CHORDOMA
FOUNDATION

Treatment guidelines for newly diagnosed chordoma

From the Global Chordoma Consensus Group

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About these guidelines

These treatment guidelines were developed in June 2025 by the Global Chordoma Consensus Group based on all available medical and scientific evidence on chordoma diagnosis, treatment, and patient outcomes. The guidelines were published in the medical journal JAMA Oncology as a reference to help doctors provide better and more consistent care to their chordoma patients.

As part of our commitment to helping patients and caregivers make the most informed treatment choices, we have made those same recommendations available to you here in easy-to-understand language. Please read this information carefully and discuss it with your doctors.

Read the paper abstract »

How these recommendations were made

The Global Chordoma Consensus Group developed these recommendations to reflect the best available evidence and the shared expertise of leading chordoma specialists worldwide. In June 2025, more than 150 expert physicians met in Milan, Italy, to update and expand the first international consensus guidelines for primary, localized chordoma, which were published in 2015. The group included specialists from every field involved in diagnosing and treating chordoma, along with statisticians, molecular biologists, and patient representatives.

Before the meeting, the group carefully reviewed 305 chordoma research articles published over the previous 10 years. During the meeting, they developed recommendations based on the strength of the evidence. The resulting guidelines cover diagnosis; surgery and radiation planning for chordomas of the skull base (clivus), mobile spine, and sacrum; drug therapy; follow-up schedules; and supportive, palliative, and rehabilitation care.

The final guidelines were published in *JAMA Oncology* in July 2026. The information in this guide is a plain-language version of those evidence-based recommendations that represent a shared agreement among these experts, describing the best way to care for primary (first-time), localized (in one anatomical area) chordoma.

Finding the right medical team

If chordoma is suspected or has been diagnosed, the most important next step is to be evaluated at a medical center with expertise in treating chordoma. Because chordoma is rare and complex, care should be provided by a multidisciplinary team of specialists who work together to coordinate treatment and have substantial experience treating tumors of the skull base and spine, including chordoma. These teams are typically found at larger academic hospitals, sometimes called referral centers, that see many patients with complex tumors.

Your care team should include specialists with experience diagnosing and treating chordoma in the following areas:

- Pathology
- Radiology
- Surgery
- Radiation oncology
- Medical oncology
- Palliative care and rehabilitation

It is also recommended that your doctors discuss your case in a multidisciplinary tumor board. This is a regular meeting where different specialists come together to review each patient's case and develop the best treatment plan. As a patient, you benefit from the knowledge and experience of many experts instead of just one or two. This is very important for treating a complicated disease like chordoma.

Getting a diagnosis and preparing for treatment

Imaging can show the possibility of a chordoma, but a definitive diagnosis can only be made by a pathologist who examines a sample of your tumor tissue. Whenever possible, avoid having a biopsy outside of a referral center. If these procedures are not carefully planned and performed by an experienced team, they can make the tumor more difficult to treat and may increase the risk of tumor cells spreading. Recommendations for performing biopsies can be found in each of the tumor location sections below.

Pathology

If your diagnosis was first made somewhere other than a center with chordoma expertise, it is strongly recommended that your tumor sample be reviewed and tested again by an experienced center.

Pathologists use immunohistochemistry (IHC) tests to confirm a chordoma diagnosis. IHC uses special stains to test for the presence of certain proteins in the tumor cells. For chordoma, one of the most important to look for is a protein called brachyury. All conventional chordomas are positive for brachyury, which helps tell chordoma apart from other conditions that can look similar, such as certain cartilage tumors (e.g., chondrosarcoma) or cancer that has spread from elsewhere in the body. **Brachyury should be tested in all suspected cases of chordoma and is considered essential for confirming a chordoma diagnosis.** Chordomas also typically stain positive for keratin, and sometimes for two other markers called EMA and S100. Benign Notochordal Cell Tumors also stain positive for brachyury.

