

TREATMENT INFORMATION SERIES

Clival and Upper Cervical Spine Side Effects

Managing challenges with vision, hearing, speech and swallowing, pain, endocrine function, balance, and sinuses

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**.

About 30 percent of chordomas form within the center of the head in an area called the skull base – usually in a bone called the clivus.

The clivus is next to the brainstem and both carotid arteries, in an area containing nerves that control important functions such as vision, hearing, speech, and swallowing. Clival chordomas can sometimes involve the upper bones of the cervical spine as well. In most cases, surgery is recommended as the first treatment for tumors in these areas, and radiation therapy is generally recommended after surgery to kill any remaining tumor cells.

People with clival (skull base) or upper cervical chordomas who have undergone surgery and/or radiation sometimes experience side effects and quality of life challenges in the months or years following treatment. These include:

- Issues with vision, hearing, speech, and swallowing
- Headaches and facial pain
- Endocrine system imbalances
- Balance impairment
- Chronic sinus issues

These side effects are typically caused by compression of the cranial, C1, or C2 nerves as a tumor grows or nerve damage that occurs as a result of surgery and radiation. They can also be caused by damage to the glands of the endocrine system or to the soft tissues of the sinuses and throat.



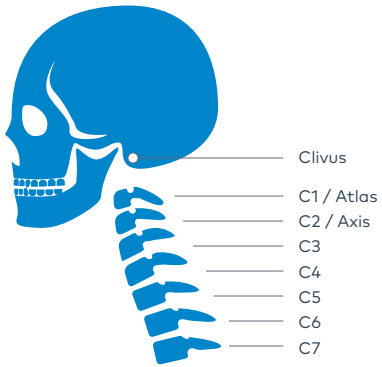
This booklet will help you:

- **Understand the possible side effects** and quality of life issues you may face with a clival or upper cervical tumor
- **Learn about the ways** these side effects are managed
- **Talk with your doctor** about what you're experiencing
- **Find the right treatments** for your particular side effects

Understanding head and neck anatomy

The **clivus** is a bone at the base of the skull. The top two bones of the cervical spine are called the **C1 (Atlas)** and **C2 (Axis)** vertebrae. The Atlas supports the brain. It is the gateway between the skull and spine, protecting and providing a path for the central nervous system to connect the brain to the body. The Axis allows the head to pivot.

All of these bones are part of the **craniovertebral junction (CVJ)**, where the head and neck meet and the brain transitions to the spinal cord.





Cranial nerves

Cranial nerves come in pairs. There are 12 pairs of cranial nerves that emerge directly from the brain and provide motor and sensory functions to the head and neck. The nerves are named for the functions they control and are numbered with roman numerals.

I **The olfactory nerves** are critical for the sense of smell and are some of the few nerves capable of regrowing.

II **The optic nerves** relay messages from the retina of the eye to the brain to create visual images.

III **The oculomotor nerves** help control muscle movements of the eyes, including the constriction of the pupil, and keep the eyelid open.

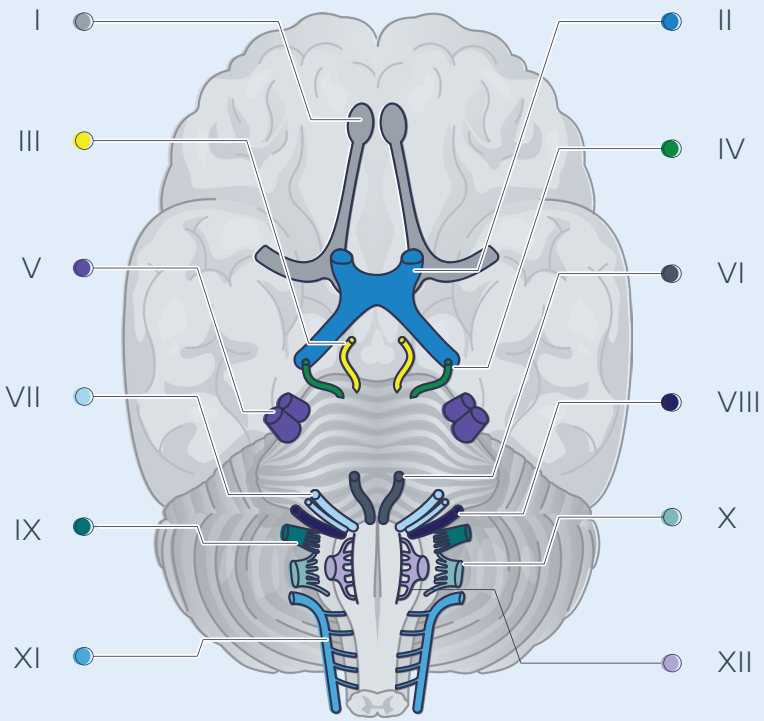
IV **The trochlear nerves** are also involved in eye movement and control the eye muscles that are responsible for rotation, allowing the eye to point downward or inward.

