A GUIDE TO PITUITARY TUMOURS

Australian Pituitary Foundation

WHAT ARE PITUITARY TUMOURS?

A pituitary tumour is an abnormal growth that develops in the pituitary gland. It is also known as an adenoma. The pituitary gland can be found at the base of the brain in line with the top of your nose. Most pituitary tumours are benign (non-cancerous) and less than one centimetre.

Pituitary tumours can exist for years without causing symptoms. Sometimes, they are found by chance when you have a brain scan for another reason. Around one in five people (10-20%) have a pituitary tumour. Most are small tumours.[1,2]

Pituitary tumours can be:

- Functioning – develops in the pituitary gland and secretes one or more pituitary hormones into the blood stream
- Non-functioning – develops in the pituitary gland and does not secrete a hormone into the blood stream

HOW COMMON ARE PITUITARY TUMOURS?

Around 1 in 1000 individuals have a clinically significant pituitary tumour.

WHAT ARE THE SIGNS AND SYMPTOMS?

NON-FUNCTIONING

Non-functioning tumours can cause low hormone levels due to the pressure they apply on the pituitary gland. This can cause signs such as:

- Fatigue
- Irregular or loss of periods
- Loss of libido (sex drive)
- Erectile dysfunction.
- Vision impairnment

Because these symptoms are common and occur with many health issues, you can have a tumour for many years before knowing about it.

FUNCTIONING

Functioning tumours cause signs of the conditions based on the excess hormone made:

- Prolactinoma – caused by too much prolactin
- Cushing's disease – is caused by too much adrenocorticotrophic hormone (ACTH)
- Acromegaly – is caused by too much growth hormone.

A guide to each of these conditions is available from the Australian Pituitary Foundation.

PITUITARY APOPLEXY

Pituitary apoplexy is a rare event that occurs if a tumour bleeds and suddenly increases in size. It is a medical emergency. It may cause a sudden loss of hormones or vision due to pressure on the eye nerves. Signs include a sudden, severe headache, nausea, vomiting and aversion to light and sound. If you or someone you know develops these signs, go to your nearest emergency room immediately.

DIAGNOSIS

Pituitary tumours are often discovered:

- **Incidentally** – after a scan for another health issue
- **Visual disturbances** – if you have vision problems (tunnel vision, blurred vision, double vision) and headaches, your doctor may order tests
- **Hormonal issues** – if you have symptoms associated with too little or too much hormone.

Tests to diagnose a pituitary tumour include:

- **Blood tests** – to measure hormone levels.
- **Scans** – a magnetic resonance imaging (MRI) or computed tomography (CT) scan can study the pituitary gland
- **Vision testing** – to check your visual field

You may need more tests, depending on the results and type of hormones your tumour is producing.

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 include montioring (no treatment), medication, surgery and radiotherapy. Treatment aims to:

- Relieve or reverse symptoms
- Prevent vision loss
- Restore hormone levels
- Prevent tumour growth.

Monitoring (no treatment)

If your tumour has no symptoms, you may not need any treatment. Your doctor will monitor your tumour regularly to make sure it doesn't get any larger.

Medication

Medication can help to treat some tumours and conditions, such as prolactinomas.

Dopamine agonists, such as cabergoline and bromocriptine, are frequently used in prolactinomas to reduce prolactin levels and shrink the tumour, but occasionally used in other tumour types as well. Medications such as somatostatin analogues (lanreotide, octreotide, pasireotide) are most commonly used in acromegaly to control growth hormone levels if surgery has not removed all the tumour. Drugs reducing production of cortisol levels are used in Cushing's disease.

In all tumour types, hormone replacement therapy may also be needed to treat hormone deficiencies.

Surgery

If you have signs and symptoms, you 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 cells. You may need another surgery several months later.

TREATMENT

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 reduces the chance of your tumour returning. You may have radiotherapy alone or with other treatments. It is usually performed where surgery or medication can not successfully control the tumour or hormone levels.[4]

After radiotherapy, your doctor will monitor your hormone levels. Radiotherapy can sometimes cause a gradual loss of pituitary function and low levels of pituitary hormones. If this occurs, you will need permanent hormone replacement therapy.

COMMON QUESTIONS

Do I have cancer?

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 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 can reverse the fertility effects of your pituitary tumour. 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

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Acknowledgement – We are grateful to the members of the Australian Pituitary Foundation for reviewing this information.

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