

## Useful organisations and further information

### BAETS

Information for patients about surgery  
<http://www.baets.org.uk/useful-links/patients/>

### NICE

Guidelines on Primary Hyperparathyroidism  
<https://www.nice.org.uk/guidance/NG132>

### SOCIETY FOR ENDOCRINOLOGY

Patient information about 'You & Your Hormones'  
<https://www.yourhormones.info/endocrine-conditions/primary-hyperparathyroidism/>

### AMEND

Patient support & advice on Multiple Endocrine Neoplasia Disorders (MEN)  
[www.amend.org.uk](http://www.amend.org.uk)

Please contact Parathyroid UK for further information, support or advice about hyperparathyroidism:

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Website: [parathyroiduk.org](http://parathyroiduk.org)

#### About Parathyroid UK

Parathyroid UK is a national patient organisation for anyone affected by a parathyroid condition causing hypoparathyroidism or hyperparathyroidism. Via its website, groups and helplines it provides support and information to empower patients to become active in the management of their particular condition. Parathyroid UK works closely with its clinical advisory team in the UK and with healthcare professionals and patients internationally to improve lives, raise awareness and bring about new treatments.

Written by Parathyroid UK with the Parathyroid UK Clinical Advisory Team, and endorsed by the Society for Endocrinology Clinical Committee of the Bone and Calcium Endocrine Network.

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#### Working together with



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# DOES PHPT NEED TREATMENT?

If there is evidence that your health is affected then treatment should be recommended. This will usually be surgery but sometimes you may be monitored or offered medical treatment, depending on your circumstances.

## Surgical treatment

A referral to a surgeon with expertise in parathyroid surgery should be considered for anyone with a confirmed diagnosis of primary hyperparathyroidism.

The only cure for PHPT is an operation called a parathyroidectomy. It involves finding and removing the abnormal parathyroid gland(s) that is causing the problem.

In preparation for surgery you may be referred for the following scans to try to locate the enlarged parathyroid(s):

- Ultrasound neck scan
- Sestamibi parathyroid scan
- CT neck scan

If the tests locate a single enlarged gland, focussed surgery may be possible. Otherwise you will be offered an operation with the intention of visualising the 4 parathyroid glands and removal of the abnormal gland(s). Enlarged glands not seen on scans can often be seen or felt by experienced surgeons.

It is always important that parathyroid surgery is carried out by an appropriately skilled parathyroid surgeon who should talk to you about the risks involved. Do not hesitate to ask about your surgeon's experience, the number of parathyroid operations they perform every year, their cure and complication rates.

After surgery, your PTH and calcium levels will be checked the next day and your calcium level will be checked again at 3 to 6 months to confirm that it has returned to normal. Some people experience an immediate improvement in their symptoms whilst for others it may take 6 – 12 months for a full recovery.

Occasionally, low calcium levels are the result of a condition called hypoparathyroidism. This is usually temporary but rarely it may be permanent, requiring lifelong treatment and regular blood tests. Some surgeons will prescribe tablets with vitamin D and calcium for you to take if you feel unwell or have tingling, numbness, or cramping symptoms. If such symptoms do not resolve within an hour you should seek medical advice.

In experienced hands, parathyroid surgery has a 90% cure rate and most patients are cured by one operation. It is normally a straightforward procedure requiring an overnight hospital stay. A multigland operation may require a 3 night stay.

## Non-surgical treatment

If your blood calcium is high but you are unable to have an operation for any reason, you might be prescribed a drug called cinacalcet (Mimpara). This drug can usually lower the concentration of calcium, reducing symptoms and improving quality of life. It does not, however, increase bone density or reduce the risk of developing kidney stones. Some patients taking this medication may develop side effects, most commonly, nausea. It may also be used temporarily to lower blood calcium pending surgery.

If your bone density is reduced, you might be prescribed an anti-osteoporosis drug such as alendronate. Alendronate is a bisphosphonate drug used in treating osteoporosis. Bisphosphonate treatment is not advised if you are planning to have surgery as it can lower calcium levels. Please discuss this with your endocrinologist or surgeon.

## Monitoring

If you have osteoporosis or renal stones specialist monitoring will continue after surgery. Around one-third of people with PHPT who do not have symptoms or indications for surgery go on to develop renal stones and fractures so regular monitoring of calcium levels is very important to ensure that timely surgery, including repeat surgery, is arranged.

## What is the outlook?

Following successful parathyroid surgery, you should be able to resume a normal life. Studies have shown that bone density improves, the risks of subsequent fractures and kidney stones are reduced, and there may well be improvements in energy, mood, and memory.



# Primary Hyperparathyroidism



## Information and advice on your condition

This information sheet is for people with primary hyperparathyroidism, their families and carers. It provides some background information and advice on PHPT. It also discusses when treatment is needed and the types of treatment available.

[parathyroiduk.org](http://parathyroiduk.org)

# WHAT IS PRIMARY HYPERPARATHYROIDISM?

Primary hyperparathyroidism (also called PHPT or 1HPT) is a disorder of the parathyroid glands that causes elevation of blood calcium levels.

## What are the parathyroid glands and what do they do?

Parathyroid glands are endocrine (hormone-producing) glands that produce parathyroid hormone (PTH). Most people have four parathyroid glands, which are each about the size of a grain of rice. These are usually located in the neck next to the thyroid gland. The parathyroid glands control the concentration of calcium in the blood, which is vital for the body to work properly.

