

Who will look after you?

You may need to see a number of doctors and specialists depending on your symptoms and if you have any complications. They all check for different things but should work together to provide you with a holistic care and treatment plan:

- **Endocrinologists:** to check your blood and urine tests and adjust your medications based on results
- **Primary care practitioners:** to monitor your overall health
- **Nephrologists:** if you have abnormal kidney function
- **Urologists:** if you have kidney stones
- **Ophthalmologists (eye specialists):** to routinely check your cataracts (opacities of the lens mainly related to genetic hypoparathyroidism)

How often do you need to be checked or monitored?

Most patients with long term HypoPT have routine check-ups every 3-6 months to monitor any symptoms related to hypocalcaemia and hypercalcaemia. Routine tests include blood tests for calcium, phosphate, magnesium, vitamin D and creatinine levels and usually an annual 24hr urine test. Your first appointment will be longer as your history will be taken. A baseline kidney scan may be ordered.

You may need to be monitored once or twice a week when you start or change your treatment, or if you feel unusually symptomatic to make sure your blood calcium level doesn't go too low or too high. In these cases you need to contact your doctor or nurse sooner than your routine check-up, as your dose of active vitamin D and calcium may need adjusting.

How to take a more active role in your treatment?

- Ask your doctor or nurse for detailed information on possible symptoms caused by high or low calcium levels and contact them immediately if you experience any such symptoms;
- Ask about possible complications from HypoPT and how and if you can prevent them;
- Ask your doctor if getting an emergency card, bracelet or necklace might help you communicate with your healthcare providers in an emergency about your condition and possible medical needs;
- Discuss benefits and side effects of your treatment and decide with your doctor or nurse the best treatment plan for your needs;
- A number of useful resources which you can refer to for more information is shown on the next page.

This leaflet is based on the guideline written by an expert Endocrine Team working with the European Society of Endocrinology, a professional organisation with a commitment to hormone-related conditions. The aim of the guideline is to help clinicians managing patients who have low or no parathyroid hormone production by their parathyroid glands .

www.e-se-hormones.org

Visit the European Society of Endocrinology (ESE) website for more information. ESE was created to promote research, education and clinical practice in endocrinology for the public benefit. Online resources include patient materials as well as links to Patient Support Groups.

Where to find out more information:

Hypopara UK

National patient organisation for people with HypoPT. Tel +44 (0)1342 316315

Website: www.hypopara.org.uk

Nordic HypoPARA Organisation

Non-profit official patient organisation, working to improve the lives of people affected by HypoPT in the Nordic countries of Europe

Website: www.hypopara-nordic.org

Danish Hypoparathyroidism Organisation

Official non-profit patient organisation, working to improve the lives of people affected by HypoPT in Denmark.

Website: www.hypopara.dk

AG Hypopara im Bundesverband Schilddrüsenkrebs – Ohne Schilddrüse leben e.V (DE)

Germany HypoPT group which aims to promote the exchange of information and experience between patients, physicians and specialists.

Website: www.sd-krebs.de/ag-hypopara

Hypoparathyroidism France

Patients' organisation working to improve the lives of people affected by HypoPT in France.

Website: www.hypopara.fr

Italian Association for patients with hypoparathyroidism (APPI)

Patients' organisation working to improve the lives of people affected by HypoPT in Italy.

Website: www.fondazionefirmo.com/appi

HypoPARathyroidism Association (US)

A non-profit patient organisation working to improve the lives of people affected by HypoPT in the USA.

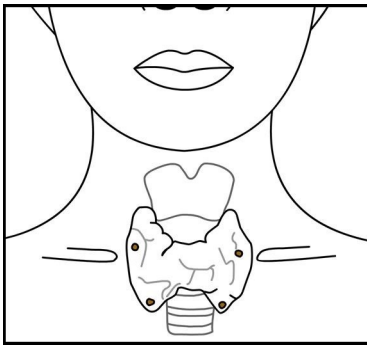
Website: www.hypopara.org



Patient Information Leaflet
on the Treatment of Chronic
Hypoparathyroidism in
Adults

What are the parathyroid glands and how do they work?

Four glands, about the size of a grain of rice, are located near the thyroid gland in the neck. These glands make parathyroid hormone (PTH). PTH is responsible for regulating calcium levels in the blood. If the parathyroids are not working properly, people can develop either too high (hypercalcaemia) or too low (hypocalcaemia) calcium levels in the body.



