

Questions to Ask Your **Oncologist** After a **Synovial Sarcoma** Diagnosis

A synovial sarcoma diagnosis can feel overwhelming, especially if you've never heard of this rare disease before. If you're feeling uncertain or have more questions than answers, you're not alone.

This guide was created to help you prepare for your appointments and better understand your diagnosis, treatment options, and what to expect throughout your care.

The questions included here were developed by people who have experienced the synovial sarcoma journey themselves, with guidance and review from sarcoma specialists, to help you feel informed, empowered, and confident in advocating for your care.

About My Diagnosis

- What type of cancer do I have, and what does my stage mean in plain language?
- Can you explain my pathology report?
- Where is my tumor located, and has it spread?
- Are there any additional imaging tests or scans I need before treatment begins?

About My Care Team

- Do you specialize in treating sarcoma?
- Approximately how many sarcoma or synovial sarcoma patients do you treat each year?
- Who is on my care team? Do I need a medical oncologist, radiation oncologist, and/or oncologic surgeon?
- Should I consider getting a second opinion or being treated at a sarcoma specialty center?
- Will my case be reviewed by a multidisciplinary sarcoma tumor board?

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About Biomarker & Molecular Testing

- Has my tumor been tested to confirm the SS18::SSX fusion, which is characteristic of synovial sarcoma?
- Are there any additional tests, such as biomarker or molecular testing, that could affect my treatment plan?
- If my tumor has spread, is difficult to resect completely, or recurs after treatment, I would like to be tested for biomarkers such as MAGE-A4 and HLA-A*02 to determine whether I may be eligible for Tecelra, and pursue broad biomarker testing for other current or future targeted therapies. How do I go about this process?

About My Treatment

- What are my treatment options, and what is the goal of treatment right now?
- Why do you recommend this treatment over other options?
- How soon do I need to begin treatment?
- What side effects should I expect, and how might treatment affect my day-to-day life?
- Could treatment affect my fertility, and should I discuss fertility preservation before starting?

About Clinical Trials

- Am I eligible for any clinical trials now?
- If not, could clinical trials become an option later in my treatment?

Before I Leave the Appointment

- Who should I contact if I have questions between appointments?
- Is there a nurse navigator or 24-hour oncology phone number I should use?
- If I have a severe reaction to treatment, what should I do?
- What symptoms require me to call your office immediately?
- At what point should I go directly to the emergency department instead of calling first?
- If I develop a fever during chemotherapy, what temperature should prompt me to call immediately?
- If I need emergency care, should I go to my local emergency room or a hospital affiliated with your cancer center?

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Looking Ahead

- How will we know if my treatment is working?
- How often will I have scans or follow-up appointments?
- What symptoms or changes should I report between visits?
- What support resources are available for me and my family?

Remember

Synovial sarcoma is rare, and it's okay to ask questions, take notes, and seek a second opinion from a sarcoma specialist.

Understanding your diagnosis, confirming appropriate biomarker and molecular testing, and receiving care from an experienced sarcoma team can help you make informed decisions about your treatment. Most importantly, know that you don't have to navigate this journey alone.

For additional educational resources, support, and the latest information on synovial sarcoma, visit:

synovialsarcomafoundation.org

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