

TREATMENT INFORMATION SERIES

Improving Balance and Mobility

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**.



Mobility — that is, the ability to move freely and easily in one's environment — can be affected by chordoma tumors and their treatments.

Chordoma patients and survivors with tumors at any location along their spine report experiencing issues that impact their mobility, including balance deficits; loss of function in their arms, hands, legs, and feet; decreased ability to walk; numbness; bone fractures; and even some types of vision issues.[1]

If your mobility has been affected by chordoma, there are ways to address and manage the issues you're experiencing. Work with your care team, including the doctors and nurses treating your chordoma, a palliative care specialist, or your primary care doctor to create a plan for managing it. Getting the right care can improve your physical functioning, decrease the length of your hospital stays, reduce your risk of injury due to falls, and improve your overall quality of life. When seeking treatment for mobility issues, it is important to:

- **Understand the possible causes** of the problems you're experiencing
- Be prepared to **talk with your doctors** about them
- Learn about the **ways mobility challenges are managed**
- Know how to **find a team** that can help



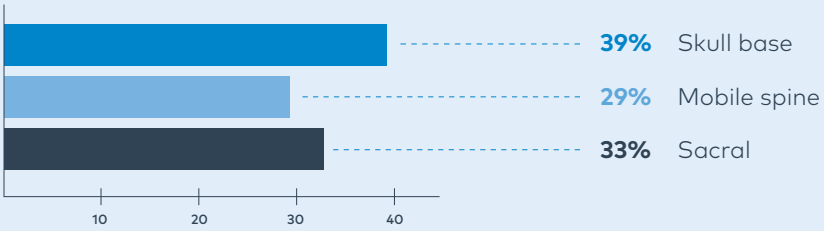
Understanding balance and mobility

Many nerves, muscles, and systems in the body allow us to keep our balance and move around freely. Four systems have an outsized impact on balance and mobility and can be affected by chordoma treatment.

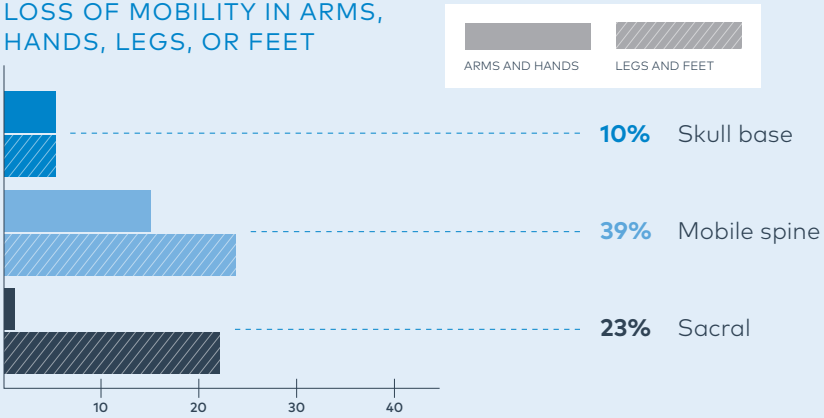
- **Central nervous system:** your brain and spinal cord, including the area of the brain called the cerebellum, located at the base of the skull and controlling functions of movement, balance, mobility, and posture
- **Peripheral nervous system:** the network of nerves that runs throughout your body and sends signals from the brain and spinal cord to all other parts of the body
- **Vestibular system:** an area of the inner ear that affects balance by sending and interpreting signals from the environment to keep you upright when you move
- **Musculoskeletal system:** the bones, muscles, tendons, and ligaments that support your body's weight and help you move

The Chordoma Survivorship Survey, completed in 2021, found that chordoma patients and survivors often experience balance or mobility issues during and after treatment.

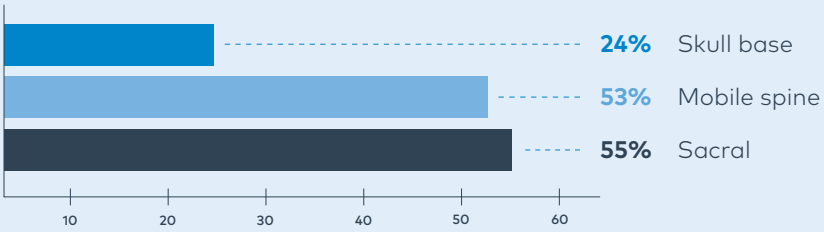
BALANCE IMPAIRMENT



LOSS OF MOBILITY IN ARMS, HANDS, LEGS, OR FEET



NUMBNESS AND TINGLING



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

Types of mobility challenges

The types of mobility issues chordoma patients experience are most often the result of damage to nerves, muscles, and bone. They can manifest in several ways, including, but not limited to:

