Treating Rhabdomyosarcoma

If you or your child has been diagnosed with rhabdomyosarcoma (RMS), your treatment team will discuss the options with you. It's important to weigh the benefits of each treatment option against the possible risks and side effects.

How is rhabdomyosarcoma treated?

The types of treatment used for rhabdomyosarcoma (RMS) include:

- Surgery for Rhabdomyosarcoma
- Chemotherapy for Rhabdomyosarcoma
- Radiation Therapy for Rhabdomyosarcoma
- High-Dose Chemotherapy and Stem Cell Transplant for Rhabdomyosarcoma

Common treatment approaches

RMS is almost always treated with both local therapy (surgery and/or radiation therapy) as well as chemotherapy. But the details of treatment can vary based on a number of factors, including the location and extent of the tumor and which risk group the patient falls into.

All children and adults with RMS will be treated with surgery to remove the tumor if it can be done without causing major damage or disfigurement. If this isn't possible, chemotherapy and/or radiation therapy may be used first to try to shrink the tumor. If it shrinks enough, surgery can be done at this point. The goal of surgery is to remove the tumor completely, but this isn't always possible.

Even if the tumor appears to have been removed completely, all patients with RMS need chemotherapy. Without it, it's very likely that the cancer will come back in distant parts in the body because small amounts of cancer have almost always reached other

parts of the body when the cancer is first found (even thought they can't be seen on imaging tests).

If cancer is left behind after surgery or if the cancer has some less favorable traits and it hasn't spread to distant sites (as is the case most of the time), radiation therapy will also be given.

Many of these treatments can be used again if the cancer continues to grow or if it comes back later on.

- Rhabdomyosarcoma That Progresses or Recurs After Initial Treatment

Who treats rhabdomyosarcoma?

RMS is not common, and treating it can be complex, so it's very important for patients to be diagnosed and treated by a team of doctors who have experience with RMS.

For children and teens, treatment is best done at a children's cancer center. For adults with RMS, treatment is typically done at a major cancer center. Doctors on the treatment team might include:

- An **orthopedic surgeon** (a surgeon who specializes in muscles and bones) who is experienced in treating RMS
- A **medical or pediatric oncologist** (a doctor who treats cancer with chemotherapy and other drugs)
- A **radiation oncologist** (a doctor who treats cancer with radiation therapy)
- A **pathologist** (a doctor specializing in using lab tests to diagnose and classify diseases)
- A **physiatrist** (a doctor who directs a person's rehabilitation and physical therapy after treatment)

For both children and adults, the team might also include other doctors, as well as physician assistants (PAs), nurse practitioners (NPs), nurses, psychologists, social workers, physical therapists and other rehabilitation specialists, and other health professionals.

- Health Professionals Associated With Cancer Care[1]
- How to Find the Best Cancer Treatment for Your Child[2]
- Navigating the Health Care System When Your Child Has Cancer[3]

Making treatment decisions

The treatment for RMS can often be effective, but it can also cause serious side effects. It's important to discuss all treatment options as well as their possible side effects with the cancer care team so you can make an informed decision. It's also very important to ask questions if you're not sure about anything.

If time allows, getting a second opinion from another doctor experienced with your child's type of tumor is often a good idea. This can give you more information and help you feel more confident about the treatment plan you choose. If you aren't sure where to go for a second opinion, ask your doctor for help.

The treatment team will also help you take care of side effects and can help you work closely with nutritionists, psychologists, social workers, and other professionals to understand and deal with medical problems, stress, and other issues related to the treatment.

For cancer in children and teens, many of these issues can be more complex. As a parent, taking care of a child with cancer can be a big job. It's important to remember that you will have a lot of help. Many people will be involved in your child's overall care. It's also important to know that the health professionals who treat children with RMS are using the experience and knowledge gained from many decades of studying the treatment of this disease.

- Questions to Ask About Rhabdomyosarcoma[4]
- How to Talk to Your Child's Cancer Care Team[5]
- Seeking a Second Opinion[6]

Thinking about taking part in a clinical trial

Today, most children and teens with cancer are treated at specialized children's cancer centers. These centers offer the most up-to-date-treatment by conducting clinical trials (studies of promising new therapies). Children's cancer centers often conduct many clinical trials at any one time, and in fact most children treated at these centers take part in a clinical trial as part of their treatment.

Adults with cancer also typically have the option to participate in a clinical trial. Clinical trials are one way to get state-of-the art cancer treatment. In some cases they may be the only way to get access to newer treatments. They are also the best way for doctors to learn better methods to treat cancer. Still, they might not be right for everyone. Talk to your treatment team to learn about possible clinical trials, and ask about the pros and

cons of enrolling in one of them.

