

TREATMENT INFORMATION SERIES

Pain Management

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 pain

Pain is very common among people who have been diagnosed with any type of cancer. In a 2014 survey[1] of chordoma patients and survivors, nearly 40 percent reported experiencing chronic pain. For those with mobile spine tumors, that number increases to 54 percent.

Pain experienced by chordoma patients and survivors is usually caused by nerve and tissue damage from either the tumor itself or its treatment. Growing tumors can cause irreversible damage to cranial and spinal nerves, nerves may need to be removed during surgery along with the tumor, and radiation can affect tissue and nerves in the area being radiated as well as weaken bone. This can result in a number of short-term and long-term side effects, including pain.

Pain can affect every part of your life — daily living activities like getting dressed and eating, enjoying being around others, sleeping, and working or going to school. It can also affect your mental and emotional health, causing feelings of isolation, exhaustion, anger, fear, anxiety, and depression.

But you don't have to accept pain as a normal part of having chordoma. It is important to remember that pain can be managed and it is your right to get treatment for it. Your pain may not always be completely relieved, but your doctors can work with you to control and manage it as much as possible.

[1] Song PH, Beyhaghi H, Sommer J, Bennett AV. Symptom burden and life challenges reported by adult chordoma patients and their caregivers. Qual Life Res. 2017 March; 26, 2237–2244. https://doi.org/10.1007/s11136-017-1544-2



If you do not yet have a pain management plan, talk with the doctors and nurses treating your chordoma, as well as your primary care physician, or request a consultation with a pain specialist to get the process started. When seeking treatment for pain, it is important to:

- **Understand** the different types of pain
- Be able to **accurately describe** the pain you are experiencing
- Know how to **find the right treatment** for you

Types of pain

It's easy to tell when you're in pain, but describing that pain and explaining how it affects you can be more difficult. Understanding the different types of pain will help you be able to accurately describe your pain to your doctors.



There are two main types of pain: neuropathic pain and nociceptive (no-sih-sep-tiv) pain.

Neuropathic pain is caused by disease in or damage to nerve tissue. Nerves can be damaged by a growing tumor or by treatments such as surgery and some types of systemic therapy. It can also feel like numbness, tingling, swelling, or muscle weakness in different parts of the body.

Neuropathic pain is a common type of pain experienced by chordoma patients and survivors.

Examples of conditions that cause neuropathic pain include:

- Peripheral neuropathy
- Trigeminal neuralgia
- Shingles

Nociceptive pain is caused by tissue injury, damage, or inflammation. Nociceptors are sensory endings on nerves. If the pain is momentary, the nociceptors are signaling potential damage. When damage actually occurs, an inflammatory response is triggered and there will be lasting effects. For instance, if you touch a hot pan and quickly pull your hand back, you will feel pain for a moment but your skin will not be burned. If you grab the hot pan and pick it up, you will feel lasting pain and will likely also have redness, swelling, and blistering.

There are two types of nociceptive pain:

- **Somatic**, which originates in the skin, muscles, joints, and bones. Examples include a sprained ankle, bone fracture, cut, burn, and arthritis.
- **Visceral**, which originates in internal organs and surrounding tissues. Examples include irritable bowel syndrome (IBS), bladder infection, and endometriosis.

Pain can also be classified in the following three ways:



Acute pain starts suddenly and is usually the result of an illness or injury — such as a cut, bruise, burn, broken bone, or infection. It might be mild pain that goes away within a few moments or it can be more severe and last longer, but typically not longer than a few weeks or months. Once the injury heals or illness is gone, the pain goes away.



Chronic pain, also called persistent pain, is ongoing and usually lasts longer than 6 months. It involves damage to nerves and pain signals in the nervous system that remain even after an illness or injury has resolved. Sometimes acute pain can become chronic if nerve damage has occurred, so it's important for acute pain to be treated and monitored appropriately.



Breakthrough pain is a sudden increase in pain that usually lasts a short time. It "breaks through" the relief of pain medicine already being taken for chronic pain. Breakthrough pain typically feels the same and occurs in the same area of the body as a person's chronic pain and is usually treated with an additional dose of pain medicine or a different kind of medicine.

Assessing your pain

Your doctor will ask you questions about your pain, review your medical history, conduct a thorough exam, and do a few tests to fully understand how pain is affecting you and decide how to treat it. This is called a pain assessment.

