Treating Rhabdomyosarcoma

Once rhabdomyosarcoma has been found and staged, the cancer care team will talk with you about treatment options. It’s important to be sure you understand your child’s options as well as their possible side effects to help make the decision that’s the best fit for your child. If there is anything you don’t understand, ask to have it explained. You can find some good questions to ask in What Should You Ask the Doctor About Rhabdomyosarcoma?

The treatment and prognosis (outlook) for patients with RMS depend to a large extent on the type of RMS and on how much of it can be removed with surgery. This is why it’s very important for patients to be diagnosed and treated by doctors who have experience with RMS. Children with RMS are best treated in a cancer center where there is experience and expertise in treating childhood cancers, such as in centers who are members of the Children’s Oncology Group.

For children and teens, a team approach is recommended that includes specialists at a children’s cancer, as well as the child’s pediatrician. For adults with RMS, the treatment team typically includes specialists at a major cancer center, as well as the patient’s primary care doctor. 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)

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. Going through cancer treatment often means meeting lots of specialists and learning about parts of the medical system you probably haven’t been exposed to before. For more information, see our document Children Diagnosed With Cancer: Understanding the Health Care System.

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 the problems you and your child might have during and after treatments such as surgery, and might be able to help you find housing and financial aid if needed.

The types of treatment that can be used for RMS include:

- Surgery
- Chemotherapy
- Radiation therapy
- High-dose chemotherapy and stem cell transplant (very rarely)

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.

Whether the tumor appears to have been removed completely or not, 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.

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.

All of these treatments can have side effects, but many of them can be made less troublesome. Your medical team will help you take care of the side effects and help you understand and deal with the medical problems, stress, and other issues related to treatment.

Because many of these things can be more complex for cancer in children, many
people will be involved in your child’s overall care. As a parent, taking care of a child with cancer can be a very big job. It’s important to remember that you will have a lot of help. It’s also important for you to know that the health care professionals who treat children with RMS are using the experience and knowledge gained from many decades of detailed scientific study of treating this disease.

**Thinking about a clinical trial**

Clinical trials are carefully controlled research studies that are done to get a closer look at promising new treatments or procedures. 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 are not right for everyone.

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

**Considering complementary and alternative methods**

You may hear about alternative or complementary methods that your doctor hasn’t mentioned to treat cancer or relieve symptoms. 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 a doctor’s medical treatment. Although some of these methods might be helpful in relieving symptoms or helping you feel better, many have not been proven to work. Some might even be dangerous.

Be sure to talk to your child’s 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. See [Complementary and Alternative Medicine](#) to learn more.

**Help getting through cancer treatment**

The 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 are an important part of your child’s care. These might include nursing or social work
services, financial aid, nutritional advice, rehab, or spiritual help.

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.

*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. It includes:

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

The biopsy is generally the first surgery done for RMS. How it is done, how long recovery takes, and how it affects later treatment depends on many factors. The type of biopsy used is based on imaging test results, the location and size of the tumor, the patient’s age and health, and the expertise of the doctor. (For a description of biopsy types, see [How Is Rhabdomyosarcoma Diagnosed?](#))

Unless it is clear that the cancer has spread to distant parts of the body, surgery is usually the first step in treating rhabdomyosarcoma (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 is clear that all of the cancer can’t be removed because it may help other treatments (chemotherapy and radiation) to work better.

During surgery, nearby lymph nodes are often biopsied to determine if the cancer has spread to these areas, especially if the main tumor is near the testicles in older boys or 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 child’s appearance or cause other problems, then surgery may be delayed until after a few courses of chemotherapy and possibly radiation therapy to try to shrink it, or surgery may not be done at all.

**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. Your child’s 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 was not 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 your child is still on the operating table, 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 may also be done, and a central venous catheter (a thin tube) may be inserted 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 will let the health care team give chemo and other drugs and to 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 used in your child, 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
For several days after surgery, you may need 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.

For more on surgery as a treatment for cancer, see our document [Cancer Surgery](#).

- **References**
  
  See all references for [Rhabdomyosarcoma](#)

Last Medical Review: November 20, 2014 Last Revised: November 21, 2014

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**Chemotherapy for Rhabdomyosarcoma**

All patients with rhabdomyosarcoma (RMS) will get chemotherapy at some point. Even if it appears that the cancer was removed completely by surgery, without chemotherapy it is likely to come back.

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 RMS cells that have spread to other parts of the body, even if they can't be seen.

After surgery, any tiny deposits of RMS that remain 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.

**Drugs used to treat rhabdomyosarcoma**

A combination of chemo drugs is used to treat patients with RMS. The drugs used depend to some extent on which risk group the child is in (described in the section How Is Rhabdomyosarcoma Staged?). Some drugs can be taken by mouth, but most are
given IV (injected into a vein).