- Weakness or loss of strength in limbs
- Tingling, numbness, or loss of function in arms, hands, legs, and feet
- Impaired balance or gait
- Muscle pain, stiffness, or spasticity
- Frequent falls
- Pain from bone fractures
- Vertigo (the sensation that you, or the environment around you, is spinning)
- Tinnitus (ringing in ears that can cause vertigo)
- Dizziness

You may find that these are short-term challenges you experience as you undergo or recover from treatment. Or they may become longer-term quality of life issues that you must adapt to and manage over time. They can be caused by the tumor itself as it grows or by treatments you receive.

If any of the symptoms in this list are sudden onset and/or severe, check with your doctors right away.



Causes of mobility challenges

NERVE DAMAGE (NEUROPATHY)

During surgery, cranial and spinal nerves may be damaged or cut to remove your tumor. These nerves can also be damaged by radiation or by the growth of your tumor before treatment. The symptoms you experience depend on which nerves are affected. Neuropathy can also affect proprioception, a continuous loop of feedback between sensory receptors throughout your body and your nervous system. Proprioception allows the body to sense its location in space, movements, and actions. It is sometimes called the "sixth sense."

Some chemotherapy drugs can damage your nerves, especially in high doses. These include cisplatin, vincristine, and etoposide. These chemotherapies are not regularly used to treat chordoma, but in some cases they can be. If you have been or will be treated with any of these drugs, talk with your doctor about your risk of peripheral neuropathy. This is especially important for people who have conditions that may put them at greater risk for developing neuropathy, such as diabetes or a personal or family history of neuropathy.

MEDICATIONS

Some medications may affect the nervous system and, by extension, mobility and balance. These include steroids, which can cause weakness in major muscles, especially if used long-term, and opioid pain relievers. Another common side effect of these medications is dizziness.

DECONDITIONING

Deconditioning — the loss of physical fitness due to decreased levels of physical activity — can be caused by cancer treatments and have both short-term and long-term implications for balance and mobility. Depending on the length and extent of inactivity, individuals may experience weakness in muscles and joints as well as decreased function in the circulatory (blood) and respiratory (breathing) systems.

What is neuropathy?

Neuropathy is a condition that results from damage to, or dysfunction of, the peripheral nervous system. It is a leading cause of chronic pain.

The symptoms of neuropathy depend on which nerves have been affected and on the severity of damage. The symptoms you experience may differ from day to day or month to month.

Possible impacts of neuropathy in cranial and spinal nerves:



WEAKNESS, TINGLING, BURNING, OR NUMBNESS

CHRONIC PAIN

BALANCE IMPAIRMENTS

VERTIGO AND DIZZINESS

Assessing balance and mobility challenges

You should be assessed for any balance and mobility issues at the beginning of your treatment and at regular intervals during and after treatment.

- **If you have recently been diagnosed with chordoma**, you will undergo various tests and exams as you prepare for treatment. Some of these tests will be used to establish a baseline measurement of your symptoms which can be revisited periodically to determine whether any of the issues you experience improve or worsen after treatment. These tests will also help your doctor tailor a treatment plan to your needs and measure progress to see if the treatments are working.
- **If you have just had surgery or radiation** and are experiencing mobility issues, your chordoma care team can refer you to specialists who can help. These may include a doctor of physical medicine and rehabilitation (PM&R), occupational therapists, physical therapists, or balance therapists. Many chordoma patients work with these rehabilitation specialists as part of their recovery from surgery, often before being released from the hospital.
- **If you have completed treatment or are in ongoing treatment with systemic therapies** and continue to experience mobility issues, make sure your providers are aware so they can help you develop a long-term mobility plan.



Talking with your doctor

No matter where you are in your chordoma journey, if you experience balance or mobility issues, talk with your healthcare team — the doctors and nurses treating your chordoma as well as your primary care doctor — about your symptoms.

