

Cancer-Related Fatigue and Anemia

Treatment Guidelines for Patients

Version II / May 2003



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The mutual goal of the National Comprehensive Cancer Network (NCCN) and the American Cancer Society (ACS) partnership is to provide patients and the general public with state-of-the-art cancer treatment information in understandable language. This information, based on the NCCN's Clinical Practice Guidelines, is intended to assist you in the dialog with your doctor. These guidelines do not replace the expertise and clinical judgment of your doctor. Each patient's situation must be evaluated individually. It is important to discuss the guidelines and all information regarding treatment options with your doctor. To ensure that you have the most up-to-date version of the guidelines, consult the Web sites of the ACS (www.cancer.org) or NCCN (www.nccn.org). You may also call the NCCN at 1-888-909-NCCN or the ACS at 1-800-ACS-2345 for the most recent information.

NCCN Clinical Practice Guidelines were developed by a diverse panel of experts. The guidelines are a statement of consensus of its authors regarding the scientific evidence and their views of currently accepted approaches to treatment. The NCCN guidelines are updated as new significant data become available. The Patient Information version will be updated accordingly and will be available on-line through the NCCN and the ACS Web sites. To ensure you have the most recent version, you may contact the ACS or the NCCN.

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Introduction

With this booklet, patients have their first access to information about how cancer-related fatigue and anemia are treated at the nation's leading cancer centers. Originally devised for cancer specialists by the National Comprehensive Cancer Network (NCCN), these treatment guidelines have now been translated for the general public by the American Cancer Society (ACS).

Since 1995, doctors have looked to the NCCN for advice on treating cancer. The NCCN Clinical Practice Guidelines were developed by a diverse panel of experts from 19 of the nation's leading cancer centers.

For more than 85 years, the public has relied on the American Cancer Society for information about cancer. The Society's books and brochures provide comprehensive, current, and understandable information to hundreds of thousands of patients, their families, and friends. This collaboration between the NCCN and ACS provides an authoritative and understandable source of cancer treatment information for the general public.

These patient guidelines will help you better understand cancer-related fatigue and anemia treatment and your doctor's counsel. We urge you to discuss them with your doctor and ask the following questions:

- Will the cancer therapy that I am receiving cause fatigue?
- Are there effective treatments to control or relieve my fatigue?
- How will you decide which treatment I will receive?
- What can be done if the treatment does not relieve my fatigue?
- What are the likely side effects of the proposed treatments?
- What other health care professionals can help manage my fatigue?
- Is my fatigue caused by anemia? If so, how will it be treated?

What Is Cancer-Related Fatigue?

Fatigue is the feeling of being tired physically, mentally, and emotionally. It means having less energy to do the things you normally do or want to do.

Cancer-related fatigue is defined as a persistent and subjective sense of tiredness that can occur with cancer or cancer treatment. It can persist over time and can interfere with usual activities. This fatigue is different from the fatigue of everyday life, which is usually temporary and relieved by rest. Cancer-related fatigue is more severe and more distressing. Rest does not always relieve it. For some people, this kind of fatigue can be even more distressing than pain, nausea, vomiting, or depression. Cancer-related fatigue can:

- Vary in its unpleasantness, severity, and amount of time that it is present
- Be overwhelming and hinder your ability to feel well
- Even make being with your friends and family difficult
- Decrease your ability to continue normal activities, including going to work
- Make it difficult to follow your cancer treatment plan

Cancer patients say fatigue is the most distressing side effect of cancer and its treatment and one that drastically affects their quality of life. People with cancer-related fatigue describe it as feeling tired, weak, exhausted, weary, worn-out, or slow; having no energy; and being unable to concentrate. They also talk about having heavy arms and legs, having little motivation to do anything, being unable to sleep or sleeping too much, or having feelings of sadness, irritability, or frustration. Patients rarely describe their symptom as “fatigue” unless their health care team suggests it.

From Susan, a cancer survivor: Fatigue means being extremely tired; not having any energy; wanting to lie down and sleep. It also means I don't have any desire to expend any energy; I do not get relief from sleep; I just take naps here and there; I'm unable to do things for myself. Sometimes I struggle to get up to get something, or do something that actually takes very little effort. I have a lot of frustration and anger over not feeling like doing ordinary things.

Cancer-Related Fatigue Is Very Common

Cancer-related fatigue is the most common side effect of cancer and its treatment. Research suggests that about 90% of cancer patients receiving treatments such as radiation therapy, chemotherapy, immunotherapy, or bone marrow transplants have fatigue. Thirty percent to seventy-five percent of cancer survivors have reported fatigue continuing for months or years after completing active treatment. Therefore, cancer survivors or patients who are no longer actively being treated must still be watched for fatigue because it can exist after treatment. Even though fatigue is a very distressing symptom,

doctors and nurses seldom focus on it, and patients and caregivers rarely report it. Although it may be difficult to talk about, fatigue is a normal and common occurrence for people with cancer. There are things that can be done to help if the health care team knows about the problem.

Describing Fatigue

Management of fatigue is an important part of care for you and your family. In fact, current cancer care emphasizes that symptom management is a patient's right.

Before starting cancer therapy, the health care team must know how severe your fatigue is. Only you know if you have fatigue and how severe it is. No laboratory test, or x-ray can diagnose or determine the level of fatigue. The best measure of fatigue is your description of your fatigue to the health care team.

You can describe your level of fatigue as none, mild, moderate, or severe, or you can use a scale of 0 to 10, where a 0 means no fatigue, and a 10 means the worst fatigue that you can imagine. The doctor or nurse should also ask you about your fatigue.

How Is Fatigue Assessed?

If you have moderate (4 to 6) to severe (7 to 10) fatigue, your doctor will talk with you further, asking you to give them as much information as you can about your fatigue. This “talk” is called a focused evaluation and looks closely just at your fatigue. You may be asked such questions as:

- When did the fatigue first start?
- When did you first realize that it is an unusual type of fatigue for you?

- How has it progressed over the course of your treatment or since your diagnosis?
- What helps relieve your fatigue?
- What makes your fatigue worse?
- How has the fatigue affected your daily activities or the activities that give meaning and enjoyment to your life?

In planning how to treat your fatigue, your doctor will consider your cancer, the type and length of treatment, their capacity to cause fatigue, and your response to treatment.

Causes of Cancer-Related Fatigue

Fatigue is common with chemotherapy, radiation therapy, bone marrow transplants, and immunotherapy. Chemotherapy, bone marrow transplants, and radiation therapy can destroy rapidly dividing healthy cells, especially the cells in the bone marrow, causing fatigue. Too few red blood cells (called *anemia*) mean too little energy to meet the body's needs. Without enough energy the patient feels tired. Rapid cell death also leads to a buildup of cell by-products. This increases the amount of energy the body needs to repair damaged tissue. Immunotherapy can cause side effects that can contribute to fatigue, such as flu-like symptoms, mental fatigue, and difficulty thinking.

The cancer itself can cause fatigue directly or indirectly by spreading to the bone marrow, causing anemia, and by forming toxic substances in the body that interfere with normal cell functions.

