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# Craniopharyngioma

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**Children's Unit**

**Patient Information**

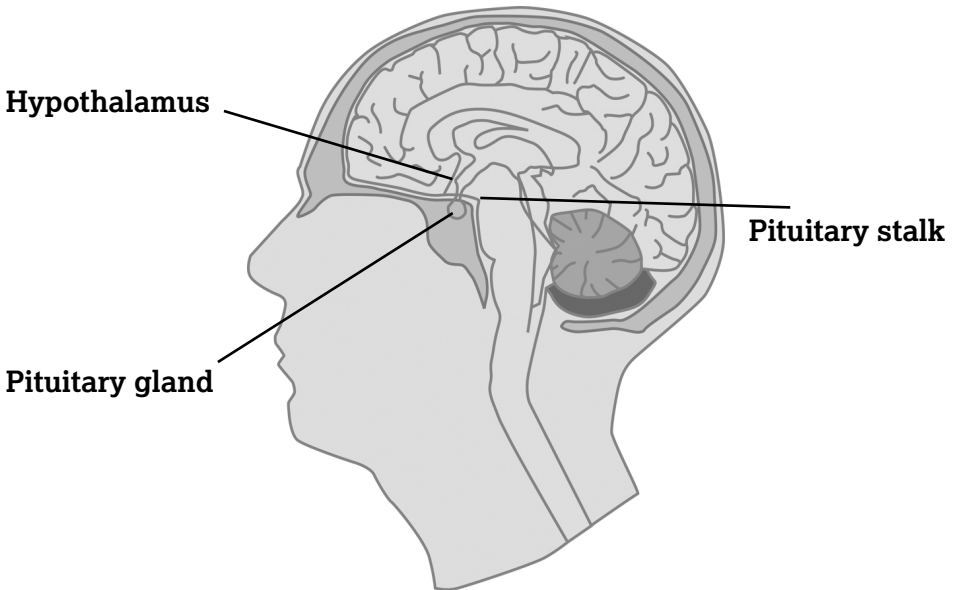




## What is a craniopharyngioma?

Craniopharyngiomas result from the growth of cells that have failed to move to their usual area early in foetal development. These tumours generally occur just above the pituitary gland. The pituitary gland is located at the bottom of the brain. It is about the size of a pea and controls many vital body functions.

Craniopharyngiomas are benign (non-cancerous) tumours that do not spread and can be solid, cystic (full of fluid), calcified (hardened), or full of debris. They are slow-growing tumours that can be present for three years (or longer) before a diagnosis is made. However, they may interfere with important structures near them, causing serious problems, which lead to diagnosis.



**The brain**

## Who gets a craniopharyngioma?

Craniopharyngiomas represent approximately 5% of brain tumours in children each year in the UK. They also occur in adults and there is no known cause.

## What are the signs and symptoms?

Symptoms may be caused by the tumour blocking the flow of fluid surrounding the brain. This increases the pressure inside the brain. Symptoms may also happen as a result of direct pressure on or damage to the pituitary gland or nerves from the eyes. Symptoms may include:

- headaches
- nausea or vomiting
- hormone disturbances
- disturbed sleep patterns
- visual disturbance
- behavioural changes
- slow growth
- increased sensitivity to cold or heat
- early or delayed puberty
- appetite and weight change.

## What tests will be carried out?

We will need to carry out some tests to find out as much as possible about the type, position and size of the tumour. This will help us to decide on the best treatment for your child. These tests include:

- **CT scan** – it is likely a CT scan of your child's brain was the first specific test carried out at your local hospital. Although MRI scans are usually the best way of seeing the tumour and the effects of treatment, sometimes CT scans are also useful.

For more information, please see The Royal Marsden leaflet *CT scan*.

- **MRI scan** – this scan allows us to see the brain and spine in great detail and is used regularly to diagnose and follow the effect treatment is having on your child’s tumour. For more information, please see The Royal Marsden leaflet *MRI scan*.
- **Ophthalmic assessment** – a full assessment of your child’s vision will need to be recorded at the time of diagnosis, during and after treatment. This is painless but sometimes difficult for young children.
- **Endocrine assessment** – if there is evidence of the tumour pressing on the hypothalamus or pituitary gland, a full test of your child’s hormones will be required. This usually involves blood tests.

