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**EASY READING**

# If You Have a Soft Tissue Sarcoma

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## What is sarcoma?

This information is about sarcomas in adults. Sarcoma is a type of cancer that starts in certain parts of the body, like bone or muscle. These cancers start in soft tissues like fat, muscle, nerves, fibrous tissues, blood vessels, or deep skin tissues. They can be found anywhere in the body, but most of them start in the arms or legs.

Sarcoma starts when certain cells, like muscle cells, grow out of control and crowd out normal cells. This makes it hard for the body to work the way it should.

Sarcoma cells can spread to other parts of the body. Sarcoma cells in an arm muscle can sometimes travel to the lung and grow there. When cancer cells do this, it's called metastasis. To doctors, the cancer cells in the new place look just like the ones from the arm muscle.

Cancer is always named for the place where it starts. So when soft tissue sarcoma spreads to the lung (or any other place), it's still called sarcoma. It's not called lung cancer unless it starts from cells in the lung.

## Different kinds of sarcoma

There are more than 50 kinds of soft tissue sarcomas. They can start in different types of cells, grow at different rates, and have different outlooks.

Your doctor can tell you more about the type you have.

### Questions to ask the doctor

- Why do you think I have cancer?
- Is there a chance I don't have cancer?
- Would you please write down the kind of cancer you think I might have?
- Where is the cancer?
- What will happen next?

## How does the doctor know I have sarcoma?

Most sarcomas start as a lump in the arm or leg. A lump that keeps growing is the most common symptom. Sometimes the lump hurts. When sarcomas start in the belly, they can cause belly pain or changes in the way you eat or go to the bathroom. If a lump doesn't go away or gets worse with time, you should go to a doctor to get it checked out. Your doctor will ask questions about your symptoms and do a physical exam.

If signs are pointing to a soft tissue sarcoma, more tests will be done. Here are some of the tests you may need:

### Tests that may be done

**X-rays:** X-rays of the part of your body with the lump are often the first tests done. If cancer is found, a chest x-ray may be done to see if it has spread to your lungs.

**Ultrasound:** This test uses sound waves to make pictures of the inside of the body. It can help show if the lump is solid or filled with fluid. (Cancers tend to be solid.)

**CT or CAT scan:** This is a type of x-ray that takes clear, detailed pictures of your insides and the tumor or lump. This test may also be done to see if cancer has spread.

**MRI scan:** MRIs use radio waves and strong magnets instead of x-rays to take detailed pictures. MRIs make it easier to see the size and shape of the tumor. This helps the

doctor plan for a biopsy (see below).

## Biopsy

A biopsy is the only way to tell for sure if you have cancer. In a biopsy, the doctor takes out a small piece of the lump to check it for cancer cells. Tests will also be done to find out what type of sarcoma it is.

There are different [ways to do a biopsy](#)<sup>1</sup>. The type used will depend on the size of the lump and where it is in your body. Ask your doctor what kind you will need.

The cancer cells in the biopsy sample will be given a **grade**: 1, 2, or 3.. This helps doctors predict how fast the cancer is likely to grow and spread. The grade is based on how much the cancer cells look like normal cells. Cells that look very different from normal cells tend to grow faster and are given a higher grade.. Ask the doctor to explain the grade of your cancer. The grade helps the doctor decide which treatment is best for you.

## Questions to ask the doctor

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain them to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

## How serious is my cancer?

If you have sarcoma, the doctor will want to find out how far it has spread. This is called staging. Your doctor will want to find out the stage of your cancer to help decide what type of treatment is best for you.

The stage is based on how much the cancer has grown in the place where it started or spread to other parts of your body. The grade of the sarcoma (see above) is also part of the stage.

Your cancer can be stage 1, 2, 3, or 4. The lower the number, the less the cancer has

spread. A higher number, like stage 4, means a more serious cancer that has spread from where it first started. Ask the doctor about the cancer stage and what it means for you.

### **Questions to ask the doctor**

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage of the cancer?
- Would you explain to me what the stage means in my case?
- Based on the stage of the cancer, how long do you think I'll live?
- What will happen next?

### **What kind of treatment will I need?**

Sarcoma is often treated with surgery . Radiation and chemotherapy may also be used.

The treatment plan that's best for you will depend on:

- The type of sarcoma
- The stage and grade of the cancer
- Where the tumor is
- The chance that a type of treatment will cure the cancer or help in some way
- Your age
- Your overall health
- Your feelings about the treatment and the side effects that come with it

### **Surgery**

Surgery is used to take out the tumor and a margin or edge of the healthy tissue around it. The type of surgery done depends on where the tumor is. Ask your doctor what kind of surgery you will have and what to expect.

