

Hypoparathyroidism

You have been diagnosed with hypoparathyroidism. Here is some information to help you manage your health.

What is hypoparathyroidism?

Hypoparathyroidism (HPTH) is a rare disorder in which insufficient levels of parathyroid hormone lead to low levels of calcium.

Parathyroid glands are four small glands which lie behind the butterfly-shaped thyroid gland in your neck. These glands produce parathyroid hormone (PTH), which closely regulates calcium levels. Calcium is important for functioning of nerve, muscle, bone and other cell functions.

What causes hypoparathyroidism?

The commonest cause is destruction of the parathyroid glands during neck surgery. The glands may also be damaged by the immune system. Some people are born with the condition (congenital). Sometimes, the cause is unknown (idiopathic).

How is the condition diagnosed?

The initial diagnosis is often done by your GP who will assess symptoms and take a simple blood test to measure calcium. If this is low, you will be referred to an endocrinologist.

Diagnosis is by means of blood tests showing:

- Low parathyroid hormone (PTH) levels **and**
- Low calcium (called adjusted or corrected serum calcium).

Your GP or Endocrinologist may also check:

- Kidney function
- Phosphate and magnesium levels
- Vitamin D levels

When hypoparathyroidism occurs as a complication of surgery, the symptoms may start within hours to a few days after surgery. Diagnosis of a rare genetic condition may take a little while.

How is hypoparathyroidism treated?

In the UK, you are likely to be prescribed:

- **Calcium:** Mild disease can be treated with calcium supplements alone. Each tablet of Calcichew®, Cacit® and Calcium-500® contains 500mg; Adcal® contains 600mg; Sandocal-400® and Sandocal-1000® contains 400mg and 1000mg of elemental calcium respectively. High doses (>2000mg per day) should generally be avoided.
- **Vitamin D:** Most patients will not achieve adequate control with calcium alone. Active forms of vitamin D such as **calcitriol** or **alfacalcidol** are favoured over high dose colecalciferol or ergocalciferol. They are easier to adjust in response to calcium levels. Maintenance dose of calcitriol or alfacalcidol is typically between 0.5 – 2.0 micrograms daily. Doses up to 3.0 micrograms are often required. Calcitriol (Rocaltrol®) capsules come in 0.25 microgram (red/white capsules) and 0.5 microgram (white capsules). Alfacalcidol (non-proprietary) capsules come in 0.25, 0.5 and 1.0 microgram strengths.
- **Magnesium** may need to be corrected in post-surgical HPTH if levels are found to be low.
- **Levothyroxine** (thyroid hormone replacement) is needed if you had your thyroid gland removed. This should be taken apart from calcium medication if possible (ideally 4h, at least 2h).

Usually, daily treatment is **essential** and lifelong. However, post-surgical HPTH may resolve. The level of calcium in your blood will need to be checked to work out the best treatment plan.

What do I need to know about my medication?

- The aim of treatment is to abolish symptoms – not to restore ‘normal’ calcium levels in the blood.
- In the absence of PTH, higher levels of calcium are found in the urine for a given blood calcium level. This can cause kidney stones or calcium deposits in the kidneys (nephrocalcinosis), even when blood calcium levels are in the ‘normal’ range.
- The target range is between 2.0-2.25mmol/L of adjusted calcium levels. The target range is approximate and depends on patient symptoms.
- This is achieved with an appropriate dose of alfacalcidol or calcitriol so that most of your calcium can come from your diet and you will not need to take too many calcium supplements. The doses are typically split over the day.
- Calcium should be taken at meal times.
- It can take several months to get the balance right.
- Over time, your medication requirements can also change. This is often revealed by an increase or decrease in your calcium levels which you may feel as recognisable symptoms.
- You and your doctor need to learn to recognise your particular symptoms so that your medication may be adjusted accordingly.
- Symptoms can still be felt when the test results are in the normal range (2.20 – 2.60 mmol/L) which is a wide range. If your levels are unstable, keep a diary of test results, doses and symptoms to help you recognise your symptoms and understand what is happening.

What should I do in a crisis?

- A ‘crisis’ can arise out of very low or very high calcium (see below).
- Seek help. You can contact your Endocrine Specialist Nurse, Endocrinologist or your GP.
- Your calcium may need to be increased or cut out for a while.
- You must **never** adjust your alfacalcidol or calcitriol doses on your own.

