Myths & Facts

About Cancer Fatigue

What You Need to Know
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Clinical opinions expressed in this book are those of the authors and do not necessarily reflect the opinions of the sponsor, editors, or the publisher and officers of CMP Healthcare Media. Patients are advised to speak to their physicians regarding questions they may have about their disease or treatment.

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About the Author

**Ann Berger, MSN, MD,** received a BS in nursing from New York University, which was then followed by an MSN in oncology nursing from the University of Pennsylvania. After working as an oncology clinical nurse specialist for several years, Dr. Berger completed her medical training at the Medical College of Ohio in Toledo. After medical school, Dr. Berger completed an internship and residency at Hartford Hospital in Connecticut and a fellowship in medical oncology and pain/palliative care at Yale University in Connecticut. Dr. Berger remained on the faculty at Yale University, where she started a palliative care service, as an assistant professor in medicine and anesthesiology.

As an assistant professor in medicine and anesthesiology at Cooper Hospital/University Medicine and Dentistry in New Jersey, Dr. Berger founded her second successful palliative care service. There, her service was actively involved in the care of patients and in education and research during her 4-year tenure. She initiated a palliative care course for medical students, residents, and fellows, and used her expertise while chairing the ethics committee. Dr. Berger also served as medical director of Lighthouse Hospice and as director of supportive care services at Cooper Hospital/University Medicine and Dentistry in New Jersey. During this time, she also received two grants as project director of a pain and palliative care scholars program and as project director for a project designed to develop pain/palliative care teams in New Jersey long-term care facilities. Currently, Dr. Berger is chief of the Pain and Palliative Care Service at the National Institutes of Health, Clinical Center, where she has clinical, teaching, research, and administrative responsibilities.

Dr. Berger is a member and co-chair of the Continuing Medical Education Committee for the Academy of Hospice and Palliative Care. Nationally, Dr. Berger is involved with many activities, including chairing the National Institutes of Health Clinical Center Pain and Palliative Care Collaborative Working Group, serving as a member of the steering committee for the National Palliative Care Consensus Project, and serving on the planning committee to improve the quality of end-of-life care in conjunction with the Washington DC Area Geriatric Education Center Consortium, The
RAND Center to Improve Care of the Dying, and the DC Partnership to Improve End-of-Life Care. On a community level, Dr. Berger is a co-facilitator of a healing service at her synagogue. Internationally, she has been involved in the All-Ireland Fatigue Coalition and the Mid-Eastern Cancer Consortium.

In 1998, Dr. Berger received the Hospice Medical Director Award, and in 1999 she was awarded the Spirit of Hospice Award from the New Jersey Hospice and Palliative Care Organization. In 1998–2000, Dr. Berger received an award for outstanding leadership in palliative care in long-term care from the New Jersey SEED project, New Jersey Department of Health and Senior Services, Office of the Ombudsman for the Institutionalized Elderly, and the Cooper Health Service. In 2001, Dr. Berger received the Director's Clinical Center Patient Care Award at the National Institutes of Health. In 2002, Dr. Berger received the Circle of Excellence Award from Samaritan Hospice, as well as a proclamation from the New Jersey State Senate and Legislative Committees. She has lectured and published extensively in pain and palliative care. She also is senior editor of the major palliative care textbook, *Principles and Practice of Supportive Oncology*, published by Lippincott--Raven in 1998, as well as senior editor of *Principles and Practice of Palliative Care and Supportive Oncology*, Second Edition, published in 2002. In 2004, Dr. Berger will have two other new books published: *Cancer Pain: A Bedside Approach* and *Chemotherapy-Induced Nausea and Vomiting*, both for health care professionals.
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Fatigue is recognized as the most common symptom experienced by patients with cancer. Between 70% and 100% of patients receiving treatment for cancer—chemotherapy or radiation therapy—report fatigue. Fatigue has also been identified as a persistent side effect after cancer treatment. Patients identify fatigue as a major impediment to both function and quality of life. Fatigue can also be associated with a broad array of physical, psychological, social, and spiritual problems, including decreased physical activity, mood and sleep disturbances, changes in social roles, and questions about the meaning of life.

Fatigue, like pain, is complex in that it has numerous potential causes. Fatigue can be directly associated with the disease or its therapy, or it may be related to anemia, depression, chronic pain, sleep disorders, electrolyte disturbances, infection, malnutrition, deconditioning, immune dysfunction, or the use of centrally acting drugs. Because fatigue usually has several different causes in one patient, the treatment plan should be personalized for each individual patient.

**Myth**

Fatigue occurs infrequently in a patient undergoing cancer treatment.

**Fact**

Fatigue is the most common side effect of cancer treatment.
Misconceptions about cancer-related fatigue are common. There is a common myth that fatigue is an inevitable side effect of having cancer and that there is no treatment for the fatigue. This belief is based on the misconception that, because the patient’s cancer is being treated and potentially cured, he or she should be happy and should not complain about the associated fatigue, which can sometimes seem worse than the cancer itself. Treatment of fatigue, like other cancer symptoms such as pain and depression, is being recognized as critical, not only to cure the cancer but to heal the patient and improve quality of life as well.

Myths and Facts About Cancer Fatigue provides you with practical information. This handbook is not a comprehensive guide to your treatment options, but it does offer important guidance to aid you, your family, and your health care team in helping to relieve your fatigue. Fatigue is no longer an inevitable, incurable side effect of cancer or cancer treatment; it is a symptom that can be treated to help improve your life.
The Modern Focus on Cancer Fatigue

Fatigue can be likened to pain research in the 1970s. Pain, a significant symptom affecting between 28% and 80% of cancer patients, was inconsistently assessed and inadequately managed for years. This situation did not change until recently when empirical data were presented to the medical community through controlled research studies. So strong were the implications of this research that pain assessment and management have been pushed to the forefront by the health care system. Health care payers are willing to pay for pain management, and credentialing agencies, such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), have made pain the fifth vital sign. JCAHO standards, and therefore the standards of the health care industry as a whole, require that pain be assessed both initially and periodically in all hospitalized patients. Patients have begun to expect that their pain will be managed.