V **The trigeminal nerves** are the largest and most complex cranial nerves. They are responsible for sensation and motor function in the face and mouth, enabling a person to chew or clench their teeth. Each trigeminal nerve splits into three branches, controlling the feeling for different parts of your face:

- The ophthalmic branch → eye, upper eyelid, and forehead
- The maxillary branch → lower eyelid, cheek, nostril, upper lip, and upper gums
- The mandibular branch → jaw, lower lip, lower gum, and some muscles used for chewing

VI **The abducens nerves** control the eye muscles that are responsible for lateral movement, enabling the eye to turn its gaze outward.

Diagram of cranial nerves



I	OLFACTORY	**VII**	FACIAL
II	OPTIC	**VIII**	ACOUSTIC
III	OCULOMOTOR	**IX**	GLOSSOPHARYNGEAL
IV	TROCHLEAR	**X**	VAGUS
V	TRIGEMINAL	**XI**	ACCESSORY
VI	ABDUCENS	**XII**	HYPOGLOSSAL

VII **The facial nerves** have both motor and sensory functions. They control muscles that help you make expressions like raising an eyebrow, smiling, or frowning. They are also responsible for most of the tongue's taste sensations.

VIII **The vestibulocochlear nerves**, also called the **acoustic nerves**, are responsible for hearing and balance.

IX **The glossopharyngeal nerves** provide motor and sensory information to the mouth and throat. Among their many functions, these nerves help raise part of the throat, enabling swallowing.

X **The vagus nerves** are the longest cranial nerves, running from the brain through the face and thorax to the abdomen. They are responsible for many tasks, including heart rate, muscle contractions that move food through the digestive tract (peristalsis), sweating, and muscle movements in the mouth, including speech and keeping the larynx open for breathing.

XI **The spinal accessory nerves** control specific muscles of the shoulders and neck.

XII **The hypoglossal nerves** control the tongue movements of speech, food manipulation, and swallowing.

Upper cervical spine nerves

Like the cranial nerves, spinal nerves also come in pairs. The nerves emerge from the spinal cord and exit through small openings between the vertebrae. There are seven cervical vertebrae, but eight pairs of cervical spine nerves, labeled C1 through C8. They stimulate muscle movement in the neck, shoulders, arms, and hands. The C1 and C2 nerves control the forward, backward, and side-to-side movements of your head and neck.

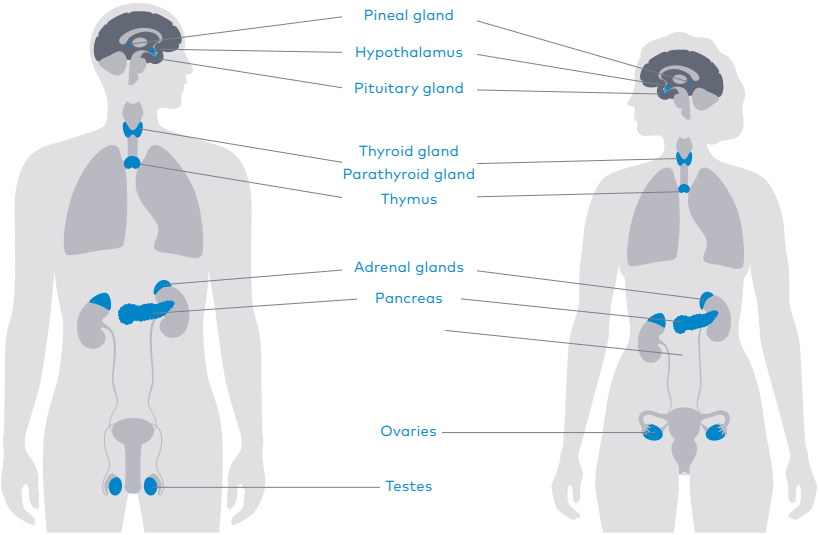


Endocrine system

The glands that make up the endocrine system influence reproduction, metabolism, growth, and many other functions. They are located throughout the body, with many in the head and neck. These include the **hypothalamus**, **pituitary**, **thyroid**, and **parathyroid** glands. Each of these glands is responsible for producing specific hormones.