Primary Factors

Fatigue is different for every cancer patient. Although many treatment-related and disease-related factors may contribute to the development of fatigue, exactly what causes cancer-related fatigue is still unknown. The NCCN panel has identified five common or “primary” conditions that are often present with fatigue and therefore should be evaluated. Managing these conditions can greatly help reduce the fatigue. These conditions are anemia, pain, emotional distress, sleep problems, and low thyroid gland function.

Anemia: Anemia occurs when the blood has too little *hemoglobin*, the part of the *red blood cell (RBC)* that carries oxygen needed by your body. Doctors often define anemia as a blood hemoglobin level of less than 12 g/dL, but many people will not feel much different until the hemoglobin level falls below 11 g/dL. Symptoms of anemia will begin to appear as the hemoglobin decreases, and these can include shortness of breath, difficulty breathing on exertion, and fatigue. These symptoms occur because your body tissues aren't receiving adequate oxygen. Anemia can be caused by a number of different factors:

- Cancer
- Cancer treatment
- Persistent bleeding
- Lack of specific vitamins or minerals in the diet
- Major organ dysfunction (including severe heart, lung, kidney, or liver disease)
- Destruction of the RBCs
- Hereditary disorders such as sickle cell disease
- A combination of these factors

Some of these causes may have nothing to do with your cancer. If anemia is causing your fatigue, by treating it, the level of fatigue may decrease.

Anemia is diagnosed with a blood test called a complete blood cell count or CBC. A careful medical history, physical examination, other blood tests, such as blood iron and vitamin levels, and a bone marrow examination may help find out what is causing anemia as well.

The goal of treatment for anemia is to treat the cause of the anemia and to improve the hemoglobin level so that the symptoms will go away. Examples of treatments for anemia include eating nutrient-rich foods, taking iron and folic acid supplements, stopping bleeding, and taking medicines such as *erythropoietin* (ee-rith-ro poy ee tin). This substance, which is normally produced by the kidneys, helps the body make its own new red blood cells. A transfusion of red blood cells also may be given to treat anemia, especially in cases where the hemoglobin level needs to be raised quickly.

For many patients, anemia develops as a result of chemotherapy and causes them to become fatigued. The use of erythropoietin has been studied in patients receiving chemotherapy. Patients who were given erythropoietin had an increase in their hemoglobin level and a reduced need for blood transfusion.

Although the evidence was not quite as strong, an equally important finding in these studies was the effect of anemia on the patients' quality of life. Patients with anemia had a lower quality of life than they had when anemia was not present. When the anemia was corrected, the patients' quality of life often improved. Some studies have now begun looking at whether or not correcting anemia during cancer treatment can help people live longer.

Pain: Chronic cancer pain can cause reduced activity, decreased appetite, sleep problems, and depression, all of which contribute to fatigue. For more information on the treatment of cancer-related pain, talk to your doctor or nurse. You may also request a copy of the *Cancer Pain Treatment Guidelines for Patients* from the ACS or NCCN.

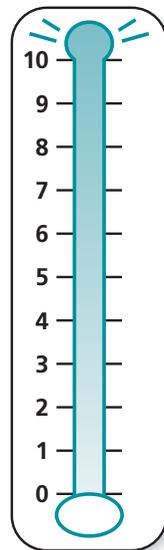
Emotional distress: *Distress* refers to the unpleasant emotions that occur in anyone diagnosed with cancer. This distress can be a feeling of sadness about the loss of good health; this is a normal feeling. Sometimes, the distress becomes so great that it causes physical symptoms. Depression and anxiety are common examples of distress that can cause physical symptoms of fatigue. The NCCN Distress Management Panel (group of doctors and other health care professionals who developed the *NCCN Practice Guidelines for Distress Management*) has developed the following tool to help you describe your level of distress. Using this tool can help the health care team better respond to this complex problem and make referrals to other services that may be helpful, such as social work and pastoral services.

Instructions:

Please circle the number (0 - 10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme
distress

No
distress



Please indicate if any of the following has been a cause of distress in the past week, including today. Be sure to check NO or YES for each.

NO	YES		NO	YES	
		Practical Problems			Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
		Emotional Problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
		Spiritual/Religious Concerns	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Relating to God	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Loss of faith	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual

Other Problems:

Sleep problems: If you wake frequently during the night or have difficulty falling asleep, you are not getting the rest you need. This disturbance in your sleep can result in fatigue. Please tell your doctor or nurse about your sleeping problem. They will try to determine why you are having trouble sleeping in order to plan appropriate treatment.

Low thyroid gland function: Because low functioning of the *thyroid gland* is very common in people in the United States, anyone with the symptom of fatigue should be evaluated for this condition. Blood tests are done to determine the amount of thyroid hormone present in the blood. If the level of thyroid hormone is low, treatment is available that consists of replacing the thyroid hormone needed by the body. In some conditions, such as head and neck cancer, when the patient's neck is treated with radiation therapy, low thyroid function may develop without being suspected.

Other Factors

If a primary condition is not identified, your doctor will do a more comprehensive assessment or evaluation to try to account for the cause of the fatigue. Other factors that may contribute to fatigue include medicines, other medical conditions, poor nutrition, and excessive inactivity.

Medicines: Several medicines can produce symptoms of fatigue and problems with thinking. The most common are analgesics (pain-relieving drugs), hypnotics, antidepressants, and antiseizure medicines. Although the degree of sedation varies among patients, taking several drugs with many side effects may worsen fatigue. It is important to tell your health care team about any medicines you are taking. Keeping a journal may help you keep track of your medicines and symptoms.

Other medical problems: Many people have other medical problems or illnesses that are not related to cancer, which may contribute to fatigue. These illnesses should be identified and treated. Examples of other medical conditions that may be present include:

- Heart problems, such as congestive heart failure
- Lung problems, such as emphysema or shortness of breath
- Kidney problems, such as kidney failure
- Nervous system problems, such as seizures or Alzheimer's disease
- Infections, such as pneumonia or viral illnesses

Poor nutrition: The body needs protein, carbohydrates, fats, vitamins, minerals, and water to do its work. In people with cancer, certain changes in nutrition can affect fatigue. These changes include the ability to process nutrients, increased energy requirements, and decreased intake of food, fluids, and certain minerals. These changes can result from:

- Changes in metabolism (the body's ability to break down products)
- Competition by the tumor for nutrients
- Poor appetite
- Nausea/vomiting
- Diarrhea or bowel obstruction

You may ask to be referred to a registered dietitian who can help you learn how best to meet your nutritional needs under these circumstances.

Inactivity: The combined effect of cancer treatment and reduced physical activity often decreases your capacity for physical performance. Thus, you must use greater effort and more energy to do your usual activities, which leads to fatigue. Exercise builds up your capacity to expend energy, leading to less effort when you do your usual activities and less fatigue. A careful evaluation by a physical therapist can help plan the right exercise program for you.

Treatment of Fatigue

Symptoms of fatigue often are caused by more than one problem. Although treating a specific problem, such as anemia, may make you feel better, other things may still need to be done. That is why many different approaches are considered that may or may not include medicines. Therefore, treatment for cancer-related fatigue may involve many health professionals, including doctors, nurses, social workers, physical therapists, nutritionists, and a number of others. Education and counseling are part of the

treatment and help the patient learn how to conserve energy, reduce stress, and use distraction to think about things other than the fatigue.

