

Craniopharyngioma

Series N. 13



Patient's Guide

Average Readability Leaflet

Craniopharyngioma - Series 13 (Revised August 2006)

This leaflet was produced by Fernando Vera MSc and Prof Gary Butler at the Institute of Health Sciences, University of Reading, Reading, UK (August, 2006). Some portions of the text were extracted or modified from the Growth and Growth Disorders Booklet Series (Third edition, 2000)* and may be used in conjunction with these as they provide a choice of leaflets providing the same information, but for people of different ages and reading abilities. The numbering sequence in each series is the same for easy cross-reference. The original leaflet series can be also obtained from the links given at the end.

All illustrations were created and produced by Fernando Vera MSc.

This leaflet is part of the Hormone Disorders Leaflet Series. The following are also available:

- Series N 3.** Puberty and the Growth Hormone Deficient Child.
- Series N 4.** Precocious Puberty
- Series N 5.** Emergency Information for Children with Cortisol and GH Deficiencies and those Experiencing Recurrent Hypoglycaemia.
- Series N 6.** Congenital Adrenal Hyperplasia
- Series N 7.** Growth Hormone Deficiency in Young Adults.
- Series N 10.** Constitutional delay of growth and puberty
- Series N 11.** Multiple Pituitary Hormone Deficiency
- Series N 12.** Diabetes Insipidus
- Series N 13.** Craniopharyngioma
- Series N 14.** Intrauterine Growth Retardation or Small Gestational Age
- Series N 15.a.** Hyperthyroidism
- Series N 15.b.** Hypothyroidism
- Series N. 16.** Type 2 Diabetes and Obesity

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*Written by Dr Richard Stanhope (Gt. Ormond Street/Middlesex Hospital, London) and Mrs Vreli Fry (Child Growth Foundation)

Introduction

The aim of this leaflet is to provide general information about a **Craniopharyngioma**, also known as a **Cranio**. It will discuss information on how it's diagnosed, treated and some of the problems it may cause.

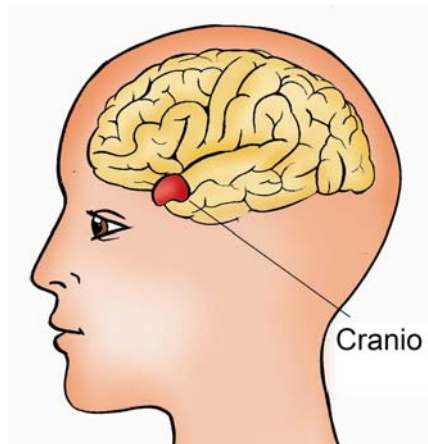
It has been written in general terms and not all of the information provided will apply to you. Hopefully, this leaflet will help you to understand this condition and give you a basis for discussions with your GP or specialist team.

What is a Cranio?

The body is made up of millions of building blocks called cells. Like building blocks, cells work together towards a common goal. Their goal is to grow together and create the muscles and organs that make up the body.

However, sometimes and for unknown reasons, cells grow together to create a lump with no function in the body.

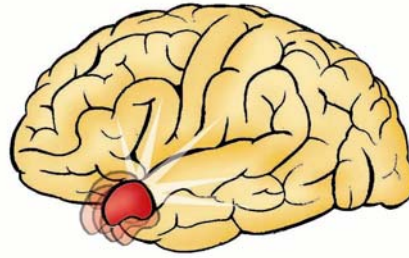
This lump is known as a **tumour**. A **Cranio** is brain tumour present from birth. It is a benign tumour, so it doesn't spread to other parts of the body like cancer does.



Although this condition is not fully understood, doctors know that it's a non-hereditary tumour (not passed from parents or grandparents). It's also not due to taking medications or illness during pregnancy.

Why is a Cranio delicate to treat?

The brain has many important functions like regulating our appetite, sleep and thirst. Often, these functions are carried out in sensitive parts of the brain. The problems caused by a Cranio result from its location nearby these sensitive parts.



As the Cranio grows, it starts to exert pressure against these parts. This tumour also becomes quite “sticky” and clings on to the surrounding tissue. This makes them delicate to remove surgically without damaging parts of the brain.

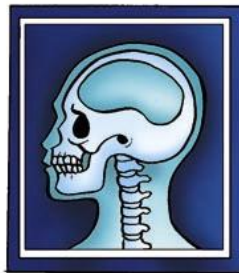
What are the symptoms of a Cranio?

The symptoms of a Cranio result from the damage it causes within the brain. This may result in some or all of the following:

- Headaches
- Reduced vision and poor growth
- Delayed or early puberty
- Thirstiness and frequently passing urine
- Tiredness and intolerance to cold temperatures

How is a Cranio diagnosed?