The poorly differentiated subtype of chordoma loses expression of a protein called INI1, so IHC testing for INI1 should be done if the tumor might be poorly differentiated. In dedifferentiated chordoma, the aggressive component of the tumor is typically negative for brachyury and keratin, and sometimes loses INI-1 staining as well.

Genomic testing of newly diagnosed tumors can be performed for research purposes, but it isn't necessary for guiding initial decisions on surgery and radiation. Additionally, the vast majority of chordomas are sporadic, so genetic testing and counseling are recommended only when there are other known chordoma cases in the family.

Imaging

Chordoma tumors are typically detected through imaging tests, which show organs and other structures inside the body, including tumors.

Suspected chordoma

The way the tumor looks on imaging tests can tell a radiologist whether the tumor might be chordoma. Magnetic resonance imaging, also called MRI, is the best way to see a chordoma and how it is affecting the tissue around it, such as muscles, nerves, and blood vessels. Chordoma is best seen on an MRI with a setting called T2 weighted imaging.

Another imaging test called computed tomography, also known as CT or "CAT" scan, is recommended in addition to MRI if it is not certain whether the tumor is chordoma. CT scans of the chest, abdomen, and pelvis are also recommended.

Confirmed chordoma

Further imaging should be done to help plan your treatment and to better understand the size and exact location of the tumor. This process is often referred to as staging. **You should have magnetic resonance imaging (MRI) of the main tumor site, an MRI of your whole spine, and a CT scan of your whole body.** This is the best way to see a chordoma and how it is affecting the tissue around it, such as muscles, nerves, and blood vessels. A whole-body MRI should also be considered for pediatric patients or those who have a genetic syndrome associated with an increased risk of developing chordoma, such as tuberous sclerosis complex (TSC).

A positron emission tomography (PET) scan is not very useful for staging conventional chordoma, because this subtype doesn't consistently show up well on PET scans. However, this type of scan can be considered when a patient is first diagnosed with poorly differentiated or dedifferentiated chordoma, since these tumor types tend to show up more clearly on PET scans. It can also help detect whether the cancer has come back after complete surgical removal, or help guide a biopsy.

Depending on where the tumor is located, doctors need to check its relationship to different nearby structures:

- **In the skull base:** the opening at the base of the skull, the brainstem, a bony structure called the dens, the middle part of the skull base, the third ventricle and optic chiasm (structures near the center of the brain), the pituitary gland area, the sinuses, and the back of the throat.
- **In the mobile spine:** the fat around the spinal canal, the fluid-filled space around the spinal cord, the spinal cord itself, and the small openings where nerves exit the spine.
- **In the sacrum:** the openings where nerves pass through, the sciatic nerve, and the layer of tissue around the rectum (the mesorectal fascia) that usually protects it from being invaded by the tumor.

Treatment guidelines by tumor location

Your first treatments will have a big impact on both your quality of life after treatment and the chances of the tumor coming back.

Appropriate chordoma treatment requires a comprehensive, team-based approach at a specialized center that handles many cases of chordoma every year. The main treatment options are surgery and radiation. Your plan should take into account the features of your tumor (e.g., the location, the subtype, the area around the tumor, what nerves it is affecting) and your overall health. Decision-making should be shared between you and your team, balancing the goal of controlling the cancer and the impact that treatment could have on your quality of life. Rehabilitation specialists should be involved early in treatment planning, and your team should communicate consistently throughout your care.

These sections include the treatment you should have based on where your tumor is located. Read the section that applies to your tumor location.

Skull base (clival) tumors

Biopsy

Biopsies in the skull base can be difficult and come with a risk of seeding. If your imaging strongly suggests chordoma, your doctors may recommend against having a biopsy before surgery. At experienced chordoma centers, testing a frozen sample during surgery can reliably rule out other conditions that would need different treatment. If your tumor does not have the usual chordoma appearance on scans or you may have poorly differentiated chordoma, a biopsy before surgery is recommended. If you have a biopsy, your surgeon should protect the nasal structures—such as the nasoseptal flap—to help with rebuilding the skull base during your subsequent surgery.

