LEUKEMIA & LYMPHOMA SOCIETY®

Cancer-Related Fatigue

No. 3 in a series providing the latest information for patients, caregivers and healthcare professionals

Highlights

- Cancer-related fatigue (CRF) is a persistent feeling of physical or emotional exhaustion related to cancer or cancer treatment. CRF interferes with mood and outlook, ability to manage daily responsibilities, and enjoyment of life.
- CRF is more severe than the fatigue that healthy people experience; the amount of fatigue doesn't match the patient's efforts. CRF may have an unpredictable pattern (better one day, worse the next). It is less likely than normal fatigue to be relieved by sleep or rest.
- CRF may be caused by cancer itself. It can also be caused by cancer treatment, including chemotherapy, radiation or immunotherapy. It may be caused by several different factors.
- Symptoms of CRF may include physical weakness, changes in mood, irritability, or little interest in social activities. CRF may make it difficult to perform daily activities, to concentrate and to make decisions.
- It is important for patients to talk with their healthcare team if they experience signs and/or symptoms of fatigue before, during or after treatment.
- There is no single effective treatment for CRF. The first steps in addressing it are often to identify and treat any underlying causes of CRF (such as anemia or poor nutrition), and then to check for any other contributing health problems (like thyroid, heart, liver or kidney disease) that may make CRF worse.
- A number of therapies are available that may help increase energy and relieve fatigue in a person who has a blood cancer. Always discuss any medications or herbal remedies with your healthcare team before taking or using them.

Introduction

Fatigue is very common in patients with blood cancers. Cancer-related fatigue (CRF) is described as excessive and persistent exhaustion related to cancer or cancer treatment that interferes with daily activity and function. CRF often begins before cancer is diagnosed, worsens during the course of treatment and may persist for months—even years—after treatment ends. Fatigue can be difficult to assess because it is unique to each person, and there are no objective measurements for it.

Unlike the fatigue that healthy people experience from time to time, CRF is more severe. It is often described as an overwhelming exhaustion that cannot be overcome with rest or a good night's sleep. Some people may also experience muscle weakness or difficulty concentrating. Many patients with leukemia, lymphoma, myeloma, myelodysplastic syndromes or myeloproliferative neoplasms find CRF more distressing and disabling than other disease-related or treatment-related symptoms such as pain, depression or nausea.

Although some clinicians, caregivers and people living with cancer consider CRF a part of the disease and its treatment, there are steps that patients can take to ease their fatigue. Regular exercise, good nutrition, psychological support, stress management and other lifestyle changes can help boost energy levels and the ability to cope with fatigue.

Untreated CRF can negatively affect a person's physical and emotional well-being and quality of life. Fortunately, CRF awareness is growing, and research is uncovering treatments to help reduce or relieve fatigue. In addition, leading health organizations such as the National Institutes of Health (NIH) and the National Comprehensive Cancer Network (NCCN) have called for better assessment and management of CRF as an essential part of quality comprehensive cancer care.

As with any cancer-related symptoms and treatment side effects, individuals should continue to report their levels of fatigue or exhaustion to members of their healthcare team.

Signs and/or Symptoms

A "sign" is a change that the doctor sees during an exam or in a laboratory test result. A "symptom" is a change that a patient can see and/or feel.

Symptoms of fatigue may include a sensation of physical weakness or muscle heaviness; depressed mood or mood changes; sleeping too much or too little, sleep that is not restorative; lack of interest; avoidance of social activities; and irritability or difficulty with mental concentration, carrying out normal daily activities (including work or school) or making decisions.