Until the mid-1980s, fatigue was rarely addressed with patients in the literature or in cancer research. In 1996, a fatigue coalition of health care providers was formed to implement a series of educational and research initiatives. The first initiative of the fatigue coalition was a national survey of oncologists, patients with cancer, and their caregivers to determine the incidence and impact of cancer fatigue. After the initial study, there were many different initiatives, which have led to annual fatigue awareness days in most hospitals across the country. The work of the fatigue coalition helped to promote greater understanding and recognition of cancer fatigue.

In 2002, the National Institutes of Health held a state-of-the-science conference on pain, depression, I do not understand why I am so tired. All they did was surgery on my chest.
—The author after bilateral mastectomies
and fatigue. At the conference, it was stated that there remain major barriers to the effective management of fatigue for patients with cancer. These barriers include a lack of awareness that fatigue is the most prevalent symptom associated with cancer, a lack of knowledge about the causes of fatigue, and a lack of proven methods to treat fatigue.

The Agency for Healthcare Research and Quality in 2002 found and analyzed all clinical randomized trials evaluating various treatments for patients with cancer-related fatigue. There were ten trials at the time. Three of the trials had exercise programs, which showed promising preliminary results, and there were also positive outcomes for interventions such as support groups, relaxation, and psychotherapy. However, the only pharmacologic treatment that demonstrated significant benefit was the use of epoetin alfa in patients with anemia due to chemotherapy.

The National Institutes of Health Consensus Statement concluded that many patients receive inadequate treatment for their pain, depression, and fatigue; that clinicians need to use brief assessment tools routinely; that research is needed on the definition, occurrence, assessment, and treatment of the three symptoms; and that all patients with cancer should have optimal symptom control, starting from diagnosis and continuing throughout the course of illness.

In the past when people were diagnosed with cancer, they went to bed and died. Fatigue was never questioned, as it was expected that fatigue was part of the illness as well as part of the dying process. Scientific discoveries have transformed cancer from a usually fatal disease to a curable illness for some people and a chronic condition for many more. Now the focus has shifted to living with cancer. It is very important to address symptoms, such as fatigue, to reduce the burden of cancer. Health care professionals are beginning to understand that fatigue is much more than a part of cancer: It is a complex phenomenon that is an alert to imbalances in body, mind, and spirit.
What Do We Mean by Fatigue?

In 1998, Winningham reviewed the history of the word fatigue. In 700 AD, the word used for fatigue was tire. From 1100 to 1400, fatigue was associated with the words sleepy, weakness, and inefficient. From 1500 to 1800, the words used for fatigue included debilitate, forced, exhausted, stressed, enervated, and cachexia, with the word fatigue appearing in 1669. From 1800 to 2000, words used for fatigue have included energetics, myasthenia (muscular weakness), neuroasthenia (psychic and emotional stress from exhaustion of the nervous system), life force, vital signs, and stressors. These different words used for fatigue reveal the difficulty of defining a complex concept.

Myth
There is only one definition for the word fatigue.

Fact
There are many definitions for fatigue, which is a complex phenomenon.
In examining the multidimensional nature of fatigue, it is clear that fatigue is not a simple symptom, but rather a complex syndrome. (A syndrome is defined as a complex group of symptoms that indicates the presence of an abnormal or undesirable condition.) In 1998, Cella et al. described 11 different symptoms that are associated with cancer-related fatigue syndrome. The 11 symptoms are:

1. Significant fatigue, diminished energy, and increased need for rest that are disproportional to any change in exertion.
2. Complaints of generalized weakness or limb heaviness.
3. Diminished concentration or attention.
4. Decreased motivation or willingness to engage in usual activities.
5. Insomnia (difficulty sleeping) or hypersomnia (sleeping too much).
6. Experience of sleep is nonrestorative and unrefreshing.
7. Perceived need to struggle to overcome inactivity.
8. Marked emotional reactivity (e.g., sadness, frustration, irritability) to feeling fatigued.
9. Difficulty completing daily tasks because of feeling fatigued.
11. Malaise (feeling of weakness) after exertion (activity) lasting several hours.
In addition to listing the 11 symptoms that define cancer-related fatigue syndrome, Cella et al. listed four diagnostic criteria for this syndrome. These criteria are:

1. Six or more of the 11 symptoms are present daily or nearly every day for a 2-week period.
2. The symptoms lead to significant distress or impairment in social, occupational (work), or other important areas of functioning.
3. There are historical, physical, or laboratory findings that indicate that the symptoms are due to the cancer or the cancer treatment (such as chemotherapy, radiation therapy, or surgery).
4. The symptoms are not primarily a consequence of psychiatric conditions such as major depression, delirium, or somatization disorder.

My whole body aches from exhaustion.
—A common complaint.
How Do We Measure Cancer-Related Fatigue?

As one would imagine, measurement of fatigue related to cancer is very difficult. Fatigue is a multi-dimensional syndrome and is an abstract, subjective concept. Terms that are frequently associated with the scientific aspects of fatigue include loss of efficiency, impairment, depression, weakness, muscle use, anxiety, exertion, rest, exercise, and lifestyle. When one looks at assessment of fatigue, considerations include measures of endurance, metabolism and muscular force (conditioning), anemia, nutritional status, amount and type of sleep, one's mood and performance, and subjective reports of how much vigor one feels. The key to diagnosis of fatigue is accurately assessing objective laboratory and clinical tests and listening to what the patient reports about how he or she feels.

Fatigue related to cancer can be either acute or chronic. Acute fatigue can be the result of a temporary treatment that exceeds the individual’s energy resources. For example, a round of chemotherapy may leave a patient extremely tired for a few days. Chronic fatigue, seen typically with cancer treatment and in cancer survivors, is a complex syndrome that involves physical, psychological, and behavioral factors. Studies have shown that the best predictors of fatigue were symptom distress as well as mood disturbances. Fatigue and symptom distress are also predictors of functional impairment related to illness. What this means to individuals with cancer-related fatigue is that they are less able to participate in their usual, pre-illness activities of daily living.
Patients describe fatigue in many different ways, relating to a variety of different problems. Fatigue is described as an overall tiredness (“I feel too tired to lift my fork”), a lack of energy, an inability to exert oneself at all (“Lifting a bag of groceries is like lifting one hundred pounds”), a loss of motor power and mobility (“I feel like I’m walking on the moon”), sleepiness and drowsiness (“I can lay in bed all day and night and still feel tired”), confusion and poor concentration (“I feel as if my brain is jumbled”), as well as a sense of being helpless and inadequate (“I cannot do anything I used to do”). The presence of one or more of these descriptors should indicate that the patient may be fatigued.

