

TREATMENT INFORMATION SERIES

Mobile Spine and Sacral Side Effects

Managing challenges with swallowing, mobility, pain, bladder, bowel and sexual function

CHORDOMA FOUNDATION

Table of contents

Understanding the mobile spine and sacrum 4

Mobile spine and sacral nerves

Understanding possible side effects of treatment 7

Causes of side effects

Managing side effects 10

Speech and swallowing

Balance and mobility

Pain, tingling, and numbness

Bone fractures

Bladder, bowel, and sexual function

Finding care 30

For caregivers 33

How we can help 35

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 20 percent of chordomas form along the spinal column at the neck, chest, or lower back level. These three areas are known as the mobile spine. About 50 percent of chordomas form at the bottom of the spine, in bones called the sacrum.

People with mobile spine and sacral 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 speaking and swallowing
- Limited mobility
- Pain and numbness
- Bone fractures
- Loss of bladder, bowel, and/or sexual function

These challenges are typically caused by compression of the spinal nerves or spinal cord as a tumor grows, nerve damage that occurs as a result of surgery or radiation, or damage to soft tissues around the spine.

This booklet will help you:

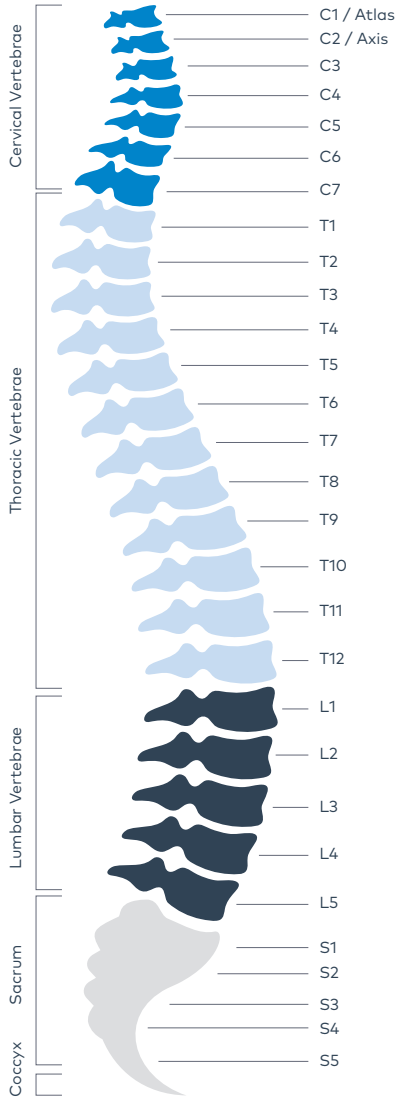
- **Understand the possible side effects** and quality of life issues you may face with a mobile spine or sacral tumor
- **Learn about the ways** these side effects are managed
- **Talk with your doctor** about what you're experiencing
- **Find the right treatments** for your particular side effects

Understanding the mobile spine and sacrum

The **mobile spine** has three sections: cervical (neck), thoracic (chest), and lumbar (lower back). The bones, or vertebrae, of the spine are the building blocks of the back and spinal column. The vertebrae and other parts of the spinal column protect the spinal cord, support head and body weight, and help the back move flexibly.

The number of vertebrae in each section of the spine varies. The **cervical spine** is made up of bones named C1-C7, the **thoracic spine** is T1-T12, and the **lumbar spine** is L1-L5.

The **sacrum** is at the very bottom of the spine and has five bones, S1-S5. These bones fuse together into one larger bone mass by 30 years of age but are still referred to as separate bones. At the very bottom of the sacrum is the **coccyx**, which is made up of three to five fused bones. Some sacral tumors involve the coccyx.





Mobile spine and sacral nerves

Spinal nerves come in pairs. They emerge from either side of the spinal cord and exit through small openings between the vertebrae. Each pair connects the brain and spinal cord with a specific region of the body. The bundle of nerves at the end of the spinal cord is known as the **cauda equina**, because it looks like a horse's tail.

