

TREATMENT INFORMATION SERIES

Dealing With Cancer-Related Fatigue

CHORDOMA FOUNDATION

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The Chordoma Foundation is committed to helping patients and caregivers make the most informed treatment decisions. We created the *Treatment Information Series* to provide you with in-depth information about each aspect of treatment that may be involved in your chordoma journey. The complete series, as well as other materials for patients and caregivers, is available at **chordoma.org/educational-materials**.



Understanding cancer-related fatigue

Fatigue is one of the most common side effects of cancer treatment. It is an extreme feeling of tiredness or lack of energy not caused by a specific activity, and it usually decreases after cancer treatment ends. However, some people may still feel fatigued for months or even years after treatment. In a survey[1] completed in 2021, **55 percent of chordoma patients and survivors reported experiencing fatigue since being treated.**

Fatigue related to cancer is different from the fatigue that healthy people feel. When a healthy person is tired from certain activities or at the end of the day, their fatigue can be relieved by sleep and rest. Cancer-related fatigue is less predictable and is not entirely relieved by sleep and rest. It can be **acute** (lasting a month or less) or **chronic** (lasting from 1 to 6 months or longer).

Cancer-related fatigue is:

- A distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion
- A common side effect of cancer and its treatment
- Not proportional to level of activity[2]

Cancer-related fatigue can:

- Affect all parts of your life, including daily activities as simple as eating, walking to the bathroom, or using a TV remote
- Cause you to miss work or school or spend less time with friends and family
- Make it difficult to pay attention, think clearly, and remember things
- Decrease your quality of life
- Persist for years after treatment has ended in otherwise healthy survivors

Patients and survivors describe cancer-related fatigue as feeling tired and weak, being worn-out, heavy, or slow, being unable to fully recover your energy after an activity, or having no energy at all. In some cases, physical fatigue — and the limitations it causes — can lead to mental fatigue and mood changes.

Getting help with fatigue may prevent or relieve some of these problems and improve your quality of life. If you are experiencing fatigue and do not have a plan for managing it, talk with your chordoma care team as well as your primary care physician to get the process started. When seeking ways to manage fatigue, it is important to:

- **Understand the possible causes** of fatigue
- Be able to **accurately describe** the fatigue you are experiencing
- Learn about the **ways fatigue is managed**
- Know where to **find the right treatments** for you



Fatigue or weakness: What is the difference?

It is worth noting that while weakness is a term often used to describe fatigue, they are actually two different sensations. **Fatigue is a feeling of tiredness or exhaustion due to lack of energy, whereas weakness is a feeling of decreased physical strength.** The two are closely related and weakness can contribute to fatigue, but it is important to know exactly what you mean when you say "I feel weak" or "I am fatigued" because it can help you and your doctor narrow down the possible causes and treatments.

Causes of cancer-related fatigue

The causes of cancer-related fatigue can be challenging to determine because there are often many factors involved. The causes of your fatigue may be completely different from those of someone else. Not everyone who has chordoma experiences fatigue, but if you do, the level of fatigue you experience can vary — you may feel a mild lack of energy or be completely exhausted.

How cancer and related treatments cause fatigue is not well understood, but possible contributing factors include:

- **Anemia:** You might develop anemia if your treatment destroys too many healthy red blood cells. Fatigue is a common symptom of anemia.
- **Anxiety, stress, or depression:** Changes in mood and feelings are common for patients and survivors at any stage of their chordoma journey, and these can cause or increase fatigue. In particular, high levels of stress and feelings of sadness, grief, and depression can drain your energy and cause fatigue. Likewise, experiencing fatigue can also cause you to feel depressed.
- **Hormonal changes:** Radiation can affect how the endocrine system functions, causing changes in the body's hormone levels that lead to fatigue. This is more common among clival and some cervical patients, but anyone can experience hormone imbalances, particularly as you age.
- **Medication side effects:** Certain medications, such as pain relievers, can cause fatigue.
- **Pain:** If you experience chronic pain, you may be less active, eat less, sleep less, or become depressed, all of which may add to your fatigue.