If the cause of fatigue is known, treatment will be directed at the cause. For example, if anemia is thought to contribute to symptoms of fatigue, the anemia will be treated. In another patient, treatment may include correcting fluid and mineral imbalances. Exercise, treatment of sleep problems, and correction of nutrition problems all seem to lessen fatigue. Exercise seems to have the greatest effect.

Another treatment, called restorative treatment, addresses one specific type of fatigue, called *attentional fatigue*. This fatigue is defined as a decreased ability to concentrate or to direct one's attention. Examples of attention-restoring activities include walking on a beach, sitting in a park, gardening, doing volunteer activities not related to the illness, and having quiet time.

Patient and Family Education

Education is an important part of treatment. By understanding fatigue, you can cope better and reduce your distress. Often, a family member who participates in the education with you can help you talk to your health care team about your fatigue. The best approach is to learn about fatigue before you have it.

Self-Care Measures to Reduce Fatigue

- List your activities according to how important they are to you when you have the most energy.
- Ask for help and delegate tasks when you can.
- Place things that you use often within easy reach to save your energy.
- Establish a structured daily routine.
- Use methods to reduce stress, such as deep breathing, visual imagery, meditation, prayer, talking with others, reading, listening to music, painting, or any other activity that gives you pleasure.
- Keep a journal.
- Balance rest and activities. Excessive bed rest promotes weakness. Try to avoid it. Schedule activities so that you have time for plenty of rest that does not interfere with nighttime sleep. Shorter rest periods are reported to be better than one long one.
- Talk to your doctor about how to manage your pain, nausea, and depression.
- Talk with your doctor before you start an exercise program.
- Unless you are given other instructions, eat a balanced diet that includes protein (meat, milk, eggs, and legumes) and drink about 2 liters (8 to 10 glasses) of water a day.

Call Your Doctor about Cancer-Related Fatigue if:

- Your fatigue does not get better, keeps coming back, or becomes severe.
- You are more tired than usual during or after an activity.
- You are feeling tired and it is not related to an activity.
- Your fatigue does not get better if you rest or sleep.
- You become confused or cannot concentrate.
- You are unable to get out of bed for more than 24 hours.
- Your fatigue disrupts your work, social life, or daily routine.

About Clinical Trials

All medicines used to treat cancer, fatigue, or other diseases must undergo clinical trials in order to determine their safety and effectiveness before the Food and Drug Administration can approve them for use.

When studying promising new or experimental treatments, researchers want to know:

- Does this new type of treatment work better than other treatments already available?
- What side effects does the treatment cause?
- Do the benefits outweigh the risks, including side effects?
- Which patients will the treatment most likely help?

During your treatment for cancer, your doctor may suggest that you take part in a clinical trial of a new treatment. You should know that scientists only conduct clinical trials when they have reason to believe that the treatment under study may indeed be better than other treatments. No one will receive a placebo (sugar pill) if a standard treatment is already available.

Whether the experimental treatment will work better than the standard treatment must be proved. The new therapy may have some side effects, which your doctor will discuss with you before you enter the trial. There are three phases of clinical trials in which treatments are studied before they can be approved by the Food and Drug Administration.

The purpose of a phase I study is to find the best way to give a new treatment and find out how much of it can be given safely. Doctors watch patients carefully for any side effects. While treatments tested in a phase I study have been well tested in laboratory and animal studies, the side effects in patients however, are not well known.

After safety has been evaluated in a phase I trial, a phase II clinical trial determines if the research treatment is effective. Patients are given the highest dose that doesn't cause serious side effects (determined from the phase I study). Doctors closely observe them for an anticancer effect by carefully measuring changes in the cancer sites that were present at the beginning of the study. In addition to monitoring patients for response, any side effects are carefully assessed and recorded.

Phase III clinical trials require a large number of patients, sometimes thousands. A "control group" of patients may receive the standard (most currently accepted) treatment, while another group may receive the treatment or drug under study. Patients are usually randomly assigned (like flipping a coin) to one group or the other. In this way researchers can compare the two treatments to find out whether the new treatment is more beneficial to survival and quality of life. Doctors carefully monitor all patients in phase III trials for side effects. The trial is discontinued if the side effects are too severe or if it becomes obvious that one group has had much better results than the other.

Taking part in any clinical trial is completely voluntary. Your doctors and nurses will explain the study to you in detail and will give you a form to read and sign. This informed consent document states that you understand the potential risks and want to participate. Even after you sign the form and the trial begins, you may leave the study at any time, for any reason. Participating in a clinical trial is an appropriate option for people at any stage of cancer. Taking part in the study does not prevent you from getting other medical care you may need. But you should check with your health insurance company to find out if they will cover the costs of your taking part in a clinical trial.

If you are in a clinical trial, you will receive excellent care. You will have a team of experts looking at your situation and monitoring your progress very carefully. The study is especially designed to pay close attention to you.

During cancer treatment, your doctor may suggest taking part in a clinical trial of a new treatment for fatigue. The fatigue you experience can affect your quality of life so greatly that researchers are conducting studies to try to improve your quality of life. These studies may involve drug treatments or nonmedical treatments such as an exercise program, participation in a support group, and so on.

Participating in a clinical trial that studies new and improved methods for managing cancer-related fatigue may help you directly, and it may help other people with cancer fatigue in the future. For these reasons, members of the National Comprehensive Cancer Network and the American Cancer Society encourage participation in clinical trials.

Summary

These guidelines suggest a way in which you are regularly evaluated for fatigue, use a brief screening tool to identify your level of fatigue, and receive treatment based on your fatigue level. The guidelines also include specific approaches to evaluating and treating anemia, a major cause of fatigue. The goal of these guidelines is to identify and treat the causes of fatigue that lead to distress or interfere with your daily activities or ability to function. Fatigue can reduce your ability to take care of yourself, your degree of motivation, and even sometimes the desire to continue treatment. Successful management of fatigue requires communication between you, your doctor, and your nurse.

Reference

Holland, JC. Update: NCCN Practice Guidelines for the Management of Psychosocial Distress. *Oncology*. 1999;13(No 5A):113–47.

