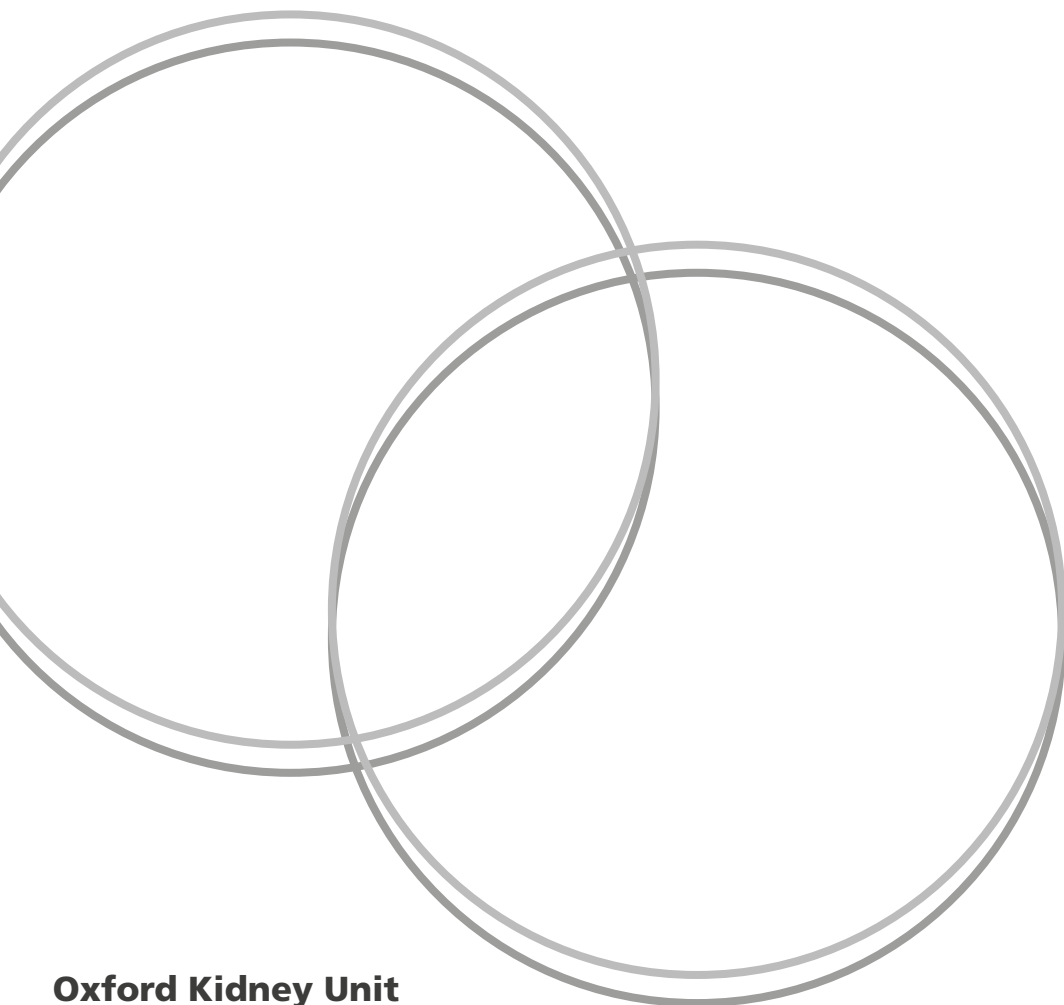




Oxford University Hospitals
NHS Foundation Trust

Chronic Kidney Disease

Information for patients
and their families



Oxford Kidney Unit

If you have been told you have “chronic kidney disease” (CKD), this leaflet is for you. Your GP or kidney doctor will also be able to explain how CKD may affect your health.

What is meant by the term CKD?

CKD is a very broad term used to describe long term damage to the kidneys (which has been present for at least three months). This damage can range from mild (as a result of natural ageing) and have little or no effect on health, to severe (when caused by diseases that harm the kidney), causing complications and even kidney failure.

About 1 in 20 people in the UK will develop CKD. Most of these will be elderly and have very mild kidney damage. CKD may get worse over time. Sometimes the kidneys may stop working altogether, but this is rare. If your kidneys stop working altogether a kidney doctor will talk to you about happens next.

What do the kidneys do?

The kidneys are the organs that filter and purify the blood, ridding the body of excess water, salts and waste products.

The blood entering the kidneys is filtered through a series of coils of small blood vessels. This filter (called the glomerulus) allows water and chemicals to pass through, but holds back the useful proteins and blood cells.

The filtered fluid is then processed as it passes down a long tube (called the tubule). By the time it reaches the end of the tubule only the excess water, salts, acids and waste products are left. This fluid, now called urine, passes into the pelvis of the kidney and flows down a long muscular tube (called the ureter) into the bladder.

