A GUIDE TO NON-FUNCTIONING PITUITARY TUMOURS

Australian Pituitary Foundation

WHAT ARE NON-FUNCTIONING PITUITARY TUMOURS?

A non-functioning pituitary tumour is a benign (non-cancerous) tumour that develops in the pituitary gland and does not secrete a hormone into the blood stream. A functioning pituitary tumour, on the other hand, does secrete one or more pituitary hormones into the blood.

The pituitary gland sits in the skull, below the brain and above the nasal passages. This gland plays a vital role in many body functions and processes.

Pituitary tumours can exist for years without causing symptoms. Sometimes, they are found by chance when you have a brain scan for another reason. Most are small tumours, less than one centimetre.

The most common symptoms of a non-functioning pituitary tumour are headaches and vision problems due to pressure on the optic nerve.

The tumour can also damage the pituitary gland resulting in hypopituitarism (where your body does not produce enough of one or more pituitary hormones). One pituitary hormone, prolactin, may be raised because of pressure on the pituitary stalk.

HOW COMMON ARE NON-FUNCTIONING PITUITARY TUMOURS?

Non-functioning pituitary tumours make up about 30% of all pituitary tumours[2].

WHAT ARE THE SIGNS AND SYMPTOMS?

Common signs include:

- Visual disturbances
- Infrequent periods
- No periods
- Reduced libido and potency in men
- Headaches.

DIAGNOSIS

A non-functioning pituitary tumour can be diagnosed through the following:

- **Blood tests** – to check the pituitary function and hormone levels
- **Scans** – a magnetic resonance imaging (MRI) or computerised tomography (CT) scan can find the size and site of the tumour
- **Visual field tests** – to see if your vision is affected

After Diagnosis

After diagnosis, it is essential to see:

- **An endocrinologist** with experience in managing pituitary diseases, and
- **A neurosurgeon** with pituitary expertise.

TREATMENT

Treatment options for non-functioning pituitary tumours include monitoring (no treatment), surgery and radiotherapy. Medical therapy may need to include hormone replacement if there is hypopituitarism.

Monitoring (no treatment)

You may not need treatment for your tumour if you don't have any signs or symptoms.

Your doctor will monitor your tumour for growth using MRI scans. You may need scans every six to 12 months and then every two to five years.

Surgery

A larger tumour (more than 1cm) along with symptoms such as headaches or visual defects may need surgery. The most common type of surgery is minimally invasive, also known as transsphenoidal. The surgeon reaches the tumour through the nose instead of making a large cut, as in open surgery.

If the tumour is large, your surgeon may be unable to remove all the tumour. Subsequent treatment may include monitoring the residual, further surgery or radiotherapy

After your surgery, you may need to take hormone replacement therapy medications if your hormones are affected by the tumour. Your doctor can give you more information about this.

If your tumour continues to grow after surgery, you may need radiotherapy.

After surgery, your vision will likely have stabilised or improved. Some people find that they have more headaches. Other issues that can occur immediately after surgery 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 medical team will monitor you in the hospital and treat any complications. Most people need to allow four to six weeks to recover and return to their usual routines.

Other complications, like cerebrospinal fluid leaks, are rare. Your neurosurgeon can discuss the risks and treatments for complications.

Radiotherapy

Radiotherapy uses radiation (X-rays or Gamma rays) to inactivate tumour cells. In most cases, you will only need radiotherapy if your tumour has grown after your surgery.

Your neurosurgeon may be able to remove more of the tumour through surgery if the tumour's location makes it possible. But if you cannot have more surgery, radiotherapy can help stop the tumour from growing.

Radiotherapy can cause hypopituitarism, so it is essential to have pituitary function tests regularly.

DIAGNOSIS

It is essential to see your doctor regularly for vision tests and scans. It is usual to have a scan 3 months following surgery and then commonly each year for 2-3 years and thereafter less depending on whether any tumour is present. 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 tumours 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.

COMMON QUESTIONS

Do I have cancer?

No. A tumour is a lump of abnormal tissue. If left untreated, your tumour may get bigger. Pituitary tumours very rarely spread to other parts of the body

Will I need treatment?

Small tumours may not need treatment. Most tumours are small and don't need treatment. You only need treatment if your tumour is growing or causing problems.

Will it go away after my treatment?

Surgery may not be able to remove the entire tumour. It is common for some of the tumour cells to remain after surgery. In most cases, you can control future tumour growth and manage your symptoms.

Will I have to take tablets in the long term?

Everyone is different. Some people may need to take medications in the long term. You might not need medication if you had surgery or radiotherapy. If your tumour stops your pituitary gland from producing enough hormones, you may need long-term hormone replacement therapy.

Will I still be able to have a family?

You can still have a family if treatment reverses your pituitary tumour's fertility effects. If your tumour or treatment has affected your natural menstrual cycle you may require hormone therapy to become pregnant.

What causes a pituitary tumour?

Doctors still aren't sure what causes pituitary tumours, but research is ongoing.

Does it run in families?

It is rare to find patterns of pituitary tumours in families.

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

Email: support@pituitary.asn.au

Phone: 1300 331 807

REFERENCES

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