serious problem. Ask for help before, during, and after treatment.
- 2 Accept help:** allow others to assist you with daily tasks that may still be too difficult for you to do
- 3 Prioritize your energy:** Some tasks may be more enjoyable than others, so consider what will be the most fulfilling to you
- 4 Plan ahead:** Participate in activities when you have the most energy, have rest periods between activities, and choose activities that you enjoy the most

If you don't notice an improvement, be sure to talk to your doctor about your fatigue before it affects other areas of your health — there may be other techniques that can be beneficial to you, or your doctor may refer you to other specialists such as physical therapists, occupational therapists, nutritionists, or counselors.

For additional information please visit our website at: <https://www.lymphoma.ca/life-beyond/my-body/late-effects-of-treatment/fatigue/>

For one on one support from a peer mentor, please visit our website at: <https://www.lymphoma.ca/resources/support/peer-support-program/>



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