Working with your providers to build a personalized plan for improving your balance, strength, and mobility is the best way to cope with any challenges that may arise. Be prepared to describe your symptoms in the most detailed way possible. **The more specific you can be, and the more examples you can provide, the more effective your plan will be.**



Tests to expect

PHYSICAL AND NEUROLOGICAL EXAMS

Your doctor may conduct a variety of tests to help determine the underlying factors of your mobility issues. These will depend on your symptoms and can include some or all of the following:

- **Balance and proprioception evaluation tests** determine your body's ability to sense its location, movements, and actions. These are similar to sobriety tests and may involve closing your eyes, standing on one foot, standing on your toes, walking, stepping over something, or moving from sitting to standing.
- **Posturography** determines which parts of your balance system you rely on most. This involves wearing a safety harness while trying to remain standing on a moving platform.
- **Vision tests** assess your eye movements, which play a role in function and balance.
- **Nerve conduction studies and quantitative sensory tests** further examine peripheral nerve function and determine the extent of neuropathy.
- **Laboratory tests** look for metabolic disturbances and nutritional deficiencies.
- **Imaging tests** look for other possible causes of nerve damage.

ANSWERING QUESTIONS OR COMPLETING A QUESTIONNAIRE

Your doctor will ask questions about your symptoms and any triggers or relieving factors throughout the day. This may take place conversationally at an appointment or through a written questionnaire. Be prepared to discuss how your balance and mobility issues affect your work environment, social habits, and daily personal tasks. You may also be asked about your exposure to toxins, alcohol use, risk of infectious diseases, and family history of neurological diseases.

Managing balance and mobility challenges

The right management strategy depends on the cause of your balance and mobility issues, whether your chordoma treatment is complete or ongoing, and your specific challenges.

If what you're experiencing is caused by the tumor itself, the symptoms may improve or go away after treatment. Rehabilitation is an important part of recovery after surgery, and plays a critical role in regaining lost functions. If you are currently planning for surgery, talk with your surgeons about what your recovery and rehabilitation plan will include.

If the damage to nerves is long-lasting or permanent, it is important to find ways to cope with and manage the challenges you experience. Treatment programs should be individualized to your needs, and will likely include different approaches, such as the ones listed below.

Physical Medicine and Rehabilitation (PM&R), also called physiatry, employs a wide variety of methods and works with different specialties to improve physical function, including:

- **Physical Therapy (PT)** can teach you movement and balance exercises that help you cope with nerve problems and improve function.
- **Occupational Therapy (OT)** can help you readjust to daily life and work activities.
- **Exercise programs** can be done at home and include activities you enjoy, such as a stationary bike, walking, swimming, stretching, yoga, tai chi, or qigong. Talk to your doctor before you start an exercise program as stress tests may be needed to evaluate your cardiovascular function before beginning a fitness plan.

- **Vestibular Rehabilitation Therapy (VRT)** involves an exercise-based program designed by a specially-trained physical therapist. The program aims to improve balance and reduce problems related to dizziness. Exercises can include posture training, balance retraining, neck mobility/stretching, vision exercises, and ergonomic training.

Medicines can help relieve pain and tingling sensations that may hinder your mobility.

- **Patches or creams of numbing medicine** can be put right on the painful area (for example, lidocaine patches or capsaicin cream).
- **Anti-seizure medicines** can be used to help alleviate different types of nerve pain.



What is prehabilitation?

Cancer rehabilitation specialists can also work with patients **before they have surgery** to improve their overall health and wellbeing. This is sometimes called "prehabilitation" and the goal is to prepare your body and mind for the upcoming stress of the surgery. This can help minimize the risk of complications and side effects following surgery, reduce the length of your hospital stay, and speed your recovery. If you have an upcoming surgery, talk with your surgeon about whether prehabilitation would be helpful.

Behavioral counseling can help you cope with feelings of distress brought on by a decreased ability to move around freely.

- **Cognitive Behavioral Therapy (CBT)** is one type of counseling that can help you manage your feelings by challenging negative thoughts and replacing them with more helpful ones.

Integrative therapies are used along with traditional treatments to help enhance your well-being.

- **Acupuncture** is believed to stimulate the central nervous system. This, in turn, releases chemicals into the muscles, spinal cord, and brain that may support the body's natural healing abilities.
- **Yoga, tai chi, and qigong** are therapeutic activities that can complement medical treatment to help improve physical functioning and quality of life.

Reconstructive neurosurgery

New and evolving surgical procedures may provide an opportunity to restore function to some chordoma patients. Reconstructive neurosurgeons are starting to use procedures such as nerve transfer, muscle and tendon transfer, tendon lengthening or release, and muscle transplants to help people with limited mobility regain function.