Patients should discuss their signs and/or symptoms with their healthcare team. An underlying condition that may cause or worsen fatigue may be evident from a patient's medical history, physical examination or laboratory test results. Signs and/or symptoms may include:

- Difficulty climbing stairs or walking short distances
- Muscle weakness
- Shortness of breath
- Weight gain or loss
- Intolerance to cold
- Anemia (low red blood cell count) or low thyroid function test results
- Skin dryness or hair loss
- Sleep disturbances

Fatigue can also be reflected in one's ability to process information, changes in mood and in social functioning, including:

- Depressed and/or anxious mood
- Lack of motivation
- Negative thinking
- Irritability
- Inability to concentrate
- Loss of memory or mental alertness
- Withdrawal from leisure and/or social activities
- Unusual strain in relationships

People with cancer who have chronic fatigue typically feel mentally and physically defeated. Many people are very hard on themselves because they are less active than they were before their diagnosis and treatment.

Coping with CRF can be frustrating, but there are steps that patients can take to boost their own energy and spirits. See *Take Care of Yourself* on page 7 for some ideas to ease fatigue and support overall wellness.

Visit www.LLS.org/booklets to view *Each New Day: Ideas for Coping with Blood Cancers* for more useful information and tips.

Possible Causes of Cancer-Related Fatigue

Understanding the causes of CRF in cancer patients is challenging because in any patient, fatigue typically has more than one cause. Fatigue is a common symptom of some types of blood cancer. When cancer patients begin treatment, many are already tired from undergoing medical tests, surgery and the emotional stresses of dealing with a cancer diagnosis. After treatment begins, fatigue may become worse. Cancer treatments almost always affect a patient's energy level and cause fatigue. CRF typically declines in the months following treatment, but sometimes it is an ongoing problem after treatment has finished.

CRF may be caused by:

- Blood cancers, including leukemia, lymphoma, myeloma, myelodysplastic syndromes or myeloproliferative neoplasms
- The side effects of cancer treatment (including chemotherapy, radiation, surgery, immunotherapy and/or other medications used to treat blood cancer). Researchers are trying to better understand how cancer treatments cause CRF. Some studies suggest that:
    - Cancer treatments not only kill cancer cells but also kill normal, healthy cells. The body then needs extra energy to repair and heal body tissue damaged by treatment.
    - Cancer treatments cause the build-up of toxic substances that remain in the body after cells are killed by the treatment. These toxic substances may cause fatigue.

Some studies suggest that fatigue may be further caused by:

- Low red blood cell counts (anemia). Many patients with anemia feel tired and weak. Anemia may be caused by the blood cancer itself or by the treatments. These treatments do kill cancer cells but may also affect the blood-forming cells in the bone marrow, decreasing the bone marrow's ability to make new red blood cells. If the level of red blood cells is too low, the body does not get enough oxygen, and fatigue results.

- Increased immune inflammatory activity. Natural chemicals called "cytokines" are proteins that are normally released by white blood cells in response to infection. Cancer and its treatment can disrupt cytokine levels. Cytokines carry messages that help regulate the immune and endocrine systems. But in high amounts, cytokines can be toxic and are linked to inflammation that may cause fatigue.

  An additional theory is that high levels of cytokines may worsen inflammation and disrupt the production of serotonin, a hormone that influences a person's sense of well-being and helps regulate mood, anxiety and sleep. Researchers are studying whether very high or low levels of serotonin may contribute to CRF.

- The effect that the cancer and/or the cancer treatments have on three specific glands in the human body. This theory is called "Hypothalamic, Pituitary, Adrenal (HPA) Axis Dysfunction." These three glands control the release of the stress hormone cortisol. Cortisol affects the regulation of blood pressure, heart and blood vessel function, carbohydrate processing and immune function. Researchers are studying whether cancer and/or cancer treatments (especially corticosteroids like prednisone or dexamethasone) reduce the levels of cortisol released in the body. Low levels of cortisol may cause or contribute to fatigue.

- The possibility that cancer and/or cancer treatments may cause disruptions to the circadian rhythm. Circadian rhythms are biological cycles that repeat approximately every 24 hours. Circadian rhythms influence sleep-wake cycles, core body temperature and hormone secretions such as cortisol. Sleep disorders are common in cancer patients and may arise from disturbances in the circadian rhythm.

