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# Prolactinoma

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A prolactinoma is a prolactin-producing adenoma of the pituitary gland. This is a benign tumour, and not a brain tumour or cancer. In this guide, learn more about prolactinoma, its causes, symptoms, and treatment.

**The**  
**● Pituitary**  
**Foundation**

For hormones • For health • For life

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# An explanation of hormones



## What is the pituitary gland?

The pituitary gland is a small gland located just below the brain that secretes hormones.

Hormones are chemicals that carry messages from one cell to another through the bloodstream. The pituitary gland controls several other hormone glands in the body, including the thyroid, adrenals, ovaries and testes. It also secretes several hormones directly (growth hormone, prolactin, vasopressin and oxytocin). The pituitary gland is therefore often described as the master gland.

If the pituitary gland is not producing sufficient amounts of hormones this is called hypopituitarism. If hormones are being over-produced, then this can cause problems depending on which hormone is being over-produced.



## What is prolactin?

The pituitary gland produces many hormones. These include:

- prolactin
- ACTH (adrenocorticotrophic hormone)
- TSH (thyroid stimulating hormone)
- GH (growth hormone)
- follicle stimulating hormone (FSH)
- luteinizing hormone (LH)
- vasopressin
- oxytocin.

Prolactin is sometimes known as the ‘milk’ or ‘breast feeding’ hormone because it stimulates milk production after childbirth. During breast feeding prolactin also stops the menstrual cycle in most women. Prolactin is also produced in men, although in smaller amounts and its role in men is not understood.

## What causes the prolactin level to be raised?

Common causes of raised prolactin include:

- Pregnancy
- Breast feeding
- Stress (e.g. worry in anticipation of a blood test)
- Anti sickness medications (e.g. metoclopramide, domperidone, prochlorperazine)
- Some medication used to treat mental health disorders (e.g. risperidone and some antidepressants)
- Polycystic ovary syndrome
- An under active thyroid gland

Once your doctor has excluded these causes, they will consider the possibility of a prolactinoma or a non-functioning pituitary adenoma (which does not make prolactin itself but affects the regulation of prolactin release).



# What is a prolactinoma?

A prolactinoma is a prolactin-producing adenoma of the pituitary gland. This is a benign tumour, and not a brain tumour or cancer.

Doctors use the words 'tumour', 'adenoma' or 'growth', all meaning a swelling on the pituitary gland. These adenomas only grow very slowly and many do not seem to grow at all or can shrink.

We do not know exactly what causes prolactinomas, but they are the most common type of hormone-producing pituitary adenoma.

Prolactinomas come in various sizes, but the vast majority are less than 10mm (3/8 inch) in diameter. These are called microprolactinomas. The rarer, large adenomas greater than 10 mm in size are called macroprolactinomas. Prolactinomas can occur in men and women.

Women tend to have microprolactinomas, whilst men tend to have macroprolactinomas.

# Signs & symptoms

There are numerous symptoms of a prolactinoma. The symptoms depend on the person's sex, how high the prolactin level is and the size of the adenoma. Below are a list of symptoms. These may not all be relevant to you depending on your gender and you may not experience all the symptoms:

- Loss of menstrual periods (amenorrhoea) or erratic periods.
- Reduced interest in sex (low libido).
- Vaginal dryness and discomfort during intercourse.
- Reduced fertility either due to the egg not being released from the ovaries or a low sperm count.
- Breast milk production (called galactorrhoea), which may leak spontaneously.
- Difficulty getting and maintaining an erection.
- With large prolactinomas you may have pressure symptoms such as headache or visual problems. This is because the nerves to your eyes pass over the top of the pituitary gland.



*There was many years of my condition gradually getting worse and feeling more unwell. I was pale, I had no hair growth, I was getting more tired and I interestingly became sort of mute. But strangely, I spent two years knowing that I had problems with my left eye. I was going blind.*

Gary was diagnosed with a prolactinoma by his optician.

# How to diagnose



The tests to diagnose a prolactinoma are relatively straightforward. They consist of blood tests to check hormone levels and a scan of the pituitary gland to show the size of the prolactinoma.

## Blood tests

Your GP would carry out initial tests of your prolactin and thyroid hormone levels, the hormones that regulate your periods (in women) or testosterone level (in men). Stress and the insertion of a needle to take a blood sample can slightly raise your prolactin level. It should be repeated more than once to ensure the result is consistently high and a true value.

If your blood tests come back with raised prolactin levels, then you should be referred to an endocrinologist to find the reason why. You would need to attend a specialist endocrine outpatient clinic for further tests, including any scans.