- **Poor nutrition or dehydration:** For your body to work efficiently, it needs the energy that a healthy diet provides. When you have cancer, your body may need even more nutrients than usual, but it can be hard to get enough when other side effects such as pain, nausea, or vomiting make it difficult to eat.
- **Radiation:** Most people start to feel overly tired after two or three weeks of radiation therapy. This happens because, in addition to killing cancer cells, radiation treatments damage some healthy cells, too. Fatigue typically improves when radiation treatment is over, but in some cases it can continue for months before starting to get better.
- **Sleep disruption:** Cancer and its treatments can disrupt your body's natural circadian rhythms and interfere with your ability to sleep normally. Sleeping less at night, sleep that is frequently interrupted, or insomnia can all contribute to fatigue.
- **Surgery:** Recovery from major surgery can cause a loss of muscle mass, resulting in weakness that contributes to fatigue. Your body is also working to heal tissues affected by the surgery.
- **Systemic therapy:** Treatments such as chemotherapy, immunotherapy, and targeted therapy can also cause fatigue. You may experience fatigue if your treatment damages healthy cells in addition to the cancer cells and your body must work to repair that damage.

Fatigue is also common in people with advanced disease even if they are not receiving any type of treatment because the body is dealing with a greater amount of cancer.



Signs of cancer-related fatigue

The way you experience fatigue and the level of your fatigue may differ from one day to the next. Common signs of fatigue you might experience include:

- Feeling tired even though you are getting rest and sleep
- Spending more time than usual in bed or staying in bed for more than a day
- Sleeping more
- Feeling unusually tired during or after an activity
- Feeling tired even when you're not doing an activity
- Not being able to do the things you normally do because you're too tired
- Inability to work, be social, or do daily routines as you normally do
- Having no energy, feeling very weak, or finding it difficult to move
- Difficulty paying attention or easily getting confused

Some fatigue during and just after chordoma treatment is to be expected. **If you find that your fatigue is interfering with your ability to go about everyday tasks or it isn't going away — lasting weeks, months, or even years — you should discuss it with your care team so they can help you.**

Assessing your fatigue

You should be assessed for fatigue at the beginning of your treatment and at regular intervals during treatment to see if any patterns emerge.

After treatment ends, fatigue can last for weeks or, in some cases, years. Continue to communicate with your chordoma doctors at your follow-up appointments. They need to know about any fatigue you are feeling and how it is impacting your quality of life. You should also discuss your fatigue with your primary care doctor.



Talking with your doctor

There is no specific test to diagnose fatigue, and no labs or scans can show the level of your fatigue or its impact on your life. **The best measure of fatigue comes from the way you describe it.** You can describe your fatigue by giving examples of how bad it is, how it affects your daily activities, and what makes it better or worse.

A first-hand report of your fatigue ensures that your experiences and needs are clear to your care team so they can help you find relief. In some cases, family member accounts of your fatigue can also be useful.

Ask your doctor or nurse the best way to describe your fatigue so they can understand how it affects your everyday life. For example, you can describe your level of fatigue as none, mild, moderate, or severe. Or you can use a scale of 0 to 10 — as suggested by the National Comprehensive Cancer Network (NCCN)[2] — where 0 means no fatigue at all, and 10 means the worst fatigue you can imagine.

If you report a moderate (4 to 6 on the 0 to 10 scale) to severe (7 to 10 on the 0 to 10 scale) level of fatigue, your care provider may ask you more descriptive questions, such as:

- When did the fatigue first start?
- How does this fatigue feel different from just being tired?
- How long have you been feeling this way?
- Does anything make it better? Worse?
- Are there times of day that you notice it more? Less?
- How has the fatigue affected your everyday life?

Additionally, your doctor will need a complete list of all prescription and over-the-counter medications, vitamins, and supplements you are currently taking. Certain medications and supplements can cause fatigue as well as affect both the levels of hormones in your body and the tests used to detect any imbalances in those hormones.



Tracking your fatigue

A good way to track and report your fatigue is to keep an **activity log**. An activity log is a list of your activities, the time you do them and for how long, and how you feel during and after them. Keeping an activity log can also help you notice any patterns to your fatigue. For example, are you more tired in the afternoon or the evening? Do you feel more exhausted while performing a specific daily task, such as emptying the dishwasher? Or is it worse after the task?

This information will help your healthcare provider assess your fatigue in order to provide you with suggestions for managing it.

Download an activity log template at
chordoma.org/activity-log

What to expect

Your doctor may do some or all of the following to help accurately assess the fatigue you are experiencing, understand its impact on your quality of life, and identify any causes of your fatigue that can be treated.



