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## After Treatment for Retinoblastoma

Get information about living well after retinoblastoma treatment and making decisions about next steps.

### 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

- [Follow-up exams and tests](#)
- [Possible late and long-term effects of treatment](#)
- [Second cancers after retinoblastoma](#)
- [Long-term follow-up care](#)
- [Emotional and social issues](#)

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.

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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:

- [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>
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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/types/retinoblastoma/treating.html](http://www.cancer.org/cancer/types/retinoblastoma/treating.html)
2. [www.cancer.org/cancer/types/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/types/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html)
3. [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)
4. [www.cancer.org/cancer/types/retinoblastoma/about/what-is-retinoblastoma.html](http://www.cancer.org/cancer/types/retinoblastoma/about/what-is-retinoblastoma.html)
5. [www.cancer.org/cancer/types/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/types/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html)
6. [www.cancer.org/cancer/types/retinoblastoma/treating.html](http://www.cancer.org/cancer/types/retinoblastoma/treating.html)
7. [www.cancer.org/cancer/managing-cancer/side-effects.html](http://www.cancer.org/cancer/managing-cancer/side-effects.html)
8. [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)
9. [www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html](http://www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html)
10. [www.cancer.org/cancer/types/retinoblastoma/about/what-is-retinoblastoma.html](http://www.cancer.org/cancer/types/retinoblastoma/about/what-is-retinoblastoma.html)
11. [www.cancer.org/cancer/types/retinoblastoma/treating/surgery.html](http://www.cancer.org/cancer/types/retinoblastoma/treating/surgery.html)
12. [www.cancer.org/cancer/types/retinoblastoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/types/retinoblastoma/treating/radiation-therapy.html)
13. [www.cancer.org/cancer/types/retinoblastoma/treating/chemotherapy.html](http://www.cancer.org/cancer/types/retinoblastoma/treating/chemotherapy.html)
14. [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)
15. [www.cancer.org/cancer/types/retinoblastoma/causes-risks-prevention/what-causes.html](http://www.cancer.org/cancer/types/retinoblastoma/causes-risks-prevention/what-causes.html)
16. [www.cancer.org/cancer/types/retinoblastoma/treating/radiation-therapy.html](http://www.cancer.org/cancer/types/retinoblastoma/treating/radiation-therapy.html)
17. [www.cancer.org/cancer/types/osteosarcoma.html](http://www.cancer.org/cancer/types/osteosarcoma.html)
18. [www.cancer.org/cancer/types/soft-tissue-sarcoma.html](http://www.cancer.org/cancer/types/soft-tissue-sarcoma.html)
19. [www.cancer.org/cancer/types/melanoma-skin-cancer.html](http://www.cancer.org/cancer/types/melanoma-skin-cancer.html)
20. [www.cancer.org/cancer/types/lung-cancer.html](http://www.cancer.org/cancer/types/lung-cancer.html)
21. [www.cancer.org/cancer/types/lymphoma.html](http://www.cancer.org/cancer/types/lymphoma.html)
22. [www.cancer.org/cancer/types/bladder-cancer.html](http://www.cancer.org/cancer/types/bladder-cancer.html)
23. [www.cancer.org/cancer/types/uterine-sarcoma.html](http://www.cancer.org/cancer/types/uterine-sarcoma.html)

24. [www.cancer.org/cancer/types/breast-cancer.html](http://www.cancer.org/cancer/types/breast-cancer.html)
25. [www.cancer.org/cancer/types/breast-cancer.html](http://www.cancer.org/cancer/types/breast-cancer.html)
26. [www.cancer.org/cancer/types/brain-spinal-cord-tumors-children.html](http://www.cancer.org/cancer/types/brain-spinal-cord-tumors-children.html)
27. [www.cancer.org/cancer/types/oral-cavity-and-oropharyngeal-cancer.html](http://www.cancer.org/cancer/types/oral-cavity-and-oropharyngeal-cancer.html)
28. [www.cancer.org/cancer/types/nasopharyngeal-cancer.html](http://www.cancer.org/cancer/types/nasopharyngeal-cancer.html)
29. [www.childrensoncologygroup.org/](http://www.childrensoncologygroup.org/)
30. [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)
31. [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)
32. [www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment.html](http://www.cancer.org/cancer/survivorship/children-with-cancer/after-treatment.html)

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