

CKD Health Check

Look after your kidneys and keep yourself well

Your introduction to Chronic Kidney Disease (CKD) and its treatment

Third Edition

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Kidney Care UK is the UK's leading kidney patient support charity working to improve the quality of life for kidney patients and their loved ones. The charity provides financial, practical and emotional support, invests in improvements to care services and represents patients' interests at a national level.



This project was developed in partnership with the Royal College of General Practitioners (RCGP).

The RCGP is the foremost organisation in the field of primary care. The Royal College of General Practitioners is a network of more than 49,000 family doctors working to improve care for patients. We work to encourage and maintain the highest standards of general medical practice and act as the voice of GPs on education, training, research and clinical standards.

Introduction

If you want to know more about chronic kidney disease (CKD), this introductory book is for you.

Many people have CKD, but most of them feel perfectly well and will never develop kidney failure. However, your kidneys have important jobs in the body. They clean your blood, regulate the chemical balance of your body and keep your blood pressure normal. So if there is anything wrong with your kidneys, your blood pressure may rise. High blood pressure increases your chances of having a heart attack, heart failure or a stroke.

This is why it is important to look after yourself if the doctor discovers you have CKD.

This book tells you how to take control of your body and protect your circulation. At the end of the book, you will find a 'jargon busting' section to help explain medical terms. There is also information about finding out more, either from books or online.

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A microscopic image of a kidney section, stained with hematoxylin and eosin (H&E). The central feature is a glomerulus, a cluster of capillaries, surrounded by a double-layered capsule. The surrounding tissue consists of various tubules and interstitial cells. Two purple callout boxes with blue arrows point to specific features: one points to the glomerulus and the other points to the tubules.

Filtering element (the glomerulus)

Tubules in the fluid balancing element

What do the kidneys do?

Most people have two kidneys. They are bean shaped and about the size of your fist. They sit in your abdomen, at the back, but protected by your lower ribs, either side of your spine.

The kidneys do much more than many people realise.

This is a quick rundown on why they keep you healthy. The main thing that the kidneys do is to produce urine. They do that by filtering your blood up 40 times every day. The kidneys sieve the blood, removing excess fluid (salt and water), getting rid of toxins in your body and keeping the chemical balance of your body just right.

1 Waste products: our body is an engine, using fuel to keep it going. As this fuel is used, waste products are made. The kidneys are the main way in which these waste products are disposed of.

2 Fluid control: fluid in our body is made up of water and salts. Too little or too much of each can be dangerous but the kidneys regulate the balance of fluid in our body. For example, if we drink too little, or it is very hot and we are sweating, the kidneys will hang onto fluid. In contrast, if we drink extra fluid, the kidneys will get rid of it.

3 Hormonal actions: hormones in our body maintain the health of various systems and parts. The kidneys are very important hormonal organs, producing several hormones.

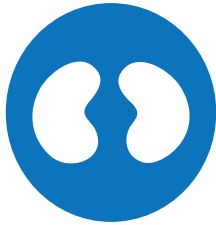
a. Vitamin D: vitamin D in our body and produced in our skin keeps the calcium levels in our body normal and strengthens bones. To work, it needs to be activated and that's what the kidneys do.

b. Haemoglobin: haemoglobin carries oxygen around the body in red blood cells. If you are anaemic you feel tired – that is because not enough oxygen is getting to your muscles. It might also make you feel short of breath as your body tries to get more air. There are many causes of anaemia, but kidney disease is one of them. That happens because the kidneys don't make enough of a hormone called erythropoietin (EPO) which stimulates the bone marrow to make red blood cells.

c. Blood pressure: the kidneys control our blood pressure, by producing hormones to tighten and relax the blood vessels in our body. If the blood vessels are too tight, the pressure of the blood will be raised.

4 Drugs: the final role of the kidneys is to get rid of drugs. Without kidneys, many drugs used to treat illness and disease would build up. Not all tablets are removed by the kidneys but the majority are.

(Almost) everything you need to know about your kidneys



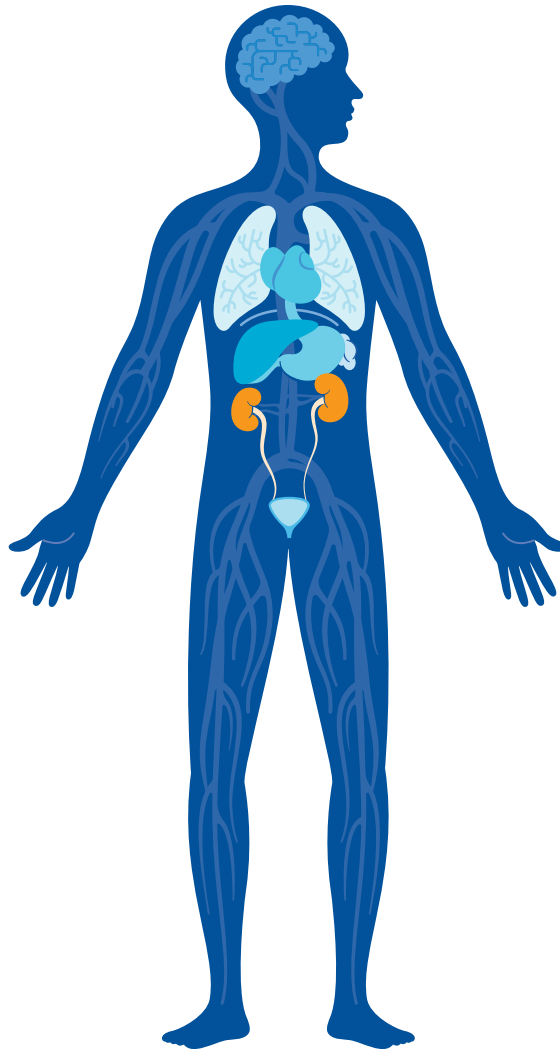
Most people have two kidneys

They are about the size of your clenched fist, they each weigh around 150g and are shaped like kidney beans



They filter your blood every minute of the day

Your blood goes through the kidneys 40 times in 24 hours. There are 140 miles of tubes and a million filters in your kidneys



They sit in your lower back under the bottom ribs

Only 50% of the population know that kidneys produce urine



They are the hardest working organs in your body

They use 25% of the blood from every beat

What do your kidneys do?

Make urine



Regulate salt and water in your body, making about 3-4 pints of urine each day



Remove waste products from your blood into your urine

Produce hormones



Regulates your blood pressure



Create erythropoietin to control the production of red blood cells

Activate Vitamin B



Keep bones healthy

Clean your blood



Remove many drugs that some people take for other conditions

How to keep your kidneys healthy

Lead a healthy lifestyle



Keep hydrated



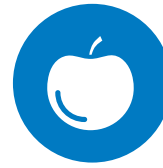
Don't smoke



Keep your weight down



Exercise regularly



Eat a healthy diet including fresh fruit, vegetables and fish



Reduce your intake of salt, processed food and high sugar drinks

If you take regular medication ask your pharmacist how it may affect your kidneys

What causes kidney problems?

One of the most common causes of kidney disease is diabetes

But there are many others including genetic and inflammatory conditions, blockages of urine flow and high blood pressure that can be a cause and/or consequence of kidney problems.

About 1 in 10 people has some form of Chronic Kidney Disease (CKD)

CKD is a long term loss of kidney function which can be harmful. Not all CKD gets worse but it can lead to kidney failure. CKD also increases the risk of heart attack or stroke and increases the risk of acute kidney injury.

Acute Kidney Injury (AKI) is serious and can occur when a person is unwell

AKI is a quick reduction in kidney function. Finding AKI in the early stages is very important as it can make other health problems more difficult to treat.

Of emergency admissions to hospital 1 in 5 people have AKI

AKI can occur after major surgery or with heart problems. Up to 100,000 deaths in hospital in the UK each year are associated with AKI. It causes harm and suffering and costs a lot.

Why you need to think kidneys



If you are worried about your kidneys visit your GP and find out if screening is necessary



Always 'Think Kidneys' when visiting your GP as CKD and AKI often show few symptoms



Your kidneys are remarkable and can look after you at just 10% functionality



AKI often gets better and can even recover fully as the underlying problems are treated

What are the symptoms of kidney problems?

In the early stages of kidney disease there are often no symptoms

There may be no pain or reduction in urine output. Kidney problems are found by a simple blood or urine test so we recommend that people at risk of CKD or AKI are tested regularly to spot problems as soon as possible.

Symptoms of more serious kidney problems can include:

Tiredness, Frequent headaches, Loss of appetite, Sleep problems, Itchy skin, Nausea or vomiting, Swelling or numbing of the hands or feet, Passing urine more (especially at night) or less often than usual, Darkening / lightening of the skin, Muscle cramps

'THINK KIDNEYS'

THINK KIDNEYS

NHS



Think Kidneys is a national programme led by NHS England in partnership with UK Renal Registry

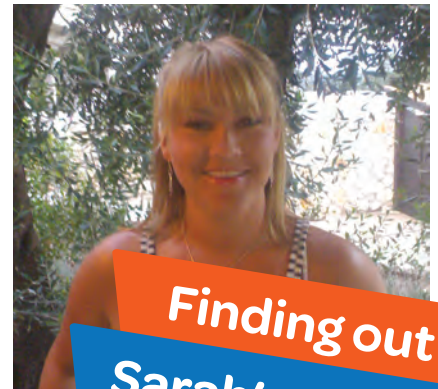
What is chronic kidney disease?