There are **31 pairs of spinal nerves** which are responsible for sensation, movement, and function in various parts of the body:

- **8 cervical nerve pairs (C1-C8)** → head, tongue, vocal cords, neck, shoulder, and arms
- **12 thoracic nerve pairs (T1-T12)** → esophagus, trachea, hands, wrists, and fingers as well as organs like the lungs, heart, and kidneys
- **5 lumbar nerve pairs (L1-L5)** → large intestine, upper and lower legs, ankles, and feet
- **5 sacral nerve pairs (S1-S5) and 1 nerve pair at the coccyx** → bladder, pelvic floor, rectum, anus, and genitalia

The spinal nerves are an important part of the peripheral nervous system (PNS). They transmit information to and from the brain and spinal cord — known as the central nervous system (CNS) — providing sensation and stimulation to the body and helping to regulate and control the functions of the trunk, internal organs, and lower limbs. If you think of the CNS as the main highway, the PNS would be the smaller connecting roads, bringing signals in and out of the CNS.

Nerve damage or injury can interfere with the ability to transfer information from one system to another, causing neurological problems such as pain, weakness, abnormal sensations, changes in spinal reflexes, and loss of organ function.

What is a nerve root?

The part of a spinal nerve where it first branches off from the spinal cord or cauda equina is called the **nerve root**. You might hear your doctors refer to this as the nerve root or they may use the terms nerve root and spinal nerve interchangeably.



Understanding possible side effects of treatment

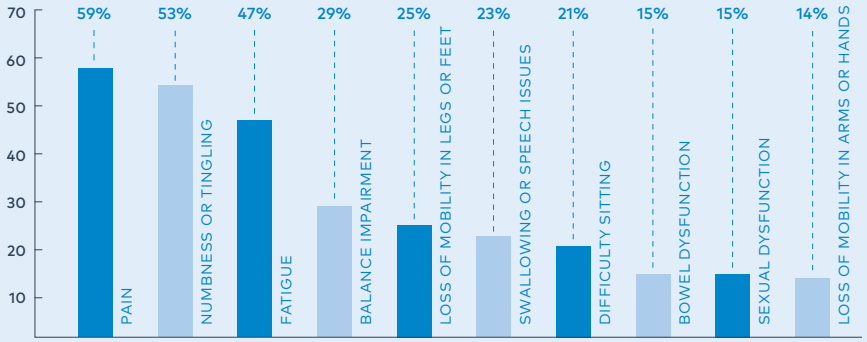
Treatment provided by doctors and teams specializing in chordoma can significantly improve outcomes for those with mobile spine and sacral chordomas. However, because chordomas are located near vital nerves, organs, and arteries, treatment is often complicated and, in some cases, can lead to serious 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.

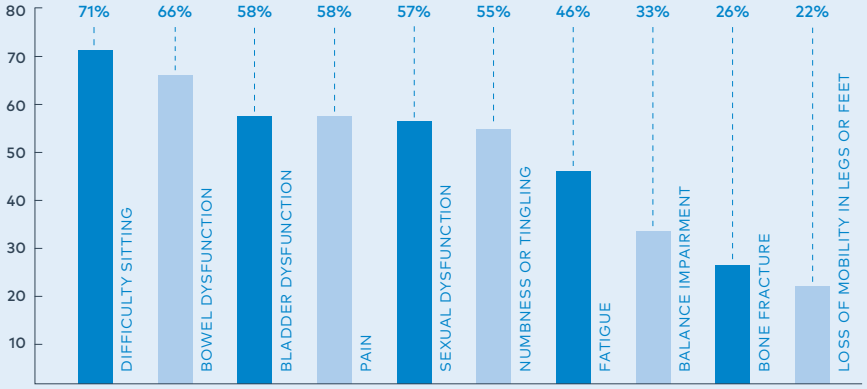
Chordoma Survivorship Survey: Patient-reported side effects

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

MOBILE SPINE



SACRAL



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

Causes of side effects

- **The tumor itself can compress nerves as it grows.** When nerves are affected by a growing tumor, it may cause pain, numbness, or weakness in the arms, hands, legs, or feet; or bladder and bowel issues such as incontinence or constipation. 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.** Nerves can sometimes be damaged during surgery or must be removed completely along with the tumor. Side effects will depend on which nerves are affected. Surgical flaps, scarring, and metal hardware used for reconstruction may also damage soft tissues or cause side effects such as limited mobility and range of motion in the spine. 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 mobile spine and sacral tumors can include fatigue and skin irritation or burns. These usually begin to develop after about 2 weeks of radiation treatments and may continue for 6 to 8 weeks after treatments end. 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, neuropathy, or bladder, bowel, and sexual dysfunction.