### **Side effects of surgery**

Any type of surgery can have risks and side effects. Ask the doctor what you can expect. If you have problems, let your doctors know. Doctors who treat soft tissue sarcomas should be able to help you with any problems that come up.

## **Radiation treatments**

Radiation uses high-energy rays (like x-rays) to kill cancer cells. It may be used to help shrink a tumor so it's easier to take out with surgery. It may also be used after surgery to kill any cancer that may have been left behind. Radiation can also help treat symptoms like pain and swelling if the sarcoma has spread.

A machine can aim radiation at the tumor. This is called external beam radiation.

Radiation can also be given by putting small pellets (seeds) of radiation in or near the tumor. This is called brachytherapy.

Sometimes, both types of radiation are used.

## **Side effects of radiation treatments**

If your doctor suggests radiation treatment, talk about what side effects might happen. Side effects depend on the type of radiation that's used and the area being treated. Common side effects of radiation are:

- Skin changes where the radiation is given
- Feeling very tired
- Bone weakness (which may lead to breaks years later)

Most side effects get better after treatment ends. Some might last longer. Talk to your cancer care team about what you can expect during and after treatment.

## **Chemo**

Chemo is the short word for chemotherapy, the use of drugs to fight cancer. The drugs are often given through a needle into a vein. These drugs go into the blood and spread through the body.

Chemo may be used before surgery to help shrink a tumor, or after surgery to try to kill any cancer cells left behind. It can also be used as the main treatment if the cancer has spread.

Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Most of the time, 2 or more chemo drugs are given.

## **Side effects of chemo**

Chemo can make you feel very tired, sick to your stomach, and cause your hair to fall out. But these problems go away after treatment ends.

There are ways to treat most chemo side effects. If you have side effects, talk to your cancer care team so they can help.

## **Targeted drugs**

Targeted drugs attack the changes in cells that cause cancer. These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatment doesn't. They come as pills that you can take at home. These drugs have different side effects from chemo, and they are often not as bad.

### **Side effects of targeted drugs**

Side effects depend on which drug is used. These drugs might cause high blood pressure, loose stools, low blood counts, heart problems, and liver problems.

There are ways to treat most of the side effects caused by targeted drugs. If you have side effects, talk to your cancer care team so they can help.

## **Clinical trials**

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials<sup>2</sup>](#) to learn more.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

### **What about other treatments I hear about?**

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be vitamins, herbs, diets, and other things. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

### **Questions to ask the doctor**

- Will I need to see other doctors?
- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- How will my body look and work after surgery?
- Will I need other types of treatment, too?
- What will these treatments be like?
- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Will I be able to have children after treatment?
- Is there a clinical trial that might be right for me?
- What about vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

### **What will happen after treatment?**

You'll be glad when treatment is over. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, you will see your cancer doctor. At first, your visits may be every few months. Then, the longer you're cancer-free, the less often the visits are needed.

Be sure to go to all of these follow-up visits. Your doctors will ask about symptoms, do physical exams, and may do blood tests or other tests to see if the cancer has come back.

Having cancer and dealing with treatment can be hard, but it can also be a time to look

at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your doctor to find out what you can do to feel better.

You can't change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

## Hyperlinks

1. [www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer/biopsy-types.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer/biopsy-types.html)
2. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
3. <http://www.cancer.org>

## Words to know

**Biopsy** (BY-op-see): Taking out a small piece of tissue to see if there are cancer cells in it.

**Leiomyosarcoma** (LIE-o-MY-o-sar-KO-muh): Sarcoma that starts in smooth muscle cells. Smooth muscles are those we cannot control, like in the blood vessels and the gut (intestines). This cancer can start anywhere in the body, but is most common in the uterus and belly.

**Liposarcoma** (LIE-po-sar-KO-muh): A type of sarcoma that starts in fat cells. It can start anywhere, but most often is found in the thigh, behind the knee, or inside the belly.

**Metastasis** (muh-TAS-tuh-sis): Cancer cells that have spread from where they started to other places in the body.

**Orthopedic surgeon** (or-thuh-PEE-dik): A surgeon who specializes in diseases and injuries of the muscles, joints, and bones.

**Sarcoma** (sar-KO-muh): Cancer that starts in connective tissue, such as cartilage, fat, muscle, and bone. **Connective tissues** connect and support other body tissues and organs.

**Undifferentiated pleomorphic sarcoma** (UN-diff-er-EN-she-ATE-id PLEE-o-MORF-ic sar-KO-muh): This is the most common kind of sarcoma in older adults. It's most often found in the arms or legs.

## How can I learn more?

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org) (<http://www.cancer.org>)<sup>3</sup>. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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