Hormones are chemicals that act as the body's communication system, coordinating different functions by carrying messages through the blood to organs, skin, muscles, and other tissues. These signals tell your body what to do and when to do it.

- **The hypothalamus** is a gland deep within your brain. It is the main link between your endocrine system and your nervous system. Your hypothalamus keeps your body balanced in a stable state called homeostasis.
- **The pituitary** is divided into two main sections: the anterior pituitary (front lobe) and the posterior pituitary (back lobe). The primary function of the pituitary gland is to produce and release hormones that help carry out important bodily functions, including growth, metabolism, reproduction, and more.
- **The thyroid** releases hormones that control the way your body uses energy. The thyroid's hormones regulate vital bodily functions, including breathing, heart rate, body weight and temperature, muscle strength, cholesterol levels, and more.
- **The parathyroid** produces a hormone that plays a crucial role in regulating calcium levels in the blood. Precise calcium levels are important in the human body as small changes can cause muscle and nerve problems.





Understanding possible side effects of treatment

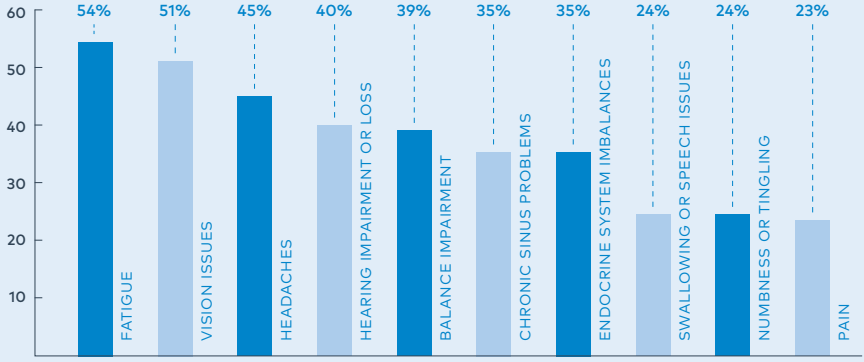
Treatment provided by doctors and teams specializing in chordoma can significantly improve outcomes for individuals with clival and upper cervical chordomas. However, because chordomas are located near vital nerves, organs, and arteries, treatment is often complicated and, in some cases, can lead to serious side effects.

Before you begin treatment, ask your doctors about the risks and what side effects are possible or likely, to ensure you are comfortable with the treatment plan.

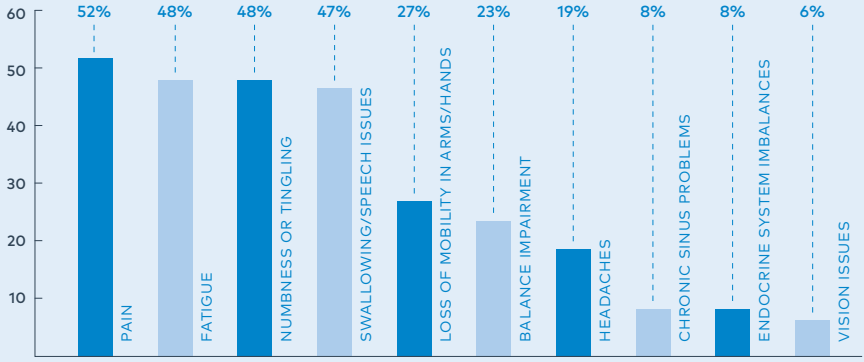
Chordoma Survivorship Survey: Patient-reported side effects

According to the Chordoma Survivorship Survey, these are the most common physical challenges faced by individuals with clival and cervical tumors.