- Adenosine triphosphate (ATP). ATP is a substance present in all living cells that provides energy for physiological processes such as muscle contraction. Disruption of ATP production, due to severe weakness and wasting of the body, or after chemotherapy or radiation, can cause long-term side effects to tissues and especially skeletal muscle. This type of fatigue is called "peripheral fatigue" and it means that muscles are either unable to perform a task or they exhibit reduced endurance.

Contributing Factors

There are several factors that make cancer patients more likely to experience CRF. Many of these factors can be treated.

- **Anemia (low number of red blood cells)**—Anemia leads to decreases in the body's supply of oxygen, nutrients and energy, causing a person to feel tired.

- **Poor Nutrition**—Many cancer patients are at risk for nutrition-related problems due to loss of appetite or side effects of treatment that may cause nausea, vomiting, diarrhea and decreased nutrient absorption. Poor nutrition and dehydration may cause a person to feel tired and listless.

- **Less Activity**—A person who is overly tired is less likely to engage in physical activity. Reduced physical activity leads to loss of muscle mass, which increases the effort needed to perform basic activities.

- **Difficulty Sleeping**—More than half of patients with cancer have trouble sleeping, which can cause or worsen fatigue. Patients with cancer report higher rates of insomnia (difficulty falling or staying asleep), poor sleep quality and shorter durations of sleep. Fatigue may also result in more daytime napping, but sleeping more than 30 minutes during the day may disrupt nighttime sleep patterns.

- **Mood Changes**—Anxiety and depression are the most common psychological causes of fatigue in patients with cancer. Depression affects approximately 15 to 25 percent of patients with cancer. Symptoms of depression include sadness, loss of interest in previously enjoyable activities, difficulty concentrating, exhaustion, difficulty sleeping or sleeping too much, and feelings of hopelessness. Symptoms of anxiety include feelings of fear, dread and uneasiness. Coping with the stress of a cancer diagnosis can also contribute to fatigue by disrupting sleep.

- **Financial Stress Due to Cancer**—Financial stress resulting from cancer treatment and the subsequent changes in daily routine may also contribute to fatigue. Money may become a problem if a cancer patient needs to stop working or reduce work hours. Financial pressures brought on by the cost of healthcare, lack of health insurance or reduced income may trigger severe stress.

  Visit www.LLS.org/booklets to view the free LLS booklet *Cancer and Your Finances.*

- **Pain**—People who have blood cancer may experience pain that can disrupt sleep, decrease appetite, limit activity and cause depression, all of which can intensify fatigue. In addition, many opioid analgesics (strong prescription pain medications) have side effects that may contribute to fatigue.

Visit www.LLS.org/booklets to view the free LLS fact sheet *Pain Management*.

- **Hypothyroidism**—Development of hypothyroidism (a condition in which the thyroid gland does not produce enough hormone) can occur after radiation therapy for some cancers and after total body irradiation in preparation for stem cell transplantation. Symptoms of hypothyroidism itself include fatigue, weight gain, muscle weakness and slowed heart rate.

  Hypothyroidism has been noted in patients who have received:

  - **Interferon alfa 2b (Intron A®)**
  - **L-asparaginase (Elspar®)**
  - Combination chemotherapies
  - Molecularly targeted anticancer treatments, for example, tyrosine kinase inhibitors such as **imatinib (Gleevec®), nilotinib (Tasigna®)** and **dasatinib (Sprycel®)**
  - Checkpoint inhibitors such as **nivolumab (Opdivo®)** and **pembrolizumab (Keytruda®)**
  - Iodine-containing medications or drugs such as **amiodarone (Cordarone®** or **Pacerone®), lithium (Lithobid®),** or **interleukin-2 (Proleukin®)**

- **Other Health Issues**—Coexisting health problems such as infection, sleep apnea, neurological (nerve) problems, and problems with heart, lung, kidney or liver function, may also cause or worsen fatigue. Medications to treat these conditions may contribute to fatigue as well.

