Fatigue (Extreme Tiredness)

Fatigue is a general term used to describe overwhelming tiredness, exhaustion and lack of energy. It is a common problem among people living with HIV, and it tends to be worse among those with more advanced disease.

Most people occasionally experience temporary tiredness—for example, after a late night or when they have the flu. But fatigue goes beyond just feeling sleepy. Some people develop severe or long-term chronic exhaustion that can interfere with daily activities. What's more, fatigue is often accompanied by physical weakness or cognitive problems, such as an inability to concentrate and poor memory (sometimes known as "brain fog").

Many health conditions and lifestyle factors can lead to fatigue, and determining the cause is the first step toward managing it. Many types of fatigue can benefit from medical treatment or lifestyle changes. For those with chronic fatigue, learning how to pace yourself can help improve your quality of life.

What causes fatigue?

There are many possible causes of fatigue among people living with HIV, and sometimes multiple causes are present at the same time. Some of the most common causes include the following:

- Inadequate sleep. Many people, whether or not they have HIV, do not get enough sleep. Most adults need at least seven hours a night. Missing an occasional night of good sleep can lead to temporary fatigue that resolves when you catch up. But consistently inadequate sleep—for example due to an overly busy or irregular schedule or sleep disturbances, such as insomnia or sleep apnea (interrupted breathing)—can lead to ongoing fatigue. Anxiety, stress, chronic pain, certain medications, substance use and inadequate exercise can all contribute to poor sleep.
- Psychological causes. Anxiety and depression, which are common among people living with HIV, are often associated with fatigue. These conditions can lead to poor sleep, but even people who get enough rest may feel exhausted or short of energy. Depression can also lead to apathy and a lack of motivation, which can resemble fatigue.

- Anemia. Anemia occurs when red blood cells don’t carry enough oxygen. This can happen when blood is lost, for example, due to heavy menstruation or bleeding ulcers. It can also happen if the body does not produce enough red blood cells or when these cells are destroyed too quickly or don’t make enough hemoglobin, the protein that transports oxygen. Inadequate iron, a major component of hemoglobin, is a common cause of anemia. Inherited conditions (such as sickle cell disease), certain infections, cancer and medications that deplete blood cells can also cause anemia. In addition to fatigue, other symptoms of anemia include shortness of breath, dizziness or lightheadedness and feeling unusually cold.
- Nutritional deficiencies. Inadequate iron can cause anemia, and low levels of other nutrients, including vitamin B9 (folate), vitamin B12 (cobalamin), vitamin D and certain minerals and electrolytes, can also contribute to fatigue. A healthy, balanced diet usually provides adequate nutrition, but some people may need supplements. These can help correct nutritional deficiencies, but there’s little evidence that more is better for people who already have adequate levels.
- Medications and substance use. Many prescription and over-the-counter medications, including antihistamines and blood pressure drugs, can cause drowsiness. Opioids, benzodiazepines and alcohol can also lead to fatigue. Stimulant drugs and caffeine, which some people use to combat fatigue, can interfere with sleep and may make matters worse.
- Infections. Fatigue is a common symptom of many infectious diseases, including influenza, hepatitis C, COVID-19 and Epstein-Barr virus. In fact, fatigue may be the first sign of an infection, including AIDS-related opportunistic infections. Infections can cause inflammation, and the immune system’s response to pathogens—such as the release of interferon—can trigger fatigue.
- Cancer. Many people with cancer experience debilitating fatigue. In addition to the disease itself and its associated inflammation, chemotherapy, radiation and other cancer treatments can damage the bone marrow, resulting in decreased blood cell production and anemia.
- Endocrine problems. Low levels of certain hormones can lead to fatigue. These conditions include adrenal insufficiency (inadequate production of cortisol or other adrenal gland

hormones), hypothyroidism (an underactive thyroid gland) and hypogonadism (inadequate production of testosterone or estrogen). These hormones help regulate mood, metabolism and energy levels. Hormone deficiencies can have many causes, including inherited conditions, aging, infections, cancer and medication side effects.

- Other medical conditions. Other conditions often associated with cause persistent fatigue include diabetes, multiple sclerosis, kidney disease, chronic lung disease, autoimmune conditions and congestive heart failure, which occurs when the heart does not pump enough blood.
- Chronic fatigue syndrome. Also known as myalgic encephalomyelitis or ME/CFS, this poorly defined condition is characterized by persistent profound fatigue that may worsen after physical or mental activity (known as post-exertional malaise). ME/CFS is often accompanied by other symptoms, including cognitive problems, sleep disturbances, chronic pain, lightheadedness when standing up and a rapid or irregular heartbeat. The causes of ME/CFS are not well understood, but it sometimes comes on after a viral infection. Some experts think long COVID is related to ME/CFS.

How is fatigue treated?

Although fatigue is a common symptom of many physical illnesses, health care providers sometimes too quickly dismiss it as a psychosomatic problem. It’s important to work with your providers to figure out the causes of fatigue. Did it come on suddenly—for example, after starting a new medication—or develop gradually over time? What circumstances make it better or worse? What other symptoms do you have? Pinpointing the cause of fatigue will enable you and your doctor to develop a plan for managing it.

Treatment for fatigue depends on its specific causes. Try to adopt good sleep habits and address any sleep problems, such as sleep apnea, which often improves with weight loss or use of a CPAP device to keep the airway open during sleep.

Get tested for underlying infections and treat them, if possible. Start and stay on antiretroviral therapy to maintain an undetectable viral load. If you think your HIV meds are causing fatigue or interfering with sleep, ask your doctor about switching to a better-tolerated regimen.

Treatments for fatigue may include hormone replacement therapy and supplements for nutritional deficiencies. Anemia may require erythropoietin, a hormone that stimulates red blood cell production, or blood transfusions in severe cases.

If you have debilitating fatigue, learn to do things in ways that preserve the energy you have. Moderate exercise often improves energy levels and promotes good sleep, but if you have ME/CFS, it could make fatigue worse. Pace yourself, and devote your limited energy to the most important tasks or the activities you most enjoy. Stress management techniques, meditation, psychotherapy and support groups can help people cope with chronic fatigue.

Last Reviewed: November 29, 2022

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