Several tests are often required to confirm the diagnosis. These commonly include a skull X-ray and a brain scan. Additional tests may include a visual test, a blood test and water balance test



How is a Cranio treated?

The primary treatment for a Cranio is surgery to remove all, or part of the tumour. This is known as a **Craniotomy**.

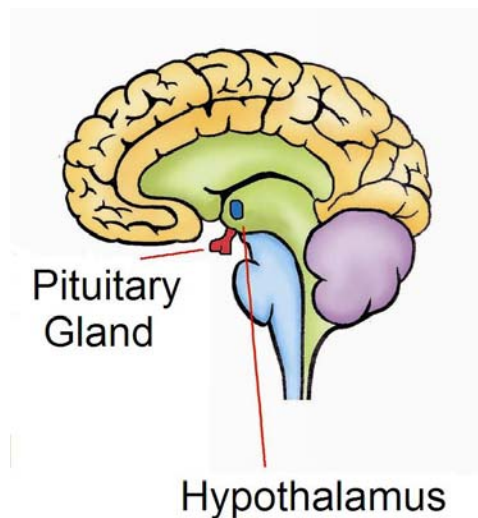
If it's not possible to remove the entire tumour, a small portion will be left behind. Further treatment using **radiotherapy** or **cyst drainage** may be used to treat the remainder or to prevent a new tumour from growing. Other treatments may include:

- Trans-nasal operation: If the tumour is small it can be removed through the nose.
- Cyst aspiration: In this small operation, a hole is made in the skull to drain the substance within the tumour.
- Drainage of the ventricles: Brain fluid may build up in the brain. If this occurs, the fluid will be drained prior to surgery.
- Radiotherapy: This procedure has been found effective in preventing re-growth of a Cranio.

What are the possible after effects of a Cranio?

The effects of a Cranio are the result of partial brain damage. In particular, the **hypothalamus** and the **pituitary gland** are most affected. When working properly, these two brain parts work to regulate the body's fluid balance.

They do this by producing and sending a "messenger" around the body to tell the organs when to retain or when to eliminate water. This "messenger" is a hormone known as **Vasopressin**.



Without Vasopressin the body will not retain fluids, even if we drink large amounts of liquid. The inability of the brain to produce Vasopressin leads to a condition known as **Diabetes insipidus** or **water diabetes**.

Individuals may develop water diabetes after surgery. This can lead to severe dehydration if left untreated.

How is water diabetes treated?

Water diabetes is treated by providing the body with a synthetic form of Vasopressin known as **DDAVP**. This may be given in tablets, intranasal drops or spray.

It's very important not to exceed the dose of DDAVP indicated by your specialist. Taking too much may result in a build up of fluid and convulsions. Under-treatment is less dangerous and causes more urine to pass and increased thirst.



What are the other treatments given before and after surgery?

- **Anticonvulsants:** These are given to treat fits or convulsions.
- **Steroids:** Big doses of steroids (dexamethasone) are given for a few days before and after surgery. This is to prevent or treat swelling. Afterwards, regular treatment may be needed for energy.
- **Thyroid hormone (thyroxine):** May be given to help with growth and metabolism, if needed.
- **Growth hormone:** This is usually needed after treatment to help grow normally.
- **Sex Hormones:** May be needed if puberty doesn't happen or is slow.

What other follow-up is needed?

Problems with sight can improve after surgery but could also be permanent. Eye tests will therefore be needed at regular intervals.

Additionally, measurements of height and weight will be recorded carefully and regularly. For children and adolescents pubertal development will also be registered. Finally, brain scans or x-rays will be taken regularly.

Are there any other effects?

The effects of a Cranio result from the damage caused to the brain. Some of these effects may persist, even after the tumour has been removed. These may include:

- Increased food intake and obesity
- Sleep disturbance
- Impaired thirst
- Memory disturbance
- Impaired temperature regulation

What are other sources of useful of information?

The goal of this leaflet was to provide a basic overview of cranios. Further information can be found in the following sources:

- **European Society for Paediatric Endocrinology**
ESPE Secretariat, BioScientifica
Euro House 22 Apex Court Woodlands, Bristol BS32 4JT - UK
Telephone No: + 44 (0) 01454 642208
Internet: <http://www.eurospe.org/>
- **British Society for Paediatric Endocrinology and Diabetes**
BSPED Secretariat, BioScientifica
Euro House 22 Apex Court Woodlands, Bristol BS32 4JT - UK
Telephone No: + 44 (0) 01454 642208
Internet: <http://www.bsped.org.uk/>
- **Child Growth Foundation**
2 Mayfield Avenue, Chiswick London W4 1PW UK.
Telephone +44 (0) 20 8995 0257
Internet: <http://www.childgrowthfoundation.org/>

You can also consult your doctor or nurse for additional information in your local area.

