



SARCOMA DIAGNOSIS QUESTION GUIDE



This question guide has been generated by the Sarcoma Foundation of America (SFA) as a resource for people experiencing a new diagnosis of sarcoma. Due to the rarity and complexity of sarcomas, SFA strongly recommends that ALL sarcoma patients seek out a second opinion. Not all of the questions below may be relevant to all sarcoma patients, but we encourage the use of this guide as part of a discussion and shared decision-making process between a patient and their doctor.



Has my doctor treated other patients with my sarcoma before? How many?

- Is my hospital a Sarcoma Center?
- Is there a Sarcoma Center near me where I can receive care?

What type of sarcoma do I have?

Can this sarcoma be subtyped?

- Do I need to have further testing done to identify or confirm the subtype of sarcoma?
- Is my sarcoma a more rare or more common subtype of sarcoma?
- Would additional details about my tumor help my doctor(s) make decisions about my treatment plan now, or in the future?
- Consider:
 - ◆ Special pathology review
 - ◆ Testing for fusion proteins
 - ◆ Sequencing
 - ◆ Second opinion

Has the tumor spread (metastasized) to any other parts of my body?

- Has any imaging or testing been done to determine this?
- Will I be monitored for metastasis?
- How likely is the cancer to spread or not based on treatment decisions I make?
- What are some symptoms of metastasis that I should be aware of?

Should my tumor be surgically removed?

- Should I receive any treatment before having surgery?
 - ◆ Chemotherapy
 - ◆ Radiation therapy
 - ◆ Immunotherapy
- What are the risks and benefits of having surgery to remove my tumor?
 - ◆ Will I lose function of any part of my body as a result of removing the tumor?
 - ◆ Will I be eligible for a prosthetic of any kind?
 - ◆ Are there multiple approaches to surgical removal of my tumor?
 - ◆ Should more than one, or a particular kind of specialist participate in my surgery?

Orthopedic surgeon

Plastic surgeon

Vascular surgeon

Pediatric surgeon

Am I eligible for any clinical trials?

- As first-line therapy?
- Will my eligibility status change because of decisions I make about other treatment (like surgery or radiation)?
- Am I eligible for clinical trials offered at institutions in other locations? (Consider applying for financial assistance for travel or other costs through SFA)

What is the recommended treatment plan for my sarcoma? Is this agreed upon by experts in the field?

- Is my doctor recommending a treatment plan consistent with other sarcoma experts?
- If this plan is different, or there are multiple opinions, why is my doctor recommending this plan for me?

What are the short-term and long-term side effects of my treatments that I will need to prepare for?

- Will I be able to work or go to school?
- Will I need assistance in my home for some period of time?
- Will I need any kind of rehabilitation services?
- Will I be able to interact with my family and friends?
- What are the long-term impacts of these treatments on my body?

What resources are available to me?

- Support groups
- Nurse navigator
- Social worker
- Patient advocate
- ^a Mental health resources





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