Work-Up (Evaluation) and Treatment Guidelines

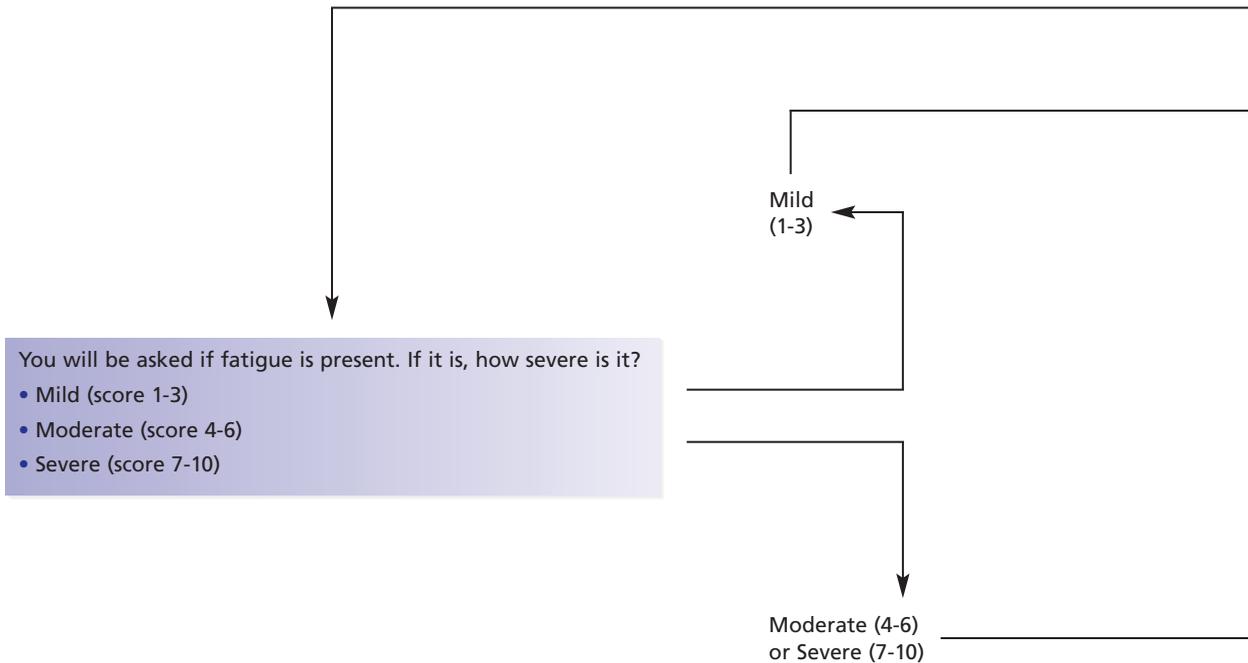
Decision Trees

The first five “decision trees,” or algorithms, on the following pages represent decisions about treatment of cancer fatigue based on how severe your fatigue is. Each tree shows step-by-step how you and your doctor or nurse can make treatment choices to manage your fatigue.

The last four algorithms (see pages 28–37) focus on cancer-related anemia. These “decision trees” show how your doctor can determine the cause of your anemia and how severe it is. They also describe when you might need to be treated for your anemia, and which treatments are recommended in specific situations.

Keep in mind that this information is not meant to be used without the expertise of your own doctor, who is most familiar with your illness, medical history, and personal preferences.

The NCCN guidelines are updated as new information becomes available. To ensure you have the most recent version, consult the Web sites of the ACS (www.cancer.org) or NCCN (www.nccn.org). You may also call the NCCN at 1-888-909-NCCN or the ACS at 1-800-ACS-2345 for the most recent information on these guidelines or on cancer in general.



Keep in mind that this information is not meant to be used without the expertise of your own doctor, who is familiar with your situation, medical history, and personal preferences.

The order in which therapy options are listed does not imply a hierarchy.

Participating in a clinical trial is an option for people with cancer. Taking part in the study does not prevent you from getting other medical care you may need.

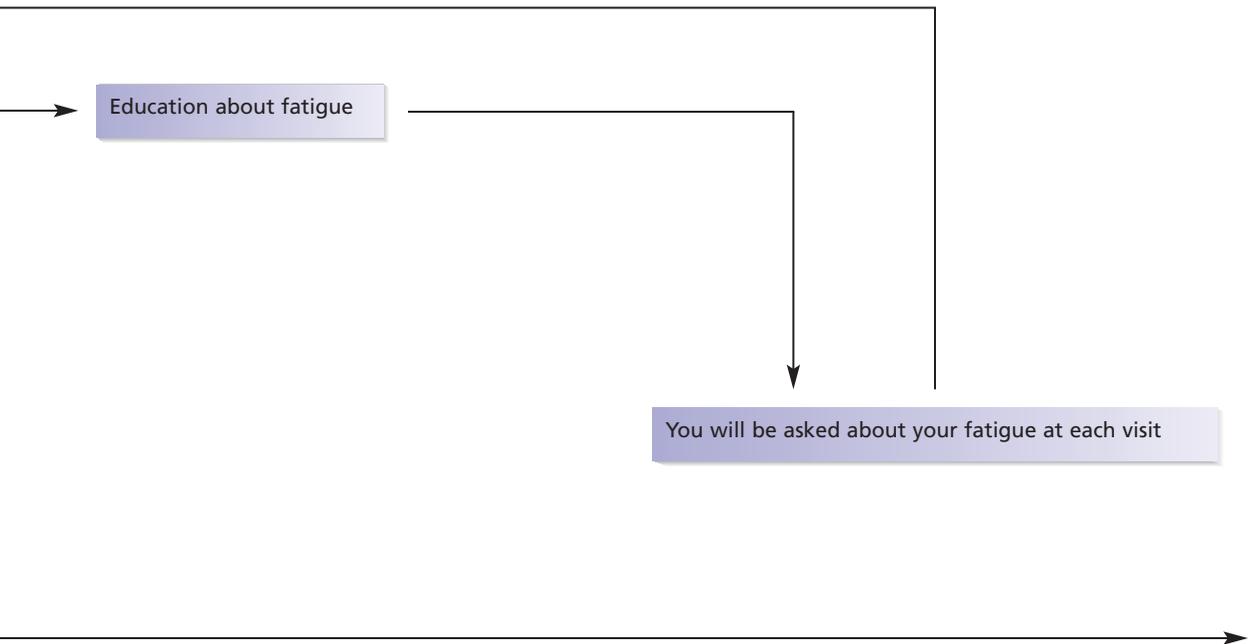
Screening for Cancer-Related Fatigue

At the first visit the doctor or nurse will ask if you have fatigue and how severe it is. They may ask you to tell them about your fatigue and to describe the level of your fatigue. No single method is used to measure fatigue, but picking a number on a scale from 0 to 10 is usually a good way to describe your fatigue. A score of 0

means “no fatigue” and 10 means “as bad as you can imagine.”

If you have no fatigue or mild fatigue (1 to 3), your doctor or nurse will talk with you about fatigue at each future visit. Your doctor can also reassure you that the presence of fatigue does not mean that your cancer is getting worse.

Screening for Cancer-Related Fatigue



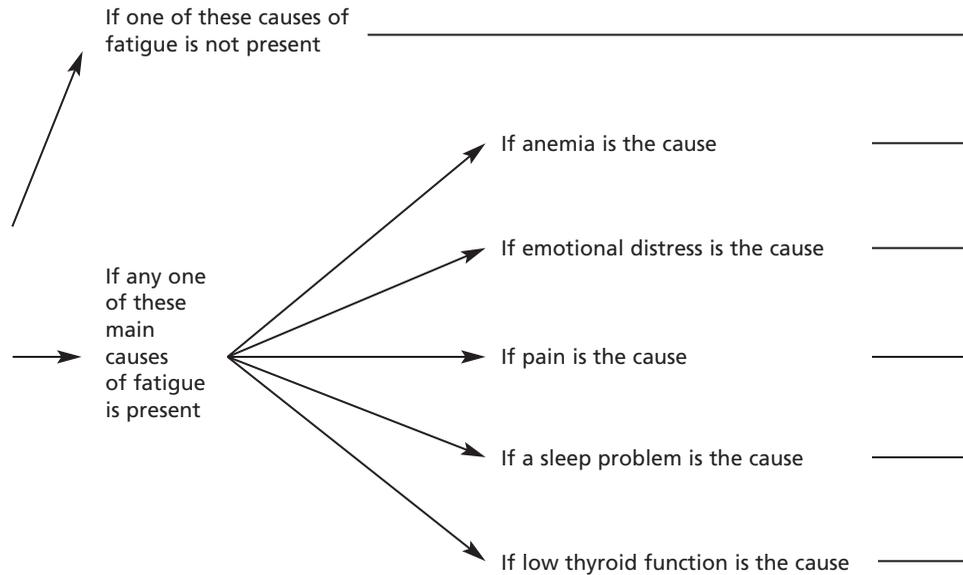
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NOTES

Your doctor or nurse will ask about your cancer and treatment. He or she will try to find the cause of your fatigue.

