

What is Hyperprolactinaemia?

Hyperprolactinaemia refers to high levels of prolactin in the blood. Prolactin is a hormone made in the pituitary gland. It plays a role in breast milk production after childbirth and affects male and female reproductive health.

What are the causes of hyperprolactinaemia?

Hyperprolactinaemia can be caused by a range of factors¹. It is important to identify the cause so the correct treatment can be provided. Causes include:

- Prolactinoma
- Other types of pituitary tumours
- Pregnancy
- Breastfeeding or nipple stimulation
- Some medications (including antipsychotic and anti-nausea medicines)
- Underactive thyroid (hypothyroidism)
- Polycystic ovary syndrome
- Kidney or liver failure
- Physical or psychological stress
- Marijuana use



What is a Prolactinoma?

A prolactinoma is a common tumour arising from the pituitary gland that produces the hormone prolactin. They are almost always benign (non-cancerous).

Prolactinomas are grouped according to their size:

- Microprolactinomas are less than 10 mm (1 cm)
- Macroprolactinomas are 10 mm (1 cm) or larger

In Australia, around 450 people each year will be diagnosed with a prolactinoma².

This is far less than the actual number of people who have prolactinomas, as many small prolactinomas never cause symptoms and are not detected. Studies of autopsy results have revealed nearly 1 in 10 people had tiny tumours in their pituitary gland.³

Prolactinomas are most common in women aged between 20 and 34 years. They are very rare in children.

What causes prolactinomas?

No one really understands what causes a prolactinoma. Most people with a prolactinoma have no family history of pituitary tumours.

If your prolactinoma developed at a young age and/or you have a family history of pituitary or other endocrine (e.g. parathyroid, pancreas and adrenal) tumours, your doctor may discuss the option of genetic testing with you to look for rare genetic changes (mutations) that may be passed on in family members.

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What are the symptoms and signs of hyperprolactinaemia?

In some people, hyperprolactinaemia causes no symptoms or signs¹.

In others, the symptoms of hyperprolactinaemia are caused by its effect on bone health, breast health and reproductive function¹.

For men and women, these include:

- Decreased bone mass and density
- Infertility
- Decreased libido (low interest in sex)

For men, symptoms and signs also include:

- Unable to get erections
- Enlarged or swollen breasts
- Decreased body and facial hair

For women, symptoms and signs also include:

- Irregular menstrual periods
- Absent menstrual periods
- Milky discharge from the breast when not breastfeeding
- Vaginal dryness and painful intercourse

If hyperprolactinaemia is caused by a prolactinoma, additional symptoms can occur. These are usually caused by large prolactinomas that put pressure on the surrounding normal pituitary gland and nearby nerves and brain tissue. These symptoms can include:

- Headaches
- Loss of peripheral vision or part of the visual field
- Nausea or vomiting
- Poor appetite
- Fatigue
- Dizziness standing up

How is hyperprolactinaemia and prolactinoma diagnosed?

1. Medical History

Your doctor may ask you questions about:

- Your periods (for women) or whether you can get erections (for men)
- Changes in sex drive
- Any discharge from your breasts (men and women)
- Headaches and visual symptoms
- Medications, supplements and herbal therapies you may be taking
- If you are pregnant (which may be confirmed with a pregnancy test).



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How is hyperprolactinaemia and prolactinoma diagnosed? (*cont'd*)

2. Blood tests

A blood test will be done only if you have symptoms or signs of hyperprolactinaemia, or a known pituitary problem¹. This test is used to measure the levels of prolactin, and other hormones in your blood. A small amount of blood is taken and sent to a laboratory for testing. An elevated prolactin will often be confirmed on a second blood collection.

Different laboratories use different methods for testing, and so normal reference ranges can vary. This can make comparison of results between laboratories and other people difficult.

What do the results mean?

- If your prolactin level is within the normal range, you do not have hyperprolactinaemia. Your doctor may do other tests to look for the cause of your symptoms.
- If your prolactin level is high (hyperprolactinaemia) without a clear explanation of a cause, your doctor will do more tests to identify the cause of your hyperprolactinaemia. They may refer you to have an (magnetic resonance imaging) or, less commonly, a CT scan (or CAT scan; computerised axial tomography). These imaging methods create pictures of inside parts of your body to allow the doctor to check the size and shape of your pituitary gland.
- High prolactin levels may require treatment. Your doctor will discuss options with you. This could involve a period of simply monitoring your prolactin levels with repeat blood tests or treatment with medications or surgery.

3. MRI scan

Your doctor may send you for an MRI (magnetic resonance imaging) to check the size and shape of your pituitary gland. An MRI scan uses a magnetic field and radio waves to take pictures of parts of the body. Before having an MRI, you will usually change into a gown and remove any watches or other metallic objects. You might be given earplugs or headphones, as the MRI machine can be noisy. Some people with metal in their body (for example, some pacemakers, welding injuries with metallic foreign bodies in their eyes) cannot have an MRI.