Research has made it very clear that fatigue and other symptoms can have a strong impact on an individual’s quality of life. These symptoms must be taken into consideration when a diagnosis of fatigue is made. Patients with fatigue report difficulties with sleep and problems with their social life, job, sex life, as well as family life. Patients with fatigue need to spend more time in bed, have more disability days off from work, and experience changes in activities related to their social roles, which all significantly add to a lower quality of life. Additionally, patients with fatigue may feel depressed or empty—as though life has no meaning—because they cannot enjoy the activities that they used to do. It is very clear that fatigue can impact every aspect of life—physical, mental, and spiritual.

There are many different measurement tools to evaluate fatigue; however, most measures consider common dimensions, including the site and intensity of fatigue (an individual’s muscles feel more tired than the rest of his or her body), how the fatigue has changed over time, the feelings related to being fatigued, and the meaning of the fatigue to the individual. Often, cancer-related fatigue makes an individual think that his or her cancer is becoming worse. Patients frequently ask, “Why would I feel so bad and weak if the treatment for the cancer is

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*I feel like I have been hit by a Mack truck head on.*
—The author after bilateral mastectomies for breast cancer
working?” Medically speaking, it is usually not true that fatigue indicates poor response to treatment.

There are at least 21 self-report assessment tools to measure fatigue that may be given to a patient. Through a patient’s answers, these tools attempt to measure the different multidimensional aspects of fatigue. There are other assessment tools that are physiologic measures, meaning that they attempt to identify different physical things in the body that could cause fatigue. Some tools measure anaerobic metabolism, which is a fatigue indicator on a cellular level. Other tools consider changes in body mass (specifically, muscle tissue), whereas still others measure energy reserve and functional capacity. There are bicycle or walking tests that measure perceived exertion and how well the heart is functioning (cardiac output). There are tools to measure muscle function and ability to perform work, as well as others that consider oxygen uptake versus work capacity (oxidative metabolism). In addition, a patient may be asked to measure caloric intake and use (both food and water) and report them to the physician.

There are several related instruments that measure possible causes of fatigue. These include tools to check activity and rest patterns, depression and mood scales, and general health scales, including checking for anemia and measuring endurance, sleep patterns and duration, and other related symptoms such as pain. With all of these tools to measure various aspects of fatigue, the health care provider should remember that a patient can only be given a few, as the process of completing the assessment tools can make an already fatigued individual even more fatigued.
Common Reasons for Cancer-Related Fatigue

To perform a comprehensive assessment, the physician should at least be using tools that seek common reasons for cancer-related fatigue. These potential reasons include anemia, depression, nutritional disorders, sleep disorders, exercise tolerance (deconditioning), and pain. Because cancer-related fatigue is common in most patients who receive chemotherapy and radiation therapy and in many who have undergone surgery as well as for long-term cancer survivors, when the different potential reasons for the fatigue are evaluated, a physician can easily find many different interventions that may help relieve some of a given patient’s fatigue.

When a patient tells his or her physician that he or she is fatigued, several blood tests are performed to determine whether the cause of the fatigue is a metabolic abnormality. The patient may be dehydrated; there may be an imbalance in electrolytes, such as sodium, calcium, potassium, and magnesium; or the patient may have a thyroid deficiency. If any of the preceding abnormalities are discovered, they can easily be treated with fluids and electrolyte replacement or thyroid replacement if a patient is thyroid deficient.

**FATIGUE OWING TO ANEMIA (OR OTHER METABOLIC ABNORMALITIES)**

Probably one of the most common reasons for fatigue in the patient with cancer is anemia. Ane-
Anemia is the inability of blood cells to deliver enough oxygen to the cells of the body; this lack of oxygen can be tied directly to fatigue. Anemia is easily diagnosed through a blood test, which examines the complete blood cell count—more specifically, the hemoglobin count and hematocrit (the volume of red blood cells). There are estimates that as many as half of all patients with cancer are anemic at some time in their illness. There are several common causes of anemia, which include the cancer treatment itself, blood loss associated with surgery, infiltration of bone marrow by cancer, or other chronic diseases such as liver or kidney diseases, arthritis, or chronic infections.

The most common symptoms of anemia include tiredness and lack of energy. Other symptoms associated with anemia are shortness of breath; feeling cold; chest pain; a rapid pulse; dizziness, especially when standing; concentration difficulties; irritability; paleness of the fingernails, lining of the eyelids, and palms; and loss of appetite. Anemia, and the associated fatigue, can affect quality of life in many ways. The patient is limited in many everyday activities, including work and social and leisure activities. This can lead to depression and loss of self-esteem. Severe fatigue can easily diminish the patient’s ability to cope with the disease and its treatment. In fact, if the patient is very anemic, chemotherapy or radiation may need to be delayed, or the treatment may not be tolerated as well. If a patient feels fatigued during or after treatment, it is essential that he or she speak with the physician immediately so that treatment for the fatigue can begin.

**Treatment of Anemia**

Traditionally, the treatment of severe anemia (usually a hemoglobin count less than 8) involves
red blood cell transfusions. Clearly, there remain times when red blood cell transfusions are essential, such as during acute blood loss; however, the transfusions may result in complications such as fever, infections, and transfusion reactions. Other options are available and should be considered by the patient and health care team.

In the 1990s, erythropoietic agents were introduced to treat chemotherapy-induced anemia without the need for blood transfusion. With the introduction of these medications, which promote healthy hemoglobin, it became clear that there may be many benefits to treating anemia earlier (hemoglobin less than 11–12). When anemia is treated earlier, it is clear that there is an improvement in hemoglobin and associated quality of life. It is also becoming clear that treating anemia earlier may have positive effects on cognitive function, treatment outcomes, and survival.

