

Craniopharyngioma - Childhood - Treatment Options [1]

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ON THIS PAGE: You will learn about the different ways doctors use to treat children with craniopharyngioma. To see other pages, use the menu on the side of your screen.

To take advantage of special expertise necessary to treat a brain tumor, children with brain tumors should be treated at a specialized pediatric center. Doctors at these centers have extensive experience in treating children with brain tumors and have access to the latest technology. A doctor who specializes in treating children with tumors is called a pediatric oncologist. A doctor who specializes in treating children with brain tumors is called a pediatric neuro-oncologist. In many cases, a team of doctors provides care to a child and the family; this is called a [multidisciplinary team](#) [3]. Pediatric treatment centers often have extra support services for children and their families, such as child life specialists, nurse specialists, nutritionists, physical and occupational therapists, social workers, and counselors. Special activities and programs to help your child and family cope may also be available.

Treatment overview

Treatment for craniopharyngioma has a high rate of success. Descriptions of the treatment options for craniopharyngioma are listed below. The treatment plan used depends on whether the tumor can be completely removed by surgery. If the tumor cannot be completely removed, radiation therapy is usually recommended. However, the side effects of radiation therapy must be considered when deciding on the best treatment for very young children. Radiation therapy can cause age-related permanent learning and memory problems, as well as slow the metabolism and decrease levels of hormones needed for the body to function normally.

There are treatments being studied in clinical trials for patients whose tumors cannot be completely removed, but who would like to avoid or delay the need for radiation therapy. Talk with your doctor whether this might be an option for your child. Your child's care plan may also include treatment for symptoms and side effects, an important part of cancer care.

Take time to learn about all of your child's treatment options and be sure to ask questions about things that are unclear. Also, talk about the goals of each treatment with your child's doctor and what your child can expect during treatment. Learn more about [making treatment decisions](#) [4].

Surgery

Surgery is the most common treatment for craniopharyngioma. A neurosurgeon is a doctor who specializes in removing brain tumors.

The goal of surgery is to confirm the diagnosis and remove as much tumor as possible. Complete removal of craniopharyngioma may also be called a complete resection. This is possible for about 70% to 85% of children.

Side effects of surgery depend on the tumor's location. Surgery may damage parts of the brain near the tumor, affecting hormone function, metabolism, vision, arm and leg movement, or consciousness. Sometimes, the tumor may have grown into the optic chiasm, which is an area of the brain that controls vision, or major blood vessels, making it difficult to remove the tumor. Some tumors cannot be removed using surgery because of their location and can only be biopsied. These tumors are called inoperable, and the doctor will recommend treating the tumor in another way.

The doctor may recommend additional treatment following surgery. Research studies have shown that people with a tumor that was partially removed who received radiation therapy live as long as those who had a complete removal of the tumor, and often have fewer side effects, such as stroke, severe bleeding, or damage to the hypothalamus. The hypothalamus is a small structure that regulates the pituitary gland's production of hormones and many other body functions. Talk with your child's doctor before treatment begins about the potential side effects for your child based on the recommended treatment plan.

Learn more about [surgery](#) [5].

Radiation therapy

Radiation therapy is the use of high-energy x-rays or other particles to destroy tumor cells. A doctor who specializes in giving radiation therapy to treat a tumor is called a radiation oncologist. The most common type of radiation treatment is called external-beam radiation therapy, which is radiation given from a machine outside the body. Because radiation therapy can interfere with the normal growth and development of a child's brain, advanced treatment planning techniques should be used to reduce the amount of radiation to the areas of the brain not affected by the tumor.

Radiosurgery is a way to deliver a single, high dose of radiation therapy to the tumor while sparing other areas of the brain. This technique requires a head frame to help localize the tumor, so doctors know exactly where to deliver the radiation treatment. This type of radiation is generally used for recurrent craniopharyngioma (see below).

Short-term side effects from radiation therapy may include fatigue, mild skin reactions and nausea. These side effects go away soon after treatment is finished. More permanent side effects can include hair loss, learning difficulties, low hormone levels, weight gain, and memory problems. Talk with your doctor about possible short- and long-term effects of your child's treatment plan.

Learn more about [radiation therapy](#) [6].

