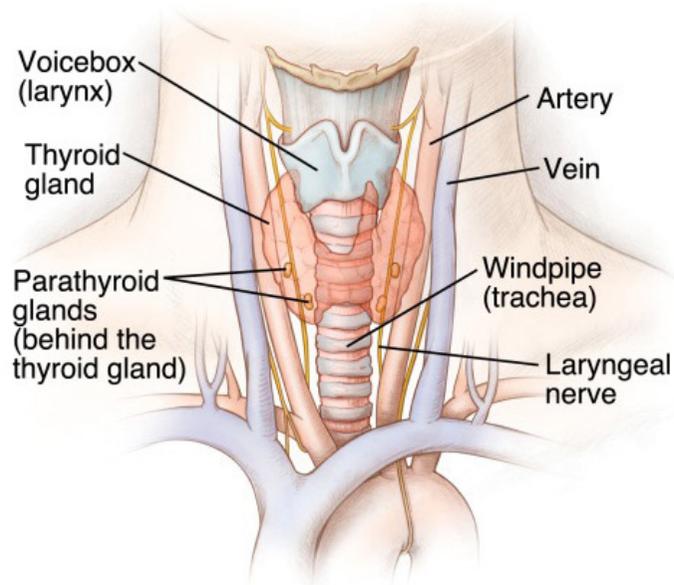


A PATIENT GUIDE TO HYPOPARATHYROIDISM

Introduction



The parathyroids are four small, pea-sized glands, located in the neck just behind the thyroid gland. They secrete a natural substance called parathyroid hormone (PTH) into the bloodstream.

PTH helps to control the levels of two salts in the body: calcium and phosphate. The most common parathyroid disorders are Hypoparathyroidism (HypoPT) and Primary Hyperparathyroidism (PHPT).

How are HypoPT and PHPT different?

HypoPT occurs when one or more of the parathyroid glands produce too little PTH. In contrast, PHPT occurs when the parathyroid glands produce too much PTH.

HypoPT or PHPT can also be caused if the PTH released does not work properly.

What happens when PTH is low?

A low level of PTH causes blood calcium levels to fall (hypocalcemia), and phosphorus levels to rise (hyperphosphatemia).

Why does the body need calcium and phosphorus?

Calcium and phosphorus combine to make calcium phosphate in the body. Calcium phosphate gives bones and teeth strength. Calcium and phosphorus are also needed to help blood clot after an injury.

They are also needed for muscles and nerves to work properly. Calcium and phosphate levels should be kept within a narrow range for your well-being. Both low and high values of these salts can be harmful to your health.

Why does HypoPT occur?

It can be:

- Something that develops in childhood or adult life (acquired)
- Short-lived (transient) or long-standing (chronic)
- Something that someone is born with (congenital)
- Passed on through your genes, from your relatives (inherited)

What are common causes of HypoPT?

Surgery to the neck is the most common cause. For example, during surgery on the thyroid gland, the parathyroid glands may be accidentally damaged or removed.

Sometimes the parathyroid glands are removed if they are overactive, or to treat a potential cancer.

What symptoms occur in HypoPT?

People experience symptoms of HypoPT in different ways. The symptoms are largely due to the effects of low levels of calcium in the blood.

Mild symptoms usually develop slowly and may not need any treatment. Severe symptoms may come on rapidly and need urgent treatment. This may be with calcium given directly into the vein via a drip (intravenously).

Possible symptoms that may occur include:

- Muscle pains
- Tummy (abdominal) pains
- Tingling, vibrating, burning or numbness of the fingers, toes or face
- Twitching of the muscles of the face
- Muscle spasms in the hands and feet
- Fits (seizures)
- Fainting
- Confusion
- Memory problems
- Tiredness
- Eyesight problems
- Headaches
- Brittle nails
- Dry skin and hair

Which tests help diagnose HypoPT?

Blood tests are used to confirm HypoPT, by assessing whether your blood calcium level is low, your blood phosphate level is high and your parathyroid hormone level is low.



What are the complications of HypoPT?