Tests before surgery

To help plan your surgery and assess changes you might experience after surgery, you will need a thorough examination that looks at your cranial nerve function, visual acuity, visual field, hearing, and endocrine function.

If the tumor is considered locally advanced by your surgeons, or a major artery might need to be removed during surgery, two other tests are required before treatment: imaging of

the blood vessels (angiography) and a balloon test occlusion, which checks to make sure your brain would be okay if the artery were removed.

Surgery

The main goal of surgery is to safely remove as much of the tumor as possible. Surgery should be done at centers with modern endoscopic and microsurgical technology and experience, as well as the ability to monitor the cranial nerves closely during surgery.

The amount of tumor removed is a key factor in overall outcomes for patients. Removing more of it is strongly linked to better survival and to a longer period of time before the cancer comes back.

A newer approach for skull base tumors, called supramarginal resection, aims to remove some tissue and bone around the tumor, including the dura and bone when they are involved. It should only be done if it does not add significant surgical risk or increase the risk of side effects. It is good to remember that removing every microscopic tumor cell is rarely possible for skull base tumors, and it is often not practical for your doctors to confirm that the margins are truly clear because the healthy tissue at the edge of a skull base tumor often includes critical structures — such as nerves, blood vessels, and the brainstem — that must be protected rather than removed for testing.

There are two main surgical routes, and your surgeons should be trained in both: the endoscopic approach (through the nose) and the transcranial approach (through the side of the skull). The endoscopic route is usually preferred for tumors located in the center of the head (midline), while the transcranial route is used for tumors that extend out to the side (lateral). The endoscopic route removes the whole tumor more often than the transcranial route and may lead to longer survival, with a similar rate of complications. Each route has trade-offs—for example, the endoscopic route has a higher risk of a spinal fluid leak and the transcranial route has a higher risk of injuring the cranial nerves.

Accidentally spreading tumor cells during surgery (seeding) is more common with the transcranial route (data shows this happening between 2.8% and 7.3% of the time) than with the endoscopic route (1.1% of the time). Your surgical team should take steps to prevent this seeding, such as protecting the tissue of the nasal and sinus passages, not cutting the tumor into pieces, and carefully checking the surgical path for tumor fragments. Tumors low on the clivus or at the craniovertebral junction (where the skull meets the spine) often need staged surgeries (done in more than one operation), closer monitoring, and additional treatments such as radiation.

Reconstruction and stabilization

Rebuilding the area where the tumor was removed (reconstruction) should be part of your surgical plan. There are a few reconstruction methods your surgeon will consider depending on your situation, such as using tissue from elsewhere in the body or doing a multilayer repair, which uses several layers of tissue stacked on top of each other. Whatever method is used, it should be done carefully to prevent cerebrospinal fluid leaks. Your surgeons may also place a drain in your lower back for a few days after surgery to help reduce the chance of a spinal fluid leak.

Sometimes surgery at the craniovertebral junction leaves the area unstable. In that case, a fusion is recommended. A fusion joins bones together to keep them stable. The best timing for fusion—during the tumor resection or a few days or weeks later—is not yet clear, so it is decided on a case-by-case basis. Fusion can also affect later radiation, particularly if metal hardware is used, so your surgeon should discuss the plan with your radiation oncology team before surgery.

Radiation

Radiation after surgery should be done in most cases. It may not be advised if your surgeon determines you are at low risk and the entire tumor was removed, since evidence has not shown a clear survival benefit from radiation after a complete resection. Radiation is strongly recommended if the tumor was only partially removed. If your tumor cannot be removed with surgery, radiation can be given as the main treatment after a biopsy confirms the diagnosis.