Assessing Cancer-Related Fatigue

CRF can affect a person's body, mind and spirit. When patients experience signs and/or symptoms of fatigue before, during, or after treatment, it is important for them to talk about it with a member of their healthcare team. Assessing CRF can be challenging because:

- Fatigue may vary throughout the day and between treatments
- Fatigue can have more than one cause
- Many patients believe that fatigue is an expected part of cancer treatment and do not mention it to a member of their healthcare team
- Some patients worry that a discussion about their fatigue could distract members of their healthcare team from treating their cancer
- Some patients worry that their fatigue is a sign of disease progression or a recurrence

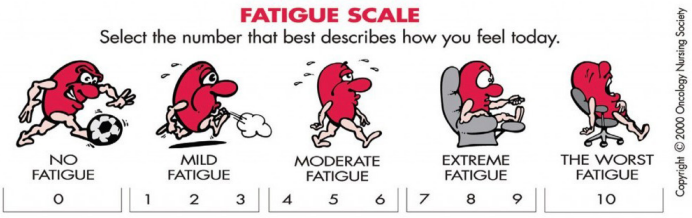
As with other cancer-related symptoms such as pain, CRF can be treated. Treatment for fatigue, along with lifestyle changes, can make an important difference and help improve energy level.

The first step in assessing CRF is to identify and address any underlying physical problems aside from, or in addition to, the cancer. While there are no lab tests that screen for CRF, your healthcare team may decide to order one or more tests to help identify potential causes. See *Lab Tests*, below.

Lab Tests

Name of Test	Purpose
Complete blood count (CBC)	Measures the number of platelets, white blood cells and red blood cells, as well as the hemoglobin and hematocrit in the blood
Peripheral blood smear	Checks the size, shape, type and maturity of platelets, white blood cells and red blood cells
Serum iron level	Measures the total amount of iron in the blood to check for iron-deficiency anemia
Transferrin level	Measures transferrin, a protein in the blood that binds to iron and transports it throughout the body
Total iron-binding capacity (TIBC)	Checks the body's ability to transport iron in the blood
Ferritin level	Measures protein in the cells that store iron
Folate level (also known as folic acid or Vitamin B_9)	Checks for deficiency of folate, an essential nutrient needed for making healthy cells
Vitamin B_{12} level	Checks for deficiency of Vitamin B12, needed to prevent anemia and nervous-system symptoms
Erythropoietin level	Measures the amount of erythropoietin, a hormone that increases the number of red blood cells
Thyroid function tests	Measures the level of certain hormones or protein to check for disorders of the thyroid gland
Adrenocorticotropic hormone (ACTH) level (also known as cosyntropin stimulation test)	Measures ACTH, a hormone that regulates cortisol, to check for adrenal gland and pituitary diseases

Your healthcare team may use a variety of other methods to assess CRF, including tools that take into account the patient's description of fatigue severity and its effects on daily living. One of these tools is the Oncology Nursing Society Fatigue Scale, below.



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This and other tools are designed to assess the severity, frequency and daily pattern of fatigue, as well as how it interferes with quality of life. Your healthcare provider may ask, "Since your last visit, how would you rate your worst fatigue on a scale of 0 to 10?" (0 = not at all fatigued; 10 = as fatigued as I could be). When a patient reports a fatigue level as moderate-to-severe (4 to 10), a member of your healthcare team should perform an in-depth assessment, including a more focused history and medical evaluation.

Good communication between patients and their healthcare team is key to successful evaluation and treatment of fatigue. People living with cancer should be asked about and encouraged to note and report symptoms of fatigue at each office visit. Tell your healthcare team if the fatigue is:

- Worse at certain times of the day
- Associated with certain cancer therapies
- Worse after, or relieved by, certain activities

Your sleep patterns and any past treatments for fatigue are also useful information to share with your healthcare team.

Treatments

Fatigue is often caused by more than one problem. Physical or psychological symptoms may be relieved by one or more of the following treatments, often used in combination with each other.

