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*EASY READING*

# If You (or Your Child) Have Osteosarcoma

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## What is osteosarcoma?

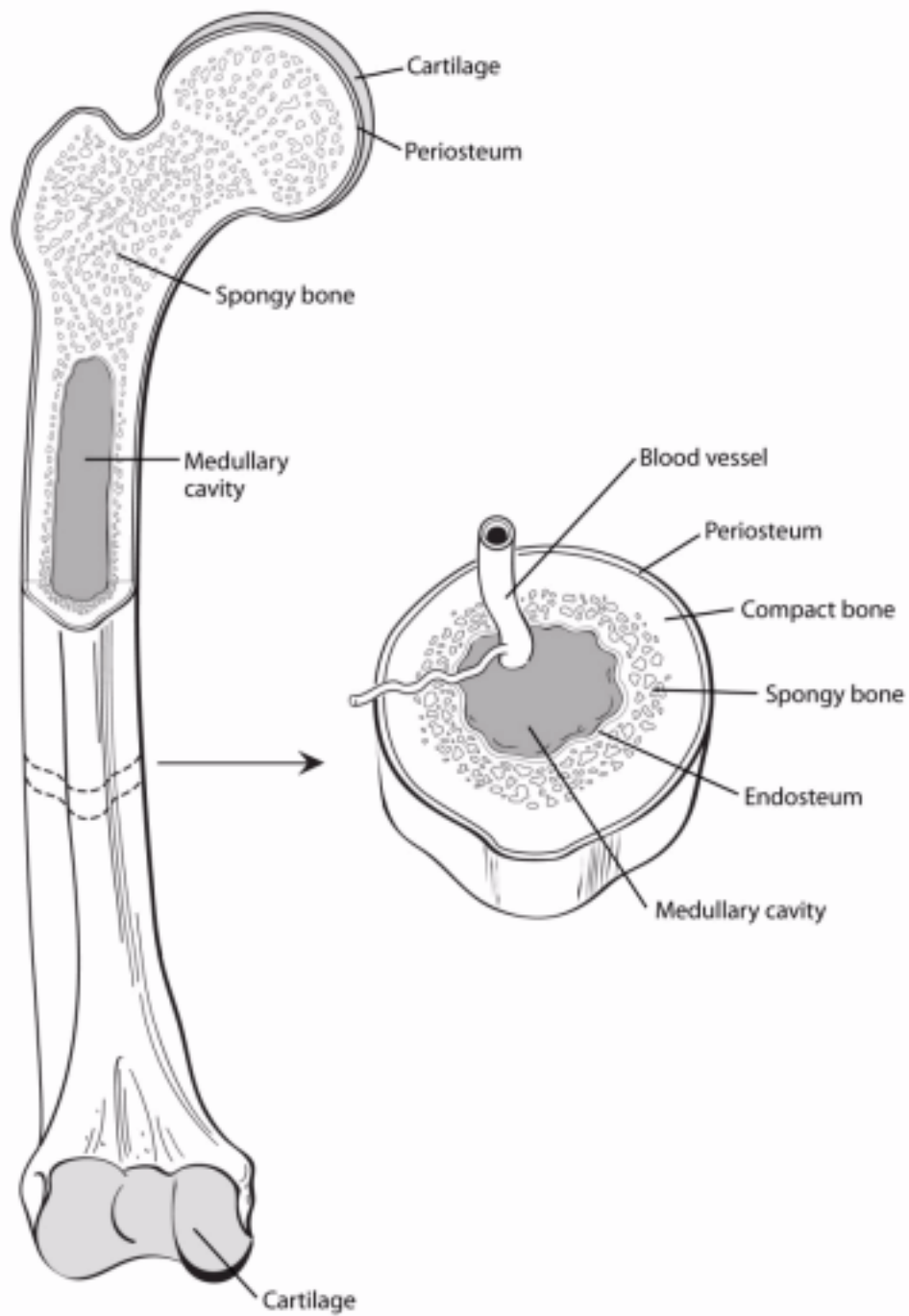
Cancer can start any place in the body. Osteosarcoma is the most common type of cancer that starts in the bones. It starts when bone cells begin to grow out of control, and can then spread to other parts of the body.

Most osteosarcomas happen in children, teens, and young adults, but older adults can get them too. There are many types of osteosarcomas.

This cancer most often starts in the bones around the knee, or in the upper arm bone. But it can also start in other bones.

Sometimes cancer cells from osteosarcoma can spread to other parts of the body, such as the lungs. When cancer cells do this, it's called **metastasis**.