## How do you treat a craniopharyngioma?

### **Surgery**

Surgery is the main treatment and if possible, the neurosurgeon will try and cure the cancer by completely removing the tumour. However, for large tumours the neurosurgeon may only be able to reduce the tumour, to avoid further damage to the child’s brain.

### **Radiotherapy**

Radiotherapy may be required to prevent the tumour from growing. Please see The Royal Marsden booklet *Radiotherapy; your questions answered* for more details on this type of treatment. The age of the child and the symptoms experienced will be important in determining whether they require treatment. Radiotherapy is very effective at controlling the tumour but does have some potential significant long-term side effects, especially in young children.

### **Proton beam therapy**

Children with craniopharyngioma may benefit from receiving proton beam therapy. Proton beam therapy delivers radiotherapy

in a way that may reduce the radiation to healthy tissue outside the treatment area. This can mean that children have fewer long-term side effects. In the UK, proton therapy is delivered at University College Hospital, London and The Christie Hospital, Manchester. If your child is eligible for NHS funding, you will be able to discuss what this will involve with the medical team. Proton therapy is not available at The Royal Marsden.

## What is the outlook?

Most children are cured of their tumour by surgery and radiotherapy, but many suffer from serious long-term problems (for example, hormone deficiencies) some of which can be life shortening.

## What are the possible long-term effects?

Craniopharyngiomas are benign (non-cancerous) but can have many serious effects on a child's health and development. These include growth, hormonal and behavioural changes and learning difficulties. Visual disturbances, which may be severe, can also result from the tumour. A specialist hormone doctor (endocrinologist) will need to be involved in the long-term care of patients. This is because the child will need replacement hormones either in the form of tablets or injections.

Your child may need urgent medical attention if they become unwell, as they may not be able to control fluid balance and blood pressure in the normal way. Children can develop severe obesity due to hormone problems and damage to the part of the brain (hypothalamus) that controls appetite. This can be very difficult to control and may need the help of more than one healthcare professional.

Behavioural problems and education difficulties can be severe. Therefore, all children are followed up after treatment is finished in the 'long-term brain tumour follow up clinic'. Your child will be seen at regular intervals in this clinic, indefinitely, so that we can help with any long-term effects of the treatment.

## Contact details

Children and Young People's Unit  
24 hour Helpline: **020 8915 6248**

## Other sources of information and support

General information on radiotherapy and side effects is available in other booklets from the PALS Help Centre, via [www.royalmarsden.nhs.uk](http://www.royalmarsden.nhs.uk) and in the 'parent held record'.

### **Macmillan Cancer Support**

Macmillan Support Line: **0808 808 0000**

Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Macmillan provides a range of free information and support on all aspects of cancer including:

- advice on benefits and other kinds of financial support
- information on local cancer support groups and organisations near you.

### **Young Lives vs Cancer**

Website: [www.younglivesvscancer.org.uk](http://www.younglivesvscancer.org.uk)

Support line: **0300 303 5220**

Young Lives vs Cancer is a UK charity for children, young people, and their families, which provides clinical, practical, financial and emotional support to help them cope with cancer.

### **The Children's Cancer and Leukaemia Group (CCLG)**

Website: [www.cclg.org.uk](http://www.cclg.org.uk)

CCLG is a national professional body responsible for the organisation of the treatment and management of children with cancer in the UK. They coordinate national and international clinical trials. They also provide information for patients and families and produce a quarterly magazine called Contact.

## **The Brain Tumour Charity**

Website: *www.thebraintumourcharity.org*

Support and information line: **0808 800 0004**

The Brain Tumour Charity is a UK charity, committed to fighting brain tumours. They fund scientific and clinical research into brain tumours and offer support and information to those affected, whilst raising awareness and influencing policy.

## **The Pituitary Foundation**

Website: *www.pituitary.org.uk*

Support Helpline: **0177 370 1320**

The foundation provides information and support to patients and their families affected by pituitary disorders including craniopharyngioma.



## Notes and questions

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## References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: [patientcentre@rmh.nhs.uk](mailto:patientcentre@rmh.nhs.uk)

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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[royalmarsden.org](http://royalmarsden.org)

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