

A GUIDE TO PITUITARY TUMOURS



INCIDENCE

Approximately 910 people are diagnosed with a pituitary tumour every year in Australia. This represents around 4 new cases per 100,000 population per year¹.

ABOUT PITUITARY TUMOURS

A pituitary tumour (also called an adenoma) is an abnormal growth on the pituitary gland. The vast majority are benign (non-cancerous). Most pituitary tumours are small (<1cm or 10mm), called **microadenomas**. Tumours that are 1cm or larger are called **macroadenomas**.

Pituitary tumours can exist for years without causing symptoms and so may never be found. Sometimes pituitary tumours are discovered by chance when imaging the brain for other reasons. These are referred to as **incidentalomas** and are quite common in the general population. It is estimated that up to 1 in 5 people (10-20%) have a pituitary tumour, with the majority being microadenomas (small tumours) ^{2,3}.

Pituitary tumours can be functioning or non-functioning. **Functioning pituitary tumours** are those that produce excess hormones. **Non-functioning pituitary tumours** do not produce any hormones.

PRESENTING SIGNS AND SYMPTOMS

There are three patterns of symptoms that can lead to a pituitary tumour being discovered.

Firstly, and most commonly, pituitary tumours can be found incidentally following scans of the head for headaches, dizziness or following a head injury. These tumours may be small and may not require any further investigation.

Secondly, pituitary tumours may be found due to pressure effects on surrounding structures. This may lead to visual disturbances (such as tunnel vision, blurring or double vision), and potentially headaches if the tumour is very large.

Finally, pituitary tumours may cause hormonal issues (either too little or too much hormone).

Non-functioning tumours can cause low hormone levels due to the pressure they apply on the pituitary gland. This may result in symptoms such as fatigue, irregular or loss of periods, loss of libido (sex drive) or erectile dysfunction. Because these symptoms are common and caused by a number of conditions, they may not be recognised for years.

PREVALENCE

Between 12,500 and 24,000 Australians currently live with a pituitary tumour. This represents around 49-94 cases for every 100,000 population¹.

Functioning tumours will cause symptoms based on the specific hormone that is produced in excess. The most common hormones produced are prolactin (prolactinoma), adrenocorticotrophic hormone (ACTH- Cushing's disease) and growth hormone (acromegaly).

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

On rare occasions, a pituitary tumour may bleed resulting in a sudden increase in size. This is called **pituitary apoplexy** and occurs in around 4-6% of pituitary tumours. Pituitary apoplexy is an emergency as it may result in sudden acute loss of hormones (in particular cortisol), and/or a sudden loss of vision due to pressure on the eye nerves. Apoplexy presents with a sudden severe headache between the eyes and nausea/vomiting, and aversion to light/sound. If this occurs, it is important that the patient is immediately taken to the emergency department for treatment.

INVESTIGATIONS

A number of tests may be used to diagnose a pituitary tumour. These include:

- Blood test - to measure hormone levels.
- Magnetic resonance imaging (MRI) or computed tomography (CT) scan - to see the pituitary gland
- Vision testing - to assess the visual field

Further investigations may be required, depending on the outcomes of these tests and the type/s of hormone/s being produced.

TREATMENT

The goals of treatment include:

- Relief of pressure symptoms
- Prevention of visual loss
- Reverse symptoms
- Restore hormone levels
- Prevention of further tumour growth

Treatment options include:

1. No treatment
2. Medication
3. Surgery
4. Radiotherapy

No Treatment

If the tumour has no symptoms, particularly for incidentalomas, no treatment may be necessary. Tumours that do not cause symptoms may be monitored to make sure they do not get larger.

Medication

Medication is the first line of treatment for some tumours, e.g. prolactinomas.

For prolactinomas, the most common medications are dopamine agonists such as cabergoline and bromocriptine, which reduce prolactin levels and shrink the tumour.

For acromegaly, medications include those that block growth hormone release (somatostatin analogues), medications that block the action of growth hormone (pegvisomant) and in some cases dopamine agonists.

For other tumour types, medications are generally used in combination with surgery. Hormone replacement therapy is needed in many cases to treat hormone deficiencies.

Surgery

Surgery is the treatment of choice for certain types, but not all, pituitary tumours. The decision will depend on the size and type of tumour, and whether the tumour is growing.

Transsphenoidal surgery is performed in most cases. This generally involves a 4-5 day stay in hospital. In rare cases, such as if the tumour is large, other surgical approaches may be required. It is recommended that surgery be undertaken in a centre for pituitary diseases, or by a neurosurgeon with pituitary surgery expertise

Surgical treatment may be followed by other treatments, such as medication or radiotherapy. Surgical removal or reduction of the tumour may result in temporary or permanent damage to the pituitary gland, resulting in low hormone levels (hypopituitarism). This occurs in around 7%, or 1 in 14, surgeries⁴. Hormonal replacement therapy may be required to restore hormone levels. Diabetes insipidus may occur after surgery (around 7% or 1 in 14 surgeries⁴), causing extreme thirst and excessive amounts of urine. This is most likely to be temporary.

Radiotherapy

Radiotherapy reduces the chance of tumours returning and may be carried out alone or in combination with other treatments. It is usually performed where surgery and/or medication do not successfully control the tumour and/or hormone levels⁴.

Following radiotherapy, hormone levels will be regularly monitored on a long-term basis. This is because radiotherapy can sometimes cause gradual loss of pituitary function, leading to low levels of pituitary hormones. If this occurs, permanent hormone replacement therapy will be needed to restore hormone levels.

COMMON QUESTIONS

Have I got cancer?

No – tumour just means a lump of abnormal tissue. If left untreated, pituitary tumours may gradually increase in size but very rarely spread to other parts of the body.

Will I need treatment?

Not necessarily. The majority of tumours are small and may not need treatment. If a small tumour is discovered accidentally, it may not be necessary to have any treatment at all. Treatment is only required if the tumour is growing and/or causing problems.

Will it go away when I'm treated?

Sometimes tumours can be removed entirely, however it is more common for some of the tumour to remain. In most cases however, the growth of the tumour and its symptoms can be controlled.

Will I have to take tablets in the long term?

This depends on individual circumstances. Medications that reduce hormone production may be needed long term. If other treatment is given (surgery, radiotherapy), medication may no longer be required. If the tumour itself, or its treatment, stops the pituitary gland from producing enough hormones, then long-term hormone replacement therapy will be necessary.

Will I still be able to have a family?

Yes, if the reason for infertility is pituitary disease. In many cases, the effects of pituitary tumours on fertility can be reversed.

What causes a pituitary tumour?

The cause of pituitary tumours is currently unknown.

Is it hereditary?

It is extremely rare to find 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, or to join or donate to the APF, please visit our website: www.pituitary.asn.au

Email: support@pituitary.asn.au

Phone: 1300 331 807

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