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# 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 After Treatment for Rhabdomyosarcoma?](#)

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# What Happens After Treatment for Rhabdomyosarcoma?

During [treatment for rhabdomyosarcoma \(RMS\)](#)<sup>1</sup>, most patients and their families are focused on getting through treatment and beating the cancer. After treatment, the focus tends to shift toward the short- and long-term effects of the cancer and its treatment, and concerns about the cancer coming back.

It's normal to want to get back to a life that doesn't revolve around cancer as quickly as possible. But close follow-up care is a central part of this process that offers the best chance for recovery and long-term survival.

## Follow-up visits and tests

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 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](#)<sup>2</sup> 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 (see below).

If [the tumor comes back, or if it does not respond to treatment](#)<sup>3</sup>, your doctors will discuss with you the various treatment options available.

### **Ask the cancer care team for a survivorship care plan**

Talk with the treatment team about developing a [survivorship care plan](#)<sup>4</sup>. This plan might include:

- A summary of the diagnosis, tests done, and treatment given
- A suggested schedule for follow-up exams and tests
- A schedule for other tests that might be needed in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from the cancer or its treatment
- A list of possible late- or long-term side effects from treatment, including what to watch for and when to contact the doctor

### **Keeping health insurance and copies of medical records**

As much as you might want to put the experience behind you once treatment is completed, it's also very important to keep good records of your (child's) medical care during this time. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. This can be very helpful later on if you (or your child) change doctors. Learn more about this in [Keeping Copies of Important Medical Records](#)<sup>5</sup>.

It's also very important to keep [health insurance](#)<sup>6</sup> coverage. Tests and doctor visits can cost a lot, and even though no one wants to think of the tumor coming back, this could happen.

## Possible late and long-term effects of treatment

Treatment for RMS might affect a person's health later in life. Young people in particular are at risk for possible late effects of their treatment. This risk depends on many factors, such as the size and location of the cancer, the treatments received, doses of cancer treatment, and the person's age when treated.

The long-term effects of [surgery](#)<sup>7</sup> depend a great deal on the location and extent of the tumor(s). Some operations leave just 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](#)<sup>8</sup> 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 [Preserving Fertility in Children and Teens With Cancer](#)<sup>9</sup>.

The long-term side effects of [radiation therapy](#)<sup>10</sup> 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 curving 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 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.

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.

## 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](http://www-survivorshipguidelines.org)<sup>11</sup>. 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 [Late Effects of Childhood Cancer Treatment](#)<sup>12</sup>.

## **Social and emotional issues**

Most often, RMS develops during the childhood or teenage years, a very sensitive time in a 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 be long-lasting 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.

These types of issues can often be addressed with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help children and teens after cancer treatment. For more information, see [When Your Child's Treatment Ends](#)<sup>13</sup>.

No one chooses to have RMS, but for many people, the experience can eventually be positive, helping to establish strong self-values. Other people 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 often recommend special support programs and services to help after cancer treatment.

Although RMS and its treatment can have social and emotional effects on children and teens (and their families), adults with this disease face many of the same challenges, and are also encouraged to take advantage of the cancer center's physical therapy, occupational therapy, and counseling services.

## Hyperlinks

1. [www.cancer.org/cancer/rhabdomyosarcoma/treating.html](http://www.cancer.org/cancer/rhabdomyosarcoma/treating.html)
2. [www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html)
3. [www.cancer.org/cancer/rhabdomyosarcoma/treating/recurrent-disease.html](http://www.cancer.org/cancer/rhabdomyosarcoma/treating/recurrent-disease.html)
4. [www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html)
5. [www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html)
6. [www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html)
7. [www.cancer.org/cancer/rhabdomyosarcoma/treating/surgery.html](http://www.cancer.org/cancer/rhabdomyosarcoma/treating/surgery.html)
8. [www.cancer.org/cancer/rhabdomyosarcoma/treating/chemotherapy.html](http://www.cancer.org/cancer/rhabdomyosarcoma/treating/chemotherapy.html)
9. [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](http://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)
10. [www.cancer.org/cancer/rhabdomyosarcoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/rhabdomyosarcoma/treating/radiation-therapy.html)
11. <http://www.survivorshipguidelines.org>
12. [www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html](http://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html)
13. [/content/cancer/en/treatment/children-and-cancer/when-your-child-has-cancer/when-your-childs-treatment-ends.html](http://content.cancer/en/treatment/children-and-cancer/when-your-child-has-cancer/when-your-childs-treatment-ends.html)

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Okcu MF, Hicks J. Rhabdomyosarcoma in childhood and adolescence: Treatment. UpToDate. Accessed at [www.uptodate.com/contents/rhabdomyosarcoma-in-childhood-adolescence-and-adulthood-treatment](http://www.uptodate.com/contents/rhabdomyosarcoma-in-childhood-adolescence-and-adulthood-treatment) on June 4, 2018.

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### Written by

The American Cancer Society medical and editorial content team  
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