After Treatment for Rhabdomyosarcoma

Living as a Cancer Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- **What Happens During and After Treatment for Rhabdomyosarcoma?**
- **Social, Emotional, and Other Issues in Treating Rhabdomyosarcoma**

Other Concerns After Treatment

Rhabdomyosarcoma survivors are at risk for possible late effects of their cancer treatment. It’s important to discuss what these possible effects might be with your child’s medical team so you know what to watch for and report to the doctor.

- **Possible Late and Long-Term Side Effects of Treatments for Rhabdomyosarcoma**

**What Happens During and After Treatment for Rhabdomyosarcoma?**

During and after treatment for rhabdomyosarcoma (RMS), the main concerns for most families are the short- and long-term effects of the tumor and its treatment, and concerns about the tumor still being there or coming back.

It’s certainly normal to want to put the tumor and its treatment behind you and to get back to a life that doesn’t revolve around cancer. But it’s important to realize that close follow-up care is a central part of this process that offers your child the best chance for recovery and long-term survival.
Doctor visits and tests

Your child will probably have to return to the doctor often during chemotherapy for lab tests to look for low blood counts that could lead to bleeding or serious infection. The doctor will also check for other side effects from treatment. Your child may need blood transfusions to treat low blood counts or antibiotics to treat an infection.

Usually chemotherapy and follow-up testing will be done in the pediatric cancer center, but if the center is far from your home, the specialists involved in your child’s care can work with your local doctor to try to reduce your need to travel.

Once treatment is finished, the health care team will discuss a follow-up schedule with you, including which tests should be done and how often. For several years after treatment, it’s very important for your child to have regular follow-up exams with the cancer care team. The doctors will continue to watch for signs of disease, as well as for short-term and long-term side effects of treatment. Doctor visits will be more frequent at first, but the time between visits may get longer as time goes on.

Checkups after treatment of RMS include careful physical exams, lab tests, and sometimes imaging tests such as computed tomography (CT), magnetic resonance imaging (MRI), or positron emission tomography (PET) scans. If the RMS comes back (recurs), it is usually within the first few years after treatment. As time goes by, the risk of recurrence goes down, although doctor visits are still important because some side effects of treatment might not show up until years later.

If the tumor comes back, or if it does not respond to treatment, your child’s doctors will discuss with you the various treatment options available (as discussed in Rhabdomyosarcoma That Progresses or Recurs After Initial Treatment).

Some side effects from the treatment of RMS might not show up until many years later, including effects on fertility and a risk of developing another type of cancer at a later time. It’s important to talk with your child’s doctors to understand what these risks are. (See the section Possible Late and Long-term Side Effects of Treatments for Rhabdomyosarcoma for more details.)

- References

See all references for Rhabdomyosarcoma

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Social, Emotional, and Other Issues in Treating Rhabdomyosarcoma

Social and emotional issues might come up both during and after treatment. Factors such as the person’s age when diagnosed and the extent of treatment can play a role here.

Most often, rhabdomyosarcoma (RMS) develops during a very sensitive time in a young person’s life. RMS and its treatment can have a profound effect on how a person looks and how they view themselves and their body. It can also affect how they do some everyday tasks, including certain school, work, or recreational activities. These effects are often greatest during the first year of treatment, but they can last a long time in some people. It’s important that the treating center assess the family situation as soon as possible, so that any areas of concern can be addressed.

Many experts recommend that school-aged patients attend school as much as possible. This can help them maintain a sense of daily routine and keep their friends informed about what is happening.

Friends can be a great source of support, but patients and parents should know that some people have misunderstandings and fears about cancer. Some cancer centers have a school re-entry program that can help in these situations. In this program, health educators visit the school and tell students about the diagnosis, treatment, and changes that the cancer patient may go through. They also answer any questions from teachers and classmates. (For more information, see our document Children Diagnosed With Cancer: Returning to School.)

Centers that treat many patients with RMS may have programs to introduce new patients to children or teens who have finished their treatment. This can give patients an idea of what to expect during and after treatment, which is very important. Seeing another patient with RMS doing well after treatment is often helpful. Support groups also might be helpful.

Parents and other family members can also be affected, both emotionally and in other ways. Some common family concerns during treatment include financial stresses, traveling to and staying near the cancer center, the possible loss of a job, and the need for home schooling. Social workers and other professionals at treatment centers can
help families sort through these issues.

During treatment, patients and their families tend to focus on the daily aspects of getting through it and beating the cancer. But once treatment is finished, a number of emotional concerns can come up. Some of these might last a long time. They can include things like:

- Dealing with physical changes that can result from the treatment
- Worrying about the cancer returning or new health problems developing
- Feeling resentful for having had cancer or having to go through treatment when others do not
- Worrying about being treated differently or discriminated against (by friends, classmates, coworkers, employers, etc.)
- Being concerned about dating, marrying, and having a family later in life

No one chooses to have RMS, but for many children and teens, the experience can eventually be positive, helping to establish strong self-values. Others may have a harder time recovering, adjusting to life after cancer, and moving on. It is normal to have some anxiety or other emotional reactions after treatment, but feeling overly worried, depressed, or angry can affect many parts of a young person’s growth. It can get in the way of relationships, school, work, and other aspects of life.