There are several types of radiation, and the type and dose of radiation recommended for you are determined by several factors. **See the information below for radiation recommendations that apply to all tumor locations.**

A specialized pathology test called fluorescence in situ hybridization (FISH) was used in a study to sort skull-base chordomas into three risk groups based on the loss of two chromosome regions (1p36 and 9p21) and how much of the patient's tumor was removed. Results showed that patients in the lowest risk group may be able to safely skip radiation, but this hasn't yet been confirmed in large studies across multiple medical centers, so it isn't recommended for widespread use at this time.

Read more about this study and the FISH test »

Mobile spine tumors

Biopsy

A biopsy to confirm the diagnosis is essential for tumors in the mobile spine because scans alone are not completely accurate. A CT-guided biopsy taken from the back through the pedicle (part of the vertebra) is recommended if a mobile spine chordoma is suspected. The biopsy path should be marked and removed during surgery and/or included in the radiation area. The biopsy needle should not pass through internal organs to reach the tumor.

Surgery

When possible, the recommended first treatment for mobile spine tumors is en bloc resection (removing the tumor in one piece) with clear margins, called an R0 resection. If en bloc resection is not possible or you decide against it, options include removing the entire tumor in pieces (gross total resection), removing some of the tumor (debulking) followed by radiation, or radiation given as the main treatment.

Reconstruction and stabilization

You will likely need plastic and reconstructive surgery to stabilize and rebuild your spine after surgery. This should be planned at the time of surgery in consultation with radiation oncology. Any hardware used should be carbon fiber or titanium, as much as possible. Compared with older stainless steel hardware, these materials cause fewer artifacts (blurry spots) on imaging and interfere less with radiation planning and treatment.

Radiation

Whether you need radiation depends on the outcomes of surgery, or whether you have surgery at all.

- **If the tumor is removed in one piece with clear margins (R0 resection)**, it is not yet clear whether having radiation after surgery gives an extra benefit, so it may or may not be recommended.
- **If the tumor is removed in one piece, but there is a positive margin (tumor cells at the edges)**, radiation after surgery is recommended to treat any cells that remain.
- **If removing the tumor in one piece is not possible**, your surgeon may remove the whole tumor in pieces (a gross total resection) or remove only part of the tumor, and

in this case, you should have radiation. If you choose not to have surgery, radiation can be given as the main treatment on its own, without surgery.

Radiation is also sometimes given before surgery for mobile spine tumors when removing the tumor with clear margins would risk serious nerve damage, or when doctors expect that a few tumor cells will be left at the edge. Giving radiation first can improve the chances of controlling the tumor. However, it comes with trade-offs: it can raise the risk of surgical complications and make it harder to rebuild the area with metal implants. For these reasons, it is used carefully and only in certain situations.

There are several types of radiation, and the type and dose of radiation recommended for you are determined by several factors. **See the information below for radiation recommendations that apply to all tumor locations.**

In selected cases, a form of internal radiation placed during surgery, called dural plaque brachytherapy, can add dose to areas at risk. Some studies have shown that stereotactic body radiation therapy (SBRT), given before or after surgery, can help with tumor control with limited side effects, but more studies are needed before it can be routinely recommended. High-dose SBRT may also be used as the only treatment, especially if the risks of surgery are high or you prefer to avoid surgery.

Sacral tumors

Biopsy

An image-guided (CT or ultrasound) core-needle biopsy should be done before surgery for sacral tumors. It should be done from the back along the midline, and the biopsy path should be included in the later surgery when possible.

Surgery

An en bloc resection (removing the tumor in one piece) with clear margins, called an R0 resection, is the strongest predictor of long-term control of the tumor, and it is recommended when possible. However, you and your care team should carefully weigh the risks of an R0 resection and possible side effects such as long-term mobility impairment and bowel, bladder, and sexual dysfunction. These risks depend on which bones and sacral nerves will be affected by the surgery. There are five bones in the sacrum—S1 (at the top) through S5 (at the bottom)—plus the coccyx (the lowest tip). For tumors at or below the S4 level, surgery is the recommended treatment. For tumors involving S3 nerves, sparing the nerve roots allows partial recovery of nerve function in more than 60% of cases. Tumors at

S2 and S1 often require sacrificing more of the nerves, increasing the risk of lasting, major side effects.

