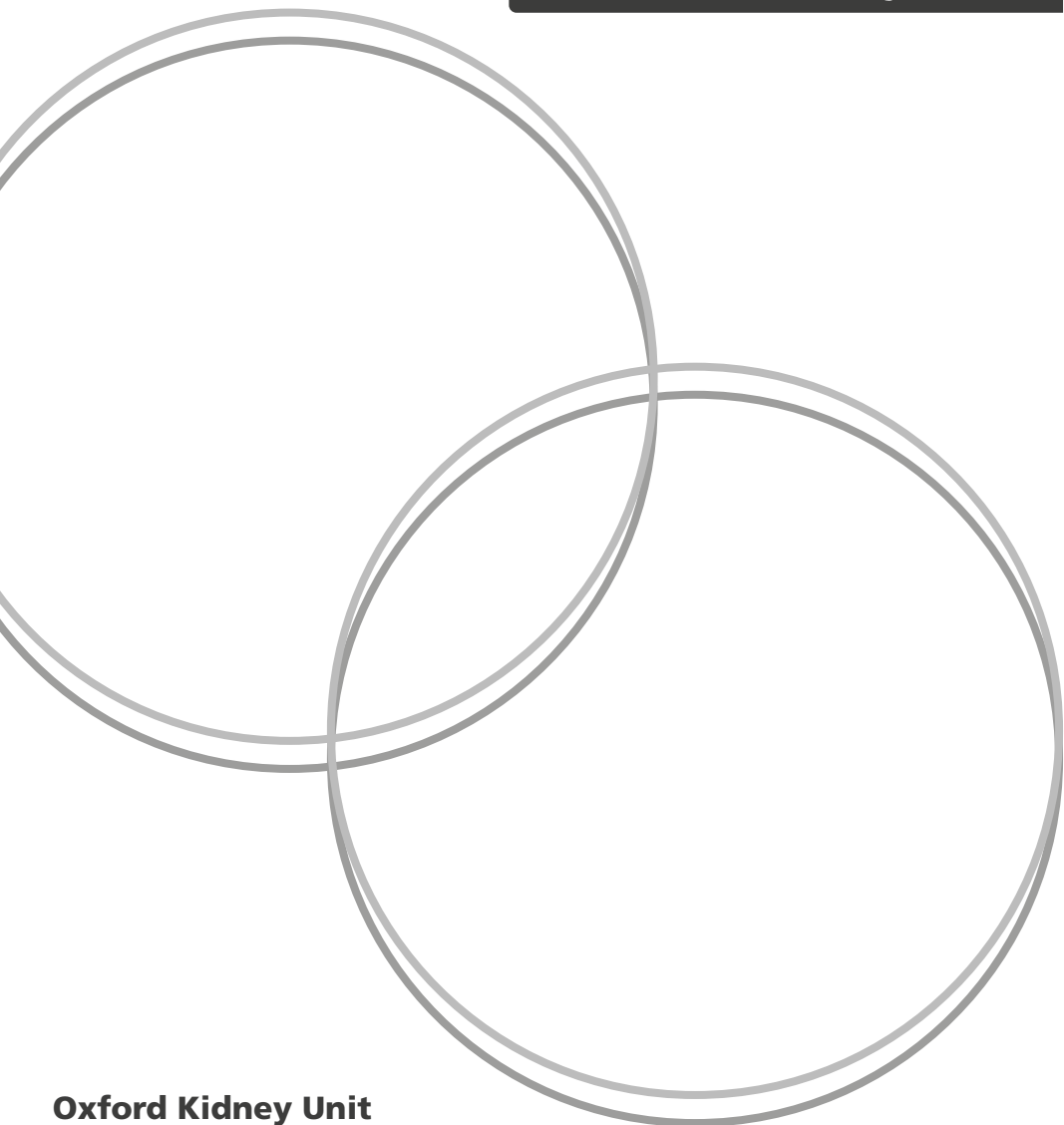




Oxford University Hospitals  
NHS Foundation Trust

# Calciophylaxis

**Information for people with  
chronic kidney disease**



**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:

- female
- overweight
- having high levels of calcium and phosphate in your blood
- receiving dialysis treatment for a long period of time
- if you have diabetes
- if you are taking warfarin (a medication to thin the blood).

## What might I experience if I have calciphylaxis?

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

You may experience one or more of the following:

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

## How is calciphylaxis diagnosed?

Calciphylaxis is usually recognised during a physical 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.

We will talk to you about **The UK Calciphylaxis study**. This is a study to find out more about calciphylaxis as we do not know enough about the illness.

## How is calciphylaxis treated?

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.

This 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:**

- Limit high-phosphate foods in your diet. Your dietitian will provide information on this.
- Adjust haemodialysis schedule for more frequent or longer sessions.
- Transition from peritoneal dialysis to haemodialysis temporarily to optimise mineral control, typically for 12 weeks.
- Switch haemodialysis fluid with a lower calcium concentration.
- Rotate injection sites, such as daily insulin, to lower infection risk.
- Tissue viability team and dermatology team would be available for supporting your wound care.

### **Manage medications:**

- Take phosphate binders with meals/snacks to reduce phosphate level.
- Review your regular medications to consider stopping calcium containing medications
- Review your anticoagulation (blood thinning) treatment, especially Warfarin.
- Cinacalcet or Etelcalcetide may be prescribed to optimise your parathyroid hormone control.
- Provide regular pain relief medications.

An intravenous injection called Sodium Thiosulfate may be prescribed by your renal doctor. This is usually administered during haemodialysis. Sodium thiosulfate is used 'off-label' for calciphylaxis (a separate leaflet is available about unlicensed and 'off-label' medicines, please ask your renal team if you would like a copy).

## **What can I do to help my condition?**

- If you are on haemodialysis 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.
- Tell your kidney team if you have any pain. Pain relief in people with chronic kidney disease needs extra care. This is because many medications for pain relief are excreted by the kidneys. It often takes several different types of medications to get it right.
- Cover any wounds or ulcers you have. This may need to be done by a specialist team known as tissue viability.

## **What can I expect?**

Calciphylaxis 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 calciphylaxis, but this may take many months.

If you are worried or you or your family are finding it difficult to cope with calciphylaxis we can refer you to our renal supportive care team. Please speak to any of the kidney team and tell them you want help.

## How to contact us

### **Renal Ward, Churchill Hospital**

Telephone: 01865 225 780  
(24 hours, including weekends and bank holidays)

You can leave a voicemail message if there is no answer. We will call you back in working hours (Monday to Friday).

### **Renal Dietitians, Churchill Hospital**

Telephone: 01865 225 061  
(Monday to Friday)

Please leave a message on the answerphone and one of the dietitians will get back to you.

## 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 Research UK**

Information about calciphylaxis.

Website: [www.kidneyresearchuk.org/conditions-symptoms/calciphylaxis](http://www.kidneyresearchuk.org/conditions-symptoms/calciphylaxis)

## **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)

## **UK Calciphylaxis Study**

Information and a study about calciphylaxis.

Website: [www.gmann.co.uk/website/trials/iccn/home.cfm](http://www.gmann.co.uk/website/trials/iccn/home.cfm)

## Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

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

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

May 2024

Review: May 2027

Oxford University Hospitals NHS Foundation Trust

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



*Making a difference across our hospitals*

[charity@ouh.nhs.uk](mailto:charity@ouh.nhs.uk) | 01865 743 444 | [hospitalcharity.co.uk](http://hospitalcharity.co.uk)

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

