



# 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
- <sup>a</sup> Mental health resources