Chronic kidney disease or CKD is the medical term used to cover a wide range of conditions that result in long-term kidney damage. A staging system is used to classify or describe how impaired the kidneys are. See the section on diagnosis for more details. The kidneys can no longer do all the usual jobs at 100% of normal.

The term CKD can be confusing or even alarming but it should not be. Chronic merely means it has been going for a long time (more than 3 months) and is unlikely to improve. Disease just means that the kidneys are damaged by ill health. And CKD is not the same as kidney failure.

But chronic kidney impairment or disease (CKD) is a common and serious problem. It is estimated that 1 in 10 adults have CKD. It increases the risk of cardiovascular illnesses such as heart attacks and strokes and means a person is at risk of a temporary reduction in kidney function. For some people, that may get worse over time. After a time, the kidneys stop working almost completely – a condition known as established renal failure (ERF), end-stage renal disease (ESRD) or end-stage kidney failure. When the kidneys stop working completely, lifesaving treatment is required (either dialysis or a kidney transplant).

At present, there are approximately 57,000 people in the UK who are either on dialysis or have received a kidney transplant for kidney failure, so it is very rare.



Finding out Sarah's Story

After an 18 month period of chronic, recurring bladder infections during which my GP found both blood and protein in my urine and revealed that my cholesterol and blood pressure were slightly raised, I thought that maybe the antibiotics I was being prescribed were not the answer. I have had diabetes for over 18 years (since I was a child).

I could sense that something wasn't right, and began to search the Internet with absolute determination to try to uncover the real cause of my ailments. It took 3 or 4 hours for me to conclude, with complete horror, that there was more than a slim possibility that I was suffering from the early stages of CKD. Four days later, with my mother as support, I told the GP of my discovery.

I was referred to the renal department of my local hospital. Following several blood tests and a kidney biopsy, these suspicions were confirmed and CKD became part of my life.



What causes chronic kidney disease?

There are hundreds of different diseases that can cause kidneys to start failing, and sometimes to fail completely. CKD is most commonly due to one of the following causes:

- **Diabetes mellitus.** Diabetes is the most common known cause of kidney failure in the developed world. Whether diabetes is controlled by insulin, tablets or diet, it can cause kidney failure (known as diabetic nephropathy). This is more likely to happen when someone has had diabetes for more than 10 years. In the UK, an average of 25% of new dialysis patients every year are thought to be suffering from diabetic nephropathy.
- **Nephritis.** The term 'nephritis' means inflammation of the kidneys ('neph' means 'kidney', and 'itis' means 'inflammation'). The term is usually applied to people with glomerulonephritis or GN. ('Glomerulo' refers to the glomeruli, which are part of the kidneys' filtration unit.) The causes of most types of nephritis are unknown. Nephritis is another condition that can only be diagnosed for certain by a kidney biopsy.
- **Autosomal Dominant Polycystic kidney disease (ADPKD).** This is an inherited disease (a disease that runs in families) in which both kidneys become filled ('poly' means 'many') with cysts (abnormal fluid-filled lumps). If someone has ADPKD, they will have a 50% chance of passing the condition on to each of their children. The problem is diagnosed by ultrasound (an investigation that uses sound waves to produce a picture of the kidneys) and from family history. Polycystic kidneys, although abnormally large because of the cysts, do not work well and many people eventually develop ERF.

Further information can be found at the PKD charity website - <http://pkdcharity.org.uk>.

- **Pyelonephritis.** 'Pyelo' (meaning 'funnel') refers to the drainage system of the kidney and 'nephritis' means 'kidney inflammation', so pyelonephritis means 'inflammation of the kidney drainage system'. Pyelonephritis can be linked to repeated kidney infections. These may have gone undetected for many years, perhaps having occurred in childhood.
- **Renovascular disease.** As people get older, their arteries tend to become 'furred' up with cholesterol and other fats. Diabetes and smoking make this process occur at a younger age. This 'furring up' (which is called atheroma or atherosclerosis) gradually narrows the arteries (the blood vessels that take blood from the heart to every part of the body) which includes the kidney blood supply.
- **Obstructive nephropathy.** This is a common cause of kidney disease in men, especially those over the age of 60 years. It is usually due to enlargement of the prostate gland, which obstructs the urethra (hence the name 'obstructive nephropathy'). The urethra is the tube through which the urine drains from the bladder. It can also be caused by tumours in the bladder or in the pelvis.

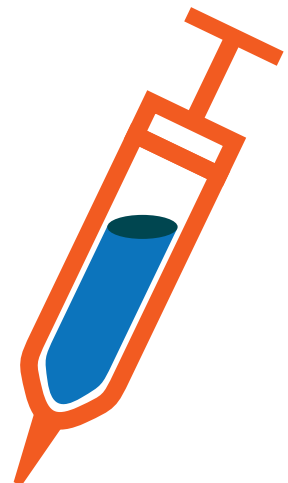
There are lots of other causes so this list is not comprehensive. Drugs and obesity are now becoming problems for kidney health and we are beginning to understand much more about how some conditions are inherited.

How is CKD diagnosed and how is it monitored?

CKD is diagnosed using two main types of test – one blood test and one urine test. The blood test is used to estimate the amount of blood that your kidneys process every minute – this is the glomerular filtration rate or GFR. The blood test is only an estimate – sometimes more complex tests are used but for most people this test based on measuring a substance in the blood called 'serum creatinine' is sufficient.

The average normal eGFR is about 100 in young adults, so the eGFR is sometimes referred to as the percentage of normal kidney function. Some young adults with normal kidneys will have an eGFR as low as 75, and this often gets even lower as people get older. So, many healthy people aged 80 will have an eGFR of 40–50.

Urine is also tested to see if the kidneys are leaking protein.



What can doctors find out from your urine?

Levels of ACR

Finding protein in the urine

Protein is one of the three major food groups that are used as building materials for the body (fats and carbohydrates are the others). Proteins are present in all the cells of our body and also transported in blood. When your body gets rid of waste via your kidneys, protein should be kept in your bloodstream and not lost.

Measuring the amount of protein that leaks out into the urine helps doctors and nurses to identify any damage to your kidneys. The specific protein that is measured is called albumin.

You can tell if there is a lot of protein in the urine by using a simple 'dipstick' test on a small sample. A special paper on the end of a small plastic stick will change colour if it comes into contact with protein. The dipstick test is not sensitive to small amounts of protein and usually the sample will be sent to the laboratory to measure the amount of albumin and creatinine in the urine.

The 'albumin-creatinine ratio' (ACR for short) can be calculated. Low levels of albumin in the urine can be found in up to 1 in 20 (5%) of the general population and will be more common after an active day. You may be asked to repeat the test in an early morning sample.

The level of your ACR is important, because if it is high, it increases the risks of complications and progression (worsening) of kidney disease compared to someone else with the same kidney function (eGFR). There is nothing you can do directly to change the ACR (eating a low protein diet will not help, indeed it could harm you), but good blood pressure control may reduce the ACR levels.

Even low levels of albumin in the urine are important in people with diabetes and it may mean that you need treatment with tablets for high blood pressure to reduce your risk, even if your blood pressure is normal.

Finding blood in the urine

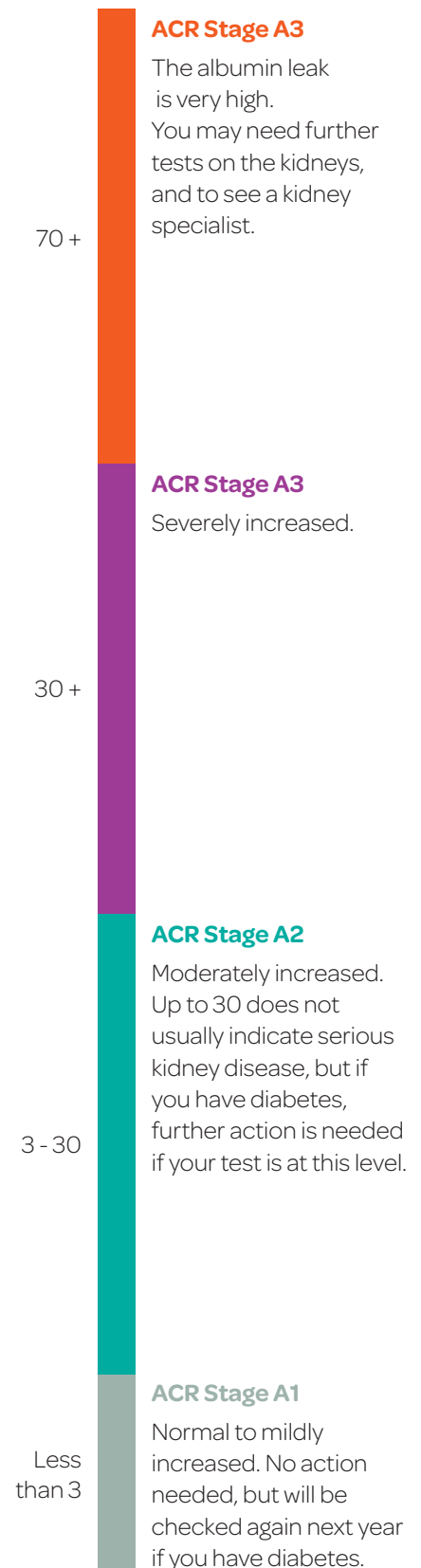
Haematuria is the medical term for blood in the urine. Small traces of blood in the urine can occur in as many as 1 in 20 (5%) of the population, and are often nothing to worry about.