In 1993, epoetin alfa (Procrit®) was approved by the U.S. Food and Drug Administration (FDA) for the treatment of certain types of anemia. It is currently indicated for patients with specific anemic states—patients with chronic renal (kidney) failure, patients with human immunodeficiency virus receiving zidovudine, surgical patients who would otherwise need transfusion, and patients with nonmyeloid malignancies whose anemia is associated with chemotherapy. The ultimate indication for giving epoetin alfa is to reduce the need for red blood cell transfusions in patients receiving chemotherapy for longer than 2 months.

In 2002, the FDA approved another recombinant erythropoietic agent, darbepoetin alfa (Aranesp®), for the treatment of chemotherapy-induced anemia in patients with cancer. Studies have shown that Aranesp®, like Procrit®, can effectively increase and maintain hemoglobin and thereby decrease the need
for transfusions in patients with chemotherapy-induced anemia. The difference between the two agents is that Aranesp® lasts longer in the body, so it needs to be given less frequently. Aranesp® is indicated for weekly administration.

Three professional cancer organizations, the American Society of Clinical Oncologists (ASCO), American Society of Hematologists (ASH), and National Comprehensive Cancer Network (NCCN), developed guidelines to address the treatment of anemia in patients with cancer. ASCO and ASH guidelines suggest that after other reversible causes of anemia—such as infection, blood loss, or bone marrow involvement—are present, an erythropoietic agent should be started in patients with a hemoglobin at or below 10, or in patients with declining hemoglobins between 10 and 12. NCCN guidelines suggest considering beginning an erythropoietic agent for hemoglobins below 11.

Currently, there are studies under way to evaluate the benefits of treating anemia earlier. Recent trials have shown that treating anemia early (when hemoglobin is between 10 and 12) can improve overall well-being and quality of life. Administration of an erythropoietic agent early may help reduce the chance of decreased energy and increased fatigue when a patient is receiving chemotherapy.

**DEPRESSION AS A CAUSE OF FATIGUE**

Another common reason a patient may be fatigued is depression. Estimates suggest that one in four patients is depressed at some point in their cancer experience, yet relatively few receive any treatment for it. There are many reasons depression is so underdiagnosed. Many people with cancer think that depression is an expected side effect of cancer and that one just has to learn to live with it.
Another reason is that many health care professionals who treat patients with cancer are not familiar with the symptoms of depression.

There are two major types of depression, both associated with fatigue. A situational depression is a common, short-lived condition that occurs after an extreme emotional event such as the death of a loved one or the diagnosis of a cancer. Situational depression is usually accompanied by emotions such as fear, anger, anxiety, thoughts of death, and inability to sleep. Usually, this type of depression is responsive to support, and, ultimately, a period of adjustment begins and the person begins to cope with the situation.

The second type of depression is a major depressive disorder. This type of depression is more than just a response to bad news: It impacts all life functions, including routine everyday tasks. The person with major depression feels empty, with a total lack of joy in life (this is called anhedonia). A major symptom of depression is exhaustion and the inability to function in any way. Individuals with major depression may respond to some support; however, they also should be treated with antidepressant medications.

**Is It Fatigue or Depression?**

Symptoms associated with depression include persistent sadness; loss of interest and pleasure in life; feelings of hopelessness; frequent crying; feeling worthless or guilty; difficulty concentrating; fatigue—so extreme in some cases that patients cannot function normally or may have sleep problems—weight issues, including decreased appetite or overeating; anxiety; and aches and pains in joints and muscles.

The difficulty in diagnosing depression and associated fatigue is that some of the symptoms of fatigue are the same as depression, and vice versa. Depression can lead to fatigue, and severe fatigue...
can also lead to signs and symptoms of depression. As one study of patients with lung cancer showed, treating the anemia with an erythropoietic agent not only relieved the anemia and fatigue, but also relieved anxiety and depression.

The job of the health care provider is to determine if the depression is leading to fatigue or if the fatigue is leading to depression. However, there is no simple laboratory test to diagnose depression or fatigue. Often, the health care team may consult a psychiatrist or psychologist for assistance in assessing a patient’s symptoms. Sometimes, when the physician is not sure but believes the problem is depression, a course of antidepressants and/or a course of stimulants (such as methylphenidate) can help relieve the patient’s fatigue and depression.

**Treatment of Depression and Fatigue in Patients with Cancer**

**Medications:** Many of the treatments that are useful for fatigue are also useful in treating depression. As already mentioned, sometimes the treatment of depression involves medications such as
antidepressants and/or stimulants. There are also many nonpharmacologic techniques that can be useful in the treatment of fatigue and depression.

**Patient Education:** There are studies that show that education about what to expect when an illness is diagnosed can help an individual deal with a symptom better. It is clear that providing information decreases anxiety and improves quality of life. Education about fatigue for patients and caregivers allows them to assist with activities of daily living, set limits on exertion when necessary, and avoid panic when fatigue and depression occur.

It is critical for the patient to understand that fatigue is normal, especially while undergoing treatment, and is not a character flaw or a sign of cancer worsening or impending death. Use of several modalities of communication and education is critical (e.g., oral and written materials), including materials patients can take home and read when they are not as fatigued.

**Cognitive-Behavioral Therapy:** Cognitive-behavioral therapy is performed either individually or in groups and uses techniques to help patients develop specific strategies for problem situations. Some examples would be helping cancer survivors become aware of what makes them fatigued and having them plan their activities accordingly. A patient may be taught how to ask for help with such activities as meal preparation or how to prioritize and put things aside until the fatigue has resolved. Other aspects of the therapy involve finding activities that help the patient enjoy life. One study found that breast cancer survivors who spent 20–30 minutes three times a week on an activity such as gardening, watching nature, or being involved in arts and crafts felt restored and had a significant improvement in concentration.

**Training the Patient in Coping Skills:** There have been many studies that show that coping styles can

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**Myth**
There is one pill that can be used to treat fatigue.