CLIVAL



CERVICAL



See more results from the Chordoma Survivorship Survey at **chordoma.org/survey-results**

Causes of side effects

- **The tumor can compress or damage nerves as it grows.** When nerves are affected by a growing tumor, it may cause pain, numbness or weakness in the arms, headache, double vision, and issues with speech or swallowing. These symptoms may go away or improve after the tumor is removed during surgery as long as there is no lasting damage.
- **Surgery can damage nerves and soft tissues.** Side effects can depend on the way surgery is performed (endonasal, transoral, craniotomy, hardware used to replace bone). Damage to the soft tissues of the nose and throat can cause sinus blockage, extra mucus production, and problems swallowing. Nerves can sometimes be damaged during surgery or removed completely, causing lasting pain and numbness, vision issues, hearing loss, speech and swallowing difficulties, and balance problems. Additionally, having multiple surgeries over time increases the risk of serious side effects.
- **Radiation can cause both short-term and long-term side effects.** These can be mild or severe and will depend on the area being radiated and radiation dose. Short-term side effects of radiation for clival and upper cervical tumors can include altered sense of taste or smell, reduced saliva, sore throat, fatigue, skin burns, and hair loss where the radiation beams enter the body. These usually begin to develop after about 2 weeks of radiation treatments and may continue for 6 to 8 weeks after treatments end. Other side effects like vision or hearing issues may be long-term. Radiation can also cause side effects that develop months or even years after treatment. These are called late effects and can include soft tissue necrosis, vision and hearing loss, and neuropathy.



Managing side effects of treatment

Assessment and treatment will depend on what you're experiencing but **should always begin with a complete and thorough evaluation of your current symptoms and your chordoma treatment history**. To make sure your doctor is prepared for your visit, be sure to have your medical records sent to their office before your appointment.

The sections below discuss side effects often experienced by people with clival and upper cervical tumors and possible treatments.

If you are experiencing any of the issues in this list for the first time or they are suddenly getting worse, let your doctors know. New or worsening symptoms can be a sign of new tumor growth, or they may be late effects of treatment as described above.

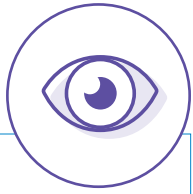
Can palliative care help?

Palliative care is very specialized care meant to help people live their best lives while dealing with a serious illness or disease, including cancer. A palliative care specialist can help you learn about, engage, and coordinate the services of different specialties that may be needed to manage side effects that come with treatment. It is recommended that all chordoma patients and survivors seek the services of a palliative care team from the time of diagnosis through all stages of treatment, recovery, and survivorship.



Read more at
chordoma.org/palliative-care

Vision



TYPES	• Double vision • Strabismus • Blurred vision • Loss of vision • Loss of depth perception
CAUSES	Typically caused by compression of or damage to 2nd-6th cranial nerves from tumor growth, surgery, or radiation.
TESTS	Vision tests – such as a neuro-ophthalmology evaluation – are usually done before chordoma treatment to establish a baseline and should be done again after treatment to compare and track progress.
SPECIALISTS	• Neuro-ophthalmologist • Ophthalmologist

An **ophthalmologist** is a medical doctor who can diagnose and medically or surgically treat eye problems and diseases. A **neuro-ophthalmologist** specializes in vision problems related to nervous system function, making them the ideal type of doctor to help address visual side effects caused by a clival or upper cervical tumor.

NEURO-OPHTHALMOLOGY EXAM

A neuro-ophthalmologic exam is one of the most comprehensive types of medical evaluations. It can take a few hours to complete. Here are some things to know:

- You will need to provide a complete medical history in advance, which may involve asking your chordoma team to share relevant medical records, images, and test results with your ophthalmic specialist.
- During the exam, you will undergo specialized vision tests to measure how clear your vision is (visual acuity), how well you see colors, and the limits to your field of vision.
- You may also receive a neurologic exam to test your eye movements, coordination, and strength.
- MRI, CT, or ultrasound may be performed if you do not have recent images from chordoma checkups.
- Once the exam is complete, your doctor will share your exam results and discuss treatment options.

