

A GUIDE TO RATHKE'S CLEFT CYST



WHAT IS A RATHKE'S CLEFT CYST?

A Rathke's Cleft Cyst is a congenital deformity that develops while the fetus is growing in the womb. It is a benign (non-cancerous) collection of fluid that forms in a gap during the early development of the pituitary gland. This is called the Rathke's pouch. Usually, this gap closes before birth as the pituitary gland forms but in some people, the gap doesn't close and leaves a space where a cyst can form.

The pituitary gland is a pea-sized structure at the base of the brain, releasing hormones that play a role in many body functions.

Most cysts don't cause symptoms and rarely get bigger. Cysts can cause symptoms when they press on the pituitary gland or an optic nerve. These cysts may disrupt hormones or cause vision problems. The average age of diagnosis in adults is 42, and cysts are more common in women than men. One of the signs is irregular periods due to a hormonal imbalance, so women may be more likely than men to notice signs.

HOW COMMON IS A RATHKE'S CLEFT CYST?

Rathke's cleft cysts affect around 2.5 million Australians at any given time.

WHAT ARE THE SIGNS AND SYMPTOMS?

GENERAL SIGNS

The vast majority of these cysts cause no symptoms. However, symptoms may include:

- Headaches – due to the cyst pressing on surrounding structures
- Vision changes – blurry vision, vision loss and loss of peripheral vision
- Hyperprolactinaemia in women – when the body makes too much of the hormone prolactin

HYPOPITUITARISM

Hypopituitarism is when the body doesn't make enough of one or more pituitary hormones. Symptoms can include:

- Appetite loss
- Low sex drive
- Loss of periods in women
- Loss of body or facial hair
- Growth changes
- Weight gain or loss
- Body temperature issues
- Tiredness and confusion.

DIAGNOSIS

Rathke's cleft cysts are diagnosed with the following:

- **Blood tests** – to check your pituitary function
- **Vision field tests** – to check if you have vision impairment
- **Scans** – a magnetic resonance imaging (MRI) or computerised tomography (CT) scan can find the size and site of the cyst.

TREATMENT

Monitoring (no treatment)

If your cyst is an incidental finding (found during a scan for an unrelated condition) and is not causing symptoms, you don't need to do anything except monitor it with an MRI scan every 12 months for the first three years.

It is rare for cysts found incidentally to get bigger.

Treatment

If your cyst is causing symptoms, the most common treatment is surgery which is most often performed through the nose (transsphenoidal surgery). The cyst is either drained but may also be fashioned to allow drainage of fluid back into the normal brain fluid.

ONGOING MANAGEMENT

After your surgery, symptoms such as headaches and visual issues should improve. However, some people develop hypopituitarism (when the body doesn't make enough of one or more pituitary hormones). Your doctor will test your pituitary function after your surgery and can give you hormone replacement medication if necessary.

Other complications of surgery can include:

- Cerebrospinal fluid (CSF) leak
- Meningitis
- Changes in blood salt levels as a result of AVP-deficiency (diabetes insipidus) or excess AVP (SIADH causing hyponatraemia).

Your neurosurgeon will discuss the risks and complications of surgery. If your cyst comes back, you can have a second surgery. Recurrences most often occur in the first five to six years after surgery.

It is usual to have a scan 3 months following surgery and then commonly each year for 2-3 years and thereafter less commonly depending on whether any cyst recurrence has been seen.

It's also essential for your doctor to assess your pituitary function, hormone deficiencies and cyst regrowth every six months to one year.

Surgery can be emotionally challenging. Ask your doctor about mental health support if you are struggling to cope.

Radiotherapy is not a standard treatment option.

If you take steroids and become very ill or stressed, you need to increase your medication dose. Your doctor can talk to you more about this and add specific advice to your ongoing treatment plan.

Seek urgent medical care if:

- Your vision gets worse or becomes impaired – this can indicate that cysts are enlarging rapidly
- You notice clear fluid dripping down the back of the throat or through the nose soon after surgery – this may indicate a cerebrospinal fluid leak.

MORE INFORMATION

The Australian Pituitary Foundation provides social support for patients and carers, and has published a range of patient resources on pituitary conditions and treatments.

For more information, please visit our website: www.pituitary.asn.au

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