Any complications arising are largely due to the low levels of calcium in the body, but can include:

- Kidney stones
- Cataracts
- Disturbance to the normal electrical activity of the heart, which can lead to rhythm irregularities and possible collapse
- Stunted growth, teeth problems and mental development issues can occur if low calcium levels are not treated in childhood

How are HypoPT patients examined?

There are a number of things your doctor may do to look for signs of low calcium levels or HypoPT when they examine you:

- They may tap in front of your ear with your mouth slightly open to detect any repeated contraction (tightening) of the muscles in your face.
- They may also inflate a blood pressure cuff around your lower arm to detect any muscle spasms in your hands.
- They may examine your eyes to look for cataracts, which can be a complication of HypoPT
- They may carry out a painless examination of your muscle reflexes, by tapping your knee or elbow, with an instrument called a tendon hammer. If your calcium level is low these reflexes can be much more pronounced than normal.



What are the aims of treatment?

The aims of treatment are to ensure that there is an adequate level of calcium in the bloodstream and to avoid complications. This should mean that you will not have symptoms associated with low calcium levels.

It is a good idea to have a medical emergency identification bracelet or equivalent to identify yourself as having HypoPT. This is so that if you collapse, are confused or are found unconscious, doctors will know that you need prompt treatment with calcium.

What are the treatment options?

- Calcium and active vitamin D taken by mouth. Active vitamin D is needed to help regulate calcium levels. It stimulates the release of calcium from bone and helps calcium to be absorbed from the gut and the kidneys.
- Regular blood tests are needed to ensure that you are taking enough calcium and vitamin D. Closer monitoring is needed during pregnancy, if you are also taking other medicines, or if you also have another illness.
- Treatment is usually lifelong. These are not dietary supplements that you can buy over the counter, but stronger medication requiring careful monitoring by your doctor.
- Exams to exclude complications such as kidney stones or cataracts are needed in longer intervals (every 2-3 years).

How are severe symptoms treated?

If you have severe symptoms, you may need calcium given directly into your vein via a drip (intravenously).

Are there any new treatments?

Synthetic PTH has been produced and is now available in case your symptoms are not well controlled by calcium and vitamin D. This is a therapy you have to self-inject daily and requires close monitoring with your doctor.

What is the prognosis of HypoPT?

If HypoPT is adequately treated with calcium and vitamin D, the outlook (prognosis) is good.

However, this relies on you taking medication daily for life.

You also need to have regular blood tests so that the dose of your medication can be carefully adjusted as needed.

Can HypoPT be prevented?

During thyroid or neck surgery, the surgeon must identify the parathyroid glands and avoid damaging them if possible.

Anybody who is undergoing thyroid or neck surgery, radiotherapy to the neck or the chest, or chemotherapy (a treatment for cancer) should be monitored for symptoms and signs of low calcium levels.

Is it safe to get pregnant while suffering from HypoPT?

Most mothers will have a healthy baby, so long as they maintain their medication daily and perform regular blood tests to assess if any adjustments are needed.

Please refer to the ESE Parathyroid Disorders during preconception, pregnancy and lactation guide.



Patients: The concise information in this guide reflects the latest expert recommendations on managing this condition. For further support, please consult your own family doctor, patient advisory group or visit the ESE Hypoparathyroidism Patient Forum via www.es-e-hormones.org/for-patients.

Clinicians: This introductory patient guide reflects the latest expert consensus recommendations of PARAT - the ESE educational programme on parathyroid disorders. The guide should not replace clinical consultation with individual patients.

Please view "European Expert Consensus on Practical Management of Specific Aspects of Parathyroid Disorders in Adults and in Pregnancy". *European Journal of Endocrinology* 186 (2) February 2022, for recommendations in full.

Faculty members Zaki Hassan-Smith (UK), Claudio Marcocci (Italy), Luis Cardosa (Portugal), Elena Tsoardi (Germany) and Nik Screen (ESE/Versatility.org.uk) prepared this patient information guide. Further patient information guides for hyperparathyroidism and preconception, pregnancy and lactation, plus all other PARAT educational materials are available at www.es-e-hormones.org or by searching; bit.ly/paratlz

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