

Guide to kidney failure

What do kidneys do?

You have been given this information because it has been found that your kidneys are not functioning properly. You have what is called Chronic Kidney Disease (CKD) and it is important that you understand what that means to you.

The purpose of this information is to help you regain the control that you may feel you have lost by giving you a better understanding of kidney failure, the drugs and the diet, the different types of dialysis and kidney transplant.

What do the kidneys do?

Most people have two kidneys, which are about the size of a clenched fist, and are found in the small of the back. Their main functions include balancing the body's water content and filtering waste products (poisons) from the blood. They do this by making urine. The kidneys also serve several other purposes; for example they produce many different hormones. These help to make red blood cells (haemoglobin) so that oxygen can be transported around the body, produce Vitamin D in its active form which ensures that bones remain strong and healthy and produce a hormone to keep blood pressure under control. So you can see that when the kidneys don't work properly the body can be affected in many ways.

You probably feel well at the moment and have no symptoms but as your kidneys worsen you may begin to feel unwell. Symptoms can vary from patient to patient but they may include: nausea and vomiting, loss of appetite, itching skin, restless jumpy legs especially at night, tiredness, lack of energy, breathlessness, puffy eyes especially in the morning, metallic taste in your mouth and swelling of hands and ankles.

How do you know when they are not working?

The kidneys can suddenly stop working, but often it happens over a long period of time, usually without any symptoms at all until the damage has been done. This is often why it is difficult to accept. Kidney failure may be detected at a routine medical for a job or insurance, a routine urine sample at the GP's or whilst visiting another hospital department for an unrelated matter. By the time you have abnormal blood tests you have lost half of your kidney function. We look at levels of creatinine and urea, which are two waste products normally removed by the kidneys.

Some of you will eventually lose the function of your kidneys altogether and will therefore stop making and passing urine. Many of you may still continue to make and pass some

urine, but this does not mean the kidneys are working well. They may not be filtering the poisons and enough fluid from the blood to keep you well.

What can cause Chronic Kidney Disease?

Chronic Kidney Disease is uncommon. For every 10 patients who start dialysis treatment each year, approximately 300 others will have a heart attack. The drawback for a kidney patient is that they need treatment for life. You may wonder whether your kidney failure was preventable and was it something that you may have done in earlier life - absolutely not. Most of the causes of kidney failure cannot be prevented. The commonest causes of kidney failure needing dialysis treatment are as follows:

- Glomerulonephritis - an inflammation of the kidneys causing protein and blood to appear in the urine.
- Hypertension - high blood pressure.
- Diabetes - up to 40% of diabetics may develop kidney damage. This is caused by damage to the very small blood vessels in the kidneys.
- Polycystic kidney disease - in which the kidneys are covered by a large number of cysts. This is an inherited form of kidney disease that you may pass on to your children.
- Pyelonephritis - scarring of the kidneys that usually arises following urinary infections in childhood.

Some patients never have the cause of their kidney failure found. This may be frustrating to the patient but in practice it does not matter, as the treatment is the same whatever the cause. Where possible we like to do a kidney biopsy (removal of a small piece of kidney tissue for microscopic examination) to identify the cause of your renal failure. However, once the kidney failure is fairly advanced, a biopsy would just show scar tissue.

Kidney failure can affect anyone and occur at any age. More than 59,000 people in the United Kingdom (2014) have end stage chronic kidney disease, best defined as the irreversible loss of kidney function requiring permanent dialysis or kidney transplantation. It is important that you know that it is possible to lead a long and healthy life on dialysis. There have been many changes over the last few years which means treatment for kidney disease is much more efficient and keeps you feeling well. Unfortunately, many people have memories from years ago of seeing very sick patients with kidney problems. Things have certainly changed for the better. There is no reason why you can't enjoy life by working, travelling abroad, swimming and exercising as normal.

Renal replacement therapy

As your kidney function deteriorates we will discuss with you the options for future renal replacement therapy - replacing the work that your kidneys do. This may involve a kidney transplant or dialysis or both over many years. Dialysis means an artificial way of cleaning your blood. We have mentioned the word 'dialysis' which we realise conjures a daunting picture for you, but you must know that it is possible to lead a long and healthy life on dialysis. True, it will mean major changes to your lifestyle, which you may find difficult to accept just now, but if you work at it and allow us to help you get your treatment right, then there is no reason why you should not enjoy a full life.