It may be related to:

- Anemia
- Emotional distress (depression)
- Sleep difficulties
- Pain
- Low thyroid gland function



Keep in mind that this information is not meant to be used without the expertise of your own doctor, who is familiar with your situation, medical history, and personal preferences.

The order in which therapy options are listed does not imply a hierarchy.

Participating in a clinical trial is an option for people with cancer. Taking part in the study does not prevent you from getting other medical care you may need.

Primary Evaluation of Cancer-Related Fatigue

If your fatigue is moderate (4 to 6) to severe (7 to 10), your doctor or nurse will talk with you further, asking you to recall as much information as you can about your fatigue. In planning your fatigue treatment, your doctor or nurse will consider your cancer, the type and length of treatment, its capacity to cause fatigue, and how you respond to treatment.

You will be asked the following questions about your fatigue:

- When did it start?
- How long has it lasted?
- Has it changed over time?
- How did it start?
- What makes it better?

Primary Evaluation of Cancer-Related Fatigue

→ Go to complete evaluation (see page 20)

→ The cause of your anemia will be determined and treated (see pages 28–29)

→ Your emotional distress will be evaluated and treated

→ Your pain will be evaluated and treated using the NCCN Cancer Pain Guidelines*

→ Your type of sleep difficulty will be determined and treated

→ The cause of your low thyroid function will be determined and treated

*For a free copy of the *NCCN/ACS Cancer Pain Treatment Guidelines for Patients*, please call 1-800-ACS-2345 or 1-888-909-NCCN.

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- What makes it worse?
- Do you have any other symptoms with the fatigue?
- Does it interfere with your daily activities?
- How much does it interfere with daily activities?

As part of this evaluation, your doctor will ask you about the five most common conditions that often cause fatigue. You will be asked about the presence of pain, emotional distress, and sleep

problems. Your doctor will also determine, based on a physical exam, history, and blood tests, whether you have anemia or low thyroid gland function.

Anemia itself has many potential causes, many of which can be treated if needed. If anemia is found to be one of the sources of your fatigue, your doctor will try to determine the cause of the anemia (see pages 28–29).

Complete Evaluation of Cancer-Related Fatigue

The complete evaluation includes the following:

A review of your body systems: If no cause for the fatigue is found, your doctor will do a more thorough evaluation. This will include asking you questions about all your body systems, such as your kidneys, liver, heart, bones, and so on, and possibly doing some tests to find out if your organs are healthy.

A review of your medicines, including prescription and over-the-counter: Your doctor will ask about all medicines you are taking because some may contribute to your fatigue. For example, certain medicines for pain, depression, and nausea can make the fatigue worse when taken together. Your doctor may change the dose or schedule of some of your medicines to reduce this effect.

A review of other medical problems: Your doctor will also ask about and may test for other problems that could be contributing to your symptoms of fatigue. You will be asked about:

- Heart disease
- Lung disease
- Kidney disease
- Liver disease
- Nervous system disease
- Low or high production of hormones
- Infection

A review of your nutrition: The doctor will ask questions about your weight, any weight changes, and what you eat on a daily basis. If any concerns are raised about your weight, a nutrition expert can help you improve your diet. You will also be asked about the amount of fluids you drink, and you may have blood tests to measure the level of needed minerals, such as sodium, potassium, calcium, and magnesium in your body.

A review of your daily activities: Exercise is helpful in lowering the level of fatigue in some cancer patients. Therefore, the doctor will ask questions about your ability to do your normal activities and if you exercise regularly.

Complete Evaluation of Cancer-Related Fatigue

The doctor will continue to look for the cause of your fatigue by:

Review of your body systems

Review of your medicines

Review of other medical problems

- Heart
- Lung
- Kidneys
- Liver
- Nervous system
- Hormones
- Infection

Review of your nutrition

- Changes in your weight or amount eaten
- Not enough or too much fluid or minerals (sodium, potassium, calcium, magnesium)

Review of your activities

- Changes in exercise or activity pattern

See treatment
on page 22

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Treatment of Cancer-Related Fatigue

Once the doctor knows the cause of your fatigue, treatment can be planned. Treatments can include education and counseling, treating the specific cause of the fatigue, improving your nutrition, treating sleep problems, and using medicine to treat certain illnesses or symptoms such as pain if it is present.

Education and counseling: It is best to learn about fatigue before you have it. The health care team should discuss fatigue with you. You should know that you might experience mild, moderate, or severe fatigue while being treated for cancer. However, fatigue does not mean that your treatment is not working or that your cancer is worse. In addition to education, you should be told about ways to cope with fatigue. These include conserving energy, managing stress, and using distraction.

Saving energy involves setting priorities, or identifying the activities that need to be done first and those that may not need to be done right away. Spreading your activities throughout the day rather than trying to get them done all at once helps to save energy. Remember

that asking others to help with your activities is a good way to reduce your energy needs. It is okay to delay or postpone activities that are not necessary if you are moderately fatigued. You might try keeping a daily and weekly diary that allows you to pinpoint when you need energy the most during any given day or week. You can then plan activities based on these peak times. Schedule your naps so that they do not interrupt or delay your sleep at night.

Learning ways to cope with the stress that often comes with having cancer and treatment can help you reduce fatigue. Some studies have shown that joining a support group can lower fatigue. Other suggestions for dealing with stress, which may also help you to relax, include meditation, yoga, aerobic exercise, massage, and visual imagery.

Monitor your fatigue level each day to determine if the stress management and energy-conserving activities are helping to lower your fatigue. Discuss your fatigue level with your doctor or nurse. They may want to adjust your activities based on your fatigue level.

Treatment of Cancer-Related Fatigue

Treatment of Fatigue: Self-Help Measures

Once the cause of your fatigue is known, your treatment will include:

Education/counseling

- Information about fatigue
- Reassurance that treatment-related fatigue does not mean your cancer is worse
- Suggestions for ways to cope with fatigue

Energy conservation

- Set priorities
- Pace yourself
- Delegate tasks to others
- Schedule activities at times of peak energy
- Postpone non-essential activities
- Take naps that do not interrupt nighttime sleep
- Plan your daily routine
- Do one activity at a time

Distractions

- Games
- Music
- Reading
- Visiting or activities with friends

Stress management

- Relaxation
- Support groups

Monitor fatigue level each day to determine if these measures work

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Treatment of the Specific Cause of Cancer-Related Fatigue

If the cause of your fatigue is found, it should be treated first. If you have too little fluid or minerals in your body, this usually can be corrected by giving you what is missing. This might include receiving more potassium for a low potassium blood level or intravenous (IV) fluids if you are unable to drink enough.