Treatment of Anemia. Treating anemia (low red blood cell count) may help reduce fatigue in cancer patients. Anemia in cancer patients is best managed by treatment of the underlying cause. When the cause is unclear or there is no specific remedy, treatment for anemia is considered "supportive care," and may include:

- Eating more foods rich in iron and taking vitamins
- Blood transfusions to raise hemoglobin levels quickly, to lessen symptoms of anemia and to ensure that enough oxygen is getting to a patient's vital organs
- Erythropoiesis-stimulating agents (ESAs) which stimulate the body to produce more red blood cells. The ESAs called **"epoetin alfa" (Epogen®, Procrit®)** and **"darbepoetin alfa" (Aranesp®)** are drugs given by injection to treat chemotherapy-induced anemia. They can relieve symptoms of anemia and reduce the need for blood transfusions, but they usually take two weeks to begin working.
    - A cancer patient who is undergoing chemotherapy and is prescribed an ESA should be given information about the drug and should discuss with a member of the healthcare team the potential benefits and risks of taking an ESA.
    - Biosimilar ESAs may be used to treat chemotherapy-induced anemia. A biosimilar is a biological product, approved based on data showing that it is highly similar to another biological product already approved by the Food and Drug Administration (FDA). Biosimilars must not have any significant clinical differences in safety and effectiveness compared to the reference drug. One example is the ESA called epoetin alfa, which is available as a biosimilar known as **epoetin alfa-epbx (Retacrit®).**

Exercise. A growing body of evidence suggests that physical activities (such as walking, riding a stationary bicycle, yoga, tai chi, swimming or water exercises, and strength training) lessen a cancer patient's fatigue and increase energy levels. Studies have shown that patients who exercise:

- Are less tired and less depressed
- Sleep better than patients who do not exercise
- Have greater stamina and strength

Another theory is that by increasing circulation, exercise may reduce excess inflammation which can worsen fatigue.

Exercises that have a mind-body component such as yoga (a combination of physical postures, breathing techniques, and meditation or relaxation), tai chi (a system of slow, controlled, meditative movements), and qigong (a system of coordinated movement, breathing and meditation) may be particularly effective in reducing fatigue. These exercises are unique because they combine physical components (such as movement,

stretching, balancing and controlled breathing) with stress management and spiritual practices (such as meditation), that may improve overall sense of well-being.

Choose exercises and activities you enjoy. Start slowly and work your way up to more time or more challenging activities. Consider using small amounts of time to spread your activity out over the course of a week. Aim to build up gradually to 150 minutes or more per week. Know there will be days when you can do more and days when you need to do less. Stay with your exercise plan for an extended period of time to see an improvement in your level of fatigue.

Before starting an exercise program, always consult with your healthcare team. It may be helpful to be referred to a physical therapist for an evaluation and an exercise plan. An exercise plan should be individualized based on the patient's age, type of cancer, and physical fitness level.

Treatment of Pain. Pain does not need to be accepted as part of cancer treatment. Patients are encouraged to speak with members of their healthcare team about treating pain. If pain is making fatigue worse, the cancer medication may be changed, or the dosage increased. If too much pain medication is causing too much fatigue, the medication may be changed, or the dosage adjusted.

Treatment of Depression. Patients suffering moderate-to-severe depression usually benefit from specialized treatment. There are many ways to treat depression including medication, counseling or a combination of both. Support groups and stress management training may also help patients deal with fatigue that is associated with depression, thereby improving quality of life.

Psychosocial Interventions. Studies suggest that interventions which reduce stress and increase psychosocial support (counseling, stress management, coping strategies) can help reduce fatigue and increase energy levels. Randomized clinical trials have shown that cognitive behavioral strategies such as progressive muscle relaxation or deep breathing exercises may relieve CRF in those receiving radiation therapy or stem cell transplantation. There is also evidence that cognitive behavioral therapy for sleep may be effective in helping patients change sleep behaviors and reduce sleep disturbances.