For R0 resection, your surgeon will remove a margin of healthy tissue all the way around it, including in front. Part of the bowel may be removed if the tumor has grown into it or an earlier biopsy passed through it. To protect healing, your surgeon may consider a temporary colostomy (rerouting bowel waste to a bag on the belly), which lowers the risk of infection and of an abnormal connection forming between organs. If the tumor has spread into nearby muscles or ligaments, the operation needs careful planning to still remove it completely with clear edges. Image guidance during surgery can improve accuracy, especially for tumors higher up in the sacrum. Your surgeon must avoid rupturing the tumor because it carries a high risk of spreading tumor cells and makes future treatment more difficult.

Reconstruction and stabilization

If the entire sacrum is removed up to the S1 level, the pelvis will become very unstable. In many cases, this requires hardware connecting the spine to the pelvis. For all cases, how the area will be rebuilt and the way the wound will be closed should be planned before surgery. To fill the space and help it heal, your surgeon can move healthy tissue—such as muscle or fat—from a nearby part of the body, like the abdomen, buttock, or back; the choice depends on how much tissue is needed and which blood vessels are available. Removing part or all of the sacrum can leave a gap at the back of the pelvis, so a supportive mesh may be placed to act like an internal wall, to help hold the nearby organs in their normal position so they do not press into that space. Using a mesh does carry some risk of infection. If nearby organs such as the rectum have to be removed along with the tumor, filling the space in the pelvis is recommended to prevent wound-healing and fluid problems.

Radiation

Radiation recommendations for sacral tumors depend on your situation:

- **If the tumor is removed in one piece with clear margins (R0 resection)**, radiation following surgery should be considered but may not be recommended in all cases.

- **If the tumor is removed in one piece but there is a positive margin (tumor cells at the edges)**, you should have radiation following surgery. If your surgeon expects positive margins or can only remove part of the tumor, you should have radiation after surgery. In some cases, radiation is given both before and after surgery in these cases.

- **If surgery is not recommended or you wish to avoid its side effects**, radiation can be given as the main treatment, without surgery. This is called definitive radiation. Early results from treatment centers in Japan and the ongoing **SACRO clinical trial** suggest that high-dose proton or carbon-ion radiation may control some sacral chordomas as effectively as surgery. Based on these findings, proton or carbon-ion radiation may be offered as a primary treatment option. However, the available evidence includes three years or less of follow-up, so we do not yet know how its long-term results compare with surgery. The decision should consider the likely side effects of each approach, the characteristics of your tumor, and your individual needs and priorities. If particle therapy is not available to you, high-dose, precise photon radiation or stereotactic radiosurgery (a very focused form of radiation) is a suitable alternative.

If you are considering radiation as your main treatment, it helps to think ahead about treatments you might need later. For example, surgery done after definitive radiation is more difficult, carries a higher risk of complications, and is less likely to remove the tumor with clear margins.

There are several types of radiation, and the type and dose of radiation recommended for you are determined by several factors. **See the information below for radiation recommendations that apply to all tumor locations.**

Radiation dose recommendations for all tumor sites

Before radiation begins, your team will create a detailed map of exactly where to aim the radiation and where to avoid it. To build this map, they combine your CT images from before surgery with MRI images from both before and after surgery. Together, these images help your team outline the target volumes, which are the areas where the radiation will be delivered.

There are three target volumes:

- The first covers everywhere that could contain microscopic tumor cells (tumor too small to see on scans).
- The second is the tumor bed, the place where the tumor was. This area receives an extra, higher dose of radiation (a "boost").

- The third is any visible tumor that could not be removed during surgery. It also receives a boost.

When the tumor involves important nerves, your team adjusts these treatment areas to protect those nerves as much as possible.

