Rhabdomyosarcoma Early Detection, Diagnosis, and Staging

Know the signs and symptoms of rhabdomyosarcoma. Find out how rhabdomyosarcoma is tested for, diagnosed, and staged.

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Rhabdomyosarcoma Be Found Early?
- Signs and Symptoms of Rhabdomyosarcoma
- Tests for Rhabdomyosarcoma

Stages, Risk Groups, and Outlook (Prognosis)

After a diagnosis of rhabdomyosarcoma, the stage (extent) and risk group of the cancer provide important information about the anticipated response to treatment.

- Rhabdomyosarcoma Stages and Risk Groups
- Survival Rates for Rhabdomyosarcoma by Risk Group

Questions to Ask About Rhabdomyosarcoma

Here are some questions you can ask your cancer care team to help you better understand your child's diagnosis and treatment options.

- Questions to Ask About Rhabdomyosarcoma

Can Rhabdomyosarcoma Be Found Early?

Rhabdomyosarcoma (RMS) is not common, and at this time there are no widely recommended screening tests for these cancers. (Screening is testing for a disease such as cancer in people who don't have any symptoms.)

Still, RMS often causes symptoms that allow it to be found before it has spread to other parts of the body. Most symptoms that might point to RMS can also have other causes, and most of these are not serious. But it's important to have them checked by a doctor. This includes any pain, swelling, or lumps that grow quickly or don't go away after a week or so.

About 4 out of 5 of these cancers is found before the cancer has clearly spread to another part of the body. But even when this happens, very small tumors (which cannot be seen, felt, or detected by imaging tests) could already have spread to other parts of the body. This is why both surgery and other treatments are typically needed for RMS.

For people with certain inherited conditions linked to RMS

Families known to carry inherited conditions that raise the risk of RMS (listed in Risk Factors for Rhabdomyosarcoma[1]) or that have several family members with cancer (particularly childhood cancers) should talk with their doctors about the possible need for more frequent checkups. It's not common for RMS to run in families, but close attention to possible early signs of cancer might help find it early, when treatment is most likely to be successful.

Hyperlinks

1. www.cancer.org/cancer/types/rhabdomyosarcoma/causes-risks-prevention/risk-factors.html

References

Okcu MF, Hicks J. Rhabdomyosarcoma in childhood and adolescence: Clinical presentation, diagnostic evaluation, and staging. UpToDate. Accessed at www.uptodate.com/contents/rhabdomyosarcoma-in-childhood-and-adolescence-clinical-presentation-diagnostic-evaluation-and-staging on May 24, 2018.

Wexler LH, Skapek SX, Helman LJ. Chapter 31: Rhabdomyosarcoma. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2016.

Last Revised: July 16, 2018

Signs and Symptoms of Rhabdomyosarcoma

Rhabdomyosarcoma (RMS) can start nearly anywhere in the body, so the symptoms of RMS can be different in each person. The symptoms depend on where the tumor is, how large it is, and if it has spread to other parts of the body.

One or more of these symptoms usually leads to a visit to the doctor. Many of these signs and symptoms are more likely to be caused by something other than RMS. For example, children and teens can have bumps or pain from play or sports injuries. Still, if you or your child has any of these symptoms and they don't go away within a week or so (or if they get worse), see a doctor so that the cause can be found and treated, if needed.

References

Okcu MF, Hicks J. Rhabdomyosarcoma in childhood and adolescence: Clinical presentation, diagnostic evaluation, and staging. UpToDate. Accessed at www.uptodate.com/contents/rhabdomyosarcoma-in-childhood-and-adolescence-clinical-presentation-diagnostic-evaluation-and-staging on May 24, 2018.

Tests for Rhabdomyosarcoma

The doctor will also do a **physical exam** to look for possible signs of RMS or other health problems. For example, the doctor might be able to see or feel an abnormal lump or swelling.

If the doctor suspects RMS (or another type of tumor), tests will be needed to find out. These might include imaging tests, biopsies, and/or lab tests.

Imaging tests

Imaging tests use x-rays, magnetic fields, radioactive substances, or sound waves to create pictures of the inside of the body. Imaging tests might be done for a number of reasons, including:

- To help find out if a suspicious area might be cancer
- To determine the extent of a tumor or learn how far a cancer has spread
- To help determine if treatment is working

People who have or might have RMS will get one or more of these tests.

Plain x-rays

X-rays[1] are sometimes used to look for tumors, but they are best for looking at bones. They don't show much detail in internal organs, so other imaging tests are usually more helpful when looking for soft tissue tumors such as RMS.