Pain management is an ongoing process and communication with your doctors is critical to getting the best care. Once you have a plan in place, it is necessary to check-in with your doctor regularly so they can continue to assess your pain and how well the plan is working.



Talking with your doctor

The best way to have a productive conversation with your doctor about your pain is to be able to describe in specific terms how it feels, how strong it is, and when and where it happens. Then you and your doctor can discuss the options you have for treating your pain.

It is important to be honest about your pain levels and describe your pain as clearly and thoroughly as possible so your doctors can help you. To prepare for your doctor visits, **consider keeping a daily pain journal** for at least a week before your appointment. Use the journal to track:

- **What** the pain feels like, using descriptive words such as burning, stabbing, throbbing, dull, aching, tingling, or cramping
- **Where** you feel it
- **When** it starts
- **How long** it lasts and what makes it feel better
- **Whether** it is constant or comes and goes
- **Anything** that triggers it
- **How bad** (or severe) it is on a scale from 0 to 10, where 0 is no pain and 10 is the worst pain possible. Some pain scales use faces instead of numbers, which may be easier to use in describing your pain.



Download a pain journal template at **chordoma.org/pain-journal**

Tests to expect

Your doctor will also perform some tests to help accurately assess your current pain. A **physical exam** will check different parts of your body including your abdomen, spine, joints, bones, and lymph nodes. A **neurological exam** will assess the functioning of your brain, spinal cord, and nerves by testing your coordination, mobility, mental status, and how well your muscles and reflexes are working.

You may also be given an ultrasound, CT scan, bone density test, or other imaging along with blood tests to assess potential causes such as inflammation, infection, osteoporosis, or hormonal imbalance.

For a list of questions that can help you think about what you might want to ask your doctor, visit **chordoma.org/treatment-questions**



Bone fractures

If you have pre-existing or previously undiagnosed osteoporosis, make sure it is being managed well by either your primary care physician or a bone endocrinologist to help prevent bone fractures that will cause pain.



Managing pain

Adequately managing pain often involves a combination of different kinds of treatment. A good pain specialist will work with you — and continue making changes as needed — to find the plan that provides you with the most relief.

Medications

Opioid and non-opioid medications are the most common forms of pain management. The type of medication your doctor prescribes will be based on the kind of pain you're experiencing and how severe it is. In some cases, your doctor may combine different types of medications to achieve pain relief. For instance, a time-release opioid might be given along with a different, fast-acting opioid to be taken as needed for breakthrough pain.

> *Please note that the medications discussed below use the name of the drug rather than the brand name. For example, ibuprofen is listed rather than Advil® or Motrin®, which are two brands of the drug. Your doctor may refer to a medication using either the drug name or the brand name. It is good to be aware of both the drug name and any brand names the drug is sold under.*

TYPES OF MEDICATION

Prescription and over-the-counter pain relievers: These are non-opioid types of pain relievers such as acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs), including:

- Ibuprofen
- Naproxen
- Diclofenac
- Meloxicam

Opioids: These drugs bind to the opioid receptors in the brain and send your brain the message that you are not in pain. These are powerful drugs that must be prescribed by a doctor. Prescription opioids used for pain relief are generally safe when taken as directed by your doctor, but they can be misused (see "Dependency and addiction" section on p. 15). This is why doctors usually prescribe them cautiously and as part of a larger pain management regimen. Types of opioids include:

- Codeine
- Fentanyl
- Hydrocodone
- Methadone
- Morphine
- Oxycodone
- Tramadol

Non-opioid medications: There are other types of drugs that may be given alone or in combination with opioids, including certain types of antidepressants and anti-epilepsy medications that are particularly helpful for nerve pain.

- **Antidepressants** that help with nerve pain include tricyclic antidepressants such as amitriptyline, nortriptyline, and doxepin as well as serotonin and norepinephrine reuptake inhibitors (SNRIs) such as venlafaxine and duloxetine.
- **Anti-seizure medications** used to treat nerve pain include gabapentin and pregabalin.
- **Corticosteroids** can also be used to treat pain, including cortisone, hydrocortisone, and prednisone.
- **Local anesthetics** like lidocaine can be applied to the skin as a cream or a patch.

HOW MEDICATION IS GIVEN

Most medications used to treat pain are taken orally, but there are some other ways they can be given if taking them by mouth is not possible or is not adequately controlling pain.

Mouth: If you do not have swallowing, stomach, or intestinal issues, medicine is usually given by mouth. Medications given orally are easy to use and are usually low-cost. Oral medications are sometimes placed under the tongue (sublingual route) or on the inside of the cheek (buccal route) to be absorbed, which can also be helpful if you have swallowing issues.