TREATMENT FOR VISION CHALLENGES

Depending on your specific symptoms, treatment may include:

- **Surgery** to loosen, tighten, or move the eye muscles so that eyes align properly
- **Special exercises** to help strengthen your eye muscles (vision therapy)
- **Prism lens for eyeglasses** that bends light rays to help you see one image instead of two
- **Botox injections** to paralyze eye muscles

Hearing



TYPES	• Hearing loss • Tinnitus (ringing in ears)
CAUSES	Typically caused by damage to or compression of the 8th cranial nerve (acoustic) during tumor growth, surgery, or radiation.
TESTS	Tests that should be done before chordoma treatment include hearing tests such as a physical exam of the ear, an audiogram, a brainstem auditory evoked response (BAER), or imaging. If there is hearing loss after treatment, similar tests should be conducted, and the results should be compared.
SPECIALISTS	• Audiologist • Neurotologist • Otolaryngologist (ENT)

TYPES OF HEARING LOSS

- **Conductive hearing loss** is when something blocks your outer or middle ear, stopping sound from reaching your inner ear.
- **Sensorineural hearing loss** is when something damages your inner ear or the nerve that connects your ear to your brain. It is the type of hearing loss most commonly experienced by chordoma survivors, and it often happens only on the side with the damaged nerve – known as unilateral hearing loss.
- **Mixed hearing loss** is when both conductive and sensorineural loss are present.
- **Tinnitus** is when you experience ringing or other noises in one or both of your ears. There are two main types of tinnitus, subjective (when only you hear the sounds) and objective (when a doctor can hear the sounds you hear).

SYMPTOMS OF HEARING LOSS

Hearing loss that results from chordoma tumor growth or treatment can be immediate or gradual. If caused by radiation, you may not have symptoms until many years later. Symptoms include:

- Ringing in your ears
- Noticing that people's voices sound different or quieter than normal
- Having difficulty hearing because of background noise
- Needing the TV, radio, or other device volume turned up very high
- Avoiding people and activities because of hearing problems
- Feeling lightheaded
- Nausea or vomiting
- Vertigo, which is the feeling that you are spinning or off balance
- Hearing sounds inside your ear sometimes or all the time

TREATMENT FOR HEARING LOSS

Depending on the cause of hearing loss, treatment may include:

- **Medical treatment** such as ear drops, ear wax removal, or surgery
- **Vestibular therapy** for vertigo or dizziness issues
- **Assistive devices** such as hearing aids, implants, or sound generators
- **Counseling techniques** like Acceptance and Commitment Therapy (ACT) or Cognitive Behavioral Therapy (CBT)
- **Lifestyle changes** such as modifications to diet, sleep, or exercise



What about sense of smell?

There are a few clival survivors who lose their sense of smell after treatment. This is called **anosmia** and can be caused by damage to the 1st cranial (olfactory) nerves. When anosmia is caused by nerve damage it may or may not be possible to treat it. An otolaryngologist is the type of doctor who treats anosmia. Lifestyle changes, such as learning new ways to cook, can sometimes help.

Speech and swallowing



TYPES

- Difficulty with speech, or dysarthria
- Difficulty swallowing, or dysphagia

CAUSES

Most often caused by compression or damage to the 9th (glossopharyngeal), 10th (vagus), and/or 12th (hypoglossal) cranial nerves as a result of tumor growth or treatment. Other causes include cervical spine hardware or radiation necrosis that affects the tissues of the esophagus.

TESTS

Besides conducting a physical exam, your doctor might order tests to identify underlying conditions.

For dysarthria:

- Imaging tests
- Brain and nerve studies
- Blood and urine tests
- Neuropsychological tests

For dysphagia:

- Imaging tests
- Dynamic swallowing study
- Visual examination of your esophagus (endoscopy)
- Esophageal muscle test (manometry)

SPECIALISTS

- Speech-language pathologist
- Otolaryngologist (ENT)

SPEECH (DYSARTHRIA)

Weakness or issues controlling the muscles of the tongue, lips, vocal cords, or diaphragm can cause problems with speech. Symptoms include:

- Slow or slurred speech
- Inability to speak louder than a whisper or speaking too loudly
- Nasal, raspy, or strained voice
- Uneven or abnormal speech rhythm
- Monotone speech

SWALLOWING (DYSPHAGIA)

Dysphagia is the subjective sensation of difficulty swallowing. Types of dysphagia are specific to which part of your swallowing action — beginning a swallow (**oropharyngeal dysphagia**) or completing it (**esophageal dysphagia**) — is affected. In both cases, symptoms of dysphagia include:

