

## QUESTIONS TO ASK ABOUT TREATMENT

### Advanced or metastatic chordoma

Advanced disease can be defined as local or regional recurrence that cannot be treated with high-dose radiation. Metastatic disease refers to tumors that have spread to other places in the body, which may not be fully treatable with surgery or radiation. The following list of questions can help you think about the types of questions you might want to ask your doctor about the right treatment approach for your situation.

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 along with you to your doctor visits to take notes, help process the information, and clarify any questions or concerns.

The Chordoma Foundation's Medical Advisory Board (MAB) recommends that patients with advanced or metastatic chordoma consult with their medical team – including an experienced chordoma medical oncologist – about whether participating in a clinical trial might be right for them. Each patient's situation is unique, but in general, the MAB recommends patients pursue systemic therapy treatment options in the following order of priority:

#### 1. **Chordoma-specific clinical trials**

Start by considering trials designed specifically for chordoma patients, or those that are enrolling a group of chordoma patients to a specific arm of the trial. These trials are likely to have strong scientific justification and to be conducted by teams with significant experience caring for chordoma patients.

#### 2. **Other relevant clinical trials recommended by an experienced physician**

If you are not eligible for any chordoma-specific trials, ask your oncologist about other clinical trials that may be open to you.

#### 3. **Off-label therapy with evidence of clinical benefit for chordoma patients**

If you are not eligible for any clinical trials, consult with your oncologist about off-label use of targeted therapies or immunotherapies. Off-label use refers to the

prescription of therapies that are approved for other types of cancer, but not for chordoma.

The Chordoma Foundation has developed resources to assist patients who are considering systemic therapies. A list of chordoma-specific clinical trials as well as chordoma-relevant trials recommended by the MAB is available at [chordoma.org/clinical-trials](http://chordoma.org/clinical-trials). A list of systemic therapies that are approved for other types of cancer and have been used off-label to treat chordoma can be found at [chordoma.org/systemic-therapy](http://chordoma.org/systemic-therapy). These resources can be shown to your doctor to help you discuss your options.

### Questions about treatment

1. What is your experience with chordoma?
  
2. **[If the doctor has little chordoma experience]** Would you be willing to consult with or even refer me to another doctor who has chordoma expertise?
  
3. Based on my situation, what are the best treatment options available to me?
  - a. Are surgery and radiation possible?
  - b. Is ablative therapy an option?
  - c. Do you recommend systemic therapies?
  - d. Is a combination of any of these possible?
  
4. Who would you recommend I see for further opinions on my case?
  
5. Is this treatment plan meant to help with symptoms, to slow the growth of my tumor, or both?
  
6. What clinical trials might be options for me? *(You can ask your doctor to look at the CF Clinical Trials Catalogue at [chordoma.org/clinical-trials](http://chordoma.org/clinical-trials) during your visit.)*

7. If I enroll in a clinical trial, would I continue seeing you or would the clinical trial doctor become my main provider?
8. What is your recommendation if I do not qualify for any clinical trials?
9. What off-label therapies are available that I could try? *(You can ask your doctor to review the list of off-label drug therapies at [chordoma.org/systemic-therapy](http://chordoma.org/systemic-therapy).)*
10. Are there any new drugs being studied that might be available to me through expanded access or compassionate use programs?
11. What types of targeted therapies are available to me? What are the benefits and risks?
  - a. What type of targeted therapy do you recommend? Why?
  - b. How is the therapy given? How often?
  - c. What are the short- and long-term side effects of targeted therapies?
12. What immunotherapies might be available to me? What are the benefits and risks?
  - a. How is the immunotherapy given, and how often?
  - b. What are the short- and long-term side effects of immunotherapy?
13. Can molecular profiling benefit my case? How can we work together to get this testing done?
14. **[If you have results of a tumor profiling test]** Based on the results of my tumor profiling test, what treatments are available to me?

15. Can you please refer me to a palliative care specialist to help me deal with side effects that I'm experiencing (pain, functional issues, etc)?  
*([Palliative medicine](#) addresses pain and any other side effects patients might experience. A palliative medicine specialist should be part of your care team throughout the treatment process.)*
16. What kind of care will I receive to keep me comfortable and manage pain if I decide not to have any treatment?
17. What is the best way to reach you with questions?

### Questions about clinical trials

18. What is the purpose of this trial?
19. What phase is this clinical trial, and what does that mean?
20. How long will the clinical trial last?
21. What are my responsibilities if I participate in this clinical trial?
22. Who will be in charge of my care during the trial?
23. Will I have to pay for medical care while I am enrolled in the trial?
24. What type of clinical visits are required during the trial, and how many visits per month?

25. Will there be any travel costs that I need to consider while I am in this clinical study?
26. Can I leave the trial anytime?
27. What are the risks and benefits of the trial? How do these compare with risks and benefits of other treatment options?
28. Do you know why researchers believe this new treatment might be effective for chordoma? Are there any medical papers that you can direct me to so I can learn more?
29. Who is best suited to explain the results of the clinical trial?
30. If I have questions about the trial, who can I contact?