Introduction to HypoPT

What is HypoPT?

This is a rare condition where low levels of PTH result in low levels of calcium in the blood.

What causes HypoPT?

For most patients, this results from accidental damage to or removal of the parathyroid glands during thyroid or parathyroid surgery.

Common reasons to have thyroid surgery are as follows:

- hyperthyroidism (thyroid makes too much thyroid hormones)
- thyroid cancer
- goitre (swelling of the neck caused by an enlarged thyroid gland)

People with high calcium levels because of parathyroid disease have surgery to remove the parathyroid gland, in general one of the glands. If such a surgery is extensive and requires removal of multiple glands, HypoPT may develop.

Why is calcium so important?

Calcium is the most common mineral found in the body and is essential to keep your body in balance. Calcium is important for bone and tooth development and proper function of the heart, muscles and nerves.

HypoPT can also be genetic, or the result of an autoimmune condition. If the cause of HypoPT is unknown, you and your family may be advised to have genetic testing to check if this is an inherited condition.

What are the symptoms of HypoPT?

The symptoms of HypoPT are due to too low calcium levels (hypocalcaemia).

Symptoms of hypocalcaemia can vary from patient to patient and include:

- Tingling and numbness around the mouth, and in the hands and feet
- Tetany: twitching or stiffness in the muscles progressing to inner trembling and muscle cramps
- Fatigue and weakness
- Confusion or disorientation, 'brain fog'

You need to be aware of symptoms of hypocalcaemia:

- **If you have previously had an operation for hyperthyroidism, goitre, thyroid cancer (or parathyroid diseases).**
- **If you or someone in your family have been diagnosed with low blood calcium levels.**

Other long-term symptoms of HypoPT and/or its treatment may include:

- Depression
- Poor memory and concentration
- Kidney problems
- Dental and eye problems

Sometimes, when being treated for HypoPT, your calcium levels may go too high. For example, this can happen if you take too much calcium and or calcitriol (active vitamin D), or other medications.

Symptoms of hypercalcaemia may include:

- dry mouth, increased thirst and frequent urinating (passing water)
- headache
- fatigue
- loss of appetite

How is HypoPT diagnosed?

Your doctor will assess your symptoms and take a blood test to check your calcium, phosphate and PTH levels. If HypoPT is suspected, you will be referred to your local hospital or specialist to see an endocrinologist, a specialist in hormones.

Post-surgical symptoms are usually quite easy to spot. But genetic forms of HypoPT can be more difficult to diagnose.

Management of HypoPT

What is the treatment goal in HypoPT?

The treatment goal is to keep the blood calcium level within the lower normal range or just below normal, if possible, and to minimise or prevent symptoms. So, it will be important to monitor any possible complications with regular calcium blood tests. Your doctor will need to work with you to develop your individualised treatment plan taking into account your wellbeing, physical and emotional health.

What is the treatment for HypoPT?

Treatment for permanent HypoPT is lifelong. You will usually be treated with the active form of vitamin D and calcium supplements. The active form of vitamin D increases calcium levels in the blood by helping the body to better absorb the calcium from a supplement and daily diet such as from milk, yoghurt and other calcium-rich foods.

The dose and frequency of treatment will depend on the degree of your symptoms and also the calcium level, which is checked with a blood test, and an annual urine test. You will also need a blood test to check your kidney function and phosphate and magnesium levels.

Depending on your body's response to treatment, in the future it may be possible to use an injection of parathyroid hormone to replace the missing hormone along with, or instead of vitamin D and calcium treatment.

Can any other medication affect calcium levels?

Some medications (on prescription or bought over the counter) can affect your calcium levels and trigger or worsen symptoms of HypoPT. You need to inform your doctor immediately if you take medication such as: reflux and indigestion remedies, diuretics (to control water balance) and steroids.

Calcium levels may also be affected by diet, alcohol, stress, strenuous exercise, infection and anaesthesia.

Pregnancy and breastfeeding.

If you are or plan to become pregnant, or you are breastfeeding it is important to have close monitoring of your calcium levels in order to prevent symptoms and complications. Your calcium level needs to be checked every 2-3 weeks depending on your needs and treatment plan.