If you would like to learn more about clinical trials, start by asking the treatment team if your clinic or hospital conducts clinical trials.

- Clinical Trials[7]

Considering complementary and alternative methods

You may hear about alternative or complementary methods that the doctor hasn't mentioned. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

Complementary methods refer to treatments that are used *along with* your regular medical care. Alternative treatments are used *instead of* standard medical treatment. Although some of these methods might be helpful in relieving symptoms or helping people feel better, many have not been proven to work. Some might even be harmful.

Be sure to talk to your cancer care team about any method you are thinking about using. They can help you learn what is known (or not known) about the method, which can help you make an informed decision.

- Complementary and Alternative Medicine[8]

Preparing for treatment

Before treatment, the doctors and other members of the team will help you understand the tests that will need to be done. The team's social worker will also counsel you about some of the issues that might come up during and after treatment, and might be able to help you find housing and financial aid if needed.

- When Your Child Has Cancer[9]

Help getting through cancer treatment

Your cancer care team will be your first source of information and support, but there are other resources for help when you need it. Hospital- or clinic-based support services can also be an important part of your care. These might include nursing or social work services, financial aid, nutritional advice, rehab, or spiritual help. For children and teens with cancer and their families, other specialists can be an important part of care as well.

The American Cancer Society also has programs and services – including rides to treatment, lodging, and more – to help you get through treatment. Call our National Cancer Information Center at 1-800-227-2345 and speak with one of our trained specialists.

- Finding Help and Support When Your Child Has Cancer[10]
- Find Support Programs and Services in Your Area[11]

The treatment information given here is not official policy of the American Cancer Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor. Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

Surgery for Rhabdomyosarcoma

Surgery is an important part of treatment for most rhabdomyosarcomas. Most people with RMS will get two types of surgery:

- The biopsy to diagnose the cancer
- The surgical treatment to remove the tumor(s)

Biopsy surgery

If RMS is suspected, a biopsy is needed to know for sure. The type of biopsy needed will depend on the results of imaging tests, the location and size of the tumor, the patient's age and health, and the expertise of the doctor. How the biopsy is done can affect later treatment, so **it's important that the biopsy is done by a doctor who is experienced in diagnosing and treating RMS**. See Tests for Rhabdomyosarcoma[1] to learn more about biopsies.

Surgery to remove the tumor

Unless it is clear that the cancer has spread to distant parts of the body, **surgery is usually the first step in treating RMS**. Complete resection (removal) of the main tumor, along with some surrounding normal tissue, is the goal whenever possible. If there are cancer cells at the edges (margins) of the removed specimen (meaning that some cancer cells may have been left behind), the surgeon may operate again to try to remove the remaining cancer.

In some cases, surgery may be done even if it's clear that all of the cancer can't be removed, because it may still help other treatments (chemotherapy and radiation) to work better.

During surgery, nearby lymph nodes might be biopsied to determine if the cancer has spread to these areas, especially if:

- The main tumor is near the testicles in a boy who is 10 years of age or older
- The main tumor is on an arm or leg

Some types of surgery might need to be done by special surgeons. For example, removing tumors in the head and neck area may require surgical teams with ENT (ear, nose, and throat) surgeons, plastic surgeons, maxillofacial surgeons, and neurosurgeons.

If a tumor is large or is in a spot where removing it completely would severely affect the patient's appearance or cause other problems, then surgery may be delayed until after chemotherapy and possibly radiation therapy to try to shrink it, or surgery might not be done at all (and radiation will be used instead).

What to expect with surgery

The type and extent of surgery can vary a great deal based on the location and size of the tumor. RMS can appear in many parts of the body, so it's not possible to describe here all of the different types of operations that might be done. The surgical team will discuss the planned surgery with you, but make sure you ask questions if there are any parts of it that aren't clear to you.

If the diagnosis of RMS wasn't confirmed by a biopsy before the main operation, the surgeon may first take only a small sample of the tumor. The sample is checked right away to see if it is cancer or not. If it can be determined that it is cancer while the surgery is still going on, the surgeon may try to remove the entire tumor and also remove some of the nearby lymph nodes to check for spread of the cancer. If the surgeon suspects the disease has spread to another part of the body, a piece of the

possible metastatic tumor may be removed and checked as well.

A bone marrow aspiration and biopsy[2] may also be done during the surgery, and a central venous catheter[3] (a thin tube) may be put into one of the large veins in the chest. One end of the catheter stays in the vein, while the other end lies just under or outside the skin. This can help the health care team give chemo and other drugs and draw blood samples without having to stick needles into the veins each time. The catheter usually stays in place for several months, and can make having chemo less painful. If such a device is put in, the health care team will teach you how to care for it to reduce the risk of problems such as infections.