The main chemo drugs used to treat children in the low-risk group are vincristine and dactinomycin (also known as actinomycin-D). This combination is often referred to as VA. Sometimes cyclophosphamide is added as well. This 3-drug combination is referred to as VAC.

The VAC regimen is the most common combination used for the intermediate-risk group. Irinotecan or topotecan may be added as well. Other drugs used to treat RMS include ifosfamide, etoposide, and doxorubicin.

The same drugs are also used for children in the high-risk group (which includes children with metastatic disease), but these drugs have not been shown to be as successful in this group. New drugs and drug combinations are continually being studied by researchers. It is hoped that they will improve the survival rate in the high-risk group.

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.

### Possible side effects

Chemo drugs attack cells that are dividing quickly, which is why they often work against cancer cells. But other cells in the body, such as those in the bone marrow (where new blood cells are made), the lining of the mouth and intestines, and the hair follicles, also divide quickly. These cells are also likely to be affected by chemo, which can lead to side effects.

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.

The side effects of chemo depend on the type of drugs, the doses, and how long they are taken. Possible side effects can 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)

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.

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. These drugs can also damage the ovaries or testicles, which might affect fertility (the ability to have children).

Vincristine can damage nerves. Some patients may notice tingling and numbness, particularly in the hands and feet. This often goes away or gets better once treatment is stopped, but it could last a long time in some people.

Recent studies have shown that children under the age of 3 years are more likely to have liver damage from chemotherapy. Doctors now use lower doses for any child younger than 3 years old.

Some chemo drugs can also increase the risk of developing a second type of cancer, 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, including fertility issues and second cancers, see the section Possible Late and Long-term Side Effects of Treatments for Rhabdomyosarcoma.

For more on chemotherapy, see the Chemotherapy section of our website.

- References
See all references for Rhabdomyosarcoma

Last Medical Review: November 20, 2014 Last Revised: November 21, 2014
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.

Radiotherapy is most useful if some of the main tumor is still left after surgery (group II or III) 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 completely removed by surgery (group I).

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. In these patients radiation therapy is started right away (along with chemotherapy).

Radiation isn’t given to the whole body to treat metastases, but it can be given to certain areas of known disease to reduce any symptoms the cancer is causing.

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.

Radiation is usually given daily (5 days a week) over many weeks. Each treatment is much like getting an x-ray, although the dose of radiation is much stronger. For each session, your child will lie on a special table while a machine delivers the radiation from a precise angle. 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.
Newer radiation techniques

Some newer techniques can help doctors aim the treatment at the tumor more accurately while reducing the radiation exposure to nearby healthy tissues. These techniques may help increase the success rate and reduce side effects. Most doctors now use these approaches when they are available.

Three-dimensional conformal radiation therapy (3D-CRT): 3D-CRT uses special computers to precisely map the location of the tumor. Depending on where the tumor is, your child may be fitted with a plastic mold resembling a body cast to keep him or her in the same position during each treatment so that the radiation can be aimed more accurately. 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 converge 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 the section What's New in Rhabdomyosarcoma Research and Treatment?

Possible side effects

The side effects of radiation therapy depend on the dose of radiation and where it is aimed, as well as a child’s age. Some effects are likely to last a short time, while others might have a longer lasting impact.

Short-term side effects can include fatigue and increased numbers of infections. Effects on skin areas that receive radiation can range from hair loss and mild sunburn-like
changes to more severe skin reactions. Radiation to the abdomen or pelvis can cause nausea, vomiting, and diarrhea. In some cases there may be damage to the bladder, which might cause urinary problems. Radiation to the head and neck can cause mouth sores and loss of appetite.

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. (See Possible Late and Long-term Side Effects of Treatments for Rhabdomyosarcoma.)

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

For more on radiation therapy, see our document A Guide to Radiation Therapy.

- References
  See all references for Rhabdomyosarcoma

Last Medical Review: November 20, 2014 Last Revised: November 21, 2014

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High-Dose Chemotherapy and Stem Cell Transplants for Rhabdomyosarcoma

A stem cell transplant (sometimes referred to as a bone marrow transplant) makes it possible to use much higher doses of chemotherapy than would normally be possible. Chemotherapy 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 gets 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 chemotherapy and then putting them back into the blood after chemotherapy 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 is 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.

For more on stem cell transplants, see our document Stem Cell Transplant for Cancer.

- References
  See all references for Rhabdomyosarcoma

Last Medical Review: November 20, 2014 Last Revised: November 21, 2014

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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 tumor, and previous treatments used.

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 tried as well.
In rare cases, surgery may be used for cancers that recur at distant sites, such as if there is a small recurrence in a lung.

Most often, chemotherapy is the best option for distant spread. This might include some of the drugs listed in the Chemotherapy for Rhabdomyosarcoma section, as well as newer drugs being studied. Because these tumors are hard to treat, clinical trials of newer treatments may be a good option in many cases.

- References

See all references for Rhabdomyosarcoma

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