
EASY READING

If You or Your Child Has Rhabdomyosarcoma

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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](#)¹. 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](#)² 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: 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 something that’s seen on another test is cancer.

Ultrasound: This test uses sound waves and their echoes to make pictures of your insides. It is sometimes used to look at tumors in the belly.

X-rays: X-rays are good at showing bones, but they’re not as good for seeing other parts of the body. An x-ray is often the first test done if a doctor thinks a tumor might be in a bone, but it’s not as helpful for other types of tumors.

Biopsy of the tumor: In a biopsy, the doctor takes out small pieces of the suspected tumor. This is most often done during [surgery](#)³, but it can also be done with a thin, hollow needle. The biopsy samples are checked for cancer cells, and other lab tests might be done on them as well. A biopsy is the only way to tell for sure if it is RMS.

Bone marrow biopsy: If RMS is found, a bone marrow biopsy is often done to see if the cancer has spread to the bone marrow (the soft, inner part of certain bones). This test is done with a hollow needle that is put into the bone marrow, usually in the hip bone. The test can be done either by itself or during surgery to biopsy or treat the main RMS tumor.

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 us?
- How and when will we get the results?
- Who will explain the results to us?
- What do we need to do next?

How serious is the cancer?

If you or your child has RMS, the doctor will want to find out some key pieces of

information to help decide how to treat it. These include:

- The **stage** of the cancer, which is based on where it started and if it has grown into nearby areas or spread to other parts of the body
- The **clinical group**, which is based on the extent of the cancer and if it is removed completely during surgery
- The patient's **age**
- If the RMS cells have certain **gene changes**

Once these things are known, they're used to put each patient into a **risk group**⁴ (low, intermediate, or high), which is then used to guide treatment. The higher the risk, the more intense the treatment will likely need to be.

We know this can be confusing. If you have any questions about the stages or risk groups, ask the doctor or nurse to explain it to you.

Questions to ask the doctor

- Do you know the stage and risk group of the cancer?
- If not, how and when will you find out?
- Would you explain to me what the stage and risk group mean?
- How might these affect treatment?
- What will happen next?

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

The main treatments for RMS are:

- Surgery
- Chemotherapy (chemo)
- Radiation treatment
- High-dose chemo and stem cell transplant (rarely)

The treatment plan will depend on:

- The risk group 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

Surgery

[Surgery](#)⁵ 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](#)⁶ 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](#)⁷ 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](#)⁸ 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 \(SCT\)](#)⁹ 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-making bone marrow stem cells.

This type of treatment is being studied for RMS that is hard to cure with other treatments. But it can cause serious side effects, and so far it's not clear if it's better than other treatments. Because of this, many doctors advise that a stem cell transplant be done only 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 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](#)¹⁰ to learn more.

What about other treatments that I hear about?

You might hear about [other ways to treat the cancer or its symptoms](#)¹¹. 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 doctors 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 (like chemo or radiation) 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 friends tell us about? How will we know if they are safe?
- How soon do we need to start treatment?
- What should be done 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 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](#)¹². 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.

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 \(CSN\)](#)¹³, a safe place to connect with others who share similar interests and experiences. We also partner with [CaringBridge](#)¹⁴, 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/rhabdomyosarcoma/detection-diagnosis-staging/signs-symptoms.html
2. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html
3. www.cancer.org/cancer/rhabdomyosarcoma/treating/surgery.html
4. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/staging.html
5. www.cancer.org/cancer/rhabdomyosarcoma/treating/surgery.html
6. www.cancer.org/cancer/rhabdomyosarcoma/treating/chemotherapy.html
7. www.cancer.org/cancer/rhabdomyosarcoma/treating/radiation-therapy.html
8. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html
9. www.cancer.org/cancer/rhabdomyosarcoma/treating/high-dose-chemo-sct.html
10. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
11. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/complementary-and-integrative-medicine.html

12. www.cancer.org/cancer/rhabdomyosarcoma/after-treatment/followup.html
13. csn.cancer.org/
14. www.caringbridge.org/
15. 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-PEE-dik): A surgeon who specializes in diseases and injuries of the muscles, joints, and bones. This is often the type of surgeon who treats RMS.

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

Sarcoma (sar-KOH-muh): A type of cancer that starts in the muscles, fat, bones, the linings of joints, or blood vessels. RMS is a type of sarcoma.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (www.cancer.org)¹⁵. 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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