

Oxford Kidney Unit
**Cinacalcet for
hyperparathyroidism caused
by Chronic Kidney Disease**

Information for patients



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 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 two further options to control hyperparathyroidism:

- removal of the parathyroid glands by surgery called parathyroidectomy (information leaflet is available)
- treatment with cinacalcet.

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

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.

	Symptoms	Treatment
Very common (about 1 in 10 people)	Feeling sick Vomiting	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)	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	Contact your renal team immediately as this could be due to low calcium levels (hypocalcaemia).
Common (about 1 in 100 people)	Dizziness or low blood pressure Headache Decreased appetite Feeling generally weak Rash	Contact your renal team if symptoms are severe.
Rare (about 1 in 1,000 people)	Seizures or muscle spasm (can be caused by very low calcium levels)	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 blood tests for calcium, phosphate and PTH, at the following times:

- 1 week after starting cinacalcet
- 2 weeks later (3 weeks 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 in within 4 months, the dose of cinacalcet may be increased.

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

Tel: **01865 225 813**

(Monday to Friday, 8.00 to 4.00pm)
(answerphone will take a message)

Renal Pharmacists

Tel: **01865 226 105**

(Monday to Friday, 8.00am to 5.00pm)
(answerphone will take a message)

Renal Ward

Tel: **01865 225 780**

(24 hours)

Where can I get further information?

Oxford Kidney Unit

The Oxford Kidney Unit website has information about the Unit, which you and your relatives and friends might find useful.

Website: www.ouh.nhs.uk/oku/

100,000 Genomes Project

World class research is carried out at Oxford University Hospitals. We are also a Genomics Medicine Centre and you may be eligible to take part in the 100,000 Genomes project. During your visit you may be approached about clinical research studies and the Genomes project. If you would like further information, please ask your healthcare professional or visit the website:

www.ouh.nhs.uk/research/projects/genomes.aspx

If you have a specific requirement, need an interpreter,
a document in Easy Read, another language, large print,
Braille or audio version, please call **01865 221 473**
or email **PALS@ouh.nhs.uk**

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Reviewed by Renal Patient Information Group, September 2017
October 2017
Review: October 2020
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