

[Retinoblastoma - Childhood - Follow-Up Care](#) [1]

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 08/2015

ON THIS PAGE: You will read about your child's medical care after cancer treatment is finished and why this follow-up care is important. To see other pages, use the menu on the side of your screen.

Care for children diagnosed with cancer doesn't end when active treatment has finished. Your child's health care team will continue to check to make sure the cancer has not returned, manage any side effects, and monitor your child's overall health. This is called follow-up care. All children treated for cancer, including retinoblastoma, should have life-long, follow-up care.

This plan may include regular physical examinations and/or medical tests to monitor your child's recovery for the coming months and years. Once a child has been free of retinoblastoma for two to four years after treatment, and is considered cured, the emphasis during periodic follow-up visits changes. Pediatric oncologists will focus on the quality of the child's life, including developmental and emotional concerns.

If enucleation took place, most young children adapt well to the loss of one eye. Rarely, both eyes will need to be removed to save the child's life. If both eyes are removed, the local educational system is required to provide special services. Parents are encouraged to investigate the school's services and advocate on their child's behalf. Other [rehabilitation](#) [3] services may also be needed to help the child cope with the vision loss.

Learn more about the [importance of follow-up care](#) [4].

Watching for recurrence

One goal of follow-up care is to check for a recurrence. Cancer recurs because small areas of

cancer cells may remain undetected in the body. Over time, these cells may increase in number until they show up on test results or cause signs or symptoms.

During follow-up care, a doctor familiar with your child's medical history can give you personalized information about the risk of recurrence. Your doctor will also ask specific questions about your child's health. Some children may have blood tests or imaging tests as part of regular follow-up care, but testing recommendations depend on several factors, including the type and stage of cancer originally diagnosed and the types of treatment given.

Managing long-term and late side effects of childhood cancer

Sometimes, side effects may linger beyond the active treatment period. These are called long-term side effects. In addition, other side effects called late effects may develop months or even years afterwards. Late effects can occur almost anywhere in the body and include physical problems, such as heart and lung problems and second cancers, and emotional and cognitive (memory, thinking, and attention) problems, such as anxiety, depression, and learning difficulties.

Based on the type of treatment your child received and whether the child has the genetic form of retinoblastoma, the doctor will determine what evaluations are needed to check for long-term effects. This may include imaging studies (CT scan or MRI) and blood tests. Counseling will also be provided for children who have an increased risk of additional tumors later in life, such as those with retinoblastoma in both eyes and those with retinoblastoma in one eye who have a family history of the disease. Yearly visits to specialized ophthalmologic and medical oncologists are necessary in order to fully monitor the child's recovery and to find any secondary cancer in its earliest stages. Follow-up care should also address any developmental or emotional concerns.

Follow-up care should address your child's quality of life, including any developmental or emotional concerns.

The Children's Oncology Group (COG) has studied the physical and psychological effects that childhood cancer survivors face. Based on these studies, COG has created recommendations for long-term follow-up care for childhood, adolescent, and young adult cancer survivors that can be found on a separate website: www.survivorshipguidelines.org [5].

Keeping a child's personal health record

You are encouraged to organize and keep a personal record of the child's medical information. The doctor will help you create this. That way, as the child enters adulthood, he or she has a clear, written history of the diagnosis, the treatment given, and the doctor's recommendations about the schedule for follow-up care. ASCO offers [forms to help create a treatment summary to keep track of the cancer treatment your child received and develop a survivorship care plan](#) [6] once treatment is completed.

Some children continue to see their oncologist, while others transition back to the general care of their family doctor or another health care professional. This decision depends on several factors, including the type and stage of cancer, side effects, health insurance rules, and your family's personal preferences. Talk with your health care team about your child's ongoing medical care and any concerns you have about his or her future health.

If a doctor who was not directly involved in your child's cancer care will lead the follow-up care, be sure to share the cancer treatment summary and survivorship care plan forms with him or her, as well as all future health care providers. Details about the specific cancer treatment given are very valuable to the health care professionals who will care for your child throughout his or her lifetime.

The [next section in this guide is Survivorship](#) [7] and it describes how to cope with challenges in everyday life after a cancer diagnosis. Or, use the menu on the side of your screen to choose another section to continue reading this guide.

Links

[1] <http://www.cancer.net/cancer-types/retinoblastoma-childhood/follow-care>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/25397>

[4] <http://www.cancer.net/node/29386>

[5] <http://www.survivorshipguidelines.org/>

[6] <http://www.cancer.net/node/25394>

[7] <http://www.cancer.net/node/34381>