



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.

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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.

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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/types/rhabdomyosarcoma/treating.html](http://www.cancer.org/cancer/types/rhabdomyosarcoma/treating.html)
2. [www.cancer.org/cancer/types/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/types/rhabdomyosarcoma/detection-diagnosis-staging/how-diagnosed.html)
3. [www.cancer.org/cancer/types/rhabdomyosarcoma/treating/recurrent-disease.html](http://www.cancer.org/cancer/types/rhabdomyosarcoma/treating/recurrent-disease.html)
4. [www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html](http://www.cancer.org/cancer/survivorship/long-term-health-concerns/survivorship-care-plans.html)
5. [www.cancer.org/cancer/survivorship/long-term-health-concerns/keeping-copies-of-important-medical-records.html](http://www.cancer.org/cancer/survivorship/long-term-health-concerns/keeping-copies-of-important-medical-records.html)
6. [www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html](http://www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html)
7. [www.cancer.org/cancer/types/rhabdomyosarcoma/treating/surgery.html](http://www.cancer.org/cancer/types/rhabdomyosarcoma/treating/surgery.html)
8. [www.cancer.org/cancer/types/rhabdomyosarcoma/treating/chemotherapy.html](http://www.cancer.org/cancer/types/rhabdomyosarcoma/treating/chemotherapy.html)
9. [www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html](http://www.cancer.org/cancer/managing-cancer/side-effects/fertility-and-sexual-side-effects/preserving-fertility-in-children-and-teens-with-cancer.html)
10. [www.cancer.org/cancer/types/rhabdomyosarcoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/types/rhabdomyosarcoma/treating/radiation-therapy.html)
11. [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)
12. [www.cancer.org/cancer/survivorship/children-with-cancer/late-effects-of-cancer-treatment.html](http://www.cancer.org/cancer/survivorship/children-with-cancer/late-effects-of-cancer-treatment.html)

## References

National Cancer Institute. Childhood Rhabdomyosarcoma Treatment (PDQ®). 2018. Accessed at [www.cancer.gov/types/soft-tissue-sarcoma/hp/rhabdomyosarcoma-treatment-pdq](http://www.cancer.gov/types/soft-tissue-sarcoma/hp/rhabdomyosarcoma-treatment-pdq) on June 4, 2018.

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.

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.

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## Written by

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

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