- Pain while swallowing
- Inability to swallow
- A sensation of food getting stuck in the throat or chest
- Frequent pneumonia
- Drooling
- Hoarseness
- Frequent heartburn
- Weight loss
- Coughing or gagging when swallowing

TREATMENT FOR SPEECH AND SWALLOWING CHALLENGES

Whether you have difficulty with speech, swallowing, or both, the following treatments may help:

- **Rehabilitation therapy** provided by a Speech Language Pathologist (SLP)
- **Exercises** or techniques to help improve speaking and swallowing
- **Prescription or oral medications** to reduce stomach acid
- **Lifestyle changes** such as modifying your diet to include softer foods
- **Surgery or feeding tubes**, in the case of severe swallowing issues



Headaches, facial paralysis, and pain



TYPES	• Headaches • Facial paralysis, tingling, and numbness • Trigeminal neuralgia
CAUSES	Tumor growth and swelling from surgery can cause headaches and pain. Facial paralysis, tingling, and numbness are typically caused by damage to the 7th (facial) cranial nerves. Facial pain can be caused by damage to the 5th (trigeminal) or 7th (facial) cranial nerves.
TESTS	Doctors will carefully consider your symptoms and your medical history, do a physical examination, and complete special investigations, if needed. Trigeminal neuralgia is diagnosed by excluding other conditions that might be causing the symptoms.
SPECIALISTS	• Neurologist • Otolaryngologist (ENT) • Pain specialist • Primary care physician

HEADACHES AND FACIAL PARALYSIS

Headaches are common when clival tumors are growing and begin to cause symptoms. Following surgery, headaches may continue while your body recovers. Nerve damage can cause pain, tingling, and numbness in your scalp, face, or neck. It can also affect your ability to move some of the muscles in your face, causing facial paralysis. These symptoms may resolve after treatment, or they may continue for months or years. They may also worsen over time if caused by radiation.

TRIGEMINAL NEURALGIA

Trigeminal neuralgia (TN) has been described as the most excruciating type of pain. It most often occurs on one side of the face only, typically in the lower face and jaw but can sometimes be felt around the nose and eye. If left untreated, trigeminal neuralgia can progressively worsen.

The pain from TN is separated into two types, TN1 and TN2, due to different types of symptoms. People can experience both types at the same time.

TN1

- Intense, stabbing, electric shock-like pain
- Sudden attacks of pain, sometimes due to a trigger but can happen randomly
- Attacks last for few seconds up to a few minutes, and then stop for a period of time

TN2

- Less intense pain, but a constant, dull ache or burning sensation
- Sudden upticks in pain level are also possible



TREATMENT FOR HEADACHES, FACIAL PARALYSIS, AND PAIN

- For headaches and other pain, **pain medication, nerve pain medication, or nerve blocks**
- For facial paralysis, **botox injections, specialized physical therapy, or nerve transfer techniques**
- For TN, **medications** such as carbamazepine are sometimes used. **Lifestyle changes** such as avoiding or reducing exposure to things that trigger TN attacks can also help.

Learn more about managing pain at **chordoma.org/pain-management**

Endocrine function



TYPES

- Adrenal insufficiency
- Growth hormone deficiency
- Hyperprolactinemia
- Hyperthyroidism
- Hypothyroidism
- Diabetes insipidus
- Low estrogen/testosterone

CAUSES

Most often caused by radiation-induced damage to the organs of the endocrine system located in the head and neck. 30-50% of patients with tumors in the skull base will develop hormone deficiencies after radiation.

TESTS

Your doctor should evaluate you using blood tests at the time of diagnosis to determine if there are any existing hormone imbalances. If there are, treatment will likely be recommended to bring them under control before surgery or therapy.

Testing should be done again about 6 weeks after surgery — before you start radiation — and every 6 months to a year after that, indefinitely.

SPECIALISTS

- Endocrinologist
- Neuro-endocrinologist

When an endocrine gland isn't functioning properly, it can't produce hormones the way it should. The glands in the system are all connected, so if one gland in the head or neck isn't producing hormones normally, it can affect the function of glands in other parts of the body.