**Fact**
There is no magic pill to treat fatigue. There are medications, such as stimulants and antidepressants, which may help the cancer fatigue syndrome; however, one also needs nonpharmacologic methods to relieve the fatigue.
affect the immune system and medical outcomes, including potentially increasing survival in many illnesses such as cancer. Positive reframing, the use of humor, and acceptance of the reality of the diagnosis were found to result in less emotional distress in women with breast cancer. In a study of patients with melanoma, a program that provided positive coping skills resulted in the patients reporting less fatigue and less depression.

**Psychotherapy:** Individual psychotherapy performed by a trained professional may help a patient with cancer deal with the trauma of cancer as well as with any past traumas or losses. Individual therapy may decrease fatigue by helping a patient release energy used in coping with the trauma of the cancer. Some studies of patients receiving radiation therapy as well as individual counseling found a decrease in fatigue. Other studies found that writing and talking about stressful events
improved patient self-esteem as well as health and immune function.

**Social Support of the Patient:** There has been extensive research on whether social support helps to decrease morbidity and mortality as well as improve immune function in individuals with many different illnesses. A study of women with metastatic breast cancer who participated in weekly support groups revealed a decrease in fatigue.

**INTERRELATION OF FATIGUE AND NUTRITION**

Anorexia, or the lack or loss of appetite, is a frequently reported cancer symptom. When an individual’s appetite is decreased, nutritional status can be dramatically affected. Fatigue then occurs when the body’s energy requirements exceed nutritional intake. Many studies indicate that early nutritional intervention increases patients’ sense of control, appetite, and self-image. Individuals who are well nourished have more rapid recovery times from interventions such as surgery and are better able to tolerate treatment such as chemotherapy or radiation therapy. Besides not eating, many individuals also forget to drink, which leads to dehydration. Studies done by NASA (National Aeronautics and Space Administration) demonstrate that dehydration leads to muscle weakness, a state of mental confusion, and fatigue. In addition, other symptoms, such as diarrhea, nausea, and pain, can increase dehydration.

There are many self-care activities to help manage cancer-related anorexia. The goal is to make eating enjoyable. Some suggestions include the following: eat small, frequent meals; eat cold foods; increase seasoning in foods; use smaller plates; eat nutrient-rich foods; drink small amounts through the day; take pain medications at least half an hour

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**Myth**

If a person with cancer feels fatigue, he or she should be strong and keep it to him- or herself.

**Fact**

Communication is critical in helping to relieve fatigue. Let the health care professionals know immediately that you are having fatigue.
before eating; keep snacks readily available; let someone else cook; create a pleasant setting for meals; change the form of food, such as adding peanut butter and fruit to a milkshake; rest before eating; try softer foods; eat sour foods, which can increase taste bud function; and rinse your mouth before and after meals.

If you are having difficulties eating because of decreased appetite, do not just assume this is part of having cancer. Speak with your doctors and nurses immediately so that they can have you see a dietitian who can discuss how to improve your appetite, including potential nutritional supplements. If the preceding techniques as well as nutritional supplements do not work to increase your appetite and your weight, your health care provider may prescribe medications that work as appetite stimulants. Do not ignore this problem; a proper diet is crucial to long-term health and the alleviation of fatigue.

SLEEP DISORDERS AND FATIGUE

Probably the most popular myth is “I must get more sleep if I am fatigued.” Research in sleep, depression, and fatigue demonstrates that this myth is incorrect. More sleep can actually be harmful. More sleep can lead to poorer physical health and increased mortality, as well as insomnia. A study of outpatients with cancer showed that the later a patient got up in the morning, the more fatigue they experienced. The other thing to know is that sleeping too late or too much can make depression worse; in fact, one of the treat-
ments for depression is sleep deprivation. People who sleep less do not have difficulties with exercise performance, and in fact those with insomnia have better reaction times at night and less daytime sleepiness.

The following is a sleep hygiene prescription to help patients sleep without causing increased problems such as increased depression or fatigue:

1. Limit time in bed to approximately 6–8 hours per day (sleep for the usual amount of time before illness).
2. Get up at the same time each day, even if you have not slept well.
3. Daytime naps should be no longer than 15–20 minutes.
4. Exercise every morning.
5. Avoid stimulants such as caffeine, nicotine, and alcohol.
6. Avoid large meals at bedtime.
7. Avoid evening stimulation.
8. Read, listen to music, or watch television at night.
9. Take a warm bath before bed.
10. Use the bedroom only for sleeping or making love.
11. If awake at night, do not remain in bed. Get up and read or do something else in another room.
12. Practice an evening relaxation technique such as imagery, meditation, hypnosis, or Reiki.

REHABILITATION TO LESSEN FATIGUE

Rehabilitation medicine is a field dedicated to preventing disability and restoring function. Usually, an initial diagnosis and treatment plan is

Myth

“I need to get up later in the morning if I am fatigued.”

Fact

More sleep can actually be detrimental. A study of outpatients with cancer showed that the later patients got up in the morning, the more fatigue they experienced.

Myth

“If I do not sleep well at night, I need to nap 2–3 hours during the day.”

Fact

Naps longer than 15–20 minutes can lead to more fatigue.
made by a physiatrist who then may involve other individuals on the rehabilitation team such as physical, occupational, recreational, or speech therapists. The rehabilitation team works to find an appropriate exercise program for each patient as well as to find ways a patient’s available energy stores can be budgeted so that he or she can attain lifestyle goals.

**Exercise**

Moderate exercise that is individually tailored by the physiatrist and rehabilitation team is an effective way of reducing fatigue. The initial studies done in the NASA aerospace program showed that even healthy, young athletes had increased depression and became weakened and deconditioned when placed on bed rest. Studies since then have shown that individuals with cancer who exercise are better able to handle stress and are less fatigued.

**Energy Conservation**

Energy conservation is one way that an individual who is fatigued can develop a plan to attain goals and at the same time budget his or her available energy stores. Budgeting involves prioritizing, planning, eliminating, delegating, modifying, and pacing.

