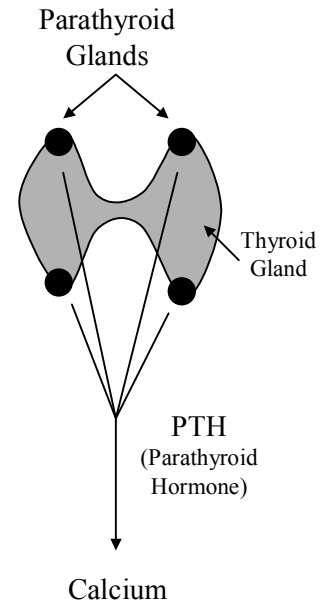


PRIMARY HYPERPARATHYROIDISM

PATIENT INFORMATION

WHAT ARE THE PARATHYROID GLANDS AND WHAT DO THEY DO?

- The parathyroid glands control the body's blood calcium level. There are usually four parathyroid glands that are located in the neck, near the thyroid gland. Occasionally there can be extra or missing parathyroid glands (this usually does not cause any problems).
- These glands control the calcium level by releasing a hormone called PTH (parathyroid hormone), which raises the blood calcium level by signalling the body to absorb more calcium from the diet and to remove calcium from the bones.
- The parathyroid glands can sense the blood calcium level, and can adjust the level of PTH to keep the calcium normal (very similar to how the thermostat can sense how much heat is in your home, and can adjust the signal to the furnace to keep your home at the right temperature).



WHAT CAUSES PRIMARY HYPERPARATHYROIDISM?

- In most cases, one of the parathyroid glands has become overactive (this is called a parathyroid adenoma). The broken gland makes PTH all the time, rather than stopping when the blood calcium level becomes high. Because too much PTH is being made, the blood calcium level becomes too high.
- Rarely, all four parathyroid glands are overactive. This is called parathyroid hyperplasia.

WHAT ARE THE SYMPTOMS OF PRIMARY HYPERPARATHYROIDISM?

- Kidney stones and osteoporosis are the main complications of primary hyperparathyroidism. These problems almost always improve with surgery to treat the overactive parathyroids glands.
- Fatigue, weakness, abdominal pain, nausea, constipation, depression, and increased urination can be caused by hyperparathyroidism (all of these symptoms can also be caused by many other conditions). These symptoms *may* get better with surgery to correct the overactive parathyroid glands.
- If the blood calcium level becomes very high, which is uncommon in primary hyperparathyroidism, people may become sleepy, confused, lethargic, or comatose. *This is an emergency that requires immediate medical attention.* This is more likely to occur when people with primary hyperparathyroidism have vomiting or diarrhea and become dehydrated. If you have untreated primary hyperparathyroidism and have severe vomiting or diarrhea, please call your doctor to see if you should have a calcium level checked, and so you may receive IV fluids if needed.
- Many people with primary hyperparathyroidism have no symptoms.

HOW IS PRIMARY HYPERPARATHYROIDISM DIAGNOSED?

- Primary hyperparathyroidism is diagnosed by finding that the blood calcium level is high, and that the PTH level is also high. Generally, these blood tests should be repeated at least one time to be sure the diagnosis is correct. Occasional people with primary hyperparathyroidism can have a calcium level in the normal range (usually at the upper end of the normal range).

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WHAT ADDITIONAL EVALUATION IS REQUIRED?

- Additional evaluation is needed to confirm that primary hyperparathyroidism is the correct diagnosis, and to decide if surgery is needed for treatment.
- Testing usually consists of blood tests to check the levels of calcium, PTH, vitamin D, and kidney function. Additionally, calcium should be measured in a 24-hour collection of urine. A special x-ray test called a DXA scan is performed to measure bone density at the spine, hip, and forearm.
- Special x-ray tests, called sestamibi scanning and neck ultrasound, can sometimes identify an overactive or enlarged parathyroid gland. Not everyone with primary hyperparathyroidism needs to have these tests done. Your doctor will discuss with you whether this testing is needed.
- Occasionally, a needle biopsy is performed to identify an enlarged parathyroid gland prior to surgery.

HOW IS PRIMARY HYPERPARATHYROIDISM TREATED?

- The only curative treatment for primary hyperparathyroidism is surgery. Surgery is recommended for people with one or more of the following:
 - A blood calcium above a certain level (generally 1.0 mg/dl above the upper end of a normal calcium level)
 - Osteoporosis or a history of kidney stones
 - Decreased kidney function
 - A high urine calcium level (above 400 mg per day)
 - Age younger than 50
- Surgery may also be considered for people with other symptoms that might improve with surgery.
- For people with a high risk of having complications, surgery may not be recommended, even if one of the conditions above is present. The risks versus benefits for surgery must be considered.
- Additional treatments, such as medication to treat osteoporosis, may also be necessary. These treatments should not be considered a substitute for surgery.

HOW IS SURGERY PERFORMED? WHAT ARE THE RISKS?

- The surgeon will generally make a small incision in the neck, will look at all the parathyroid glands, and will remove any gland (or glands) that appear to be overactive. The surgery is curative 95% of the time or more.
- The main risks to surgery are (1) damage to the nerve controlling the vocal cords, and (2) underactive parathyroid glands. When an experienced surgeon performs the operation, these occur less than 3% of the time, and are very rarely permanent. There are treatments available should these problems occur. If you are having surgery, the surgeon can tell you more about the specific risks in your case.

WHAT IF I DO NOT HAVE SURGERY? HOW WILL I BE FOLLOWED?

- If you or your doctor decide that surgery is not right for you, it will be important make sure that the primary hyperparathyroidism is not progressing. You should have your calcium checked at least twice per year, and should have your bone density and kidney function measured once per year.