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# After Treatment for Retinoblastoma

## Living as a Cancer Survivor

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

- [Living as a Retinoblastoma Survivor](#)

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# Living as a Retinoblastoma Survivor

During and after [treatment](#)<sup>1</sup> for retinoblastoma, the main concerns for most families are the daily aspects of getting through treatment and beating the cancer. After treatment, the concerns tend to shift toward the 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 a process that offers your child the best chance for recovery and long-term survival.

## Follow-up exams and tests

Once treatment is finished, your child's health care team will discuss a follow-up schedule with you, including which [tests](#)<sup>2</sup> 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 (or new cancers), 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 removal of that eye (enucleation), 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 heritable (bilateral) retinoblastoma, it's very common for new tumors to form until the child is 3 or 4 years old. This is not a failure of the treatment, but the natural process in heritable retinoblastoma. Therefore, it's very important that these children are examined regularly by specialists after completing treatment.

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.

Children with the heritable form of 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 beneath the middle of the brain. It can have cells similar to retina cells, which is why tumors can start there. Many doctors recommend that MRI scans of the head be done regularly for several years after treatment to try to detect these tumors as early as possible.

It's also 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.

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

Talk with the treatment team about developing a [survivorship care plan](#)<sup>3</sup>. This plan might include:

- A summary of the [diagnosis](#)<sup>4</sup>, [tests done](#)<sup>5</sup>, and [treatment](#)<sup>6</sup> 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](#)<sup>7</sup> 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 in [Keeping Copies of Important Medical Records](#)<sup>8</sup>.

It's also very important to keep [health insurance](#)<sup>9</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

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 a child'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 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, the [type of retinoblastoma](#)<sup>10</sup> (heritable or non-heritable), 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](#)<sup>11</sup> or [external radiation](#)<sup>12</sup>)
- Reduced kidney function
- Heart problems after getting certain [chemotherapy](#)<sup>13</sup> drugs
- Slowed or delayed growth and development
- Changes in sexual development and [ability to have children](#)<sup>14</sup>
- Increased risk of other cancers (especially in children with hereditary retinoblastoma – see below)

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

## Second cancers after retinoblastoma

### Heritable (hereditary) retinoblastoma

Children with the [heritable form of retinoblastoma](#)<sup>15</sup> have a much higher risk of developing other types of cancer throughout their lives. This is because each cell in the body has an abnormal *RB1* tumor suppressor gene, which if it were normal would help stop some of these cancers from forming.

The risk for these cancers is even higher in any parts of the body that got [radiation](#)<sup>16</sup> during treatment for retinoblastoma.

Most of these cancers are very treatable if detected early, which is why it's very important that these children are followed closely throughout their lives.

The most common second cancers among hereditary retinoblastoma survivors include:

- [Osteosarcoma](#)<sup>17</sup> (a type of bone cancer)
- [Soft tissue sarcomas](#)<sup>18</sup> (cancers that develop in muscle, tendons and ligaments, and fatty tissue)
- [Melanoma of the skin](#)<sup>19</sup>
- [Lung cancer](#)<sup>20</sup>
- [Lymphoma](#)<sup>21</sup>
- [Bladder cancer](#)<sup>22</sup>
- [Uterine cancer](#)<sup>23</sup>
- [Breast cancer](#)<sup>24</sup> [e](#)<sup>25</sup> [r](#)
- [Brain tumors](#)<sup>26</sup>

- Cancers in the [mouth](#)<sup>27</sup> or [nose](#)<sup>28</sup>

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.

As noted above, children with the heritable form of retinoblastoma also have a small risk of developing a tumor in the pineal gland within a few years. This is why many doctors recommend that MRI scans of the head be done regularly for several years after treatment to try to detect such tumors as early as possible.

### **Non-heritable (sporadic) retinoblastoma**

Children who do not have the heritable 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 as a result of 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.

### **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 \(COG\)](#)<sup>29</sup> 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)<sup>30</sup>. The guidelines themselves 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>31</sup>.

### **Emotional and social issues**

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 types of issues can often be helped 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. For more information, see [When Your Child's Treatment Ends](#)<sup>32</sup>.

Parents and other family members can also be affected, both emotionally and in other ways. 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. Social workers and other professionals at treatment centers can help families sort through these issues.

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.

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 the appearance of the treated eye and the area around it might change. Such changes 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.