**Prioritizing:** It is clear that priorities are highly individualized and may change from day to day. Prioritizing involves deciding what needs to be done and then putting the more essential items on the top of the list, with the less essential items on the bottom of the list. We all routinely do this when we are faced with many things to do and do not have enough time or money with which to do them. Patients who are fatigued can extend this skill to their activities.

**Planning:** Planning involves helping to sequence tasks. Planning also allows movement from activity to activity with the least amount of stress and
wasted energy. For example, sometimes it might be better to do a task, such as food shopping, on a Saturday morning rather than right before a big holiday such as Christmas.

Eliminating: Eliminating is the step that helps the individual see that if a task is not necessary, perhaps it should be eliminated. Sometimes just limiting one part of a task may help the task be completed while helping to save some energy. For example, one can eliminate ironing if one chooses to wash and wear clothes or take shirts to a cleaner’s instead.

Delegating: Enlisting the help of friends and family is something that many individuals with cancer are reluctant to do. However, many people want to be supportive when their friends or family members have cancer, but they do not know what to do. Allowing others to help makes them feel good and can help conserve energy for the person undergoing cancer treatment.

Modifying: Can necessary tasks be done differently, more simply, or with less energy? Is it possible to cook a meal using prepared foods rather than starting from scratch? Other helpful tips are to use cookware that can be served from and to store frequently used items at chest level to avoid bending and stretching.

Pacing: The last step, pacing, involves breaking down a large task into smaller tasks and not doing the entire thing at once. It is clear that to learn how to conserve energy a fatigued individual needs help and needs to work with others, such as a rehabilitation team, who can provide tips for energy conservation.

Energy Conservation at the Workplace

Returning to work may be impossible for some patients with cancer, but if an individual works with his or her employer, it may be possible, even if fatigue is a problem. It is crucial for patients to communicate with employers and co-workers about cancer fatigue...
to help create a supportive and productive work environment. Some suggestions include arranging the workspace so everything is easy to reach, planning the workload around the best times of the day, taking periodic short rest breaks, lying down during lunch, looking into eligibility for handicapped license plates, and requesting modified schedules or duties if necessary. Working with an employer to set realistic goals and asking co-workers for help is essential. Also, speak with human resources staff and review your employer's policies in relation to sick leave, disability, flexible scheduling, and work retraining options in advance.

**RELATION OF PAIN TO FATIGUE**

Pain, another common symptom for individuals with cancer, can lead to increased fatigue. Pain can be thought of as an energy leak. Pain takes away energy by disrupting sleep, causing alterations in breathing and posture, as well as decreasing movement. Any type of pain can further be exacerbated by muscles going into spasm as the body attempts to guard itself. This not only leads to more pain (myofascial pain) but leads to more fatigue as well.

If you are experiencing pain, it is essential to alert your physicians and nurses immediately. There are many different pharmacologic and nonpharmacologic treatments to relieve pain. Examples of pharmacologic techniques include using nonsteroidal medications, opiates, or drugs such as anticonvulsants or antidepressants. Nonpharmacologic techniques include using acupuncture, massage, imagery, hypnosis, biofeedback, relaxation, Reiki, labyrinths, counseling, and spiritual ministry.
Complementary and Alternative Medicine in the Treatment of Fatigue

There are many complementary and alternative medicine (CAM) approaches that have some value in treating fatigue. Because many cancer symptoms, including stress, anxiety, depression, sleep difficulties, nausea and vomiting, and pain, are related to fatigue, many of these CAM approaches may be useful in helping prevent or treat fatigue by treating the underlying problem.

**ACUPUNCTURE**

Acupuncture uses needles at specific points in the body to relieve different symptoms. Studies have shown that acupuncture is particularly helpful in treating pain as well as nausea and vomiting related to chemotherapy. Acupuncture may also be useful in alleviating hot flashes and sleep disturbances. This is a technique that should be performed by a licensed practitioner.

**MIND-BODY TECHNIQUES**

Different mind-body techniques include relaxation, imagery, hypnosis, and biofeedback. All of these techniques are usually done with a certified practitioner. These techniques are particularly useful for treating pain, stress, anxiety, and sleep dis-

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**Myth**

There are only medications that can be used to treat fatigue.

**Fact**

There are many nonpharmacologic modalities, such as exercise, energy conservation, and complementary and alternative medicine modalities, that may help cancer-related fatigue.
turbances. Studies have shown that hypnosis is particularly useful for treating anticipatory nausea and vomiting associated with chemotherapy.

**MUSIC AND ART THERAPY**

Music and art therapy are done with trained professionals. Studies have shown that these techniques are particularly useful for reducing anxiety and pain as well as improving quality of life.

**ENERGY MEDICINE: REIKI, THERAPEUTIC TOUCH, AND HEALING TOUCH**

Reiki, therapeutic touch, and healing touch are done with trained professionals. These techniques use touch to help balance the human energy field. Reiki can be taught to the patient to do him- or herself. These techniques help patients with cancer restore their inner balance—their physical, emotional, and spiritual health. These techniques appear to have benefit in reducing anxiety and pain and helping with sleep problems. Further research is needed with these modalities.

**MASSAGE**

Massage performed by a licensed practitioner is one of the oldest CAM therapies. Research has shown that massage reduces stress, anxiety, and pain and increases alertness. There is some evidence that massage relieves chronic pain. There are numerous types of massage. Sometimes, the massage therapist may use aromatherapy (use of perfumed oils), which has been found to be helpful in reducing muscle tension, anxiety, and insomnia.
SPIRITUAL MINISTRY

Even if an individual is not religious, spiritual counseling is helpful in relieving stress, anxiety, sleep problems, and pain. Spirituality involves finding hope, peace, and meaning in spite of cancer, decreased energy, and fatigue. Different techniques a spiritual advisor may use include counseling, spiritual reflection, and labyrinths.

The cancer experience has been a gift from God in that it has healed me in ways that I have never been healed before.