Hormone replacement therapy (HRT)

HRT is the use of medication to replace hormones when the body cannot produce enough on its own. It is often necessary for children with craniopharyngioma because the tumor or its treatment may damage parts of the brain that make hormones, particularly the pituitary gland and the hypothalamus. An endocrinologist is a doctor who specializes in problems with glands and the endocrine system. This specialist will work with you and your child to determine the hormonal therapy that is needed.

Getting care for symptoms and side effects

A brain tumor and its treatment often cause side effects. In addition to treatment to slow, stop, or eliminate the tumor, an important part of care is relieving a person's symptoms and side effects. This approach is called palliative or supportive care, and it includes supporting the patient with his or her physical, emotional, and social needs.

Palliative care can help a person at any stage of illness. People often receive treatment for the tumor and treatment to ease side effects at the same time. In fact, patients who receive both often have less severe symptoms, better quality of life, and report they are more satisfied with treatment.

Palliative treatments vary widely and often include medication, nutritional changes, relaxation techniques, and other therapies. Your child may also receive palliative treatments similar to those meant to eliminate the tumor, such as surgery and radiation therapy. Talk with your child's doctor about the goals of each treatment in the treatment plan.

Before treatment begins, talk with the health care team about the possible side effects of your child's specific treatment plan and supportive care options. Be sure to tell your child's doctor or another health care team member if your child is experiencing a problem during and after treatment so it is addressed as quickly as possible. Learn more about [palliative care](#) [7].

Chance of the tumor coming back or worsening

When the tumor cannot be seen on an MRI scan, this is called "no evidence of disease" or NED. The uncertainty of whether the tumor will come back causes many patients and families to feel worried or anxious. While the chance of the tumor coming back may be low, it is important to talk with your child's doctor about the possibility of the tumor returning. Understanding the risk of recurrence and the treatment options may help you and your family feel more prepared if the tumor does return. Learn more about [coping with the fear of recurrence](#) [8].

If the tumor does return or grow back after the original treatment, it is called a recurrent tumor. When a recurrence happens, craniopharyngioma most commonly comes back in the same place (called a local recurrence) or nearby (regional recurrence).

When this occurs, more tests may be done to learn as much as possible about the recurrence. After testing is done, your child's doctor will talk about your treatment options. Often the treatment plan will include the therapies described above such as surgery and/or radiation therapy, but the same type of radiation therapy cannot usually be used more than once. There are also treatments being studied in clinical trials for patients with recurrent or worsening craniopharyngioma. Talk with your doctor whether this might be an option for your child.

When a tumor recurs, patients and their families often experience emotions such as disbelief or fear. Families are encouraged to talk with their health care team about these feelings and ask about support services to help them cope. Learn more about [dealing with a recurrence](#) [9].

If treatment fails

Although treatment is successful for the vast majority of children with craniopharyngioma, sometimes it is not. If a child's tumor cannot be cured or controlled, this is called an advanced or terminal tumor. This diagnosis is stressful, and it may be difficult to discuss. However, it is important to have open and honest conversations with your child's doctor and health care team to express your family's feelings, preferences, and concerns. The health care team is there to help, and many team members have special skills, experience, and knowledge to support patients and their families.

Parents or guardians are encouraged to think about where the child would be most comfortable: at home, in a home-like setting elsewhere, in the hospital, or in a hospice environment. Hospice care is a type of palliative care for people who are expected to live less than six months. It is designed to provide the best possible quality of life for people who are near the end of life. Nursing care and special equipment can make staying at home a workable alternative for many families. Some children may be happier if they can arrange to attend school part-time or keep up other activities and social connections. The child's health care team can help parents or guardians decide on an appropriate level of activity. Making sure a child is physically comfortable and free from pain is extremely important as part of end-of-life care. Learn more about [caring for a terminally ill child](#) [10] and [advanced care planning](#) [11].

The death of a child is an enormous tragedy, and families may need support to help them cope with the loss. Pediatric cancer centers often have professional staff and support groups to help with the process of grieving. Learn more on [grieving the loss of a child](#) [12].

The next section helps explain clinical trials, which are research studies. Use the menu on the side of your screen to select About Clinical Trials, or you can select another section, to continue

reading this guide.

Links:

- [1] <http://www.cancer.net/cancer-types/craniopharyngioma-childhood/treatment-options>
- [2] <http://www.cancer.net/about-us>
- [3] <http://www.cancer.net/node/25356>
- [4] <http://www.cancer.net/node/24582>
- [5] <http://www.cancer.net/node/24720>
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