Possible risks and side effects

Short-term risks and side effects: Depending on where the tumor is, surgery for RMS can be a long and complex operation. Serious short-term side effects are not common, but they can include reactions to anesthesia, excess bleeding, blood clots, and infections. Pain is common after the operation, and the patient might need strong pain medicines for a while after surgery as the site heals.

Long-term side effects: The long-term side effects of surgery depend mainly on where the tumor is and what type of operation is done. Physical changes after surgery can range from little more than a scar to changes in appearance or in how some parts of the body function, which may require physical rehabilitation.

More information about Surgery

For more general information about surgery as a treatment for cancer, see Cancer Surgery[4].

To learn about some of the side effects listed here and how to manage them, see Managing Cancer-related Side Effects[5].

Hyperlinks

1. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html
2. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html
3. www.cancer.org/treatment/treatments-and-side-effects/central-venous-catheters.html
4. www.cancer.org/treatment/treatments-and-side-effects/treatment-

types/surgery.html
5. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html

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Chemotherapy for Rhabdomyosarcoma

Chemotherapy (chemo) is the use of drugs to treat cancer. Chemo is *systemic* therapy, meaning that the drugs enter the bloodstream and go throughout the body to destroy cancer cells. This makes chemo useful for killing cancer cells that have spread to other parts of the body, even if they can't be seen.

Chemo is an important part of treatment for rhabdomyosarcoma (RMS). Even if it appears that all of the cancer was removed by surgery, without chemo it is likely to come back.

After surgery, any tiny deposits of RMS that are still in the body can often be destroyed by chemo. If larger areas of tumor remain after surgery (or if surgery couldn't be done for some reason), chemo (along with radiation) can often shrink these areas. In some cases it may shrink the tumor enough that surgery can remove the remaining tumor completely.

Chemo drugs used to treat rhabdomyosarcoma

Doctors give chemo in cycles, which is usually treatment on 1 or 2 days in a row, followed by days off to give the body time to recover. For RMS, chemo is typically given once a week for the first few months, and then less often. The total length of treatment usually ranges from 6 months to a year.

Some drugs can be taken by mouth, but most are given IV (injected into a vein).

A combination of chemo drugs is used to treat patients with RMS. Which drugs are used will often depend on which risk group[1] the patient is in.

For people in the **low-risk group**, the main combinations of drugs used are:

- **VA:** vincristine and dactinomycin (also known as *actinomycin-D*)
- **VAC:** vincristine, dactinomycin, and cyclophosphamide

For the **intermediate-risk group**, the most common regimens are:

- **VAC:** vincristine, dactinomycin, and cyclophosphamide
- **VAC/VI:** vincristine, dactinomycin, and cyclophosphamide, alternating with vincristine and irinotecan

Doctors are also studying whether adding the targeted drug[2] temsirolimus to the VAC/VI regimen might help it work better.

For people in the **high-risk group** (which includes those with metastatic disease), the **VAC** regimen is the most common one used. Because these cancers can be hard to treat, doctors have also studied the use of more intense chemo that includes several other drugs (such as doxorubicin, ifosfamide, and etoposide). Another approach that has been studied is to give higher doses of chemo, sometimes followed by a stem cell transplant. But so far it's not clear that either of these approaches is any better than standard chemo, and they can cause more side effects.

Most doctors recommend that people in the high-risk group be treated in a clinical trial[3] testing new drugs and drug combinations. It is hoped that newer drugs will help people in the high-risk group live longer.

Possible side effects

Chemo drugs can affect cells other than cancer cells, which can lead to side effects. The side effects depend on the type and doses of drugs, and the length of time they are given.

Children tend to have less severe side effects from chemo than adults and often recover from side effects more quickly. This is why doctors can often give them higher doses of chemo to kill the tumor.

General side effects: Side effects common to many chemo drugs include:

- Hair loss
- Mouth sores
- Loss of appetite
- Nausea and vomiting
- Diarrhea
- Increased chance of infections (from having too few white blood cells)
- Easy bruising or bleeding (from having too few blood platelets)
- Fatigue (from having too few red blood cells)

Most of these side effects tend to go away once treatment is finished. There are often ways to lessen these side effects. For example, drugs can be given to help prevent or reduce nausea and vomiting. Be sure to ask your doctor or nurse about medicines to help reduce side effects, and report any side effects your child has so they can be managed effectively.