For the scan, you will lie on a platform that slides into the MRI machine. You will need to lie very still while inside the machine, as movement can blur the images. When inside the MRI machine, you will still be able to talk to the operator through an intercom system. The scan can take up to an hour. If you have significant claustrophobia, your doctor may be able to arrange for you to have light sedation during the scan.

What do the results mean?

- If your pituitary gland is normal in shape and size, your doctor may conduct other tests to identify why your prolactin is high. Some prolactinomas are so small that they cannot be seen on the MRI scan and the high prolactin level may be still treated with medications, or your doctor may repeat blood tests to monitor your prolactin levels.
- If a small prolactinoma (microadenoma) is found, your doctor will decide if treatment is necessary. Your doctor may recommend medication which will need to be followed with regular checkups to make sure the medication is working. You will usually have a repeat MRI scan in 6-12 months. Other treatment options such as surgery are occasionally required if the medications are not working or causing significant side effects.
- If a large prolactinoma (macroadenoma) is found, this is usually treated with medications. Sometimes other treatments are required, such as surgery or radiotherapy. In most cases, you will have a repeat MRI scan in 3-6 months.

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How is hyperprolactinaemia and prolactinoma diagnosed? (*cont'd*)

4. Vision test

Your doctor may organise to test your vision. This is because prolactinomas can push on the nerves that connect the eye to the brain, called the optic nerve. This causes patchy or blurred vision, particularly at the far edges of your sight. Vision tests are most often conducted through eye specialists (an optometrist or ophthalmologist).

What do the results mean?

Reduced vision: your doctor will start medication to shrink the prolactinoma. This will help reduce the pressure on the optic nerve and your vision should improve. In some cases, surgery is required to remove the prolactinoma. You will require close monitoring of your vision by an optometrist or ophthalmologist.

Normal vision: the prolactinoma has not resulted in damage to the optic nerve. Sometimes a prolactinoma can be close to the optic nerve but not yet cause any visual loss and your doctor may recommend regular monitoring of your vision by an optometrist or ophthalmologist.

5. Bone mineral density (BMD) test

Your doctor may test your bone mineral density. This is because prolactinomas can increase the risk of osteoporosis (thinning and weakening of the bones, resulting in an increased risk of fracture). The best way to test bone mineral density is using a DEXA scan (Dual Energy X-ray Absorptiometry scan). This is a fairly quick (10-30 minutes) and painless imaging procedure with very little radiation exposure. It involves lying fully clothed on a platform while a scanner passes over you to take pictures of your hip, spine and, sometimes, forearm.

What do the results mean?

Results are generally reported as a T score.

- **T-scores above -1.0** indicate normal bone density.
- **T scores between -1.0 and -2.5** indicate osteopaenia (slightly reduced bone density).
- **T scores below -2.5** indicate osteoporosis (low bone density and increased risk of bone fractures).

Your doctor may recommend calcium and/or vitamin D supplements and potentially other medication to strengthen bones and reduce the risk of fractures. Treating hyperprolactinaemia may also stop further loss of bone density.

How is hyperprolactinaemia treated?

Your doctor will tailor the treatment of your hyperprolactinaemia based on your symptoms and test results. Some people do not require any treatment, while others may require medication and/or surgery. Prolactinomas often stay the same size for many years and if they grow, they do so very slowly. The treatment plan will depend on the cause of your hyperprolactinaemia.

Hyperprolactinaemia caused by medications

If the hyperprolactinemia is due to medications you are taking, your doctor will discuss whether you can stop taking the medication, or whether an alternative exists that will not increase your prolactin levels. Sometimes your medications cannot be changed, in which case your doctor will discuss other options with you.

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How is hyperprolactinaemia treated? (cont'd)

Hyperprolactinaemia caused by hypothyroidism

If the hyperprolactinemia is due to hypothyroidism, your doctor will treat the hypothyroidism first, and monitor your prolactin levels to make sure they return to normal.

Hyperprolactinaemia caused by prolactinoma

The first step in treatment is generally medication, but if there are no symptoms and only a very mild elevation in prolactin level, no treatment may be necessary. Surgery and radiation therapy are occasionally used to control prolactinomas that continue to grow despite medication or where the medications cause troublesome side effects.

Medication

The medication used to treat prolactinoma is called a dopamine agonist. Commonly used dopamine agonist medications include cabergoline (trade name, Dostinex), bromocriptine (trade name, Parlodel) and quinagolide (trade name, Norprolac). Dopamine agonists act like dopamine, causing the pituitary gland to make less prolactin. In many people, prolactin levels return to normal within a few weeks to a few months of starting treatment. It usually takes longer to see a reduction in the size of the prolactinoma.

