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EASY READING

If You or Your Child Has a Ewing Tumor

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What are Ewing tumors?

[Cancer](#)¹ can start any place in the body. Ewing tumors (also known as Ewing sarcomas) are a group of cancers that start in the bones or nearby soft tissues (like muscles and tendons). These cancers start when cells in these areas change and begin to grow out of control.

Most Ewing tumors happen in older children and teens, but younger children and adults can get them, too.

There are different types of Ewing tumors. Your doctor can tell you more about the type you or your child has.

This cancer most often starts in the hip bones, the ribs or shoulder blades, or in the middle of the leg bones, but it can also start in other bones, or even in the soft tissues next to bones.

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

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

Questions to ask the doctor

- Why do you think this is a Ewing tumor?
- Is there a chance it's not a Ewing tumor?
- What will happen next?

How does the doctor know I have (or my child has) a Ewing tumor?

Pain in a bone is the most common [symptom of a Ewing tumor](#)². A lump or swelling in the same area can be another symptom. If symptoms of pain or swelling don't go away or get worse over time, you should go to a doctor to get it checked out. The doctor will ask questions about the symptoms and do a physical exam.

If signs are pointing to a bone tumor, [tests](#)³ will be needed to find out for sure.

Tests that may be done

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 make detailed pictures of your insides. MRIs make it easier to see how much tumor is in the bone and in other areas of the body. This can help the doctor plan for a biopsy (see below) and surgery.

CT scan: This test uses x-rays to make detailed pictures of your insides. This may be done to see if cancer has spread to the chest.

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 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.

Biopsy of the tumor

In a **biopsy**, the doctor takes out a small piece of the suspected tumor to check it for cancer cells. This can be done during surgery or with a thin, hollow needle. A biopsy is the only way to tell for sure if it is a Ewing tumor.

If the tumor is in a bone, it's very important that a surgeon who treats a lot of bone tumors does the biopsy. This might affect treatment later on.

Bone marrow biopsy

If a Ewing tumor is found, this test might be done to see if the cancer has spread to the bone marrow (the inner part of some bones). For this test, a hollow needle is put into the back of the hip bones to remove some of the bone marrow, which is then checked in the lab for cancer cells.

Questions to ask the doctor

- What tests will need to be done?
- 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 to me?
- What do we need to do next?

How serious is the cancer?

If you or your child has a Ewing tumor, the doctor will want to find out how far it has spread. This is called the [stage⁴](#) of the cancer. The stage describes the growth of the cancer in the place where it started (such as the bone). It also tells if the cancer has spread to other parts of the body. Your doctor will want to know the stage of the cancer to help decide which treatment might be best.

For Ewing tumors, what is most important is if tests show the cancer has spread to other parts of the body.

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 to me what the stage means?
- How might the stage of the cancer affect treatment?
- What will happen next?

What kind of treatment will I (or my child) need?

The main [treatments for Ewing tumors](#)⁵ are:

- Chemotherapy (chemo)
- Surgery
- Radiation treatment

Chemo is almost always the first treatment. This is followed by surgery or radiation (or both), and then usually more chemo

The treatment plan will depend on:

- The stage (extent) of the cancer
- The chance that a type of treatment will cure the cancer or help in some way
- A person's age and overall health
- Concerns about [treatment side effects](#)⁶

Chemotherapy (chemo)

[Chemo](#)⁷ is the use of drugs to fight cancer. These drugs go into the bloodstream and are carried all over the body. Chemo is an important part of treatment for Ewing tumors. It is given both before surgery or radiation, and then again afterward, usually for a total of about 6 to 12 months.

Chemo is given in cycles or rounds, each of which last 2 to 3 weeks. Each round of treatment is followed by a rest break. Most of the time, 2 or more chemo drugs are given.

Side effects of chemo

Chemo can make you feel very tired or sick to your stomach, and it might cause your hair to fall out. You might also have diarrhea or mouth sores. Chemo can also raise your risk of infection, bleeding, and bruising. Some chemo drugs can also harm the nerves, bladder, or heart.

