

## The Culprit Is Too Much Prolactin

Prolactin is a hormone that causes the breasts to produce milk during and after pregnancy. It also controls a person's sex drive. Too much prolactin (a condition called hyperprolactinemia) can result from a tumor blocking the flow of **dopamine** from the brain. Other medical conditions and certain medications can also cause the level of prolactin to rise in the body. Another possible cause is a prolactinoma—a noncancerous tumor found near or in the pituitary gland. Your doctor might call this tumor a prolactin-secreting **adenoma** of the pituitary gland. Other culprits that can cause increased prolactin are:

- Breast stimulation
- Certain prescription drugs\* that treat:
  - Depression
  - Gastrointestinal reflux
  - High blood pressure
  - Mental disorders
  - Nausea caused by cancer therapy
- Polycystic ovary syndrome
- Underactive thyroid gland (hypothyroidism)

\*Provide your doctor with a complete list of all the medications you are currently taking.

## For More Information

### **American Association of Clinical Endocrinologists**

([www.aace.com](http://www.aace.com))

Provides information about endocrine disorders and helps you locate an endocrinologist in your area.

### **The Hormone Foundation** ([www.hormone.org](http://www.hormone.org))

Answers general questions about various pituitary tumors, medical treatments, and hormone replacement therapy.

### **MEDLINEplus® Health Information**

([www.medlineplus.gov](http://www.medlineplus.gov))

Has a medical encyclopedia that contains facts about prolactinomas and pituitary disorders in general.

### **National Institute of Child Health and Human Development**

(**NICHHD**) ([www.nichd.nih.gov](http://www.nichd.nih.gov))

Conducts research on the various processes that determine and maintain the health of individuals, families, and populations.

### **National Institute of Diabetes and Digestive and Kidney Diseases**

(**NIDDK**) ([www.niddk.nih.gov](http://www.niddk.nih.gov))

Provides links to national organizations serving patients concerned about endocrine and metabolic diseases.

### **Pituitary Network Association** ([www.pituitary.org](http://www.pituitary.org))

Provides information about ongoing clinical trials, medical resources and terminology, and links to other organizations.



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# Living with a PROLACTINOMA

Very Common

Very Treatable



## Prolactinoma: An Unpredictable Foe

Prolactinomas are the most common type of diagnosed pituitary **tumors**. A prolactinoma is a noncancerous benign tumor found in the **pituitary gland**. Many of the symptoms are subtle and often ignored. But if left untreated a prolactinoma can lead to more serious problems.

If you have a prolactinoma, the good news is that it is treatable and in many cases it is curable. You need to seek care from your doctor or an endocrinologist, a doctor who specializes in diseases of the endocrine glands and their **hormones**. Treatment can restore the balance of hormones in your body and can help you return to a normal life. The next step is for you to take an active role in your treatment and recovery.

*“I felt better and stronger after starting therapy.”*



## You Are Not Alone

Many healthy people have a pituitary tumor and do not know it. Prolactinoma is the most common type of diagnosed pituitary tumor. It occurs usually in adults under age 40 and is rarely seen in children. Prolactinomas occur more often in women than in men. The cause of these tumors is not known.

## Don't Ignore the Subtle Symptoms

Many of the symptoms of prolactinoma are not obvious, and people often ignore them, especially men. Symptoms are caused by the release of too much prolactin (also known as hyperprolactinemia) in the blood. The symptoms are different for women and men (see below). Some symptoms may be caused by pressure on the surrounding brain tissue. Men often are not diagnosed until the tumor has grown large. When that happens the tumor can press on the nerves connected to the eyes and can cause visual changes or problems.