When bone cancer spreads to the lung (or any other place), it's still bone cancer. It's not lung cancer unless it starts from cells in the lung.



## The bone

### Questions to ask the doctor

- Why do you think I have (or my child has) osteosarcoma?
- Is there a chance it's not osteosarcoma?
- What will happen next?

## How does the doctor know it's an osteosarcoma?

Pain in the bone is the most common [symptom](#)<sup>1</sup>. Swelling in the same area is another symptom. These symptoms might come and go at first, but after a while they might not go away or might get worse with time. Of course, pain and swelling can have other causes as well.

The doctor will ask questions about the symptoms and do a physical exam.

If the doctor thinks it might be a bone tumor, they may send you (or your child) to an **orthopedic surgeon**. This is a doctor who treat problems in the bones, muscles, and joints.

## Tests that may be done

If signs are pointing to a bone tumor such as an osteosarcoma, here are some of the [tests](#)<sup>2</sup> that might be done to find out more:

**Bone x-ray:** This is often the first test done if a doctor suspects a bone tumor.

**MRI scan:** MRIs use radio waves and strong magnets instead of x-rays to take pictures. MRIs can show details about the bone and nearby areas. This helps the doctor plan for a biopsy (see below) and surgery.

**CT scan:** This test uses x-rays to make detailed pictures of a person's insides. A CT scan of the chest may be done to see if cancer has spread to the lungs.

**Bone scan:** A bone scan can help show if a cancer has spread to other bones. This test is useful because it can show all of the bones in the body at once.

**PET scan:** PET scans use a special kind of sugar that can be seen inside the body with a special camera. If there is cancer, this sugar shows up as “hot spots” where the cancer is found. This test can help show if the cancer has spread, as well as if the cancer is being helped by treatment. PET scans are sometimes done at the same time as a CT scan (known as a PET/CT scan).

## ***Bone biopsy***

In a biopsy, the doctor takes out a small piece of bone to check it for cancer cells. A biopsy is the only way to tell for sure if a person has a bone cancer like osteosarcoma.

**For tumors in a bone, the biopsy should be done by doctors who often treat bone tumors.** The biopsy and surgery to remove the tumor should be planned at the same time, and the same doctors should do both. This can help prevent problems later on.

The biopsy can be done either by surgery, or by putting a hollow needle into the bone. Ask your doctor what kind will be done.

## ***Grading osteosarcoma***

The cancer cells in the biopsy sample will be given a **grade**, based on how they look. This helps doctors know how fast the cancer is likely to grow and spread. Higher grade cancers tend to grow faster. Low grade cancer cells usually grow slowly and are less likely to spread. Ask the doctor to explain the grade of the cancer.

## **Questions to ask the doctor**

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

## **How serious is the cancer?**

If osteosarcoma has been found, the doctor will want to find out how far it has spread. This is called the [stage<sup>3</sup>](#) of the cancer. The tests above are used to help stage the cancer.

You may have heard other people say that their cancer was “stage 1” or “stage 2.” The doctor will want to find out the stage of the cancer to help decide what type of treatment is best.

The stage describes the growth or spread of the cancer within the bone or into nearby areas. It also tells if the cancer has spread to other parts of the body that are farther away.

The lower the stage number, the less the cancer has spread. A higher number means the cancer has spread more. Be sure to ask the doctor about the cancer stage and what it means.

### Questions to ask the doctor

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage?
- Would you explain what the stage means?
- How might the stage of the cancer affect treatment?
- What will happen next?
- Will we need to see other doctors?

### How is osteosarcoma treated?

The main treatments for osteosarcoma are surgery and chemotherapy (chemo). Radiation might be used sometimes as well.

The treatment plan that's best will depend on:

- The stage and grade of the cancer
- The chance that a type of treatment will cure the cancer or help in some other way
- A person's age and overall health
- Your feelings about the treatment and the side effects that come with it

### Surgery

[Surgery](#)<sup>4</sup> is a major part of treating nearly all osteosarcomas. This includes both the biopsy to tell for sure that it's an osteosarcoma and the surgery to take out the tumor(s). The type of surgery done depends on where the tumor is. Ask the doctor what kind of surgery will be done and what to expect.

A special doctor called an **orthopedicsurgeon** does the surgery.

## ***Side effects of surgery***

Any type of surgery can have risks and side effects. Be sure to ask the doctor what you can expect. If you have problems, let your doctors know.

## **Chemo and other drugs**

[Chemo](#)<sup>5</sup> is short for chemotherapy, the use of drugs to fight cancer. Chemo drugs go into the blood and spread all over the body. Chemo is often given both before surgery (for about 10 weeks) and then again after surgery for up to a year. 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.