Rectum: If you cannot take medications by mouth, they can sometimes be given as rectal suppositories.

Skin patches or topical: Medications are placed on the skin (transdermal route).

Nose spray: Medications may be given in the form of a nasal spray.

Intravenous (IV) line: Medications are given into a vein through an IV line only when simpler and less costly methods cannot be used, don't work, or are not wanted by the patient.

> **Patient-controlled analgesia (PCA)** pumps are one way to control pain through your IV line. A PCA pump allows you to control the amount of drug that is used. With a PCA pump, you receive a set dose by pressing a button on a computerized pump that is connected to a small tube. Once the pain is controlled, the doctor may prescribe regular medication doses based on the amount you used with the PCA pump.

Subcutaneous injection: Medications are given by injection into the fatty layer of tissue just under the skin.

Intraspinal injection: Medications are injected into the fluid around the spinal cord. These may be combined with a local anesthetic to help some patients who have pain that is hard to control.

SIDE EFFECTS

The most common side effects of pain medications are drowsiness, dizziness, and nausea. These often resolve after taking the medication for a few days.

Opioids can also cause constipation, which can be an ongoing issue. It is important to drink plenty of water, exercise, and make sure you have enough fiber in your diet. Laxatives can also help with constipation. If opioids are part of your pain management regimen, your doctor should provide you with a plan to help avoid major issues with constipation.

Talk with your doctor about any side effects that are severe or difficult to manage. A change in the type of medication you're taking, the dosage, or the way it's taken may help, but should only be made under your doctor's supervision.



Dependency and addiction

People who follow their doctor's directions when taking prescription pain medications rarely become addicted. However, the risk of addiction is a concern you may have. The following strategies can help if you're concerned about addiction:



Communicate openly with your doctors, including your oncologist, primary care provider, and pain specialist. Check in with them regularly about your use of medications and how well they're working.



Follow your doctor's instructions precisely on when to take your medications and how much to take. Do not take more than prescribed without talking to your doctor first.



Know the warning signs of possible addiction, such as taking more medication than you were prescribed, taking pain medication when you're not in pain, mood changes, and taking pain medications that have not been prescribed to you.



Contact a palliative care specialist if you have a history of or are at high risk for substance misuse or addiction. They can help come up with a plan for how to manage your pain while keeping you safe.

Some people stop getting pain relief from pain medications if they take them for a long time. This is called **tolerance** and is not the same thing as addiction. Larger doses or a different drug may be needed if your body stops responding to the same dose. If you are no longer getting relief from your medications, talk with your doctor.

It is important to be aware that many patients feel withdrawal symptoms, such as sweating or abdominal pain, when they stop taking opioid medications. This is normal and typically not a sign of addiction. If you're planning to stop taking all opioids, your doctors may have you taper off the medication slowly to help avoid these symptoms.

Other treatments

Pain can often be controlled with the right combination of medications. However, some people experience too many side effects from their pain medications, or have pain in a certain part of the body that needs to be treated in a different way. For these situations, there are other types of pain management treatments that may help.

Nerve blocks: These are injections of either a local anesthetic or other drug into or around a nerve to block pain. Nerve blocks help control pain that can't be controlled in other ways. Nerve blocks may also be used to find where the pain is coming from, predict how the pain will respond to long-term treatments, and prevent pain after certain procedures.

Neurological treatments: Surgery can be done to implant a device in your body that delivers mild electrical impulses to the brain, spinal cord, or nerves that interrupt pain signals. These devices are used when a person has not responded to other available pain treatments.

Palliative care: This specialized type of medical care aims to help people have the best quality of life possible while dealing with a serious illness. Palliative care providers may also be called supportive care providers. **Many people confuse palliative care with hospice care, but they are not the same thing.** Hospice care is intended specifically as end-of-life care, while palliative medicine focuses on improving the quality of life of people with serious or chronic illnesses, including cancer. Palliative specialists work in teams that include doctors, nurses, mental health specialists, social workers, chaplains, pharmacists, and dietitians.

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



Physical medicine and rehabilitation: Physical therapy or occupational therapy can help some people with pain. You may also be referred to a physiatrist (a doctor who specializes in physical medicine) who can develop a personal plan for you. Physiatrists work with a wide range of conditions that affect the brain, spinal cord, nerves, bones, and connective tissues. Some physiatrists are trained in procedures to treat and manage pain, such as injections, nerve blocks, and ablation procedures. They can also help you learn safe ways to be physically active while reducing the risk of injury, such as fractures that may occur due to weakened bone.