Mindfulness-based Interventions. A review of studies showed that mindfulness and relaxation techniques were effective at reducing the severity of fatigue in cancer patients and transplant recipients. Patients practice self-awareness of thoughts, feelings and sensations in the present moment. Other interventions may involve meditation, stress reduction, art therapy or gentle exercise.

Nutritional Counseling. Many cancer patients suffer from loss of appetite, nausea, diarrhea and vomiting, due to either the cancer or the cancer treatment. These patients are unable to eat normally. A dietitian can work with a patient to ensure that he or she is getting sufficient calories, fluids and nutrients for support in remaining as active as possible.

Clinical Trials. Ask your healthcare team about participating in studies to treat CRF using medications (such as psychostimulants, corticosteroids or antidepressants), complementary therapies (such as acupressure, aromatherapy or bright light exposure), or dietary supplements, vitamins or herbs. In fact, the National Institute of Health (NIH) has an ongoing Cancer-Related Fatigue Research Study to look at how a person's immune system and quality of life are affected by fatigue.

Clinical Trials for Blood Cancers

Every new cancer drug goes through a series of carefully controlled research studies before it can become part of standard cancer care. These research studies are called "clinical trials" and they are used to find better ways to care for and treat people who have cancer. In the United States, the FDA requires that all new drugs and other treatments be tested in clinical trials before they can be used. At any given time, there are thousands of cancer clinical trials taking place. Doctors and researchers are always looking for new and better ways to treat cancer.

Researchers use cancer clinical trials to study new ways to

- Treat cancer using
  - A new drug
  - A drug that has been approved, but to treat a different kind of cancer
  - A new combination of drugs
  - A new way of giving a drug—by mouth, intravenously (IV), etc.
- Manage cancer signs and/or symptoms and ease treatment side effects
- Find and diagnose cancer
- Keep cancer from coming back (recurring) after treatment
- Manage long-term side effects

By taking part in a clinical trial, patients can see doctors who are experts in their disease, gain access to new, cutting-edge therapies, and provide helpful information for future patients. The treatments and information we have today are due in large part to patients being willing to join clinical trials. Anyone interested in being part of a clinical trial should talk to their hematologist-oncologist about whether a clinical trial might be right for them. During this conversation it may help to:

- Have a list of questions to ask about the risks and benefits of each trial (visit www.LLS.org/WhatToAsk for lists of suggested questions)
- Ask a family member or friend to go with you when you see your doctor—both for support and to take notes

Clinical trials can be difficult to understand and to navigate, but The Leukemia & Lymphoma Society is here to help. Patients and caregivers can work with **Clinical Trial Nurse Navigators** who will help find potential clinical trials, overcome the barriers to enrollment and provide support throughout the entire clinical-trial process. Our Clinical Trial Nurse Navigators are registered nurses who are experts in blood cancers and clinical trials. Your Clinical Trial Nurse Navigator will:

- Talk with you about your treatment goals
- Help you understand the clinical-trial process, including your rights as a patient
- Ask you for details about your diagnosis (such as past treatments, treatment responses, and your cancer genetic profile), your current health, and your medical history, because these might impact whether you can take part in certain clinical trials
- Help you understand how your finances, insurance coverage, support network, and ability and willingness to travel might impact your choice of clinical trials
- Guide and help you in your efforts to find and enroll in a clinical trial, including connecting you with trial sites
- Help deal with any problems you might have as you enroll in a trial
- Support you throughout the clinical-trial process

Please call an LLS Information Specialist at (800) 955-4572 or visit www.LLS.org/CTSC for more information about clinical trials and the Clinical Trial Support Center at LLS.

Also, visit www.LLS.org/booklets to view *Understanding Clinical Trials for Blood Cancers.*

Take Care of Yourself

Here are some suggestions that may help patients with CRF improve their own well-being.