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 mobile spine and sacral survivors as well as 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

Speech and swallowing



TYPES

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

CAUSES

Can be caused by compression or damage to the C1-C8 nerves as a result of tumor growth or treatment. It may also be caused by 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

- Otolaryngologist
- Speech-language pathologist

SPEECH (DYSARTHRIA)

Inability to control the muscles of the face, mouth, tongue, or throat can cause difficulty speaking. Symptoms include:

- Slow or slurred speech
- Inability to speak louder than a whisper
- 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 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

Balance and mobility



TYPES

- Balance impairment
- Numbness or loss of strength in arms, hands, legs, feet
- Loss of overall physical fitness

CAUSES

Most often these issues are the result of damage to nerves, muscles, and bone which can sometimes 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
- Nerve conduction studies and quantitative sensory tests
- Laboratory tests
- Imaging tests

SPECIALISTS

- Physiatrist
- Physical therapist
- Occupational therapist
- Vestibular rehabilitation therapist

TREATMENT FOR BALANCE AND MOBILITY 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
- **Medicines** to help relieve pain and tingling sensations
- **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**

Pain, tingling, and numbness



TYPES	• Neuropathic pain • Nociceptive pain
CAUSES	Usually caused by nerve and tissue damage from either the tumor itself or its treatment.
TESTS	Your doctor will ask you questions about your pain, review your medical history, conduct a thorough physical exam, and do a few neurological tests to fully understand how pain is affecting you and decide how to treat it.
SPECIALISTS	• Pain and palliative care specialists • Physiatrists

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.

TYPES OF PAIN

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

TREATMENT FOR PAIN

Treatments can include over the counter or prescription **medications**. Neuropathic pain can sometimes be treated with certain types of antidepressants and anti-seizure medications. Other treatments include **nerve blocks, electrical nerve stimulation devices, palliative care, physical medicine and rehabilitation techniques, or low-dose radiation.**

Integrative medicine strategies like acupuncture, massage, mental health counseling, meditation, and yoga can also be part of a comprehensive pain management plan.

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

Bone fractures

TYPES	• Insufficiency fractures
CAUSES	Usually caused by radiation, which can reduce the collagen and calcium in bone cells, making them weak and brittle.
TESTS	Bone fractures tend to occur more commonly in women and are often underdiagnosed. Imaging tests like PET/CT scans, bone scans, and MRI are used to determine bone strength and differentiate fractures from tumor lesions.
SPECIALISTS	• Bone endocrinologist • Interventional radiologist • Neuroradiologist • Pain or palliative care specialist



Insufficiency fractures occur when normal pressure is applied to weakened bones that are too fragile to support someone's weight when they perform daily activities like standing or walking, causing them to fracture. While they can sometimes be asymptomatic, these fractures usually cause a great deal of pain.

Insufficiency fractures are different from fractures caused by accident or injury and are often the result of damage to osteoblast cells in the bones caused by radiation. This damage is called **osteopenia**. Osteopenia typically occurs in the bones that are located in the area where radiation was given. For chordoma patients this can be any of the vertebrae, as well as the ribs (thoracic patients) and pelvis (sacral patients).