Radiation therapy: Low doses of radiation can sometimes be used to relieve pain from tumors that have spread to other areas of the body. This is called palliative radiation therapy. It may be given as local therapy directly to the tumor or to larger areas of the body. Radiation therapy can help by slightly shrinking the tumor that is causing pain and allowing pain medications to work better.



Integrative medicine

Integrative medicine is a type of medical care that combines conventional medical treatment with complementary and alternative (CAM) therapies that have been shown to be safe and effective.

There are a number of integrative therapies that can be helpful additions to a pain management plan, including those listed below. Talk with your doctors about whether these therapies are safe for you and would be helpful additions to your pain management plan.

- Acupuncture
- Biofeedback
- Cannabis
- Exercise
- Hypnosis
- Massage
- Meditation
- Mental health counseling
- Spiritual counseling
- Yoga

Finding care

If you are currently in treatment or recovering from recent treatment for chordoma, your care team should be talking with you about your pain. They will either create a pain control plan with you or refer you to a pain specialist or palliative care doctor who can.

If you do not live close to the medical center where you are being treated, your pain control plan can be transferred to your primary care provider or a local pain specialist when you go back home. Ask your chordoma team for a referral to a pain specialist in your area.

If you have completed treatment, there are a few options to consider:

- During an in-person follow up visit with your chordoma doctors, **ask for a consultation with a pain or palliative care specialist.** Talk with the specialist about how to find a good pain management doctor at home.
- **Contact the palliative care or pain management department at your nearest cancer center.** They have experience treating the type of pain experienced by cancer patients, even if they haven't worked specifically with chordoma patients.
- Some primary care providers will treat pain, but if the plan a primary provider develops is not controlling your pain, **ask for a referral to a pain specialist who has experience working with people with cancer.**

Be your own advocate

You have the right to be treated for pain.

You may not be pain-free all the time, but a good pain control plan should provide you with substantial relief. If this is not the case, communicate with your doctor to talk about how your plan can be adjusted. Sometimes small changes in dosages or the type of medication can make a big difference. It is also okay to get a second opinion from another pain specialist, if needed. A doctor who is committed to your well-being will continue making changes until you figure out what works best for you.

Locate a provider

To help you find specialists to address the many quality of life needs that may arise following treatment, we created a Survivorship Specialist Directory within Chordoma Connections, our online community. It is a supplement to the Doctor Directory, an invaluable tool on our website for locating surgeons, radiation oncologists, and medical oncologists who have extensive experience treating chordoma.

The Survivorship Specialist Directory allows chordoma community members to share information with one another about providers who have been helpful in addressing quality of life concerns, including pain specialists, palliative medicine providers, physical therapists, and more.



Search the Survivorship Specialist Directory at **chordoma.org/specialists**



Not a member of Connections yet?
Join today at **community.chordoma.org**

For caregivers

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

Safety

- **Watch for new or worsening side effects**, particularly when a new type of medication is started or the dose is changed.
- **Help your loved one keep track** of when it's time to take their medications, if needed.
- **Make sure they have a complete list** of all pain medication they are taking, as well as other types of medication.
- If you are helping your loved one apply pain patches, **learn how to avoid contact with the medication on the patch** as well as how to safely dispose of used patches.
- **Do not crush or dissolve pain pills to make them easier to swallow before checking with the doctor**, even if your loved one is having trouble swallowing pills. The medication may not work the same or it could cause dangerous side effects.



Comfort

- **To help with pain,** try offering cold packs, warm baths, focused pressure, weighted blankets, and gentle massage, all of which can sometimes reduce discomfort.
- **To help with constipation,** provide your loved one with plenty of fluids and fiber-rich foods, and remind them to take laxatives or stool softeners as recommended by their doctor.
- **To keep their mind off the pain,** assist your loved one in doing activities they enjoy and plan visits from friends and family during the time of day when the patient is usually in the least amount of pain.
- **Be patient.** Pain often causes anger, irritability, sadness, and physical limitations. Sometimes the best way to help is to be patient with your patient — listen, understand, and encourage them.

And remember, it's important to take care of yourself, too — make plans to spend time with others, continue with hobbies when you can, and do things you enjoy.



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**.

Important note about this publication

The content herein 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 our educational materials.

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