Side effects of certain drugs: Along with the risks above, some chemo drugs can have specific side effects (although these are relatively uncommon). For example:

- **Cyclophosphamide** and **ifosfamide** can damage the bladder, causing blood in the urine. The risk of this happening can be lowered by giving the drugs with plenty of fluids and with a drug called *mesna*, which helps protect the bladder.
- **Vincristine** can damage nerves. Some patients may notice tingling and numbness (called neuropathy[4]), particularly in the hands and feet. This ioften goes away or gets better once treatment is stopped, but it could last a long time in some people.
- Some drugs can also damage the ovaries or testicles, which might affect fertility[5] (the ability to have children) later in life. Talk to the cancer care team about the risks of infertility with treatment, and ask if there are options for preserving fertility[6], such as sperm banking or ovarian tissue banking.
- Some chemo drugs can also increase the risk of developing a second type of

cancer[7], usually a form of leukemia, years after the RMS is cured. But this is rare, and the importance of chemotherapy in treating RMS far outweighs this risk.

For more on some of these possible long-term side effects, see What Happens After Treatment for Rhabdomyosarcoma?[8]

More information about chemotherapy

For more general information about how chemotherapy is used to treat cancer, see Chemotherapy[9].

To learn about some of the side effects listed here and how to manage them, see Managing Cancer-related Side Effects[10].

Hyperlinks

1. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/staging.html
2. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/targeted-therapy.html
3. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
4. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/peripheral-neuropathy.html
5. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/how-cancer-treatment-affects-fertility.html
6. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html
7. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/second-cancers-in-adults.html
8. www.cancer.org/cancer/rhabdomyosarcoma/after-treatment/followup.html
9. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/chemotherapy.html
10. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html

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Radiation Therapy for Rhabdomyosarcoma

Radiation therapy uses high-energy radiation to kill cancer cells. It is often an effective way to kill cancer cells that can't be removed with surgery. When radiation therapy is used to help treat rhabdomyosarcoma (RMS), it is typically given along with chemotherapy.

When might radiation therapy be used?

Radiation is most often used when some of the main tumor is still left after surgery (clinical group II or III[1]), or if removing the tumor completely would mean loss of an important organ, like the eye or bladder, or would be disfiguring. It is not usually needed for children with embryonal rhabdomyosarcoma (ERMS) that can be removed completely by surgery (clinical group I[2]).

Usually radiation therapy is given to any area of remaining disease after 6 to 12 weeks of chemotherapy. An exception is when a tumor near the meninges (linings of the brain) has grown into the skull bones, into the brain itself, or into the spinal cord. These patients are usually given radiation therapy right away (along with chemotherapy).

If the cancer has spread to another part of the body, radiation might be given to certain

areas of known cancer spread to reduce any symptoms it is causing.

How radiation therapy is done

This type of treatment is given by a doctor called a **radiation oncologist**. Before treatments start, the radiation team takes careful measurements with imaging tests such as MRI scans to determine the correct angles for aiming the beams and the proper dose of radiation.This planning session is called *simulation*. Patients may also be fitted with a plastic mold resembling a body cast to hold them in the same position each time so that the radiation can be aimed more accurately.

Radiation is usually given 5 days a week for many weeks. Each treatment is much like getting an x-ray, although the dose of radiation is much stronger. For each session, the patient lies on a special table while a machine delivers the radiation from precise angles. The treatment is not painful.

Each session lasts about 15 to 30 minutes, with most of the time spent making sure the radiation is aimed correctly. The actual treatment time each day is much shorter. Some younger children may be given medicine before each treatment to make them sleep so they won't move during treatment.

Types of radiation therapy

Modern radiation therapy techniques help doctors aim the treatment at the tumor more accurately than they could in the past.

Three-dimensional conformal radiation therapy (3D-CRT): 3D-CRT uses the results of imaging tests such as MRI and special computers to precisely map the location of the tumor. Radiation beams are then shaped and aimed at the tumor from several directions. Each beam alone is fairly weak, which makes it less likely to damage normal body tissues, but the beams come together at the tumor to give a higher dose of radiation there.

Intensity-modulated radiation therapy (IMRT): IMRT is an advanced form of 3D therapy. Along with shaping the beams and aiming them at the tumor from several angles, the intensity (strength) of the beams is adjusted to limit the dose reaching the most sensitive normal tissues. This lets doctors deliver a higher dose to the cancer areas. Many major hospitals and cancer centers now use IMRT.

Brachytherapy (internal radiation therapy): Another approach is to insert a radioactive source into or near the tumor for a short time. The radiation travels only a

short distance, so the tumor gets most of the radiation. This approach may be especially useful in treating some bladder, vaginal, and head and neck area tumors. Some early studies suggest that this may be a good way to preserve the function of these organs in many children.