A chest x-ray is sometimes done to look for cancer that might have spread to the lungs, although it isn't needed if a chest CT scan is being done.

Computed tomography (CT) scan

The CT scan[2] combines many x-ray pictures to make detailed cross-sectional images of parts of the body, including soft tissues such as muscles. A contrast material may be injected into a vein before the scan to help see details better..

This test can often show a tumor in detail, including how large it is and if it has grown into nearby structures. It can also be used to look at nearby lymph nodes, as well as the lungs or other areas of the body where the cancer might have spread.

Magnetic resonance imaging (MRI) scan

Some machines can do a PET and CT scan at the same time (PET/CT scan). This lets the doctor compare areas of higher radioactivity on the PET scan with the more detailed appearance of that area on the CT scan.

Ultrasound

Ultrasound[6] uses sound waves and their echoes to make a picture of internal organs or tumors. For this test, a small, wand-like instrument called a *transducer* is moved around on the skin (which is first lubricated with gel). It gives off sound waves and picks up the echoes as they bounce off the organs. The echoes are converted by a computer into an image on a screen.

Ultrasound can be used to see if tumors in the pelvis (such as prostate or bladder tumors) are growing or shrinking over time. (This test can't be used to look at tumors in the chest because the ribs block the sound waves.)

This is an easy test to have, and it uses no radiation.

To learn more about these and other imaging tests, see Imaging (Radiology) Tests[7].

Biopsy

The results of a physical exam or imaging tests might suggest that someone has RMS (or another type of soft tissue tumor), but a **biopsy** (removing some of the tumor for viewing under a microscope and other lab testing) is the only way to be certain.

Biopsies can be done in several ways. The approach used depends on where the tumor is, the age of the patient, and the expertise and experience of the doctor doing the biopsy.

Surgical biopsy

The most common biopsy approach is to remove a small piece of tumor during surgery[8] while the patient is under general anesthesia (asleep). In some cases, nearby lymph nodes are also removed to see if the tumor has spread to them. The samples are then sent to a lab and tested.

Needle biopsies

If for some reason a surgical biopsy can't be done, a less invasive biopsy using a thin,

hollow needle may be done. There are 2 kinds of needle biopsies, each of which has pros and cons.

Core needle biopsy: For a core needle biopsy, the doctor inserts a hollow needle into the tumor to withdraw a piece of it (known as a *core sample*). If the tumor is just under the skin, the doctor can guide the needle into the tumor by touch. But if the tumor is deep inside the body, imaging tests such as ultrasound or CT scans might be needed to help guide the needle into place. The removed core sample is then sent to the lab for testing.

The main advantage of a core needle biopsy is that it does not require surgery, so there is no large incision. Depending on where the tumor is, adults and older children might not need general anesthesia (where they are asleep for the biopsy), but some younger children might. On the other hand, the specimen is smaller than with a surgical biopsy, and if the needle isn't aimed correctly, it might miss the tumor. If the specimen is not a good sample of the tumor, another biopsy will be needed.

Fine needle aspiration (FNA) biopsy: For this technique, the doctor uses a very thin, hollow needle attached to a syringe to withdraw (aspirate) a small tumor sample. An FNA biopsy is best suited for tumors that can be reached easily (such as those just under the skin), although it can also be used for tumors deeper in the body.

The downside of FNA is that the sample is very small. The pathologist must be experienced with this technique and be able to decide which lab tests will be most helpful on a very small sample. In cancer centers that have the experience to extract the most information from very small amounts of tissue, FNA can be a valuable – though certainly not foolproof – way to diagnose RMS, but it is not usually the preferred biopsy technique.

See Testing Biopsy and Cytology Specimens for Cancer[9] to learn more about different types of biopsies, how the tissue is used in the lab for disease diagnosis, and what the results can tell you.

Bone marrow aspiration and biopsy

These tests are often done after RMS is diagnosed to find out if the cancer has spread to the bone marrow (the soft inner parts of certain bones).

The 2 tests are usually done at the same time. The samples are usually taken from the back of both of the pelvic (hip) bones, but in some patients they may be taken from other bones.

These tests might be done during the surgery to biopsy or remove the main tumor (while the child is still under anesthesia), or they might be done as a separate procedure.