TREATMENT FOR BONE FRACTURES

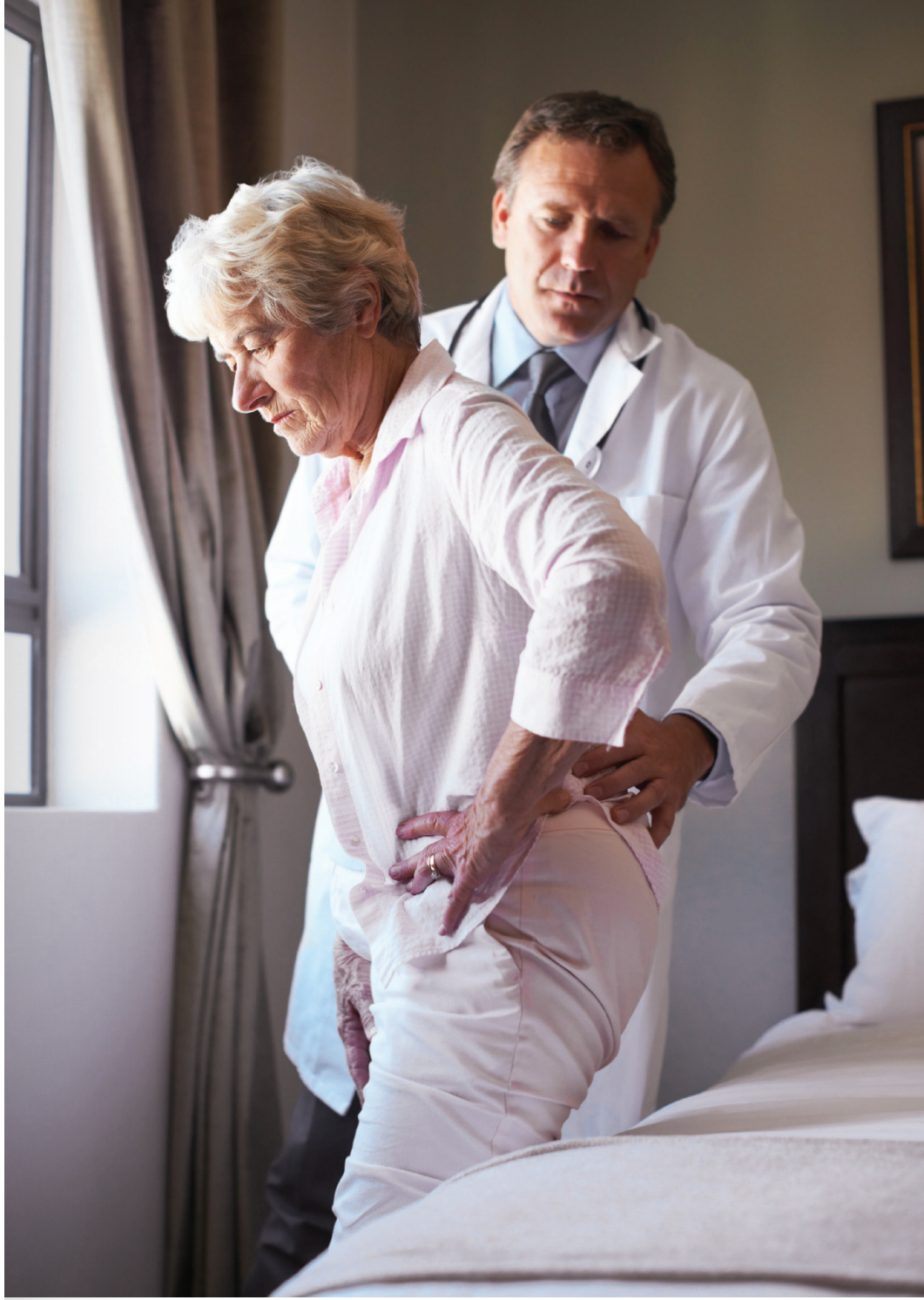
Insufficiency fractures can sometimes be confused for metastatic tumor lesions, so your chordoma treatment team may conduct initial imaging tests like PET/CT scans, bone scans, and MRIs to assess the extent and causes of damage to your bones.

Bone endocrinologists and **pain specialists** should be involved in treatment planning. Most insufficiency fractures are treated noninvasively with bed rest, pain medication, and treatment for underlying osteoporosis or osteopenia.

If these treatments are not successful, **surgeons, interventional radiologists**, and /or **neuroradiologists** should be consulted.

Surgical interventions may include:

- **Vertebroplasty**: An outpatient procedure for stabilizing compression fractures in the spine. Bone cement is injected into vertebrae that have cracked or broken and when it hardens, the cement stabilizes the fractures and supports your spine.
- **Kyphoplasty**: Similar to vertebroplasty, but is performed when the bone has lost height. First, the fracture is expanded with a balloon device to return it to its original height and then the cement is injected into the space.
- **Sacroplasty**: A minimally invasive procedure that involves inserting a bone needle into the sacrum and injecting bone cement to stabilize the fracture.



Bladder, bowel, and sexual function



TYPES	**Bladder** • Retention • Leakage • Lack of control **Bowel** • Constipation • Leakage **Sexual** • Sensation • Stimulation • Lubrication
CAUSES	Typically, these challenges are the result of compression or damage to the nerves at S1, S2 and S3 caused by tumor growth, surgery, or radiation.
TESTS	Depending on your symptoms, you should receive a thorough physical examination and discuss your symptoms with your doctor. Tests such as a bladder pressure test may also be performed.
SPECIALISTS	• Colorectal specialist • Endocrinologist • Gastroenterologist • Pelvic floor specialist • Physiatrist • Urologist

Depending on the tumor's location and the extent of surgical resection, every survivor's experience with bladder, bowel, and sexual function during and after treatment will vary. **Dealing with these challenges is common for individuals with sacral tumors, but they are often not talked about or treated adequately.** There are treatments and strategies that can help, though, so don't hesitate to talk with your doctors if you experience these challenges.