If there is enough blood in your urine for you to be able to see it yourself, you may have an infection. If you don't have any infection, bleeding like this may need to be investigated by a doctor specialising in urology just to make sure that it is not caused by kidney stones or cancer, for example.

Amounts of blood that are too small to be seen by the naked eye can be detected in the same way as protein, by a dipstick test. This blood could be coming from the kidneys. You may need to be assessed by a kidney specialist, depending on your eGFR and ACR levels.

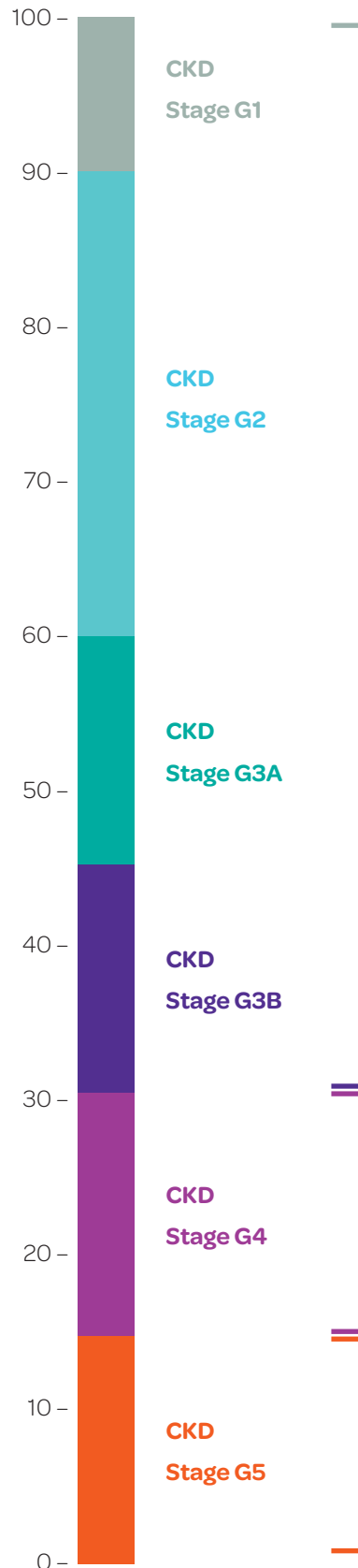
Using these two tests, the kidney disease is 'staged'. This still doesn't tell us what the cause is and it doesn't tell you what will happen in the future. So, other tests are used to look at the cause of the kidney disease. These include additional blood and urine tests plus X-rays, scans and biopsies of the kidney. The need for these is decided by the history that you give (which will give the doctors an idea of what the possible causes may be), the examination and basic tests and then discussion with you. Scans and X-rays can look at the size and shape of your kidneys, the blood supply and the drainage as well as looking for large scars. A kidney biopsy on the other hand looks at the microscopic appearance of your kidneys.

The results of these two types of tests are used together to find out the diagnosis.



CKD is divided into Stages:

- **CKD Stage G1** is eGFR greater than 90, with the kidneys still clearing waste from the bloodstream normally, but another sign (on urine test or kidney scan) that they are not completely normal, for example in polycystic kidney disease. If there are no other signs of kidney damage, an eGFR over 90 is not CKD.
- **CKD Stage G2** is eGFR 60–90 with another sign of kidney damage on urine test or kidney scan. If this other sign is not present and eGFR is 60–90, this is not considered to be CKD.
- **CKD Stage G3A** is eGFR 45–59, a moderate reduction in kidney function which should be monitored at least once a year.
- **CKD Stage G3B** is eGFR 30–44, a reduction which is considered significant.
- **CKD Stage G4** is eGFR 15–29, a severe reduction in kidney function.
- **CKD Stage G5** is eGFR less than 15, established kidney failure, when dialysis or a kidney transplant may be needed in the future.



How common is CKD?

CKD Stages G1–G3

20 per 1000 in young people
(300 per 1000 in older people)

CKD Stage G4

2 per 1000 of population

CKD Stage G5

1 per 1000 of population

Seeing a kidney specialist

If you have CKD you will also need regular monitoring. The frequency of that will be judged by how severe your kidney problem is. It is simple to do by regularly measuring the GFR and the amount of protein in your urine. For most people, the monitoring and diagnosis can be done by your GP but many people get referred to a specialist.

What is a kidney specialist?

- Urologists perform surgery on kidneys, bladders and other 'waterpipes'. They look after people with kidney and bladder tumours, kidney stones, and men with enlarged prostate glands.
- Nephrologists are doctors who know about diseases of the tissues of the kidneys. They also look after people who are on dialysis or who have had kidney transplants.
- You are more likely to be sent to a urologist if you have traces of blood in your urine or a bladder problem. You are more likely to be sent to a nephrologist if your eGFR is low or protein has been found in your urine.

What does a specialist do?

- The specialist will ask you about any medical problems in your family, and about the symptoms of your kidney disease.
- When you come to the hospital, it will be helpful for the specialist if you can bring a list of any tablets and other medicines you are taking, along with any recent blood pressure results.
- The specialist will talk to you about whether you need any more tests, for example:
 - An ultrasound (sound wave) scan
 - A CT scan or a magnetic resonance (MR) scan
 - A biopsy of your kidney (not advisable for everyone and does carry some risk of bleeding).
- The specialist will also give advice on what treatment will be best for you:
 - Most people then go back to their own GP for care.
 - Some people do need to carry on having specialist care on a long-term basis. This may involve seeing a number of different members of the renal team, including nurses, dietitians, pharmacists and a social worker.

It is easy to forget exactly what the specialist says to you in a hospital clinic. If you can get friend or relative to go with you, one of you is more likely to remember. Do ask for copies of any letters sent to your GP, and for copies of your blood tests results and scan reports too. These may help you to understand what the specialist has said.

The specialist may also invite you to take part in a research study. Research improves the future care of CKD, but you are under no obligation to take part in research or to make a decision about research immediately. Read the information you are given and make your own mind up.

Having a kidney biopsy

Alan's Story

I started to lose protein in my urine and was seen by a consultant who suggested I should have a kidney biopsy.

In hospital, a doctor talked me through the procedure and the risks. At the given time I was wheeled down to the biopsy suite on my bed. The doctor scanned both my kidneys to determine which kidney to use as I have an enlarged spleen. I was then asked to lie on my front with a pillow under my tummy and my arms above my head as if sunbathing, to position the kidney near the surface of my back. I was then given a local anaesthetic followed by a needle to locate the kidney. Following this I was told to expect a popping noise, which the doctor demonstrated, so that I did not jump when it was being activated, as I had to hold my breath for them to remove the sample. I found there was no discomfort at all.

The whole thing usually takes about 20 minutes. After all this is done you are put back on the ward and asked to lie on your back for six hours. Your urine is then checked for blood. Then, if everything is fine, you are allowed to go home.

Why is CKD potentially bad for you?

CKD may result in several important and potentially harmful effects upon you and your wellbeing.

- **Progressive kidney disease resulting in failure of kidney function:** although CKD is common, kidney failure and the need for a transplant or dialysis is rare. It is a serious complication and one which most people are very worried about. Part of the testing and monitoring of your kidney function is to determine whether it is declining and what can be done.
- **Increased risk of heart attacks and other cardiovascular problems:** CKD affects the circulation in your body. For very complicated reasons problems like heart attacks and strokes are more common in people with CKD. While the CKD itself cannot be cured, having CKD should be a reason to make sure you lower your heart risks – stop smoking, eat sensibly, take exercise and keep your blood pressure and cholesterol as normal as possible.
- **Acute kidney injury:** this is often called AKI, and refers to when your kidney function drops suddenly in response to illness, such as sepsis or infection. Normally this recovers but having AKI can worsen the severity of the underlying illness. For people with CKD, AKI may not reverse so easily and it is more common. There is lots of advice on AKI on page 22 and Kidney Care UK provides useful leaflets for patients at www.britishkidney-pa.co.uk.