Physical exam

This is an exam of the body to check general signs of health such as temperature, blood pressure, heart rate, breathing, muscle tone or weakness, posture, and joint movements.



Answering questions or completing a questionnaire

You may be asked about the medications you are taking, your eating and sleeping habits, how the fatigue affects your daily lifestyle and ability to participate in work or school, whether you're experiencing depression, anxiety, or pain, and how long your fatigue has lasted.



Rating your level of fatigue

Your doctor may also ask you to rate your fatigue on a numeric scale — from 0 to 10 — or by degree of severity (based on how much it impacts your daily life).



Blood tests to check for anemia and hormonal imbalances

The most common blood test to check for anemia is a complete blood count (CBC) with differential. The CBC looks for the number of red blood cells and platelets, the number of white blood cells, and the amount of hemoglobin in your blood. Hormones like cortisol, prolactin, TSH (thyroid), estrogen, and testosterone are also detected through blood tests. Those with clival or cervical tumors should have these tests done on a regular basis, but it can be helpful to check your levels of these hormones no matter where your tumor is or was located.

Managing cancer-related fatigue

Although there is no way to know if you will experience fatigue, how bad it will be, or how long it will last, there are a number of ways to help manage it if it occurs.

TREAT UNDERLYING CONDITIONS OR CAUSES

Anemia and endocrine system imbalances can be the main cause of fatigue or can make fatigue worse. If blood tests find imbalances, **medication can be given to increase iron or regulate hormone levels**.

Pain and pain medications can increase fatigue. If this happens, **adjusting your pain management regimen may help**.

EXERCISE OR YOGA

Research studies have shown that physical activity during and after cancer treatment can decrease fatigue. **Light exercise like walking, stationary bike, yoga, or swimming may help you feel better and have more physical and mental energy.** Your healthcare team can refer you to exercise or rehabilitation specialists to help you establish a safe exercise plan that is tailored to your needs.

PHYSICAL AND OCCUPATIONAL THERAPY

Physical therapists (PTs) and occupational therapists (OTs) are healthcare professionals who can help you manage your fatigue. **PTs help improve your ability to move by helping you build strength and balance.** They can also help you come up with an exercise plan that works for you. **OTs help improve the skills you need for important everyday activities such as getting dressed, taking a shower, or cooking a meal.** Both PTs and OTs can help you stay motivated and set goals.

MASSAGE THERAPY

Massage therapy has helped some individuals undergoing cancer treatment **reduce stress levels and improve sleep**, which can improve fatigue. Talk to your doctor before starting massage therapy.

BEHAVIORAL COUNSELING

Therapists and counselors help people with cancer explore how they think, feel, and react to certain things. Anxiety, fear, hopelessness, or lack of social support can make fatigue worse. **Behavioral therapy or mindfulness-based stress reduction can give you ways to cope.** Complementary therapies, such as relaxation techniques, may also help.

NUTRITIONAL COUNSELING

Nutritional deficits can add to the problems of fatigue and weakness. **Your doctor may refer you to a dietitian to check your calorie and nutritional intake.** You may also be prescribed vitamins or supplemental electrolytes (such as sodium, potassium, calcium, iron, or magnesium) to help reduce your fatigue symptoms. Discuss these with your doctor or dietician to help you know what and how much to take.

STAY SOCIALLY ACTIVE

Stay connected to family and friends, but make sure to pace yourself. **There are many ways you can keep in touch with your friends and family,** including spending time with them in person, talking on the phone or through a video chat, or sending emails and text messages.

STICK TO A ROUTINE

Changes in your daily routine can cause the body to use more energy. **A regular routine can help you manage your activity levels so you have more consistent energy throughout the day.** It can improve the quality of your sleep as well.



Tips for saving your energy:

- **Schedule** regular times for activity and rest
- **Take** short naps or rest breaks (30 minutes or less) during the day, rather than one long nap
- **Prioritize** your activities each day so you focus on the most important things you need to do
- **Learn** how to change or avoid activities that cause stress and fatigue
- **Pace** yourself
- **Alternate** sitting and standing
- **Install** grab bars in your shower or use a shower bench
- **Organize** and store the items you use regularly in easy-to-reach places
- **Ask** family and friends for help with meals, yard work, housework — anything that causes you to feel tired

Finding care

Because the symptoms of fatigue are usually caused by more than one problem, it is likely that you will need to interact with more than one care provider to address them. Your care team for fatigue-related issues may include doctors, nurses, counselors, physical therapists, endocrinologists, pharmacists, dietitians, nutritionists, or others.