Briefly, there are three types of dialysis:

- CAPD - which uses a natural lining in your abdomen. Fluid is run in through a permanent tube and left in for between 4 and 6 hours during the day and 8 – 10 hours overnight. It is then drained out to clean the body of waste and then the process starts again. This procedure is done 4 times a day, every day but does not need to be done in hospital – usually in your own home, workplace, car or on holiday.
- APD - uses the same principle as CAPD but is performed by a machine whilst you are sleeping for about 8 hours. This is suitable for the majority of people.
- Haemodialysis - where blood is cleaned by a machine. You come into the dialysis unit three times a week, either in Reading, Windsor or Bracknell depending on where you live, and the treatment is done for you. It usually lasts about 4 hours per session. Your blood is accessed by what is called a fistula, which is created usually in your forearm by joining an artery and vein together under the skin. Once healed it allows two needles to be inserted during dialysis to take the blood from you to the kidney machine and then return it to you. In case you need haemodialysis at any time in the future, we would suggest you protect the veins of one arm from blood tests and blood pressures from now onwards. We would normally suggest this is your non-dominant arm (the arm you don't write with) unless you have had any injuries to this, in which case please discuss this with the clinic doctor.

Transplantation

This is the treatment that would work in the closest way to your own kidneys. It can be from a living relative or from the kidney donor list. Waiting time varies depending on your blood group, tissue type and donor availability and not how long you have been waiting. Age is not necessarily the deciding factor on suitability for transplantation. The most important thing is general health. Some unfit 40-year-olds would benefit less than a fit 70-year-old from transplantation.

Following the transplant it will be necessary for you to take drugs for the life of the transplanted kidney to stop your body rejecting it. These drugs do have some side effects. Transplants are performed at the Churchill Hospital in Oxford. After the six months, your care will be transferred back to Reading.

If the doctors feel your kidney function has reached the point where you are likely to need Renal Replacement Therapy in the future they will transfer your care a Low Clearance Clinic (either in Reading, Windsor, Bracknell or Newbury) where there are doctors and nurses that specialise in caring for people approaching dialysis or transplantation. They will be able to spend time explaining the different options to you and your family in detail and provide you with written information.

Medication

All kidney patients will need to take drugs. Some of you will need slightly different drugs than others. The more knowledge you have about the drugs you are taking, the more likely you are to feel in control of your life. For this reason we list the following drugs that you may be taking or need to take at some stage. The side effects are included but these are quite uncommon. Your medication is very important and may help prevent the deterioration of your kidney function. So, you must tell the doctor if you are unable to take them.

Drug	Purpose	Possible Side Effects
Beta Blockers e.g. Atenolol, Bisoprolol	To lower blood pressure or to treat angina.	Tiredness, lack of energy, cold hands.
Diuretic e.g. Furosemide	To treat fluid retention, heart problems and high blood pressure.	Low potassium levels and dehydration.
Drug	Purpose	Possible Side Effects
Calcium channel blocker e.g. Diltiazem, Verapamil	To lower blood pressure or to treat angina.	Headaches, flushing, nausea, swollen ankles.
ACE Inhibitors e.g. Lisinopril	To lower blood pressure and protect the heart.	Dry cough, higher potassium.
Statins e.g. Atorvastatin, Simvastatin	Lower cholesterol and protect the heart.	Muscle pain.
Phosphate binder e.g. Calcichew, Calcium Acetate or Renagel	Taken before food to lower phosphate levels in the blood.	High calcium levels in the blood.
Vitamin D e.g. One Alpha, Alpha Calcidol	Taken to protect bones. These are best taken at night.	Calcium level may rise leading to nausea and vomiting.
Erythropoietin e.g. Eprex	To treat anaemia by raising the red blood cell count. This is an injection, which you can be taught to give yourself.	High blood pressure.
Iron e.g. Ferrous Sulphate or Ferrous Gluconate	Use to restore iron levels in some types of anaemia. Take before food and not with phosphate binder.	Nausea, diarrhoea, constipation, black stools (don't be alarmed).
Sodium Bicarbonate	To regulate the acid balance in the body and lower potassium.	Blood pressure, ankle and leg swelling due to water retention with the salt.

