After Treatment for Retinoblastoma

Living as a Cancer Survivor

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

- What Happens After Treatment for Retinoblastoma?
- Emotional and Social Issues for Children With Retinoblastoma and Their Families
- Genetic Counseling and Testing for Retinoblastoma

Other Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about possible late effects of treatment, as well as concerns about developing another cancer.

- Second Cancers After Retinoblastoma
- Late and Long-Term Effects of Treatment for Retinoblastoma

What Happens After Treatment for Retinoblastoma?

During and after treatment for retinoblastoma, the main concerns for most families are the short- and long-term effects of the cancer and its treatment, and concerns about the cancer 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 follow-up care is a central part of this process that offers your child the best chance for recovery and long-term survival.
**Follow-up exams and tests**

Once treatment is finished, your health care team will discuss a follow-up schedule with you, including which tests should be done and how often. It’s very important to go to all follow-up appointments. Follow-up is needed to check for cancer recurrence, as well as possible side effects of certain treatments. Doctor visits and tests are done more often at first. If nothing abnormal is found, the time between tests can then be extended.

If a child with retinoblastoma in only one eye has been treated by enucleation (removal of the eye), regular exams are needed to look for tumor recurrence or spread, or any growth problems related to the surgery. It’s also important to have the remaining eye checked regularly so that if a second retinoblastoma develops later on it can be found and treated as early as possible.

For children who have had treatment other than removal of the eye, close follow-up exams by an ophthalmologist (eye doctor) are very important to look for signs of the cancer coming back or other problems. In children with hereditary retinoblastoma, it’s very common for new tumors to form until they are 3 or 4 years old. This is not a failure of the treatment, but the natural process in bilateral retinoblastoma. Therefore, it’s very important that even after completing all treatments, children are examined regularly by specialists.

During these exams, general anesthesia (where the child is asleep) may be needed to keep a young child still enough for the doctor to do a thorough eye exam. This is done to be certain the cancer has been destroyed, to find recurrences as early as possible, and to look for problems caused by treatments.

It’s important for you to report any new symptoms your child is having, such as pain or vision problems, to your doctor right away, since they could be an early sign of cancer coming back or long-term side effects of treatment.

**Keeping good medical records after treatment for retinoblastoma**

As much as you might want to put the experience behind you once treatment is done, it’s very important to keep good records of your child’s medical care during this time. This can be very helpful for your child later on as an adult and for his or her doctors. Gathering these details during or soon after treatment may be easier than trying to get them at some point in the future. Be sure your child’s doctors have the following information (and always keep copies for yourself):
• A copy of the pathology report(s) from any biopsies or surgeries
• If your child had surgery, a copy of the operative report(s)
• If your child stayed in the hospital, copies of the discharge summaries that the doctors wrote when he or she was sent home
• If chemotherapy was given, a list of the drugs, drug doses, and when they were given
• If radiation therapy was given, a summary of the type and dose of radiation and when and where it was given
• If genetic testing was done, the results of those tests
• The names and contact information of the doctors who treated your child’s cancer

It’s 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 cancer coming back, this could happen.

• References
See all references for Retinoblastoma

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Genetic Counseling and Testing for Retinoblastoma

If you have a child with retinoblastoma, your doctor may suggest your family consider genetic counseling. This is because some retinoblastomas are caused by a genetic mutation that can be inherited.

If a child is diagnosed with retinoblastoma in both eyes, it can be assumed that they have the hereditary form of the disease (even if there is no family history of the disease), which means they carry the mutant RB1 gene in all their cells. Some children with retinoblastoma in only one eye might also carry the mutant RB1 gene in all their cells. This can be confirmed with a blood test. Children with this mutant gene are at increased risk for developing other cancers later in life, and will have a 1 in 2 chance of passing the RB1 gene change on to each of their children.
If the child carries the mutated *RB1* gene, then other children in the family might have inherited the same abnormal gene as well. Meeting with a genetic counselor can give you a better idea of what this risk might be and if other children in the family should be tested for the mutation. The genetic counselor will:

- Review the child’s medical records and ask questions about other relatives to estimate the likelihood of an inherited gene affecting some family members.
- Provide information and answer questions about genetic testing, and schedule tests for other children in your family (if needed) to help determine their risk of developing retinoblastoma.

If tests show your children are at risk of developing retinoblastoma, their doctors will follow them very closely to find retinoblastoma at the earliest possible stage, if it occurs. It’s very helpful to be able to tell which children have inherited the mutation that leads to retinoblastoma, since those children will need to be monitored closely.

Sometimes it’s not possible to tell with certainty if a child inherited the *RB1* gene mutation. In those cases the safest plan is to monitor children in the family closely for retinoblastoma with frequent eye exams.

- **References**
  
  See all references for Retinoblastoma

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Late and Long-Term Effects of Treatment for Retinoblastoma

With major advances in treatment in recent decades, most children treated for retinoblastoma are now expected to have normal lifespans. But some of the treatments needed to cure the cancer can 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.