While planning, your team also outlines the healthy structures near the tumor that are sensitive to radiation. Which structures should be protected depends on where your tumor is. This includes the brainstem and the nerves for vision near the skull base, the spinal cord along the spine, or the bowel and other organs near the sacrum. Each of these is given a safe dose limit, so the radiation stays within amounts known to keep them protected.

Chordomas resist radiation, so they need a high dose to be controlled. To give these high doses safely while protecting the healthy tissue around the tumor, doctors recommend either particle therapy (protons or carbon ions) or highly precise photon (X-ray) radiation. Some studies suggest people may live longer with particle therapy than with standard photon therapy, though the evidence is not yet firm, and more research is needed on carbon-ion therapy in particular.

Radiation dose is measured in units called Gray (Gy). For the tumor bed and any visible tumor, the recommended total is 70-79 Gy for protons and photons. This total is given in small daily amounts (called fractions) of about 1.8 to 2 Gy per session, spread over several weeks. Giving it a little at a time lets the healthy tissue recover between sessions. This approach is used for the two most common types of radiation: photons (standard X-ray radiation) and protons.

For carbon ions, slightly larger daily doses are given over fewer sessions, reaching a total of about 66 to 67.6 Gy for the tumor bed and any visible tumor, and 36 Gy or more for the area that may hold microscopic tumor cells.

Considerations for younger patients and rare subtypes

In children and adolescents, skull base chordomas are often more aggressive and complex. Radiation after surgery can improve the likelihood of controlling the tumor for these age groups.

For poorly differentiated chordomas, drug therapy before surgery must be considered as an option. See the Drug therapies section for further guidance.

Long-term effects on function and on brain development in young patients are probably underreported, so standardized follow-up is important.

Read more about chordoma in children and young adults »

Interventional radiology

Image-guided treatments that kill tumor cells with heat or cold are done by interventional radiology specialists. Heat methods include radiofrequency ablation, microwave ablation, laser therapy, and high-intensity focused ultrasound. Irreversible electroporation (IRE) uses electricity, and percutaneous cryoablation (PC) uses extreme cold.

Radiofrequency ablation can work well for small tumors (less than 2 cm) but does not allow real-time monitoring. Percutaneous cryoablation can treat irregularly shaped tumors using several freezing probes. It also lets doctors watch the frozen zone in real time.

The evidence for percutaneous cryoablation in chordoma comes from small studies looking back at past cases, mostly in the sacrum and tailbone area, showing pain relief and local control for small recurrences (less than 5 cm). Therefore, cryoablation is not a substitute for wide surgical removal, but it may be considered when surgery or radiation are not possible. It should be used cautiously since its long-term ability to control the tumor is still unknown.

This type of treatment is often limited by nearby critical structures, including blood vessels and nerves, the covering around the spinal cord, organs such as the bowel, and sensitive tissue such as in the nasopharynx. Some protective measures may lower this risk. Based on early experience at referral centers, freezing the tumor before removing it may make the jelly-like chordoma tissue firmer, which could reduce the spilling and spreading of tumor cells during surgery. However, there is not yet enough evidence for a recommendation to be made on this approach.

Any type of interventional radiology approach should be carefully and thoroughly discussed with your doctors.

Drug therapies

Standard chemotherapy has shown very little benefit for conventional chordoma. For that reason, drug therapy is not recommended as the first treatment if your tumor is in one location and can be treated with surgery and/or radiation.

Poorly differentiated chordoma (PDC) and dedifferentiated chordoma (DC) are more aggressive subtypes and may respond to chemotherapy. When PDC is confirmed, chemotherapy should be considered, possibly before surgery. Combinations of several drugs—including anthracyclines, platinum agents, irinotecan, alkylating agents, vincristine, and etoposide—have been used and show response rates above 50%. There is not much evidence for treating DC with drug therapies, but chemotherapy may be considered since DC can resemble a high-grade sarcoma.

Because the benefit is uncertain and side effects are possible, drug therapy should be considered only if you are in good enough overall health.