You will need to continue taking the medication as prescribed. Otherwise, the prolactinoma can grow and/or symptoms can return. In many cases, you will need to keep taking the medication for a long period of time. In some cases, the medication can eventually be reduced or even stopped. Your doctor will regularly measure your hormone levels to make sure the dose is correct, and the medication is working.

Your doctor will generally start you on a low dose and may increase the dose over time. This can help avoid any side effects, including nausea, nasal stuffiness, dizziness/faintness, constipation, sleepiness, headache, worsening of anxiety and/or depression. Rare side effects can include

addictive behaviours (e.g. involving sexual activity, gambling, shopping or eating), auditory hallucinations (hearing things), mood changes and delusions. You should notify your doctor as soon as possible if these rarer side effects occur as they may recommend that you reduce or stop your medication. These side effects usually resolve very quickly once medication is stopped. Other treatments may be considered if the prolactinoma is still present.

In other medical conditions where cabergoline is used in higher doses it can cause scarring of the heart valves leading to heart failure. However, current evidence suggests that cabergoline does not cause heart valve scarring in the low doses usually used to treat hyperprolactinaemia.

In women, successful treatment usually results in restoration of fertility (particularly in microprolactinomas). To prevent unwanted pregnancy, birth control may be needed. In women with microprolactinomas who do not wish to fall pregnant in the near future, the oral contraceptive pill may be used instead of dopamine agonist medications in order to restore normal sex hormone (oestrogen and progesterone) levels and improve bone density.

If you are pregnant or planning to get pregnant, your doctor may change your medication. In microprolactinomas, the medication can often be stopped once you are pregnant. If surgery is required – for instance, in large prolactinomas – your doctor may try to arrange for this to occur well before any planned pregnancies. It is helpful to discuss any plans for children with your doctor ahead of when you start trying to conceive.

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How is hyperprolactinaemia treated? (cont'd)

Surgery

Most prolactinomas respond to medication, and do not require surgery. Surgery may be needed if the prolactinoma is large and pressing on nerves or brain tissue or is growing despite medication or if the medication is not tolerated. There are two types of surgery to remove prolactinomas. Your surgeon will choose the best method based on the size and extent of the prolactinoma.

Transnasal transsphenoidal surgery

Transnasal transsphenoidal surgery is the most common procedure. This surgery is often done by two surgeons: a neurosurgeon; and an ear, nose and throat (ENT) surgeon. The ENT surgeon uses an endoscope (a very thin fibre optic tube with a camera on the end) to navigate through one of your nostrils to the back of the nose where a small cut is made to access the pituitary gland. The ENT surgeon uses the endoscope to assist the neurosurgeon to see and remove the tumour. Larger tumours may need to be removed in smaller pieces. Once the tumour is removed a piece of tissue from the inside of your nose or some fat tissue is used to patch the hole at the back of the nose. This surgery leaves no visible scars.

The surgery takes about 2-3 hours and you will stay in hospital for 3-5 days. During your hospital stay your urine output is watched carefully and you may be prescribed some steroid medication for a few days. You will have regular blood tests while in hospital. After surgery, it is fairly common to have a mild headache and nasal congestion for up to 2 weeks. You will have another blood test 4-6 weeks after surgery to check your prolactin and other hormones levels. Thereafter, your prolactin and hormone levels will be checked periodically. An MRI scan will be done after 3-6 months. If symptoms reappear, blood tests and scanning will be repeated.

Transcranial surgery

Transcranial surgery is when the pituitary is operated on through a cut in the forehead. It is only rarely performed in very large prolactinomas, which can make it difficult to remove all the tumour through the back of the nose.



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FAQs about prolactinoma and hyperprolactinaemia

Will my prolactinoma go away?

With treatment, either medication or surgery, the prolactinoma may disappear. However, often it does not go away, and the goal of treatment is to control symptoms and stop the growth of the tumour. For unknown reasons, prolactinomas can sometimes disappear after pregnancy or menopause.

What is the likely outcome of my treatment?

With use of medications or combined medical and surgical therapy, the symptoms and size of prolactinomas are usually controlled.

How long before my symptoms disappear?

Reversal of symptoms depends on a number of factors including the size of the prolactinoma, your prolactin levels and how well it responds to treatment. Most people respond well to treatment, and prolactin levels return to normal within weeks. Symptoms generally subside within a few months, including the return of periods for women with amenorrhea. Macroprolactinomas can take longer to respond to treatment or may require surgery. Your doctor can discuss your circumstances with you.

Will I always need medication?

This depends on your individual circumstances. Some people who respond well to treatment have normal prolactin levels on low dose dopamine agonist medication and disappearance of tumour on MRI, and their medication may be stopped after 2-3 years. After surgery, most people can stop taking dopamine agonist medications, but some people may need to continue their medication. After the menopause, women may also no longer need to be treated with medication. If treatment is stopped, it is important to have regular checkups with your doctor to ensure the prolactinoma does not return.