Just as the treatment of childhood cancer requires a very specialized approach, so does
the care and follow-up after treatment. The earlier any problems can be recognized, the more likely it is they can be treated effectively.

Young people treated for retinoblastoma are at risk, to some degree, for several possible late effects of their cancer treatment. It’s important to discuss what these possible effects might be with your child’s medical team.

The risk of late effects depends on a number of factors, such as the specific treatments used, the doses of treatment, and the age of the child when being treated. These late effects can include:

- Reduction or loss of vision in the affected eye(s)
- Deformities in the bones around the eye (especially after surgery or external radiation)
- Reduced kidney function
- Heart problems after getting certain chemotherapy drugs
- Slowed or delayed growth and development
- Changes in sexual development and ability to have children (see Fertility and Women With Cancer and Fertility and Men With Cancer)
- Increased risk of other cancers (especially in children with hereditary retinoblastoma – see the section Second Cancers After Retinoblastoma)

Other complications from treatment are possible as well. Your child’s doctor should carefully review any possible problems with you.

### Long-term follow-up care

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 type of 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). 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.
Second Cancers After Retinoblastoma

Hereditary retinoblastoma

Children with the hereditary form of retinoblastoma have a much higher risk for developing other types of cancer throughout their lives. This is because each cell in the body has an abnormal \(RB1\) tumor suppressor gene, which would normally help stop some of these cancers from forming.

The risk for these cancers is even higher in any parts of the body that received radiation during treatment for retinoblastoma. Younger children treated with radiation therapy are more likely than older children to develop side effects such as second cancers or problems with bone growth in the irradiated area. Chemotherapy with certain drugs can also increase the risk of some cancers.

Most of these cancers are very treatable if detected early, which is why it is very important that these children are followed closely throughout life. The entire body must be examined carefully to avoid missing these second cancers.

The most common second cancers among retinoblastoma survivors include:

- \(\text{Osteosarcoma}\) (a type of bone cancer)
- \(\text{Soft tissue sarcomas}\) (cancers that develop in muscle, tendons and ligaments, and fatty tissue)
- \(\text{Melanoma}\) (a type of skin cancer)
- \(\text{Lung cancer}\)
Because of the increased risk these children face, it’s important that they’re taught about other factors that might increase their risk of cancer as they get older. For example, too much sun exposure can increase the risk of melanoma even further, and smoking can increase lung cancer risk, so avoiding these types of risk factors is very important. It’s also important to know what types of cancer screening tests these children might need as they get older. Of course, these children are also at risk of other cancers as they get older, just like children who did not have retinoblastoma.

Children with hereditary retinoblastoma also have a small risk of developing a tumor in the pineal gland within a few years. (This is known as trilateral retinoblastoma.) The pineal gland is a bean-sized structure lying under the middle of the brain. It can have cells similar to retina cells, which is why tumors can start there. This is why doctors often recommend that MRI scans of the head be done regularly for up to 5 years to try to detect such tumors as early as possible.

**Non-hereditary (sporadic) retinoblastoma**

Children who do not have the hereditary form of retinoblastoma don’t have the RB1 gene change in all of their cells, so they don’t have such a high risk of other cancers. Still, their risk of some cancers might be higher from getting chemotherapy and/or radiation therapy. These children are also at risk for other cancers as they get older, just like children who did not have retinoblastoma.

**References**

See all references for Retinoblastoma
Emotional and Social Issues for Children With Retinoblastoma and Their Families

Most children with retinoblastoma are very young at the time of diagnosis. Still, some children may have emotional or psychological issues that need to be addressed during and after treatment. Depending on their age, they may also have some problems with normal functioning and school work. These can often be overcome with support and encouragement. Doctors and other members of the health care team can recommend special support programs and services to help children during and after treatment.

Parents and other family members can also be affected, both emotionally and in other ways. The treatment center should evaluate the family situation as soon as possible. Some common family concerns include financial stresses, traveling to and staying near the cancer center, and the need for family members to take time off from work. If the patient or family members have concerns, they can be addressed before they become a crisis.

Centers that treat many patients with retinoblastoma may have programs to introduce new patients and their families to others who have finished their treatment. This can give parents an idea of what to expect during and after treatment, which is very important. Seeing another patient with retinoblastoma doing well is often helpful.

If needed, centers can also refer patients to special programs and facilities for the visually impaired. Most patients treated for retinoblastoma in only one eye will have normal vision in the unaffected eye, but they may have a cosmetic deformity in the treated eye. The cosmetic problems can often be lessened by treatment in a center with expertise in reconstructive surgery. Early intervention and counseling can also help address any psychological effects of changes in appearance.

Support groups for families of children with cancer can also be helpful. If you need help finding such a group, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

- References
  See all references for Retinoblastoma

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