

Cinacalcet for treating secondary hyperparathyroidism in people with kidney disease who are on dialysis

This leaflet is about when **cinacalcet** should be used to treat people on dialysis who have hyperparathyroidism because of their kidney disease in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with hyperparathyroidism associated with kidney disease, but it may also be useful for their families or carers or anyone with an interest in the condition.

NICE 'technology appraisal guidance' advises on when and how drugs and other treatments should be used in the NHS.

It does not describe hyperparathyroidism in people with kidney disease or the treatments in detail – your specialist should discuss these with you. Some sources of further information and support are on the back page.



What has NICE said?

Cinacalcet is not generally recommended for treating people on dialysis who have hyperparathyroidism because of their kidney disease. However, it is recommended for people on dialysis who:

- have very high levels of parathyroid hormone in their blood that can't be lowered by other treatments, **and**
- cannot have an operation to remove the parathyroid glands (a parathyroidectomy), because of the risks involved.

People who do receive cinacalcet should have regular checks. Treatment should be stopped if the parathyroid hormone levels in their blood do not fall substantially within 4 months.

There are several possible treatments for hyperparathyroidism associated with kidney disease. Your healthcare team should talk to you about the treatment options available.

Hyperparathyroidism associated with kidney disease

The parathyroid glands produce parathyroid hormone (PTH), which controls the levels of calcium and phosphate in the blood. Excessive production of parathyroid hormone is called hyperparathyroidism, and it can cause problems with bones, joints, blood vessels and other tissues. When hyperparathyroidism is caused by another condition, such as kidney disease, it is called secondary hyperparathyroidism. Almost all people who need dialysis because of kidney disease have secondary hyperparathyroidism.

Cinacalcet

Cinacalcet (also known as Mimpara) is a type of drug known as a 'calcimimetic'. It works by reducing the amount of parathyroid hormone

that the parathyroid glands produce, which also results in lower calcium and phosphate levels in the blood.

What does this mean for me?

There is not enough reliable evidence that cinacalcet is more effective than existing treatments for most people on dialysis who have hyperparathyroidism because of their kidney disease. This means that for the time being it should not be prescribed routinely on the NHS. Your doctor should talk to you about other treatment options available to you.

However, if you are on dialysis, you have very high parathyroid hormone levels that can't be lowered by other treatments, you can't have a parathyroidectomy, and your doctor thinks that cinacalcet is the right treatment for you, you should be able to have the treatment on the NHS. Please see www.nice.org.uk/aboutguidance if you appear to be eligible for the treatment but it is not available.

More information about hyperparathyroidism associated with kidney disease

The organisations below can provide more information and support for people with hyperparathyroidism associated with kidney disease.

Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- National Kidney Federation, helpline 0845 601 02 09
www.kidney.org.uk
- British Kidney Patient Association (BKPA), 01420 472021/2
www.britishkidney-pa.co.uk
- Kidney Alliance, 01483 724472
www.kidneyalliance.org

NHS Direct online (www.nhsdirect.nhs.uk) may be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further advice and support.

About NICE

NICE produces advice (guidance) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider all the research on the disease or treatment, talk to people affected by it, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet and other versions of the guidance aimed at healthcare professionals are available at www.nice.org.uk/TA117

You can order printed copies of this leaflet from the NHS Response Line (phone 0870 1555 455 and quote reference N1185).

National Institute for Health and Clinical Excellence

MidCity Place, 71 High Holborn, London, WC1V 6NA; www.nice.org.uk

ISBN 1-84629-347-2

N1185 5k 1P Jan 07

© National Institute for Health and Clinical Excellence, January 2007. All rights reserved. This material may be freely reproduced for educational and not-for-profit purposes. No reproduction by or for commercial organisations, or for commercial purposes, is allowed without the express written permission of the Institute.