

## Retinoblastoma

### What is retinoblastoma?

Retinoblastoma is a rare cancer that begins in the part of the eye called the retina. About 40% of children have the genetic form of retinoblastoma, meaning it is caused by a specific mutation or change in a gene. When treating children with retinoblastoma, an important goal is preserving vision. Most children (more than 90%) who begin treatment before the retinoblastoma has spread beyond the eye are cured.

### Where does retinoblastoma occur?

The retina is a thin layer of nerve tissue that coats the back of the eye and enables the eye to see. Usually, retinoblastoma is unilateral, which means it occurs only in one eye. But it can be bilateral, which means it occurs in both eyes. Retinoblastoma can spread to the lymph nodes, bones, or bone marrow, which is the spongy tissue inside of bones. Rarely, it involves the central nervous system (brain and spinal cord).

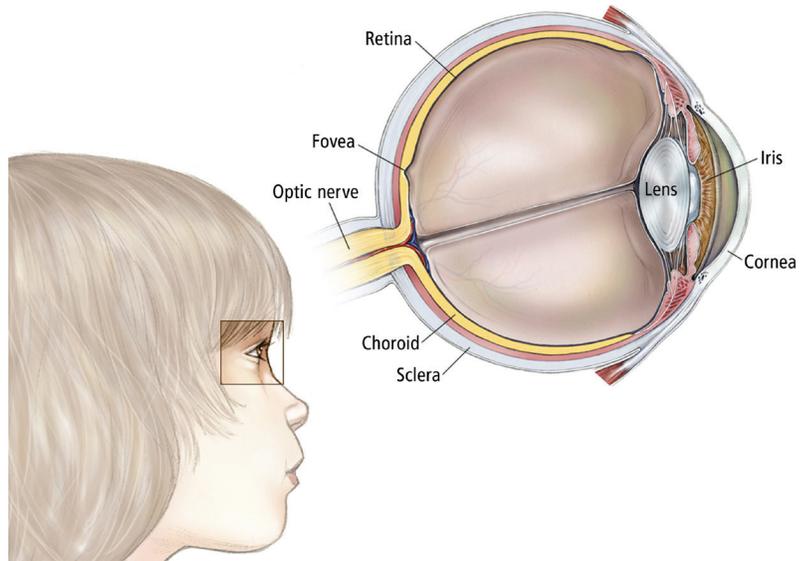


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### What does stage mean?

The stage is a way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body. Retinoblastoma is described as intraocular (only located in one or both eyes) or extraocular (has spread to tissues around the eye or to other parts of the body). The International Classification System is used for staging. Find more information at [www.cancer.net/retinoblastoma](http://www.cancer.net/retinoblastoma).

### How is retinoblastoma treated?

Several types of treatment are used for retinoblastoma. Children with a tumor in one eye can often be cured with enucleation surgery to remove the eye. Children usually adapt well to the change in vision. A prosthesis, which is an artificial eye, is used to fill the eye area. Children with a tumor in both eyes have enucleation if vision cannot be preserved using other treatment. Radiation therapy, cryotherapy (destroying cancer cells by freezing them), or laser therapy (shrinking tumors using heat or light) are other treatment options. Chemotherapy may also be used to shrink tumors in the eye or eliminate any remaining smaller tumors after other treatments.

When making treatment decisions, consider a clinical trial; most children with cancer are treated as part of one. Talk with your child's doctor about all treatment options. The side effects of retinoblastoma treatment can often be prevented or managed with the help of your child's health care team. This is called palliative care and is an important part of the overall treatment plan.

### How can I help my child or teen cope with retinoblastoma?

Helping your child understand a cancer diagnosis is a key part of the coping process. Children with cancer should be treated at a cancer center with access to pediatric specialists. Absorbing the news of a cancer diagnosis and communicating with your child's health care team are key parts of the coping process. Seeking support, organizing your child's health information, making sure all of your questions are answered, and participating in the decision-making process are other steps. Talk with your child's health care team about any concerns.

## Questions to ask the health care team

Regular communication is important in making informed decisions about your child's health care. Consider asking the following questions of your child's health care team:

- Does my child have the genetic form of retinoblastoma?
- Can you explain my child's pathology report (laboratory test results) to me?
- Would you explain my child's treatment options?
- What clinical trials are open to my child? Where are they located, and how do I find out more about them?
- What treatment plan do you recommend for my child? Why?
- What is the goal of each treatment? Is it to eliminate the cancer, help my child feel better, or both?
- Who will be part of the treatment team, and what does each member do?
- What is the likelihood that the recommended treatment can save my child's vision?
- If enucleation is needed, how soon can my child receive an artificial eye, and what support services are available to help my child adjust to a partial/total loss of vision?
- How will this treatment affect my child's daily life? Will he or she be able to go to school and perform his or her usual activities?
- What short-term and long-term side effects may be associated with my child's cancer treatment?
- What follow-up tests will my child need, and how often will he or she need them?
- If I'm worried about managing the costs of my child's cancer care, who can help me?
- Where can I find emotional support for my child? For my family?
- Whom should I call with questions or problems?

Find more questions to ask the health care team at [www.cancer.net/retinoblastoma](http://www.cancer.net/retinoblastoma). For a digital list of questions, download Cancer.Net's free mobile app at [www.cancer.net/app](http://www.cancer.net/app).

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## TERMS TO KNOW

### Benign:

A tumor that is not cancerous

### Biopsy:

Removal of a tissue sample that is then examined under a microscope to check for cancer cells

### Chemotherapy:

The use of drugs to destroy cancer cells

### Chemoreduction:

The use of chemotherapy to shrink a tumor to help preserve vision

### Clinical trial:

A research study that tests a new treatment or drug

### Lymph node:

A tiny, bean-shaped organ that fights infection

### Malignant:

A tumor that is cancerous

### Metastasis:

The spread of cancer from where it began to another part of the body

### Ocular oncologist:

A doctor who specializes in treating eye cancer

### Ophthalmologist:

A doctor who specializes in diseases of the eye

### Pediatric oncologist:

A doctor who specializes in caring for children and teens with cancer

### Radiation therapy:

The use of high-energy x-rays to destroy cancer cells

### Tumor:

An abnormal growth of body tissue

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