

# A GUIDE TO PROLACTINOMA



## WHAT IS A PROLACTINOMA?

A prolactinoma is caused by a tumour of the pituitary gland, a small gland at the base of the brain. In the vast majority of cases these tumours do not spread outside of the pituitary gland. They usually grow slowly and some don't grow much at all. Prolactinomas cause the pituitary gland to produce too much of the hormone prolactin. This causes a decrease in the levels of some sex hormones namely oestrogen and testosterone.

Prolactin plays a role in milk production and breast tissue development. High levels can cause irregular periods, infertility, erectile dysfunction (via low testosterone levels) and galactorrhoea (breast milk secretion). If large they may cause headaches or visual changes.

There are two types:

- **Microprolactinoma** – less than 1cm and more common in women
- **Macroprolactinoma** – greater than 1cm and more common in men

## HOW COMMON IS IT?

Between 500 and 1200 Australians are diagnosed with prolactinomas each year. About 6400 to 16000 Australians are currently living with a prolactinoma.

## WHAT ARE THE SIGNS AND SYMPTOMS?

### MEN

- Reduced libido
- Erectile dysfunction
- Infertility due to low sperm count

In men, the symptoms can be more subtle and develop slowly, resulting in a later diagnosis.

### WOMEN

- Irregular or absent menstrual cycle
- Milk secretion from breasts
- Infertility
- Reduced libido
- Vaginal dryness or pain during sex

Prolactinomas are often found early in women, as symptoms are more evident.

### BOTH MEN AND WOMEN

Large prolactinomas can press or invade surrounding brain tissue, causing:

- Some loss of peripheral vision
- Headaches
- Fatigue

Some people may develop hypopituitarism, where the body doesn't make enough pituitary hormones. More information about hypopituitarism is available from the Australian Pituitary Foundation.

## DIAGNOSIS

Tests to diagnose a prolactinoma and work out a treatment plan include:

- **Blood tests** – to measure levels of prolactin and pituitary function (including sex hormones, thyroid function tests, steroid and growth hormones)
- **Scans** – magnetic resonance imaging (MRI) or computed tomography (CT) scan can see the pituitary gland and the site of tumour
- **Eye testing** – to check the visual field
- **Bone mineral density test** – to check bone health.

High levels of prolactin may also be due to another cause, including:

- Pregnancy or breastfeeding
- Stress
- Side effects of other medication (dopamine antagonists, antipsychotics, some antidepressants, opiates)
- Polycystic ovarian syndrome
- Hypothyroidism (low thyroid function)
- Pituitary stalk dysfunction
- Kidney failure

### 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 aims to reduce symptoms by reducing prolactin levels. Options include:

- **Monitoring (no treatment)** – if there are no symptoms and prolactin levels are only slightly high, or after menopause
- **Medication** – called dopamine agonists, medications can reduce prolactin levels, return oestrogen or testosterone levels to normal and shrink the size of the tumour
- **Surgery** – to reduce tumour size or remove the tumour
- **Radiotherapy** – rarely used when other treatment options are not working to control the tumour.

Medication is often successful in reducing prolactin levels, decreasing tumour size and relieving symptoms in many people. If prolactin levels are difficult to return to normal, women may also need to take oestrogen and men may need to take testosterone. The most common medications that reduce prolactin production and tumour size include:

- **Bromocriptine** – a daily tablet
- **Cabergoline** – a tablet taken once or twice per week; more effective than bromocriptine<sup>3</sup>

Sometimes, the prolactinoma does not respond to medication, or the medication causes side effects. In these cases, you may need surgery or radiotherapy. Increasingly, these days, surgery may be an option for some patients with small tumours who wish to avoid long-term medication.

## MEDICATION MANAGEMENT

Most people need to take medication in the long term. You may be able to try stopping after three to five years, depending on your prolactin levels, tumour size and location, and menopausal state. Medications can cause side effects in some people, including dizziness, nausea and headaches.

You can limit these side effects by:

- Taking your tablets before bed at night
- Starting with a low dose
- Increasing your dose gradually, as guided by your doctor.

Cabergoline or bromocriptine may sometimes cause behaviour changes which should also be discussed with your doctor. These include obsessive-compulsive behaviour (eg excessive gambling or video gaming), hypersexuality and increased anxiety or depression. It's essential to have regular check-ups with your doctor to monitor your symptoms and any side effects. Very rarely with high dose cabergoline or bromocriptine the heart valves can become leaky. Regular heart ultrasounds will be recommended if you are on long term/high dose cabergoline or bromocriptine.

## PREGNANCY AND PROLACTINOMAS

Tell your doctor if you are planning to become pregnant or fall pregnant while taking medications. If you take bromocriptine or cabergoline, there is no evidence of an increased risk to the pregnancy or baby.<sup>5</sup> Women with microprolactinomas can generally stop taking medications after a pregnancy is confirmed and may only need to restart after finishing breastfeeding.

If you have a macroprolactinoma, you may need to keep taking your medication and have regular eye tests during pregnancy. It is safe to have MRIs in the second and third trimesters if needed. During pregnancy, there is a slight risk of tumour enlargement. If this occurs and causes a threat to your vision, medication may be restarted in pregnancy and occasionally surgery is required.

## COMMON QUESTIONS

### **Why have my periods stopped?**

High prolactin levels can stop the body from making hormones that regulate the menstrual cycle, causing irregular or missed periods.

### **Why am I no longer interested sexually in my partner?**

High prolactin levels stop your body from making sex hormones, which can lead to low libido (sex drive).

### **Why is sex painful?**

High prolactin levels cause oestrogen levels to fall. Low oestrogen can lead to thinning of the inner lining of the vagina. Treatment helps restore normal oestrogen levels.

### **Can a microprolactinoma grow into a macroprolactinoma?**

In the majority of cases, no.

### **Why do I have a discharge from my breasts?**

As prolactin increases to help women produce milk to breastfeed, high prolactin levels can cause the same effect.

### **How long will I need to take my medication?**

Prolactin levels can return to normal a few weeks after you start taking your medication, but it is essential to keep taking medication until your doctor tells you otherwise. Some people may try stopping after three or five years or after surgery to see if their prolactin levels remain normal. If you stop taking the medication, your prolactin levels may rise, and the tumour size may increase. It is important to see your doctor for regular check-ups to monitor your prolactin levels and tumour size.

## 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](http://www.pituitary.asn.au)**

**Email: [support@pituitary.asn.au](mailto:support@pituitary.asn.au)**

**Phone: 1300 331 807**

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