

## [Craniopharyngioma - Childhood - Follow-Up Care](#) [1]

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 05/2016

**ON THIS PAGE:** You will read about your child's medical care after treatment is finished and why this follow-up care is important. To see other pages, use the menu.

Care for children diagnosed with craniopharyngioma doesn't end when active treatment has finished. Your child's health care team will continue to check to make sure the tumor has not returned, manage any side effects, and monitor your child's overall health. This is called follow-up care. All children treated for craniopharyngioma should have life-long, follow-up care.

Your child's follow-up care may include regular physical examinations, MRI scans, or both. Doctors want to keep track of your child's recovery in the months and years ahead. Follow-up care is important to find out whether the tumor has returned or is starting to grow again.

Learn more about the [importance of follow-up care](#) [3].

### **Watching for recurrence**

One goal of follow-up care is to check for a recurrence. A tumor recurs because small areas of tumor cells may remain undetected in the body. Over time, these cells may increase in number until they show up on test results or cause signs or symptoms.

During follow-up care, a doctor familiar with your child's medical history can give you personalized information about the risk of recurrence. Your doctor will also ask specific questions about your child's health. Some children may have blood tests or imaging tests as part of regular follow-up care, but testing recommendations depend on several factors, including the type of tumor originally diagnosed and the types of treatment given.

A child treated for craniopharyngioma should have regular MRI scans to check for any growth or recurrence of the tumor. Because craniopharyngioma is slow-growing, MRI scans are often only needed once or twice a year. If your child received radiation therapy, there is a small possibility that a different type of brain tumor may develop years later.

## **Managing long-term and late side effects of a childhood brain tumor**

Sometimes, side effects may linger beyond the active treatment period. These are called long-term side effects. In addition, other side effects called late effects may develop months or even years afterwards. Late effects can occur almost anywhere in the body and include physical problems, such as heart and lung problems and second cancers, and emotional and cognitive (memory, thinking, and attention) problems, such as anxiety, depression, and learning difficulties.

Based on the type of treatment your child received, the doctor will recommend what examinations and tests are needed to check for late effects. For children with craniopharyngioma, it is important to monitor the person's visual, endocrine (hormone), and metabolic functions. As a result of the tumor and its treatment, hormone replacement (see below) is almost always needed. Children who received treatment for craniopharyngioma often have problems with a slow metabolism and weight gain. A regular exercise program and dietary changes to the foods they eat are often recommended. Follow-up care should address your child's quality of life, including any developmental or emotional concerns.

### **Hormone replacement**

Hormone replacement is the use of medication to replace hormones that 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, including 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.

The Children's Oncology Group (COG) has studied the physical and psychological effects that childhood survivors face. Based on these studies, COG has created recommendations for long-term follow-up care for childhood, adolescent, and young adult survivors that can be found on a separate website: [www-survivorshipguidelines.org](http://www-survivorshipguidelines.org) [4].

### **Keeping a child's personal health record**

You are encouraged to organize and keep a personal record of the child's medical information. The doctor will help you create this. That way, as the child enters adulthood, he or she has a clear, written history of the diagnosis, the treatment given, and the doctor's recommendations about the schedule for follow-up care. ASCO offers [forms to help create a treatment summary to keep track of the treatment your child received and develop a survivorship care plan](#) [5] once

treatment is completed.

Some children continue to see their oncologist, while others transition back to the general care of their family doctor or another health care professional. This decision depends on several factors, including the type of tumor, side effects, health insurance rules, and your family's personal preferences. Talk with your health care team about your child's ongoing medical care and any concerns you have about his or her future health.

If a doctor who was not directly involved in your child's care for craniopharyngioma will lead the follow-up care, be sure to share the treatment summary and survivorship care plan forms with him or her, as well as all future health care providers. Details about the specific treatment given are very valuable to the health care professionals who will care for your child throughout his or her lifetime.

*The [next section in this guide is Survivorship](#) [6]. It describes how to cope with challenges in everyday life after a diagnosis of craniopharyngioma. Or, use the menu to choose another section to continue reading this guide.*

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## **Links**

[1] <http://www.cancer.net/cancer-types/craniopharyngioma-childhood/follow-care>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/29386>

[4] <http://www.survivorshipguidelines.org/>

[5] <http://www.cancer.net/node/25394>

[6] <http://www.cancer.net/node/33676>