With support from family, friends, other survivors, mental health professionals, and others, many people who have survived cancer can thrive in spite of the challenges they’ve had to face. If needed, doctors and other members of the health care team can recommend special support programs and services to help after cancer treatment.

Although the psychological impact of this disease on children and teens is most obvious, adults with this disease face many of the same challenges. They should also be encouraged to take advantage of the cancer center’s physical therapy, occupational therapy, and counseling services.

- References

See all references for Rhabdomyosarcoma

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Possible Late and Long-Term Side Effects of Treatments for Rhabdomyosarcoma

More children and teens with rhabdomyosarcoma (RMS) are now surviving this cancer. Doctors have learned that the treatment might affect children’s health later in life, so watching for health effects as they get older has become more of a concern in recent years.

It’s important to discuss what these possible effects might be with your child’s medical team before starting treatment. Doctors try to limit these potential side effects as much as possible when planning treatment.

The long-term effects of surgery depend a great deal on the location and extent of the tumor(s). Some operations leave few physical changes other than a scar, while more extensive operations can lead to changes in appearance or in how some parts of the body function, which might require physical rehabilitation afterward.

Some chemotherapy drugs can damage cells in the ovaries or testicles, which might affect a patient’s ability to have children later on. For parents, it’s important to discuss this with your child’s health care team before treatment. In some cases there may be ways to help preserve fertility. For more information, see our documents Fertility and Women With Cancer and Fertility and Men With Cancer.

The long-term side effects of radiation therapy can sometimes be serious, especially for young children. Bones and soft tissues that get radiation might not grow as well. Depending on the area getting radiation, this might cause problems such as curvature of the spine, a shortened arm or leg, limited motion of a joint, hardening of the surrounding soft tissue, or poor development of the facial bones. Other problems linked to radiation can include stiffening of the lungs, cataracts and poor vision in an involved eye, and later problems with sexual function. Young children’s brains are especially sensitive to radiation to the head, which can lead to learning problems or other issues, so doctors do their best to avoid this when possible.

Children who get chemotherapy and/or radiation therapy also have a small, but definitely increased, risk of second cancers later in life. These include bone cancer, leukemia, or other soft tissue tumors. The bone cancers seem to be linked with radiotherapy, while the leukemias are more often seen after treatment with cyclophosphamide and related chemo drugs. These second cancers affect only a small
number of RMS survivors, and these are children who most likely would not have survived without these treatments. For more information on second cancers, see our document Second Cancers Caused by Cancer Treatment.

There may be other possible complications from treatment as well. Your child’s doctor should carefully review any possible problems with you before your child starts treatment.

Along with physical side effects, some childhood cancer survivors might have emotional or psychological issues. They might also have problems with normal functioning and school work. These can often be addressed with support and encouragement. If needed, doctors and other members of the health care team can recommend special support programs and services to help children after cancer treatment.

**Long-term follow-up care for children and teens**

To help increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives, the Children’s Oncology Group (COG) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines can help you know what to watch for, what screening tests should be done to look for problems, and how late effects can be treated.

It’s very important to discuss possible long-term complications with your child’s health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child’s doctors about the COG survivor guidelines. You can also read them on the COG website: www.survivorshipguidelines.org. The guidelines are written for health care professionals. Patient versions of some of the guidelines are available (as “Health Links”) on the site as well, but we urge you to discuss them with your doctor.

For more about some of the possible long-term effects of treatment, see our document Children Diagnosed With Cancer: Late Effects of Cancer Treatment.

**Keeping good medical records**

As much as you might want to put the experience behind you once treatment is completed, it is very important to keep good records of your child’s medical care during this time. This can be very helpful later on as your child changes doctors. Gathering these details during and soon after treatment may be easier than trying to get them at some point in the future. Be sure the doctors have the following information (and always
keep copies for yourself):

- A copy of the pathology report(s) from any biopsies or surgeries.
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)
- If there was surgery, a copy of the operative report(s).
- If your child stayed in the hospital, a copy of the discharge summary the doctor wrote when the child was sent home.
- If chemotherapy was given, a list of the final doses of each drug your child received.
- If radiation therapy was given, a summary of the type and dose of radiation and when and where it was given.
- The names and contact information of the doctors who treated your child’s cancer

It is also very important to keep health insurance coverage. Tests and doctor visits cost a lot, and even though no one wants to think of the tumor coming back, this could happen.

- References
  See all references for Rhabdomyosarcoma

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