It is important to not stop taking any medications without talking to your doctor. If you are experiencing side effects from your medication, see your doctor immediately to discuss alternatives.

Can I get pregnant while taking medication for hyperprolactinaemia?

It is important that women planning a pregnancy discuss a treatment plan with their doctor. Prolactinomas often interfere with fertility and, conversely, starting dopamine agonist medications to treat the prolactinoma can restore fertility. Most women are able to have a pregnancy after starting treatment. Contraception is therefore required if you are not wishing to fall pregnant.

If you fall pregnant while taking medications, tell your doctor who will make sure you are taking a medication that is safe in pregnancy. Often medication can be ceased once you are pregnant, and may not need to be restarted until you have completed breastfeeding. Your doctor will conduct regular check-ups in pregnancy, however you should see your doctor sooner if you have any changes in your symptoms (e.g. changes in vision, headaches).

Are there any natural remedies for hyperprolactinemia?

There are no proven natural remedies for treatment of hyperprolactinemia caused by prolactinoma. Although the herbal extract Vitex agnus-castus (common names chaste tree, Monk's pepper) can lower prolactin levels in certain groups⁴, there is no evidence this herbal remedy controls symptoms or affects the size of the prolactinoma. Vitex agnus castus should not be taken when pregnant or lactating, or with other common medications (eg. hormone replacements, oral contraceptives, other drugs that act on the dopamine system)⁵. It is important to discuss taking any natural remedies with your doctor.

Where to go for more information and support?

Your doctor (GP)

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The Australia Pituitary Foundation : <https://pituitary.asn.au/>

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When to see your doctor

You should see your doctor (GP) if you have the following symptoms. Your GP can refer you to an endocrinologist – a doctor specialising in hormones and glands.

For women, you should see a doctor if you have the following symptoms:

- Periods stop or become irregular
- Discharge from the breasts when not breastfeeding
- Difficulty getting pregnant
- Decreased libido (lower sex drive)
- Loss of part of visual field
- Headaches
- Nausea or vomiting

For men, you should see a doctor if you have the following symptoms:

- Unable to get erections
- Swollen or enlarged breasts
- Difficulty getting partner pregnant
- Decreased libido (lower sex drive)
- Loss of part of visual field
- Headaches
- Nausea or vomiting
- Decreased body or facial hair growth

If you are taking medications to treat a prolactinoma, see your doctor if symptoms change or get worse.

See your doctor if you have any side effects after starting your medication, such as nausea, nasal stuffiness, dizziness/faintness, constipation, sleepiness, headache, worsening of anxiety and/or depression, addictive behaviours (e.g. involving sexual activity, gambling, shopping or eating), or you start hearing or seeing things that aren't there. These side effects can usually be lessened or eliminated by your doctor prescribing a lower dose or a different medication, or stopping the medication altogether. These decisions should always be made in conjunction with your doctor/endocrinologist.

Questions to ask your doctor

Seeing your doctor or having a medical problem can be stressful. It often takes time for information to sink in and it is very common to feel overwhelmed by what is happening.

Sometimes it is helpful to write down questions for your doctor before you go.

Some questions that might be useful for you are:

- Do I need medication for my hyperprolactinaemia?
- Do I need to take other hormone supplements or medications?
- What are my choices for medication?
- How quickly should the medicine work?
- For how long do I need to take my medications?
- What should I expect with my symptoms?
- Does my medication have any side effects?
- Do I need to have an MRI?
- Do I need a bone mineral density scan?
- Do I need surgery?
- Can I get pregnant if my medication works?
- Do I keep taking my medication if I get pregnant?
- Will I be able to breastfeed while taking medication?
- Do I need another appointment?



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Common terms and definitions

Adenoma – A non-cancerous tumour that occurs in glands.

Amenorrhoea – Absent menstrual periods.

Benign – A benign tumour is one that is not cancerous.

Galactorrhoea – Milky discharge from the breast in men and in women (not due to breastfeeding).

Gynaecomastia – Enlarged or swollen breasts.

Libido – Interest in sex; sex drive.

Microprolactinoma – A tumour that is less than 10 mm (1 cm) in size.

Macroprolactinoma – A tumour that is 10mm (1cm) or larger.

Malignant – Contains cancerous cells.

Oligomenorrhoea – Irregular menstrual periods.

Pituitary Gland – A gland located at the base of the brain. It is often called the master gland, because it controls several other glands in the body.

Prolactinoma – A tumour of the pituitary gland.

Tumour – An abnormal swelling or growth in the body. Can be benign or malignant.

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About this fact sheet

The content on this page was medically reviewed by Dr Ann McCormack, Dr Morton Burt, Dr Carmela Caputo and Dr Sunita De Sousa.

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