A low blood level of thyroid hormone, which is produced by the thyroid gland, should always be considered in all patients as a cause of fatigue. This problem is treated by giving thyroid hormone to replace the amount that is missing from the body.

Anemia occurs frequently in cancer patients. If your blood is low in iron, then replacements of iron or folic acid may help to correct the anemia and reduce the fatigue. If blood has been lost through bleeding, then you may receive a transfusion. You may also be given erythropoietin, a substance that helps build new red blood cells. (For more information on treatment of anemia, see pages 7–8.)

Physical Activity: Try to be as active as possible as you go through treatment. Some patients, especially those who have extensive disease, should be referred to a physical therapist or an expert in physical medicine to help decide on a specific exercise program. A careful evaluation will help start a program that is safe for you.

The exercise program should be planned for your specific situation and needs. Factors to consider include your overall health and other medical conditions, age and gender, your type of cancer, and your treatment.

Your exercise program should begin at a low level of intensity and length of time, progress slowly, and be changed with your changing condition. The program must be prescribed with care when patients have such medical problems as:

- Bone metastasis (spread of cancer to the bones)
- Decreased immune system function
- Low platelet count (blood cells that help your blood to clot)
- Fever
- Other treatment complications

Treatment of the Specific Cause of Cancer-Related Fatigue

Treatment Based on the Cause of the Fatigue

- For anemia, see pages 28–29
- For low thyroid gland function:
 - Thyroid hormone replacement therapy
- For pain, see *ACS/NCCN Treatment Guidelines for Cancer Pain*

Nonmedicine Treatment

- Exercise
 - Maintain some level of activity
 - Regular, moderate-intensity walking
- Correct nutrition and fluid problems
- Correct sleep disturbances

Exercise with caution when the following are present:

 - Bone metastasis
 - Lowered immune function
 - Low platelet count
 - Fever
 - Other complications of treatment
- Attention-restoring therapy
 - Gardening
 - Quiet time, meditation
 - Volunteer activities not related to illness
 - Walking or sitting in a natural environment
- Spend time with family

→ Your doctor will check you to see if there has been any change in your fatigue

Medicines that May Be Used

- Steroids
- Stimulants
- Medicines for depression

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Attention-Restoring Activities: Having difficulty understanding new information and not being able to think clearly is called attentional fatigue. Activities related to the natural environment may help relieve these symptoms. Examples of activities to restore your ability to think and understand include walking on a beach, sitting in a park, and gardening.

Nutrition: Your health care team will look for changes in your weight or the amount of food that you are eating. These changes could mean that you are not getting the nutrition your body needs. Also, imbalances in the fluids and needed minerals in your body will be checked to see if an imbalance is the cause of your fatigue. If you

have too much or too little fluid, this will be corrected. If you have too little or too much of certain minerals, such as sodium, potassium, calcium, and magnesium, this will also be treated. For example, too little potassium can make you feel weak or fatigued. This can be corrected by increasing potassium in your diet and taking a potassium supplement if needed.

Sleep Therapy: If you are having trouble falling asleep or are waking after falling asleep, your health care team will try to find the cause of your sleep problem. Are you taking naps too late in the day? Or are you drinking caffeine before going to bed? Some suggestions for helping your sleep might include:

NOTES

Treatment of the Specific Cause of Cancer-Related Fatigue (continued)

- Taking a hot bath before going to bed
- Drinking a warm glass of milk
- Avoiding caffeine drinks after dinner
- Emptying your bladder before going to bed
- Scheduling naps earlier in the day

If these approaches are not successful, your doctor might offer you a medicine to help you fall asleep or help you stay asleep so you get the rest you need.

Medicines for Treatment: Antidepressants may be needed for treating depression. Corticosteroids have been helpful in increasing energy levels in some patients. Stimulants have

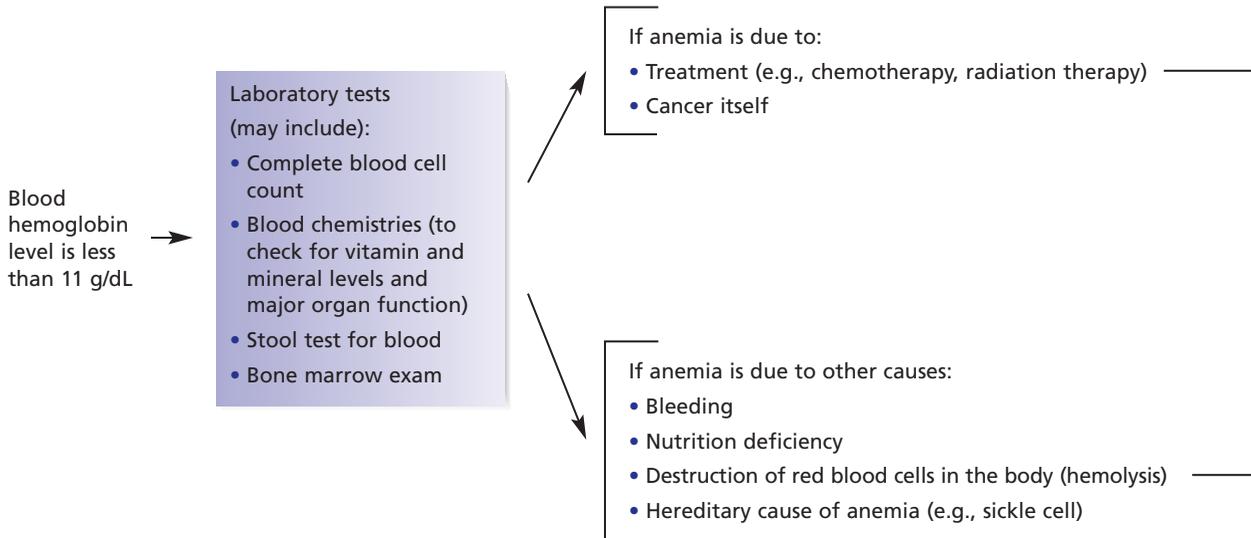
been found to reduce fatigue in patients with other chronic conditions and are now being studied in patients with cancer. There is not sufficient evidence to use other medicines for cancer patients with fatigue at this time.

Re-evaluation phase

Because fatigue can happen anytime in the course of your disease and treatment, your health care team will re-evaluate your fatigue regularly. They will make changes when needed to be certain that you are getting treatment for your type of fatigue.

NOTES

Primary Evaluation



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Primary Evaluation of Cancer-Related Anemia

Anemia by itself may or may not cause a person to feel fatigued. People with blood hemoglobin levels above 11 g/dL usually do not need treatment.