An **endocrinologist** is a medical doctor who can diagnose and treat hormone imbalances. Some endocrinologists focus specifically on the interaction between the nervous system and the endocrine system. These doctors are sometimes referred to as **neuro-endocrinologists**. They are very well suited to treat hormone imbalances in chordoma survivors, but all endocrinologists can provide this treatment.

SYMPTOMS OF HORMONE IMBALANCES

Symptoms can appear soon after radiation treatment but are more likely to start a few years later, which is why it's very important to undergo regular testing of your hormone levels. Symptoms depend on which hormones aren't being produced and can include:

- Fatigue
- Loss of appetite
- Nausea/vomiting/diarrhea
- Weight loss
- Low libido
- Loss of bone density
- Loss of muscle mass

TREATMENT FOR HORMONE IMBALANCES

Medication or a combination of medications to help balance hormone levels is the main treatment for endocrine issues. Some medications you may be taking for other reasons can mimic hormone deficiencies, so be sure to **keep careful track of all your medications and provide them to your neuro-endocrinologist**.



Learn more about the endocrine system and fatigue at **chordoma.org/fatigue**



Are replacement hormones safe? Will they make my tumor grow?

These are common questions asked by chordoma survivors. Adrenal and pituitary deficiencies can be life-threatening so these should always be treated. Thyroid imbalances can also safely be treated. However, there isn't enough evidence to know for sure whether replacement growth hormone or sex hormones (estrogen, testosterone, etc.) will affect chordoma growth. Determining whether to treat these deficiencies should be done in careful consultation with both your chordoma team and a neuro-endocrinologist, taking risks and quality of life into consideration.

Balance



TYPES	• Balance impairment • Vertigo or dizziness • Loss of mobility
CAUSES	Often caused by a number of the challenges addressed above, such as double vision, vision loss, vertigo, or dizziness. Balance issues can also be caused by medications or deconditioning (loss of physical fitness).
TESTS	You should be assessed for any balance and mobility issues at the beginning of your treatment and at regular intervals during and after treatment with tests such as: • Balance and proprioception evaluation • Posturography • Vision tests • Nerve conduction studies and sensory tests • Laboratory tests • Imaging tests
SPECIALISTS	• Physiatrist • Physical therapist • Occupational therapist • Vestibular rehabilitation therapist

TREATMENT FOR BALANCE CHALLENGES

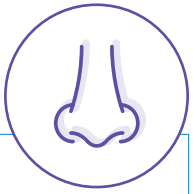
Treatment should address the cause of your specific balance issues, and can include:

- **Physical medicine and rehabilitation (PM&R)**, also called physiatry, to improve physical functioning
- **Vision therapy or correction** if vision issues are affecting balance
- **Vestibular therapy** if dizziness or vertigo are causing you to be unsteady
- **Behavioral counseling** to help cope with feelings of distress
- **Integrative therapies** such as acupuncture, yoga, tai chi, and qigong
- **Appropriate footwear and assistive devices**, such as a cane or walker, when surfaces are uneven
- **Small adjustments within your home** to remove tripping hazards and keep commonly used items (such as remote controls and toiletries) within reach to minimize bending over



Learn more about improving balance and mobility at **chordoma.org/balance**

Sinuses



TYPES	• Mucus buildup • Crusting or dripping • Bleeding from nose • Irritation or infection (characterized by redness, tenderness, heat, or puss)
CAUSES	Surgery through the nose (endonasal or transsphenoidal) or the mouth (transoral) can require soft tissue reconstruction and/or create scar tissue. This can lead to abnormal mucus production and irritation.
TESTS	Your doctors will examine your nasal passages, sinuses, and throat both before and after surgery.
SPECIALISTS	• Otolaryngologist (ENT)

TREATMENT FOR SINUS PROBLEMS

- Regular **saline rinses** with a nasal irrigation device such as a neti pot
- Use **dehumidifiers** in your home if dryness is an issue
- **Debridement** (removal) of more severe mucus crusts or infected tissue by an otolaryngologist (ENT)

Finding care

Depending on the particular side effects you are experiencing, you may need to speak with more than one specialist to address them. Your care team may include rehabilitation therapists, neuro-endocrinologists, otolaryngologists, neuro-ophthalmologists, and others.

