

Hormone Disorders

Craniopharyngioma

Patient's Guide



Average readability



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 is diagnosed, treated and some of the problems it may cause.

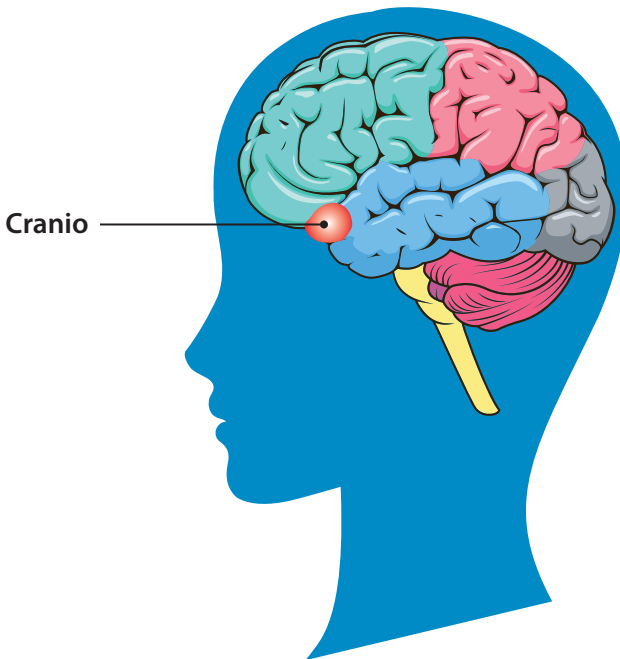
It has been written in general terms and not all of the information provided will apply to you. Hopefully, this leaflet will help you to understand this condition and give you a basis for discussions with your GP or specialist team.

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 a brain tumour present from birth. It is a benign tumour, so it doesn't spread to other parts of the body like cancer does.

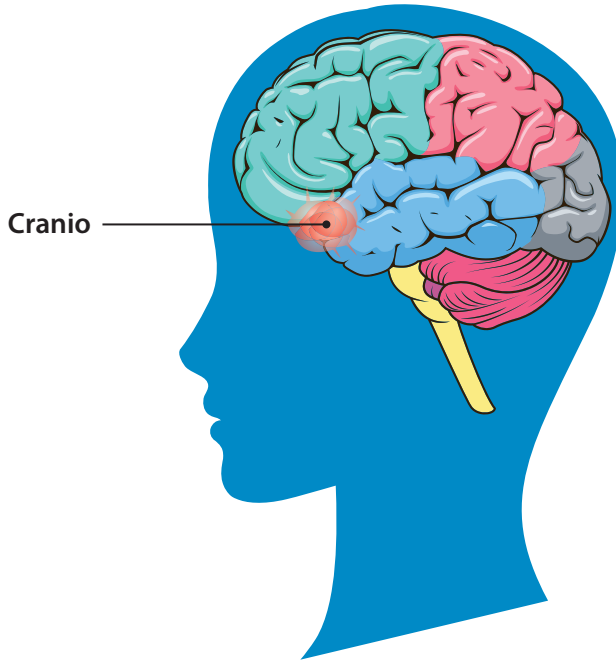


Although this condition is not fully understood, doctors know that it is not a hereditary tumour (meaning it is not passed to you from your parents or grandparents). It is also not due to taking medications or illness when your mum was pregnant.



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 close to these sensitive parts.



As the Cranio grows, it starts to put pressure against these parts. This tumour also becomes quite "sticky" and clings on to the surrounding tissue. This makes it tricky to remove during an operation without damaging other parts of the brain.

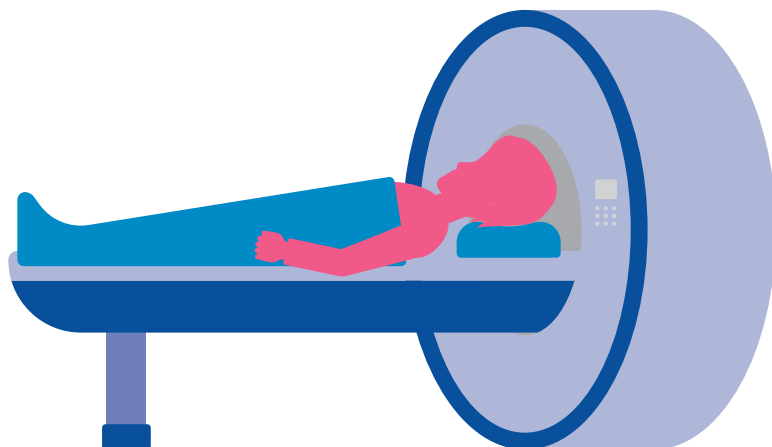
What are the symptoms of a Cranio?