Previously reserved for patients experiencing peripheral nerve paralysis, some neurosurgeons are now applying these interventions to individuals with damage to the central nervous system that result in similar mobility deficits. **This type of surgery may be an option for mobile spine patients experiencing functional loss and muscle spasticity.**

While the sophistication and availability of these reconstructive strategies is still maturing, it is possible that in the future they may be able to help chordoma patients with loss of bowel, bladder, and sexual function.

Tips from Physical Medicine & Rehabilitation experts

PM&R doctors specialize in the prevention, diagnosis, and treatment of nerve, muscle, and bone disorders that can change how people move and function. They can work with you both before and after treatment to help you regain strength and increase mobility.



HOW TO PREVENT FALLS

Wear appropriate footwear and use a walking aid, such as a cane or walker, when surfaces are uneven. Within your home, make small adjustments to remove tripping hazards and keep commonly used items (such as remote controls and toiletries) within reach. And make sure you're getting proper nutrition — your body will be weaker without enough calories and hydration, which can increase your risk of falling.



HOW TO AVOID INACTIVITY

Slowly increase your level of activity by doing light exercises that you enjoy at regular intervals. Track your progress to assess whether those exercises become easier or harder over time.



HOW TO ESTABLISH NEW ROUTINES

Return to normal daily activities as much as possible as soon as possible, even if you cannot do them the same way you did before. This includes showering, cleaning, and household chores. Take things slowly and rest when you need to, but don't give up! The more you move, the faster and easier your recovery will be.

Finding care

Managing the balance and mobility issues that accompany chordoma may require a team of doctors and specialists. Start by talking with your chordoma team and requesting referrals to specialists. Even if your chordoma care team is not in your local area, they may still be able to help you find and contact local providers who can address your specific needs.

PM&R or palliative care are also good places to seek guidance. Doctors who specialize in these areas can perform initial assessments and act as a coordinator to gather a team of supporting specialists — such as dieticians and acupuncturists — to work with you on your mobility plan.



Palliative care experts can help assess and address mobility and functional issues, as well as fatigue, pain, mental and emotional health, nutrition, and many other concerns to help you feel well and live fully while managing your chordoma. They make a valuable addition to your care team.

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

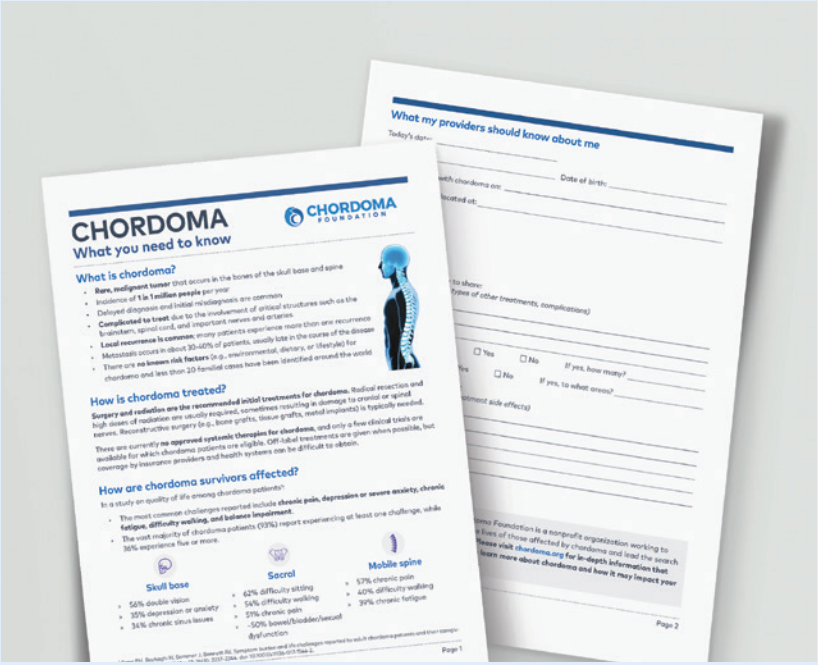


Locate a provider

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 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 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**



Educating providers on chordoma

Many of the care providers who can help you deal with balance and mobility issues 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 chordoma who is experiencing balance and mobility issues, there are several things to keep in mind and ways you can support them.

- Keep rooms, hallways, and stairways well lit
- Remove things that your loved one could slip or trip on, such as loose rugs or clutter
- Help your loved one find the best clothes and shoes for staying safe and comfortable
- Join your loved one in their exercise and mobility routine
- Help with household tasks that could trigger balance issues, such as laundry or cleaning
- Be patient with your loved one — mobility issues can last months or years after treatment and may come and go





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



Contact a Patient Navigator 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 September 27, 2021.

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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