Other important functions of the kidneys include produce:

- (1) an active form of vitamin D, which is necessary for calcium absorption from the bowel and healthy bone formation
- (2) renin, which controls blood pressure
- (3) erythropoietin, which stimulates the production of red blood cells, which carry oxygen around the body.

What causes CKD?

The common causes of CKD are:

- diabetes
- inflammation of the filters (glomerulonephritis)
- infection of the kidney
- obstruction of the flow of urine, causing back pressure on the kidney itself
- inherited abnormalities of the kidney's structure, e.g. polycystic kidney disease
- very high blood pressure (hypertension)
- blockage of the blood vessels supplying the kidney.

There are a number of other rarer causes of CKD. Your kidney doctor will discuss these with you.

CKD is more likely to be found in:

- older people
- men
- people of African and South Asian descent
- people with heart or circulatory problems (such as previous heart attacks or strokes).

It is not always possible to find out the cause of CKD and your doctor may suggest you have a kidney biopsy. Your kidney doctor will discuss this with you in clinic.

How is CKD diagnosed?

A routine blood or urine test is likely to pick up CKD before you experience any symptoms. This may have been done as part of a health assessment or because of another condition, or because you already suffer from one of the common causes listed previously.

The important signs of kidney damage are:

- Reduced kidney function, which is detected by a blood test that measures your estimated glomerular filtration rate (eGFR).
- An excess of protein in the urine.
- Blood in the urine that is coming from the kidney itself, not the ureter or bladder.
- Abnormal appearances of the kidneys, seen on a scan.

The stages of CKD

An effective way of assessing how well your kidneys are working is to calculate your glomerular filtration rate (GFR). GFR is a measurement of how many millilitres (ml) of fluid your kidneys can filter from your blood in one minute (measured in ml/min). A healthy pair of kidneys should be able to filter more than 90ml/min.

It is difficult to measure the GFR directly, so it is estimated using a formula. The result is called the estimated GFR or eGFR. Calculating your eGFR involves taking a blood sample and measuring the levels of a waste product called creatinine, which is filtered by your kidney. The formula takes into account your age, gender and ethnic group.

The result is similar to the percentage of normal kidney function. For example, an eGFR of 50ml/min equates to 50% kidney function. The normal rate in young fit people is 90 to 120ml/min. It is much lower in older people (50 to 80ml/min).

Your kidney function will be staged relating to your eGFR (stages 1 to 5) and by measuring how much protein is being lost in your urine. The staging system describes the severity of your kidney damage and the likelihood of it getting worse.

Protein loss is also measured in stages:

- A1 means hardly any protein in the urine
- A2 means a small amount of protein in the urine
- A3 is a significant amount of protein in the urine.

Stage 1:
Kidney function as eGFR: More than 90ml/min.
Description: Normal kidney function but other damage found, e.g. protein in the urine.

Stage 2:
Kidney function as eGFR: 60 to 89ml/min.
Description: Normal to mildly reduced kidney function but other damage found.

Stage 3:

Kidney function as eGFR: 45 to 59ml/min.

Description: Mild to moderate reduction.

Stage: G3B A1-3.

Kidney function as eGFR: 30 to 44ml/min.

Description: Moderate to severe reduction.

Stage 4:

Kidney function as eGFR: 15 to 29ml/min.

Description: Severely reduced kidney function.

Stage 5:

Kidney function as eGFR: Less than 15ml/min.

Description: Advanced kidney disease.

Many people with stage 1 to 3 CKD do not need to see a kidney specialist. If they do, it is for diagnosis and advice.

After you have been diagnosed, we will share your care with your GP, who will monitor your kidney function and refer you back to the Kidney Unit if your kidney function gets worse.

If you have stage 4 or 5 CKD, a large amount of protein in your urine, or have a specific kidney disease, you will need to see a kidney specialist. Only a few people with CKD will develop kidney failure and may need dialysis or a kidney transplant. Your kidney doctor will explain whether your kidney function is declining and whether you are at risk of developing kidney failure.

In the early stages of CKD (stages 1 to 3) you are unlikely to have symptoms. In CKD stages 4 or 5 you may experience none, some, or all of the following:

- tiredness and lack of energy
- breathlessness
- swollen ankles
- poor appetite
- difficulty sleeping
- difficulty concentrating
- itching
- loss of libido
- feeling the cold.