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
- 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 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**.

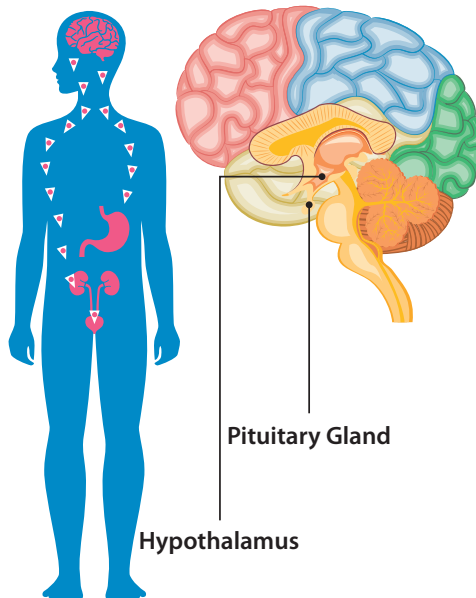
If it's not possible to remove the entire tumour, a small portion will be left behind. Further treatment using **radiotherapy** or **cyst drainage** may be used to treat the remainder or to prevent a new tumour from growing. Other types of treatments may include:

- **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**.

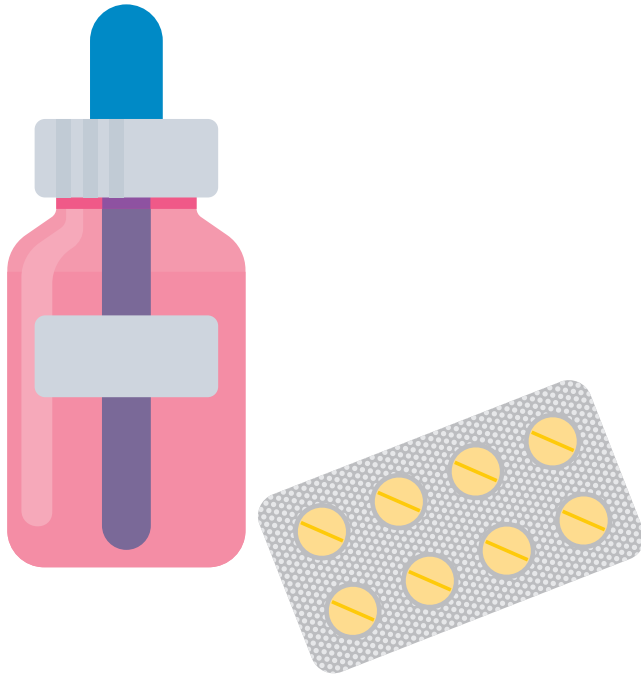
Individuals may develop water diabetes after surgery temporarily. This can lead to severe dehydration if left untreated.



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 is very important not to exceed the dose of DDAVP indicated by your specialist. Taking too much may result in a build up of fluid in the body which can cause convulsions. Under-treatment is less dangerous but causes you to pass more urine and have an 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) may be 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 checked. 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 information?

The goal of this leaflet was to provide a basic overview of a Cranio.

Educational material can also be found by contacting the following organisations:

- **European Society for Paediatric Endocrinology**
Starling House
1600 Bristol Parkway North
Bristol
BS34 8YU
espe@eurospe.org
Telephone +44 (0) 1454 642246
www.eurospe.org
- **British Society of Paediatric Endocrinology and Diabetes**
bsped@endocrinology.org
<https://www.bsped.org.uk/>
- **Child Growth Foundation**
info@childgrowthfoundation.org
Telephone +44 (0) 208 995 0257
www.childgrowthfoundation.org
- **The Endocrine Society**
www.endo-society.org

You can also consult your specialist team for additional information in your local area.



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This leaflet is part of the **Hormone Disorders Series**

The following are also available:

Growth Hormone Deficiency

Puberty and the Growth Hormone Deficient Child

Precocious Puberty

Emergency Information for Children with Cortisol and GH Deficiencies and those Experiencing Recurrent Hypoglycaemia

Congenital Adrenal Hyperplasia

Growth Hormone Deficiency in Young Adults

Constitutional Delay of Growth and Puberty

Multiple Pituitary Hormone Deficiency

Diabetes Insipidus

Intrauterine Growth Retardation or Small for Gestational Age

Hyperthyroidism

Hypothyroidism

Type 2 Diabetes and Obesity

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