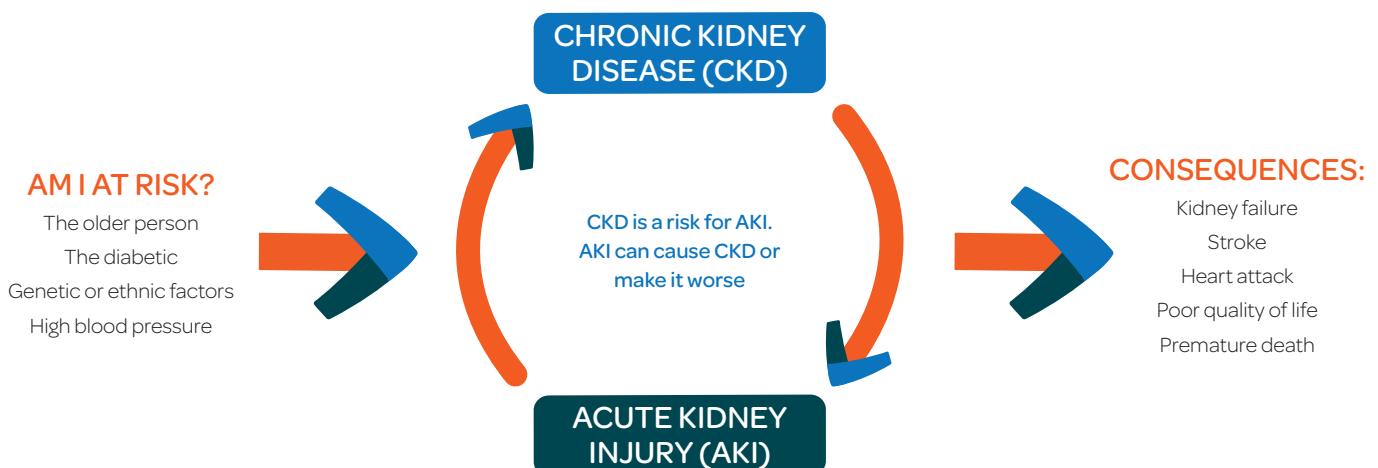
In addition to these risks to your wellbeing, there are other complications from losing kidney function and these are based on what the kidneys usually do. High blood pressure, fluid accumulation, anaemia, bone problems such as fractures and salt problems such as high potassium levels in your blood may cause symptoms. So, this may affect how you feel – people may feel tired, lack energy, sleep poorly or feel sick. Depression and other psychological problems are common. It is important to stress that most people with CKD will not have any symptoms – only the tests will show there is a problem.

How long will I live?

Research has shown that young people with CKD Stages G3, G4 and G5 may die earlier than people of the same age who have normal kidney function. Very few people with CKD Stage G3 or G4 actually die of kidney failure.

If they die early, this is much more likely to be due to circulatory diseases such as stroke or heart attack. The likelihood of having one of these is 2–5 times higher for younger people who have CKD than for people without CKD.

However, once you reach the age of about 70, if you have CKD Stage G3A, you can expect to live almost as long as someone of a similar age without CKD. It is difficult to give exact survival rates for any individual, as the survival of someone with CKD depends very much on whether they already have a problem such as heart disease or diabetes.



What can be done?

Just because CKD cannot be cured doesn't mean there is no treatment. There are lots of things that could and should be done. Treatment is about reducing the risk of the 'big three' of kidney failure, heart problems and AKI. It's also about dealing with complications and for those people who will develop kidney failure, supporting them in making the necessary choices about dialysis and transplantation. There is a lot of advice and information available to help support people through these choices. Please see the resources section at the end of this booklet

Blood pressure

Blood pressure control is a mainstay of reducing the risk of heart problems but also reduces the risk of progressive kidney failure.

Why does blood pressure matter?

Everyone has blood pressure. Blood under no pressure at all would be unable to move around your body. But the pressure can be at a healthy level or an unhealthy one.

Each time the heart beats, it pumps blood to the tissues through tubes called arteries. Arteries expand with every heartbeat and tighten between heartbeats, so the flow of blood is kept even. Arteries have a layer of muscle in their walls, and can tighten and relax to help direct blood to the right parts of the body, for example to the muscles during exercise. Having high blood pressure can put a strain on the blood vessels and may be damaging.

What is high blood pressure?

High blood pressure is blood pressure greater than 140/90 mmHg.

The first number (140) is the highest pressure after a heartbeat, and is called the systolic blood pressure.

The second number (90) is the lowest pressure between heartbeats, and is called the diastolic blood pressure.

Most people with high blood pressure feel completely well. Very severe high blood pressure can cause headaches, or make it difficult to see properly, but this is rare. A few people get headaches with moderately high blood pressure, but this is not very common.

How should your blood pressure be measured?

Your blood pressure will vary from minute to minute, according to how much oxygen your body needs at any given time. You should sit quietly for 5 minutes before your blood pressure is measured, with the cuff around your arm.

Even if you don't feel stressed, your blood pressure is usually higher in hospital or clinic than it would if you were sitting comfortably in your own living room. One way round this is to measure your own blood pressure at home. You should take your blood pressure 2–3 times.

Details of the best machines and the approved method can be found on the British Hypertension Society website (www.bhsoc.org).

Blood pressure machines are not expensive and are widely available from high street chemists but make sure you get an approved model. They are easy to use, but the nurses at the hospital or at your GP practice will be very happy to give you a lesson in "Taking your own Blood Pressure". Ask how often you need to check your blood pressure – in most cases once a week is more than enough.



Treating high blood pressure

You are likely to be given tablets to treat your blood pressure if it is still 140/90 or more after you have lost any excess weight and made the healthy changes to your lifestyle that your doctor advises (see page 12). Cutting salt from your diet may help too.

The aim is to get your BP below 130/80 and most people with CKD need several tablets to do that. Tablets called ACE inhibitors or ARB are often the first to be used based on the research. Tablets don't cure BP so you will need medication for life.

Blood pressure monitoring at home

Jim's Story

I have been monitoring my blood pressure at home for three years now, not always very consistently, but frequently enough to keep an eye on how it is doing. I was born with one kidney and need to ensure that both cholesterol and blood pressure levels are kept in check in order not to put undue strain on my remaining kidney which is undersized and does not perform to full levels anyway.

I find that having access to a blood pressure monitor at home makes me more aware of the need to ensure that my levels are kept reasonably low, much more so than the occasional visit to the GP does. It also gives me a sense of being able to manage the problem much better myself.

The BP monitor has been a good investment and will be even more so now that they have come down quite considerably in price.

I use a machine with a sleeve that goes round my upper arm, as these are apparently more reliable.



Controlling blood pressure

Enid's Story

I'm 78 years old. I've had high blood pressure since my eldest was born, and she's 52 now. Thinking back, I nearly died at the time.

I've taken treatment ever since and had another two girls, worked, and I'm still active. I've taken the tablets religiously – well usually, except sometimes. I've had several different types over the years according to my blood pressure and side effects.

The nurse at the doctor's says my cholesterol level is fine, and the only other tablet I take is an aspirin a day. Although I'm slowing up now, I can still walk to the bus stop and get out on my own. I'm amazing – it's a wonder I'm still here!

Keeping healthy

Keeping your cholesterol level low

Lowering your cholesterol is also very important. Cholesterol can be lowered by diet and exercise but tablets such as statins are very important and effective. There is a lot in the general press about statins that might worry you so talk to your doctor or pharmacist if you are concerned. Side effects are quite rare and the drugs are very effective in reducing your chances of a heart attack.

Keeping fit

Looking after yourself is as important as BP control. Don't smoke, drink alcohol in moderation, eat a balanced diet, avoid salt and processed foods and keep active. Again, this helps both the heart and the kidneys.

Drugs are handled by the kidneys. It is important to ask your doctors, pharmacist and anyone else who gives you medication to check they are safe for you and that the dose is right. For example, some medication (such as NSAIDs) can cause AKI and kidney failure in people with CKD. Always check with your pharmacy if buying non-prescription over the counter tablets that they are safe for you. Make sure that your vaccinations are kept up to date to reduce your risk of AKI from infections such as influenza.

Eating for health

In the early stages of CKD, you should eat a balanced and healthy diet, with plenty of fresh fruit and vegetables. Avoid processed foods, junk foods and salty foods wherever possible.

If you have CKD Stage 4 or 5, your doctor will probably refer you to a dietitian for advice. A kidney that is not working too well can have difficulty helping your body to get rid of certain substances such as sodium (found in salt), potassium or phosphate, so you may be advised to be careful about eating particular foods.

There are also specific things that can be done to treat the complications of kidney disease. These may need the support of your GP, nurses, pharmacists, dietitians and specialists – kidney doctors and others. Other patients, patients' groups and psychologists may also offer support and advice.

There are some treatments that are used for kidney related bone problems and to treat anaemia related to CKD. The treatment of anaemia has been transformed with the development of synthetic forms of EPO and the use of intravenous iron. The recommendations for using these is always changing so it is important to get the up to date guidance from your team.



If you have CKD, you should:

- Pay attention to your diet and lifestyle. In particular, check the amount of salt (sodium) in your diet.
- Have your blood pressure and cholesterol checked regularly (see page 12).
- Talk to your doctor about your risk of having a heart attack or stroke, and what treatment and management you may need to reduce this risk, if required.
- Discuss with your doctor whether you need to have the vaccination against flu, and the vaccination against pneumonia caused by the pneumococcus bug.
- Have a review of the tablets you are taking, to make sure the doses are correct and that you are not taking drugs which could be harmful to the kidneys.

CKD Stages G1–G3

If your CKD is in Stages G1–G3, your GP will look after you. Most people with CKD Stage G1–G3 do not need to see a kidney specialist or have scans of their kidneys. If you have CKD Stages G1 to G3, a check of your eGFR once a year is enough. However, if you have protein in the urine or high blood pressure, you may have it checked every 6 months.

