

Understanding Chronic Hypoparathyroidism in Adults: A Quick Guide for Patients



This patient leaflet is based on the Revised European Society of Endocrinology (ESE) Clinical Practice Guideline for the Treatment of Chronic Hypoparathyroidism in Adults (2025). It has been written by a panel of international experts together with representatives of patient organisations, who were involved in the development of the Guideline. The aim is to support patients living with this rare condition. This leaflet does not replace advice from your medical team.

What is Chronic Hypoparathyroidism?

Hypoparathyroidism (HypoPT) is a rare endocrine disease where your body does not produce enough parathyroid hormone (PTH). This hormone is essential for maintaining the normal balance of calcium in your body. There are four small parathyroid glands located behind the thyroid gland in the neck whose main function is to produce PTH (Figure 1). When PTH levels are too low, your calcium levels drop (hypocalcaemia), and your phosphate levels rise (hyperphosphataemia).



Figure 1: Parathyroid glands

What causes HypoPT?

The most common cause – accounting for about 75% of cases – is following neck surgery, for example of the thyroid or parathyroid glands. In other cases it could be caused by an autoimmune condition, where

the body's immune system attacks the parathyroid glands, or it may be caused by other rare causes such as genetic conditions or infiltrative diseases.

Managing Your Symptoms

The goals of treatment are to improve your quality of life, minimise symptoms and protect your long-term health, particularly your kidneys.

Common Symptoms of Low Calcium (Hypocalcaemia):

- Tingling, numbness in the fingers, toes or around the mouth
- Muscle cramps, spasms, inner trembling
- Fatigue and weakness
- “Brain fog” (difficult to focus and concentrate, loss of memory etc.)
- Anxiety and depression

Symptoms of High Calcium (Hypercalcaemia) – this may occur from non-optimised treatment:

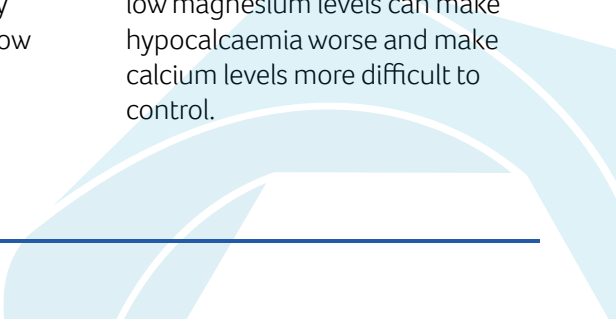
- Headaches
- Thirst and frequent urination
- Nausea and vomiting
- Loss of appetite and constipation
- Low mood, drowsiness and confusion
- Kidney stones, renal dysfunction

It is important to understand that symptoms do not always correlate closely with blood calcium levels. Some patients may experience symptoms despite laboratory values being within the target range, whereas others may be without symptoms, while having low calcium levels.

Treatment Options

Treatment is personalised based on your specific needs and overall well-being.

1. Conventional Treatment: This is the standard approach for most patients. It typically includes:

- **Activated Vitamin D analogues:** Drugs like **alfacalcidol** or **calcitriol** are often the preferred treatment because they help your body absorb calcium.
 - **Calcium Intake:** Adults should aim to get **800–1000 mg of dietary calcium** each day through diet (food, drinks). You can find information on increasing your calcium intake here: <https://parathyroiduk.org/living-with-hypopara/self-help-guide/diet/diet-in-hypoparathyroidism-calcium/>. If you cannot achieve the recommended levels through your diet, your doctor may prescribe calcium supplements.
 - **Vitamin D:** Standard supplements (800–2000 IU daily) are used to ensure your vitamin D levels are sufficient.
 - **Magnesium:** Some patients require magnesium supplements, as low magnesium levels can make hypocalcaemia worse and make calcium levels more difficult to control.
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2. PTH Replacement Therapy:

If conventional treatment does not adequately control your symptoms or if you experience frequent calcium fluctuations, your doctor may suggest PTH replacement. This treatment reduces the quantity of medication and supplements you need to take, improves **calcium and phosphate levels** and may improve your quality of life.

Protecting Your Kidneys

Because the lack of PTH affects the way your kidneys process calcium, you are at a higher risk of kidney stones and reduced kidney function. To minimise this risk:

- Doctors usually aim to keep your blood calcium levels slightly below or in the **lower part of the normal range** when you are treated with conventional therapy. When using PTH replacement therapy however, this risk is minimal and calcium levels may be kept in the normal range.
- You may be advised to follow a **low-salt diet** (< 6 g or 1 teaspoon of salt per day).
- In some cases, a “water pill” (thiazide diuretic) may be prescribed to reduce the amount of calcium lost through urination.

Monitoring Your Health

Regular check-ups are vital for managing this lifelong condition.

- **Blood Tests:** Every 3–6 months, your doctor will check your calcium, phosphate, magnesium and kidney function. If changes are made to your treatment more frequent check-ups will be needed.
- **Urine Tests:** Every 1–2 years your doctor should arrange for you to have a **24-hour urine collection** to check how much calcium your body is passing in your urine.
- **Annual Reviews:** At regular intervals, your doctor may assess for complications such as cataracts, kidney disease, changes in bone health and other long-term effects of HypoPT. They will then adjust your treatment if necessary.

Pregnancy

If you are pregnant or planning to conceive, it is very important to discuss this with your medical team. While most women have healthy pregnancies, your calcium levels will need **more frequent monitoring** (every 3–4 weeks). Your medication needs may change significantly during pregnancy, immediately after delivery and during/after breastfeeding.

Currently, PTH replacement therapy is not recommended during pregnancy because of limited safety data.

Q & A

Q1: Is my HypoPT permanent?

A1: This is dependent on the cause. If you developed HypoPT after neck surgery, doctors generally wait 12 months before diagnosing it as “chronic”, as parathyroid function can often recover during the first year. However, some patients have been known to regain parathyroid function many years later. Your doctor may want to check your PTH levels occasionally to see if your glands are showing signs of recovery.

Q2: Why does my doctor want my calcium levels to stay “low-normal”?

A2: When you are using conventional treatment, maintaining calcium at the lower end of the normal range helps prevent your kidneys from filtering too much calcium into your urine. This reduces your long-term risk of developing kidney stones or chronic kidney disease. If higher calcium levels are needed to improve your wellbeing, urinary calcium excretion should be more regularly monitored.

Q3: What should I do if I feel sudden tingling or muscle cramps?

A3: These are often signs of low calcium (hypocalcaemia). You should follow the “rescue” plan provided by your doctor, which may involve taking extra calcium in some form. Read more here: <https://parathyroiduk.org/living-with-hypopara/self-help-guide/how-to-manage-your-calcium-levels-practical-steps/>

Q4: Should I carry an Emergency Card?

A4: It is highly recommended to carry the European Emergency Card that explains your condition to medical professionals in case of an emergency. The Card is available in multiple languages, making it useful even when travelling. You can obtain the Card through ESE’s website: ese-hormones.org/emergency-card-hypoparathyroidism

Q5: Where can I find more help?

A5: The following groups are affiliated with ESE and provide information, advice and support for HypoPT patients and their families. You will also find well-run support groups on Facebook.

AECAT, Espana

<https://www.aecat.net>

APPI, Italia

<https://www.associazioneappi.it>

Hypopara Norge

<https://www.hypopara.no>

Hypoparathyroidisme France

<https://hypopara.fr>

Netzwerk Hypopara, Germany

<https://hypopara.de/cms>

Parathyroid UK

<https://parathyroiduk.org>



European Society
of Endocrinology

T: +44 (0)117 440 64897

E: info@ese-hormones.org

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