Newer, **targeted drugs** can sometimes be helpful if chemo is no longer working. Targeted drugs don't work the same way as chemo drugs, and they tend to have different kinds of side effects.

## ***Side effects***

**Chemo** can make a person feel very tired or sick to their stomach, and it might cause their hair to fall out. It can also cause diarrhea, mouth sores, a higher chance of infection, bleeding, and bruises. Some chemo drugs can also harm the kidneys, bladder, or heart.

There are ways to lessen and treat most chemo side effects. Be sure to talk to your cancer care team so they can help.

**Targeted drugs** can cause side effects like feeling tired, not wanting to eat, having high blood pressure, losing weight, and having diarrhea or belly pain. Less often, these drugs can have more serious side effects like bleeding, problems with blood flow to the heart, or holes forming in the stomach or intestines. The side effects depend on the drug being used.

## **Radiation treatments**

[Radiation](#)<sup>6</sup> uses high-energy rays (like x-rays) to kill cancer cells. For the most part, radiation is not a main treatment of osteosarcoma. Sometimes it may be used when surgery can't get rid of all of the cancer. Radiation can also help treat symptoms like pain and swelling if the cancer has come back and more surgery can't be done.

## **Side effects of radiation treatments**

If the 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

Most side effects get better after treatment ends. Some might last longer.

Side effects can be more serious in children, who are more likely to be affected by radiation. For example, it might slow the growth of bones or cause other problems. Talk to the cancer care team about what to expect.

## **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 (or your child), start by asking your doctor if the clinic or hospital conducts clinical trials. See [Clinical Trials](#)<sup>7</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 the doctor can find one that might be a good fit, 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 we hear about?**

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

Some of these might 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**

- What treatment do you think is best?

- What's the goal of this treatment? How likely is it to cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- Will rehab be needed after surgery? What will that be like?
- Will other types of treatment be needed, too?
- What's the goal of these treatments?
- What are the side effects of these treatments?
- What can we do about side effects?
- Is there a clinical trial that might be right for me (my child)?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- Is there anything we 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](#)<sup>8</sup>. Even when cancer never comes back, people still worry about it. For years after treatment ends, it's still important to see the cancer doctor. Be sure to go to all of these follow-up visits. Exams and maybe other tests will be done to see if the cancer has come back and check for late effects of cancer treatments.

At first, these visits may be every few months. Over time, the visits might be needed less often. The cancer care team can tell you more about these visits, when you might need to contact them if problems come up, and what else to expect after treatment.

## For connecting and sharing during a cancer journey

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the [Cancer Survivors Network \(CSN\)](#)<sup>9</sup>, a safe place to connect with others who share similar interests and experiences. We also partner with [CaringBridge](#)<sup>10</sup>, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

## Hyperlinks



1. [www.cancer.org/cancer/osteosarcoma/detection-diagnosis-staging/signs-and-symptoms.html](http://www.cancer.org/cancer/osteosarcoma/detection-diagnosis-staging/signs-and-symptoms.html)
2. [www.cancer.org/cancer/osteosarcoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/osteosarcoma/detection-diagnosis-staging/how-diagnosed.html)
3. [www.cancer.org/cancer/osteosarcoma/detection-diagnosis-staging/staging.html](http://www.cancer.org/cancer/osteosarcoma/detection-diagnosis-staging/staging.html)
4. [www.cancer.org/cancer/osteosarcoma/treating/surgery.html](http://www.cancer.org/cancer/osteosarcoma/treating/surgery.html)
5. [www.cancer.org/cancer/osteosarcoma/treating/chemotherapy.html](http://www.cancer.org/cancer/osteosarcoma/treating/chemotherapy.html)
6. [www.cancer.org/cancer/osteosarcoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/osteosarcoma/treating/radiation-therapy.html)
7. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
8. [www.cancer.org/treatment/survivorship-during-and-after-treatment/long-term-health-concerns/recurrence.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/long-term-health-concerns/recurrence.html)
9. [csn.cancer.org/](http://csn.cancer.org/)
10. [www.caringbridge.org/](http://www.caringbridge.org/)
11. [www.cancer.org](http://www.cancer.org)

## Words to know

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

**Osteosarcoma** (OS-tee-oh-sar-**KO**-muh): A type of cancer that starts in the bones and is mainly seen in children, teens, and young adults, although it's also seen in older adults.

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

**Metastasis** (muh-TAS-tuh-sis): The spread of cancer from where it started to other places in the body.

## 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) ([www.cancer.org](http://www.cancer.org))<sup>11</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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