Your endocrine specialist may recommend further tests to better assess your overall pituitary gland function. These will be explained to you and may involve timed blood tests, or a hormone or specific drug to be given to produce stimulation or suppression of a specific hormone.

## Scans

A scan is usually carried out to give detailed pictures of the pituitary gland. There are two types of scan:

- MRI (magnetic resonance imaging, using a special magnetic technique)
- CT or CAT (computerised tomography, using X-ray imaging)



MRI is the scan normally used. You will lie on a flat table which will move into the cylindrical scanner. The examination can be noisy or claustrophobic, but you will be given earplugs or headphones to wear. Speak to your doctor if you are worried about this. During the scan, the radiologist may inject a dye into your arm so that any prolactinoma can be seen more clearly. A small minority of patients are allergic to this injection, so do tell the specialist if you have asthma or any allergies to previous contrast dye tests.

## **Other tests**

If you have any problems with your vision, you will be seen by an eye specialist. They will check your eyesight and chart your fields of vision.

Sometimes a special X-ray scan of your spine and hip bones may be recommended. This is to see whether there is any evidence of thinning of the bones (osteoporosis). This is a painless and straightforward test called a DEXA scan.



# How is a prolactinoma treated?



## Medication treatment

Most prolactinomas are treated with tablets called dopamine agonists, regardless of their size. These reduce the amount of prolactin produced by the prolactinoma and shrink the adenoma. They are:

**Cabergoline:** long acting and generally requires one or two doses per week. The usual dose of cabergoline is one tablet (0.5mg) once or twice a week, although higher doses are occasionally required. Sometimes the dose can be reduced later during long-term treatment.

**Bromocriptine:** usually given twice or three times daily (one tablet 2.5mg)

**Quinagolide:** taken once daily, with the dose increased gradually to 75 mcg (microgrammes).

These drugs are safe, and any side effects usually resolve within a few weeks of starting the drug. Side effects may include:

- dizziness on standing up
- nausea & loss of appetite
- headaches
- slight constipation
- tiredness
- abdominal pain
- breast discomfort
- nasal congestion
- psychological disturbance may be a rare complication of either cabergoline or bromocriptine, for example
  - (i) low mood
  - (ii) impulse control disorders such as pathological gambling and hypersexuality.

The tablets should be taken at night when going to bed with some food. This should reduce the chance of early side effects, including dizziness, nausea and loss of appetite.



*I was taking it [cabergoline] twice a week, I had a check-up and my prolactin levels halved. I had the typical nausea and so tired that I was just written off. But I've had a lot of brain fog as well. I was doing things like making a sandwich and putting the bread in the fridge or I need Google Maps to drive around where I live because everything was completely alien to me.*

**Teagan**, a university student diagnosed with prolactinoma in October 2021

Your doctor should give you instructions on how to build up the dose slowly to help minimise side effects. Increasing the amount of fibre in your diet, for example, wholemeal bread, fruit, vegetables or beans, can help with constipation.

As your body becomes used to the medication, then the side effects should reduce. If they continue or become too unmanageable then you should speak to your consultant or endocrine nurse specialist.

Very rare cases of heart valve damage have been reported in people who have taken long-term high dose cabergoline or bromocriptine. Your doctor may listen to your heart before starting treatment and may arrange an echocardiogram heart scan (similar to an ultrasound scan). This may be repeated if you need long-term high dose treatment.

Prolactin levels often fall to normal within a few weeks of starting the treatment. Once prolactin has fallen to normal, most symptoms should improve.

This includes menstrual cycles, interest in sex and fertility. You may need to discuss contraceptive options with your endocrinologist if pregnancy is not desired.

Most prolactinomas shrink in size following treatment with the tablets. If your prolactinoma has caused issues with your vision, then this should improve as the adenoma shrinks. If you have a large prolactinoma, you may have several pituitary scans to assess the shrinkage.

## Surgical treatment

Surgery and radiotherapy for prolactinomas is uncommon due to the effectiveness of tablet treatment. You may need surgery if:

- your prolactinoma doesn't shrink with tablets, particularly if your vision has not improved. This is less than 10% of people, OR
- you suffer unmanageable side-effects on the medication.

The operation is called trans-sphenoidal surgery. Traditionally, the surgery used an operating microscope inserted through the nose. This has predominantly been superseded by endoscopic trans-sphenoidal surgery. This is the same surgery but uses a camera.

If you do need surgery you can find more information in our Surgery booklet, or on our website: [www.pituitary.org.uk/surgery](http://www.pituitary.org.uk/surgery).