Follow-up care

Conventional chordoma recurs in the same area in up to 50% of patients after an R0 resection. This rate is higher after a partial resection, and in the skull base. Recurrences can happen up to 15 years after treatment, so long-term follow-up is essential. You should have an MRI of the original site every 6 to 12 months for the first 4 to 5 years, then every 1 to 2 years for at least 15 years. A chest CT and whole-spine MRI can be used to watch for distant spread and to check on any recurrence.

Poorly differentiated and dedifferentiated chordoma are more likely to spread to other areas of the body, so follow-up should match the schedule used for high-grade bone sarcoma. This means an MRI of the original site plus checks for distant spread (whole-spine MRI and chest imaging) every 2 to 3 months for 2 years, then every 3 to 6 months until year 5, then once a year for at least 10 years. In children, adolescents, and young adults, chest X-ray and low-dose CT can be alternated to limit radiation exposure.

If you had a skull base chordoma, a referral to an endocrinologist and hormone testing are recommended, because the pituitary gland can be affected by surgery or radiation. Appropriate treatment for any imbalances should be consistently maintained. Vision (visual field) testing is also recommended, depending on the radiation dose your optic nerves received.

Follow-up recommendations from the U.S. National Comprehensive Cancer Network

In addition to the Global Chordoma Consensus Group guidelines, the U.S. NCCN Bone Cancer Guidelines for chordoma recommend a CT scan of the chest every 6 months for 5 years, and then annually thereafter, to see if chordoma has spread to the lungs.

Read the NCCN Guidelines »

Palliative care and rehabilitation

Chordoma and its treatment can cause a range of impairments. Common issues include pain, muscle weakness, numbness or altered sensation, difficulty with movement or balance, fatigue, and problems with the cranial nerves (which control functions like facial movement, swallowing, and vision), as well as difficulty swallowing, speech problems, and bowel, bladder, or sexual difficulties. Two kinds of specialists can help you manage these: rehabilitation medicine specialists and palliative care specialists. Their roles overlap, and many patients benefit from both.

Rehabilitation medicine

A rehabilitation medicine specialist (also called a physiatrist) focuses on restoring function and independence. Care should begin with a thorough assessment to identify what's causing each symptom, pinpoint any nerve, muscle, or bone problems, and understand how these affect your daily life. From there, the physiatrist sets rehabilitation goals together with you and the rest of your treatment team, taking into account whether symptoms might worsen, any activity restrictions needed for safety, and what you and your caregivers hope to achieve.

Rehabilitation may include:

- Physical and occupational therapy tailored to your needs around strength, mobility, balance, and daily activities, including any equipment that might help, such as a walker or wheelchair. This can include specialized therapy for balance (vestibular), vision, or pelvic floor issues.
- Speech therapy for trouble swallowing or communicating.
- Braces to help with positioning, stability, and compensating for weakness.
- Bowel and bladder management programs and personalized exercise plans.

Rehabilitation can take place in the hospital, in an outpatient clinic, or at home, depending on what you need.

Palliative care

A palliative care specialist focuses on relieving symptoms and improving quality of life at any stage of the disease. Pain is a common and often difficult symptom, because chordoma affects the bones and can compress or grow into nearby nerves, and because treatment itself can cause side effects. A palliative care specialist can carry out a thorough pain assessment to understand what's causing it and guide the right treatment, and can also help manage other burdensome symptoms such as fatigue. They can also help identify which other specialists you might need to address specific side effects, and coordinate that care. Beyond physical symptoms, palliative care can also connect you with counseling, complementary therapies, and support for you and your caregivers. They can also help you and your loved ones navigate difficult decisions and ensure that your treatment continues to reflect what matters most to you.

Working as a team

Throughout your care, your rehabilitation and palliative team should watch for other treatment-related health problems and for any signs that the disease is returning, adjusting your plan along with the oncology team as needed.

Learn more about dealing with side effects »