### **Hyperlinks**

1. [www.cancer.org/cancer/retinoblastoma/treating.html](http://www.cancer.org/cancer/retinoblastoma/treating.html)
2. [www.cancer.org/cancer/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html)

3. [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)
4. [www.cancer.org/cancer/retinoblastoma/about/what-is-retinoblastoma.html](http://www.cancer.org/cancer/retinoblastoma/about/what-is-retinoblastoma.html)
5. [www.cancer.org/cancer/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html)
6. [www.cancer.org/cancer/retinoblastoma/treating.html](http://www.cancer.org/cancer/retinoblastoma/treating.html)
7. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html)
8. [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)
9. [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)
10. [www.cancer.org/cancer/retinoblastoma/about/what-is-retinoblastoma.html](http://www.cancer.org/cancer/retinoblastoma/about/what-is-retinoblastoma.html)
11. [www.cancer.org/cancer/retinoblastoma/treating/surgery.html](http://www.cancer.org/cancer/retinoblastoma/treating/surgery.html)
12. [www.cancer.org/cancer/retinoblastoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/retinoblastoma/treating/radiation-therapy.html)
13. [www.cancer.org/cancer/retinoblastoma/treating/chemotherapy.html](http://www.cancer.org/cancer/retinoblastoma/treating/chemotherapy.html)
14. [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)
15. [www.cancer.org/cancer/retinoblastoma/causes-risks-prevention/what-causes.html](http://www.cancer.org/cancer/retinoblastoma/causes-risks-prevention/what-causes.html)
16. [www.cancer.org/cancer/retinoblastoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/retinoblastoma/treating/radiation-therapy.html)
17. [www.cancer.org/cancer/osteosarcoma.html](http://www.cancer.org/cancer/osteosarcoma.html)
18. [www.cancer.org/cancer/soft-tissue-sarcoma.html](http://www.cancer.org/cancer/soft-tissue-sarcoma.html)
19. [www.cancer.org/cancer/melanoma-skin-cancer.html](http://www.cancer.org/cancer/melanoma-skin-cancer.html)
20. [www.cancer.org/cancer/lung-cancer.html](http://www.cancer.org/cancer/lung-cancer.html)
21. [www.cancer.org/cancer/lymphoma.html](http://www.cancer.org/cancer/lymphoma.html)
22. [www.cancer.org/cancer/bladder-cancer.html](http://www.cancer.org/cancer/bladder-cancer.html)
23. [www.cancer.org/cancer/uterine-sarcoma.html](http://www.cancer.org/cancer/uterine-sarcoma.html)
24. [www.cancer.org/cancer/breast-cancer.html](http://www.cancer.org/cancer/breast-cancer.html)
25. [www.cancer.org/cancer/breast-cancer.html](http://www.cancer.org/cancer/breast-cancer.html)
26. [www.cancer.org/cancer/brain-spinal-cord-tumors-children.html](http://www.cancer.org/cancer/brain-spinal-cord-tumors-children.html)
27. [www.cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer.html](http://www.cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer.html)
28. [www.cancer.org/cancer/nasopharyngeal-cancer.html](http://www.cancer.org/cancer/nasopharyngeal-cancer.html)
29. <https://www.childrensoncologygroup.org/>
30. <http://www.survivorshipguidelines.org>
31. [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)
32. [7](http://www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-</a></li></ol></div><div data-bbox=)

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## References

Hurwitz RL, Shields CL, Shields JA, et al. Chapter 27: Retinoblastoma. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 7th ed. Philadelphia, Pa: Lippincott Williams & Wilkins; 2016.

Kaufman PL, Kim J, Berry JL. Retinoblastoma: Treatment and outcome. UpToDate. Accessed [www.uptodate.com/contents/retinoblastoma-treatment-and-outcome](http://www.uptodate.com/contents/retinoblastoma-treatment-and-outcome) on September 25, 2018.

Marees T, Moll AC, Imhof SM, et al. Risk of second malignancies in survivors of retinoblastoma: More than 40 years of follow-up. *J Natl Cancer Inst*. 2008;100:1771–1779.

National Cancer Institute. Retinoblastoma Treatment (PDQ®). 2018. Accessed at [www.cancer.gov/types/retinoblastoma/hp/retinoblastoma-treatment-pdq](http://www.cancer.gov/types/retinoblastoma/hp/retinoblastoma-treatment-pdq) on September 25, 2018.

Rodriguez-Galindo C, Orbach DB, VanderVeen D. Retinoblastoma. *Pediatr Clin North Am*. 2015;62:201–223.

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