— The author
The Cancer Survivor and Fatigue

In speaking with cancer survivors even years after treatment, especially those who underwent intensive treatment such as bone marrow transplantation, it is clear that both “chemo brain” (cognitive changes such as memory loss and concentration issues) as well as fatigue remain problems in their lives. Little research has been done on these problems for cancer survivors; however, they are clearly issues that should be addressed by the health care team. Patients who communicate and work with a health care team help them assess needs and create a treatment plan to combat both the fatigue and perhaps deal with any cognitive changes. Sometimes, antidepressant or stimulant medications are helpful in relieving symptoms. Some of the energy conservation techniques, exercise programs, and CAM modalities may help improve fatigue and quality of life for the cancer survivor.

Myth
Fatigue is part of cancer treatment and will get better with time.

Fact
Some long-term cancer survivors have fatigue that can be treated.
Fatigue in the Caregiver

Caring for a loved one with cancer is extremely difficult and challenging for the family. In addition to conducting his or her routine role, the caregiver may need to take on new family responsibilities. The caregiver may need to take some of the patient’s roles because the patient is so fatigued. Additionally, the caregiver may need to administer medications, such as pain medications, and assess treatment; in effect, acting as an extension of the cancer treatment team. Unfortunately, this usually leaves little time for the caregiver to take care of his or her own needs. A survey conducted by the Fatigue Coalition found that 49% of caregivers needed to make changes in their work situations to be able to care for a loved one, including taking time off from work. Another survey found that 62% of caregivers said their own health had suffered as a result of caregiving, 70% said their families were not working well together, and 46% reported inadequate financial resources. Some ideas for how caregivers may avoid becoming fatigued are:

1. Take quality time away—even if it is only half a day.
2. Ask other family members and friends for help and suggest specific tasks that can be done.
3. Educate yourself about your loved one’s illness.
4. Use resources in the community such as transportation services and home health aides. A social worker may be able to help you with these resources.
5. Acknowledge your feelings and share them with others. Support at this time is critical.
6. Watch for signs of stress in yourself and use techniques such as relaxation and diversion.
7. Give yourself credit for all you do.
8. Communicate, communicate, communicate! It is very important to let the health care team, family and friends, and your loved one with cancer know that help is needed!
Conclusion

Fatigue is the most common symptom experienced by patients with cancer, both during and after treatment. Fatigue can be associated with a broad array of physical, psychological, social, and spiritual problems, including decreased physical activity, mood and sleep disturbances, changes in social roles, and questions about the meaning of life.

Although fatigue research is in its infancy, enough is known at this time for health care providers to assess a patient’s cancer-related fatigue syndrome and develop a comprehensive, individualized treatment plan. Cancer, as well as cancer-related fatigue, can be experiences that lead to growth and healing in unforeseen ways.

Myth
Fatigue is inevitable with cancer and cannot be treated.

Fact
There are many different treatments for fatigue.
APPENDIX I

Cancer-Related Fatigue Resources

AMC Cancer Research Center
1600 Pierce Street
Denver, Colorado 80214
(800) 525-3777 (The Cancer Information and Counseling Line)
www.amc.org

American Cancer Society
National Cancer Information Center
CanSurmount
I Can Cope
1599 Clifton Road NE
Atlanta, Georgia 30329
(404) 320-3333
(800) ACS-2345 (227-2345)
www.cancer.org

American Medical Association
515 North State Street
Chicago, Illinois 60610
(312) 464-5000
(800) 621-8335
www.ama-assn.org

American Pain Foundation
201 North Charles Street, Suite 710
Baltimore, Maryland 21201
(888) 615-PAIN (615-7246)
www.painfoundation.org
American Society of Clinical Oncology
1900 Duke Street, Suite 200
Alexandria, Virginia 22314
(703) 299-0150
www.asco.org

Association of Cancer Online Resources
173 Duane Street, Suite 3A
New York, New York 10013
(212) 226-5525
www.acor.org

Cancer Care, Inc.
275 Seventh Avenue
New York, New York 10001
(800) 813-HOPE (813-4673)
www.cancercare.org

Chemotherapy Foundation
183 Madison Avenue, Suite 403
New York, New York 10016
(212) 213-9292

Corporate Angel Network, Inc.
One Loop Road
White Plains, New York 10604
(914) 328-1313
www.corpangelnetwork.org

Hospice Education Institute
Hospice Link
3 Unity Square
Machiasport, Maine 04655
(800) 331-1620
www.hospiceworld.org

Look Good…Feel Better
(800) 395-LOOK (395-5665)
www.lookgoodfeelbetter.org
Patient Advocate Foundation
700 Thimble Shoals Boulevard, Suite 200
Newport News, Virginia 23606
(800) 532-5274
www.patientadvocate.org

National Cancer Institute
Cancer Information Service
CancerNet
NCI Public Inquiries Office
Suite 3036A
6116 Executive Boulevard, MSC8322
Bethesda, Maryland 20892
(800) 4-CANCER (422-6237)
(800) 332-8615 (for the hearing impaired)
www.cancer.gov

National Coalition for Cancer Survivorship
1010 Wayne Avenue
Silver Spring, Maryland 20910
(877) NCCS-YES (622-7937)
www.canceradvocacy.org

National Comprehensive Cancer Network
Patient Information Service
(888) 909-NCCN (909-6226)
www.nccn.org

National Hospice and Palliative Care Organization
1700 Diagonal Road, Suite 625
Alexandria, Virginia 22314
(703) 837-1500
www.nhpco.org

OncoLink
Abramson Cancer Center of the University of Pennsylvania
3400 Spruce Street, 2 Donner
Philadelphia, Pennsylvania 19104
www.oncolink.upenn.edu
Oncology Nursing Society
125 Enterprise Drive
Pittsburgh, Pennsylvania 15275
(866) 257-4ONS (257-4667)
www.ons.org
www.cancersymptoms.org

People Living With Cancer
American Society of Clinical Oncology
1900 Duke Street, Suite 200
Alexandria, Virginia 22314
(703) 299-0150
www.plwc.org

R.A. Bloch Cancer Foundation, Inc.
4400 Main Street
Kansas City, Missouri 64111
(800) 433-0464
www.blochcancer.org

StopPain.org at Beth Israel Medical Center
Department of Pain Medicine and Palliative Care
www.stoppain.org

The Wellness Community
919 18th Street NW, Suite 54
Washington, DC 20006
(888) 793-WELL (793-9355)
www.thewellnesscommunity.org
APPENDIX II

Glossary

Activities of daily living: All of the things people do on an average day; these can be made difficult by fatigue.