### Women

- Fatigue
- Infertility
- Irregular or no menstrual periods
- Joint pain
- Loss of sex drive
- Milk leaking from breasts
- Osteoporosis
- Painful sexual intercourse
- Severe headaches

### Men

- Enlarged breasts
- Impotence
- Infertility
- Joint pain
- Loss of sex drive
- Severe headaches

*“With treatment my life has completely changed.”*



## Figuring It All Out

If you have symptoms associated with a prolactinoma, your doctor can test the level of prolactin in your blood. If it is high, a thyroid function test may be done to check your thyroid gland. Your doctor may ask what medications you are currently taking. Provide a complete list of all your medications. If your thyroid and/or your ovaries are working fine and medications aren't the problem, the next step may be an MRI or CT scan of your pituitary gland. These images can show if a tumor is present, how big it is, and how it is affecting other surrounding tissues in the brain. If a tumor is pressing on the nerves to the eyes, visual problems may occur. Your doctor may request a vision test to diagnose any eye problems.

## A Very Treatable Problem

Medications are usually the preferred way to treat prolactinomas. Medications combined with either surgery or radiotherapy may be used to manage stubborn tumors. You and your doctor can decide what's best.

**Medications** are used to reduce the release of prolactin and, in some cases, to decrease tumor size. They may slow or stop growth of the tumor. Your doctor may prescribe bromocriptine (Parlodel®), pergolide (Permax®), or cabergoline (Dostinex®). You may need to take these medications for several years or longer.

**Surgery** (transsphenoidal resection) is used to remove the pituitary tumor if medications no longer work, if medications cannot be tolerated, or if bleeding occurs into the tumor (apoplexy). This operation usually reaches the pituitary gland through either a nostril or under the lip, not through the brain. Patients are best referred to medical centers that specialize in the procedure.

**Radiotherapy** is seldom used in treating prolactinomas. Radiation kills off tumor cells. It is used when a rapidly growing tumor does not respond to medication or surgery.



## Don't Put Your Head in the Sand

If you ignore the prolactinoma, it may grow larger and cause more problems. It may cause permanent loss of vision and bleeding. In women, prolactinomas can cause low levels of estrogen. This can bring about vaginal dryness, painful intercourse, loss of menstrual periods, and **osteoporosis**. In men, prolactinomas also can cause osteoporosis. Large prolactinomas may cause weakness and tremors, water on the brain, apoplexy, or **hypopituitarism**. If the pituitary tumor is left untreated, high levels of prolactin can reduce or stop production of certain sexual hormones. This in turn can cause shrinkage of breasts in women and testes in men and can lead to infertility.

## Conquering the Foe

Patients who receive aggressive medical therapy for treating prolactinomas generally have good outcomes. Many people do very well with the medications that their doctors prescribe. In most patients, tumors do not grow for 4 to 6 years after treatment. Some doctors recommend discontinuing medical treatment every 2 years on a trial basis.

Occasionally, tumors can return or begin to grow again. Larger tumors have a tendency to grow back with time. They may require more aggressive treatment to prevent complications. The rate of growth varies and can't be predicted for sure.

*Once you're on track, keep it up.*



## Follow-up Monitoring

Treatment should help put an end to many of the symptoms associated with the prolactinoma. Your doctor can help you stick with a program to keep you healthy. Here is some advice from a patient previously treated with a prolactinoma:

- Eat healthily and exercise regularly
- Keep regular appointments with your doctor
- Tell your doctor if your symptoms return or get worse
- Have your prolactin levels checked regularly
- Read the latest information about prolactinomas
- Schedule an MRI or CT scan regularly to check tumor growth
- Schedule a bone density scan to check for osteoporosis
- Get your vision checked regularly
- Consider getting counseling or psychological support

## Glossary

**adenoma** - A noncancerous tumor made up of cells that form glands.

**dopamine** - A hormone-like substance found in the nervous system. It transmits signals between nerves.

**hormones** - "Chemical messengers" that are made and released by endocrine glands and that target one or more parts of the body.

**hypopituitarism** - A medical condition where the pituitary gland produces lower than normal levels of certain hormones.

**osteoporosis** - Loss of calcium and other minerals from bones, which can lead to weakening of bones and fractures.

**pituitary gland** - Master gland of the endocrine system that produces several hormones, including prolactin.

**tumor** - An abnormal growth that may be cancerous or noncancerous depending on the cell type. It may cause visual impairment or may be life-threatening depending on the location.