

# Cinacalcet for Hyperparathyroidism Caused by Chronic Kidney Disease

**Information for people  
with chronic kidney  
disease**

If you have been prescribed a medication called cinacalcet, this leaflet is for you.

## **What is hyperparathyroidism and why might I need cinacalcet?**

Hyperparathyroidism can be caused by the long term effects of Chronic Kidney Disease (CKD).

It is sometimes called 'secondary hyperparathyroidism'. When you have CKD, the levels of some minerals and hormones in your body become difficult to control. These include calcium, phosphate, vitamin D and parathyroid hormone (PTH). This can cause Mineral Bone Disorder, which can lead to hyperparathyroidism. Please ask your kidney team for a copy of our leaflet about Chronic Kidney Disease – Mineral Bone Disorder.

Hyperparathyroidism is usually treated by taking vitamin D medication such as alfacalcidol and maintaining normal levels of calcium and phosphate. However, in some people these treatments are not enough to control the PTH. If this happens, there are other options to control hyperparathyroidism:

- Removal of the parathyroid glands by surgery called parathyroidectomy (information leaflet is available).
- Treatment with cinacalcet.
- If you are on haemodialysis and cinacalcet is not right for you your kidney doctor will talk with you about treatment with etelcalcetide. Etelcalcetide is given intravenously whilst you are on haemodialysis.

Your kidney doctor has decided that the best treatment for you at this time is cinacalcet.

## **How does cinacalcet work?**

Cinacalcet works by signalling the parathyroid glands to produce less parathyroid hormone so that the amount of calcium and phosphate in your blood are reduced. This reduces the risks of bone damage and calcification (the buildup of calcium in body tissue or blood vessels).

## How should I take my cinacalcet?

Cinacalcet comes as a tablet and is usually taken once a day. It should be swallowed whole and not chewed. Do not crush or break the tablets. It should be taken with or just after a meal.

Taking cinacalcet after 6.00pm may help to reduce any side effects. You may find it best to take your cinacalcet with your evening meal.

### **Very common (about 1 in 10 people)**

**Symptoms:** Feeling sick. Vomiting.

**Treatment:** Usually gets better after 3 days.  
Contact your renal team if it lasts longer than 3 days or if the vomiting is severe.

### **Common (about 1 in 100 people)**

**Symptoms:** Paraesthesia (pins and needles), prickling, tingling, itching, feeling hot or cold, skin crawling or numbness, especially around the mouth and lips or in the fingers and toes.

**Treatment:** Contact your renal team immediately as this could be due to low calcium levels (hypocalcaemia).

### **Common (about 1 in 100 people)**

**Symptoms:** Dizziness or low blood pressure.  
Headache.  
Decreased appetite.  
Feeling generally weak.  
Rash.

**Treatment:** Contact your renal team if symptoms are severe.

### **Rare (about 1 in 1,000 people)**

**Symptoms:** Seizures or muscle spasm (can be caused by very low calcium levels).

**Treatment:** Dial 999.

If you have any questions or concerns, please talk to your kidney doctor, pharmacist or renal nurse.

## **Will I need extra blood tests?**

You will require regular blood tests when you first start cinacalcet. Your renal nurse will discuss with you the best place for these blood tests to be taken. You will need bloods tests for calcium, phosphate and PTH, at the following times:

- 1 week after starting cinacalcet
- Monthly blood tests (unless advised otherwise).

It is important that you have these blood tests to detect and correct any low calcium levels in your blood.

## **How will I know if the cinacalcet is working?**

Your kidney doctor and specialist nurse will monitor the levels of calcium and PTH in your blood. If these levels have not improved within 4 months, the dose of cinacalcet may be increased.

## **What should my corrected calcium, phosphate and PTH blood levels be?**

Corrected calcium 2.2 to 2.5mmol/L for both dialysis and pre-dialysis.

Phosphate 1.1 to 1.7mmol/L on dialysis and 0.9 to 1.5mmol/L for pre-dialysis.

PTH 14 to 108 pmol/L on dialysis and pre-dialysis.

## **What else do I need to know?**

If you miss a dose of cinacalcet, take it as soon as you remember. If it is closer to the time of your next dose (within 12 hours), skip the missed dose and then continue at your normal time. Never take 2 doses at the same time.

You need to continue to take cinacalcet unless advised otherwise. Your medication will be supplied by the Renal Unit and not your GP. Please contact your renal team when you have 2 weeks supply left.

## **How to contact us**

### **Renal Bone and Mineral Metabolism Specialist Nurse**

Telephone: **01865 225 813**

Monday to Friday, 8.00 to 4.00pm

(Please leave non-urgent messages on the answerphone)

### **Renal Pharmacists**

Telephone: **01865 226 105**

Monday to Friday, 9.00am to 5.00pm

(Please leave non-urgent messages on the answerphone)

Email: [oxfordrenalpharmacists@ouh.nhs.uk](mailto:oxfordrenalpharmacists@ouh.nhs.uk)

### **Renal Ward**

#### **Churchill Hospital**

Telephone: **01865 225 780**

24 hours, including weekends and bank holidays

## Useful websites

### **Oxford Kidney Unit**

Lots of information about the Oxford Kidney Unit for patients and carers.

Website: [www.ouh.nhs.uk/oku](http://www.ouh.nhs.uk/oku)

### **Kidney Patient Guide**

Information for patients with kidney failure and those who care for them.

Website: [www.kidneypatientguide.org.uk](http://www.kidneypatientguide.org.uk)

### **Kidney Care UK**

A charity which has lots of practical support and information for people with kidney disease.

Website: [www.kidneycareuk.org](http://www.kidneycareuk.org)

### **Six Counties Kidney Patients Association**

The SCKPA is run for patients by patients or family members.

They offer support to people suffering from kidney disease or who are on dialysis. They work closely with the Oxford Kidney Unit and have branches in Oxfordshire, Northamptonshire, Buckinghamshire, and Milton Keynes, and parts of Wiltshire, Gloucestershire and Berkshire.

Website: [www.sixcountieskpa.org.uk](http://www.sixcountieskpa.org.uk)

### **National Kidney Federation**

A charity which has lots of practical support and information for people with kidney disease.

Website: [www.kidney.org.uk](http://www.kidney.org.uk)

## **Health for Me (patient portal)**

Health for Me is an on-line system that allows you to easily view parts of your digital health record safely and securely from your computer or smartphone.

Please ask a member of the renal team to sign you up to the patient portal.

If your bloods are taken through the Oxford Kidney Unit you will be able to see these results. We can give you a leaflet that explains what the blood test results mean. If you would like a copy please ask a member of the renal team.

## Further Information

Please speak to the department where you are being seen if you would like an interpreter. You will find their contact details on your appointment letter. Please also ask them if you would like this information leaflet in another format, such as:

- easy read
- large print
- braille
- audio
- electronically
- in another language.

We have tried to make this information meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They will be happy to help.

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Oxford University Hospitals NHS Foundation Trust

[www.ouh.nhs.uk/information](http://www.ouh.nhs.uk/information)



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