Low calcium (hypocalcaemia)

Early symptoms include varying degrees of 'inner shaking', dizziness, 'brain fog', blurred vision, irritability, sensitivity to sounds, diarrhoea, anxiety, extreme weakness, chills, headache. 'Tetany' is involuntary contraction of muscles and this may progress to seizures.

- Symptoms can arise through, or be made worse by, anxiety and over-breathing. It is important to remain calm.
- Most mild symptoms usually pass.
- If they don't, try drinking some milk or calcium-fortified orange juice or eating some food.
- If after an hour symptoms still do not improve, take an extra calcium tablet. Stay calm and keep warm. Calcium tablets take about 20 minutes to work.
- Sometimes you may just need to take some of your day's dose a little earlier than usual without actually taking more.
- If this keeps happening you should get a blood test as it might mean your medication needs adjusting.
- If you feel severely unwell or there is a sudden onset of severe symptoms, don't wait, take extra medication and call your doctor. You need to take sufficient extra medication to prevent a crisis. An emergency injection of calcium may be needed if your calcium levels have dropped very low to prevent spasms developing.

High calcium (hypercalcaemia)

Warning signs include thirst, frequent urination, severe headache and nausea, stomach ache, depressed mood, constipation, extreme fatigue, heavy, painful limbs, confusion. None of the symptoms are specific and may be due to conditions other than raised calcium.

- Mild symptoms may be averted by drinking water.

- If symptoms persist or get worse, seek help and advice.
- Stopping the tablets altogether can lead to big swings in calcium levels. Do not do this on your own.

Taking Tablets

- Always carry spare medication with you.
- Try to maintain a month's supply in reserve.
- Carry an extra supply of medication on holiday.
- Carry your medication in your hand luggage when travelling by plane, with prescription labels visible.

Does anything affect my calcium level?

- **Diet:** It is better to get your calcium from your food than from supplements. However, some foods, e.g. too much wholemeal bread, spinach or tomatoes, alcohol and fizzy drinks can deplete calcium. Dehydration also affects calcium levels: drink eight glasses of water daily.
- Calcium levels can be affected by: illness, infection, fever, sweating, vomiting, diarrhoea, dehydration, surgery (including dental), stress, smoking, menstrual periods, menopause (oestrogen affects calcium), exercise, and various medications (e.g. iron, aspirin, diuretics, bisphosphonates, beta-blockers, PPI's).

What kind of medical support will I need?

- **Endocrinologist:** Initial visits at the outpatient department may be frequent (about 3 monthly), then 6-12 monthly visits afterwards.
- **GP:** Your GP will continue to provide advice in-between visits. Your GP will issue repeat prescriptions. You are entitled to receive your medication free of prescription charges. Your GP needs to endorse your entitlement.
- **MedicAlert:** We recommend that you wear a MedicAlert bracelet. Hypoparathyroidism UK members are entitled to a 5% discount.

Living with hypoparathyroidism

Many people with HPTH can expect to lead normal lives with a normal life span.

- With permanent but mild HPTH, temporary symptoms may occur from time to time.
- Severe HPTH is rare but you may experience constantly unstable calcium levels (or brittle HPTH) and a range of symptoms which can be very challenging. You should be referred to a specialist in calcium metabolism.
- You may experience episodes of unusual fatigue or muscle weakness. At times you will need to allow your body to catch up, with extra rest.
- Women with HPTH can have a healthy pregnancy and a normal childbirth. Calcium, vitamin D and thyroid hormone doses may need adjusting throughout pregnancy.
- You may need extra medication during strenuous physical exercise. Rarely, with severe HPTH, exercise may be difficult with bone pain and muscle weakness. Try to be gently active.

Further information and support are available from **Hypoparathyroidism UK**, a national voluntary organisation, working to support people with hypoparathyroidism and other rare parathyroid conditions and to promote better medical understanding. Hypoparathyroidism UK offers a website, a telephone helpline, and free membership that includes an online forum and newsletters.

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This leaflet has been prepared by the HPTH UK Clinical Advisory Team and HPTH UK in conjunction with The Society for Endocrinology. HPTH UK Clinical Advisory Team is a group of Endocrinologists with an interest in the parathyroid glands and calcium metabolism who advise HPTH UK on medical matters.