There are ways to lessen and treat most chemo side effects. Be sure to tell the cancer care team about any side effects so they can help.

Surgery

[Surgery](#)⁸ is an important part of treating most Ewing tumors. Surgery includes both the biopsy to tell for sure that it's cancer and the surgery to take out the tumor(s). The type of surgery done depends on where the tumor is and other factors. Ask the doctor what kind of surgery will be needed and what to expect.

A special doctor called an **orthopedic surgeon**, who treats problems of the muscles, joints, and bone, does the surgery.

Side effects of surgery

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

Radiation treatments

[Radiation](#)⁹ uses high-energy rays (like x-rays) to kill cancer cells. It can be used after surgery to try to kill any cancer cells that might have been left behind. Or it might be used instead of surgery if all of the cancer can't be removed. Radiation can also help treat symptoms like pain and swelling if the cancer has come back and more surgery can't be done.

Getting radiation is a lot like getting an x-ray. Although the radiation is stronger, it is still painless. Treatments are usually given 5 days a week for several weeks.

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 include:

- Skin changes and hair loss where the radiation is given
- Feeling very tired
- Feeling sick to your stomach or having loose stools if the radiation is aimed at the belly area

Radiation also can cause some long-term side effects in growing children, such as slowed bone growth. Talk to the cancer care team about what to expect.

Stem cell transplant

A [stem cell transplant](#)¹⁰ (SCT) lets doctors use very high doses of chemo to kill the Ewing tumor cells. The high doses of these drugs destroy the bone marrow, which keeps new blood cells from being made. But stem cells given after the chemo can bring back the blood-making bone marrow stem cells.

This type of treatment is being studied for Ewing tumors that are hard to cure with other treatments, such as tumors that have spread to other parts of the body or that have come back after standard treatment. But so far, it's not clear if a stem cell transplant is better than other treatments, so many doctors advise that it only be done as part of a clinical trial.

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. Clinical trials are one way to get the newest cancer treatment. They are often the best way for doctors to find better ways to treat cancer. But they might not be right for everyone. If you do sign up for a clinical trial, you can always stop at any time.

If you would like to learn more about clinical trials, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)¹¹ to learn more.

What about other treatments that I hear about?

You might hear about [other ways to treat the cancer or its symptoms](#)¹². These may not always be standard medical treatments. These treatments may be vitamins, herbs, special diets, and other things.

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

- Will we need other tests before deciding on treatment?
- Who else will be on the treatment team? What do they do?
- What treatment do you think is best?
- 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?
- Is the surgery likely to have any long-term effects?
- Will other types of treatment be needed, too?
- What's the goal of these treatments?
- What might the side effects be from these treatments?
- Can anything be done about these side effects?
- Are there any clinical trials we should look into?
- What about special vitamins or diets that we've heard about? Are they safe?
- How soon do we need to start treatment?
- What should we do to get 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 [once treatment is over](#)¹³. But it can be hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For many 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 to check for late effects from treatment.

At first, these visits may be every 2 to 3 months. Then, as long as no cancer is found, the visits will be needed less often.

Hyperlinks

1. www.cancer.org/cancer/cancer-basics/what-is-cancer.html
2. www.cancer.org/cancer/ewing-tumor/detection-diagnosis-staging/signs-symptoms.html

3. www.cancer.org/cancer/ewing-tumor/detection-diagnosis-staging/how-diagnosed.html
4. www.cancer.org/cancer/ewing-tumor/detection-diagnosis-staging/staging.html
5. www.cancer.org/cancer/ewing-tumor/treating.html
6. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html
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11. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
12. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html
13. www.cancer.org/cancer/ewing-tumor/follow-up.html
14. <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.

Orthopedic (or-thuh-PEE-dik) **surgeon**: A surgeon who treats 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>)¹⁴. 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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