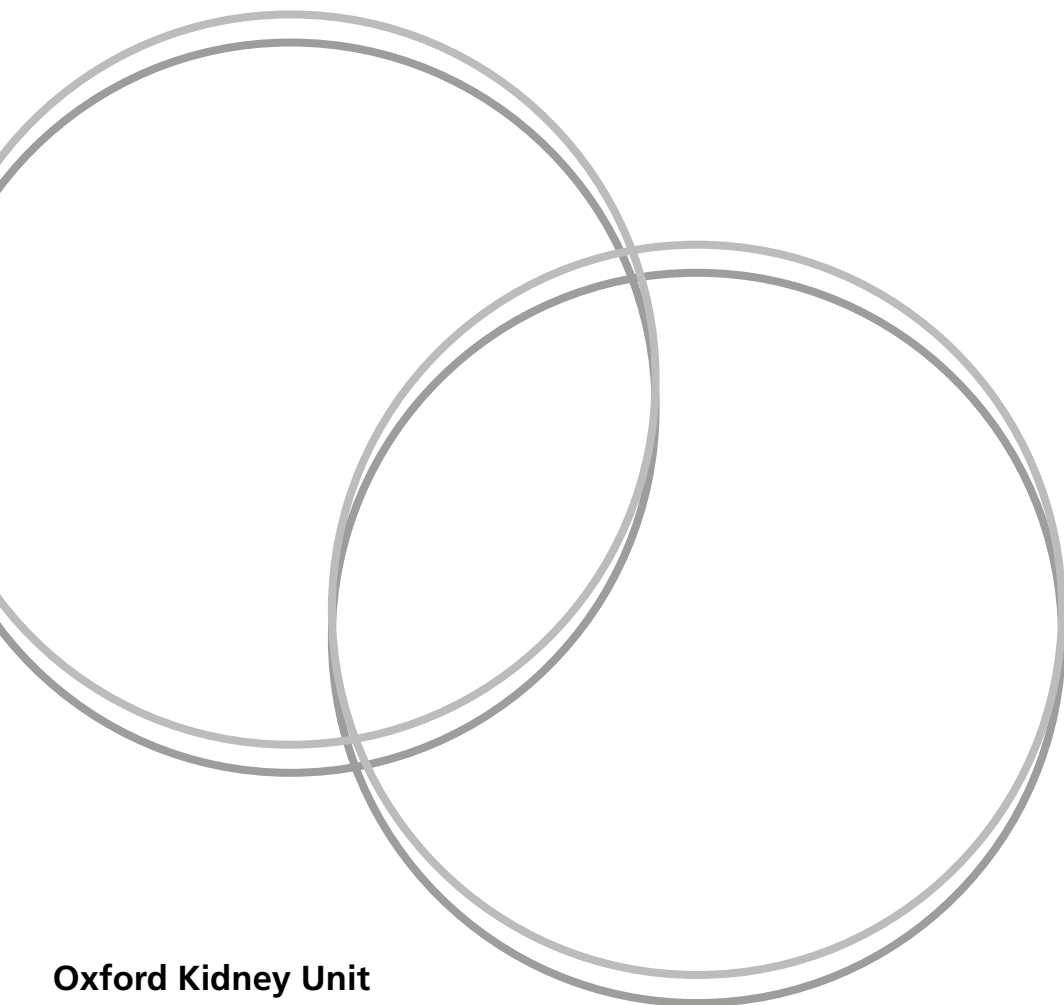




Oxford University Hospitals
NHS Foundation Trust

Calciophylaxis

Information for Patients



Oxford Kidney Unit

If you have been told you may have calciphylaxis, this leaflet is for you.

What is calciphylaxis?

Calciphylaxis or “calcific uremic arteriolopathy” is a rare condition which can develop if you have chronic kidney disease (CKD).

Calciphylaxis is a build-up of calcium and phosphate in the body, which causes chalky deposits to form in the small blood vessels. This can cause narrowing of blood vessels, reducing blood supply to the body’s organs, such as the heart, soft tissues and skin. This may cause damage to the organs, as well as skin wounds that are slow to heal and may become infected. Your kidney team will explain how calciphylaxis is affecting you.

What are the causes of calciphylaxis?

The causes are not fully understood. It is thought to be due to several factors, including:

- an imbalance of a hormone called parathyroid hormone (PTH) and the minerals calcium and phosphate. This is more likely to occur if you have CKD
- if you are receiving dialysis treatment
- if you have diabetes
- if you are taking warfarin.

What might I experience if I have calciphylaxis?