Your GP may refer you to a kidney specialist if your eGFR falls significantly. You may also be referred if your ACR is over 30, if your blood pressure levels are hard to control, or if the cause of your kidney disease needs to be determined.

CKD Stages G4–G5

At this Stage, your doctor may refer you to a kidney specialist. This won't be necessary for everyone, but it is advisable if your eGFR is slowly getting lower, or if you have complications such as anaemia (see page 20).

You are more likely to have side effects from tablets if your kidney function is poor.

Stage G5 CKD is also called 'established renal failure' or 'ERF'. Most patients with Stage G5 CKD become ill from kidney failure or its complications, such as anaemia or bone problems. This is why your doctor may refer you to a specialist.

Ultimately, some people may need to talk about kidney failure and make plans. Kidney Care UK has produced a leaflet to help you understand this part of your journey.



Living with CKD

Most people with CKD do not have any symptoms or feel at all ill. They should be able to carry on leading a perfectly normal life. Learning to cope with the disease will really help to manage symptoms and remain as healthy as possible.

After being told they have CKD, many people will feel shocked. They may have had no idea there was anything wrong with them until they had a blood or urine test.

Most people with CKD, however, will be able to prevent their kidney function getting worse by taking tablets and making changes to the way they live their lives. Some people with CKD may not need to take tablets at all. Changing your lifestyle and getting used to taking tablets on a daily basis isn't necessarily easy. Most people want to be able to understand what they are being asked to do and why. They also need ways of keeping motivated to continue with their treatment and lifestyle changes.

It is important to be able to feel you can talk to your doctors and nurses, and trust them to listen to you and be honest with you. You should be able to feel that you can tell your doctor about any problems which crop up so that they can be dealt with speedily and efficiently. For example, some people can have unpleasant side effects from drugs, which can easily be dealt with by simple adjustments to your medication.

Depression may also be a problem. If you feel that your mood is very low and that 'things are getting on top of you', talk to a doctor or nurse. Don't think that you are bothering your doctor. They want to help you to stay as healthy as possible. It is important to remember that carers play an important role in any chronic disease and sharing problems will help both of you.

No-one can manage everything on their own – support from family, friends or health care staff is essential. No-one wants to be a burden on anyone else, but hiding your feelings from the people who are important to you will make life more difficult in the long term.

Support is a two-way process, and no-one should feel guilty about asking for the type of help they would be willing to offer others.

Taking control

Having a good understanding of your kidney problems, what causes them and how they are treated is very important. People who develop their knowledge, acquire the right skills to look after themselves and are more confident about their own healthcare often feel much more in control and tend to be happier. It is also more likely that having a better understanding of your health will help you to make better choices about your health, treatments and manage your condition more effectively.

You can log into PatientView (www.patientview.org) from your tablet or computer at home and keep an eye on your test results.

There are many places that you can find out information and learn:

- **The internet.** There is plenty of information available on the internet; however it is important to remember that the information on some web sites is not always reliable or accurate. The authors have listed some recommended websites at the back of this booklet that you might want to explore.
- **Clinic visits.** Take the opportunity at clinic visits or GP appointments to ask questions about things that you don't understand or that have been worrying you. Think about what you want to talk about and write down a list of the things you want to discuss. There might not always be a lot of time available with the doctor during the clinic visit. Ask before you go how much time you have and then prioritise the questions to make sure that you have the chance to ask the most important ones.
- **PatientView** (often known as PV). This is an excellent tool to help you to become more involved in your treatment and care. It is a web site that is designed to be used by both patients and the renal unit to keep a record of your test results, medicines and other information. It is very secure and each patient has a user name and password which gives them access to their personal information.



Understanding your medicines

People who have kidney disease may have to take medicines. It is important to know what each medicine is for, how often you need to take it, what to do if you forget a dose and how to order more supplies.

Knowing about your drugs can help you to make decisions about your treatment and prevent problems. For example, if you are taking tablets for high blood pressure, and you notice that your blood pressure has gone down, you can talk to the doctor about the need to take the tablets.

Keep track of your test results

You can look up your own blood tests results online at PatientView (www.patientview.org).

To join PatientView, you need to be registered at a kidney unit, which is not necessary for people with stable CKD, for example stage G3a. If you have a falling eGFR or CKD stage 3b, you are more likely to have been referred to a kidney unit.

If you are registered at a kidney unit, you can ask for the registration form to join PatientView. Your details are not sent to the secure server without your written consent. It is all paid for by the specialist kidney units, so it is free to you.

Once you are on PatientView, there will be an upload of your blood test results each time you have tests, so you would usually be able to see your blood test results the day after the blood has been taken.

Sexual problems

Sexual problems are more common for everyone as they get older, particularly if they have CKD Stages G4 or G5. Not so much is known about the effect of Stage G3 CKD. Emotional problems are more likely to occur, and there are a number of additional medical problems (such as diabetes) as well as some medications that can affect sexual function in men and women.

If you find you do have problems of this nature, please discuss them with your doctor, who can then decide whether any treatment may help. More information about sexual problems and what to do about them may be found on the National Kidney Federation website (see page 28).

Having babies

If you have CKD Stages G4 or G5, this may well affect your fertility, whether you are a man or a woman. Many women stop having periods which is probably because they are no longer ovulating. This is not always the case, however, so it is important to continue using contraception.

In its early stages, CKD is unlikely to make having babies difficult. Women with Stage G3 CKD are usually able to have children, but they will need special attention during pregnancy as their blood pressure may get very high. Pregnancy in CKD Stage G4 or G5 is more complicated, especially for women who are anaemic. If you are hoping to start a family, it is really important for your own health and for your baby's that you talk to your doctor before getting pregnant so that you can plan together for a healthy pregnancy. This may include, for example, using different blood pressure tablets as some are safer than others for a developing baby.

Work

The majority of people with CKD have stable Stage G3 kidney disease, and this should not affect their working life. The small number of people with Stages G4 or G5 kidney disease may be restricted in the work they can do, especially if their job is very physical. However, even people on dialysis or with a transplant may be able to continue working normally and many of them don't need a great deal of time off.

People who have serious heart problems or other complications may find it difficult to carry on working but this will depend on the type of job.

Insurance

If you are applying for life insurance, critical illness insurance or holiday insurance, you are likely to be asked questions on the application form about your blood pressure levels, or whether you have been seeing a hospital doctor. It is a good idea to give yourself plenty of time to arrange insurance. It can also be helpful if you have some of the information to hand, such as your current eGFR.

If getting insurance is a problem, there are some brokers and companies with experience of insuring people with chronic health problems. If you also have diabetes, information is available through Diabetes UK. (see page 28 for address)



Mike's Story

For Mike, it all began with a routine urine test which revealed traces of blood and protein.

Finding out

I was referred to the hospital where blood tests showed high levels of urea, and creatinine readings that were rising fast.

After many different tests, I was diagnosed with the kidney disease focal glomerulosclerosis. It was not until I had a kidney biopsy that it was discovered. My blood pressure had been rising over the last couple of years and I was eventually admitted as an emergency case with an extremely high BP of 240/160. I was told that the reason for my illness was an autoimmune reaction.

Adjusting to treatment

The first course of treatment was to reduce my blood pressure. The first tablets I was prescribed did not suit me and I had a bad reaction to them. My legs turned purple and became very swollen but, after a change of medication, things settled down.

Other side effects from the tablets were dizzy spells, fainting and deadening of the fingers (Raynaud's phenomenon). It was usually during the hot summer months and in stuffy atmospheres that I passed out, and only when the weather was cold that my fingers turned 'dead' and white.

Getting used to taking tablets was new to me, and came as a bit of a problem at first.

Trying to remember them when going away was the worst, and we had a panic on one occasion when I forgot them and had to get replacements. However I got used to the routine, and now if I miss one occasionally it is not too serious for me.

Eating and drinking

With regard to diet, one of the main things I avoid is salt, too much being very bad for the kidneys. I find that I can eat or drink most things in moderation and maintain a healthy diet. I have chosen not to drink tea, coffee, spirits or beer but I enjoy a glass of wine occasionally or a glass of cider some evenings.

Thinking positively

I was informed that my projected creatinine readings indicated that I could be on dialysis after about 3–6 months. I attended dialysis clinics on a weekly basis to gain an understanding of the procedure. I also saw a dietitian.

All this came as something of a shock, but being of a pragmatic nature (I think) I soon accepted the situation and resolved that it would not ruin my life. I took a positive attitude and decided to fight it. And so far, now nearly six years on, I am not on dialysis and have remained stable. I think that having a positive attitude is paramount.

On the whole I find that my life is not too disrupted. I can cope well within my limits, just taking care not to overdo things.

Specific conditions and the health of your kidneys

Most people with CKD have kidney function that has been damaged slightly by age or increased blood pressure. Many other things affect the kidneys. You can find out more by looking at information using the resources listed on page 28.