Other newer techniques, such as stereotactic radiotherapy and proton beam radiotherapy, are discussed briefly in What's New in Rhabdomyosarcoma Research?[3]

Possible side effects

The side effects of radiation therapy depend on where the radiation is aimed, the dose of radiation, and the person's age. (Young children are much more likely to be affected by radiation.) Some side effects are likely to last a short time, while others might last longer.

Short-term side effects can include:

- Fatigue
- Increased risk of infections
- Effects on the skin in areas that receive radiation, ranging from hair loss and mild sunburn-like changes to more severe skin reactions
- Nausea, vomiting, and diarrhea (from radiation to the abdomen or pelvis)
- Damage to the bladder, which might cause urinary problems (from radiation to the abdomen or pelvis)
- Mouth sores and loss of appetite (from radiation to the head and neck area)

Long-term side effects can be more serious, especially in growing children, so doctors try to limit them as much as possible.

Small children's brains are very sensitive to radiation, so doctors try to avoid using radiation to the head whenever possible. If it is needed, it is aimed very carefully to try to limit how much reaches the brain. Side effects of radiation therapy to the brain can include headaches and problems such as memory loss, personality changes, and trouble learning at school. These problems tend to become most serious 1 or 2 years after treatment.

Other long-term problems can include the formation of scar tissue and the slowing of bone growth in areas that get radiation. Depending on the child's age and what parts of the body get the radiation, this could result in deformities or a failure to grow to full height. Radiation can also raise the risk of cancer many years later. (For more on long-

term side effects, see What Happens After Treatment for Rhabdomyosarcoma?[4])

To limit the risk of serious long-term effects from radiation, doctors use the lowest dose of radiation therapy that is still effective.

More information about radiation therapy

To learn more about how radiation is used to treat cancer, see Radiation Therapy[5].

To learn about some of the side effects listed here and how to manage them, see Managing Cancer-related Side Effects[6].

Hyperlinks

1. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/staging.html
2. www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/staging.html
3. www.cancer.org/cancer/rhabdomyosarcoma/about/new-research.html
4. www.cancer.org/cancer/rhabdomyosarcoma/after-treatment/followup.html
5. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/radiation.html
6. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html

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High-Dose Chemotherapy and Stem Cell Transplant for Rhabdomyosarcoma

A stem cell transplant (sometimes referred to as a *bone marrow transplant*) makes it possible to use much higher doses of chemotherapy (chemo) than would normally be possible. Chemo drugs kill rapidly dividing normal cells (such as those in the bone marrow, where new blood cells are made) as well as cancer cells. Higher doses of these drugs might be more effective in treating some cancers, but they can't be given because the severe damage to the bone marrow would cause life-threatening shortages of blood cells.

A stem cell transplant can get around this problem by taking out and saving some of the patient's own blood-forming stem cells (either from the blood or bone marrow) before high-dose chemo and then putting them back into the blood after chemo is over. The stem cells then travel to the bone marrow, which lets the normal marrow regrow.

Stem cell transplants are used to treat some aggressive childhood cancers, but so far it's not clear if they can help rhabdomyosarcoma patients. Because of the severe side effects they can cause, most doctors recommend they be used only as part of a clinical trial[1] at this time.

More information about stem cell transplant

To learn more about stem cell transplants, including how they are done and their potential side effects, see Stem Cell Transplant for Cancer[2].

For more general information about side effects and how to manage them, see Managing Cancer-related Side Effects[3].

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
2. www.cancer.org/treatment/treatments-and-side-effects/treatment-types/stem-cell-transplant.html
3. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html

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Rhabdomyosarcoma That Progresses or Recurs After Initial Treatment

Rhabdomyosarcoma (RMS) that continues to grow during treatment or that comes back once treatment is finished is often hard to treat. The treatment options will depend on a number of factors, including:

- Where the cancer comes back
- The type of RMS
- Which treatments were used previously
- The patient's age and overall health

For tumors that recur in the same spot as the original tumor, surgery may be used if it can be done. If radiation therapy wasn't part of the initial treatment, it may be used as well.

In rare cases, surgery may be used for cancers that recur in other parts of the body, such as if there is a small recurrence in a lung. Radiation therapy might be another option here as well.

Most often, chemotherapy is the best option if the cancer has spread to other parts of

the body. This might include some of the drugs listed in Chemotherapy for Rhabdomyosarcoma, as well as newer drugs now being studied.

Because these tumors are often hard to treat, clinical trials[1] of newer treatments may be a good option in many cases.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html

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