You may experience one or more of the following:

- skin discolouration, mottled skin
- skin lesions, such as hard black scabs or skin wounds/ulcers, that don't heal
- hard lumps underneath your skin
- itching or tenderness of your skin
- persistent pain in the area of skin affected.

Calciphylaxis tends to happen on the thighs, abdomen, buttocks, lower legs, breasts or penis, but may occur anywhere in the body.

How is calciphylaxis diagnosed?

Your doctor probably recognised calciphylaxis during an examination. Your blood tests may have shown an imbalance of calcium, phosphate and PTH, and a high level of a marker in the blood known as C-reactive protein (CRP). Levels of CRP are usually high in conditions where there is infection or inflammation and can also be raised in people with calciphylaxis.

Some people are diagnosed with calciphylaxis after a skin biopsy. This is when a small sample of your skin is taken for testing. This is usually carried out by a dermatologist. However, a skin biopsy is not always recommended, as the wound may take a long time to heal if you have calciphylaxis. Your doctor will discuss with you whether you should have a biopsy.

What will my doctor do to treat my calciphylaxis?

There is no specific treatment to stop the calcium being deposited in the small blood vessels. Your treatment will involve controlling any calcium, phosphate and PTH imbalances you may have.

Treatment is coordinated by a team of healthcare professionals, which includes a dietitian, pharmacist, bone and mineral metabolism nurse, pain management team, dermatologist, tissue viability (wound care) specialist and kidney specialist.

The right combination of treatments for you may involve the following:

- an increase in the amount of dialysis you have each week, if you are on dialysis
- a review of all of your medications. If you are taking tablets containing calcium they may be stopped or changed to a non-calcium containing alternative
- starting medications which help prevent your body from absorbing phosphate from food. These are called phosphate binders and should be taken with meals and snacks
- improving your parathyroid hormone control with a medication called cinacalcet. (A separate leaflet is available about cinacalcet; please ask your kidney team for a copy.)
- a review by your doctor of whether you should continue to take warfarin, if you take this. Please don't stop taking your warfarin without discussing with your doctor first. Your kidney doctor may suggest you take a different anticoagulation medication
- prescribed painkillers, if you need them
- a review by your doctor about prescribing an intravenous medication called sodium thiosulphate that is given while you are on haemodialysis. Sodium thiosulphate is being used 'off-label' for calciphylaxis. Off-label use means that the medication has a manufacturer license to treat some conditions, but they have not yet applied for a license to treat your condition. (A separate

leaflet is available about unlicensed and 'off-label' medicines, please ask your kidney team if you would like a copy). Your doctor will talk with you about this.

What can I do to help my condition?

- If you are on dialysis, try to make sure that you don't miss any dialysis sessions. Sometimes we may suggest that you have more dialysis.
- It is really important to control your phosphate level. You should reduce the amount of phosphate you have in your food. A renal dietitian will advise you on how to manage your phosphate intake.
- Try to make sure that you take all your prescribed medications.
- Try to avoid injury to your skin.

What can I expect?

Calciophylaxis is a serious condition. Despite treatment, you may develop further skin lesions. These can cause your health to deteriorate. Your kidney team will work with you to manage your calciophylaxis, but this may take many months.

For more information please contact your kidney team.

Useful numbers

Renal Ward, Churchill hospital

Tel: **01865 225 780**

24 hours, including weekends and bank holidays

Renal Bone and Mineral Metabolism Specialist Nurse

Churchill Hospital

Tel: **01865 225 813**

Main Haemodialysis unit, Churchill hospital

Tel: **01865 225 807**

Tarver Haemodialysis Unit, Churchill hospital

Tel: 01865 225 695

Milton Keynes Haemodialysis Unit

Tel: **01908 996 496**

Stoke Mandeville Haemodialysis Unit

Tel: **01296 316 996**

Banbury Haemodialysis Unit

Tel: **01295 229 811** or **01295 224130**

High Wycombe Haemodialysis Unit

Tel: **01494 426 347**

Swindon Haemodialysis Unit

Tel: **01793 605 286**

Useful websites

Oxford Kidney Unit

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

Website: 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

Kidney Care UK

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

Website: 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

National Kidney Federation

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

Website: www.kidney.org.uk

UK Calciphylaxis Study

Information and a study about calciphylaxis.

Website: www.gmann.co.uk/website/trials/iccn/home.cfm

Further Information

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.

Author: Myleen Almanza, Renal Bone and Mineral Metabolism Specialist Nurse
Chen Tseng, Renal Pharmacist

October 2020

Review: October 2023

Oxford University Hospitals NHS Foundation Trust

www.ouh.nhs.uk/information



Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

