

QUESTIONS TO ASK ABOUT TREATMENT

New or suspected chordoma diagnosis

Chordoma is a complex disease to treat. It is important that you carefully consider your options to help you make informed decisions about your treatment. This list can help you think about the types of questions you might want to ask your doctors during your first consultations.

Some things to note:

- Remember to thank the doctor for their time.
- You may not need to ask all of these questions, and there may be questions you want to ask that are not on this list. We encourage you to print out this list and write down any other questions ahead of time.
- Be sure to take notes during your appointment to help you remember important information.
- Bring someone with you to your doctor visits to take notes, help process the information, and clarify any questions or concerns.

Questions about the doctor's chordoma experience

1. How many cases of chordoma have you treated in the last 5 years?
2. Have you treated a case the same as or similar to mine before? If so, what were the outcomes?
3. Do you work with a multidisciplinary care team? Who are they and what are their specialties? What is their experience with chordoma?
4. Who would you recommend I see for second opinions on my case? Do you know if they provide remote (no travel) consultations?
5. Are you willing to consult with chordoma specialists regarding my case if warranted?

Questions about diagnosis

6. Has a multidisciplinary tumor board reviewed my case? Can you provide me with a copy of their findings?
(If the answer is no, ask how this review can be done.)
7. How confident are you in my diagnosis?
8. **[For spinal and sacral chordoma patients]** Where is my tumor located exactly — which vertebrae and nerves are affected?
9. **[For clival chordoma patients]** Where in my skull is the tumor located exactly — are any critical structures, nerves, or arteries being affected?
10. How large is my tumor? Can you please give me a visual representation?
11. **[If a pre-surgical biopsy is planned]** What are the risks of the biopsy? What will be done to reduce the risk of tumor seeding in the track of the biopsy needle?
(Skull base biopsies are often done at the time of surgery, to reduce the risk of seeding.)
12. **[If a biopsy has been done]** What subtype of chordoma do I have? What should I know about this specific type of chordoma?
(See page 3 for more information about chordoma subtypes.)
13. **[For patients under the age of 35]** Has testing been done on my tumor tissue to look for INI-1 loss?
(If the answer is no, request that this be done. This test can be done by a pathologist and is inexpensive. INI-1 loss can indicate that your tumor is the poorly differentiated subtype.)

There are four subtypes of chordoma, which are classified based on how they look under a microscope:

- **Conventional (or classic) chordoma** is the most common form of chordoma. It is made up of a unique cell type that resembles notochordal cells and can have areas of chondroid appearance.
- **Poorly differentiated chordoma** is a subtype that has recently been identified in the medical literature, but is not yet recognized by the World Health Organization (WHO). It can be more aggressive and faster growing than conventional chordoma, and is more common in pediatric and young adult patients, as well as in skull base and cervical tumors. Pathologists can diagnose poorly differentiated chordoma by testing a tumor sample for deletion of a gene called INI-1. All poorly differentiated chordomas have loss of the INI-1 gene.
- **Dedifferentiated chordoma** is more aggressive and generally grows faster than other types of chordoma, and is more likely to metastasize than conventional chordoma. It can also have loss of the INI-1 gene, but this is not common. This type is rare, occurring in only about 5 percent of patients, and is more common in pediatric cases.
- **Chondroid chordoma** is a term more commonly used in the past when it was difficult to distinguish conventional chordoma from chondrosarcoma. This is no longer a problem because brachyury is expressed in nearly all conventional chordomas, making them easier to distinguish from cartilaginous tumors like chondrosarcoma that do not express brachyury. There is no evidence that chordomas with a chondroid appearance behave differently than conventional types that do not have this appearance.

General questions about treatment

14. What treatment(s) do you recommend, and why?
15. **[If your tumor is classified as poorly differentiated or dedifferentiated chordoma]** Should traditional sarcoma chemotherapy regimens be considered in combination with surgery and/or radiation?
16. **[For patients under the age of 18]** Will you be consulting with a pediatric surgeon or pediatric oncologist to plan my child's treatment?
17. How soon do you recommend that I begin treatment?

18. What are the potential benefits and risks of each of my treatment options?
19. How will treatment affect my daily life?
20. Is there an option to “watch and wait”? If so, how fast could the tumor grow if I do nothing right now, and what am I risking?
21. Will palliative care be available to me through the entire treatment process? How do I access that care?
([Palliative care](#) addresses pain and any other side effects patients might experience during any part of the treatment and survivorship journey. A palliative medicine specialist should be part of your care team throughout the diagnosis and treatment process.)

Questions about surgery

22. How much of the tumor do you expect to be able to remove? If not 100%, can you please help me understand why not?
23. What will be done to reduce the risk of tumor seeding during surgery?
24. **[For mobile spine patients]** If I need spinal reconstruction, what type of hardware will be used? How might this affect radiation plans?
25. What is your opinion on my long term prognosis?
26. What mobility and/or functional impairment will I experience as a result of surgery? Will this be permanent or temporary?

27. What are the normal and abnormal complications that can occur with this type of surgery? How often do those occur?

28. What type of rehabilitation and follow-up will I need after my surgery?

29. Can you walk me through the stages of hospitalization and rehabilitation after surgery? Who from my care team will be available to me while I am hospitalized and how can I reach them?

If you'd like to have tumor tissue saved or donated

30. Will I have access to my tumor tissue in the future? If so, how long will it be stored?

31. Can my tissue be stored so that it's possible to use it in the future for tumor profiling? (*Tumor tissue can NOT be decalcified if it is going to be used for testing.*)

32. **[For patients having surgery in the United States]** Will this facility work with the Chordoma Foundation (CF) if I want to donate my tissue to their [Biobank](#)?

Questions about radiation

33. Can you walk me through the process, duration, and type of radiation treatment I'll be receiving?

34. Will the dose of radiation I receive be at least the recommended dose of 74 Gy (gray) as recommended by the CF Medical Advisory board?

35. Do you recommend that I have any radiation before surgery? Should I consider radiation only, instead of surgery?

36. **[If radiation is planned before and after surgery]** How long will I receive preoperative radiation before my surgery? How long will I receive postoperative radiation after my surgery?
37. What are the short and long term benefits to receiving radiation treatment? What are the short and long term risks?
38. What side effects should I expect from radiation during and right after the treatments? What long term effects might occur years down the road (e.g., mobility issues, hearing loss, vision loss, neuropathy, hormone, or other issues)?
39. Will the radiation therapy I receive now affect any radiation therapy I could receive in the future?
40. What follow-up imaging and tests are suggested after my treatment is complete?

Questions about side effects and quality of life

41. What will my daily life be like once I recover from treatment?
42. What mobility and/or functional impairment will I experience as a result of treatment? In your opinion, will this be permanent or temporary?
43. Will I be able to work during and/or after treatment?
44. Can I exercise? If so, what kind of exercise?

45. Are there any activities I should avoid before, during, or after treatment?
46. Would you recommend wearing a medical ID bracelet? If so, what information should I include?
47. What can I do to preserve my fertility?
48. **[For skull base patients]** Will my pituitary gland be affected by surgery and/or radiation? If so, will I need replacement hormone therapy?
49. **[For cervical and mobile spine patients]** Will there be hardware inserted and if so, do you anticipate reduced mobility? If yes, how much?
50. **[For sacral patients]** Will any nerves be severed or impacted, and will I need a colostomy bag or a catheter after treatment? If yes, would these be temporary or possibly even permanent? Will my sexual function be impacted?

Other

51. What is the best way to reach you with questions?