

Calciphylaxis (cal-ci-phy-lax-is)

Renal Unit Patient Information Leaflet

Introduction

This leaflet is about a condition called calciphylaxis. It will give you a better understanding of the condition and how it can be managed.

What is calciphylaxis?

Calciphylaxis is the term used for a condition called calcific uraemic arteriolopathy. It is a chronic (long term) condition that occurs as a result of a build-up of calcium and phosphate within the small arteries of the body. This build-up of calcium and phosphate causes a brittle, chalky material to form that can often look like bone.

The condition is very rare and at the moment there is no known cure.

Calciphylaxis can affect the heart, blood vessels and other tissues in the body.

Calciphylaxis and the heart

Calciphylaxis can occur in the heart valves causing them to become narrow. This can increase your risk of having a heart attack and so you may need to have heart valve replacements.

Calciphylaxis and the blood vessels

This can lead to narrowing of the blood vessels which can mean the blood supply to your feet or other parts of the body can be reduced causing other complications. Problems such as diabetes or peripheral vascular disease can act with the calciphylaxis to increase this problem.

Calciphylaxis of the tissues

Any tissue in the body can develop calciphylaxis and generally this does not cause any medical problems. However if you have diabetes or skin conditions which mean you are more likely to develop wounds, this may increase your risk of developing calciphylaxis of the skin.

What are the causes of calciphylaxis?

At the moment calciphylaxis is still being researched and the causes are not fully understood. It is thought to have a combination of causes as follows:

- Calcium imbalance in the body
- Phosphate imbalance in the body
- Parathyroid hormone imbalance in the body (the parathyroid is a gland that controls calcium levels)

How will I know if I have calciphylaxis?

People who have calciphylaxis often have pain and itchy areas of skin around their abdomen (tummy) or arms and legs. This is caused by inflammation of the tissues or blood vessels in these areas.

How is it diagnosed?

Consultants use a number of tests to diagnose the condition such as blood tests, X-rays or other imaging such as ultrasound scans or CT scanning, and heart scans. You may also be referred to a skin specialist who will carry out a skin biopsy and analyse it underneath a microscope.

What is the treatment for calciphylaxis?

There are many combinations of treatment that can be used to manage the symptoms of calciphylaxis, Research groups from the Renal Association and other scientists are still looking into other treatments for this condition.

Current treatment includes managing calcium levels, keeping them stable and avoiding high calcium levels. High levels will increase your risk of calciphylaxis and increase the build up of calcium in your body. Ways of doing this include:

- Controlling high phosphate levels by using non-calcium based phosphate binders such as Sevelemer. Phosphate binders are important as they help to absorb excess phosphate that your kidneys cannot remove. Phosphate is used to repair bone but too much in your body can increase calcium levels.
- Stopping any phosphate binders that are calcium based to help to reduce your calcium levels.
- Reducing the phosphate in your diet by avoiding large amounts of high-phosphate foods such as cheese, crisps and nuts. Your dietician will give you specialist advice.
- Reducing calcium in your diet. Your dietician will give you specialist advice about this.
- Vitamin D supplements such as 1-alfacalcidol may also be stopped as these can affect your calcium levels.
- Reducing the calcium in the dialysis fluid on the dialysis machine if you are having dialysis.
- Undergoing a parathyroidectomy (removal of the parathyroid gland) as this can help your body to control calcium better.
- Avoiding injections into the body where possible as this can cause a wound that may become calcified and hard to heal.
- Discontinuing any warfarin therapy (blood thinning treatment) or possibly using an alternative as it may cause small blood vessels to bruise easily and create a wound.
- Managing blood pressure to avoid hypotension (low blood pressure). Low blood pressure can cause tissues to be restricted of blood supply which can then cause skin ulceration.

Calciphylaxis is a condition that seriously affects peoples' lives and currently there is no cure so it needs to be managed properly.

Your consultant will suggest which combination of treatments is suitable for you based on your individual needs. It will really help if you complete your treatment as prescribed and attend for dialysis if you need to.

If you have any questions, or if there is anything you do not understand about this leaflet, please contact:

Renal Unit on 01384 244384. Lines are open:

Mondays, Wednesdays, Fridays – 7.30am to 11pm

Tuesdays, Thursdays, Saturdays - 7.30am to 9pm

Sunday – 8am to 4pm.

Russells Hall Hospital switchboard number: 01384 456111

This leaflet can be downloaded or printed from:

http://dgft.nhs.uk/services-and-wards/renal/

If you have any feedback on this patient information leaflet, please email dgft.patient.information@nhs.net

This leaflet can be made available in large print, audio version and in other languages, please call 0800 073 0510.

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此宣传单可提供大字版本、音频版本和其它语言版本,请拨打电话: 0800 073 0510。

Ulotka dostępna jest również w dużym druku, wersji audio lub w innym języku. W tym celu zadzwoń pod numer 0800 073 0510.

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Aceasta brosura poate fi pusa la dispozitie tiparita cu caractere mari, versiune audio sau in alte limbi, pentru acest lucru va rugam sunati la 0800 073 0510.

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6