## Hormone replacement

You may need your hormones to be supplemented if you have co-existent underactivity of the pituitary gland. This usually occurs only in those with larger adenomas (macroprolactinoma).

This could include:

- steroid tablets for adrenal under-activity
- thyroid hormone tablets for thyroid under-activity
- oestrogen HRT or testosterone supplements
- growth hormone replacement therapy

# Prolactinoma continuing care



**You will be reviewed by your endocrinologist.** Initially, this may be every 3-6 months but once blood levels and treatment doses are stabilised you will be reviewed once a year. You may also have a repeat MRI scan. During this time, you should be able to contact your endocrine department if you have any problems.

**You should not stop taking medication without speaking to your endocrinologist.** Some people with microprolactinomas respond very well to tablet treatment, and can discontinue treatment after two to three years. This decision is based on blood test and scan results. Monitoring will continue after treatment has been discontinued to ensure there is no recurrence.

**Not all microprolactinomas need treating.** If you have no symptoms you can be monitored by blood tests.

**Treatment recommendations may change with time.** For example a microprolactinoma may not need treatment after a pregnancy or after the menopause. Your endocrinologist will discuss these decisions with you.

## Transgender people

There is limited research around prolactin levels, prolactinomas and transgender people. Transgender women receiving gender affirming hormone therapy may be at increased risk of prolactinoma and their prolactin levels may be monitored. Trans and non-binary people being treated for a prolactinoma would be under specialised endocrine and gender service care.

# Living with a prolactinoma



A prolactinoma is a long-term condition, and it may impact your day to day life. Below we outline some things you may need to consider. More information to help you live well with your condition can be found on our website: [www.pituitary.org.uk/living-with-a-pituitary-condition](http://www.pituitary.org.uk/living-with-a-pituitary-condition).

## Fertility

Fertility can return quickly. If you, or your partner, do not wish to become pregnant, you will need to use contraception. This conversation should happen with your doctor before you start treatment. If pregnancy is desired, you should see your endocrinologist for pre-pregnancy planning and advice.

## Pregnancy and breast feeding

Usually you should stop taking your medication on confirmation of a pregnancy, and not resume it until you have finished breast feeding and been reassessed, but you should speak to your endocrinologist for individual advice. You shouldn't need to check for levels of prolactin in the blood, as these rise during a normal pregnancy.

Your endocrinologist will advise about the need for any specialist monitoring during your pregnancy. Rarely, women with large macroprolactinomas will be advised to continue cabergoline treatment in pregnancy and not to breast feed. Your endocrinologist would discuss these decisions with you.

Following the birth and breast feeding, you will be reassessed by your endocrinologist regarding the need for further treatment of your prolactinoma.

# More information

We have a full range of booklets to support people with their pituitary conditions, as well as information across our website.

You can find this at [www.pituitary.org.uk](http://www.pituitary.org.uk).

**If you would like more support then we have a range of services that may be suitable:**



## Endocrine Nurse helpline

Our specialist endocrine nurses can provide medical advice.



## Information and Support Helpline

Our volunteers and staff run helpline allows you to speak to others with pituitary conditions, and ask practical questions about living with a pituitary condition.



## Telephone Buddy

This service provides one to one support with someone with a similar pituitary journey as you. For example someone with the same condition, or a parent of someone with a condition.



## Support Groups

We have a number of volunteer-led support groups across the UK, which host meetings with endocrinologists and peer support for patients.



## Events

We host online and in-person events with endocrinologists on specific conditions/topics. These give people the opportunity to hear from professionals and ask questions.

## About

# The Pituitary Foundation

We're a dedicated team offering practical, emotional and peer support to everyone living with or impacted by a pituitary condition, to feel empowered and live with a greater sense of wellbeing.

For over 25 years, we've been amplifying voices and striving towards positive developments for the pituitary community. We work alongside healthcare professionals, clinical research teams and specialist organisations to raise the profile of pituitary conditions, finding better solutions for everyone affected by these life changing illnesses now and in the future.

## Become a member and support our work

Becoming a member is an excellent way to show your commitment to our work at The Pituitary Foundation.

As members you'll enjoy a range of benefits including free copies of Pituitary Life magazine - full of great articles from endocrinologists and inspiring stories from people living with pituitary conditions. You'll also be able to have a say on how the charity is run, and get early access to our fantastic events.

**A yearly donation of £25 allows us to continue our work now and in the future.**

You can become a member at: [www.pituitary.org.uk/membership](http://www.pituitary.org.uk/membership)

All information in this guide is general. If you have any concern about your treatment or any side effects please read the Patient Information booklet enclosed with your medication, or consult your GP or endocrinologist.

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