If your hemoglobin level is below 11 g/dL, your doctor will likely order certain tests. These could include the following blood tests:

- Complete blood cell count (CBC)
- Blood chemistries to check for levels of iron, folate, and liver function

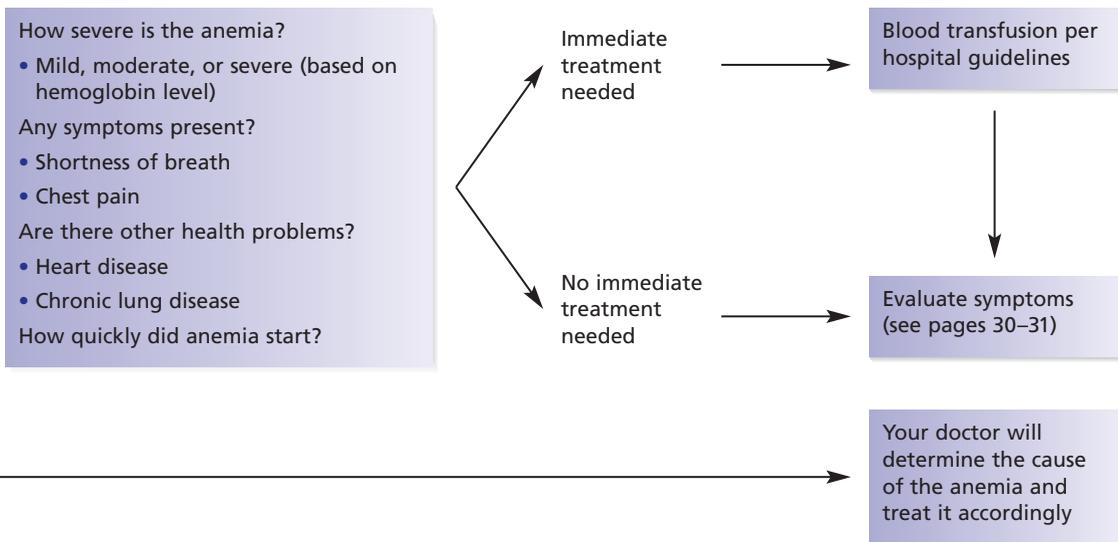
- A thorough review of your blood cells through a microscope
- A test to check for blood in your stool (feces)

A sample of bone marrow may also be taken. Your doctor can use this information, along with the results from your medical history and physical exam, to get an idea of what might be causing the anemia. Sometimes no cause can be found other than “anemia associated with chronic disease,” which occurs in diseases like cancer.

While finding the cause of anemia is important, determining the severity of the anemia is even more important. Anemia causes fatigue

Primary Evaluation of Cancer-Related Anemia

Is There an Immediate Risk?



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when cells in the body are not able to get enough oxygen. In some cases, this may be severe enough to become life threatening.

Therefore, your doctor may first want to determine your risk of serious problems from the anemia, based on any symptoms you are having and the level of hemoglobin in your blood. A hemoglobin level between 10 and 11 g/dL is usually considered to be mild anemia. A level between 8 and 10 g/dL is considered moderate, and less than 8 g/dL is severe. Chest pain and difficulty breathing when you exert yourself are serious symptoms of anemia, and possibly other problems, and should be reported to your doctor right away.

Other medical conditions such as heart disease or chronic lung disease may already be affecting how much oxygen circulates in your body. The presence of these conditions may also be important in determining your risk of serious problems. If your anemia is a serious threat to your health, you may receive immediate treatment.

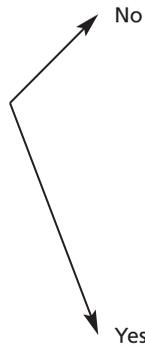
Once your doctor has determined that your anemia is not (or is no longer) an immediate, serious threat to your health, the more complex question of whether you will benefit from treatment can be addressed.

Evaluate Symptoms

Are symptoms present?

Based on:

- Your reported fatigue level (using visual or numeric scales, such as 0 to 10)
- Your activity level
- Your response to certain questions to measure the impact of fatigue on you



No

Yes

Is There a Risk of Developing Symptoms?

Are you *at risk* of developing symptoms?

Based on:

- Hemoglobin level
- Past cancer treatments
- Potential of current treatment to cause anemia
- Blood transfusion history
- Age

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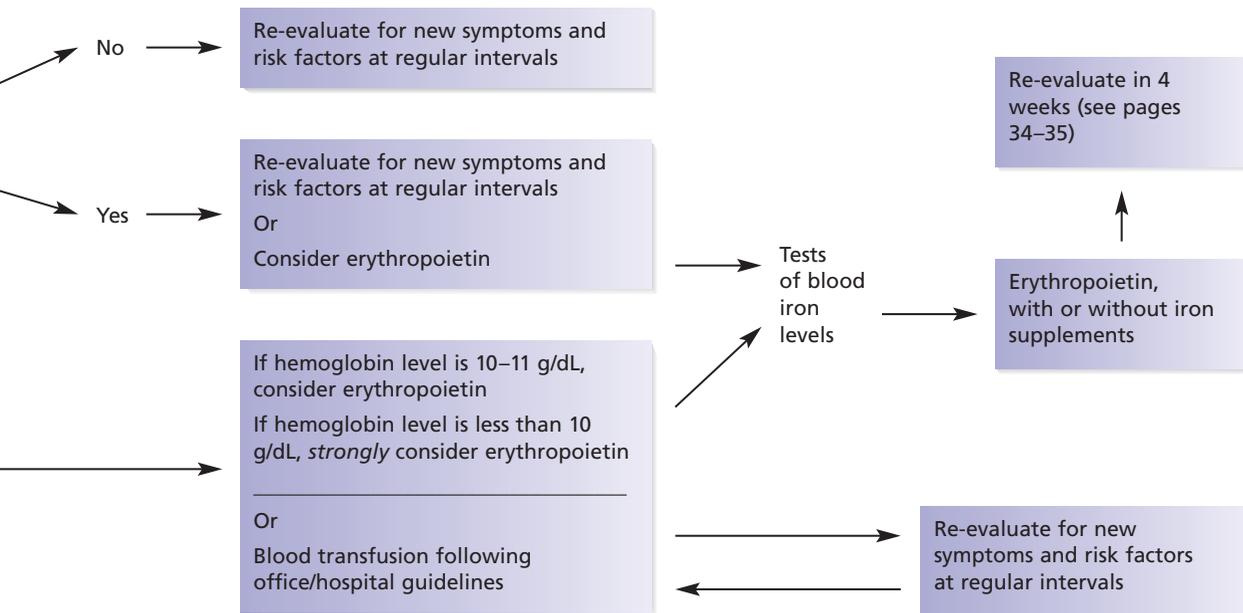
Evaluating and Treating Cancer-Related Anemia

As with any medical problem, the benefits of treatment should always outweigh the risks. Weighing the benefits and risks is not always easy with anemia.

At one time, red blood cell transfusions were the most common way to treat anemia. While very effective, transfusions do carry small risks. The most common problem is known as a transfusion reaction, in which a patient's immune system attacks the foreign blood cells being transfused. Most of these reactions are minor and can be treated, but sometimes they can be more serious.

