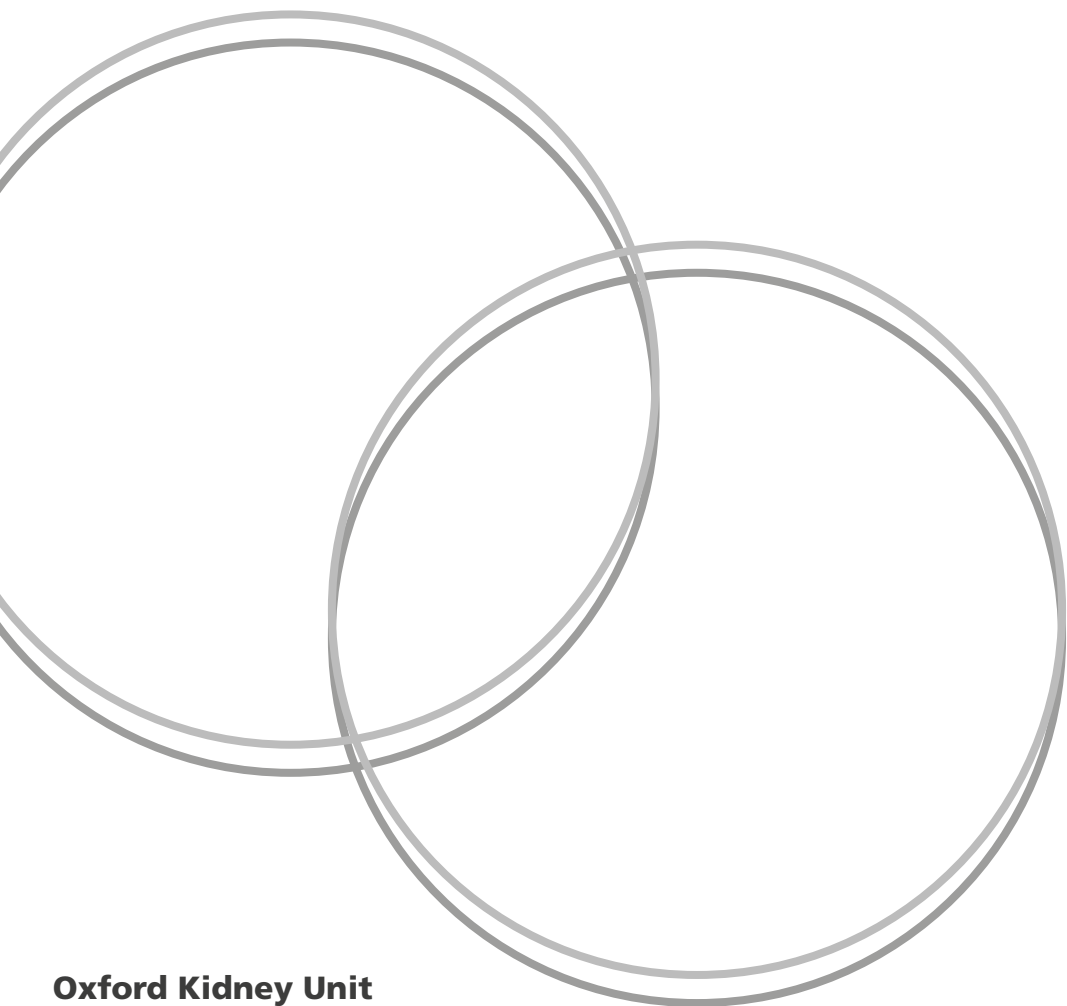


Chronic Kidney Disease – Mineral Bone Disorder (CKD-MBD)

Information for patients



Your kidneys remove waste and fluid from the body. When your kidney function reduces as it does in chronic kidney disease, the kidneys do not work as well as they should. This leads to changes in minerals and hormones which are important to keep bones healthy. This is known as Chronic Kidney Disorder - mineral bone disease or CKD-MBD.

How does having chronic kidney disease affect my bones?

CKD-MBD affects most people with kidney disease. This includes people in the “low clearance” clinic, those who are treated with dialysis and those who have had a kidney transplant.

When mineral bone disorder is not treated, your bones may become weak.

This can lead to bone and joint pain. It can make your bones brittle or likely to fracture.

High levels of calcium and phosphate can damage your blood vessels. This makes them hard like bone and can cause heart disease and blood vessel disease.

High phosphate levels can make your skin itchy and can be unpleasant.

How will my bone health be monitored?

Your kidney doctor or nurse will arrange for you to have regular blood tests. These can help us identify any blood levels which are out of range (see table on page 6) and organise treatment, if needed. This can help reduce your risk of developing serious problems with your bones.

It is unlikely you will experience any symptoms, unless you have advanced CKD-MBD. In advanced CKD-MBD, you may have damage to your bones that never goes away completely.

Why are calcium, phosphate, vitamin D and PTH important?

These help to maintain healthy bones in the body.

Calcium

Calcium provides bone strength, it is carried around in the blood. The levels are carefully controlled by the body. Calcium enters the body from the food you eat.

With chronic kidney disease, your kidneys are unable to make active vitamin D; this is needed to control the amount of calcium that you absorb from your food. Your kidney team may prescribe you active vitamin D supplements. These are not the same as the vitamin D supplements you can buy over the counter at a pharmacy. They are specially made for people for kidney disease.

Vitamin D

Healthy kidneys activate vitamin D into a form that helps your body absorb calcium from your food. It is more difficult to produce the activated form of vitamin D when you have chronic kidney disease. Your kidney team may recommend that you have your vitamin D level measured. This involves taking a small sample of blood; this is usually taken with other blood samples.