If the bone marrow **aspiration** is being done as a separate procedure, the patient lies on a table (on their side or belly). After cleaning the skin over the hip, the doctor numbs the area and the surface of the bone with local anesthetic, which can briefly sting or burn. Children may also be given other medicines to help them relax or even go to sleep for the procedure. A thin, hollow needle is then inserted into the bone, and a syringe is used to suck out a small amount of liquid bone marrow.

A bone marrow **biopsy** is usually done just after the aspiration. Small pieces of bone and marrow are removed with a slightly larger needle that is pushed down into the bone. Once the biopsy is done, pressure will be applied to the site to help stop any bleeding.

but not to other cancers. The stains produce a distinct color that can be seen under a microscope. This lets the pathologist know that the tumor is a rhabdomyosarcoma.

If a diagnosis of RMS is made, the pathologist will also use special lab tests to help determine which kind of RMS it is. This is important because it affects how the cancer is treated. For example, alveolar rhabdomyosarcoma (ARMS), which tends to be more aggressive, typically requires more intense treatment than embryonal rhabdomyosarcoma (ERMS). An important part of this testing is looking for gene or

Once rhabdomyosarcoma (RMS) has been diagnosed and the type of RMS[1] identified, doctors need to assess how much cancer there is and where it has spread. This is known as the **stage** of the cancer. The stage is one of the most important factors in determining a person's prognosis (outlook). It's also important when deciding on the best treatment options.

Doctors use the results of imaging tests and biopsies and the examination of the organs during surgery[2] to learn how far the cancer has spread. If there is any doubt about the extent of the cancer, more biopsies or other tests may be done.

RMS is staged differently from most other cancers. Doctors first determine 3 key pieces of information:

- The **TNM stage**
- The **clinical group**
- Whether the cancer cells have a *PAX/FOX01* fusion gene[3]

These factors are used to divide patients into **risk groups**, which then are used to guide treatment.

The stages and risk groups for RMS can be confusing. If you have any questions about the staging or risk groups, ask the doctor or nurse to explain it to you in a way you understand.

The TNM stage

The TNM stage is determined before treatment starts, and is based on 3 key pieces of information:

- **T:** The characteristics of the main **tumor** (location and size)
- **N:** Whether the cancer has spread to nearby lymph **nodes** (bean-sized collections of immune system cells)
- **M:** Whether the cancer has **metastasized** (spread) to distant parts of the body

These factors are combined to determine an overall stage:

Stage 1

- The tumor is no more than 5 cm across but has spread to nearby lymph nodes
- The tumor is larger than 5 cm across and may or may not have spread to nearby lymph nodes

In either case, the cancer has not spread to distant parts of the body.

Stage 4

The tumor can have started anywhere in the body and can be of any size. It has spread to distant parts of the body such as the lungs, liver, bones, or bone marrow.

- Children 10 years of age or older with widespread (stage 4) RMS, in which the cancer cells do not have a *PAX*/*FOX01* fusion gene
- Children with widespread (stage 4) RMS, in which the cancer cells do have a *PAX*/*FOX01* fusion gene

Hyperlinks

1. www.cancer.org/cancer/types/rhabdomyosarcoma/about/what-is-rhabdomyosarcoma.html
2. www.cancer.org/cancer/types/rhabdomyosarcoma/treating/surgery.html
3. www.cancer.org/cancer/types/rhabdomyosarcoma/causes-risks-prevention/what-causes.html
4. www.cancer.org/cancer/types/rhabdomyosarcoma/treating/surgery.html

References

National Cancer Institute. Childhood Rhabdomyosarcoma Treatment (PDQ®). 2018. Accessed at www.cancer.gov/types/soft-tissue-sarcoma/hp/rhabdomyosarcoma-treatment-pdq on May 29, 2018.

Okcu MF, Hicks J. Rhabdomyosarcoma in childhood and adolescence: Epidemiology, pathology, and molecular pathogenesis. UpToDate. Accessed at www.uptodate.com/contents/rhabdomyosarcoma-in-childhood-and-adolescence-epidemiology-pathology-and-molecular-pathogenesis on May 29, 2018.

Wexler LH, Skapek SX, Helman LJ. Chapter 31: Rhabdomyosarcoma. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2016.

Last Revised: July 16, 2018

Survival Rates for Rhabdomyosarcoma

by Risk Group

Survival rates can give you an idea of what percentage of people in a similar situation (such as with the same type and stage of cancer) are still alive a certain amount of time after they were diagnosed. They can't tell you exactly what will happen with any person, but they may help give you a better understanding about how likely it is that treatment will be successful.