Eating and renal failure

Healthy kidneys remove waste products and excess fluid from the body. Damaged kidneys lose this ability and the level of waste products in the blood can increase and fluid may be retained in the blood and tissues. Since some of the waste products come from food and drinks, it is important to consider your diet more carefully. When appropriate, the doctors will refer you to the renal dieticians to receive individual advice.

The information below is to give you an idea about what nutrients are important in a renal diet.

- Energy (Calories) - Being a healthy weight for your height is important for everybody and even more so if your kidneys are not working properly. Achieving your ideal body weight prior to starting dialysis will probably be easier than when you have started dialysis. This is true whether you are currently underweight and need building up, or whether you are overweight and could do with losing some weight. The dieticians can offer advice in either case.
- Fluid - If your kidneys do not get rid of enough fluid from your blood and tissues, this may cause high blood pressure, and put extra strain on your heart and your kidneys, and it may cause oedema (fluid retention in tissues – e.g. swollen, puffy ankles). If this is the case, you may be advised to limit the amount of fluid you drink each day.
- Salt/Sodium - A high salt intake is also linked to high blood pressure so it is sensible to try to cut down on your intake of salt and salty foods. Many processed and convenience foods contain a lot of salt so cutting back on these is a good start.
- Potassium - This is a mineral that is found in many different foods and drinks. The amount of potassium in your blood needs to be kept within set limits. Usually, if there is too much potassium in your blood, then the kidneys will filter it out and get rid of it. Sometimes your kidneys will not get rid of enough potassium from your blood and you may need to limit foods and drinks that contain potassium in order to keep the level in your blood safe.
- Phosphate - This is another mineral that is found in many foods and drinks. Like potassium, there are set limits for the amount of phosphate in the blood and your kidneys may not be able to remove enough. You may be asked to limit your daily intake of certain foods and drinks that contain high levels of phosphate and you may be prescribed tablets called phosphate binders. These tablets should be taken just before you have a meal – they will help to prevent your body from absorbing some of the phosphate in foods and drinks.
- Protein - We need protein for growth and repair of body tissues and to help fight off infections. Normally, there is no need to change your usual intake of protein, but in some cases you may be advised to reduce the amount of protein in your diet. You should then be seen by a renal dietician who will calculate the correct amount of protein for you.

A varied diet is essential in order to achieve the right balance of nutrients and to keep meals interesting and appetising. The renal dieticians are always happy to discuss any diet-related issues with you.

In the future

Keeping to your diet and taking your medication can prevent your kidneys getting worse, but there may come a time when these are unable to keep you well. This is then known as end-stage renal failure. Renal replacement therapy will soon be needed for you to remain well. Dialysis will not stop your kidneys from working altogether but will support what little kidney function you have. Your kidneys may stop functioning altogether and you may gradually stop passing urine. Please don't be alarmed at this - there are ways of measuring the dialysis that we give you to ensure that we keep you fit and well.

When the doctors feel you are ready to talk about your future treatment the kidney care nurses will arrange to meet you, your partner and your family and discuss the options for treatment. Many people with kidney failure feel that they have lost control of their lives. Some of you may be feeling angry and resentful that your kidneys have failed. Couldn't something be done to prevent this from happening? Hasn't anyone developed a drug that you could take instead of the dialysis? And how can the doctors be sure that your kidneys will never recover by themselves? And why has it happened to me? This is obviously a difficult time and adjustments do need to be made to your lives but please be reassured there is a specialist team of doctors and nurses who are skilled in helping you through.

Please don't be frightened at home and worried about the future. Do ring and we will try and reassure and allay your fears, or if you should have any questions following this information. Most patients are concerned that they will no longer be able to work and holiday abroad. This is absolutely not the case and we try very hard to fit the dialysis into your own individual lifestyles so that you don't need to change your life a great deal. You will be able to have a full, active life but that life must include renal replacement.

We do hope this information has been helpful to you. We realise that there is an awful lot to absorb. Dialysis treatment options and transplantation will be discussed with you in detail and written information will be provided at a later date.

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This document can be made available in other languages and formats upon request.

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