Evaluating and Treating Cancer-Related Anemia

Treatment



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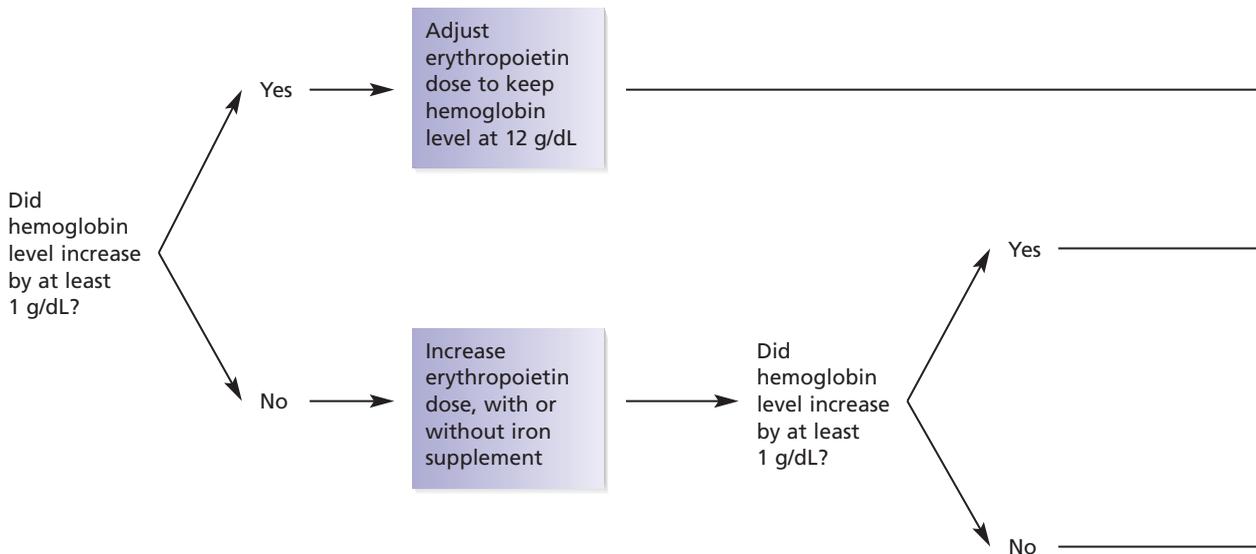
Another possible risk is the transmission of certain infectious agents, such as the hepatitis B virus. Blood screening tests have made the risk of infection very small.

In recent years, erythropoietin has become available as another way to raise hemoglobin levels. Erythropoietin is a synthetic version of the hormone normally made by the kidneys.

It helps the body make its own blood cells, removing the need for transfusion, but it often takes several weeks before an effect on the hemoglobin level is seen. It also requires injections, usually just under the skin (subcutaneously), either 3 times a week and sometimes just weekly, or less frequently, and treatment can be expensive.

4 Weeks After Starting Treatment

8 Weeks After Starting Treatment



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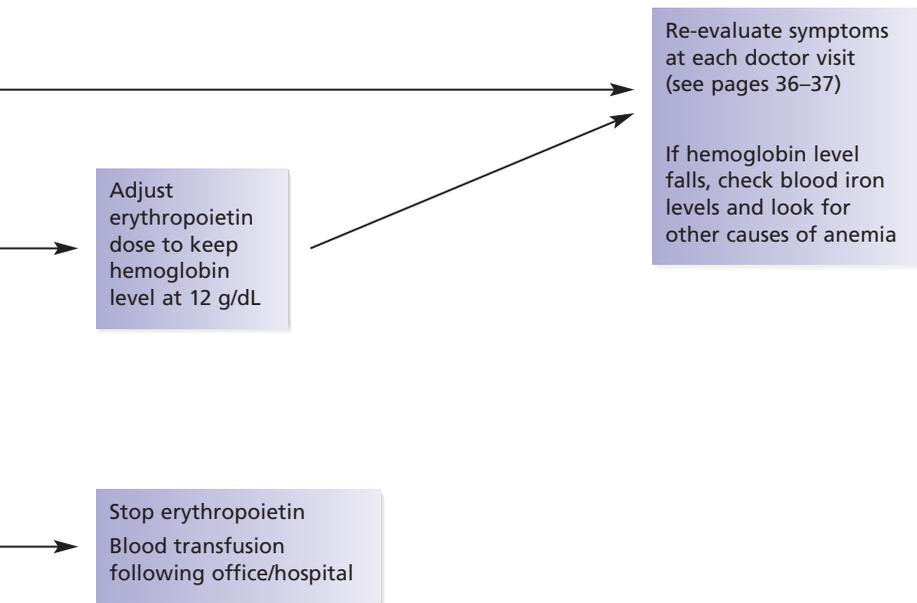
Assessing the Response to Treatment of Cancer-Related Anemia

It will likely be several weeks before you and your doctor can tell if erythropoietin is working for you. Your doctor will check your hemoglobin level about 4 weeks after starting erythropoietin. If the level has increased by at least 1 g/dL, your doctor will continue to prescribe it, adjusting it as needed to keep your level around 12 g/dL.

If your hemoglobin level has not increased, your doctor will raise the dose of erythropoietin and check it again after another 4 weeks. Iron also may be given. If this dose works, your doctor will continue to prescribe it and adjust it as needed. If it is not effective, your doctor will stop the erythropoietin and consider a blood transfusion.

Response to Treatment of Cancer-Related Anemia

Follow-Up



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NOTES

Hemoglobin level stayed at 12 g/dL, or has increased by at least 2 g/dL since starting treatment

Have fatigue symptoms improved?

Yes

No

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Assessing the Symptom Response to Treatment of Cancer-Related Anemia

If erythropoietin does raise your hemoglobin level, the next important question is whether this reduces your fatigue or other symptoms. If your symptoms improve, your doctor will continue to prescribe and adjust your erythropoietin dose as needed.

If your hemoglobin level has improved but you still feel fatigued, there may be other causes of fatigue that still need to be addressed. Your doctor may do this with or without continuing the erythropoietin.

Watching your anemia and symptoms carefully throughout your treatment will help you and your doctor know that you are being treated only when needed.

Symptom Response to Treatment of Cancer-Related Anemia

→ Adjust erythropoietin dose to keep hemoglobin level at 12 g/dL

→ Look for other causes of fatigue (see pages 18–19)

Consider adjusting erythropoietin dose to maintain hemoglobin level

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NOTES

Current ACS/NCCN Treatment Guidelines for Patients

Breast Cancer Treatment Guidelines for Patients, Version IV

Breast Cancer Treatment Guidelines for Patients (Spanish)

Cancer Pain Treatment Guidelines for Patients, Version I

Cancer Pain Treatment Guidelines for Patients (Spanish)

Cancer-Related Fatigue Treatment Guidelines for Patients, Version I

Cancer-Related Fatigue Treatment Guidelines for Patients (Spanish)

Colon and Rectal Cancer Treatment Guidelines for Patients, Version II

Colon and Rectal Cancer Treatment Guidelines for Patients (Spanish),

Fever and Neutropenia Treatment Guidelines for Patients with Cancer, Version I

Fever and Neutropenia Treatment Guidelines for Patients with Cancer (Spanish)

Lung Cancer Treatment Guidelines for Patients, Version I

Lung Cancer Treatment Guidelines for Patients (Spanish)

Melanoma Treatment Guidelines for Patients, Version I

Nausea and Vomiting Treatment Guidelines for Patients with Cancer, Version I

Nausea and Vomiting Treatment Guidelines for Patients with Cancer (Spanish)

Ovarian Cancer Treatment Guidelines for Patients, Version I

Ovarian Cancer Treatment Guidelines for Patients (Spanish)

Prostate Cancer Treatment Guidelines for Patients, Version III

Prostate Cancer Treatment Guidelines for Patients (Spanish)

The Cancer-Related Fatigue and Anemia Treatment Guidelines for Patients were developed by a diverse group of experts and were based on the NCCN clinical practice guidelines. These patient guidelines were translated, reviewed, and published with help from the following individuals:

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