Most people with CKD don't develop any other problems as a result of their kidney disease, but if you are at stage 4 or 5 CKD you are more likely to experience the following:

- High blood pressure. You may require several different medications to keep your blood pressure well controlled.
- Increased risk of having a heart attack or stroke. You should discuss this with your GP, who can estimate your risk and discuss measures to reduce this. These include stopping smoking, as well as medicines to reduce your blood cholesterol.
- Fluid retention, causing breathlessness due to fluid on the lungs, or swelling of your ankles and sometimes legs. Your doctor may prescribe 'water tablets', also called diuretics, which promote the loss of excess salt and water in the urine.
- Anaemia (see page 9).
- Abnormal levels of calcium and/or phosphate in your blood, which can lead to bone problems (see page 9).
- Changes in the acidity of your blood. The kidneys help to prevent the blood becoming acidic. If the acid level in your blood is too high, this can cause breathlessness and also thinning of the bones. Your kidney doctor may prescribe sodium bicarbonate tablets to help balance the acid level in your blood.
- Reduced ability to get rid of medications that are usually removed in your urine. This can cause a build-up of medications in the blood, which can cause side effects.
- Erectile dysfunction in men.
- Changes to menstrual cycle in women. This could mean irregular or absent periods or a reduced fertility.

Anaemia

Anaemia is a condition in which you have too few red blood cells to carry the oxygen around your body. Symptoms include:

- lack of energy
- tiredness
- feeling the cold
- shortness of breath
- palpitations (awareness of your heartbeat).

There are many other causes of anaemia which can also affect people with CKD. Your doctor may need to arrange tests to rule out these other causes.

There are two reasons why you could develop anaemia if you have CKD:

The kidneys produce a hormone called erythropoietin ('epo' for short), which stimulates the bone marrow to produce red blood cells. If you have CKD (usually stage 4 or 5) your kidneys may not produce enough epo. This can be treated with injections of artificially produced epo, which are injected under your skin to top up the levels in your body.

You may not absorb iron from your food. Iron is essential for the production of red blood cells. This can be treated with occasional intravenous infusions of a concentrated iron solution.

CKD and bone health

The damage to the kidneys at stage 4 and 5:

- limits the production of activated vitamin D
- prevents the kidneys from removing excessive phosphate from the blood.

This causes a hormonal imbalance which interferes with the production of healthy bone.

People with CKD usually have low levels of activated vitamin D. This is because healthy kidneys activate the vitamin D produced in your skin from sunlight and from food. Your kidney team may prescribe you the active form of vitamin D. This is not the same as regular over the counter vitamin D supplements. You should not take supplements you buy yourself without checking with your kidney team.

Phosphate comes from the diet; mainly from dairy produce, red meat, eggs and fish products. You may be advised by the renal dietitian on how to limit the amount of foods you eat that contain phosphate, without reducing your healthy intake of other nutrients.

If reducing the amount of phosphate in your diet does not lower your blood phosphate level enough, you may be prescribed medicines called phosphate binders. These bind to the phosphate contained in the food, inside your stomach, and stop it from being absorbed into your bloodstream.

How can I help myself?

- Take **all your medications** as prescribed.
- Follow a renal diet that has been adapted for you especially the advice on salt intake.
- **If you smoke then you should stop.** Smoking may make your kidney function worse more quickly. It also increases the risk of heart attacks and strokes.
- Have your **blood pressure measured regularly**, as good blood pressure control is very important in protecting your kidneys from progressive damage. You should consider buying a blood pressure machine, so you can monitor your blood pressure at home. We have a leaflet called 'measuring your blood pressure at home'. Ask a member of staff for a copy or you will find this on the Oxford Kidney Unit website.

Your GP or kidney doctor will give you a blood pressure target. They will review your blood pressure at each outpatient appointment and recommend ways to reduce it further, for example by achieving an ideal body weight, reducing salt in your diet, and adjusting your medication.

- **Take regular exercise.** This will help you to achieve an ideal weight and reduce blood pressure.
- **If you have diabetes**, talk with your diabetes nurse or doctor, as good glucose control may help to protect your kidneys.
- **Avoid some painkillers** that are known to cause kidney problems, such as non-steroidal anti-inflammatory tablets. These include over the counter medications such as ibuprofen (Nurofen, Brufen) and diclofenac (Voltarol). You should not use these, either in tablet or cream form.
- If you are seeking treatment from a pharmacy or a new doctor, tell them you have CKD. Some **medications** should be avoided, while the dose of other medications may need to be adjusted.

What happens in the renal clinic?

A kidney doctor will see you in the renal clinic regularly, to monitor your blood and urine tests, measure your blood pressure and adjust your medications. If you have stage 4 or 5 CKD, the kidney team will discuss options for the treatment of renal failure. These include dialysis, kidney transplant or conservative care.

What should I do if I become unwell?

You may need to stop some of your medications if you are dehydrated and your blood pressure is low. This is especially with medications such as ACE inhibitors (ramipril, lisinopril or any tablet ending with a 'pril') or an ARB (candesartan or anything ending with 'artan'). If you are unsure seek advice from your kidney doctor, GP or pre-dialysis nurse.

Where can I find more 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

National Kidney Federation

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

Website: www.kidney.org.uk

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

NHS website

Website: www.nhs.uk/conditions/kidney-disease

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

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.

Author: Pre Dialysis Team
August 2024
Review: August 2027
Oxford University Hospitals NHS Foundation Trust
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