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 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.
• new medication called cinacalcet to reduce your calcium levels. (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.
• prescribed painkillers, if you need them.
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.
- 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?

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.

For more information please contact your kidney team.

Further information

**Oxford Kidney Unit website**

This has useful information about the unit for patients and their families, as well as other information leaflets.

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