Phosphate

Phosphate is an essential mineral found in food that helps to maintain strong bones and gives strength to your muscles. Phosphate enters the body from the food you eat.

Your kidneys are responsible for removing excess phosphate from your blood. However, as your kidney function declines, phosphate levels can increase and contribute to CKD-MBD. If you need to make changes to your diet to reduce your phosphate intake, a renal dietitian will be able to help you. Your kidney team may also prescribe a medication called a phosphate binder to help better control your phosphate levels.

We can give you a separate leaflet on phosphate binders. Please ask your kidney team if you need a copy.

Parathyroid hormone

Parathyroid hormone (PTH) is a hormone (chemical messenger) that helps control the level of calcium in your blood. PTH comes from the four small parathyroid glands in your neck, behind your thyroid gland. If your calcium level falls, the parathyroid glands produce more PTH to keep the calcium levels normal. If the phosphate level increases, the parathyroid glands produce more PTH to keep the phosphate levels normal.

In chronic kidney disease, the parathyroid glands need to work harder to try and control calcium and phosphate levels in your blood. This is called **hyperparathyroidism**. Treating hyperparathyroidism is complex. It involves ensuring your phosphate and calcium levels are maintained in the recommended range and that you are on the correct dose of active vitamin D and phosphate binder. Your kidney team will discuss this with you.

A high PTH level can make your bones weaker. If left untreated, the parathyroid glands can become overactive and be difficult to control. Your kidney team may recommend a calcimimetic medication. (Cinacalcet, a tablet or etelcalcetide, given intravenously on haemodialysis) to help control the level of calcium in your blood. There is a separate leaflet available on cinacalcet and etelcalcetide, please ask your kidney team if you would like a copy.

Occasionally, an operation is needed to remove the parathyroid glands; this is called a **parathyroidectomy**. There is a separate leaflet available on this. Your kidney team will talk to you more about this, if it is needed.

Recommended blood levels of calcium, phosphate and PTH for people with chronic kidney disease

Mineral Corrected calcium (this is the most accurate way of measuring your calcium levels)	Recommended levels (ranges) On dialysis 2.2 - 2.5mmol/L
	Recommended levels (ranges) Not on dialysis (your levels may vary depending on the stage of your kidney disease) 2.2 - 2.5mmol/L
Mineral Phosphate	Recommended levels (ranges) On dialysis 1.1 - 1.7mmol/L
	Recommended levels (ranges) Not on dialysis (your levels may vary depending on the stage of your kidney disease) 0.9 - 1.5mmol/L
Hormone Parathyroid hormone (PTH)	Recommended levels (ranges) On dialysis 24 - 108 pmol/L
	Recommended levels (ranges) Not on dialysis (your levels may vary depending on the stage of your kidney disease) Less than 20pmol/L

What symptoms may I experience if I have CKD-MBD?

Common symptoms

- itching (this could be anywhere over your body).

Rarer symptoms

- bone pain (especially around your shoulder and hip joints)
- swollen joints (such as fingers and toes) due to calcium deposits
- tingling in your lips and fingers, twitching and spasms, especially in your face and arms (usually caused by low calcium level)
- muscle weakness
- gritty, bloodshot eyes.

Other problems you may experience

- increased risk of heart disease and stroke (the excess phosphate and calcium can be deposited in tissues and blood vessels)
- increased risk of bone fracture
- severe skin wounds that are very difficult to heal. This rare but serious condition is known as calciphylaxis (please see the calciphylaxis leaflet for more information).

How can I help to protect my bones and treat CKD-MBD?

The following is a list of ways to help your CKD-MBD.

- **Diet:** If your phosphate levels are high you may be advised to reduce the amount of phosphate in your diet.

The renal dietitians are a specialist team who will be able to provide individualised advice on your diet, including how to manage phosphate intake.

- **Phosphate binders:** These are medications that bind to the phosphate in your food and decrease the amount of phosphate absorbed into your body each time you eat. Your body can then get rid of the phosphate each time you open your bowels.

There are many different types of phosphate binders available and your kidney team will look at all of your blood results to discuss which phosphate binder is best for you and treat CKD-MBD?

There is a leaflet on phosphate binders, please ask your nurse or dietitian for a copy.

- **Vitamin D:** You will need to take an activated form of vitamin D supplement (alfacalcidol). These are not the same as the vitamin D supplements you can buy over the counter at a pharmacy. They are specially made for people with kidney disease.
- **Calcimimetics:** Calcimimetics help to reduce the amount of PTH produced by the parathyroid gland.
 - Cinacalcet, is a tablet taken once or twice a day with food.
 - Etelcalcetide, is an intravenous drug given on haemodialysis.
- **Dialysis:** (both PD and HD) filter some phosphate from your blood. But you still will need to follow dietary restrictions and take the medications.

What happens if I have had a kidney transplant?

A successful kidney transplant improves mineral and hormone levels, but it may not fully reverse previous bone damage. You may need to continue some medications after your transplant.

Further information

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

OUH Patient Portal Health for Me

Please ask a member of the renal team to sign you up to the patient portal.

Website: www.ouh.nhs.uk/patient-guide/patient-portal

How to contact us

Renal Bone and Mineral Metabolism Specialist Nurse

Telephone: **01865 225 813** (Oxford)

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

Renal Dietitians

Telephone: **01865 225 061** (Oxford)

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

Renal Pharmacy Team

Telephone: **01865 226 105** (Oxford)

Email: [**oxfordrenalpharmacists@ouh.nhs.uk**](mailto:oxfordrenalpharmacists@ouh.nhs.uk)

Please leave a voicemail message if there is no one available to take your call.

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.

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