TEMPORARY VS. PERMANENT LOSS OF FUNCTION

If bowel, bladder, and sexual functions are affected immediately following surgery, they can sometimes be regained over time and with the help of physical medicine and rehabilitation specialists.

Surgeons and radiation oncologists who have experience treating chordoma can tell you what to expect regarding temporary and permanent loss of function. If you have not yet had treatment, be sure to ask what to expect after treatment and what your recovery will be like.

En-bloc (entire tumor removed in one piece) removal of tumors that involve S1 and S2 requires sacrificing the nerves, which will affect functions. Sometimes, if one of the S2 nerves is spared, some level of function might return, but it is unusual.

For tumors at S3 and below, if the S2 nerves are not damaged, it is possible to regain function in some cases. For tumors at S4 and S5, most functions can be preserved.



Improving control of these bodily functions is important for independence and quality of life. As part of our Chordoma Survivorship Initiative, we published a series of guest blogs written by sacral chordoma survivors and doctors about managing these issues.

Read our sacral side effects blog series at **chordoma.org/sacral-challenges**

BLADDER CONTROL

Most sacral chordoma survivors are dealing with bladder retention challenges; however, some have the opposite problem and experience bladder spasms and leakage.

Symptoms

- **Retention** is the result of the urethra not being able to open properly. The urethra is the tube that leads from the bladder to the outside of the body that urine passes through. It is surrounded by a sphincter, which is a special type of circular muscle that opens and closes certain body parts. The urethra is always closed until your brain signals it to open, while at the same time signaling your bladder to contract, which pushes the urine out of your body.
- **Leakage** or no control at all is the result of the urethra always being open.

Treatment

- **Pelvic floor physical therapy**: Physiatrists and physical therapists can help with pelvic floor therapy and other techniques as you work to regain function after treatment.
- **Intermittent catheter**: A catheter tube is run through the urethra into the bladder a few times per day to drain the urine out. The tube isn't permanent, so there is no bag or anything else visible.
- **In-dwelling catheter**: Similar to the intermittent catheter, but the tube is inserted by a doctor and left in place. The tube is held in place by a small water-filled balloon inside the bladder and attached to a bag outside the body. This is also called a **Foley catheter**.

- **Suprapubic catheter**: A tube is run into the bladder through the lower abdominal wall and stays in place all the time. The tube attaches to a bag outside the body for drainage. The procedure is done under a local anesthetic or a light general anesthetic and takes about 10 minutes.
- **Mitrofanoff (or Monti) procedure**: A surgical procedure that uses the appendix or intestine to create a channel that connects the bladder to the outside of the body. The channel exits through the navel and a catheter tube is inserted into the channel a few times a day to drain urine. This is a major procedure that requires a week-long hospital stay and a 4-6 week recovery period; however, it can be very beneficial if you and your doctor determine that this is the right procedure for you.
- **Medications**: There are two classes of bladder medications. **Anticholinergic medications** block certain signals between cells. These drugs tend to have side effects like dry mouth, dry eyes, and constipation. **Beta-adrenergic medications**, or beta-blockers, reduce blood pressure and cause relaxation of the smooth muscle of the bladder.
- **Botulinum toxin (Botox®)**: Injections of Botox paralyze overactive bladders, which helps with urgency and incontinence. It is typically only used when behavioral and exercise therapies and medications have not been effective in treating symptoms.
- **Surgery**: In extreme cases where other interventions have not worked, there are surgical options such as bladder augmentation or urostomy, which diverts urine into a bag worn outside the body before it reaches the bladder.

BOWEL CONTROL

Learning how to effectively manage your bowel issues can take a few weeks and sometimes even months, but patience and sticking to a routine will help. If things with your bowels change suddenly, though, or if there's blood in your stool, talk with your doctor to see if you need a colonoscopy.

Symptoms

- **Constipation** or dry stool is what sacral chordoma survivors deal with most often. Nerve signals usually tell the rectum to empty; but when nerves are damaged, the brain and body don't know when the rectum is full and can't control the muscles that allow it to empty. This causes stool to solidify, creating constipation.
- **Leakage** can happen when constipation is chronic and liquid stool leaks around the solidified stool.