It is sometimes possible to schedule visits with specialists at the center where you were treated for chordoma. For instance, if you see your chordoma team in-person for follow-up visits, ask for referrals to other specialists in the medical center and make appointments to see the specialists while you are there for follow-up. You can then ask the specialist to consult with a specialist local to you so they can plan and follow your treatment together.

If you can't be seen by a specialist at the center where you were treated, ask your chordoma care team for referrals in your local area. Some chordoma doctors will do consultations with local specialists, even if you haven't seen them in person.

Seek out specialists at your nearest academic medical center. These specialists will likely not have experience with chordoma, and that's okay. You and your chordoma care team can help educate them on chordoma and your experiences with it.

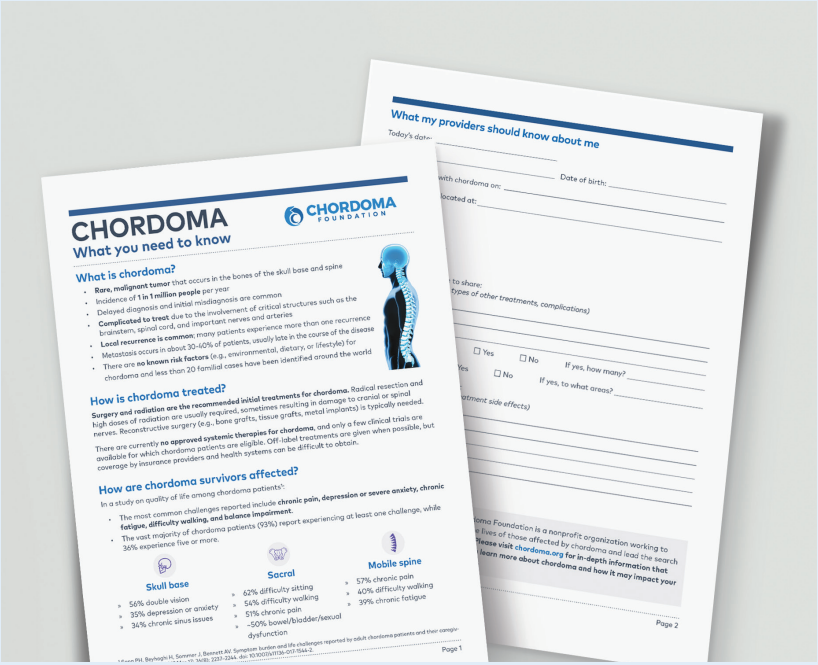


Locate a provider

To help you find specialists to address the side effects of treatment, we created a **Survivorship Specialist Directory** within Chordoma Connections, our online community. It is a supplement to our **Doctor Directory**, an invaluable tool on our website you can use to locate surgeons, radiation oncologists, and medical oncologists who have extensive experience treating chordoma.

The Survivorship Specialist Directory allows chordoma community members to share information about providers who have helped address quality of life concerns, including pain specialists, neuro-ophthalmologists, rehabilitation therapists, and more.

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



Educating providers on chordoma

Many care providers who can help you manage side effects 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, nurses, 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 situation so your providers can understand how chordoma has affected you personally. **Share this fact sheet with your providers to help them learn about chordoma.**

Find the fact sheet at
chordoma.org/fact-sheet

For caregivers

If you are caring for someone with clival or upper cervical chordoma who is experiencing side effects, there are a number of things to keep in mind and ways you can support them. Remember that if they are dealing with more than one type of side effect, they may require the care of multiple types of doctors and specialists. It can be a lot to keep track of. Things you can do include:

- **Help schedule and manage doctor's visits**, writing down a list of questions to ask at each appointment beforehand.
- **Find a good cadence of checkups with different doctors and specialists**, making sure the number and timing of appointments is manageable and that information is being shared across the care team, such as care instructions and medication lists.
- **Watch for worsening side effects**, particularly after changes in your loved one's care plan or periods of higher stress.
- **Consider adjusting your living environment to accommodate your loved one's side effects.** This could mean lowering or raising the volume on TVs or stereos, preparing food a certain way, or removing items that may be tripping hazards.
- **Get support for yourself as well.** Seeing your loved one experience ongoing challenges can be emotionally and psychologically taxing, and having someone to talk to can make a big difference.



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 side effects
- 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 through our online community, Peer Connect program, and virtual support groups



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

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.



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