Anaemia

Anaemia occurs when there are not enough red blood cells to carry oxygen from your lungs throughout your body. Anaemia can be caused by blood loss, damage to the blood cells, a deficiency of iron or some vitamins, or your kidneys being unable to produce enough of the chemical messenger (hormone) called erythropoietin, which stimulates the bone marrow to produce red blood cells.

Common symptoms of anaemia are loss of energy and shortness of breath. You may become irritable and frustrated if you start finding ordinary daily tasks difficult. You may feel lethargic and have mood swings.

Your sleep patterns may be disturbed and you may lose interest in sex or (if you are a man) have problems getting an erection.

Anaemia makes some people look very pale. But the most reliable way to find out whether or not they are anaemic is by a blood test to measure their haemoglobin.

A normal haemoglobin level is 130–170 grams per litre (g/L) for men and 120–150 g/L for women.

How is anaemia treated?

The level of iron in your blood will be measured by a blood test, which also looks at the levels of two important vitamins (vitamin B12 and folic acid).

The doctor will want to know whether or not you are losing any blood from your bowel. You can help by telling him or her if you have had any indigestion, or if you have noticed that your poo is bloody or black.

If your levels of iron, vitamin B12 or folic acid are low, then you will be given supplements to increase the levels. Iron may be prescribed either as a tablet or an intravenous injection; directly into your blood stream (if you are not able to absorb enough iron by mouth). These injections are usually given in hospital.

If you have CKD Stages G4 or G5, or if you have diabetes, your anaemia might be caused by your kidney disease. If it is, you may require medication called an 'erythropoiesis stimulating agent' (ESA) to stimulate your bone marrow to produce more red blood cells.

ESAs are artificial versions of the natural chemical messenger (or hormone) erythropoietin (EPO) produced by healthy kidneys.

They are given by regular injections, just under the skin using a small needle. You can give yourself your ESA injections at home, or the practice nurse can give them to you at your local surgery. High blood pressure can be a side effect of the drug and so is regularly monitored. You will also have your haemoglobin level checked to make sure the drug is working effectively.

It is likely that you will need treatment with iron medication as well.

National guidelines say that doctors may prescribe ESA when a person's haemoglobin level falls below 110 g/L. It can then be used to keep the haemoglobin between 105 and 125 g/L. If you have just started on ESA, the injections will take a few weeks to raise your haemoglobin level. You are likely to carry on needing injections for as long as you have CKD, unless you have a successful kidney transplant.

Diabetes

Diabetes is a condition where the body is not able to control the sugar levels in the blood properly. These levels can go too high after meals. If your kidneys are affected by diabetes, protein will leak into your urine. Diabetic kidney disease occurs in up to a third of people with long standing diabetes, so everyone with diabetes should have a urine test for protein every year. (For more information on protein in the urine, see page 8.) If there is protein in your urine, careful control of your blood pressure, cholesterol and blood sugar levels will help to slow down the damage to your kidneys. It will also make you less likely to have problems in other parts of your circulation.

Unfortunately, some people with diabetic kidney disease develop kidney failure in spite of these measures.

Heart failure

Heart failure is a condition where the heart cannot pump blood around the body very well. This usually occurs in people who have had a heart attack. Many people with heart failure also have CKD.

When this occurs, it can be difficult to keep both the heart and the kidneys working well. This is because the heart works best when there is a lower level of fluid in the body. Healthy kidneys however work better with higher fluid levels in the body.

You will need detailed advice from your doctor about how to keep the levels of fluid in your body steady, while keeping both your heart and your kidneys on an even keel. Keeping an eye on your weight, and reducing the amount of salt in your diet, may help. You may see a heart failure specialist nurse who will monitor both your heart and your kidney function.

Some of the tablets used to treat heart failure have to be used carefully if you also have CKD.

Urine infections

Urine infections are due to germs that cause inflammation or irritation in the lining of the bladder, causing pain and stinging when urine is passed (known as 'cystitis'). Urine infections are much more common in women than in men, and hardly ever cause CKD.

However, urine infections are more frequent in people who have any condition affecting emptying of the bladder, such as kidney stones, a large prostate gland in men or diabetes, and in people who have a catheter in place to drain their urine.

A more severe infection may spread upwards to the kidneys and cause damage. This is called pyelonephritis. It can cause pain in the back, where the kidneys are, along with fever and sweats.

Urine infections should be treated as early as possible to prevent them from getting too bad and causing damage. The first step is to increase how much you drink to at least 2 litres of fluid a day (5 large glasses). You may also be given a course of antibiotics for 3–7 days. This will depend on how severe the infection is and whether you have CKD and or diabetes.

Passing urine frequently and incontinence

Losing control of your bladder is not linked to kidney failure. Incontinence and bladder problems have major effects on people's lives, and no one should have to suffer in silence. See your GP if you have this type of problem. He or she may then refer you to a doctor specialising in bladder function.

Sarah's kidneys were damaged as a result of her diabetes, but she faces whatever the future may bring with courage and a positive mindset.



Living with CKD Sarah's Story

It took over a year for me to take in the reality of my condition, what it might mean for my future and the impact it would have on my plans for a family, my career and my relationships. At the moment, my kidney function is still considered normal and has 'absolute stability'. My consultant tells me this is not uncommon. Most of the time I get on with life in the same way I always have and, when I need to, I ask questions and I find out more.

I will never control CKD completely, but I'm determined that it won't defeat me. I take my medication, I see a clinical psychologist to help me prepare, I question as many people as I can along the way and, sometimes, I take a break and let it sink in again. I never rush myself.

Acute Kidney Injury (AKI)

Acute kidney injury occurs when the kidney function gets worse over a period of days or weeks. This is different to CKD, where the kidney function may change over months or years. The problem is quite common, but the people most likely to get it are those with abnormal kidneys to start off with – in other words, people with CKD. Not everyone with CKD will have an episode of AKI, but you need to know what to look out for so that if one does occur, it can be found early and treated effectively.

Signs of acute kidney injury

Many different conditions can cause AKI but, in someone with CKD, the most common causes are infection and dehydration. The symptoms of infection can include a high temperature, feeling sweaty and aches and pains in the muscles. If the infection is in the urine, you may have to pass urine more often than usual and this may be painful.

Dehydration most often occurs if there is vomiting or diarrhoea – but is worse if you get both.

The chances of getting AKI vary from person to person. However, as a general rule, if you have CKD, have a fever, can't drink fluid for 24-28 hours and are not passing much urine, it is best to be checked to make sure you do not have AKI. Call your GP in the first instance.

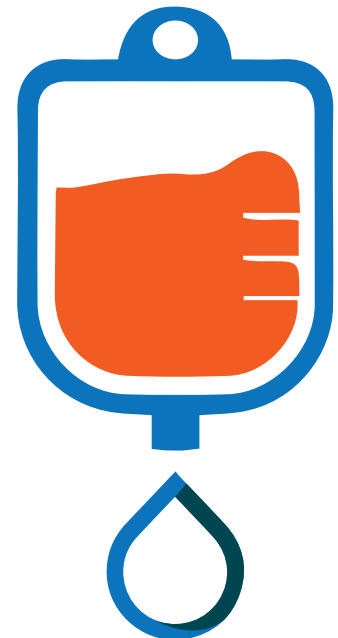
One sign of severe AKI is not passing urine for more than 24 hours. However this is a late sign, and it is best not to wait until you have stopped passing urine before seeking help.

How is AKI diagnosed and treated?

Acute kidney injury is diagnosed by a blood test to measure the level of creatinine in the blood. If your creatinine level has doubled, there is severe AKI and urgent treatment is necessary, usually in hospital.

If the creatinine level has gone up a small amount, you may need follow up checks in the next few days but there is less of an emergency. Your GP will look after you making sure you drink extra fluid and checking your medication if appropriate.

The treatment for AKI depends on the cause. Since the most common cause of AKI is a combination of infection and dehydration, treatment often involves antibiotics (if the infection is thought to be related to bacteria) and giving fluids into a vein through a drip. In less severe cases, it may be possible to drink extra fluid rather than have a drip.



How can AKI be prevented?

If you have CKD and have vomiting or diarrhoea, you may be able to stop yourself getting dehydrated by drinking extra fluids. Some people who have had an episode of AKI before can spot the warning signs early, and get prompt treatment by contacting their doctors' surgery when they feel unwell.

AKI can also occur after an operation, or indeed after any illness severe enough to require admission to hospital. Therefore, if you have CKD, it is important that doctors in hospital know this so they can take action to reduce the risk. This might mean avoiding dehydration by giving fluids into a vein through a drip if someone is 'nil by mouth' before an operation. It is also important to avoid some types of painkillers after an operation (all non-steroidal anti-inflammatory drugs, sometimes referred to as NSAIDs, such as ibuprofen and 'diclofenac').

Acute kidney injury may also be exacerbated when people are taking medications to lower blood pressure or treat heart conditions. You may be advised to stop or reduce the dose of these tablets temporarily in these circumstances, and restart them when you are better. If you are not sure, to contact your GP or specialist nurse. This is sometimes called 'Sick Day' rules or guidance, and you may be given a card to advise you what to do. Normally, when you are better, these medications will be restarted.

What will happen if I have AKI?

AKI is usually reversible, and once the causes of the acute injury have been treated, kidney function will improve over a period of a couple of weeks.