Be Flexible. Do not measure yourself based on your energy level before your diagnosis. Set realistic goals. You may not be able to take care of everything that you want to do every single day. Decide which tasks are most important for you and focus on completing those priorities. When you are feeling fatigued, let others help you.

Distract Yourself. Allow yourself to shift your focus from fatigue (and what you may not be able to get done) by listening to music, reading a book, looking at pictures, meeting friends, watching a movie, going for a walk or enjoying time in nature.

Stay Active. Staying physically active may help some people ease fatigue. If you do not already have an exercise regimen, begin one gradually and aim to exercise at least three to five times a week. Adjust your exercise routine if you feel overly tired. Focus on activities that will help you gradually build strength but that do not use up all your energy. Light exercise, such as walking, can also help you relax and sleep better.

Practice Good Nutrition. Patients with cancer are at risk for malnutrition and other problems such as loss of appetite, nausea, vomiting and inability to absorb nutrients resulting from either cancer or cancer treatment. It is important for patients to eat a balanced diet that provides sufficient fluid, calories, protein, vitamins and minerals. Iron intake is vital, so try to consume iron-rich foods such as green leafy vegetables and red meat. Maintain energy levels by eating frequent small meals or snacks throughout the day. You may find it useful to work with a dietitian to create a plan to suit your caloric needs and to learn about easy-to-prepare, healthful meals and snacks. Drink plenty of noncaffeinated liquids throughout the day. Adequate hydration is very important in preventing and treating fatigue.

Visit www.LLS.org/nutrition for information about free nutrition consultations and links to *Food and Nutrition Facts* and the *Nutrition Handbook*.

Manage Stress. The effects of stress can be offset, in part, through exercise, relaxation techniques, mindfulness meditation, spiritual and/or religious practices, socializing and counseling.

Visit www.LLS.org/booklets to view *Managing Stress – How Stress Affects You and Ways to Cope* for more information.

Address Sleep Habits. The following suggestions may help improve sleep quality:

- Engage in relaxing activities before bedtime, such as taking a warm bath or shower, reading, writing in a journal, yoga, meditation or listening to calming music.
- Go to bed at the same time every night.
- Use the bedroom only for sleep.
- Keep the bedroom cool, quiet and dark.
- Use comfortable bedding and sleepwear.
- Avoid caffeine, alcohol or high-sugar foods before bedtime.
- Avoid video game playing, television, computer, cell phone use and social media use before bed and overnight.
- Forgo daytime naps that may interfere with nighttime sleep. If you need to nap, do not sleep for longer than 30 minutes.

Ask for Help. Ask for help with routine tasks such as shopping, cooking, housekeeping, laundry or driving. Rest when you feel tired.

Plan Ahead. If possible, schedule cancer treatments for those times that will have the least effect on your job or other activities. For example, if you work, schedule treatments in the afternoon or at the end of the week, so you can be the most productive at your job.

Keep a Journal. Keep track of your experiences of fatigue. Take notes on a regular basis regarding:

- The severity of your fatigue (on a 0 to 10 scale, with 0 = no fatigue and 10 = the worst fatigue you can imagine)
- When your fatigue occurs
- How long your fatigue lasts
- Activities or treatments that make you feel either better or worse
- How fatigue interferes with your daily activities
- Symptoms of your fatigue, such as tired legs or eyes, difficulty with concentration, weakness or sleepiness, shortness of breath, irritability or impatience.

A detailed record will help you when you discuss possible causes, treatments and coping strategies with your healthcare team.

Also note daily activities, medications and treatments, eating and sleeping habits, weight changes and emotional stressors, including financial concerns. Write down strategies that have worked to reduce fatigue, such as undertaking difficult tasks when your energy is highest and pacing yourself and scheduling rest when you feel tired.

Feedback

Visit **www.LLS.org/PublicationFeedback** to make suggestions about this booklet.

