



[cancer.org](http://cancer.org) | 1.800.227.2345

## If You or Your Child Has Rhabdomyosarcoma

- [What is rhabdomyosarcoma \(RMS\)?](#)
- [How does the doctor know I have \(or my child has\) RMS?](#)
- [How serious is the cancer?](#)
- [What kind of treatment will I \(or my child\) need?](#)
- [What will happen after treatment?](#)

### What is rhabdomyosarcoma (RMS)?

Cancer starts when cells in the body begin to grow out of control. Cells in nearly any part of the body can become cancer.

**Rhabdomyosarcoma (RMS)** is a cancer that starts in very early forms of muscle cells. Most often, RMS happens in children, but teens and adults can get it, too.

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

RMS can start just about anywhere in the body. But the most common places are:

- The head and neck area (such as near the eye, inside the nose or throat, or near the spine in the neck)
- The bladder, prostate gland, or female organs
- The arms and legs
- Inside the chest or belly

Sometimes cancer cells from RMS can spread to other parts of the body, such as the

lungs. When cancer cells do this, it's called **metastasis**.

Even if RMS spreads to the lungs (or to any other place), it's still called RMS. It's not called lung cancer unless it starts from cells in the lung.

### Questions to ask the doctor

- Why do you think this is RMS?
- Is there a chance it's not RMS?
- What type of RMS is it? What does this mean?
- Would you please write down the exact type of cancer you think I (or my child) might have?
- What will happen next?

### How does the doctor know I have (or my child has) RMS?

RMS can start in almost any part of the body, so each person might have different [symptoms](#)<sup>1</sup>. One of the most common symptoms is a lump or swelling where the tumor is, which might be painful and get worse over time. Tumors in the head might cause vision problems or headaches. Tumors in lower parts of the body might cause bleeding, belly pain, or vomiting.

If you or your child has symptoms that could be from RMS (or another type of tumor), the doctor will want to get a complete medical history to find out more about the symptoms, and will do a physical exam. [Tests](#)<sup>2</sup> might be needed as well.

### Tests that may be done

**CT scan:** This test uses x-rays to make detailed pictures of a person's insides. It can often show soft tumors, such as RMS. It can also show if cancer has spread to other parts of the body.

**MRI scan:** MRIs use radio waves and strong magnets instead of x-rays to make detailed pictures. MRIs make it easier to see the extent of the tumor. This can help the doctor plan for a biopsy (see below) and surgery.

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

**PET scan:**



## **Surgery**

[Surgery](#)<sup>5</sup> includes both the biopsy to tell for sure that it's cancer and the surgery to take out the tumor(s).

Surgery to remove the tumor is part of treatment for nearly all patients with RMS if it can be done safely. If not, other treatments (like chemo and/or radiation) might be done first. If the tumor shrinks enough, surgery can be done at this point.

The type of surgery done (and the type of surgeon who does it) depends on where the tumor is. Ask the doctor what kind of surgery will be needed and what to expect.

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

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

## **Chemotherapy (chemo)**

[Chemo](#)<sup>6</sup> is the use of drugs to fight cancer. These drugs go into the blood and spread all over the body. Chemo is important for all patients with RMS. If it's not given, the cancer is much more likely to come back.

To treat RMS, 2 or more chemo drugs are given. Chemo is typically given once a week for the first few months, and then less often. The total length of chemo often ranges from 6 months to a year.

### ***Side effects of chemo***

Chemo can make a person feel very tired, sick to their stomach, and can cause their hair to fall out. It can also cause mouth sores, loose stools, and a higher chance 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.

## **Radiation treatments**

[Radiation](#)<sup>7</sup> 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, ask about what side effects might happen. Side effects depend on the type of radiation that's used and the part of the body being treated. Common side effects of radiation are:

- 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](#)<sup>8</sup> 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 \(SCT\)](#)<sup>9</sup> lets doctors use very high doses of chemo to kill the RMS 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-

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](#)<sup>10</sup> to learn more.

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

You might hear about [other ways to treat the cancer or its symptoms](#)<sup>11</sup>. 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 special diet, or anything else.

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

- Do we need to do other tests before we can decide on treatment?

Will any other /GS257 gs (You might hear about)Tj 0 g 0 0 09Ts (l)Tj 0 Ts 0 g ET Q BT ts, and oth

You'll be glad when treatment is over. 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](#)<sup>12</sup>. Exams and maybe other tests will be done to see if the cancer has come back and to check for late effects from cancer treatments.

At first, these visits may be every month or so. Then, as long as no cancer is found, the visits are needed less often.



13. [www.cancer.org](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 surgeon** (or-thuh-PEHa(BY-op-see))Tj 0 g /F1 12 Tf 0 00 0 rg /GS320 gs (: )Tj 0 g /F2 12

**cancer.org | 1.800.227.2345**