There are however two potential problems:

- If you do have AKI, your level of kidney function may be so low that levels of toxins in the blood build up too high. This may mean that the usual dose of your tablets needs to be reduced, or in some cases stopped temporarily.
- If your kidney function gets very poor, or there is a build up of fluid in your body, artificial kidney treatment with dialysis is required on a temporary basis at least.

Following an episode of AKI, the kidneys may improve, but they may never get back to their original level. For example, if you had an eGFR of 30 and had an episode of AKI, you may only recover to an eGFR of 25.

If the same thing happens two or three times, your kidney function may go below an eGFR of 10, and long term dialysis for kidney failure might need to be considered.

This is one of the reasons why it is important to detect AKI early and give effective treatment.

Top tips to prevent and treat AKI

- Be aware that if you have CKD you are at extra risk of acute kidney injury.
- If you have had acute kidney injury, your GP should be able to give you specific advice about what you can do to help avoid a repeat of it.
- If you have an illness with fever or diarrhoea or vomiting, and are unable to drink for more than 24 hours, get your kidney function checked and seek advice.
- If you've had acute kidney injury before, be very aware of early warning signs of another episode. Your specialist or GP may give you some blood tests forms so you can get a blood test without delay if needed.
- Make sure that you understand what your medications are, and which ones may be a problem if you become dehydrated.

Kidney disease research

Kidney disease affects very many people and is becoming more and more common. We know little about how to prevent it, the treatments can be very expensive and there is currently no cure.

Doctors and scientists are always looking for new ways to prevent and treat CKD as well as focussing on the ultimate goal of a cure. Research is an important process that will help improve the lives of patients both now and in the future.

Getting involved

There are a number of benefits to getting involved with research and clinical trials. For example, you will have the opportunity to play an active role in your own health care and get more of an understanding of your own disease or condition.

There might be an opportunity for you to have a new drug or treatment that isn't available to most patients. The treatment that is being trialled may be more effective than the alternative; in fact there may not be anything else available.

During a clinical trial you will be closely monitored and supported by the research team who will be specialist in your disease and may have a better understanding than most. A 'medical ethics committee' oversees all clinical trials. This committee will make sure that all the patients who participate in the research are treated appropriately.

By participating in research, you will also be contributing to society. Even if you don't benefit personally, the results will certainly help others in the future.

However, before volunteering, it is important that you and your family consider the possible downsides. Being in a clinical trial will probably mean that you need to go to the hospital more often; for tests, treatments and monitoring. If you are having a new treatment, there may be some unpleasant side effects and of course, the experimental treatment may not work.

You should talk to your doctor and your family so that you are sure it's what you want. The decision to get involved is yours and no one can put you under pressure to participate. Before you start the trial, you will need to sign an 'Informed Consent' document. This will explain all of the details of the trial including the risks and possible benefits. You are also free to leave a trial at any time.

Kidney Research UK is the largest kidney research organisation in the UK who is responsible for funding and managing many research studies every year. You can find out more about their work at www.kidneyresearchuk.org

There are very many different kidney diseases, some of which are very rare; only affecting a handful of patients. Rare diseases are difficult to study at just one or two hospitals because the numbers of patients are so small. The Renal Association (the professional group for kidney doctors), has set up a National Registry for Rare Diseases known as RaDaR. This enables doctors to collect information from lots of patient across the country.

RaDaR has been designed to gather information from patients with certain rare kidney diseases. This will give a much better understanding of how these illnesses affect people. It will also speed up research.

RaDaR takes information from Patient View (see page 15), an online system that records renal patient's results, medications and clinic letters.

Research outcomes such as improved diagnosis, treatments or general advice for patients and families with rare renal diseases, are publicised on RareRenal.org





Useful Reading

You will find many information leaflets from the National Kidney Federation. A DVD featuring patients and kidney specialists and entitled **Living with Kidney Disease** is available from Kidney Research UK or the NKF. The following books are also likely to be helpful:

Eating Well for Kidney Health

Helena Jackson, Claire Green and Gavin James. Class Publishing

Eating Well With Kidney Failure

Helena Jackson, Annie Cassidy and Gavin James. Class Publishing

High Blood Pressure:

Answers at your fingertips

Professor Tom Fahey, Professor Deirdre Murphy and Dr Julian Tudor Hart. Class Publishing

Kidney Failure Explained.

Janet Wild and Dr Richard Fluck. Class Publishing

Kidney Failure: the facts

Dr Stewart A Cameron. OUP

Kidney Transplants Explained.

Dr Andy Stein, Dr Rob Higgins and Janet Wild. Class Publishing

Living Well with Kidney Failure.

Juliet Auer. Class Publishing

Type 1 Diabetes:

Answers at your fingertips.

Dr Charles Fox and Dr Anne Kilvert. Class Publishing

Type 2 Diabetes:

Answers at your fingertips.

Dr Charles Fox and Dr Anne Kilvert. Class Publishing

Jargon busting

ACE inhibitor

(angiotensin converting enzyme inhibitor) A class of drug that reduces blood pressure levels, and may be especially helpful for people with CKD and protein in the urine. Names end in -opril.

ACR

Albumin-creatinine ratio, the amount of protein leaking into the urine.

Acute

Short-term and of rapid onset, usually hours or days.

Acute kidney injury

(AKI) A rapid deterioration in kidney function over hours or days associated with a fall in urine output and rise in creatinine levels. If severe, AKI may result in long-term loss of kidney function.

Albumin

A type of protein. If protein appears in the urine this can be a sign of kidney damage. Albumin is the preferred type of protein for laboratories to measure in the urine.

Anaemia

A shortage of red blood cells in the body, measured as haemoglobin levels or red blood cell count. Anaemia may be treated if the haemoglobin level is below 110 g/L.

ARB

(angiotensin receptor blocker) A class of drug that reduces blood pressure levels, and may be especially helpful in people with CKD and protein in the urine. Names end in -sartan.

Arteries

Blood vessels that carry blood from the heart to the rest of the body.

Autoimmune

Conditions where the body reacts against its own cells. This can cause kidneys disease and also other conditions such as thyroid disease. These conditions are detected using specialist blood tests.

BP

Abbreviation for blood pressure. The pressure in the arteries measured by a cuff and a sphygmomanometer. High blood pressure is associated with heart attack and stroke and low blood pressure may reduce the healthy functioning of the kidneys.

Calcium

Mineral important throughout the body, especially in bones. Blood level may fall as the kidneys fail to produce activated vitamin D in CKD Stages 4 and 5.

Calcium channel blockers

Tablets which are used to treat blood pressure and angina. Names usually end in -pine.

Cardiovascular

A group of conditions where there is disease of the arteries in the body such as heart attack and angina, stroke and peripheral vascular disease where there is narrowing of the large arteries in the legs.

Catheter

A flexible plastic tube used to enter the interior of the body. Different types of catheter may be used for dialysis or to drain urine from the bladder.

Cells

The tiny units from which all living things are built up. Cells in different parts of the body look different from each other and perform different functions (for example, skin cells are very different from blood cells).

Cholesterol

A fatty substance, one of several different types of fat found in the body. If blood vessels are damaged, cholesterol can be deposited, eventually causing narrowing. Associated with heart attacks and strokes.

Chronic

Present for a long time – in CKD for at least 3 months and of slow onset, not usually requiring immediate action.

CKD

Abbreviation for chronic kidney disease.

Clearance

The removal of the toxic waste products of food from the body. Clearance is one of the main functions of the kidneys. In CKD, clearance is reduced and toxins from metabolism, and also medications, built up in the blood.

Creatinine

A waste substance produced by the muscles. The higher the blood creatinine level, the worse the kidneys are working. The blood creatinine level is used to calculate the eGFR, an estimate of kidney function.

CT scan

A specialised scan which can identify the structure and function of the organs in your body. If you have CKD, then extra care needs to be taken if you need a CT scan.

Diabetes

a condition where your body is not able to deal with glucose in your blood. It may be associated with a deficiency of insulin (type 1) or a loss of sensitivity to insulin often associated with being overweight (type 2). Long standing diabetes of both types may be associated with kidney damage. The first sign of this is a leak of albumin into your urine.

Dialysis

An artificial process by which the toxic waste products of food and excess water are removed from the body. This can be directly from the blood as in haemodialysis, or from the lining of the abdominal cavity (peritoneal dialysis). It usually needs to be performed several times each week over several hours. Dialysis improves symptoms but is not a cure.

Diastolic blood pressure

A blood pressure reading taken when the heart is relaxed. It is the second figure in a blood pressure measurement.

eGFR

Abbreviation for estimated glomerular filtration rate.

Erythropoiesis-stimulating agent

(ESA) A substance which is used for the treatment of anaemia.

Erythropoietin

(EPO) A hormone made by healthy kidneys, which stimulates the bone marrow to produce red blood cells.

Established renal failure

(ERF) A term for advanced chronic kidney failure, which is also Stage 5 CKD. People who develop ERF may die within a few months unless they are treated by dialysis or transplantation. These treatments control ERF but cannot cure it.

Estimated glomerular filtration rate

(eGFR) Measurement of kidney function, calculated from the blood level of creatinine. The eGFR defines the Stage of CKD.

g/l

Abbreviation for grams per litre, the units used for the concentration of haemoglobin in the blood.