Acupuncture: The insertion of fine needles into the body, performed by a specialist, that helps relieve fatigue, pain, insomnia, etc.

Acute fatigue: Short-term fatigue caused by a single event or treatment.

Anaerobic metabolism: An indicator of fatigue on the cellular level.

Anemia: A deficiency in the number of red blood cells that reduces the ability of the blood to carry oxygen; anemia is a frequent side effect of chemotherapy.

Anhedonia: A feeling of emptiness or that life lacks joy that typically accompanies depression.

Anticonvulsants: Medications that prevent seizures or abnormal muscle contractions. Also used for treatment of pain.

Antidepressants: Medications that alleviate symptoms of depression. Also used for treatment of pain.

Aranesp®: See darbepoetin alfa.

Aromatherapy: A type of therapy that uses aromas, usually through oils, to trigger positive emotions and memories. Can decrease anxiety.

Biofeedback: A program in which a person can learn to monitor and control automatic body functions such as heartbeat or blood pressure. Helpful in treatment of pain and anxiety.

Cancer-related fatigue syndrome: The collection of symptoms, such as tiredness or depression, associated with cancer and its treatments.

Cardiac output: The ability of the heart to pump blood.
Caregiver: Any person—family member, friend, doctor, nurse, etc.—who helps care for a patient.

Centrally acting drugs: Medications that act on the brain, such as painkillers or antidepressants.

Chemotherapy: The infusion of potent chemicals into the body to reduce the size of a tumor or spread of cancer.

Chronic fatigue: Long-term fatigue, often associated with lengthy periods of cancer treatment or cancer survivorship.

Chronic pain: Pain that lasts over a long period, often associated with other long-term disorders.

Cognitive-behavioral therapy: Individual or group therapy that helps patients plan new ways to react to various situations.

Complementary and alternative medicine: Any approach to improve a health problem that is not routinely taught to conventional practitioners of Western medicine.

Coping: An individual’s ability to respond to and overcome a particular problem, such as fatigue. Positive coping styles, such as humor, can help relieve fatigue.

Darbepoetin alfa (Aranesp®): A new erythropoietic medication that helps combat chemotherapy-induced anemia.

Deconditioning: A loss of muscle tone associated with long periods of illness.

Depression: A medical illness that involves extended periods of sadness; depression is often associated with fatigue, and can be treated with medical and complementary techniques.

Endurance: An individual’s ability to withstand resistance or stress; muscle endurance can be tested to help diagnose fatigue.

Energy conservation: A method of coping with fatigue that involves planning one’s activities so as to use the least amount of energy possible.

Epoetin alfa (Procrit®): A medication that combats chemotherapy-induced anemia.
Erythropoietic agents: Medications that assist in the production of new red blood cells to combat anemia; examples include epoetin alfa and darbepoetin alfa.

Fatigue: Imbalance of mind, body, and spirit.

Functional capacity: An individual's ability to live normally and perform various physical or mental tasks.

Functional impairment: A lessening of an individual's ability to live normally or perform various physical or mental tasks.

Hematocrit: The volume of red blood cells in a blood sample; this can aid in the diagnosis of anemia.

Hemoglobin: A substance found in red blood cells that carries oxygen; a hemoglobin count can aid in the diagnosis of anemia.

Hypnosis: A therapy that involves a state of relaxation that quiets the conscious mind.

Imagery: A therapy that involves showing or asking an individual to visualize images that aid in relaxation.

Insomnia: The chronic inability to sleep.

Interventions: One of several therapies or techniques designed to help relieve fatigue or other illness.

Labyrinths: A type of maze that can be walked or traced with a finger, promoting contemplation and relaxation.

Meditation: Focusing on specific thoughts, in silence, to help calm oneself.

Metabolism: The body's normal chemical processes that are frequently affected by fatigue.

Methylphenidate (Ritalin®): A centrally acting stimulant.

Myofascial pain: A feeling of tightness in the muscles that is associated with muscle spasms.

Nonpharmacologic techniques: Therapies, other than medications, designed to alleviate a disease or symptoms; see also complementary and alternative medicine.
Nonsteroidal medications: Class of medications that reduce swelling, fever, and pain.

Occupational therapist: A therapist who assists patients with activities of daily living.

Opiates: A class of potent pain medications, including morphine and codeine.

Oxidative metabolism: The functioning of cells with oxygen.

Pharmacologic techniques: Therapies that involve the use of drugs, such as erythropoietic agents or antidepressants, to help alleviate a symptom or disease.

Physiatrist: A physician who specializes in rehabilitation medicine.

Physical therapist: A therapist who uses exercise and other similar techniques.

Procrit®: See epoetin alfa.

Psychotherapy: The treatment of mental and emotional disorders through the encouragement of communication about conflicts and insight into problems.

Quality of life: The ability to live a healthy, active, fulfilling life; one’s satisfaction with one’s life.

Radiation therapy: The use of high-energy radiation to control the size of tumors and spread of cancer.

Recreational therapist: A therapist who specializes in the use of recreational activities such as music, art, pets, crafts, etc.

Reiki: The use of “spiritual energy” to help balance an individual’s own energy.

Relaxation: Any technique that involves the lessening of stress.

Sleep deprivation: The lack of sleep. Sleep deprivation can help alleviate depression.

Sleep disorders: A group of disorders that affect an individual’s ability to obtain a full night of restful sleep.

Somatization: A psychological disorder that presents as physical symptoms.
Speech therapist: A therapist who assists patients with proper speech.

Spiritual ministry: Religious or nonreligious guidance to help find an individual’s “soul” (i.e., what gives a person’s life meaning).

Stimulants: A class of medications that increase the activity of the brain or part of the brain, usually to improve mood or increase energy level.

Syndrome: A group of related symptoms.

Thyroid deficiency: A medical disorder involving the thyroid gland that may lead to fatigue.