Start with your chordoma care team, primary care provider, or palliative care specialist if you have one. Any of these doctors can help assess your fatigue and refer you to specialists who should be involved in managing your fatigue.

Palliative care

Palliative care is an important part of cancer care. Sometimes called supportive care, it is recommended for all cancer patients from the time of diagnosis, through all stages of treatment, and after treatment is complete. It can address symptoms of the disease itself or side effects of its treatment.

Chordoma experts recommend that all chordoma patients' treatment plans and survivorship care plans include palliative care. No matter what treatment you have for chordoma, palliative care can help address pain, mobility and functional issues, mental and emotional health, nutrition, fatigue, and many other concerns to help you feel well and live fully while managing your chordoma.



Learn more about palliative care at **chordoma.org/palliative-care**

Educating providers on chordoma

Many of the care providers who can help you manage fatigue won't know a lot about chordoma. And that's okay. The Chordoma Foundation developed a fact sheet you can use to help your doctors and other healthcare providers learn about chordoma. It includes general information on chordoma, how it's treated, and the common side effects of those treatments. There is also space for you to add information about your particular situation so your providers can understand how chordoma has affected you personally.

Download or print the fact sheet for non-chordoma providers at **chordoma.org/fact-sheet**



Call your care team immediately if:

- You are dizzy, lose your balance, or fall
- You experience confusion
- You are too tired to get out of bed for more than a day
- You have difficulty breathing

These could be a sign of a more serious issue.



For caregivers

If you are caring for someone with chordoma who is experiencing fatigue, there are a number of things to keep in mind and ways you can support them.

- Help schedule friends and family members to prepare meals, clean the house, do yard work, or run errands. Consider using online tools to create signups for these tasks, or ask a family member to assist.
- Try not to push your loved one to do more than they are able.
- Help your loved one set up a predictable routine of activities during the day.
- Remember to be patient with your loved one. Cancer-related fatigue can last months or even years past treatment, decreasing your loved one's quality of life, making it harder for them to remember things or think clearly at times, and decreasing their ability and desire to engage with others.



How we can help

The Chordoma Foundation Patient Navigation Service is here to help. Our dedicated Patient Navigators are available to:

- Answer questions about chordoma and quality of life challenges
- Provide information on treatment, both for chordoma and common quality of life needs
- Identify and provide information on clinical trials open to chordoma patients, and other options for systemic therapy
- Give information about programs and organizations that offer travel and lodging assistance, co-pay relief, and other benefits
- Support requests and appeals to insurance companies
- Connect you with others in the chordoma community



Learn more about our Patient Navigation Service at **chordoma.org/request-help**

Learn more

Visit the Chordoma Foundation's website at **chordoma.org** for more information on chordoma, including research updates, the latest news on treatments, and ways to get involved.

Get help from a Chordoma Foundation Patient Navigator at **chordoma.org/request-help** or by calling +1 (888) 502-6109.

Connect with other patients and caregivers through the Chordoma Connections online community at **community.chordoma.org**.

References

1. Chordoma Survivorship Survey Results. Chordoma Foundation website. https://www.chordomafoundation.org/learn/survivorship-survey-results/. Last updated January 29, 2021.

2. Berger AM, Mooney K, Alvarez-Perez A, et al. Cancer-Related Fatigue, Version 2.2015. *J Natl Compr Canc Netw.* 2015;13(8):1012-1039. doi:10.6004/jnccn.2015.0122

Important note about this publication

This content was developed by the Chordoma Foundation in consultation with members of our Patient Services Committee. It is not meant to take the place of medical advice. You should always talk with your doctors about treatment options and decisions.

We would like to thank the members of our Patient Services Committee for providing their expertise in contributing to the content and review of this information.

Edward Les, MD, Chair

Yen-Lin Chen, MD

Karen Cox, RN, FACHE, FAAN

Al Ferreira, RN

Sasha Knowlton, MD

Paula Song, PhD



PO Box 2127, Durham, NC 27702
(919) 809-6779 • chordoma.org



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