Glomerulus

The delicate filtering part in the kidney, about the size of a pinhead.

Glomerulonephritis

Disease of the glomerulus, which will be autoimmune.

Haemoglobin

(Hb) A substance in red blood cells that carries oxygen around the body. A low Hb level indicates anaemia.

Hormone

A chemical messenger that travels around the body in the blood and controls how other parts of the body work.

Hypertension

High blood pressure, usually over 140/90.

Kidneys

The two bean-shaped body organs where urine is made. They are located at the back of the body, below the ribs.

mmol/L

Abbreviation for millimoles per litre. A unit used to measure the blood levels of many substances. Creatinine is measured in smaller units called micromoles per litre (mol/L or micromol/L).

Nephrologist

A doctor who specialises in kidney disease, dialysis and transplantation.

Phosphate

A mineral that helps calcium to strengthen the bones. Phosphate is obtained from foods such as dairy products, nuts and meat. In CKD Stages G4 and G5, phosphate tends to build up in the blood and the intake in the diet may need to be restricted.

Potassium

A mineral that is normally present in small amounts in the blood. Either too much or too little potassium can be dangerous, causing the heart to stop. People with CKD will have their potassium level measured when the eGFR is checked, and will be advised if the level of potassium is abnormal.

Protein

An important building block in the body. Carried around the body in the blood, appears in the urine in some people with CKD.

Protein-creatinine ratio

(PCR) A measurement of the level of protein in the urine, superseded by albumin-creatinine ratio (ACR).

Red blood cells

Cells in the blood which carry oxygen from the lungs around the body. Also known as erythrocytes.

Renal

Relating to the kidneys.

Salt

Sodium chloride, which is used in food as a preservative and for flavour. (Lo-Salt contains potassium which may not be safe if potassium levels are high.)

Sodium

A mineral, normally present in the blood, that comes from salt (sodium chloride). Sodium retention exacerbates high blood pressure, and most people with CKD will benefit from reducing the sodium in their diet.

Statin

A group of similar drugs used to reduce the blood levels of cholesterol. The names of the drugs end in -statin.

Systolic blood pressure

A blood pressure reading taken when the heart squeezes as it beats. The systolic blood pressure is the first figure in a blood pressure measurement.

Transplant kidney

A kidney removed from one person (the donor) and given to another person (the recipient). Transplant kidneys may come from a donor who has died, or from a living donor who should have a genuine relationship with the person needing the kidney even if they are not related by blood.

Ultrasound

A scan of the kidneys or bladder (and other internal organs) using sound waves to take pictures. This does not use radiation and is safe in pregnancy.

Urine

The liquid produced by the kidneys, consisting of the toxic waste products of food and the excess water from the blood.

Urologist

A surgeon specialising in the kidneys and bladder.

Veins

Blood vessels which carry blood from the body back to the heart.

Patient Charities

Kidney Care UK

3 The Windmills
St Mary's Close
Turk Street
Alton GU34 1EF

Tel: 01420 541424

www.kidneycareuk.org

National Kidney Federation

The Point
Coach Road
Shireoaks
Worksop
Notts S81 8BW

Tel: 01909 544999
Helpline: 0800 169 0936

www.kidney.org.uk

Kidney Research UK

Nene Hall
Lynch Wood Park
Peterborough PE2 6FZ

Tel: 0300 303 1100

www.kidneyresearchuk.org

Diabetes UK

Wells Lawrence House
126 Back Church Lane
London E1 1FH

Tel: 0345 123 2399
Fax: 020 7424 1001

www.diabetes.org.uk

The Internet

As well as the websites listed, there are many more which you may find useful. Here are some suggestions:

<https://aakp.org>

The American Association of Kidney Patients

www.bhf.org.uk

The British Heart Foundation

www.bhsoc.org

The British Hypertension Society

[www.dh.gov.uk/ PolicyAndGuidance/ HealthAndSocialCareTopics/ Renal/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Renal/fs/en)

Department of Health publications for the NHS on kidney diseases

www.edren.org

The website of the Edinburgh Renal Unit. For general information go the EdRenInfo link at the top of the home page.

www.jbs3risk.com

Risk calculator for the prevention of cardiovascular risk, devised by the Joint British Societies.

www.kidneydirections.com

Information for kidney patients, and suggestions for ways to plan treatment.

[www.kidney.org.uk/Medical-Info/ drugs/vacc2.html](http://www.kidney.org.uk/Medical-Info/drugs/vacc2.html)

The section of the NKF website giving information about medicines and vaccinations that can and can't be used for people with kidney transplants.

www.kidneypatientguide.org.uk

Information for people with kidney failure, and those who care for them.

www.nephron.com

Exhaustive information on everything to do with kidney diseases.

www.nice.org.uk

National Institute for Health and Care Excellence, produces clinical guidelines for the NHS, which include treatment of anaemia in CKD, treatment of diabetes, and treatment of high blood pressure. CKD guidance was updated in 2014.

www.organdonation.nhs.uk

National Health Service site giving information about transplantation and organ donation.

<https://patient.info>

Provides a wide range of patient leaflets including information on prescribed drugs.

www.patients-association.com

Provides advice on patients' rights.

www.patientview.org

Enables patients in some UK kidney units to view their own results and care pathways on the Internet.

<http://pkdcharity.org.uk>

www.renal.org

Renal Association, the UK national body of kidney specialists. Has a useful section on CKD, with information on how eGFR is calculated and links to national guidance.

www.thinkkidneys.nhs.uk

The NHS campaign to improve the care of people at risk, or suffering from, AKI.

To order these books, please call our Order Line 01752 202301 or go to www.classhealth.co.uk

For enquires please email: info@class.co.uk

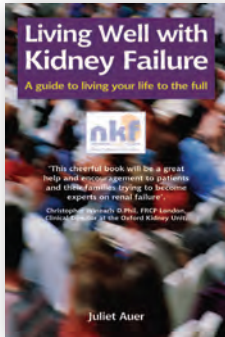
Further Reading

BOOKS



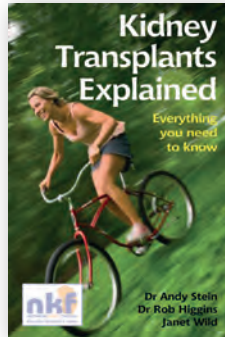
Eating Well With Kidney Failure

Helena Jackson, Annie Cassidy and Gavin James (ISBN 978 185959 116 1)
RRP £19.99



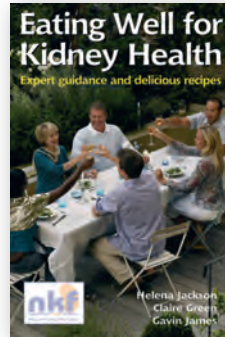
Living Well With Kidney Failure

Juliet Auer (ISBN 978 185959 112 3)
RRP £17.99



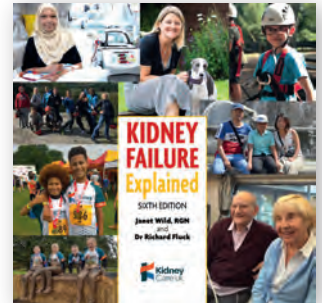
Kidney Transplants Explained

Dr Andy Stein, Professor Rob Higgins and Janet Wild (ISBN 978 185959 193 2)
RRP £19.99



Eating Well for Kidney Health

Helena Jackson, Claire Green and Gavin James (ISBN 978 185959 204 5)
RRP £19.99

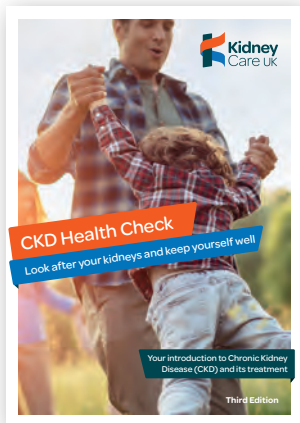


Kidney Failure Explained

Dr Richard Fluck and Janet Wild (ISBN 978 185959 792 7)
RRP £24.99

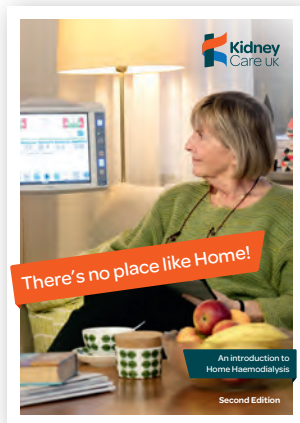
Further copies of these booklets are available from Kidney Care UK. Please call 01420 541424.

BOOKLETS



CKD Health Check

Dr Richard Fluck and Janet Wild RGN (ISBN 978 185959 649 4)



No Place Like Home

Janet Wild RGN and Dr Richard Fluck (ISBN 978 185959 651 7)



Help! I've got kidney failure

Janet Wild RGN and Dr Richard Fluck (ISBN 978 185959 647 0)

Text by Dr Richard Fluck and Janet Wild RGN



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No one facing kidney disease alone

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- Patient Information leaflets
- Improving patient services
- Campaigning for change

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01420 541424

www.kidneycareuk.org

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