

## QUESTIONS TO ASK ABOUT TREATMENT

### Recurrent chordoma

Local recurrence is defined as tumor that has come back in the same place or very close to the original tumor. If you have a locally recurrent chordoma, the first steps are to determine if further high-dose radiation is an option and whether to consider another surgery. This list can help you think about the types of questions you might want to ask your doctor about diagnosis and treatment options for a recurrence.

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.

Some information about treatment for recurrences:

- According to recently-published treatment guidelines for recurrent chordoma<sup>1</sup>, if high-dose (at least 74 GyE) radiation is possible, that is the recommended treatment option.
- Radiation is most effective when there is minimal residual tumor so if radiation is going to be given, it may be beneficial to do additional surgery to remove as much of the tumor as possible.
- If high-dose radiation is not possible, there are a number of other possible treatment options to delay tumor progression as long as possible. A multidisciplinary team of surgery, radiation oncology, medical oncology, palliative medicine, and radiology should be consulted to learn about all your options.

## Questions about doctor experience

1. How many cases of recurrent chordoma have you treated?
2. Have you treated a case the same as or similar to mine before? If so, what were the outcomes?
3. Is my case being evaluated by a multidisciplinary care team? Who are they and what are their specialties?
4. Who would you recommend I see for second opinions regarding my case?
5. Are you willing to consult with chordoma specialists regarding my case if warranted?

## Questions about diagnosis

6. Can you explain to me what has changed from my previous scans, to now?
7. Do you recommend a biopsy? If so, can you please tell me about any risks?
8. Is there any evidence that the tumor has spread to other areas in my skull, spine, lungs, or other parts of my body?
9. **[If a biopsy has been done]** Has the subtype of my chordoma changed from the previous diagnosis? If so, does this change indicate a particular treatment approach?
10. Is it possible to just observe the recurrence for a period of time (1, 3, or 6 months?) before deciding on treatment options?

## Questions about treatment

11. Am I able to receive high-dose radiation (at least 74 Gy, according to treatment recommendations)?
12. What type of radiation do you recommend for me, and what dose?
13. What are the short and long-term benefits to receiving radiation treatment in my case? Can you please outline the short and long-term risks? For example, what side effects should I expect in the weeks, months, or years after treatment?
14. Is surgery recommended in my case?
15. Based on my situation, how much of my tumor can be removed? Is it possible to have a complete en-bloc resection with good margins?
16. What mobility or functional loss will I experience as a result of surgery and/or high-dose radiation? Will it be temporary or permanent?
17. If high-dose radiation isn't possible, what other treatment or combination of treatments can you recommend for me?
18. What are my options for treatments like cryoablation, radiofrequency ablation (RFA), and high-intensity focused ultrasound (HIFU)?
19. What are my options for clinical trials and/or drug therapies?
20. Will palliative care be available to me through the entire treatment process?  
*(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.)*

## Questions about side effects and quality of life

21. What will my daily life be like once I recover from treatment?
22. What mobility and/or functional impairment will I experience as a result of treatment? In your opinion, will this be permanent or temporary?
23. Will I be able to work during and/or after treatment?
24. Can I exercise? If so, what kind of exercise?
25. Are there any activities I should avoid before, during, or after treatment?
26. Would you recommend wearing a medical ID bracelet? If so, what information should I include?
27. What can I do to preserve my fertility?
28. **[For skull base patients]** Will my pituitary gland be affected by surgery and/or radiation? If so, will I need replacement hormone therapy?
29. **[For cervical and mobile spine patients]** Will there be hardware inserted and if so, do you anticipate reduced mobility? If yes, how much?
30. **[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?

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

31. Will I have access to my tumor tissue in the future? If so, how long will it be stored?
32. 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.*)
33. **[For patients in the United States]** Will this facility work with the Chordoma Foundation if I want to donate my tissue to their [Biobank](#) for research?

## Questions about follow-up care

34. After my treatment, how often should I get MRIs and any other x-rays, CTs, etc.?
35. Do you recommend that I receive routine scanning of my whole body? If so, how often?

## Other

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

## Reference

1. Stacchiotti S, Gronchi A, Fossati P, et al. [Best practices for the management of local-regional recurrent chordoma: a position paper by the Chordoma Global Consensus Group](#). *Annals of Oncology* 2017; 28:1230–1242.