Acknowledgement

The Leukemia & Lymphoma Society appreciates the review of this material by:

Carmelita P. Escalante, MD
Professor and Department Chair
Department of General Internal Medicine, Division of Internal Medicine
The University of Texas MD Anderson Cancer Center
Houston, TX

We're Here to Help

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has regions throughout the United States and in Canada. To find the region nearest to you, visit our website at www.LLS.org/LocalPrograms or contact an Information Specialist at (800) 955-4572.

LLS offers free information and services for patients and families affected by blood cancers. This section lists various resources you may find helpful.

For Help and Information

Consult with an Information Specialist. Information Specialists can assist you through cancer treatment, financial and social challenges and give accurate, up-to-date disease, treatment and support information. Our Information Specialists are highly trained oncology social workers and nurses. Language services are available. For more information, please:

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email and Live chat: www.LLS.org/InformationSpecialists

Clinical Trials (Research Studies). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Pediatric and adult patients and caregivers can work with our Clinical

Trial Nurse Navigators who will help find clinical trials and provide personalized support throughout the entire clinical trial process. Visit www.LLS.org/CTSC for more information.

Nutrition Consultations. Schedule a free one-on-one nutrition consultation with one of our registered dietitians who have expertise in oncology nutrition. Consultations are available to patients and caregivers of all cancer types. Dietitians can assist with information about healthy eating strategies, side effect management and more. Please visit www.LLS.org/nutrition for more information.

Free Information Booklets. LLS offers free education and support booklets for patients, caregivers and healthcare professionals that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit www.LLS.org/programs for more information.

Financial Assistance. LLS offers financial support to eligible individuals with blood cancer for insurance premiums, co-pays, and non-medical expenses like travel, food, utilities, housing, etc. For more information, please:

- Call: (877) 557-2672
- Visit: www.LLS.org/finances

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe to access exclusive content, submit ideas and topics, and connect with other listeners.

Free Mobile Apps.

- LLS Coloring For Kids™ – Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit www.LLS.org/ColoringApp to download for free.
- LLS Health Manager™ – Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit www.LLS.org/SuggestedReading to find out more.

Connecting with Patients, Caregivers and Community Resources

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients and caregivers reach out and share information. Please visit www.LLS.org/chat for more information.

Local Programs. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection® Program* (a peer-to-peer support program), local support groups and other great resources. For more information about these programs or to contact your region, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/LocalPrograms

Advocacy and Public Policy. Working closely with dedicated volunteer advocates, LLS's Office of Public Policy elevates the voices of patients to state and federal elected officials, the White House, governors and even courts. Together, we advocate for safe and effective treatments. We pursue policies that would make care more accessible to all patients. And, most of all, we advocate for the hope for a cure. Want to join our work? Visit www.LLS.org/advocacy for more information.

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to view the directory.

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: www.publichealth.va.gov/exposures/AgentOrange

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center Health Program. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov and enter "depression" in the search box

Other Resources

National Cancer Institute (NCI)
www.cancer.gov
(800) 422-6237

The National Cancer Institute, part of the National Institutes of Health (NIH), is a national resource center for information and education about all forms of cancer.

National Center for Complementary and Integrative Health (NCCIH), National Institutes of Health
www.nccih.nih.gov
(888) 644-6226

NCCIH conducts and supports research and provides information about complementary health products and practices. Their website contains reliable, objective and evidence-based information on integrative healthcare.

National Comprehensive Cancer Network (NCCN)
https://www.nccn.org/
(215) 690-0300

NCCN is a not-for-profit alliance of 32 leading cancer centers devoted to patient care, research, and education. Visit the website to access the latest NCCN Clinical Practice Guidelines in Oncology: Cancer-Related Fatigue.

Office of Patient Recruitment - National Institutes of Health Clinical Center
NIH Cancer Related Fatigue Research Study
https://clinicalcenter.nih.gov/recruit/protocols/11_fatigue.html
(800) 411-1222

The Office of Patient Recruitment serves to educate the public about clinical trial participation at the NIH Clinical Center in Bethesda, MD. Researchers are conducting a study to understand fatigue in people with cancer.

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