What is a survival rate?

Statistics on the outlook for people with cancer are often given as survival rates. The survival rate is the percentage of people who live at least a certain amount of time (usually 5 years) after being diagnosed with cancer. For example, a 5-year survival rate of 70% means that an estimated 70 out of 100 people who have that cancer are still alive 5 years after being diagnosed. Of course, many people live much longer than 5 years (and many are cured).

But keep in mind that survival rates are estimates, and they can't predict what will happen in any person's case. Each person's outlook can vary based on a number of factors specific to them. Your cancer care team can tell you how the numbers below may apply, as they are familiar with your (child's) particular situation.

Survival rates for rhabdomyosarcoma

For a person with RMS, the risk group is important in estimating their outlook. But other factors can also affect a person's outlook, such as their age and how well the cancer responds to treatment. For example, the overall 5-year survival for childrechild'srechhts

these children will be cured.

Intermediate-risk group

For those in the intermediate-risk group, the survival rates range from about 50% to about 70%. The rate varies based on tumor location, stage, and the age of the child. (Children aged 1 to 9 years tend to do better than older or younger children.)

High-risk group

The survival rate in this group is generally around 20% to 30%. Again, it's important to note that other factors, such as the patient's age and the location and type of tumor can affect these numbers. For example, children with embryonal rhabdomyosarcoma (ERMS) and limited spread (to only 1 or 2 distant sites) have a higher 5-year survival rate. Also, children 1 to 9 years of age tend to have a better outlook than younger or older patients.

Even when taking risk groups and other factors into account, survival rates are at best rough estimates. Your cancer care team is your best source of information on this topic, as they know your situation best.

References

Breitfeld PP, Meyer WH. Rhabdomyosarcoma: New windows of opportunity. *Oncologist*. 2005;10:518-527.

Meza JL, Anderson J, Pappo AS, Meyer WH. Analysis of prognostic factors in patients with nonmetastatic rhabdomyosarcoma treated on Intergroup Rhabdomyosarcoma Studies III and IV: The Children's Oncology Group. *J Clin Oncol*. 2006;24:3844-3851.

Okcu MF, Hicks J. Rhabdomyosarcoma in childhood and adolescence: Epidemiology, pathology, and molecular pathogenesis. UpToDate. Accessed at www.uptodate.com/contents/rhabdomyosarcoma-in-childhood-and-adolescence-epidemiology-pathology-and-molecular-pathogenesis on May 29, 2018.

Wexler LH, Skapek SX, Helman LJ. Chapter 31: Rhabdomyosarcoma. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2016.

Last Revised: March 2, 2023

Questions to Ask About Rhabdomyosarcoma

It’s important to reatment

- What's the goal of treatment?
- Should we get a second opinion[4]? How do we do that? Can you recommend a doctor or cancer center?
- What are the risks and side effects to the suggested treatments?
- Which side effects start shortly after treatment and which ones might develop later on?
- Will treatment affect my child's ability to grow and develop?
- Could treatment affect my child's ability to have children later on?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How will treatment affect our daily lives (school, work, etc.)?

During and after treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything we can do to help manage side effects?
- What symptoms or side effects should we tell you about right away?
- How can we reach you or someone on your team on nights, weekends, or holidays?
- Who can we talk to if we have questions about costs, insurance coverage, or social support?
- What are the chances of the cancer coming back after treatment? What might our options be if this happens?
- What type of follow-up[5] and rehab will be needed after treatment?
- Are there nearby support groups or other families who have been through this that we could talk to?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about recovery times so that you can plan your work or school schedules.

have the answers to some of your questions. You can find out more about speaking with your health care team in The Doctor-Patient Relationship[6] and How to Talk to Your Child's Cancer Care Team[7].

Hyperlinks

1. www.cancer.org/cancer/types/rhabdomyosarcoma/about/what-is-rhabdomyosarcoma.html
2. www.cancer.org/cancer/types/rhabdomyosarcoma/treating.html
3. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html
4. www.cancer.org/cancer/managing-cancer/finding-care/seeking-a-second-opinion.html
5. www.cancer.org/cancer/types/rhabdomyosarcoma/after-treatment/followup.html
6. www.cancer.org/cancer/managing-cancer/finding-care/the-doctor-patient-relationship.html
7. www.cancer.org/cancer/survivorship/children-with-cancer/during-treatment/talking-to-team.html

Last Revised: July 16, 2018

Written by

The American Cancer Society medical and editorial content team (https://www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.