Treatment

- **Hydration**: Staying hydrated is critical to getting the stool to pass through more easily and enable the rectum to empty. If you're taking fiber supplements it is especially important to increase your intake of fluids.
- **Digital stimulation**: Use of a gloved finger to touch the wall of the rectum and trigger a bowel movement.
- **Suppository**: A solid medication inserted directly into the rectum. As the suppository melts, the medicine slowly releases into your body.
- **Enema**: An injection of fluid into the rectum using a bag or other device that flushes out stool.
- **Peristeen device**: If an enema does not do enough, this type of device attaches to the anus and pushes fluid up with pressure. The Peristeen requires a prescription from a doctor.
- **Colostomy**: A surgical operation in which a piece of the colon is diverted to an artificial opening in the abdominal wall where stool can be emptied into a bag outside the body.

SEXUAL FUNCTION

Cancer survivors can often experience a decreased interest in intimacy and sex following diagnosis and treatment, for many reasons — some physical, some psychological or emotional. In addition to these common challenges, many sacral chordoma survivors, both men and women, experience impacts to their physical ability to have sex. This can be experienced as decreased sensation, lack of lubrication, or inability to maintain an erection, orgasm, or ejaculate. Additionally, if you have difficulty controlling your bladder or bowels, intimacy can be challenging. There are ways to manage many of these issues, and some people find that sensation does return to some degree over time.

Treatment

For women, start by talking with your gynecologist or primary care physician about your symptoms and what treatments are available. **For men**, ask your chordoma team or primary care physician for a referral to a urologist who specializes in sexual function, preferably at an academic medical center.

Treatment for women includes:

- Over the counter lubricants and moisturizers
- Topical estrogen
- Insertable estrogen/testosterone combo
- Medications for hypoactive sexual disorder or decreased sexual desire



Treatment for men includes:

- Oral erectile dysfunction medications
- Medication inserted into the urethra to produce an erection
- Injection therapy, which involves using a very small needle to inject medication directly into the penis
- Non-medication therapies such as vacuum erection device
- Penile implant surgery is an option if other treatments have not been successful

Communication with your spouse or partner and your doctors is key for both men and women. **It is important to determine what your goals are and what treatments are right for you based on those goals.** Individual and couples counseling can help with these conversations and to determine what's important to you.

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, bone endocrinologists, pain specialists, urologists, pelvic floor specialists, colorectal specialists, 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 local specialist near your home 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 them on chordoma and your experiences with it.

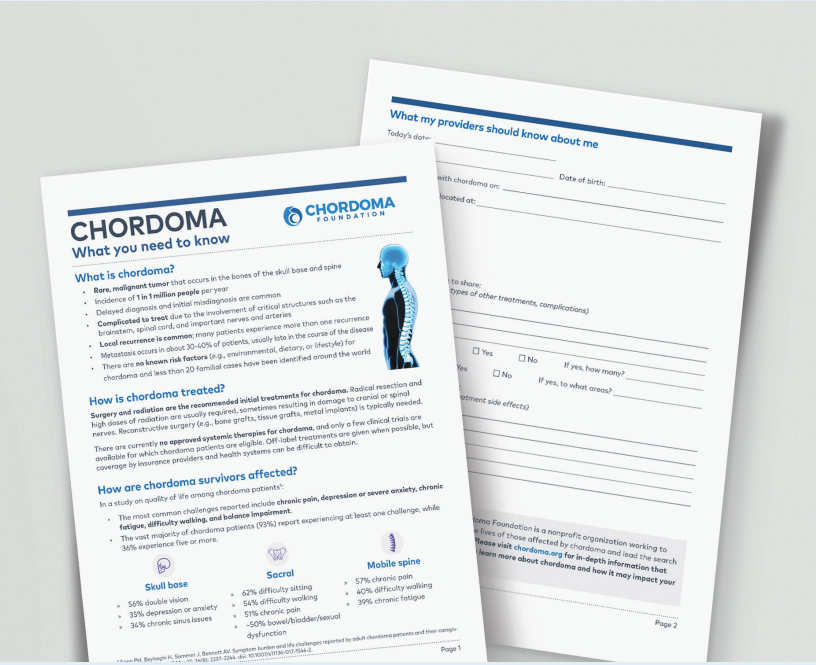


Locate a provider

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, urologists, 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 mobile spine or sacral 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 removing items that may be tripping hazards or creating a place in the bathroom where they can manage their bladder and bowel needs.
- **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. If you are the spouse of a sacral survivor, it can be helpful to get support for any changes in your relationship that might result from chnages in your spouse's sexual function.



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

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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