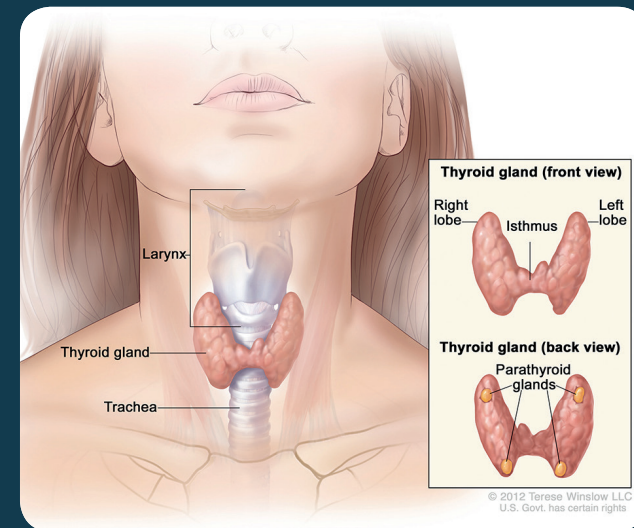
When the parathyroid glands sense that the calcium in the blood is low, they release PTH. PTH increases the level of circulating calcium through direct and indirect actions on the kidneys, the intestines and the bones, increasing the blood calcium back to normal. When the blood calcium is normal, the parathyroid glands stop releasing PTH.

In PHPT, usually one, but sometimes more than one, parathyroid gland starts to produce too much PTH. This results in calcium being moved from the bones into the blood causing high blood calcium (hypercalcaemia). This condition can cause problems and make you feel unwell.

## What causes PHPT?

The most common cause is a benign (non-cancerous) growth, called an adenoma, in a single parathyroid gland. In other cases, the condition may affect more than one gland and occasionally, all four glands may be affected (which is sometimes called hyperplasia). Exceedingly rarely, the growth may be cancerous.

## Anatomy of the Thyroid and Parathyroid Glands



## Who gets PHPT?

PHPT is the third most common endocrine condition. It is more common in women than men and is most frequently diagnosed in women after menopause. It does not usually run in families. However, there are rare inherited conditions such as multiple endocrine neoplasia (MEN) types 1 and 2, familial isolated hyperparathyroidism (FIH) and hyperparathyroidism-jaw tumour syndrome (HPT-JT) and others.

There is some evidence of an increased risk of PHPT in people who have had radiotherapy to the head or neck but most often the cause of PHPT is not known.

## What are the symptoms of PHPT?

PHPT can go unrecognised for a considerable time. Initially you may not feel unwell at all even if your blood calcium is high or you may feel some of the following symptoms, especially if your calcium increases or remains elevated for a long time.

### The symptoms may include:

- Loss of energy
- Tiredness
- Feeling thirsty
- Frequent urination
- Passing an abnormally high amount of urine
- Stomach pain
- Constipation
- Bone pain

### Some patients also report having:

- Mood changes
- Confusion
- Memory issues
- Depression

### You may also suffer from more severe symptoms or conditions including:

- Nausea and vomiting
- High blood pressure
- Pancreatitis
- Kidney stones
- Osteoporosis (low bone density)
- Bone fractures

In exceptional cases of severe untreated high blood calcium the level of consciousness can be affected.

Symptoms of hypercalcaemia can also be associated with other disorders so it is important to see your doctor to get the right diagnosis.



## How is PHPT diagnosed?

It can be difficult to diagnose PHPT because the symptoms can be subtle or similar to other conditions but if you have symptoms of hypercalcaemia, osteoporosis or kidney stones your GP should test your blood calcium level. If this is high on two occasions, you will be referred to an endocrinologist who will arrange further tests.

PHPT is usually confirmed after finding a high level of calcium on a blood test along with a high or 'inappropriate' level of PTH. Your phosphate levels may be normal or low. Your vitamin D level may also be low. You may be asked to provide a urine sample for analysis of calcium levels to help confirm the diagnosis.

Some people may feel symptoms of high calcium even though their blood calcium is within the reference range (usually the upper end of normal). The term 'insidious' or normocalcaemic PHPT has sometimes been used to describe this but the diagnosis is difficult to demonstrate and there is very little reliable evidence on how best your doctor should advise you and treat this condition. It is important to exclude vitamin D deficiency and other causes.

## What other tests may be performed for PHPT?

Various blood tests and scans may be done to help with diagnosis. The most common are:

- **Blood testing** - for kidney function, other possible causes of hypercalcaemia, and vitamin D status (both 25(OH)D and 1,25dihydroxyVitD which may be low and high respectively)
- **DXA scan** - a special type of X-ray that measures bone mineral density (BMD)
- **Morning fractional calcium excretion test or a 24 hour urine collection** - to measure calcium in urine
- **Kidney ultrasound or CT scan or X-ray** - to check for kidney stones

## What are the risks with PHPT?

Patients with PHPT have an increased risk of developing problems in a number of organs, particularly the bones and kidneys. There is a higher chance of developing osteoporosis, kidney stones and gradual deterioration in kidney function. Other risks include neuropsychiatric symptoms (such as depression, anxiety and forgetfulness), falls and fractures and pancreatitis.